

Loving Louie

prepared for Kristy Schneider on February 10, 2020



**EXHIBIT
A**

My Story

Journal

February 14, 2019

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Valentine's Day is a day focused on love, which makes it the perfect day to tell Louie's story. You don't have to go further than a mirror to know what Louie loves...because Louie loves YOU... Let me explain...

Louie was born in [REDACTED] into a home filled with drug addiction, alcoholism, and ultimately significant neglect. When he was a year and nine months old, Louie, his brother and half-brother were removed from the home and placed in foster care. At the time Louie weighted only 11 pounds and was not walking or talking.

It was discovered that he had a rare chromosomal abnormality that led to him being globally developmentally delayed. Thus, in the first few years of his life there was minimal investment in his growth and development. He did not learn to walk until he was 3 years old. At 4 years old he only spoke 5 words. He remained in foster care for 2.5 years before my husband, Erik, and I came across this beautiful picture of Louie (almost 4) and Peter 9 (age 5) in little green suits through Project Zero. Immediately God spoke to our heart and we knew we had seen our children.

In July of 2013, the boys moved into our home. Louie weighed 24 pounds and was in 24 month old clothes. Immediately we found that Louie had some undiagnosed GI issues, but it didn't stop his smile from stealing hearts. We poured into various medical appointments and therapies to get him on the right track developmentally. Louie began to thrive and grow as never before as he was for the first time surrounded with all the support he needed medically, emotionally, and developmentally.

The adoption of Peter and Louie was final in September of 2014. Through the great grace of God, during the process, we also added a biological little girl named Selah and two years later in 2016 Liana was born. We continued to truck through life so incredibly blessed as a family of 6. (FYI, we are also working still to adopt their older half-brother from foster care.)

In July of 2017, Louie had his first seizure at the breakfast table. It was frightening and we didn't know then that this would be the beginning of decline for his body. Over the next year and a half, Louie's body would begin to fail him. He was hospitalized 6 times in 2018 for a total of almost 3 months. His fine and gross motor skills regressed. His GI, neurological, and other systems declined. He became dependent on continuous j-tube feeds and about 15 different medications to sustain life. He began to see a number of specialists including neurosurgeons, neurologists, geneticists, complex care physicians, and more.

In December 2018, Louie and I traveled to Cincinnati Children's Hospital for what was suppose to be a series of GI tests to help aid with understanding where his GI system is failing. However, the day before we were to admit to the hospital for the tests, Louie became very lethargic and could not hold himself up. By the time we got to the ER, his heart rate and blood pressure were critically low. He was given significant medical intervention and sent straight to the Pediatric Intensive Care Unit. Over the next 12 days, some of the best doctors in the country fought to understand what his body was doing and how to stabilize it. During that time, his heart stopped three times during seizures requiring more emergency intervention. His heart rate at night was often in the upper 30's with blood pressures of 60's over 30's. They tried all the typical medication to support his body and yet would get minimal to no response. It was determined that his autonomic nervous system was failing to send the correct signals to his cardiac system. On December 28th, he was air ambulated to Arkansas Children's Hospital

where the PICU here took over his care for the extreme bradycardia and severe hypotension. Over the next month, he was stabilized on rarely used (and very expensive) medication for his cardiac system and a pacemaker was placed on January 9th. The hope was that by keeping his heart rate up through the pacemaker that his blood pressure would also rise to a life sustaining place. However, this was not the case and he was placed on epinephrine to help support his blood pressure. After multiple attempts to transition off of this medication to other meds not requiring PICU status, it was determined that his body was not able to hold his blood pressure successfully and other organs were showing that they were beginning to shut down. After seeing multiple specialists, trying everything possible, and consulting with doctors in multiple other states/facilities, it was determined that the recommended course of action was to come home on hospice care.

This was the hardest decision we have had to make as a family but we felt the Lord giving us peace that this was the path for Louie. Doctors felt that once we got home and removed the epinephrine that his body would likely not live more than a few hours or at most a day or two. That was 2.5 weeks ago. Each day at this point is a tremendous gift. Louie is fighting for every day he is alive. His vital are low and his body/organs are struggling, but you wouldn't know it when you catch him during his little bit of awake time.

You see, throughout all of this, Louie's love and passion for people has never waived. During painful procedures, he would still smile and ask to hold a nurse's hand. He would kiss the hand of whoever gave him a shot or drew his blood. And EVERY single person he meets, even today, will be asked Louie's favorite series of questions: "What you doing? What you doing tomorrow?" And when Louie looks at you with his beautiful green eyes and asks you these questions, you know he genuinely wants the answers. Louie loves people in a way that I strive for each day. Thus, he LOVES mail because it signifies that someone is thinking of him and connected to him. He will open every piece of mail and hold it - some for a moment and some stay in his bed all day. Louie will want to know the names of the people who send him mail and will watch as we place a push pin on where they live. It is a simple thing that brings him joy.

The outpouring of support from all over our community, the nation, and even the world, has been overwhelming. It has brought us strength to see Louie's story and legacy continue to be built. We pray that everyone will see his smile and know that he sees them and loves them. If you were here, you would each be given hugs by Louie and leave smiling...that is just who Louie is... So today, on Valentine's Day, hold tight the ones you love and know that there is a 9 year old in Arkansas who counts you as a friend for knowing and sharing his story.

Photos









Comments

Louie, Aunt La Vone & Uncle Ray love you very much. I love seeing your smiling face on facebook, you are a special little boy. Jesus love you, this I know. Happy Valentines Day.

—*La Vone Cording, February 14, 2019*

Praying for Louie and all of your family! ♥

—*Laurie Dombrosky, February 14, 2019*

Thanks for sharing your sweet boy's story. We are praying for him and for all of you.

—*Charis Lau, February 14, 2019*

Love and hugs to you, Louie!

—Tracey Adams, February 15, 2019

I love that your hearts are open for these children . Louie seems so wonderful ! I pray for your family through this rough time .

—Dawn Reynolds, February 15, 2019

Louie!

Praise God for you. Even though we haven't met, I am so happy that I get to read about you. Your smile lights up the screen! I can clearly see you love people and want them to feel your love for them. What a special gift you have been given by the Lord! I pray that you have peace, hope, comfort, joy, and life more abundantly as God see fit to grant it to you.

God Bless you and your wonderful family, Sweetheart!

Nesha Evans

—Jason and Nesha Evans, February 18, 2019

Hi Louie!

My name is Toney Green and I am a Detective with the Bryant Police Department! I just wanted to take time out to tell you that I am thinking and praying for you. I will come see you really soon. Your smile makes my day brighter. Thank you for all your smiles and continue smiling!!!

The Green Family

—Yenot Black, February 19, 2019

You are a light to my heart today! From an Arkansas girl now in Kentucky and with lots of friends and relatives in one of your favorite states, TEXAS!

—Elaine H, February 20, 2019

My name is Shane Preator and I am a ex fire fighter, I learned of Louie through our friend Adam and even though I have never met Louie he has a special place in my heart. His love and courage is very contagious! Thank you for allowing us to be part of Louie. I will never forget and I will do my best to love like Louie! #LouieStrong

—Shane Preator, March 4, 2019

I learned of Louie through Facebook and I have never been so touched. I think about him everyday and say a prayer for him and his family. I will never forget such a strong little boy and to have the faith he has. God hold this special little guy close.

—Lonnie Whittemore, March 5, 2019

Louie,
You are such a special little boy. I love your smile.
I pray for you and your family.
Hugs! From a Grandma of 6.
Love
Kathleen

—Kathleen Mitala, March 5, 2019

Such a beautiful picture of love. I have been following his story since it aired on TV. My friend's little girl was in the room next door to Louie last week. Thank you for sharing the gift of love you were given with the rest of us. I want a heart for Jesus like Louie. I want to love like Louie. I have a grandbaby with a very chromosome abnormality. There are so many unknowns. We love him and lift him to the Lord day by day. Love and prayers for your family.

—Dana Collins, March 7, 2019

February 14, 2019

February 14, 2019

IF YOU WANT TO SEND CARDS OR ANYTHING TO BRING A SMILE TO LOUIE, HERE IS THE ADDRESS:

Louie Schneider
c/o Project Zero
10 Kings Court
Little Rock, AR 72211

Comments

What a precious family. It is a blessing to walk with you through this heart breaking story and an amazing testimony of God's grace, love and even joy amidst the tears.
Love and Prayers, Trisha

—Trisha Norton, February 14, 2019

Preparing to Leave the Hospital

February 18, 2019



January 19th was the first time a doctor I trust sat me down and said, "we believe we are at a place with Louie's health where we are delaying death and no longer delaying life." Words you never can be prepared for regarding anyone, especially your child. Over the next week, we made preparations to bring him home. The logistics felt they would crush my spirit at times. The tears could only be counted by God and the fear always right below the surface. Yet, in the midst, there were moments every day where Louie would confirm in his own way that we were on the right path.

During that week, there was tangible support that reminded us we are not alone on this unthinkable path. The week before we left Arkansas Children's Hospital, the Child Life, Palliative Care, and therapy teams went into overdrive to help us make the most of every moment. They worked with us to create memories we will cherish forever. There were heart beat strip ornaments, footprint moldings, sand art, and a memory plate all made and now displayed in our home. These were all beautiful examples of love that were designed truly to help us as a family walk this path and have memories.

But they also stepped in to make some of Louie's dreams come true. Here are a few that I want to highlight...

1. The therapists made his dream to run again a possibility as we ran with him in a wheelchair throughout the hospital with poles and tubes and all. He would smile and giggle the whole way and say "more, more!"
2. The music therapist, Andrew, put together the most beautiful gift for Louie and our family. He took a recording of Louie's actual heartbeat and then he recorded it while he played Louie's very favorite song. Louie lit up at hearing it and we all sat and cried at the beauty of it. The song is 10,000 Reasons by Matt Redman. (I plan to attach the song to my personal FB page because I don't know how to make it a youtube file to attach here.) If you don't know the words, please take a moment and look it up...verse three will take your breath away as you think of Louie and his love for the Lord and his own journey preparing to head home to Heaven...
3. Then everyone came together for the most amazing celebration of Louie's life...his going home party! There were hundreds of people who have been impacted by his life who came to the hospital that beautiful Saturday morning to honor Louie. They brought him mail and took pictures and remembered all the incredible moments where we have seen Louie shine. We shared stories, hugs, and tears. There were doctors, nurses, friends from school, neighbors, teachers, therapists, our church family, and more. I sat in awe of the number of lives changed because of Louie...and the consistent thread...joy. You can't meet Louie without seeing joy - a joy that doesn't come because of circumstances or position. It is a joy that is born through innocent faith in Jesus...a joy that permeates all things...a joy that overcomes even the most challenging and painful of life and comes out so bright it impacts everyone around. Everyone who has met Louie

has been changed by the joy shining so bright in his eyes and smile.

4. After the party, we then had a beautiful moment with some of our dearest friends where Louie was baptized in the therapy pool of the hospital. We sang a few songs and cried many tears, as happiness was eluded from his every giggle as he was baptized. He was so proud and excited and the room was filled with great emotion. It was a moment that will be held dear to our hearts forever.

Friends, there is such hope in knowing that in the days to come, with life and death so closely tied for Louie right now, that there will never be good-bye - it will always be "See you later son." We remain so thankful the those days at the hospital that captured so many memories to be cherished and thus we wanted to share glimpses of them with you.

Photos









Comments

Praying for you all!

—*Natalie Hill, February 18, 2019*

Continued prayers! You have all touched so many hearts & lives...especially your precious Louie! God bless you all with peace, strength & comfort in the days to come.

♥□□□□

—*Jenna McDonnough, February 18, 2019*

I sure do love Louie and your precious family! Thinking of you often.

—*Sydney Davenport, February 18, 2019*

Such a beautiful story and testimony. My heart breaks for the family who I know will miss Louie so much, but, what a wonderful reunion they all will have one day! Prayers for you all.♥

—*Lori Yeager, February 18, 2019*

Thank you for sharing your sweet Louie moments! Praying for many more special memories for you and your family.

—*Ellie Williams, February 18, 2019*

Hello! Thank you for sharing Louie's story with the world. I showed his news story with my fifth grade students and it touched their hearts. They couldn't wait to write him letters from across the world, Abu Dhabi, and let him know he has people rooting for him. I hope the letters reached Louie. Best wishes to Louie and his whole family from the UAE! □□□□

—*Summer Dickinson, February 19, 2019*

Louie, you are such a cutie patootie!!!! Sure hope we can meet you, your brother's and sister's one day soon! Tell your mom and dad hello for Alvin and I!

Love,
Dana

—Dana Shepard, February 19, 2019

The World Sees my Son

February 20, 2019

We can go through so much of our life feeling invisible...even to those closest to us. We walk around with our eyes down, when we really want and long for our gaze to be met...but not just by anyone, but by someone who will not offer empty greetings but one who will see deep into us and care.

Louie was born into an invisible life of neglect and foster care, but it didn't stay that way. Everything for him and his brother changed with a picture. A simple act. Two sweet and innocent boys dressed up and smiling and believing they could be seen. Christie Erwin, a volunteer photographer, and the great vision of Project Zero opened our eyes to Louie and Peter.

As we met the boys for the first time at the Project Zero Disney Extravaganza of 2013, we bent down and looked into their eyes and were amazed at the hope in them. We knew that day, that their hope was now ours. We were paving the way to be a family. I was no longer desiring motherhood, but would be first called mom by these little boys. My front row view into their eyes and lives has transformed me.

Louie has a knack for seeing people. He will smile at everyone. He never sees race, socio-economic differences, handicaps, genders...none of it. Louie sees ALL people. He will find those no one else notices and be drawn to them. He looks everyone in the eye, even those whom it makes uncomfortable. He speaks to everyone. I remember in the grocery store turning for a moment in the produce section to get bananas and as I turned back around I see Louie a few feet away. He is standing next to a man in a motorized wheelchair and on oxygen. Louie is holding his shirt up showing the man his feeding tube. He points to the man's nose and says, "I have a tube too." He then smiles and tells the man he will pray for him...then prays right there in the produce section. This is Louie's life. It is who he is. When he sees you, he doesn't do it for his own gain, but to simply give you the opportunity to meet his gaze...to smile back...to have the innocence of a child fill your eyes with hope again.

Over the years, we have stayed connected to the beautiful mission and passion of Project Zero. As Louie has battled for his life, Christie and Project Zero have faithfully

checked on him and cared for him in various ways. But as we prepared to come home on hospice, Project Zero provided us an unrepayable gift. They stepped in to open the door for others to see Louie, the way Louie sees them. They took his love for mail and gave it a voice. They advocated for him to have as much joy as possible as he faces what crumbles us as adults. In doing so, Louie has received mail of love, support, stickers, gifts, and more from all over the world. It has provided smiles and purpose to his days.

But even more than that, the investment of Project Zero has allowed the world to have a glimpse of THE SON through my son. Louie's sees and loves because of who he knows Jesus to be. Our faith in God has been our strength and for Louie it is his eyes into the world. Louie seeing people, has made the world a better place. Now I pray that the world seeing Louie, will make us better people. May it give us courage to step into the light and see we are not invisible. There is a God who sees us...

Comments

Indeed he does. I remember at the Ballpark when LRC was playing Softball meeting these two precious children for the first time. They immediately reached my heart. I love and cherish the little winks that Louie and I shared at church. He would turn around and we would wink back and forth and smile. Louie and Peter are definitely both treasures. You and Eric have done an amazing job of loving and parenting these two boys. Love you all!

—pat downs, February 20, 2019

Love you bunches, Louie! Your kind heart and your love for people makes my heart smile. You are one fine kiddo!!! Hugs to you, Tracey

—Tracey Adams, February 20, 2019

Thank you for sharing this journal Kristy. You have really done something to this old heart of mine. I feel the difference!

—Dana Shepard, February 20, 2019

What a touching and heartfelt story that you shared with us! I have been following Louie's story ever since I saw it on Project Zero's Facebook page. I have been praying for your family and Louie. It is so heartwarming to see God's love going to work in your family and with those who are making Louis so happy with all the mail he receives. Prayers are going up for you all from Smithville, AR in northeast Arkansas. ♥

—Kristy Whitmire, February 20, 2019

Such a beautiful message! I love the work that Project Zero does!!

—Anna Bowman, February 20, 2019

good luck guys i hope your story inspires others

—Dylan Gray, February 26, 2019

This is great. i hope Louie gets better. Sending prayers from St. Francisville, Louisiana

—Michael Orr, February 27, 2019

Hello Louie's mom i'm happy that Louie loved his cards.

—Breanna Spangler, February 28, 2019

—Marissa Patterson, March 1, 2019

You're inspiring a lot of people.

—T C, March 1, 2019

You are my Hero Louie and your Mom, I am writing this through a river of tears, you are so precious and you have touched me and my husband in a mighty way, God Bless you Sweetheart and your family, we will continue to pray for you and your family ☺☺☺☺☺☺

—Joy Stuckey, March 1, 2019

From Acquaintance to Friend

February 23, 2019



We know many people in our lives. We have many acquaintances. But where is the point when a person crosses from acquaintance to friend? When does the impact of their life on your own become great enough that you value the relationship high enough to consider them a friend?

Louie has me thinking a lot about people and relationships. As I have had a front row seat to seeing him draw people into friendship, I have been amazed at the ease of the process. Friendship with Louie is simple...it is acceptance...it is honesty...it is time in conversation...and it is forgiveness. As an adult, I can get so consumed by friendship being about me and my own needs or expectations. For Louie, friendship is making someone smile even on the hard days...it is love removing barriers.

After the news story aired asking for mail for Louie, the outpouring of love and support from the community (and even around the world) has been overwhelmingly beautiful. During that time, we were contacted by an acquaintance...someone who we knew and traveled in similar circles, but had minimal personal connection. He had seen Louie's story and wanted to know more about Louie and his interests. As he discovered Louie's love for law enforcement and people in uniform, he began a series of events that has forever left a mark on our family.

With 7 emails and about 24 hours of notice, he arranged a parade of close to 150 police cars, fire trucks, ambulances, mounted patrol, and a medflight helicopter from about 26 different agencies past our house...THE LOUIE PARADE... My sweet 9 year old, with the biggest smile, sat in our driveway as the lights and sirens passed our house one after the other. In the process, it was more than just a parade of vehicles, it was a parade of hope and joy and support that flooded our hearts. The finest men and women of our community - the ones who serve and protect each and every day - were lining up to honor and stand with Louie. The amazing thing for me is that these first responders save lives each day...and my son, in the simple way he loves people, saves lives as he points others to Jesus - points us towards being better people - points us to love enough to allow acquaintances the risk of friendship...

You see, as Louie looks into the eyes of whoever is before him and asks them his favorite questions, "what you doing? What you doing tomorrow?", he does so with an innocent hand of friendship extended. Louie doesn't desire to have acquaintances that you simply wave as you pass by. Louie wants to look you in the eye and know you. He wants to connect. He wants to laugh and smile with you. There are no strings attached. It is simple and pure and like Jesus. It is the truest form of friendship I have ever witnessed.

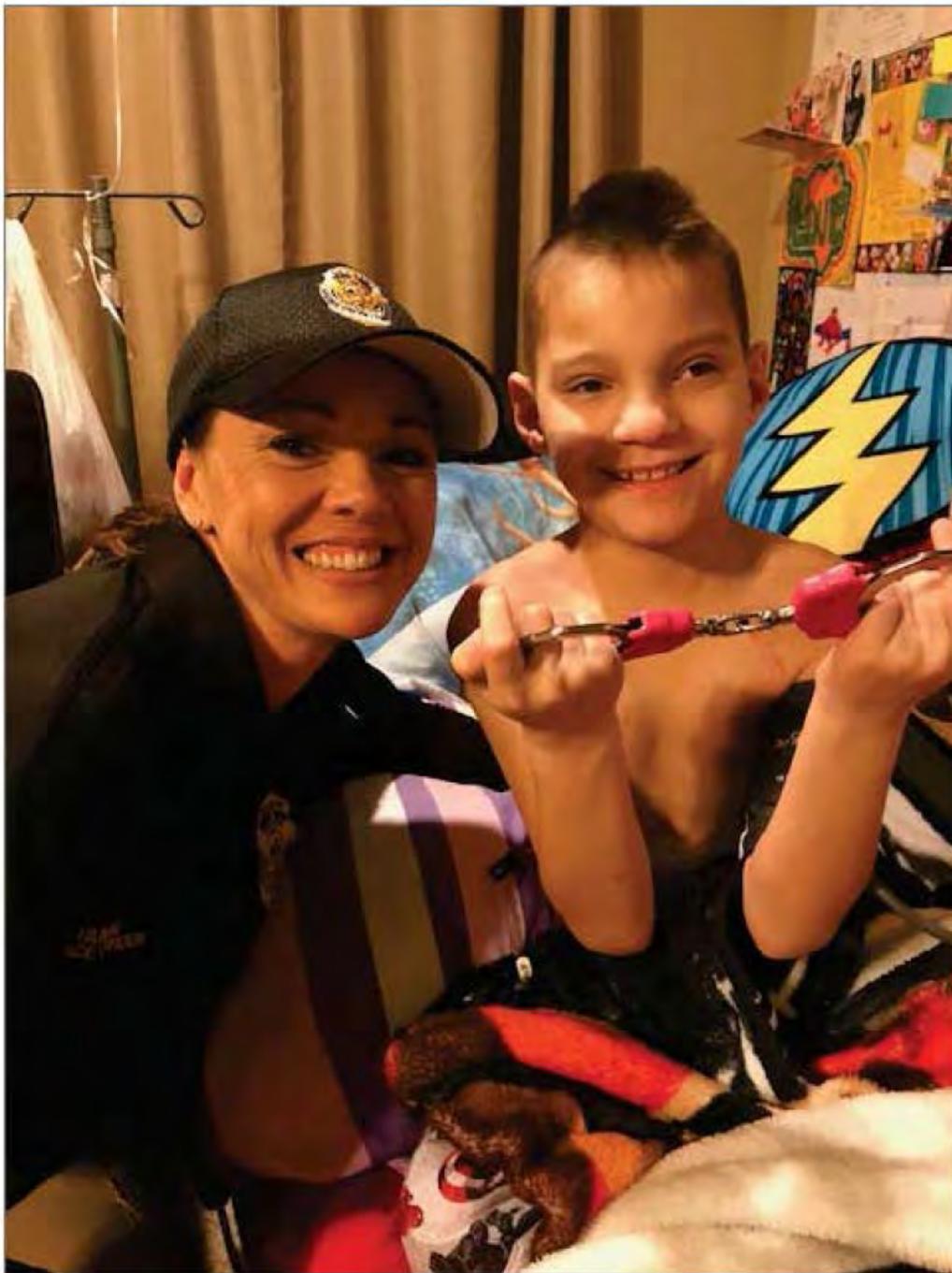
So as I think back on that beautiful morning, it is one I will cherish forever in great part because an acquaintance became a friend. Adam Baker, your friendship with Louie the

past two weeks has brought immeasurable joy to him and our family. As you have spent time with him and shared your friends in uniform every day since, we have been blown away by your love for our family. It is an honor to count you a friend.

Photos









Comments

Our mutual friends, the Bakers, are a wonderful family with such caring hearts. I'm so grateful that Adam shared Louie's Parade and that I could come to know Louie's story. Most especially, to know Louie's faith!

Already, Louie, you have blessed myself and my family and so many other people across the world! What a marvelous gift you have given to us all! You've made Jesus smile!

What a wonderful meeting you will have in heaven!!

Thank you, Louie! And thanks to your Mommy and Daddy for letting us share just a little of your time on earth. Prayers and blessings for your beautiful family.

Vicki

—Vicki Barney, March 2, 2019

From Mail to Mission

February 25, 2019

Louie loves mail! There couldn't be a simpler but more true sentence. I wrote it about a month ago as we prepared to bring him home from the hospital. What transpired then is nothing short of amazing! He was flooded with letters. This then began the goal of having mail from all 50 states. Then when that goal was too small, it turned into mail from all over the world (over 30 countries). Louie has received the most creative homemade cards, plus stickers, jokes, letters, patches, activity books, hats, stuffed animals, and so much more from literally THOUSANDS of people of all ages and places. Louie has daily enjoyed looking at his mail.

Yet what has been overwhelming to us as parents is that each letter represents a person...a person with their own story. A person who in the midst of their own joys and hurts, took a moment to know the name of our little boy. A person who paused their life to bring a smile to his. Oh how I wish I could meet and hug and thank every one of them. I wish I could sit over hot chocolate (because it is better than coffee) and hear their stories. I wish each of them could look Louie in his green eyes as he smiles and asks them "What you doing?" and they see the beautiful peace and joy in him.

However, Louie's time on earth is coming near an end. There won't be opportunities for all the conversations and moments I wish we could have. But what there is, is a childlike faith present in my little boy that is leading me through the tears. Louie's challenge for mail from all over the country and world has been met. Louie has unbelievable peace about what is to come for him (something I will write more about later)...

But the question for us is, will Louie's quest for mail transition to a call to live his mission, his legacy in our own lives? Will it be something neat we did once, or will it be a marker of growth and change in our own journey? Louie knows mail is not eternal...but he also knows what is eternal. All the mail and stuff will decay but the two eternal are God and the souls of man. It only takes talking to him for 5 minutes to see his love and understanding of God and his passion for loving people. His faith in God and love for others runs so deep it draws you in and leaves you wanting more.

Selfishly I want that to be more time with him. I want that to be more time this side of Heaven. However, only God determines the number of his days, or ours...but we determine what we do with those days. I want to live the simple pursuit of knowing God and loving others that I have seen in Louie. This has been his pursuit...his mission. Will it be yours too?

Comments

Just WOW! ☐☐

—*Dana Shepard, February 25, 2019*

I had the opportunity to briefly meet Louie Saturday. The moment I stepped into his room, I felt loved. This young man truly embodies the spirit & love of God.

—*Marvon Browning, February 25, 2019*

Thanks for allowing us to worship with Louie yesterday! His love for Jesus is so real and his faith so strong that he should've been serving me communion instead of the other way around. Still praying for all of the Schneiders..

—*Jack Ciak, February 25, 2019*

Louie, you make me smile! I will keep your sweet love for people in my heart forever. You have challenged me to love people like you would love them. Little man, love and big hugs your way! I am a heart that has grown larger because of you..

—*Tracey Adams, February 27, 2019*

I have never met Louie personally but can feel his love for God and everyone around him through what you write. I have been praying for him tonight. May God be with you all through this difficult time and grant you peace in your hearts. God is the ultimate healer. I will do my best to live like Louie!

—*Kristy Whitmire, February 27, 2019*

Hello Louie,

I wanted to tell you that you have touched my heart in away that is covered in Gods love. Although I don't know your story I am grateful for your courageous heart and soul. I am asking that the Lord send a circle of angels to protect and guide you through your journey. As I sit here with the sun on my face I know that his glory is with you. Love you and may peace be with you all the days of your life.

Love,
Jesse

—*Jessica Toombs, February 28, 2019*

A New Path

February 28, 2019

Nine days ago, Louie woke up in the morning and with great confidence proclaimed, "ready see Jesus in Heaven." With those five words, my heart stopped for a moment. I knelt next to his bed and looked deep into his green eyes, and what I saw I will never forget. Peace. Joy. Hope. Love. The purest of all of these that I have experienced on earth radiated from his eyes. As we spent time talking about what he meant, it was clear that God was preparing him for a new path...for a path back to Himself.

My instinct over the past few days has been to fight against this new path. My humanity craves more...more time, more giggles, more moments of him playing with his siblings, more...just more of everything. I selfishly want to beg my little boy to fight longer and fight harder because the sadness of all I will miss about his beautiful presence is so big.

Yet each day, he looks deeper into my eyes with the peace and resolve of Jesus, and I know Louie is ready to not hurt anymore...not have medication and machines around constantly...and ready to RUN on this new path. He sees Jesus before him and with the innocence of childlike faith, nothing of this earth can compare to that glorious path.

For Louie, the path is paved with all that he longs for. For me, the path is tainted by all I will miss...that is until I fall on my knees. When I take a moment to stop in the grief and turn my eyes to Jesus, the very place Louie has been pointing me all along, I am able to see the presence of God holding my trembling hands as I open them before Him and cry out, Lord, not my will but yours be done. In that moment, I am able to bring into vision all the beautiful ways God is walking us, guiding us, and carrying us on this path. And in that moment, I too am overcome with God's peace...the peace that Louie has not waived in.

Today is another step on this path... Today we return to the hospital and prepare for the final "see you later." As I weep in my closet writing and thinking about all that is coming, I return again and again to the words of the song Natalie Grant sang over me yesterday, "Help me want the Healer, more than the healing; Help me want the Savior, more than the saving; Help me want the Giver, more than the giving; Help me want you Jesus, more than anything." Oh how my flesh cries out against this path, but Lord I want you more than anything. I want you Lord like Louie does...so we hold hands and take these steps one at a time on this new path, together, as a family...

Comments

Love you Kristy, thank you for sharing your heart and a glimpse into His heart! Praying for and crying with you all!

—*Kayla Romero Dombrosky, February 28, 2019*

May God be with you today as you continue to prepare for Louie's "going home".
♥♥☐☐☐☐☐☐☐ You are such an amazing family, and it has been my greatest blessing to send cards to this most precious young man. I pray to Jesus, with you and your beautiful family, that Louie is soon pain-free, and will be walking into the gates of Heaven.
☐☐☐☐☐☐☐☐☐♥♥

—*Candy Gates, February 28, 2019*

I don't know you but I have been following Louie's story ! What an amazing little boy! I hurt for you as his mom but I know God will be all you need! Continued prayers!

—*Kim Dillard, February 28, 2019*

My thoughts and prayers are with your family. You are such a strong person. Louie is a special little boy. He has been blessed to be part of such a wonderful family.

—*Parthenia (Tena) Taylor, February 28, 2019*

Kristy, I cannot imagine your grief. Know that I am praying for Louie and your whole family. May Christ give you strength and peace beyond understanding.

—*LaNell Crook, February 28, 2019*

Oh, how my heart is heavy for you. What a testimony you and Louie are sharing with is! I can't begin to imagine what you are feeling, but I am keeping you close in my thoughts and prayers. Louie, a precious soul, your earthly journey to Jesus has forever touched me. I will love others following your kind ways.

—*Tracey Adams, February 28, 2019*

We have mutual friends and I have followed your family through this journey. The love you all show is truly inspiring and Louie is amazing! I pray God heals you all and give you the peace you all deserve. I wish I could meet that wonderful little boy. Stay strong and know that we all are still praying for you all

—*Michelle Hardy, February 28, 2019*

♥□□□□□□□□□□□□♥□□□□

—*Laurie Dombrosky, February 28, 2019*

Kristie, I find strength from you and Louie. Your words and his journey have guided me daily on a path of faith, hope, and belief! Caden and I talk about and pray for Louie, and he truly cares about the two of you and your family. Love and hugs, my dear friend!

—*Melinda Gilley, February 28, 2019*

Oh sweet friend! I know our paths are different, but I wanted you to know you are heavy on my heart. I prayed this morning that God would do for you what He has been doing for me, that your needs would be met before you even know you have need and that you would have the strength to get up each morning. Praying!

—*Rachel Bennett, February 28, 2019*

Louie has taught us SO much about life, about Jesus, and about true Love. Praying for him to make an easy and peaceful transition to live with our Savior. He will wait for you there. One day I will meet Louie, too. Be blessed.

—*Tena Sanders, February 28, 2019*

I don't know you or Louie but I feel like I do because you are my brother and sister in Christ! This story about Louie has touched my heart and soul. I'll be praying for Louie and all of his family! May God Bless all of you!

—*Dorothy Chaffin, February 28, 2019*

You have great faith Kristy and so does Louie. Praying for you all in the coming days. Love you much!

—*Anna Bowman, February 28, 2019*

The faith of your little boy has inspired me and I pray that I have that faith and love like his! I'm making that my goal from this day forward. You are in my prayers!

—*Debbie Ball, February 28, 2019*

My heart is heavy for you all and Louie. Through my fellow brothers and sisters in blue I have been able to follow Louie's fight. I am so humble I have gotten to see his happiness of others visiting with him and sending him little pieces of them and others that support him. His faith is strong as he is and it's such a blessing to know and see it in him. My thoughts and prayers have been and will continue to be with and for all of you. Much love being sent your way.

—*Amanda Chaney, February 28, 2019*

Your wonderful son has such great faith in his Heavenly Father! I wish we could all be such faithful followers and just trust in God's chosen path for us. Let us learn a valuable lesson from this amazing young man!

—*Kristy Whitmire, February 28, 2019*

Sending many prayers to your precious son and to your family!!

—*Stacey Ray, February 28, 2019*

Louie's faith & joy have inspired me so much. He has shown me how to look past illness & pain & see Jesus clearly. I have seen joy on Louie's face every time I see his picture. May I always remember to love like Louie.

—*Marvon Browning, February 28, 2019*

Thanks for giving me the opportunity to pray for you and for Louie. ♥□□□♥

—*Vicki Barney, February 28, 2019*

Praying for Louie and the family. I pray for y'all to have complete peace and the comfort of the Holy Spirit with you always.

—*Doris Perkins, February 28, 2019*

Praying for you and your family. Louie, you are such an inspiration to so many people. May God Bless you!

—*Susan Blue, February 28, 2019*

I love you precious friend. I love you very much. :(

—*Kelly Murrie, February 28, 2019*

Hugs Kristy praying peace upon your family, your family has been on my mind all night for today. I see your precious babies eyes in my head and thankful what a warrior he is and that the joy Louie has brought to many as we come together reading your journey. Louie will never be forgotten and always in my heart.
April

—*April Garcia-Woodard, February 28, 2019*

Hug and love to you kristy praying for peace and comfort for you and your family as and educator I see and learn a lot this is such a beautiful word and brings be to tears I'd love to meet your son you are truly blessed

—*Kevin Johnson Jr., February 28, 2019*

Hug and love to you kristy praying for peace and comfort for you and your family as and educator I see and learn a lot this is such a beautiful word and brings be to tears I'd love to meet your son you are truly blessed

—*Kevin Johnson Jr., February 28, 2019*

Hug and love to you kristy praying for peace and comfort for you and your family as and educator I see and learn a lot this is such a beautiful word and brings be to tears I'd love to meet your son you are truly blessed

—*Kevin Johnson Jr., February 28, 2019*

Prayers that God will comfort you and bring you peace in the days to come. Prayers for

all of you. Louie is such a precious boy and loved by many. You had an awesome escort buddy!

—*amanda lake, February 28, 2019*

God bless you and your whole family during this time. Thank you for sharing Louie's walk here and into his faith. #lovelouie #forever

—*Louann Smith Harasym, February 28, 2019*

God bless you Louie!! Louie's mom, dad, Brothers and Sisters you all are amazing to me! God's grace will see you all through this amazing Angel's life! I am so touched by Louie's story thank you and with all of my love, a GREAT BIG OLE HUG!

—*Larry Collins, February 28, 2019*

What a testimony Louie has shown to the world! Thank you, Louie, for this amazing gift! And thank you, Jesus, for your awesome power You have demonstrated through this journey.

—*Barbata McCreight, February 28, 2019*

Louie you have shown strength like no other. Your family is truly amazing. May God continue to strengthen each of you as you walk out this journey. ♥

—*Tanya Brooks, February 28, 2019*

Prayers for you and your family. ♥☐☐☐☐

—*Angela Shepard, February 28, 2019*

Out of the mouths of babes! ♥ Louie you are such an inspiration to all of God's children! Your journey has inspired so many people to be prepared to meet Jesus and to renew our faith! Prayers for comfort and peace for you and your family as you complete your journey!☐☐☐☐♥

—*Cathy Perkins, February 28, 2019*

☐☐☐☐☐☐

—*Siernna Wallace Harris, February 28, 2019*

God is truly taking this precious young man under his wings, I have never been so

touched ever by such faith and courage Louie has, my prayers are with him and his entire family..God Bless you all♥

—*Debbie Thomas, February 28, 2019*

Prayers for Louie and his family. This baby is wise beyond his years. Prayers for peace and comfort in the coming days. ♥

—*Whitney Ussery-Nowlin, February 28, 2019*

I was on the interstate this morning when you went by,your story had touched my heart, we are all longing to see Jesus! Your in my prayers!

—*Julie Bryant, February 28, 2019*

Jim and I just want you to know that we love you all and are praying for you.

—*Donna Hathcock, February 28, 2019*

God Bless you sweet Louie and all your family!! My heart and prayers are with you all!!

—*Terry Blair, February 28, 2019*

I just found out about you this week. My heart breaks for you. I've also been down this road with my 5 yr grandson. My thoughts have been with you all day. I'm sending prayers for your family. I have all these young children pictured in Heaven playing and running together. All healthy & whole again. They are having the best time ever in Heaven! ♥

—*Beverly McKinley, February 28, 2019*

Thank you for sharing your love story with god be blessed your family has my continued prayers

—*Myra Ferrell, March 1, 2019*

I do not know you, but thank you so much for sharing your heart. We are in the process of losing a grandbaby. Your words we're a great strength to me to keep my eyes & focus on Jesus.

—*Pam Rosinbaum, March 1, 2019*

May god give you the comfort you and your family need to get thru this time. God bless

the children.

—Wanda Cook, March 1, 2019

I have been keeping up with Louie's journey closely. My daughter is Katelyn Bates and she had the honor of having Louie the last couple of summers at Peds Plus. She immediately fell in love with your sweet boy on Day 1 and came home telling me about "the most precious boy she has ever met".... she loves him fiercely! He has impacted her forever and we believe that her ministry of OT will reflect his legacy! My husband and I are executive pastors for New Life Church for the state of Arkansas, we currently have 17 campuses.... I tell you that because we have placed Louie and your family in our prayer request and our entire church is coming alongside you, your friends, family, church, and community in lifting you up to our Heavenly Father. There is NO DOUBT, that Louie's life and legacy will leave a major imprint on this world and point people to the only thing that matters, Jesus! God bless you all! ♥

—Sherlyn Bates, March 1, 2019

My heart was sooo blessed seeing your sweet Louie being escorted to Children's yesterday. The outpouring of love and his sweet waves brought the tears rolling down my cheeks. Louie has such a blessed relationship with Jesus ♥ This has to be comforting to your heart.

Sending much love and prayers to you and your family ♥□□□♥

—Dee Mack, March 1, 2019

Louie you are such a brave lil boy! Your life is a testimony. Dream big and they will soon come true when you see the one and only Jesus! We all love you very much! Prayers for peace and comfort for Louie and his family. Fly high buddy!!!

—Patti Stroud, March 1, 2019

Louie, you have given me so much inspiration and hope From our family at PPG to the entire Schneider family, we are with you in our thoughts and in our prayers.

—Neal Nicastro, March 1, 2019

I have just heard of Louie today. May God take him in his arms and show him the love that you have shown to him. I myself am a mother to adopted foster children. It breaks my heart for you and with you. May God also put his loving hand on yours when the final day comes.

—Pamela Dropkin, March 1, 2019

You have conveyed your heart of passion and grief vividly and pointed us all directly to what our souls long for: peace with God through Jesus. See, I don't know you but I'm instantly drawn to you as if I do, because I recognize my Lord right there in your poignancy and faith. And I will know Louie the instant I step on that other shore. Thank you for sharing him with the WORLD! I am praying for you all.

"The LORD gives perfect peace to those whose faith is firm. So always trust the LORD because He is forever our mighty rock."

Isaiah 26:3-4 (CEV)

—*Lannece Mayo, March 1, 2019*

I have been following Louie's journey on Facebook. What a remarkable young Christian man you have. I can't imagine what heartbreak you and your family are going through. Please know that people like me, who you don't know, are praying for all of you.

—*Sally Harris Barnett, March 1, 2019*

What a beautiful testimony to the one who gave it all for us. Louie knows it's a see you later and in this take comfort. Sending love and prayers.

—*Jana Barnett, March 1, 2019*

Stay strong Louie! We all love you and are praying for you and your family. God is waiting for you.

—*Beverly Frye, March 1, 2019*

I have never met you or any of your family, Louie. I just saw your story on Facebook. Your faith has given me so much courage. You are leaving a BIG mark on this world...a love for and faith in God, compassion and peace. Thank you for your testimony. God is going to be so happy to see you!

I am so glad I learned about you. Prayers for you and your family.

—*Debbie Hamilton, March 1, 2019*

Louie, You are a wise boy with a beautiful heart and soul. Hugs and prayers to you and your family. I'm truly blessed and honored to have read about you. You have the best smile. Much love to you from St. Peter's, Missouri.

—*Carla Clapp, March 1, 2019*

Thank you Louie for sharing your faith and journey in Jesus. Your faith has given me

courage and strength. Your compassion, love and faith for Christ has touched many souls and will continue to be a testimony to others. Sending nonstop prayers Louie for you and your family. Love to all Sweetheart. God bless.

—Kelli J. Hunter, March 1, 2019

Louie, you are such an encouragement to me! You have showed me what a true Christian is. Please know that I love you and are praying for you.

—Marquita Schneider, March 2, 2019

Louie so many of us have fallen in love with you and your family!! You are a superstar!! We are all praying for you and your family!! You are the just the best!!
♥♥

—Vada Harris, March 2, 2019

Louie, even though we've never met, I have come to love you and your family. You are such a brave and strong young man. Thank you for being a shining example of how we are supposed to be. We at Salem Elementary are praying for you. ♥

—Kim Wilson, March 2, 2019

Prayers for this sweet baby :(prayers for his momma and family too.

—Megan Ford, March 4, 2019

When Words Fail

March 2, 2019

"Use your words!" It is a phrase I use constantly with my toddlers. When they are sad...when they are angry...when there is a fit in progress...many times a day I remind them to use their words. As parents part of our job is to help our children learn to communicate. We want them to articulate their needs, wants, fears, hopes, dreams - everything. When we have words, it is so much easier to navigate the world.

When Louie first moved into our home at the age of 4, he didn't have words. He had no voice. He had never had the investment it takes to learn how to speak for himself. Yet, Loue has always loved music. I remember early on, Louie, with a massive smile, would

hold a toy guitar and sing his favorite song which went like this, "oh da-da....oh da-da....oh da-da!" The whole time his eyes would be locked on his dad. It was beautiful music to our ears.

Then after working with him tirelessly and having him engaged in many hours a week of therapy, Louie began to grow mightily in his vocabulary and ability to orally communicate. He might not always have the right grammar, but you knew what he wanted as we taught him to "use his words." Over the years, there have been many Louie-isms in our house. Phrases like, "no me like it" and "sweet pa-potatoes". But my favorite is, "all ever." Instead of forever, Louie has always said "all ever."

In facing death, Louie's words have been very simple, "ready to see Jesus" or "going to heaven" or "no more hurting." His peace and resolve as he says it, screams volumes. Yet as an adult, as his mother, each day there are more and more moments where I fail to have words to comprehend the moment. Death is not something most of us are comfortable talking about or facing. There is such a sadness and desire to resist it, that it clouds our ability to hold on to the only hope that is present in death... "Christ in you, the hope of glory." Colossians 1:27.

Our heart cries out to understand. Our sadness draws us to the whys. And when we sit in a world filled with sin and so much hurt, pain, anger, and just ugliness around us, our words will fail us. The answers to the why questions will be empty words and trite statements that don't soothe our aching hearts. Instead of using words, our pain will keep the tears focused on the questions without answers.

So how do we cope with the unimaginable? How do we walk ourselves through the depths of grief and pain? How do we respond when there are no answers? Right now, as my son lays in bed next to me sleeping, days away from death, friends, I don't have it figured out. My words have failed and I grasp to each moment left... BUT...

But there is one thing I keep returning to... One moment on Thursday where I opened my mouth and what came out wasn't refined thoughts, but an instinctual response from God. I was talking with a reporter about Louie's story and the amazing ride to the hospital. The reporter through tears said, "I guess it shows how much he is hurting that he longing to 'be with Jesus' so badly." Without hesitation, I found myself saying, "or maybe it is that Louie sees the greatness of the glory of Heaven so clearly that it far outweighs anything of this earth. Maybe it is not about fleeing the pain here, but running to the goodness of God there."

As I strive to make it through each moment we have left, the words are failing me more and more. But when I remember the beauty of knowing God and the longing Louie has to be complete and whole in Heaven, I am able to take a deep breath. I am able to find the courage, not the words, to sit in the heaviness of the moment and know that what is

to come for him far outweighs what he is leaving behind. Louie has peace because he knows he was never created for this world to be his "all ever." His "all ever" was always intended to be with Jesus in Heaven....dancing on streets of gold without braces on his legs...singing with no lack of words in worship of God...and tickling Jesus as he snuggles in his lap.

If only we lived our life with the simple resolve to love God and others in a way that when our words fail, we only see the finish line...."all ever" with Jesus...

Comments

So beautiful Kristy! Thank you for this perspective of running to the goodness of God instead of focusing on what we are losing here on earth ♥

—Anna Bowman, March 2, 2019

Beautiful thoughts put into words.

—Parthenia (Tena) Taylor, March 2, 2019

Beautifully expressed! Lives have been touched by Louie and his impact will last "all ever"!

—Kim Dillard, March 2, 2019

Your words are so insightful. Louie has stolen the hearts of thousands of people. He has restored my faith. I know we are a selfish people because we never want our loved ones to go. Reading his way of thinking brings joy that he knows what is coming and he is ready for that almighty hug and tickle. God bless you Louie!

—Wanda Cook, March 2, 2019

Kristy, again I have no words. Just visions of Louie in Heaven with Jesus "all ever"! ♥□□□□□□□

—Laurie Dombrosky, March 2, 2019

Oh, Kristy.

It is quite obvious, in coming to know you through this beautiful world of Caringbridge, that you will continue to be Louie's voice.

Long after he is gone, you will carry his story. It is no wonder, honestly, why God chose YOU to be his mama.

So often in life, we assume things will go our way. The way we imagined in our heads.

The way we, without saying it out loud, presume it will go, because we want it to....dammit!

But, in the real world, we bury our babies. We face unimaginable challenges. We are left to carry scars far too heavy and wide for our simple human minds to have ever fathomed. And, perhaps, that is why we didnt ever foresee them in our futures.

Your words are so perfect. Your descriptions so crisp and eloquent. Your love is so Christ like. You chose Louie. He chose you. And God chose you both.

I am so honored to have "met" you both, thanks to my friend, Lewis. I am so happy that you've come here, to the Caringbridge world. A world that helped me heal my broken heart when I, myself, lost my son. This safe place of other people just like us, is where I found MY words.

Words heal. They help our hearts. They allow us to let the pain out in a trickle, and to have some kind of control over our out of control moments.

This place is safe. You are not alone here. You are not a minority here...because Caringbridge is full of "us."

Keep writing. Soak in every second of Louie. And keep letting your words flow like healing ointment through your heart, onto this page, and into all of our hearts.

You are so obviously doing Gods work here. And, you are never, ever alone.

—Jennifer Naeger, March 2, 2019

I have seen your story and as I watch from afar at all the people your son has truly touched I can't help but to think of the song " It is Well With My Soul". Your son can truly say this and know that while he is an amazing example to those around him It is Well with his Soul and know he has an eternity with our Lord. What Peace!

—Denise McClain, March 2, 2019

I JUST JOINED, but want to simply say that this is a beautiful testimony of God at work ☺☺ prayers for Louie and all of your family and friends...love and hugs from WI

—Debbie Hauser, March 2, 2019

Oh Kristy! What a beautiful child you were blessed with. And God certainly gave him THE parent. "Running to the goodness of God" God appointed then, anointed those words. What power.

Asking God to pour out sweetness and peace and contentment. Physical and emotional well-being. To make you, Louie and your family so aware of His nearness.

Love and prayers.

—*Debbie Hamilton, March 2, 2019*

What an amazing God we have! This is a true testimony to Gods grace and sovereignty. One day we will all be reunited. Louie will be waiting for you with open arms and you will be together "all ever".
Absolutely amazing!

—*aprill garretson, March 2, 2019*

Beautiful words of hope, peace, and comfort. We are sending prayers to you all from Texas. May we all strive to have Louie's faith and strength!

—*Anna Hederman, March 2, 2019*

God is pouring goodness out of your grief. What a powerful message. Im praying for you all now.

—*Lajuana Magee, March 2, 2019*

Your words & heart are beautiful. Please know my prayers are with Louie & your entire family. And that, through this journey, you all have been a witness & blessing to many.

—*Leigh Russell, March 2, 2019*

God Bless You All Allways.

—*Cynthia Harris, March 2, 2019*

I was honored to be a part of Louie's walk down the red carpet at GKTW to see Mayor Clayton and Miss Mary. My prayers are with all of you as you continue this journey. God bless♥☐☐

—*Laura Verbrugge, March 2, 2019*

I pray that the next few days are filled with joy for you all and Louie as he prepares to meet his great and awesome Lord! What an awesome child of God that Louie is!!

—*Kristy Whitmire, March 2, 2019*

Your in our prayers, may the God of all comfort be especially near you all♥♥♥

—Julie Bryant, March 2, 2019

Sigh.... y'all were chosen to be his family sweet friend. God knew what that would mean and what a precious blessing it would be to you all. What a poignant new hunger for Heaven you all must have. I love you my friend. All ever. ♥

—Kelly Murrie, March 2, 2019

You and Louie are such an inspiration! May our sweet Jesus continue to hold you all in His arms.

—Brenda Kimbell, March 2, 2019

Words have not failed you at all, Kristy. Your writing is not just words strewn together. It is a passionate and heartfelt crying out of the soul that touches the world in a way that you can't possibly know. You have a gift and you are using it for the glory of God. Thanks be to God! Much love to you and Louie and all your family. May God bless you all-ever.

—Barbata McCreight, March 3, 2019

As I sit here and cry, I really have no words. I long for words to provide comfort to your sweet Louie and your family, but alas they escape me. What a beautiful story of love for a beautiful little boy. What an incredible difference he has made in humanity n such a short time. Thank you for sharing his story for others to catch a glimpse of his sweet spirit.

Wishing you peace to pass all understanding and memories to sustain you "all ever".
Alisha Stane Guest

—Alisha Long, March 3, 2019

So sad. love to family

—Dorothy Morlan, March 3, 2019

Praying so hard for you. Praying that yiu not be suffering or struggling or hurting at anytime you are here on the earth. Jesus Christ's is the great doctor and he has healed ne on the earth many times and all things are possible with God. None of us know what God's plan is for any of our lives but I want you to be healed and in no pain for as long as God wants you to be here so that you can continue to shine your sweet loving light and hug your family and friends and make us all smile. One day, we will all meet in heaven. I look forward to that day ☺☺. But, I ask for God's Kindgom here on earth for all of us too

until we get to go to heaven. Please God, in your name, Jesus Christ, amen.

Ms. Cyndi
(Aunt Cyndi ☐☐)
Beautiful Blessings!

—*Cyndi Kelly, March 3, 2019*

Praying so hard for you. Praying that you not be suffering or struggling or hurting at anytime you are here on the earth. Jesus Christ's is the great doctor and he has healed me on the earth many times and all things are possible with God. None of us know what God's plan is for any of our lives but I want you to be healed and in no pain for as long as God wants you to be here so that you can continue to shine your sweet loving light and hug your family and friends and make us all smile. One day, we will all meet in heaven. I look forward to that day ☐☐. But, I ask for God's Kingdom here on earth for all of us too until we get to go to heaven. Please God, in your name, Jesus Christ, amen.

Ms. Cyndi
(Aunt Cyndi ☐☐)
Beautiful Blessings!

—*Cyndi Kelly, March 3, 2019*

Just left lunch after attending church and I see a friend's post on Facebook so I sit here and read this!!! What a powerful, beautiful post!! Thank you for sharing it with all of us. Praying for you and your sweet child. I know God will be with you.

—*Kelly Marie Davis, March 3, 2019*

May God be there for all of you. Provide peace, strength, and comfort. God bless you.

—*Jack Soliman, March 3, 2019*

May God be there for all of you. Provide peace, strength, and comfort. God bless you.

—*Jack Soliman, March 3, 2019*

Thank you for sharing your story. You have touched my heart. I am praying for Louie and your entire family. I have passed your story on to several members of our church in Broken Arrow, OK. My wife and I have a son that was just diagnosed with cancer. Your Use Your Words post struck a parental nerve. I am standing with you and praying for you. Oh how I long for the day that God redeems this fallen world. We desperately need the Savior, Jesus Christ. May God pour out His grace and mercy on you and your entire

family.

—Jimmy Carter, March 3, 2019

I will pray for your son and all that love him also. I was diagnosed with stage 4 cancer in May of 2018. It is not always easy, but with God I have found a peace. I pray for peace for your son and I pray for peace for you as his parents. I see that my diagnosis is easier for me than it has been for my family. Cancer touches everyone. I will keep you all in my prayers. We must all live like Louie.

—Alisha Long, March 8, 2019

Horizontal or Vertical??

March 4, 2019

The last two days with Louie have been sweet and tender. He has been alert and playful and filling our hearts with precious memories. The kids have laughed and played and painted until there was a beautiful mess everywhere. Overall, Louie has felt better than he has in months. It has been a tremendous blessing but has brought such internal conflict as well.

The conflict comes in the comparison. The conflict comes because on the outside looking in, for a moment, he doesn't look "that sick"...not sick enough to be dying. When I compare how he feels now to the agonizing decision to come to the hospital for his last days, satan begins to use the comparisons to draw out doubts and insecurities, and fears in me. Comparison steals my peace.

Peace is defined by the Webster dictionary as, "a state of tranquility or quiet...a freedom from disquieting or oppressive thoughts or emotions..." When I sit allowing comparison to dwell in my thoughts, the quiet in my soul is gone and the thoughts refuse to be still. I realize this truth is present not just in this moment, but has played out repeatedly in my life. When I compare what I have to what others have...when I compare what I look like to what I want to look like...when I compare my struggles to the seeming struggles of others...time and time again the comparisons bring discontent and steal any chance for peace. The intrusive and oppressive thoughts and emotions cause the tranquility to flee.

This has been the same struggle since the Garden of Eden. In that first story after creation in Genesis 3, we see a comparison of what could be, driving Adam and Eve to

buy into a lie and act on that lie. Their acting on the lie changed the trajectory of man as sin entered the world. So comparison is not a new struggle and is just as damaging today as it was in the garden...

Friends, where are you walking in comparison? Where are you lacking peace because your eyes are looking horizontally instead of vertically? One thing I have learned from Louie is to look vertically if I want peace. When I look at the world around me, when I look at my circumstances, I can't help but compare and sit in discontent over what I wish were different. This is not how Louie lives. Louie only looks horizontally to see people and help them look up. He looks vertically for his peace.

As Louie's body and skills have deteriorated, do you know that he has never once complained? He hasn't grown frustrated or compared himself to what others can do around him. Louie has stayed steadfast and rooted in a peace that allows him to smile, connect with people, and point them to the source of his joy - the Lord. As Louie faces death, we ask him how he feels and he constantly talks about seeing Jesus and all the things he wants to do in Heaven. There is never a concern or comparison for what he will miss on earth, there is a simple innocence as he looks vertically for his peace.

The last two beautifully good days for Louie are rooted in a body that is able to relax and not have to fight any longer. The days will begin to get harder...not for him but for us. For him, he will continue to undoubtedly look up and see Jesus closer and closer. He will sit with the hope of what is to come because that is the confidence and peace Louie has in eternity. The challenge for me is to join his gaze upward...to take my eyes off all the places of comparison and to instead see the glory that is to come. To look vertically is where peace is found...and that peace is the only way we can walk through the hard places of life with purpose in the pain.

Comments

Thank you! I am prayed for Louie and your family last night. I woke up praying for you this morning. I will pray for you throughout this day.

—*Jimmy Carter, March 4, 2019*

This child of god has really opened my eyes to a world beyond. To a god I have questioned why so many times. Your child was sent to this earth with gods work in his heart and soul. To save others and let them know heaven is the place to be. And a child shall lead them. This child has led me for sure. Thank you for sharing him with us.

—*Wanda Cook, March 4, 2019*

Saturday night I learned that we have a mutual friend, Jeanie Shook. She is more like a sister than a friend. Oh, how she makes me laugh.

Our sermon yesterday was about reaching for greener grass. Comparison often drives us to stick our heads through the fence in search of it instead of resting in contentment within our fence. As I read your post, I see your fenced area is a place of such struggle. Our mother's heart want what it wants. As God's daughters, we try to want what He wants or rest in what He allows. And there is the struggle. Praying God leads you beside still waters and into green pastures today. That He lifts your face to His.

To Louie: Young man, do you have any idea what a teacher you are? What a blessing you are? How much God has used you? We have never met, but in the last week your testimony has caused me to confess some of my sin and whining and refocus. Your peace and faith in God has encouraged me. Thank you for teaching me. Oh, how He loves you.

—*Debbie Hamilton, March 4, 2019*

Love the up dates and keeping yall in my prayers..America loves yll

—*Paulette Tatum, March 4, 2019*

Continue prayers ☺☺☺☺☺☺♥☺☺love all y'all

—*Angela Milam, March 4, 2019*

Thank you for sharing Gods Angel Louie with us. Because of him, I am a better person today. I pray for peace and comfort in the days ahead. I have read his journey and to see this child in front of us is a blessing to all. He is such a miracle to us all. I can only imagine what you are going through but at the same time, having your Angel beside you is comfort and a Blessing. God will see you through. Many prayers to all.

—*Phyllis Childers, March 4, 2019*

Although I've just been following your families journey a few days, I see God is BIG in you all. I wonder if this painful and difficult experience has brought you to this place. God has used the faith of your sweet son to build faith in the masses. He makes the thought of Heaven vibrant. My thoughts and prayers have been with you often Since I heard about all that's going on in your family. Thank you for being open and pouring out your heart in the post. I hear that pray connects the heart one one to another. My heart has been connected to yours ♥ May God be near you today.

—Lajuana Magee, March 4, 2019

What an amazing truth for all of us, Kristy. And what a beautiful picture of how Louie lives this truth, looking faithfully to Jesus. Love you friend!

—Kayla Romero Dombrosky, March 4, 2019

What a powerful message of truth. Thank you for sharing your faith through your struggles. Praying for peace and comfort for your family.

—carla Elder, March 4, 2019

I've been following Louie's story since Skeet & Lisha first shared something on Facebook. I'm conflicted between heartbreak for your family and pure awe at your spiritual strength.

It cannot be easy to share these precious moments with a world of strangers, but we applaud your strength so that we too may feel Louie's passion for the Lord and the security of knowing He has a plan for each of us! Continued prayers from Boerne, TX! ♥

—Lori Benich, March 4, 2019

Praying for all of Louie's family. Much love and peace and God's blessings as this beautiful young man continues to bless all of our hearts. Special prayer for Mom and Dad☺☺

—Debbie Bentley, March 4, 2019

Kristy, Thank you for sharing Louie with us. When we get heavy hearted and sad, we can look at his sweet pictures and that BIG Smile. We can hear his voice and take comfort in knowing he knows where he wants to go. His love for Jesus is so amazingly pure and beautiful. Your wonderful family is lifted in love and prayer and you will never walk alone. Louie has brought joy and the love of Jesus to so many that will never know him~ what an amazing legacy for your son! Louie is the living testimony of the fruit of the Spirit. I pray you feel the warm and comforting arms of Jesus wrapped around you ~ and the Love of all of us ~xoxo

—Jennifer Tarvin, March 4, 2019

Such a beautiful perspective! I would like to gift you with a teddy bear ☺☺ with Louie's heartbeat inside for you to have forever through a program set up in my sons memory, Catons Cubs. If you can find a small Doppler device there where you are (in the hospital?) and record his heartbeat on your phone and send it to me with your address I will send this to you . Can e-mail me the file with his heartbeat sound, try to capture

30-45 seconds :
lisarjones525@yahoo.com
Many blessings and peace in the days ahead ☺☺☺

—*Lisa Rose Jones, March 4, 2019*

Kristy, I just read your post. WOW. To read of the beautiful faith that Louie has in this journey leaves me speechless. It speaks volumes of the witness that you have been in his life and of teaching him about an Eternal life with Jesus after this one is done. What a different world this would be if WE could have that childlike faith. Thank you for sharing yourself and sharing Louie's journey. So many people have losses and such sadness of not knowing if their loved one will see Jesus. Not so with Louie. I hope and pray Louie's legacy and his testimony will continue to live on through you and all those whose lives he has touched. I look forward to meeting sweet Louie and Jesus one day. God bless you, Louie, your family, and ALL those who hold you close.

—*Tammy Parchman, March 4, 2019*

Hi Louie. Hope your day is great! Tell Jesus I love him!!! Prayers for peace and comfort!

—*Patti Stroud, March 4, 2019*

So Beautiful

—*Teena Harder, March 4, 2019*

What a beautiful message we all need to hear! Thank you for sharing and encouraging others in the midst of this time. Love to you all from Texas.

—*Anna Hederman, March 4, 2019*

Thank you for sharing your words and encouraging others in the twilight of Louie's life here on earth! This has been an inspiration for many people touched by his life & your family. Love Conquers All and it will... Praying for all of you!

—*Donna Berry, March 4, 2019*

Thank you for sharing, God bless you all.

—*Wendy Wilkins, March 4, 2019*

I've debated even sharing this, because our situation is so different, but I've prayed and felt like maybe you'd like to know..

My son has a genetic disorder that affects his neurological system and may or may not cause regression. He suffers mild seizures and several severe delays, but he is surpassing all the diagnosis lists he will do, so far! With every single milestone he passes, I have panicked. Not because I'm Not proud, but because it means there is a chance I could get my hopes up and he could regress and where will we all be then?! These words hit home so hard for me. Peace doesn't come from feeling prepared or knowingly what's ahead, because it's impossible to ever feel full prepared or ready. Peace comes from God. Full trust in Him. No matter what. Thank you for sharing such raw emotion. I will all ever remember this message from your boy!

—*Olivia Brewster, March 4, 2019*

Praying for everyone

—*Carolyn Seigrist, March 4, 2019*

I just spent some time in prayer for your precious son and family. Thank you for sharing this. ♥

—*Tera White, March 5, 2019*

I am in constant prayer in my Spirit that the hands of Father God will be upon Louie, you and your family. I pray that the angels will continue to minister to you as well.

—*Angelena Van Don, March 5, 2019*

Your words are inspirational. It is obvious God is working through you and Louie. I keep your family in my prayers.

—*Jennifer Hardeman, March 5, 2019*

Your words are inspirational. It is obvious God is working through you and Louie. I keep your family in my prayers.

—*Jennifer Hardeman, March 5, 2019*

The Schneider is constantly in my thoughts and prayers.

—*Pam Crosswhite, March 6, 2019*

Dear Kristy, God has blessed you with an amazing gift/ability to share your thoughts and wisdom to the rest of the world. You may never truly understand the positive, inspirational impact that you and sweet Louie have had in my life in these past few

weeks. I have felt an increase in my faith in Jesus. Please tell Louie that he has made another mommy and grammy feel his spiritual Joy! I have held my own private prayer vigil, Kristy, for you and your entire family over the past few weeks. God's Blessings always to you and your incredible family. Love, Susan

—Susan Anderson, March 6, 2019

Your words of encouragement from the Lord has resonated with my soul. Thank you and may God bless you and Louie in this time of need.

—Lynn Sadler, March 6, 2019

Stinky Breath... By Louie (and mom)

March 6, 2019

I sat down to write a number of times this morning. I started thoughts and found myself deleting them. I wrestled with words...something that typically comes natural to me. So then I asked Louie if he wanted to write with me. He said yes and this is what happened next...

I asked Louie what we should write about. He said without hesitation, "God. I see Him." The ambiguity of the statement was beautiful. There seemed to be a resolve that he knows and sees God now, and is also waiting in the eager expectation of seeing him face to face very soon. There was a deep confidence in his eyes. Louie, at 9 years old, seemed in that moment to be holding wisdom and peace that most of us spend our lifetime trying to find.

I asked him what else he thought we should write about regarding seeing God. Louie said, "not upset, not scared...good thoughts!" Then he grinned and said, "no stinky breath in Heaven!" And we giggled together.

As the giggles subsided I found myself fighting tears. The pain in the hard moments of life can be so great, that we lose the ability to see through an eternal lens. We focus only on the immediacy of what is around us. The feelings overtake us. We can often miss the voice of God calling us to Himself.

Louie sits staring death in the face, and yet his gaze is on Jesus. He hears God calling him. He isn't caught up in missing the things of this world. He proclaims he isn't upset

or afraid. But then I see his sweet half smile and I wonder if there is much more to his simple words...maybe Louie is challenging us. Maybe his declaration isn't only that he isn't upset or scared, but he is telling us not to be. He is walking us through the grief of releasing him back to his Creator. Maybe he is hoping we can see that death isn't about an ending but living the beautiful eternity we were always created for.

The reality is, the only eternal purpose we can have on this earth is to know God and to make Him known. When we live striving to see God, following Louie's example, then I think the peace he exudes is no longer so unusual. Instead we close our eyes, slow down the chaos of our thoughts, and it will naturally engulf us. The peace will overtake even the hardest of moments.

So as we wait for the day that God calls us back to Himself, we are made to long, without fear, for the place where stinky breath no longer exists... but until then, brush your teeth and seek to live a life where you can proclaim as Louie did today, "God. I see Him!"

Comments

I was just sitting here thinking about y'all and praying for you. When you run out of words Louie is right there to help you. He is such an amazing boy. I hope you and Louie sleep well tonight.

—*Judy Kramer, March 6, 2019*

Your child is a smart beautiful soul. If we could all see what he sees we would be much better. I love your stories and thank you for sharing. Even though it seems like it's not fair that he has to go so soon,, if you really think about it, he's the one that so blessed. I can't wait to meet him one day. Praying for your family everyday. #LouieStrong

—*Wanda Cook, March 7, 2019*

God put you all on my heart this morning. Lifting you and praying for peace and comfort and courage. Love you. ☺☺

—*Kristina Mete, March 7, 2019*

Thanks for the challenge Louie and Kristy! I continue with so many to lift you all in prayer.

—*Jennifer Walters, March 7, 2019*

♥♥♥ love your hearts!

—Julie Bryant, March 7, 2019

This is the most AMAZING group of words i have read in my entire life. Louie Thank You!! This little boy has grabbed a hold of my heart strings from the minute i watched his ride to the hospital. The connection? My dad's name was Louis, and he joined our heavenly father on February 26 1994. My mother got called to sit at God's table December 19th 2017. New years eve 2017 i watched a preacher talk about going into our 2018 with un-forgiveness. He was an Amazing story teller and he expressed the reality of Jesus's last moments. His words were so moving the picture crystal clear. He then explained that our father while hanging on the cross had his feet bound, one hand bound and just before the other hand was doneHe looked to the sky and said "father forgive them; they know not what they do" and if he can do that Who are we to go into our 2018 with un-forgiveness? I asked God to take that from me in that moment. And he did. i got the ugly cry and the snot bubbles and felt as if all of the stuff i had been carrying all my life was removed. I truly let it all go. Any harm that was done to me from 20 minutes until the very beginning of my existence. The burden of all that mess was gone.....I now dont focus on what happened yesterday..We all make mistakes. God does not promise us tomorrow.....So when i open my eyes i Thank God and ask him to walk with me in my life that day "the present".....My goal for my 24? Is to simply make him proud.....Not having ever met Louie in person is not important. He came into my life to help me see what "problems" i wanted to waste space in my mind was NOTHING to focus on..... It is taking away from the the precious moments i could be enjoying.....Like blowing bubbles for the fun of it.....Thanks Louie YOU SHINE brighter than the Sun!!! Thanks for reminding me of what my "present" is for~ Love love love you young man! You and your family have my continued prayers.

—Myra Ferrell, March 7, 2019

We, here at Geyer Springs First Baptist Church are lifting your family up to our Lord. God's has certainly gifted Louie with something special that enables him to see Jesus and heaven from a different perspective than most of us do. What a brave little boy. Praying that God will hold your family close and sustain you with His grace and mercy during these special days with your sweet Louie.

—Rosanne Ramer, March 7, 2019

Thank you so very much for the prayers and support. We plan to hold his service at GSFBC... The prayers lifted up on our behalf are holding our arms up to the Lord in the hard days.

—Kristy Schneider, March 7, 2019

Your stories and writings are so inspirational! May God bless Louie and your family!!

—*Susie Goebel, March 7, 2019*

I am always so blessed whenever I read your blog. Louie is such a blessing to the whole world. He truly is an angel on Earth. Your family is beautiful and strong. You and your family are in my prayers. #Louiestrong

—*Winette Knight, March 7, 2019*

Thank for for sharing Louie so beautifully with us! ♥

—*Deann Wagner, March 7, 2019*

Louie your faith and courage is amazing. You are such a blessing. Praying for you and your sweet family.

—*Nancy Skinner, March 7, 2019*

Our family is praying for strength and peace for Louie's family.

—*Danis Albornoz, March 7, 2019*

Thank you for being so brave and sharing your life with us. It's Inspiring! Your faith is very admirable!

—*Patty Sexton, March 7, 2019*

Louie,
I love you Little Buddy.. and I know that Mr. Jason will be there waiting on you with William right beside him.. I'm jealous that you will get to see them first but I know you will keep them company until it's my time Keep going little Man, you are so brave. ♥
Love you BIG...

—*Braille Braddock, March 7, 2019*

Beautiful.

—*Debbie Hamilton, March 7, 2019*

May the Lord bless your family. Thank you for the journal. Louie is an amazing person.

—*Michael Peterson, March 7, 2019*

Louie, hugs to you young man. Thank you. I know we've never met but I just love you! I'll see you one day soon! Hugs and prayers for you and your family.

—*Suzanne McGuire, March 7, 2019*

Such wisdom from this young man! We often have the wrong perspective. Prayers for Louie and your family! Thank you for such a great reminder about what matters most!

—*Sheila Fitts, March 7, 2019*

Louie Thank you for sharing your journey with us! Your faith is so inspiring. God bless you and your family.

—*Pam Radtke, March 7, 2019*

An old song says: Turn your eyes upon Jesus, look full in His Wonderful face, Then the things of earth will grow strangely dim, in the light of His glory and grace. Thank you, sweet boy, for reminding us of this truth.

—*Tina Hice, March 7, 2019*

I sing this song to him every night as he falls asleep...

—*Kristy Schneider, March 7, 2019*

You all are just amazing! What a way for you to glorify God!

—*Michelle Brown, March 7, 2019*

This child of yours is so amazing. Just like his mama...incredible faith. As we pray for you, you are teaching us. God mercy, grace and peace to you.

—*Hazel Cording, March 8, 2019*

Louie you are amazing!! Hope you had a awesome day and as always... Tell Jesus I love him!!!

—*Patti Stroud, March 8, 2019*

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Louie you are amazing!! Hope you had a awesome day and as always... Tell Jesus I love him!!!

—Patti Stroud, March 8, 2019

Thank you Louie for your amazing heart for God and your wisdom in simplicity of living and leaving. I want to say more and more 'I see You God' and therefore 'I am not afraid'. And in times when I 'forget' or the pain of the moment seems to cloud my vision - Lord help me see You - not allow the hurt from those close to me - or fear for the future - or disappointments of unmet expectations - to lose my hope, joy and peace.

—Trisha Norton, March 8, 2019

Continued prayers for all.

—Fran Brotherton, March 10, 2019

Louie you have taught me so much about faith ,and being strong, you are an amazing little boy with the insight for Jesus that makes me a better person and I Thank you for that , continued prayers going up for you and your family, I love you and I don't really know you except the FB and Caringbridge , you have a beautiful precious smile and you are so precious to all of us ,I hope I can be just like you now and when my time comes to see Jesus, I will see you in heaven Little Man ☺☺☺☺☺

—Joy Stuckey, March 10, 2019

Defective Marshmallows

March 9, 2019



Control....it is something I seek. I prefer things to always go the way I planned or envisioned. I will research, ask questions, seek knowledge, anything that will help me gain the illusion of control over a situation. I feel safe and protected that way. I even remember explaining to someone that I like planned surprises. I want to know something unexpected or surprising is coming, then it can be fun...but just an all out surprise can bring more anxiety than excitement.

Yesterday, I had an idea that didn't go as planned. There was a moment I thought I had control of that changed directions suddenly due to a bag of defective marshmallows. I came up with an idea to let the kids play and build with toothpicks and marshmallows. Everything was going according to plan until I opened the bag of large marshmallows. Immediately they looked a bit different. As I took one out, it was evident that they had gotten stuck on the assembly line in the corn starch area for far too long. They were covered with what acted like a large layer of powdered sugar. As I dumped some out for the building project, everything changed directions quickly. The next thing I know, the kids are rubbing them on their faces and in their hair. They are smashing them in their hands. White powder is going everywhere. It looked like a box of powdered sugar had exploded in Louie's bed and all over my kids. My natural instinct was to control the mess and I almost told them to stop and we would just use the little marshmallows. But in that moment of defective marshmallows, something caused me to pause...it was the giggles. It was the great joy I saw covering their faces as they helped each other apply the "make-up". It was watching Liana sneak and eat them over and over with a sly grin on her face. It was the fact that in the mess of the unexpected, there were great memories forming.

As the beautiful moment came to an end, there wasn't a lot that was built. All of my kids needed baths and their clothes were covered in white powder. Yet I couldn't help but thank God for the defective marshmallows. I thanked him for doing something unexpected and reminding me that I am not the one in control.

We can spin our wheels all day long trying to control moments. We can plan and pursue that which makes sense. Yet ultimately, there is only one who is Sovereign and has the ability to hold every detail in the palm of His hand and direct every moment. God alone knows, sees, and controls all that is life.

When those unexpected moments are like the defective marshmallows and make life seemingly better, we are able to embrace them more. However, there are the unexpected, out of control situations that are excruciatingly painful. I never imagined when Louie and I left for Cincinnati that he would end up in PICU fighting for his life. I never fathomed watching medical professionals flood his room as his heart stopped 3 times. Fast forward to now and it was never in my plan to be sitting and typing a caring

bridge update as my son is slowly dying across from me. I am not in control no matter how much my flesh wants to be.

For every person reading this, you have had or are in struggles beyond your control. It may be a financial crisis, a child making really bad decisions, a health issue, wounds caused by the decisions of another person, the death of someone you love, and the list can go on and on. The fact is, since we are still this side of heaven, these out of control, gut-wrenching moments will come. It is a truth present since sin entered the world in the Garden of Eden.

So what do we do with these defective marshmallow moments? Well, we can try to manage and control them ourselves, or we choose to dig in and trust God. I believe that God isn't the orchestrator of the hard places, he is the comforter in them. We live in a sinful world which is the origin of pain. But we serve a God who counts our tears, carries us when we are weak, and sees the greater picture at play. Sure, I could be angry and blame God for Louie's health decline. Yet, then I look at Louie who will soon see Jesus face-to-face and is completely and utterly peaceful as he awaits the moment when he runs into the arms of Jesus. Louie knows his time here was always meant to be but a blink of the eye in comparison to an eternity in heaven. If we only see the hard, we miss the beauty of a God who is calling us to Himself. When instead we look to God and trust that He is enough even in the painful places, then we will find the strength to release control and sit with unanswered questions in the presence of the God who loves us completely. It will still be hard, but when we choose God to walk us through it, there will be purpose in the pain.

I hope for more defective marshmallows...more moments where in the pain, the unexpected brings joy instead of fear....more moments where the giggles are greater than the tears...more moments of releasing control to the God who made me, sees me, loves me, and will never give up on me. When you are handed defective marshmallows today, I hope you will pause and smile and know that you are not alone...God is right there with you...

Photos







Comments

Every post leaves me happier than the one before.

My heart breaks for you, and my prayers are riddled with you and your family.

But, at the same time, I cant help but feel a peace when I read your posts.

I know you are scared of all of the what ifs. I am a control freak, too. And, having a sick kiddo is DEFINITELY not good for us weirdos! But, it definitely changes the way we see things. Do things. Feel things.

You and Louie are changing lives.

I'm so honored to get to witness it.

—Jennifer Naeger, March 9, 2019

Kristy, I love what you said about God is not the originator of the hard times but our comforter during them. I also believe that to be true. It is heartbreaking to me when people have been taught incorrectly or simply don't know or understand enough about God that they blame all the bad things in our lives on Him, then justify it by saying they don't believe in a "god" that could let such bad things happen to people. People don't seem to want God to "run" their lives, but when life gets tough they blame God for not controlling things the way they want them to be. My prayers for Louie are unceasing in my heart and I am built up in my own life to see how our precious God lifts you and carries you daily.

—Cindy Krueger, March 9, 2019

Kristy, I love what you said about God is not the originator of the hard times but our comforter during them. I also believe that to be true. It is heartbreaking to me when people have been taught incorrectly or simply don't know or understand enough about God that they blame all the bad things in our lives on Him, then justify it by saying they don't believe in a "god" that could let such bad things happen to people. People don't seem to want God to "run" their lives, but when life gets tough they blame God for not controlling things the way they want them to be. My prayers for Louie are unceasing in my heart and I am built up in my own life to see how our precious God lifts you and carries you daily.

—Cindy Krueger, March 9, 2019

Thank you! Beautiful reminder! I am continuing to pray for Louie, you, and your

wonderful family.

—*Jimmy Carter, March 9, 2019*

Prayers always in my heart! Reminding me of Who Is In Control, I needed to hear this today♥

—*Shandra Tipton, March 9, 2019*

Love this!!! You are all in our prayers.

—*Anna Hederman, March 9, 2019*

I love this story! I need some of those marshmallows. It made me laugh and it made me cry. My life has changed so much since Louie's story came into my life. Prayers everyday for you all.

—*Wanda Cook, March 9, 2019*

You write beautifully! I will continue to pray for all of you. You are all amazing! Thank you for such inspiration in such a desperate world! May God continue to strengthen you. Love in Christ, Sylvia

—*Sylvia Leach, March 9, 2019*

Yum yum marshmallows!!! Hope you had a great time with them Louie!! We love you big!! Tell Jesus I love him. Praying for peace and comfort for all!!

—*Patti Stroud, March 9, 2019*

Praying for more giggles and fun messes!

—*Debbie Hamilton, March 10, 2019*

You don't know me but my daughter, Taylor is Peters teacher at Baptist Prep. Your testimony. Is incredible, we pray for you all constantly! I've learned so much from you, your constant faith is unwavering. We love your family, and we've never met you. Taylor has the joy of having Peter in her class, and she chats with you. I pray that she's learning and growing in Christ, if just from your example. Thank you for your honesty in your posts, thank you for sharing Louie with us. Just thank you, and God bless you all!!
Debbie Ramsey (Ms. Ramsey's mom)

—*debbie ramsey, March 10, 2019*

♥♥♥we're praying for you guys everyday!

—Julie Bryant, March 10, 2019

What a great story! And the memories of the defective marshmallow day will always be part of your family lore - way more than if you had made what you planned. Praying for each of you every day - and hoping that every day brings you giggles, even when there are tears.

—Tanya Nugent, March 10, 2019

As I read all your journal entries, this is the one nearest and dearest to my heart. I hope you get many more defective marshmallow days.. I live in Arkansas and would be honored to meet sweet Louie..☐☐

—Kerrie Brown, March 21, 2019

In the Pause...

March 10, 2019

I have people asking me often how Louie is doing. Each time I pause...and try to breath...

In the same token, I have people asking me often how I am doing. Each time I pause...and try to breath...

I think we have all been there... We have all had moments where life is so crazy hard that you aren't sure what is going to come out if you open your mouth to answer with honesty. It is the seasons of life where survival is all you can hope for because the truth is you are drowning. Often, it is the times when there isn't anything anyone else can do to relieve your pain, yet inside you want to cry out and scream to each person you meet, hoping there will be the grace to see you through the moment.

When we are emotionally exhausted or overwhelmed, the question of how you are doing takes on a whole new meaning...which is why we pause...

It is in the brief moment of pause, so much is considered... The questions race... Is this person safe? Can I actually be honest? What is the right answer because I am not even

sure if I am okay? Is this the right time or place to hold honesty well? Do they really care about the answer? So many questions... The questions are then intensified by the reality of the situation stirring inside of you... There is so much you long to say, but you don't know if it warrants an escape - at least not at this moment or with this person. So the pause is really about sizing up the question and our emotional availability to an honest answer. In that very brief moment, we are evaluating the depth of the relationship with the person and will we be okay if we answer with complete authenticity.

All of this happens in almost an instant.

I believe that the vast majority of people crave places where we can be raw and real, yet more often than not, we leave the interaction with not much more than a trite response. We will walk away from seemingly good, caring people without an honest exchange. This leaves me contemplating, do we do this because of our lack of trust in the person asking the question or our lack of trust in ourselves to handle a truly honest answer from within?

But maybe none of that is the root of the issue at all. Maybe the pause is also reflective of a struggle to be real before the Lord. Maybe at our core we try to hide, even from God the depth of our sin, pain, sadness, fear, or whatever else feels so big that it causes us to pause. It is foolish to think we will ever be successful in hiding from a God who is Omniscient, all-knowing. But boy do we try...often passively. I believe that we passively hide from God when we keep ourselves so busy that we "don't have time" to spend daily in His presence...when we stop making prayer a priority...when we put down our Bible instead of picking it up in times of hardship. In the times of passive disregard for God, the beautiful thing is He hasn't changed His love, commitment, or presence with us one iota.

When we wrestle to be real with others because everything feels so overwhelming, God is still present waiting for us to pour out in honesty with Him. He longs for us to share our thoughts and feelings and even anger with Him. He wants us to trust Him with the raw pieces of our brokenness...not because He doesn't know the answer and needs us to disclose it to him...but BECAUSE He already knows. He already sees. He already counts your tears. He isn't shocked by the depth of your feelings or struggles or fears or loneliness or depression or addiction or _____ (fill in the blank). These things are not news to Him. And just as confidently as He knows these things, He stands confidently saying, child, "Come to me, all who are weary and burdened, and I will give you rest." Matthew 11:28. He loves us still...even in the middle of our messes or deepest pains...even in the times when we pause...

So back to the question... How is Louie doing? Well, if you were here asking me now, I may pause, but my honest answer is Jesus is giving Louie rest and time for joy to radiate, but He is still calling Louie to His side...and it is a beautiful thing to be a part of.

And how am I doing? Well, if you were then to ask me this question, I still will pause, my breath may leave me for a moment, my eyes fill with tears, but my raw answer is found in striving to walk the truth of an old hymn...

Turn your eyes upon Jesus,

Look full in his wonderful face.

And the things of earth will grow strangely dim,

In the light of his glory and grace.

Comments

Thank you again! I am living your pause. I continue to pray for Louie, you, and your family.

—Jimmy Carter, March 10, 2019

Sometimes those of us asking the questions pause before we ask.....unsure if we even SHOULD ask.....but knowing that we want you to know how much we care. Those pauses both on your side and on ours give us a chance to let God take over and breathe for us. And in those moments of God breathing, we know we are safe. Love to you all.

—Barbata McCreight, March 10, 2019

Thank you for sharing.

—Sylvia Leach, March 10, 2019

Prayers always for Louie and family. May God give you all peace and comfort. As always, Louie tell Jesus I love him!!!

—Patti Stroud, March 10, 2019

God bless you and your family. I pray for you all everyday. Today for the first time in a very very long time, I went to church. Before I learned about your beautiful child I never even thought about going back to church. I know it sounds crazy to a lot of people, but your son has moved me so much. I check this several times a day to see if you have posted another update. I love the lessons I learn from what you post about your faith. I pray that you have peace and comfort. #iwanttobelikelouie

—Wanda Cook, March 10, 2019

Hugs my sweet friend Kristy scream and cry to the heavens it's all ok , praying

continuously precious Louie is on my heart constantly your entire family strength and peace.

—April Garcia-Woodard, March 10, 2019

Love you, Kristy and praying for all of you as you travel this road with Louie! ♥, hugs and
□□□□□□□□!

—Laurie Dombrosky, March 10, 2019

Lifting up you, Louie and all of your beautiful family members with constant prayers and humility to God our most merciful Father. Like others have stated, Louie has had a profound affect on my spirituality. Your journal entries are truly inspired writings. Thank you for sharing your son, Louie with us as well as your sincere thoughts and words. Love and prayers for you all.

—Susan Anderson, March 10, 2019

Praying for your family! Turn your eyes on Jesus...one of my favorites.

—David Barnes, March 10, 2019

Praying for you all!

—Natalie Hill, March 10, 2019

Well said. Prayers and hugs sent to you and your precious family.

—Betty Franklin, March 11, 2019

Prayers for comfort and strength for you all.

—Hayley Strickland, March 11, 2019

Wow, thank you for these words. I've been struggling about how open and honest I should be in my own situation. Your words were powerful to my heart.

I'm glad Louie is still with you right now. I can't imagine how much your mommy heart aches for him, to see him so sick and in pain. I'm praying that God continues to give your family strength and comfort during this time.

—Nicole Hummel, March 11, 2019

Thank you for this. It spoke so much to me! Your strength is incredible. I wore my Love Like Louie shirt yesterday. Sending prayers of comfort and peace to you.

—Anna Hederman, March 11, 2019

What beautiful words. They ring true no matter our situation.

—Tammy Becvar, March 11, 2019

I call this a “Selah” moment. In the book of Psalms the word Selah appears often. Scholars think the word means a pause or rest between musical stanzas allowing the listener to reflect on what Has been said and prepare for what is ahead. It’s the resting place... a time to just be and reflect and wonder and spend time with God has you move forward. Everything seems surreal as the world continues its daily processes around you but you have this time to rest and Breathe. Selah.

—Hollie Sanders, March 11, 2019

I found when I was asked this question about my daughter, and myself, I didn't know the answer. It was as if each day was a rollercoaster ride. The one constant was her trust in God, and her desire to go to Him at His will. No, she didn't want to leave her son and daughter, nor her husband and the rest of us, but the last 3 years of her 12 year battle had been a time of preparing her children to understand what Heaven meant to her, for her to alleviate their fears of them losing her, and there in lay all the answers to the question. We were fine, by the Grace of God, which didn't mean we weren't struggling with the earthly trials of her pain, treatments, surgeries, and our knowledge of an inevitable loss.

It has been almost 6 years, and we are, by the Grace of God, still ok and have the blessed knowledge of a Happy Reunion Day.

God Bless all of you. Your faith will be your strength.

—MaryAlice James-Hewitt, March 11, 2019

Thank you for sharing your heart. I send you my love and my prayers for all of you. I praise God for you and your heart for Him and others.

—Kay Gaddis, March 11, 2019

Thank you for sharing your heart. I send you my love and my prayers for all of you. I praise God for you and your heart for Him and others.

—Kay Gaddis, March 11, 2019

Thank you for sharing your heart. I send you my love and my prayers for all of you. I praise God for you and your heart for Him and others.

—Kay Gaddis, March 11, 2019

□□□□□□□□□□

—Cathey Hancock Cowger, March 11, 2019

Sis, I don't know you and I didn't have to say completely bye to my son but you spoke directly to My PAIN.. So.. I'll join you in YOURS! LIFTING UP LOUIE! AND HIS MOM---THE DAUGHTER OF PAPA!□□ Aka The KING of kings!!

—L Fullerton, March 12, 2019

The Day My Phone Took a Swim.....in the Potty

March 13, 2019

The day started early. The weight of the most important decision of my life, weighed heavily on my shoulders. My sweet son lay sleeping soundly as I sit on the edge of his bed. I watch him sleep. I cry. I know that the ramifications of the decision before us effects him profoundly. I pray. I wait for peace. I hope for peace... But the thoughts keep turning. The questions keep coming. My flesh stands at war with my spirit. I beg God to make just the very next step clear...even if the rest of the road stays out of view. I try to breath as the tightness in my chest intensifies.

Then Louie starts to stir. He stretches, yawns, and gazes up at me with his sleepy eyes. He smiles and says "mom your face is pretty." Then he snuggles up next to me and I stroke his hair. I can't control the tears pouring off my face and onto his. Louie grabs and pulls his blanket over his head to keep from getting "more wet". As he does, he asks, "you crying happy tears?" And I answer honestly, "baby, I don't know...today is a big day."

Erik makes it to the hospital just prior to our scheduled meeting... A meeting where we have been asked to make an impossible choice between two really bad paths. Path one brings Louie into the arms of Jesus very soon. Path one is filled with the beauty and peace of knowing our son will no longer hurt or struggle or be poked and proded. Path one will end 100% of the time in "see you later" as Louie runs to tickle Jesus in

eternity...and we are left to grieve. Path two has a chance of success of less than 5%. Path two likely brings Louie physical pain and possibly suffering. Path two means more tests and doctors and medical jargon to sift through. Path two is likely only diverting from path one for a very short time.

It is an impossible choice that has us as parents questioning everything. What do we value most? What is quality of life? What can we ask our son to endure? What of the wrestling in our hearts is our flesh and what is the Holy Spirit?

Erik and I try to talk through things a little more as we head to the meeting. We are grasping for unity and peace but there are still questions and doubts. Yet we are about to enter a room filled with medical professionals we trust, that are expecting us to have answers.

Then on the way to the meeting, I had to make a quick stop by the bathroom. Somehow in the process, it happens... Yes, the dreaded awful thing happens. My phone, in total slow motion, slips out of a pocket on my shirt and heads straight for the potty. I flail around trying to juggle and catch it. But I fail. I completely fail and my phone takes a swim in the potty. At this point, the instincts kick in. I grab it immediately without hesitation. I throw open the stall door to get to the counter with paper towels as fast as possible, so thankful it wasn't a bathroom with only the hot air blowers. I snap the case off as fast as I can and start drying it frantically. Literally I am saying out loud, "Please God save my phone. I need the pictures...save the phone!" It is at that point, I realize there is something much worse than the phone...MY PANTS...they are still down around my knees as I have yet to pull them up. My whole self is just there, exposed, ready to greet anyone who might innocently enter the bathroom. Somehow I manage to get my clothing in place literally a second before the door opens and another lady walks in. I smile and say hello and run out of the bathroom mortified....and did I mention I never actually used the restroom!!

As I find Erik waiting to enter the meeting, I can't help but laugh at what has taken place. So here I am...about to enter a meeting to make a decision about the life and death of my son, and I am laughing at the completely unsanitary phone in my hand that just swam in a potty as my pants were down in the public part of the bathroom at the hospital. And the laughter brings calm to my heart. The laughter allows me to breathe deep as I step into the room. The laughter reminds me for an instant that I am a fumbled up mess and only God has control over the life and death of Louie...of all of us.

Over the next two hours, there were many beautiful tears as the treatment team sat alongside us and we processed through the choice at hand. In the end, God showed up in big ways. God answered prayers I didn't even know how to pray going into the meeting. God brought us as a team to a concensus on a path that removed the pressure from us as parents as we shared the load with amazing professionals who love our son

and family fiercely.

So how does the story end... For starters, my phone still works... However, I am sure you would rather know how the meeting ends... Well, God has only revealed one step, not the whole path...but for this moment that step involves path two. It involves trusting God to make Himself known through the life and probable death of my son. It means that we will step forward on a medical road that offers very minimal hope but we do so with a great team of medical professionals and a God who is able to work miracles. And we pray... We pray for that miracle to occur for and in Louie. We pray for him not to be in pain. We pray for the doctors coming on board to pour out their best to see if Louie can sustain life.

Plus, we thank God. We thank God for people supporting and standing with us in this crazy hard time. We thank God for this very special medical team fighting for Louie. And we thank God for a now very sanitized and clean phone because the quick swim in the potty brought sweet laughter...and that moment of laughter reminds us of our humanity and utter need for a God who doesn't rely on a phone to capture moments - because He created all the moments and forgets none of them. Will you trust God will each moment of your day?

Comments

I absolutely loved this! God knows just when and where to do things to let us know no matter which way it goes., it'll be alright.

—*Wanda Cook, March 13, 2019*

Kennedy just said, "If she doesn't write a book, I'm going to be VERY disappointed." We love y'all and are praying God will show out with sweet Louie!

—*Courtney Kinley, March 13, 2019*

It's the little things (aka phone) that reminds us of how Big Our God truly is and always in control! Prayers continue for your family!

—*Shandra Tipton, March 13, 2019*

I am still praying for you guys daily. Louie has captured my heart. Your example is such an encouragement to love and good works. God's good grace is so evident in Louie, in you, and in your family. May God work a miracle in Louie's life. May God ease Louie's pain. May God continue to pour out His grace and mercy on you. May you continue to point people to our Savior, Jesus Christ. God bless you.

—Jimmy Carter, March 13, 2019

Hi Louie!! Hope you had a great day! I am praying for peace and comfort for you all! As always Louie tell Jesus I love him!!

—Patti Stroud, March 13, 2019

I love reading updates about Louie! He's such an awesome person! Your writings are beautiful too. I know God is in control of Louie's life. God has a plan for sure! Keep trusting Him!

—Paula McGinty, March 13, 2019

Continued healing prayers for for your sweet Louie!☺☺. Thank you for sharing this journey and bringing people together and closer to God! You are all such good Christian people!✝☺☺ Hug Louie for me and tell him that I'm praying for him and I love him!♥☺☺

—Cathy Perkins, March 13, 2019

The way you relate your journey is so vivid; I was right there with you juggling your phone into the potty....it was probably my fault that you couldn't catch it, haha! But I can't REALLY know the all feelings you describe. I only know that grace is carrying you. I do recognize that, and I thank God that He makes that available! "Thank You, LORD!!!!" I love that God answered prayers you didn't even know were prayed. Each of your entries is pure devotional time. Peace to you, precious mama!! And to your husband and family during this very difficult time.

—Lannece Mayo, March 13, 2019

I know God is in control ! I also know that God is carrying you along this journey. May comfort and peace resound in your hearts along these next steps. God, bless this precious family... Louie, we love you☺☺

—Tracey Adams, March 14, 2019

Praying for peace and comfort, love your momma heart ♥♥♥

—Julie Bryant, March 14, 2019

Your writing is so, well so God-driven. I know He is writing these things on your heart. Thank you for sharing your most inner thoughts and some funny thoughts in all your posts. Praying for God's comfort and mercy for your sweet family.

—Rosanne Ramer, March 14, 2019

Thank you for sharing this hard journey with us .Thank you for sharing God moments with us. It has increased my faith . Praying for you and your precious family.

—Sam Bartolotta, March 14, 2019

God bless Louie, your family, and the medical team. God bless your path. Our family continues to stand in the gap for all of you. God hears our prayers. Louie's smile and strength is a blessing and inspiration.

—Kenny Diffy, March 14, 2019

From all of us at the Shannon Hills Fire Department we love you captain Louie stay strong buddy

—Tommy Meyers, March 14, 2019

Praying so hard for Louie and his family this is one strong little man we all love you Louie keep strong you and God has this

—Theresa Leslie, March 14, 2019

Louie is spreading God's love for all through his parents as they share Louie's story. Evangelizing from a bed as Paul did in a jail.

Our prayers are for all of you. Your FAITH will show you the way!

Jesus loves the little children!!

Aunt and Uncle

of Trent and Jenny Worsham.

—Barbara and Al Reinhardt, March 14, 2019

I am so thankful for that decision, I feel it's the right one. Prayers for you and your whole family, and prayers that Louie will grow old on this earth if it's Gods will.

—Liz Harris, March 14, 2019

You are such a wonderful writer. I know you made the right decision for you and Louie and your family. Prayers for Louise and all his family. I am just amazed by you and your sweet family.

—Parthenia (Tena) Taylor, March 15, 2019

Prayers for your sweet Louie.

—Paula Darter, March 17, 2019

Small Spaces

March 15, 2019



Last night was unexpectedly hard. Last night I wept over small spaces. Let me explain... We had spent the last two weeks on an amazing unit with nurses that we had fallen in love with. We had processed this hard road with them. They had spent amazing time with Louie and truly let him into their hearts. We had a huge room where my other three kids and family could visit and enjoy time with Louie. It was a safe place for Louie. But it was also a safe place for me.

Then at shift change came the message....you are moving units. I knew this was possible, but the thought of it still caused me to pause. I refocused myself and started to pack up our stuff. I said a little prayer, Lord wherever we go, please go before us to make it just as perfect for Louie. After I packed up our belongings, I asked our nurse, who I love dearly, if I could take down some of our stuff and go ahead and start putting it in the new room as we waited for the nurses to give report and move Louie. She gave the approval and I headed downstairs.

I got to the new room, and I stopped in my tracks. I have been in a lot of hospital rooms over the past years with Louie...A LOT...yet, I have never been in a hospital room this size...this small. It was the smallest space in this hospital that I have seen before. I envisioned his hospital bed and wheelchair in the room and began to weep as I headed back upstairs. I cried because there wasn't even an extra chair for someone to sit and hold my hand or talk with me on the hard days. I cried because there wasn't room for my kids to come visit. In that small space I felt totally and completely isolated and alone.

Small spaces have a way of doing that to us...they either isolate us completely or mask the intensity of the emotions in our lives. Small spaces can provide us a place to hide and be so alone that people only see a glimpse of reality as they glance in from the door. Small spaces are where we live too often.

In fact, I realize that with social media, most of us have taken up residence in the small spaces. We use facebook and other media outlets to give a tiny taste of our life to others. We let people see the small spaces because the thought of them seeing everything is overwhelming. We keep the ugly parts, the vulnerable parts, mostly to ourselves. We show happy pictures, tell funny stories, and keep people at an arms distance of the truth....that is living in the small spaces.

I realize that I am guilty of this even now. I was looking back at pictures I have posted of Louie over the past few days. He is dressed nice (because that is what he loves), he is smiling, and looks like life is good and carefree. But that is only a small space. Louie has spent most of the last few days on a pretty significant decline...yesterday being the worst day yet. So if I am brave and open up the view past the small space...then you see

that the smile on the sweet boy in the red vest is mostly a facade today. He spent most of the day struggling and fighting and feeling so poor that he was hardly alert. And I spent most of the day trying to make sense of it all and determining where to stand in this moment...

Small spaces may feel more comfortable but each day we look ourselves in the mirror and know the truth of who we are...the places we hurt...the struggles we bury. So how do we balance the limited view of the small spaces? I believe the challenge for us is to make sure that we are not using the small spaces of others to judge how their life truly is or how our life should be. Plus, we must allow ourselves to risk at times allowing others to see a little more of us or else we miss the beauty of relationships. God designed us to walk life hand in hand with others. He designed us to crave connection with people. Not everyone in our life needs to see beyond the small space, but to live completely is to risk it with a few. Who sees you? Do they know the beauty of the risk you take to let them see more than the small space? Tell them...encourage those places because they will be the ones to hold you up when even the small spaces are crumbling.

For me last night, it meant walking back upstairs and crying with two of my favorite nurses at the grief I felt for moving to such a small space. It meant letting them see my fear that my kids couldn't visit and that as the days get harder I would be alone. And in the small space, they hugged me and understood and grieved with me. People that are more than small space people will always stand with you. These two ladies then went and advocated for us...not because they had to, but because I allowed them to see me and my hurt and not cover it up. God honored that process and made a way out of the small space. He used the vulnerability of the moment and care of two precious nurses, to open the door to an answered prayer...a regular size hospital room.

I am thankful for the small space last night because it reminded me of the gift people can be to us on this crazy hard journey when we allow them to see more than the good moments...when we allow the view to open just a little...

Comments

Praying for you today that God will continue to sustain you and your family during this sad time of saying "see you later" to Louie. May God get the glory from all your tears and your sweet words in your very honest posts.

—Rosanne Ramer, March 15, 2019

Thank you for bearing your soul. I needed to hear this on the cancer journey we are on with our adult son. I am trying to not live in the small places.

I continue to pray for Louie, for you, for your family, and now the staff as well that minister to you and Louie. May God continue to pour out his grace and mercy on you in your time of need.

—*Jimmy Carter, March 15, 2019*

Louie is so blessed to have you and I know God hand picked you to make this very difficult journey with him. May God continue to supply the strength you and your family need until God calls sweet Louie to his forever home. Praying for you and your family.

—*Nancy Skinner, March 15, 2019*

It seems when we feel the weakest, as if our hearts can stand no more, that's when we find Jesus. He is there standing in the gap for us. I pray for you daily, for your sweet boy, and your family. I pray that Father God and all of heaven help you find comfort in the big and small spaces.

—*Angelena Van Don, March 15, 2019*

... just bless you , your family, and that precious Louie! He is so sweet in his red vest and looking so good! You would never know how hard of a day he had.

—*Tracey Adams, March 15, 2019*

You are an amazing woman. As I read your post today, I thought of all the little insignificant things I let clutter my day and then I read your story and it reminds me to embrace my day, forget those things, they don't matter. I pray for you and your family everyday , as I know so many are doing. Thank you for sharing and letting us know this wonderful boy. Thank you the most for sharing God's love for each of us.

—*Ellen Davis, March 15, 2019*

So grateful God strengthened you to speak up. God opened some hearts and "wised up" the necessary people to provide a genuine need. Prayers for so many things....Louie's comfort and joy and yours, too. Finding joy in this? I do not comprehend but asking God to give it in ways only He can.

—*Debbie Hamilton, March 15, 2019*

You should be a Christian author. Seriously.
My husband and I think about and pray for you all daily.
So glad we heard about y'all's story.
Blessed to be able to pray with and for you.

—Candace Mohr, March 15, 2019

May God bless you all.

—Jack Soliman, March 15, 2019

Thanking God for those two nurses! Love you, Kristy and praying for all of you! ♥☐☐☐☐☐☐☐☐

—Laurie Dombrosky, March 15, 2019

I have never met you Kristy nor Louie or your family but I love you, I pray for you! Thankful those nurses and thankful you let them see how much a small space can hamper a family from being together in such hard and difficult times. Thankful for the good people in this world and thankful that I got to be just a very small space in your life if only for a brief passing. You have made a difference in my life, you and Louie and your entire family's amazing strength! Prayers always on your family's behalf.

—Diane Huggins, March 15, 2019

Stay strong. I know it is so hard. Your writing is so amazing and you express yourself so well. Louie is so blessed to have a family like yours. I am thinking of you guys often.

—Parthenia (Tena) Taylor, March 15, 2019

Thanking God for the two compassionate nurses who went to bat for you and Louie (and the rest of his/your team). Praying for all of you during this difficult time. Hugs

—Linda Davis, March 15, 2019

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—Linda Davis, March 15, 2019

—Teresa Clardy, March 15, 2019

—Teresa Clardy, March 15, 2019

I can relate all to well, some people don't need to see past the small spaces, some people ignore the space or not want to see no matter if you show them or not and yet some come and stay with you in that messy space. The true balance is figuring this out during an already fragile state. Love you friend. ♥ There is no manual on this sort of thing, you just get through it the best way you can. You are doing a tremendous job..
♥♥♥

—Braille Braddock, March 15, 2019

What a beautiful way to put it. Bless you all.

—Louann Smith Harasym, March 15, 2019

Your momma bravery is unmatched. I pray for this sweet boy and you every day. This entry describes most of us. Thank you for sharing your heart in a vulnerable way.

—Debbie McAnally, March 15, 2019

Yes. You are SO right. Perfectly articulated! And no matter how small the space you occupy, Your Savior, Lord and Friend will fit; despite the fact that He is borderless, incomprehensively vast and infinite! Continuing prayers for you all. ♥☐☐

—Lannece Mayo, March 15, 2019

Thank you so much for this post, Kristy. It is spot-on. Love and hugs to you all.

—Sarah Henry, March 16, 2019

Questions without Answers

March 17, 2019

"Mom will I ever go down the drain?" "Mom will I ever get taped up?" "Mom how does the cat get from the vet to Heaven after she's dead?" "Mom where is Heaven and how long does it take to get there?" "Mom can I turn into ice cream one day?"

My sweet four-year-old is filled with beautifully innocent questions... We are taught early

as a child to ask questions. We are educated on asking the who, what, when, where, why, and how questions to broaden our understanding of situations. We are told there are no stupid questions in order to encourage more questions to be asked.

But then there are the questions my sweet Selah asks that grab and hurt my heart. "Mom why is Louie so so sick?" "Mom will Louie go to Heaven soon?" "Mom I miss you. How come you can't be home like before?" "Mom will you and Louie ever come home?"

These questions are often followed by silence...hugs...and a few words that often include "I don't know" or "baby we pray and it is up to God." These questions are so much more complicated because they don't have easy answer...or often answers at all...

Louie's body has been a mystery to medical professionals for quite a while. I have sat with some of the most brilliant doctors and they have scratched their heads and said repeatedly, "I don't know...it doesn't make sense." I have heard countless times, "we haven't seen anything like this before." Medically he is a anomaly. Behind the sweet smile is a body that doesn't operate by the book and thus makes treatment complex and at times impossible. In fact one of his doctors today said, "We could consult lots of other places but the truth is, what his body is doing is completely against everything we have been taught as a doctor...against everything we have seen...I don't think you will get answers."

There are many moments in life when there are questions without answers...or questions without answers that are enough to carry the weight of what we feel - the weight of the question itself. For example, "why do bad things happen?" "Why did _____ have to die? Why now?" "When will the pain go away?" "Why would God allow a child to suffer abuse?" "How come God isn't healing _____?" "What is the purpose of this pain?" "Does the hurt ever get better?" "Why hasn't God given us the cure for cancer?" Or one of the questions I wrestle with, "Do we accept the death of our son, or do we fight no matter the cost to him and our family?" So many questions...

Oh how our heart cries out for answers. We want to make the hard places make sense...and the truth is, it doesn't...it won't this side of Heaven. So how do we reconcile ourselves to a God who knows the answers and seemingly leaves us in the dark?

At the heart of many of these questions is the idea of fairness. We want life to be fair. We want to believe that if we are good people, making good choices, then only good things will happen. We want to believe that if we are good then the bad will somehow pass over us...that our goodness will be enough to save us from the hurt that is in this world. However, fairness doesn't exist in a world of sin. If fairness existed, we would have no grasp of the grace of God. Fairness means we don't deserve anything but death. But God's grace is what offers us eternal life...not because of our goodness but because of HIS goodness. Yet even if we know this to be true in our heads, how do we

navigate the unanswered questions?

I remember as a teenager going rappelling for the first time with a group from Young Life. I stood on the top of a large cliff with a man at the bottom holding the rope. A man who had experience and had done this time and time again. Yet I was a novice. I felt great fear. My heart was racing. I knew everyone was watching me. I had tears in my eyes. I wanted in that moment to be anywhere but there. Sure I had seen others go and make it down okay...but that wasn't enough to calm the paralyzing emotions in me. I didn't even have the words to pray. I just knew my heart was so scared and overwhelmed. Then I remember as I stood there shaking and crying, I heard the voice of the man below. I remember vividly him yelling up to me, "Kristy, listen only to my voice. I am here. I have the rope. I am protecting you. You are not alone. Trust me to get you down." And with that, I leaned back over the cliff and released my grip just enough to start the descent. And when after a few long moments, my feet hit the ground, that same voice was there saying, "I had you the whole time, Kristy. We did it." And then there was a beautiful hug of relief...of survival...

The hard places in life are just like this. The places with the questions are no different than when I stood on the edge of that cliff. The emotions are so incredibly big and overwhelming. We want to be anywhere but here. We don't feel brave. We don't want to do it. Yet, we aren't alone. We aren't walking it with someone who doesn't know the way. We have a God who knows everything. Who loves us completely. Who counts our tears. Who is with us in the questions begging us to trust Him with the answers. He is the one who sees the whole story and knows how it ends when our view is only the page before us. He is the one calling to us saying, "Listen to my voice. I am here. You are not alone."

I firmly believe that when the questions don't have answers, we have a choice. We can continue to try to make sense of what will never make sense on our own...or we can be angry and bitter at the lack of answers...or we can choose to trust the one who sees us, knows us, loves us, and does have the answers. I tie myself and my hope to the God that declares to His people in Deuteronomy 31:6, "Be strong and courageous. Do not be afraid or terrified because of them, for the Lord your God goes with you; He will never leave you nor forsake you."

So as I sit in a hospital room with really big questions...questions that can be so all-consuming...questions that suffocate...questions without answers, I hear God's voice saying, "Kristy listen only to me. I am here. I have the rope. I am protecting you. You are not alone. Trust me to get you through."

And so I lean back over the edge of the cliff and I release my grip just enough to start the descent because I know who is holding the other end of the rope... Do you??

Comments

Praying everyday for your family. Your faith is so inspirational. May god watch over you all.

—*Wanda Cook, March 17, 2019*

I know who holds my tomorrow!! Praying for your family. As always , tell Louie I love him and to tell Jesus I love him too!!

—*Patti Stroud, March 17, 2019*

Oh my I love how you write! I would love to meet you and Louie. I bought a tshirt by the way! Please let me know if you need anything I would live to help

—*Sylvia Leach, March 17, 2019*

The unanswered questions are always the hardest. I have only recently started following Louie and the journey you are having with him. With you and Louies story I am following in Louies steps, in your steps and trying to bring myself to let go to our God. I have not been the best at following Gods word in the past, I have recently started to attend church again. Your faith and Louies faith in the everlasting life with God is what is helping me.

Thank you! Thank you for inspiring! Thank you for guiding! Thank you for giving Louie the best life that this young man has seen since being in your families care. Tell Louie that I am thanking him as well! His love of life, of God and his ever loving family is my inspiration.

Thank you for sharing your story!

Prayers to you all

—*Pamela Dropkin, March 17, 2019*

Thank you for sharing your mama heart and experiences. Praying for you often and for your whole family.

—*Elaine H, March 17, 2019*

“If fairness existed, we would have no grasp of the grace of God.”

I’m letting that sink in.....While I’m praying for you and thanking God for the messages

he sends through you! ☐☐♥

—Lannece Mayo, March 18, 2019

Kristy you are a gifted writer! I am a friend of Everett Davis and was “introduced” to Louie through his posts on FB. I am praying that you continue to have God’s peace and hear his voice through this journey. You might not ever get the answers this side of Heaven, but one day ...! Your son is a huge inspiration to so many and now I see you are as well. Thank you for sharing your heart so openly.

—Paula Bush, March 18, 2019

You touch many hearts with your writing as does Louie with his tremendous strength! God is giving you the strength to be an example to all of us to know true strength and from where it comes, Our Lord and in Him we should put our trust We won't know the answers to many of these questions, God tells us many things we won't understand but we must trust in Him. You are in my prayers and though we have never met personally you and your entire family are loved and prayed for. God Bless you and hold you!

—Diane Huggins, March 19, 2019

Amen.

—Jason and Nesha Evans, March 19, 2019

A Secret Grief

March 19, 2019

93 days. We have walked a touch-and-go medical crisis with Louie for 93 days...and the number of days continues to rise... The light at the end of the tunnel is not quite visible...nor do we know if the light will be of angels running to meet my son or of the nightlight in his bedroom being plugged back in.

The 93 days have brought such a vast array of emotions for me. I have sat in fear when Louie's heart wasn't beating. I have laughed at him playing with his siblings. I have wept and begged God to spare his life. I have rejoiced in the good days. I have felt hope as his body fights, only to be met with sadness as doctors shake their heads in dismay.

So many feelings...but there is one I wasn't ready for...one that is gripping me in different ways each day.

Grief.

As a counselor I know a lot about grief clinically. I understand it and can pass all the tests regarding stages of grief, theories related to grief and loss, etc. Yet, it is different now because for most of the past 93 days, I have personally walked it...or actually, it is more accurate to say I have sat down in it.

Here is the thing though, there is a grief that makes sense. Grief with obvious loss. The grief people expect. The grief we anticipate when someone is terminally ill. Since January this has been a present reality for me. We were told in the PICU that there was nothing more they could do for Louie...that we were prolonging death and not prolonging life. In that moment, the sadness and fear turned to grief for the first time. I began to anticipate saying good-bye to my son. The tears I cried over the next 7 weeks could fill many bottles as grief flooded my soul. Louie's body fought at home on hospice for almost a month...but even in the good moments, just under the surface, grief was waiting. The grief only intensified as we made the hard decision to return to the hospital for end of life care. Even though we were looking forward towards the end of his life, instead of backwards, the grief was just as real...which is the reality in many situations. A physical death may not have occurred, but the loss had already begun.

What I am learning is that when you grieve because of an obvious loss or anticipated loss, there is such graciousness from others because most grasp on some level the depth of sadness. There are people willing to sit with you and cry with you. Your loss is visible. It is seen. It is understood and even expected. When the death has occurred or people know it is coming, there is support from others to love you in the pain.

But then there is a different grief I am discovering more and more every day. A secret grief. A grief that doesn't have the tangible explanation but grips you just the same. A grief that causes you to choke back tears but you can't even put to words what the loss is in the moment...or if you tried, you would seem a bit insane.

For example, 2 days ago, I grieved alone because my daughter's hair is growing... Yes, you read that right...I grieved because her hair is getting longer. You see, I took a break from the hospital and went home for a few hours. While I was there, I bathed my two year old for the first time in a long time...probably almost 93 days. In doing so, her hair was so much longer than when this crisis for Louie began in December. It overwhelmed my heart that I have missed most of the past 3 months of her life. And I grieved - a secret grief...

Then there was the sweet lady at the hospital gift shop. We made small talk as we were

waiting in line. Her daughter was discharging from the hospital and she was purchasing a toy for the car ride home. She politely asked me if my son was getting better so he could go home soon. I stared at her, opened my mouth, but no words came out. The feelings paralyzed me for a moment. As tears filled my eyes, I found myself saying, "one way or another, my son will be going *home* and it will be a beautiful day!" She knew nothing of our story...it was grief seeping out when I wasn't ready...a secret grief...

The truth is, when you love big, you grieve big...sometimes that grief is in secret...in places people don't see or know. Sometimes it is so far down the road or so unexpected that there aren't any words to explain it. In fact, I venture to say that every day of our lives we walk past someone that is holding the grief of a loss just out of sight...trying to contain the sadness of what they miss.

I know for me there are days I want to scream to everyone I meet, "MY SON IS DYING" just in hopes that their eyes will be kinder and offer grace to meet my hurt...then there are days I want to blend in and smile and look like I have it together. Truth is, grief is hard...grief is big...no matter the reason...no matter how long it has been...no matter the smallest thing that causes the flood of emotion to rise up and threaten to pour out...grief is real. There is no timetable for it. When the lump rises in our throat, we must pause to give grief the moment it needs so we can reset and breathe again. We must give ourselves the grace to feel or else numbness will overtake.

But in the midst of grief and the battle to walk through it, or in my case sit in it, we have a God that is still present with us in these places. He holds us when no one else knows we are crying. When we lay in bed at night feeling so sad and alone, God yearns for us to turn our eyes towards Him because He has not left us. When the world around us continues on...when everyone else's life goes back to normal and we are struggling still, He is waiting for us to trust Him enough to carry the sadness with us...

...Because the secret grief is not a secret to God... He holds us in it and loves us still... And will for as long as it takes... For eternity...

Comments

♥□□□□□□□□□□

—Laurie Dombrosky, March 19, 2019

You have and will continue to be in my prayers.

—Elaine H, March 19, 2019

Grief is common to all and most of the time we can turn it off because it doesn't feel pleasant. Thanks for sharing. Grief is the evidence that we love. Grief is a reminder to me that we were created to live in Eden, but we're not there. Maranatha... Lord come quickly.

—Alesa Garner, March 19, 2019

You have so eloquently put into words everything I have been thinking and feeling. ♥ Grief is multifaceted....it grips you when you least expect it. Praying for you! ♥

—Rachel Bennett, March 20, 2019

Praying for the whole family. So very sorry for your grief!

—Dorothy Chaffin, March 20, 2019

Blessings sweet girl, Your words are so eloquent in carrying your message of love. Your Love for God, your love for Louie, and the love for your daughter's hair growth and the secret grief happening during it all. Bless you for sharing your thoughts and fears. The reality is relate able on so many levels. I have cried so many tears with you. They i know are healing tears, when our hearts are so full God simply turns on our faucets. YOU are an AMAZING MOM. Thank you for your kindness in sharing your life with us all. Continued prayers for you all.

—Myra Ferrell, March 20, 2019

Your words continue to amaze me! In spite of your grief, you still are able to write those beautiful words about grief. We all know that grief is a part of living that none of us ever want to experience, especially the grief of the loss of a child. I pray that our loving Lord and Savior will be especially close to you and your family during these next days, weeks ahead.

—Rosanne Ramer, March 20, 2019

My dear friend, I love you. And I love your words, which uplift me. Continued prayers for you, Louie, and your family.

—Melinda Gilley, March 20, 2019

My heart breaks for you and your family; you have spoken words that I have always felt from losing my own son; but could never put into words, how grief really is. Many prayers for you today and the days ahead.

—Sally Keffer, March 20, 2019

Thank you for sharing your heart. I have been following your journey with Louie for about 2 months. I continue to pray for your family with each update. I haven't walked the same path as you, but I have grieved obviously, and in secret also.

—Nicole Hummel, March 20, 2019

Having a little, private cry for my own secret grief as I read your heart. Thank you for being the tool that chipped away at my damned-up tears tonight. God is so close to us, and gives us the perfect little squeeze, and He never sleeps! I'm praying for all of you! Thanking God for allowing me to care so much for Louie & his mama. ☺☺

—Johnnie Burgess, March 20, 2019

I Am Calling My Daddy

March 22, 2019

Louie has good days and Louie has bad days. But all of his days are hard. All of his days are painful. All of his days are a fight that I wouldn't wish on anyone. All of his days leave me wishing I could take his place. Yet today, I am thankful that it was a good day. It was a day with a little more energy and a few more smiles. As he lays right now sleeping beside me, I am processing so much that has happened this week. This week can be summed up by say, we are waiting. We are waiting for the next steps to take place and the right people to approve those next steps... In the meantime, I am reminded of something that happened this week, and I want to share what has been stirring in me since...

This week I had a dear friend care for my girls during the day while Erik worked and I was at the hospital. At lunch she pulled out a coke zero to drink. As she poured it into a glass, my girls were completely intrigued. We don't drink soda at all so they had never seen fizz before. My friend would pour a little at a time and show each of my girls. When she showed Liana, she would giggle in amazement. But when she showed Selah, she would gaze intently at it looking perplexed. After a few times of doing this, Selah looked at her and said firmly, "My daddy told me that if I am with an adult and they are making a bad choice that I should call him!"

When my friend shared this story with me, I erupted in laughter as I envisioned Selah's face as she is trying to take it all in. I can also see her resolve to do the right thing in the midst of a moment that was unfamiliar. All of it brought me to great laughter and for a moment I forgot. I forgot the 4 walls threatening to close in on me at the hospital. I forgot Louie's teetering between life and death. For a brief moment, I was just a mom trying to hold close the fun moments of a toddler.

Then everything came flooding back... As it did, if I am honest, there was a little envy in my heart. Envy that the world for everyone around me seems to keep going, as mine is paralyzed in this crisis...a crisis that has relentlessly consumed the past 3-4 months of our lives. I am missing time with my children and family that I can't get back. Part of me wants to scream that it is not fair. Part of me wants to run away and weep.

BUT then in that tiny space of a moment when I was tip-toeing towards despair, God gently reminded me of the beauty in Selah's words. Reread them..."My daddy told me that if I am with an adult and they are making a bad choice that I should call him!" You see there was an innocence in Selah that was articulating a firmly rooted belief that her daddy can fix anything...that he can rescue her from any uncomfortable moment...that he is always available to her...that she doesn't have to figure it out on her own, he will be there...

As God brought that to mind, I realized that HE is that daddy to me. Whatever the circumstances are that leave us feeling stuck, overwhelmed, angry, alone, or walking towards despair, God is present and available saying, "call on me." When we adjust our gaze to meet His, the burden we are carrying lightens and His love moves our perspective. It doesn't necessarily change our perspective because so much of what we see this side of heaven takes place with our eyes...and it is hard sometimes to stop our flesh from seeing only what is before us. Yet, when we look to God, He moves our perspective to allow us to see a glimmer of what our eyes can't see... The glimmer is love...true and pure and perfect love...love that drives out fear...love that says we are not alone. Love that only comes from a perfect Father to His children.

When we pause and call on our Daddy God in the hard places, He gives us the courage to keep going. He is the one able to rescue us from our bad choices, our painful places, or our deepest secrets. He is the only one who is always available when we call him.

So tonight I refuse to allow the envy or other emotions to overtake me. I refuse to see only with my eyes. Tonight I choose to simply say, "I am calling my daddy..." because I know that He alone will always answer...

Comments

Praying ever day that Louie gets a miricale and his little body heals. Praying that whatever the next step is, that the doctors find the right thing.

—*Wanda Cook, March 23, 2019*

To me, Louie is a bright and shining light that reflects the face of our loving Father - a light that shows me a way to follow the complicated path of life. The lessons in life that Louie unknowingly is providing to so many of us absolutely affirms the worth of this little child with his broken body but with the purest of heart and soul. for those of us touched by his life, we laud him among those mighty men and women that God has raised up above the masses of humanity to guide us and teach us something beautiful and mystical about God. Thank you Louie, for giving so much of your life to help the rest of us.

—*Cindy Krueger, March 23, 2019*

With out a doubt your child "knew" exactly what to do..... Thank you for sharing this moment. Continued prayers for all.

—*Myra Ferrell, March 26, 2019*

Nothing to Lose But Turning 10 to Gain

March 24, 2019



The past 24 hours have been particularly discouraging. I have watched Louie's body struggle more than it has since his pacemaker was placed on January 9th. I have been frustrated with a medical system that is dragging its feet to enact a plan, because medically the plan is a dangerous paradoxical longshot. I have talked and explained until I have no words. So I decided to write. I wanted to sit and process since it is therapeutic for me, and for some reason you guys keep reading my ramblings. So I sat down in front of my computer. My thoughts just spinning. I couldn't slow them down to even put a sentence together. I found myself questioning why I write...I found myself questioning a lot of things...

Then I remembered...

I remembered Louie.

Louie is my reason. My love for Louie and his love for people is the only reason I continue to fight against a system that yearns for things to make sense. God so creatively crafted Louie and only HE can understand his intricacies. Thus, I often want to throw-up my hands and say this is too hard...but then I see Louie's sweet green eyes looking intently into my mine and he blows me a kiss from across the room. The strength in his resolve screams at me to not give up. So today as I write, I do so for the purpose of you knowing my son better. I do so, in hopes that his determination will give you a renewed strength...a fresh perspective...as we all tackle our own battles.

When we came to the hospital 25 days ago it was for Louie to "go see Jesus." We were at peace with allowing his body to do what it had been trying to do for a long time - to shut down. As we embraced the next 9 days, making the most of every single moment, we saw a miracle begin to transpire. Without going into the complexities of his medical issues, what we experienced was a complete medical anomaly. It was unexplainable. It was beautiful. But it left us with only impossible choices. As we asked the hard questions on how to proceed since we were doing a very bad job at dying, we consulted amazing medical professionals. We were able to develop a plan to buy us a little time to determine if we had peace with Louie dying or if there was any path for possible treatment. Erik and I prayed and agonized over the decision. We ultimately decided that what we value most is life. Thus we began to walk down an uncertain road of one last shot at extending his life.

The path for treatment has not been easy for Louie. His body is taking hits it shouldn't have to take. He is in pain frequently and on meds that would knock out most adults. Louie doesn't complain. Louie doesn't allow the pain in his body to steal the joy in his heart. Louie smiles. Louie still asks everyone he talks to "What you doing? What you doing tomorrow?" Louie still holds the hands of the ones giving him meds. Louie still

likes to dress nice in his "church clothes" and fix his hair each day. (FYI: Louie has perfected three hair styles that he calls the mohawk, the whipback, and the daddy hair!) Louie still looks at you in a way that draws you in and leaves you wanting to be with him more. Louie makes you feel you are cared for and important.

For example, Louie is teetering on the line between death and life...yet there have been 3 times lately when someone has been in Louie's hospital room and they have mentioned a loved one that has recently died. Each time he has heard this, Louie asks about the person and solemnly bows his head. He will then say a pray for that person, for that family. Then he asks to see a picture of the person. He will say that he wants to know what they look like so he can recognize them in Heaven. Then he will talk about what he wants to do with that person in Heaven. The innocence, peace, and confidence that Louie displays in that moment takes your breath away...because as his body is fighting to live, he is comforting you.

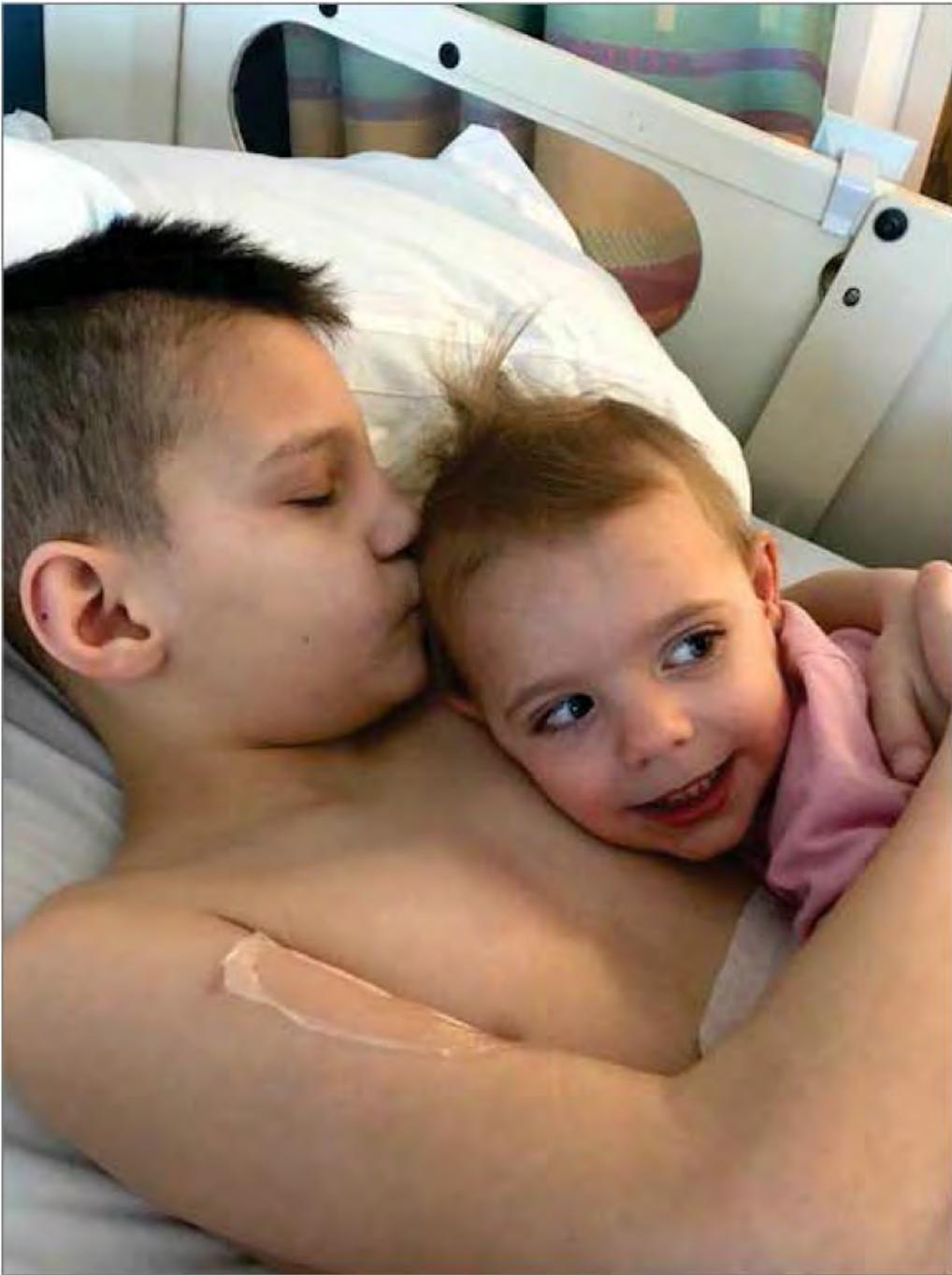
Louie is not afraid of death. Louie has more peace about death than the vast majority of adults I know. Someone told me recently when discussing Louie's longing for Heaven, that he is so mature for his age. The more I have thought about it...the more I don't agree with this at all. Maturity teaches us to fear what we haven't seen. Maturity teaches us to run from and avoid pain at all costs. Maturity teaches us that death is uncomfortable because grief is all-encompassing. Maturity tells us to hold on and value this life. What Louie shows us is not maturity, but a childlike innocent faith. It is a faith that takes God at His word without having to see everything with our own eyes first. It is an innocence found in loving God more than we love this world. It is a peace that doesn't need answers...only to rest knowing the joys of Heaven far outweigh the pain of this world. Louie doesn't have maturity...he has Jesus.

Tonight and in the days to come, Louie needs each of us to find that childlikeness. A childlikeness that gives courage in the face of hardship. A childlikeness that sees hope when circumstances are bleak. A childlikeness that sees and prays for others not as a last desperate hope, but as the first place you turn.

Tonight, Louie is being moved to a higher level of care at the hospital because of decline in his body over the past 2 days. As my heart is nervous about the days to come, Louie fell asleep telling me that he wants to have a popsicle party with his new nurses in the morning. Louie is forever thinking of others. So as he sleeps and I wait for us to move units, I ask for your childlike prayers. The next few days are crucial for Louie. We have come to the end of conventional treatment. The steps the doctors will be taking now are very risky. His body tends to react opposite to certain types of treatments. However, if he does not...if he reacts as the medications are intended...he will likely be running into the arms of Jesus. If he responds opposite - if he defies traditional medicine again - Louie could possibly celebrate his 10th birthday.

Louie has nothing to lose. He has everything to gain. But whether that gain is singing "Ever Be" face to face with God himself or whether that gain is turning 10...I am simply asking for God's will to be done. I am choosing to trust that God has already written Louie's story and just as Philippians 1:6 says, "He who began a good work in you, will be faithful to the day of completion." God is and will be faithful to Louie and through Louie's life. God will determine the day of completion for Louie...for all of us... But do we trust him enough to say, we have nothing to lose...

Photos



Comments

Thank you. I am praying with childlike faith.

—Jimmy Carter, March 24, 2019

I want to live with that childlike faith. I will be praying for Louie through the night. I have never met Louie in person, but he is close to my heart. God has given me a LOVE for that PRECIOUS, almost 10 year old that is beyond ones understanding!!! Jesus please comfort our Louie

—Kathy Bettis, March 24, 2019

Oh sweet friend!! You and Louie are teaching me so much! You are reminding me of lessons I learned when Brian was sick. Please hug that sweet boy for me. As I have learned to trust that God knows the why even if I don't, I can honestly say as i have a feeling you can too, "It is well with my soul." Big hugs. Praying.

—Rachel Bennett, March 24, 2019

Dear Jesus, I come to you with a childlike mind . Please do what is best for Louie. Take care of this littlest angel. Teach us Jesus to love like Louie.

—Wanda Cook, March 24, 2019

Praying that you feel God himself lift you up and you feel the Comfort of our heavenly father. I pray Louie feels no pain and his smile is always big. I know our Gods will ~will be done and his plans for Louie are so much bigger than we will ever know. That sweet precious boy is amazing. I pray your family will continue to see God's love and feel his presence ♥☺☺

—Jennifer Tarvin, March 24, 2019

It is Louie's childlike faith that has inspired me since I first "met" him on the TV news shows. Kristy, you have also profoundly inspired me as I have never met such a strong, faith-filled, "ferocious", and everloving Mother as yourself! God knew you would be the perfect Mom for Louie long before you were born. Thank you for sharing your life and faith with us as you, Louie, and your family travel along this unknown road. Lifting you all up in prayer with childlike faith in a loving and merciful Father. May the peace of the

Lord be with you always. Amen.

—Susan Anderson, March 24, 2019

Xoxoxo

—Jacki Bruning, March 24, 2019

In your writings, I find much wisdom and hope. Praying for Louie and your family with a "childlike" innocence is what I am doing for him tonight. May God bring our prayers to fruition. God loves Louie and will see him through. I pray for peace and answers for you.

—Linda Duncan, March 24, 2019

Keeping "Team Louie" in my prayers. Hugs
□□□□□□□□

—Linda Davis, March 24, 2019

You are so right...Louie has that pure, childlike faith that Jesus wanted us all to have. That is why he has such peace and such love for others. He is a shining example of what we should long to be. Another sweet little boy, who now lives with angels showed me that faith as well. I think we all need to be reminded of that, it slips away so easily in the chaos of this world. Thank you dearest Louie!

—Joey Daniel, March 24, 2019

Praying and praying and praying some more

—Sylvia Leach, March 24, 2019

Praying for Louie and his family. He is a remarkable little boy!!

—Virginia Colbert, March 24, 2019

I don't even know where to begin...My heart goes out to Louie, you and your family. Thank you for sharing your journey and faith during this extremely difficult time. Even though I don't know you, I feel as though I do. Such a joy to get to know Louie and seeing how he has touched so many people through his love for Christ! What a blessing he is to us all. What a blessing you are to him! I am so thankful to God that he chose you to be Louie's Mother. I have been praying for you all daily and will continue to lift you up in prayer as your journey continues. I know you know this already, but remember that God's timing is

perfect.! May God cradle you in his arms and give you peace.

—*Debra Worsham, March 24, 2019*

Oh my heavens. What a beautiful spirit is Louie. We are all praying in peace and rest for you all. Big hugs.

—*Jennifer Gibbs, March 24, 2019*

Prayers for Louie. He's so sweet. He has more faith in Jesus Christ than most people. I pray that Louie family have Peace and Strength .

—*Brenda Hugg, March 24, 2019*

Praying for God's will and also that Louie will have an amazing testimony Also prayers for his family

—*Cadie Franks, March 24, 2019*

I'm praying for God's perfect will. That He will grant you & your family the same strength and peace He's given sweet Louie.

—*debby douglas, March 25, 2019*

Praying for amazing miracles that only God the great physician can perform. Prayers for strength and peace that his will be done.

—*Louann Smith Harasym, March 25, 2019*

I only got to meet Louie once when we did the parade and I was able to give him my Police beanie.

My prayer would be for Louie to be completely healed of course, but I also believe the Lord is using Louie as testimony to who He is. Louie is showing us, as you so eloquently put it, the faith of a child. What a different world it would be if all had the same type of faith. The strongest type of faith. I don't know that I'll ever get the chance to meet him again but for me, as for many others, Louie has forever touched my life and it is richer for that. An amazing young man. Stay strong Louie! You are loved.

—*David Wollard, March 25, 2019*

I hope he has the best Popsicle party ever!! My favorite is strawberry so i hope he gets his favorite!!!

—Myra Ferrell, March 25, 2019

You and your beautiful young man have touched MY heart like no other may the Lord Jesus Christ give you peace and strength to do his will my prayers and thoughts are with you all love you all lots my beautiful friends

—Karen Kerr, March 25, 2019



—janie cole, March 25, 2019

Oh his precious heart for others!! What a tenderness to the loss others have experienced. Makes me want to send him a picture of my mom so he can look for her! I love his perfect faith. We do all need more of that! I'm praying for meds to extend his life and for the best 10th birthday ever. Love u.

—Jennie Loftis, March 25, 2019

Kristy, When my words seem so inadequate to convey my heart and prayers for you , I run to God's Words.

From my reading today by Amy Carmichael:

Psalm 32:10 "He that trusteth in the Lord (leaneth on the Lord), mercy (loving-kindness) shall compass him about."

Psalm 56:3 "What time I am afraid, I will lean on Thee."

Isaiah 26:3 Thou wilt keep him in perfect peace ...because he leaneth on Thee."

Praying these for you today
Love, Trisha

—Trisha Norton, March 25, 2019

I have never met Louie in person but I am in love with him and his beautiful spirit. I lost my Mom and baby sister to cancer and I know those feelings. Louie I hope you get to see them, they would love you just like I do. May God give you and your precious family peace that passes all understanding♥

—Vada Harris, March 25, 2019

I am just in awe of how you so eloquently put your heart into words. I pray for Louie, you

and your family. This post particularly touched me today. Thank you so much for sharing Louie and your heartfelt thoughts with all of us. ☺☺

—*Laura Sloate, March 25, 2019*

Thank you for sharing your Louie moments--his heart and yours--Kristy, so we can better understand. Miss you so much and thankful for those moments you have with Louie! Continuing to pray for him and the rest of your precious family! Love y'all!

—*Ellie Williams, March 25, 2019*

I am glad you made all this with Louie public God is using this to show people the way to salvation, peace and the love that only he can bestow upon us through HIS own son JESUS. I cannot start to feel or understand the pain you are going through with Louie's illness and prognosis. What I can offer is maybe some advice about the medical decisions that are becoming irritating to you and that would be to turn Louie over to the greatest physician, GOD the FATHER and trust him completely, you see that is why Louie is so at peace with his situation. You stated that there was an unexplainable medical anomaly when he went in the hospital this time, that was most likely GOD showing the doctors that he alone has the power to make Louie well or not. Maybe GOD is waiting for you to turn loose of Louie and put him into HIS hands instead of the Doctors who can't decide what to do. Please don't take this the wrong way, but when you took Louie to the hospital this time you seemed to be more at peace with what was going to eventually happen to Louie until the doctors gave you a glimmer of hope that now they seem to be wavering on now. Louie is ready to go to his heavenly FATHER and only the Father can heal Louie. Please let go and let GOD's will be done, then and only then can you find the peace. You and Louie has been a blessing to me in trying to learn to live without my late wife who passed in Dec 2018. seeing Louie's unwavering love, faith and trust in GOD have helped me tremendously. GOD bless you and your family, I will continue to pray and look forward to your future writings.

—*David Brooks, March 25, 2019*

Precious and incredible! Heartfelt thoughts and prayers. Shame for the "little" things I complain about.

—*Mellonie Fuell, March 25, 2019*

We all need to be more like Louie. What a precious and amazing child of God!! Sending prayers and so much love!

—*Jennifer Sowa, March 25, 2019*

God love your heart, we pray for you all, you have a beautiful gift of expressing your heart and handsome louie! ♥♥♥

—Julie Bryant, March 25, 2019

□□□♥□□□

—Cathey Hancock Cowger, March 25, 2019

□□□□□

—Tacarra Wright, March 25, 2019

Louie I have never met any of ya'll but Prayer's for you and your family your so brave love your smiles to Louie's mom I have read what you write ty for shareing

—Judy Ford, March 26, 2019

I never had the privilege of meeting Louie face to face. I was, however, in the group of Forest Hills Presbyterian church volunteers who virtually "walked" Louie down the red carpet at Give Kids The World the day before he was transferred to the hospital. it was an experience I will always remember. We have kept tabs on Louie through your Caring Bridges postings and through the folks we know at GKTW who have kept us abreast.

I cannot begin to convey how touching your posts are. I devour them and see how they can apply to my life, my grown children, my grandchild. I marvel at your strength and at Louie's tenacity and peace. And you have helped me with my own spiritual walk. I wonder where you get your strength. I can only stare in wonder at your words. And then I realize that your trust in your God and your unwavering belief is what it is all about. so I will do as you ask and step into my own childlike mind frame and find wonder and goodness in every moment of the day. May God be with you as you travel this most treacherous road and know that we pray for you, and for Louie every day.

—Judy Herrick, March 26, 2019

I had open heart surgery when I was under 10 years old (1958) so you hang in there it can get better I am living proof.

—Kenneth Clafin, March 26, 2019

Praying for miracles that defy all odds. Asking Jesus to comfort you and give you faith in the middle of this storm. You're an amazing mom and it's evident. Prayers from Mozambique. -Andrea

—Matt Andrea Marlin, March 27, 2019

Fine Line

March 28, 2019

I have had a hard time writing an update the past few days. I have struggled because I haven't known how to process things going on with Louie medically. There are pieces of the puzzle that I just can't rectify. My sweet boy has good days and bad days. Recently there have been more bad days than good. The bad days come primarily due to his underlying complex medical issues which significantly effect his blood pressure causing it to be very low. The by-product of this is a reduced quality of life during the day...and overall the quality of his days are diminishing.

Day after day, I look at my son and want to take his place. I want with all I am to make it better...to make it easier for him. I long to remove his pain. On the flip side, I also miss greatly. I miss the spark in his eyes that is absent on the bad days. On the bad days, I miss seeing his smile light up a room each time the door opens. I even miss the mischievousness that makes him Louie.

As I watch him struggle, my mind races. I have pondered every possible scenario. I see ways that his quality of life can be improved as we hope for transfer to Houston. So I have talked and advocated to everyone who will listen - and probably many who didn't want to listen. There have been almost daily meetings with doctors regarding Louie. In these meetings, I have fought and failed in having interventions initiated that I believe will help my son. As one day ends, I wipe the tears and wake up the next day to fight some more. Yet wearily I have come face-to-face with the lonely realization that I am utterly and completely powerless in these moments. My words are not enough. My heart and love for my son is not enough. There is no way to have the doctors making decisions step in my shoes for a moment and experience the desperation of fighting for the life of a child you have prayed for since before you knew their name. There is no way to convince the them to take a risk on my son. I don't have their perspective. I am not a doctor.

I am simply a mom. Louie's mom.

Mom's reading this, you get it. You understand the fight we have for our children. You understand how in desperation we can teeter way too close to the **fine line** between

control and release. We want to keep our little ones close and hold their lives tenderly in our hands...protecting them and the dreams for their lives at all cost. We want to believe we have control...so we toe the line of self-reliance. A line that says if we can do all the parenting things correctly, then things will go as planned and they will grow into exactly who we want them to be. But as we near the line, we have to recognize the truth that control is a mean illusion in this sin-filled world. In the quietness of our soul, release is the side of the line we want to be on. For deep in the recesses of our spirit we know without a doubt that releasing our children to God for Him to protect and hold them, frees us of the burden we were never meant to bear. Release allows us to love relentlessly without cause for pause when life doesn't make sense. Release provides peace and hope and freedom...freedom to love our children well even in the moments we can't control...or even in the moments we fail them - which we will. Release provides the freedom to just be a mom - nothing more and nothing less.

This week I have experienced Louie's body continuing to forge ahead on its own uncharted course. I have found myself lagging behind calling out for him to slow down so I can get ahead of him. I want to lead the path...to shape the path...or in honesty, I want to control the path. I have toed the **fine line** of control and the powerlessness has overwhelmed me. I can't change this course for Louie. So I choose tonight to release him... I choose to see that as I lag behind, it is God standing ahead of Louie calling out to him, "Come to me son! You are not alone! No doctor can make you whole, but I already have!" Release isn't giving up or failing. Release is trusting God enough to stop fighting (or in my case stop talking) because HE IS. (Exodus 14:14 "You need only to be still, the Lord will fight for you.")

It is such a **fine line** between control and release...you can't tight rope it for long... So the question becomes, which way do you want to fall? Do you want to fall into the illusion of control or release into the hands of the One who never fail you?

Comments

You continue to amaze me. Be strong my friend. Love you!

—Rachel Bennett, March 28, 2019

Sending love, prayers and understanding my dear friend.

—Suzette Goodman, March 28, 2019

My heart grieves for you. I simply can't imagine the brokenness of seeking to release Louie - and holding fast to every moment God continues to give you, Erik, and the kids, with him. Prayers being lifted to the only One who can meet your broken heart.

Love you, Trisha

—*Trisha Norton, March 28, 2019*

Dear lord in heaven, please let your will be done. Comfort this family and please don't let your angel suffer. We all pray for healing and the pain to end. Please guide these doctors to do what is best for Louie. We love you Louie!

—*Wanda Cook, March 28, 2019*

I sit here in tears because I cannot fathom what you are feeling. Louie is my hero. He loves his God and knows where he is going. So many of us who have never met Louie love him...we love his honesty, his love and trust in God. Louie has made all of us who follow in his journey better people. My prayers are with all of you now and in the days to come.

—*Sally Harris Barnett, March 28, 2019*

Continuing to pray for "Team Louie." Praying for complete healing and comfort. Sending love and hugs to you.

—*Linda Davis, March 28, 2019*

Hello. I follow your posts from project 0. I am a foster adoptive mom of a 4 and 7 year old. I just wanted to say...your words inspire me and so does your son. He is beautiful. I love your testimony...it has lifted me up and I hope you will always share Louie's story. I am praying.

-Brooke in KY

—*Brooke Slone, March 28, 2019*

Sweet Kristy-

I have been keeping up with Louie's story. I can not fathom the how your heart must ache watching your precious child during these days. I was recently put in a situation I quite frankly DID NOT want to be in. After hours of crying out to the Lord WHY?!? I heard a song called so will I- these lyrics spoke to me...

If the stars were made to worship so will I

If the mountains bow in reverence so will I

If the oceans roar Your greatness so will I

For if everything exists to lift You high so will I

If the wind goes where You send it so will I

If the rocks cry out in silence so will I

If the sum of all our praises still falls shy
Then we'll sing again a hundred billion times
Specifically 'if the wind goes where you send it so will I' - I thought 'okay Lord- here I am-
if this is where you want me to be right now, then here I am.'
I am so sorry you, Louie and the rest of your family are going through this. Know that
lovers of Christ all over the US are bringing Louie's name to the feet of Jesus. ☐☐

—*Karley Duhon, March 28, 2019*

Sometimes people think letting go is giving up. You are such an encouragement. Letting
go is trusting God to do only what He can do. Getting up every morning and fighting for
your son is what mom's do. You can let go and trust and still go to bat for your son. I
won't even pretend to understand what you are going through and although I am sure a
few can...most can't and shouldn't pretend. Thinking of your sweet boy tonight as i go to
sleep. I will pray for a peace for you that can only come from Him and that Louie will be
free from pain. Isaiah 26:3

“You keep him in perfect peace whose mind is stayed on you, because he trusts in you”

—*Krista Spoon, March 28, 2019*

I have been following Louie's story and praying for all of you. I have to say that you are a
very gifted writer (just in case no one has ever told you that). I can't imagine going
through what you are going through. But I have had mountains of my own that I pray for
God to move. I have had to learn to give up trying to control situations and surrender it
all to God. He certainly is more equipped at handling things than I am. And He knows
things that I don't. He is worthy of our trust, but it is not always easy. Thank you for
sharing your story with us. Louie is so blessed to have you for a mom. God certainly
knew what he was doing when he gave Louie to you. God bless you all

—*Lana Lander, March 28, 2019*

I love reading your updates and feel your pain. Please realize that some dads also
struggle with the decisions and struggles that you are facing every day.
You are right about which side we need to land on in these heart wrenching times, GOD
is the GREAT HEALER and he can only work for us if we let him. He can heal Louie if he
desires or he can heal Louie's family who is left behind.
I just buried my wife last December after watching her die slowly over the past 5 years I
to wanted her to get better but it just wasn't GOD'S plan, she left behind a handicapped
son who is now 29, he was not expected to live to his teen years, Drs had given up on
him ever getting better during his younger years, he was bedridden during her final year
on earth, but he very near being able to get back into his wheelchair. I have always
thought of him as my son also, and since it's just him and I left at home I asked him if he
would like for me to adopt him and he said yes. I have started that process. His biological

father has never been in his life, he's had 37 surgeries and his biological father has not been there for any of them.

So don't give up just give him over to GOD and let him handle your heavy burden.

I will continue to pray for GOD'S will be done with Louie and to give you the strength to accept his decision.

GOD BLESS you and your family.

—*David Brooks, March 28, 2019*

God Bless you!! My daughter too has had a rough year and all these thoughts have entered my mind. I keep telling myself Let Go and Let God!! It is so hard when we just want to fix it, we just want the doctors to fix it. I am praying for your family. This is something we surely do not sign up for, but like I have been told so many times. There is a reason God chose you to be Whitney's mom and I know it's the same with you. God has a reason. BUT BOY, don't we wish we knew his reason. Thinking about you sweet lady.

—*DeAnn Williams, March 28, 2019*

Through what Louie is going through and your inspired writings, and especially this one, you are speaking into hearts of many. I feel certain this is speaking to many circumstances , not just illness.

God bless and strengthen you all as many offer prayer on you all's behalf.

—*David Barnes, March 28, 2019*

Dear Louie's mom, You write so eloquently, about such heartbreaking reality. Letting God take it from here on, will be His gift to you and Louie, allowing you to spend all of your time and energy giving your son a lifetime's worth of your love.

May God bless you and your family

—*Andy Worthington Cox, March 28, 2019*

Dear Louie's mom, You write so eloquently, about such heartbreaking reality. Letting God take it from here on, will be His gift to you and Louie, allowing you to spend all of your time and energy giving your son a lifetime's worth of your love.

May God bless you and your family

—*Andy Worthington Cox, March 28, 2019*

INCREDIBLE ... You are absolutely incredible. Through it all you continue to share and shine light on God's path with encouragement for others. I pray for you, your family and Louie daily. God bless you.

—Betty Franklin, March 29, 2019

Wow. Praying for sweet Louie and that love and know him.

—Ashley King, March 29, 2019

Praying for Louie and you and your family. Your words are beautiful and true. May the Holy Spirit comfort you all as you live these hard days.

—Tracy Green, March 29, 2019

I can't imagine giving one of our sons up BUT (there is that little word BUT), if we are completely honest, our children were never ours, they are given to us for a short time by our Lord. Until I reach heaven, I don't think I will ever understand God's ways, BUT (oh, yes, there is that little word again) i know when I get to heaven, it will really not matter whether I understand God's ways or not. While we are here in this fallen world, there are certainly times when we don't have to like God's ways, but we certainly proclaim that He is always sovereign. Praying for you today that God will give you an extra amount of grace and mercy and peace about your day to day life with Louie.

—Rosanne Ramer, March 29, 2019

Louie,
Love you and praying for you every time I think of you.
I will be writing you a letter very soon.
Love, Love, Love you♥♥♥♥♥♥♥♥

—Kathy Bettis, March 29, 2019

God is showing you so much, Kristy. We are praying for you.

—Linda Hitt, March 29, 2019

Praying for you and your family, Kristy. Hold tight to your faith and God will reveal his plan. I know of your story through Suzette Goodman. I am a current Mayo Clinic patient, living in Rochester, MN. If I can be of any help please don't hesitate to ask.

My phone number is(501) 230-8850 . I am here from Searcy! I have been here since February 14th time. Mayo has been a God sent to me.

Love and prayers,
Rista Nichols

—Rista Nichols, March 29, 2019

I can't imagine the strength it must take for you, Kristy, and we are praying so hard for peace and comfort. I hope the package made it to you for Louie...I meant to include a note, but in my hurry to get it sent off I forgot. Please let Louie know that every one of those patches and coins came from a police officer who is praying for him. Much love to you and yours.

—Crystal Robinson, March 31, 2019

The Second Emotion

April 1, 2019

Overwhelmed. Worried. Disappointed. Loved. Thankful. Humbled. Sad. Inadequate. Frustrated. Lonely. Blessed. This list describes a taste of what I have felt this weekend. Striving to be the wife and mother I desire to be is on the verge of impossible when caring for a critically ill child. At this point I think it would be easier for me to be nominated as the country's next president...wait...stranger things have happened (this is the part where you chuckle)!

Back to what I was saying... Each day I must recognize that I can not be what everyone in my family needs me to be. I can not physically meet all of the needs in our home while advocating for Louie at the hospital. I am letting someone down each day. I have come to a place where I must embrace the fact that God is using others to fill in the gaps for me because I have a child in crisis. Recognizing this, isn't failure or a pitty party...it is my reality...it is truth. The truth is, when a crisis is present in our life, we must trust in HIS presence to hold us up...to keep the pieces of our life in balance. Thus, at the end of the day, my hope is simply to fall asleep without regret...to know that I gave my best to the Lord and to my family.

Well, yesterday I failed...and I failed big. Yesterday I let the list of emotions get the best of me. There was a moment when the disappointment was so big, I yelled at my husband and one of my children. I scolded them and deflated them with my words. It was a moment I am not proud of and one that snuck up on me. Quite by surprise, the second emotion quickly engulfed me to the point that I, for a moment, didn't like who I was or what I was saying. Yesterday I struggled with the second emotion. Yesterday I struggled with ANGER.

You see I am a firm believer that anger is never the first emotion you feel at anyone or anything. We never start there...but we can get there quickly. The origin of anger is always what you feel in the brief moment before the explosion. For me, today, that emotion was disappointment. I was disappointed at a situation and my response to the disappointment came out in anger. The hardest thing is once you give anger the smallest spark, it fuels itself and grows into a raging fire. When anger attacks a person, it is sin. Oh how the fire of anger can wound and leave scars... Well, I know yesterday, I wounded in anger.

The other problem with the second emotion is that our mind will try to rationalize it and make any anger a righteous anger. We naturally try to justify our anger. However, anger that is directed at a person, is never righteous anger. Righteous anger is the anger you feel at sin...at the fallen state of man. Righteous anger doesn't keep score or point fingers. Righteous anger doesn't leave scars but instead leaves one longing for more holiness in their life and in the world. For me, I can tell you all the reasons my anger yesterday seemed justified. I can explain the number of sleepless nights. I can tell you what the other person/people did wrong and how I tried to prevent the moment from occurring. I can tell you how sick my son is and how I deserve a free pass from the destruction the second emotion caused.

But the truth is, there is no reason adequate enough to cover the sin of my anger...there is only God's forgiveness. Forgiveness is the only thing capable of healing the wounds caused by my words...by my anger. Forgiveness is the only thing capable of reconciling me before God and before man. I don't need a pat on the back from others telling me it's okay because I have so much hard stuff going on right now. I simply need the mercy of a God who throws my sin into the sea of forgetfulness.

The second emotion grabbed me up in such a quick instant yesterday. It caused damage. BUT thankfully that doesn't have to be the end of the story for any of us. Forgiveness begins when we humble ourselves to confess our faults regardless of the response of others...regardless of if the other person confesses any wrongdoing back...regardless of if they extend forgiveness to you. Forgiveness starts and ends with my confession to the Lord and to the other person. Once I humble myself, pray, and confess to the Lord, then the Bible assures us that he is "faithful and just to forgive us our sin and cleanse us of all unrighteousness" (1 John 1:9) At that point my slate is clean regardless of the other person or their response. However, I still have a responsibility to value people enough to seek reconciliation with them.

So yesterday I went to my husband and my child and acknowledged my sin before them. I explained the first emotion I felt was disappointment and instead of acknowledging it and staying with that feeling, I allowed myself to skip on to the second emotion of anger. I told them I was wrong to have lashed out in anger. I told them there

was no justifying it...it was simply sin. I purely asked for their forgiveness...not desiring an apology back, but truly hoping for only an extension of grace from them. This process of acknowledging the wounds caused by the second emotion, brings healing and a foundation of grace to move forward.

I am certain this won't be the last time the second emotion of anger gets the best of me. I am positive I will find myself in need of grace again. But the more we take the time to figure out the first emotion, talk through it, and stay with that emotion in the moment, the easier it is to set down the match without starting the fire. Each time we do, relationships win. Each time we seek forgiveness regardless of response, relationships win. And in this crazy hard world where there is so much brokenness, I hope that we long for relationships to win...I know that I do.

So for today, I choose to begin my day thanking God for yesterday and the ability to grow and learn through it all. I begin my day thankful for a husband and child that extended grace to me and love me still. I begin my day more aware of my feelings and asking God for help in avoiding the carelessness of the second emotion as I have a long day of waiting on answers for Louie.

My prayer today is for every person who reads this to ask themselves, where has my anger caused pain? Take time today to allow a relationship to win...to seek forgiveness regardless of response...to release the second emotion in favor of grace. And if you will, please also join me in praying that we hear a YES back from The Mayo Clinic today...

Comments

Praying that Father God sends His grace and mercy. Prayed that He will open the doors needed immediately and continue to find a way. Continuing to pray for a miracle.

—*Angelena Van Don, April 1, 2019*

Heavenly Father, we ask that you would graciously give Louie a YES from Mayo today. In Jesus name we ask and pray.

—*Jimmy Carter, April 1, 2019*

Isn't our father great in the way he forgives us and helps us through our hardest times? Praying that God sends His grace and mercy. Prayers he will open the doors needed.

Continuing to pray for a miracle, you and your family.

—Wanda Cook, April 1, 2019

Prayers for you as well as for Louie and answers.

—Vicki Barney, April 1, 2019

Sending lots of hugs to you Kristy. I have been where you were yesterday. It is so frustrating when we advocate for our sick kids.

The disappointment and anger will boil to the surface at times and you have to let it out. Your family knows how much you love and value them and the forgiveness is always there. Hang in there and know that God is in control and loves you.

—Judy Kramer, April 1, 2019

Dear Louie's mom, Psalm 55:22 tells us to bring our burdens unto him and leave them there. I once had this explained to me in the following simple way: a child brings his most prized toy which is broken to his father with tears streaming down his cheeks and asks him to fix it, his dad assured him that if he will leave it with him that he would fix it, but the child just can't bear to be without it and picks it up and takes it with him. A few days later the boy had brings the broken toy back and with tears in their eyes says, you said that you would fix my broken toy, his dad told him simply that he could not fix it because he didn't leave it with him.

This is what GOD wants us to do. Take all those burden to GOD and lay them at his feet and leave them there. If you take them back with you he can't fix them.

I say this with the utmost respect for you but it seems as if you are not leaving all your burdens with GOD. You are fighting a losing battle with all the medical problems with Louie. GOD can do what we can't, if it's GOD'S will for Louie to be transferred to another hospital he will make it happen in an instant.

You have way too much to do without trying to do GOD'S work for him. Please turn this over to GOD and just be a mom and wife. May GOD bless you and your family during this trying time.

—David Brooks, April 1, 2019

I'm a person who's been praying about this to, n for Louie n his family i love how you answered this bout truneing prayer's over to god n leaveing them with him

—Judy Ford, April 2, 2019

Thank you.

—David Brooks, April 2, 2019

Kristy,

Thank you for today's comments. I pray every day for God's divine will and his Holy Spirit's hour by hour direction. I am Mrs. Kinley's daddy, so before she connected me to this site, she kept her mom and I updated.

We've never met, but feel like I know you and Louie. I cannot begin to know what you deal with daily, but I know very well the source of your strength to do so.

I am so thankful God allowed Courtney and Louie's paths to cross and know even that was the plan of God. Tell Louie, I love Mrs. Kinley too. She lights up any room she enters. Give Louie and family hugs from Mrs. Kinley's mom and dad.

Gary & Betty

—Gary Waddle, April 1, 2019

Praying Mayo will take Louie and you will continue to feel Gods grace and allow Him to continue to carry you through this trial of life.

Continued prayers for Louie and your family as you walk through this together.

—Michelle Coffman, April 1, 2019

Your words are always on point! Thank you for sharing your heart. My prayers are with you! And I am asking specifically for a yes from the mayo clinic!

—Fallon Jones, April 1, 2019

I'm so sorry that you and Louie are going through this, and I realize that it's not just the 2 of you, it's your whole family, we are lifting you and your family up in prayer everyday and night faithfully, I will be praying for the Yes answer from the Mayo Clinic, God is in control ,He has you and Louie and your whole family in the palm of his hand ,Jesus is a Great Big God and He uses the earth as his foot stoole , so you hold on too Jesus and He will see you and your family through this, and tell Precious Louie I have added him too several of my family's churches prayer list , so there is alot of Pentecostal People praying for you and your family, Love y'all so much ☺☺☺☺☺☺

—Joy Stuckey, April 1, 2019

Praying you hear back from Mayo today.☺☺☺ I am so sorry I can't imagine how helpless you feel waiting. Please know you are not alone, we are lifting Louie and your family up daily to our Heavenly Father who loves us beyond our comprehension.

—Rista Nichols, April 1, 2019

Praying for you, Louie and your entire family! Prayers for good news from the Mayo Clinic today! God Bless!

—Sonia Peyton, April 1, 2019

Thank you for sharing.

—Noel Hutcheson, April 1, 2019

Praying for a favorable report from the Mayo Clinic. Praying that you have already received that positive nod and that Louie's treatment can move forward.. praying for peace and comfort for all of Team Louie. Prayers for strength in those hard moments. Hugs to all

—Linda Davis, April 1, 2019

Many prayers that you receive a positive answer from Mayo

—Sally Harris Barnett, April 2, 2019

How precious your posts are to me as you live transparently and honestly to the rest of us and you obviously journey with the Lord. You daily learn more about His character as you seek the next step for Louie, then you wisely invite us to join you in seeking His desire and making sure that we honor God as we do. Thank you for including us! When God made mamas, he put such a fire of love in their hearts! I believe that's modeled after His protective love of His own children; I wouldn't want to be on the wrong side of that, LOL!!!

"Lord You are so awesome! So loving, and so, so good! Here we are...asking for Your direction....waiting for Your answer, and knowing You have been our stronghold and the rock of our refuge. You are our deliverer; our God in whom we trust. Blessed be Your Name forever! Amen!"

—Lannece Mayo, April 2, 2019

You are an amazingly wise woman, far beyond your years. Hold tight to Jesus and continue to recognize shortcomings, identify and overcome, as you did in this situation. Jesus loves you! Praying!

—Lisa Moody, April 3, 2019

WHAT'S NEXT???

April 2, 2019

So many of you have faithfully been keeping up with Louie's journey. He has defied death 3 times over the past 4 months. He has fought to live and done so with a smile everyday. He has taught me so much about courage, love, purpose and faith in God. The beauty of his soul is unlikely anything else I have known.

But right now we sit at an impasse. As a family we have chosen one last go at treatment for him...yet the doctors at Arkansas Children's Hospital have come to the end of their capabilities. There is no treatment for him here. So it is decision time again...

As many of you have prayed for the Mayo Clinic to accept him, we received our answer...and it is not exactly as we had hoped. They have explained that they will not accept a hospital transfer except in acute crisis stabilization situations. Since this does not apply to Louie, they have instead offered an outpatient option. They are wanting him to come for a few days of appointments followed by possible inpatient tests and treatment planning. This would require us to come home again on hospice services as we wait for the appointments to be set up.

Thus, we will be working to set plans in motion for a discharge in the next few days. It is a scary path with still so much uncertainty. Louie is still struggling medically...so to have him home is both beautiful and overwhelming. Yet, Erik and I made a decision a few weeks ago when Louie's body defied death for the third time, that we value life and would pursue treatment one last time. Therefore, we will embrace the hard and walk this path at home...until we can't any longer...until God changes the course.

When it comes down to it, I know that Louie has surprised so many doctors and medical professionals...but not once has any of it surprised God. As we prepare for the days to come, we ask for your continued prayers. Please pray for the appointments needed with Mayo and other providers to be scheduled quickly. Pray that we are able to get in place the support we need at home to walk this well. Pray for Louie's body to defy all odds and find a way to thrive again. Pray for our family to enjoy sweet time together as we figure out a whole new way of living. We may not know how many days are left...but we know and worship the one who does...

There truly are no words to express the appreciation we have for each of you that read and pray and support our family. When we see pictures of people wearing Louie shirts or with the bumper stickers, it just warms our hearts and often brings us to tears. The way the community has wrapped its arms around our son and our family is breathtaking...it is

a reflection of what community and relationships are meant to be. Thank you all for loving us and holding us up on the hardest road we have ever walked.

Comments

God's not finished yet! Praying for speed in getting appointments scheduled and for sweet time together at home as a family! Love you, Kristy, and praying for answers for sweet Louie! I'm waiting on my shirt now!

—*Laurie Dombrosky, April 2, 2019*

Prayers all of this works and Mayo Clinic gets these appointments made for you all. Prayers god holds Louie right and keeps him comfortable until he can make this trip. WE LOVE YOU BUNCHES LOUIE! God bless this little angel!

—*Wanda Cook, April 2, 2019*

Keeping prayers coming.

—*shawndra oglesby, April 2, 2019*

Trusting and praying♥

—*janie cole, April 2, 2019*

Lord Jesus, we approach Your throne of grace with confidence so that we may receive mercy and find grace to help us in our time of need. We are in that time of need. We need You to pour out Your mercy and your grace on Louie and his family. We need open doors at Mayo. We need healing for Louie, but most of all we need You. Please meet Louie and his precious family in this new chapter and carry them through it. May they sense Your love and Your presence every step of the way. May You put the right people in their path at the right time for Your glory and their good. In Jesus name we ask this.

—*Jimmy Carter, April 2, 2019*

Dear heavenly father, I lift Louie up to you for a complete healing..healing from the inside out and to his head to his toes..We know you are the mighty physcian and through you all things are possible..please send your angels to watch over him and his family...In your sons name, Amen
God bless your family

—*Cheryl Williams, April 2, 2019*

Thank you for talking to us. For you to share your feelings and thoughts through the spiritual grid you have embraced is soul lifting. You know Louie captured my heart at first meeting. I love you all. God alone can work good for each of you and us all. I'm so glad you trust him. I wouldn't want to live in this world without God.

—*Theresa Bittle, April 2, 2019*

Prayers to all, and especially Louie! God is the Great Physician and has plans that have to be played out in his time not ours. Miracles still happen. Have faith in the awesomeness of our Great and powerful Savior and Father. I also pray that you might find a place close to stay to that travel will not be as hard on you. In Jesus name I pray. Amen.

—*Louann Smith Harasym, April 2, 2019*

Keeping you all in prayer on the next leg of life's journey with Louie. I can't even imagine what you all are going through, but the grace you go through it with is such a testimony to what God can do. Love, hugs and prayers from Sheridan, Are. ☐☐

—*Laura Sloate, April 3, 2019*

Hi my name is Lenda I would love to talk to you about care ! My son was at children's in Arkansas where they told me there was nothing else to do! We left children's and immediately came to okc thru the emergency room ! They immediately admitted him that was two years ago! They won't do a hospital transfer but if you bring him thru the emergency room they will see him with Arkansas Medicaid ! My Number is 4056413133

—*Lenda MILES, April 3, 2019*

Continued prayers and hugs!♥♥♥

—*Julie Bryant, April 3, 2019*

It has been my pleasure too pray for Sweet Louie and you all too ,and my husband Wayne and I want stop until he is healed or what Jesus has planned for him , I feel in my heart that I was called on from Jesus too pray for your precious family, and so does my husband, we have grown too love you all so very much, tell Louie we Love Him and the prayers are touching the Throne of Jesus for him and you all too, Good Night and Sweet Dreams too you all , Thank You Jesus for bringing this precious family too our attention, In Jesus Precious Name Amen ♥♥♥♥

—Joy Stuckey, April 3, 2019

I don't think you will ever know the impact you all have had on our communities. Shining the light of Christ along this journey is planting seeds in the hearts of so many people and bringing much needed unity. Thank you for your boldness during this difficult time & for keeping us updated. I have no doubt that the smile Louie has is the joy of the Lord which the Bible says is our strength. We serve an amazing God! I have been and will continue to pray for your precious Louie and for all of you. :-)

—Julie Watson, April 4, 2019

Prayers continue for your family.

—Nancy Skinner, April 4, 2019

Praying for you and your family. My boys miss Louie at school and always ask me how he's doing. I have read all your posts and cried many nights thinking about you and your family. Praying that God will answer everyones prayers and heal sweet Louie. He is an inspiration to me and my family and his faith and helped us grow closer. We love you all

—Mary Carcamo, April 4, 2019

God is up to something. Praying for Louie, for the God who loves him to provide every need. Praying for Mayo, every doctor or technician or nurse. Praying for your strength, finances, boldness. For laughter and joy in the middle of all this. God sees. Thank you for your testimony of faith. Hugs to Louie.

—Debbie Hamilton, April 7, 2019

Hey Louie!! Praying for this sweet boy and family. We love you and tell Jesus I love him too!!!

—Patti Stroud, April 9, 2019

A New Type of Hard

April 7, 2019

Louie has been home on hospice for 72 hours. I have had many people ask how he is

doing or how the transition home has gone... So here is the raw and honest answer. It is a new type of hard.

You see, the struggle Louie's body endures on a day to day basis is the same. The medication is the same. The basic schedule for him is the same. His very low blood pressure is about the same (although tonight is the worst its been in a while). But overall, the prognosis is the same. Louie's body is in the same fight for life that it was in before we came home... Behind the smile, his body is failing - and that is the same.

The beautiful thing is those are not the only things that have remained the same. The way Louie longs for his siblings is the same. The joy in his laughter is the same. The hope in his eyes are the same. The love for law enforcement and first responders is the same. His request to open mail each day is the same. The firm resolve that Louie has when he speaks of Jesus is the same. And the most prominent characteristic that radiates from Louie...is his peace...and that has also remained the same.

Yet, the scenery has changed drastically. There are no more 4am blood draws or shift changes or doctors coming by daily. There is just us. As a family we are working to figure out how to be what Louie needs while also maintaining some semblance of family life. Most moments during the day are spent figuring out logistics or dividing and conquering...but honestly we are left often trying to figure out what exactly we are conquering.

The truth is our normal was hard before. Now there is nothing normal about it. It is a new type of hard. When we chose to come home on hospice to await appointments at The Mayo Clinic, we did so because ACH had given up on being able to provide any type of care that would or could improve Louie's quality of life. We expected the transition home to be hard since we have done it before...but this is a new type of hard.

The difference this time is we refuse to just survive...we are striving to live. When we came home before, it was basically expecting to die. This time, we are committed to hope and trusting in a God who has sustained Louie longer than anyone ever expected. This shift in mindset has resulted in new challenges. We had to order a special seat for our vehicle so we have a safe way to transport Louie when needed. We had a wheelchair lift put on the back of our vehicle. We are scheduling appointments and striving to get therapists involved, believing he can get stronger. All the while balancing every other aspect of family life - sometimes better than others. This keeps my already overloaded mind in overdrive.

The truth is, when there is a big crisis in a family with one person, it effects everyone else. And it not only effects everyone else, it dominates them...dominates family life as a whole. You find your world revolving around the crisis (and the person in crisis) whether you want it to or not. You want to bury your head and wish for it to be

better. Then you wake up again to the same reality. Each day in crisis brings a new type of hard.

So while the four walls of my bedroom are very familiar, this path for us remains a very new type of hard. Louie, in his innocence, probably couldn't tell you the difference. I believe that much of the sameness for him comes from knowing a God who is the same. God hasn't changed because we are at home versus in the hospital. God hasn't changed because we are hoping for life instead of preparing for death. God hasn't changed because this new type of hard scrapes away every part of me and leaves me empty and exhausted at the end of the day. God hasn't changed because the hurt I feel is a bit more buried. God hasn't changed in the moments I reflect Him well to my children versus the moments I blow it in anger. God hasn't changed. Period. He is the same. No matter what, God is completely and totally unchanged by all that has and is and will continue to happen with Louie.

When I sit and grasp the unchanging nature of God, there is a peace that fills my soul. A peace that Louie has always had. It is a peace that takes the new type of hard and reveals my inadequacies...but not in a way that brings me despair...instead in a way that gives me the strength to get up for another day knowing the hard hasn't caught God off guard. But even still, sometimes, if I am honest, this new type of hard still feels too big a burden to carry. But then I think of a friend reminding me to "be confident in our prayers for you and your family." And I can't help but find strength knowing so many people all over the country are lifting us up to a God who hasn't changed. So the new kind of hard may be different, but tonight I am thankful for so much that is the same...the love of God and the support of so many...

Comments

i am continuing to pray that Mayo would open up and take Louie. "Father, intervene for Louie. We need to receive mercy and find grace to help Louie in this time of need."

—*Jimmy Carter, April 7, 2019*

Louie and family!!!!Louie and family, We LOVE YOU!!! I am a Registered Nurse and I pray for you so much!!!! I Love You!!! You are a SURVIVOR. You are the most amazing little boy!!!! Keep Fighting!!!!!!! I Love You, Cindi, RN

—*Cynthia Johnson, April 7, 2019*

Know that your voice is heard and struggle is felt through your words. My the Holy Spirit comfort you and strengthen you as you care for your child, His child.

—Tracy Green, April 8, 2019

Kristy, continued prayers for you, Louie & the family. We are seeking a breakthrough! May you continue to find that assurance that you need & long for. My heart aches for all of you. May God continue to bless you with divine peace. Sending you much love, lots of hugs & continued prayers. ~Tina

—Tina Folsom, April 8, 2019

Prayers for you and your new type of hard!!! I love that you recognize that God is vast and unchanging (immutable) ! In our Bible Study we are nailing down some truths about God like this. Also that He is infinite and unsearchable and inexhaustable! He is limitless and endless! These things apply to His love, His mercy, His justice, His grace and more!!! I'm so glad to be acquainted with this "much more God" and relieved to know you and Louie and your whole family are objects of God's profound love and, oh yeah!!!! POWER! Which is also without limit! "Lord, WOW!!! This is Who You are and You are inviting "little us" to experience all of You we can take in!!! I plead with You to be visible to Kristy and bring her much encouragement and abundant strength!!!! I love the courage she has and the faith in You that is necessary to please You; knowing You reward those who seek You!!!! In all things You have said to give thanks, so thank You for being an ever present help in these times of trouble for this family! We love You, and it is in that beloved Name we send this prayer, Jesus Christ, Amen!!!!!"
Much love sweet Mama!!!! ☐☐

—Lannece Mayo, April 8, 2019

Love to you all!!!☐☐☐☐☐☐☐☐☐☐

—Laura Stiles, April 8, 2019

There is no hole too deep or too dark for Gods light. I've been praying for you guys, and will continue to pray.

—Nick Smith, April 8, 2019

It is all So. Very. Hard. When my mom was diagnosed with cancer my sister said it best - the whole family now has cancer. It is all consuming. I am so grateful for the God who sustains us!

—Jennie Loftis, April 8, 2019

I was up at 5am with your family on my mind - and I prayed! Strength and everything else you need! And God's perfect will!!

—Debbie McAnally, April 8, 2019

Continuing to pray before all of you.

□□□□□

—Linda Davis, April 8, 2019

Praying for this Precious Family, and, our Louie.

—Kathy Bettis, April 8, 2019

Keeping prayers coming for all.

—shawndra oglesby, April 8, 2019

Prayers going up for Louie and you all too, I know how hard this all is ,but like you I serve the same Big God and He carries you and I threw another hard day , Love you Louie and your family , God Bless you all □□□♥♥

—Joy Stuckey, April 8, 2019

I have been following your family for awhile now, reading your journal entries. Your son amazes me with his peace about God. He is a very special boy that God is using in many ways. My son, Jaco, who is now 9 has always had a connection with God I have not seen before. Since he could talk he has said he was with Jesus before he was in my belly. When he was a few days from being 7 he told me he would go to heaven when he turned 7. That scared me a little. The morning of his 7th birthday he woke with a peace in his eyes that I long for. He told me of his dream. How he was playing outside and God came and took him up to heaven. We did not go to church but God and Jesus have always been apart of our family. He has had a few of these dreams. Every time he woke up he had such a peace in his eyes. When he has told me his dreams the peacefulness he has amazes me. They also go along with the Bible. Things he has never really heard about. You dont go into strong detail with a small kid but his knowledge, love, and peace when it comes to God is way beyond that of most adults. God has told him he has plans for him. He has told him many things and it blows my mind. Jacob also could not see out of his left eye. Recently we decided to have surgery on it because his eye was crossed. He went through a lot of praying and mediating(something he made up on his own) because he didnt want to mess up what God made. We did decide to have the surgery and he has slight vision in his eye now. Everyday God amazes me. What Jacob has seen and been through has made my faith in God stronger. Louie has a peace with God also most people yearn for. I pray that God gives all your family peace, guidance, love, faith, strength, and comfort during this time. I also pray that Louie can continue to help people

see the real God. Thank you for sharing his life and your families life with us all.

—Jennifer Davis, April 8, 2019

You are strong and brave! Yes, all of us are still praying!! We are here for you, walking beside you, but more than that, GOD IS!!! LOVE!!!

—Carol Lybarger, April 8, 2019

Sending prayer to all□□□□□□□□□□□□

—Denise Tovar Rocha, April 8, 2019

I am praying for you. It is hopelessness and despair that set in when one is consistently given no answers. Not, that the medical community is not trying. It is difficult cases that push everyone to their limits. Thankfully, you have God's foundation that keeps you pushing for the miracle of life we are seeing. Thank you for all the positivity you continue to spread under the most difficult circumstances. I am familiar on a much smaller level. I can tell you this about the Mayo Clinic and this small city of Rochester. I call it my "City of Hope". My sister is a living testimony to being medically difficult since we were kids. She is in her fifties now and we still get into difficult situations and travel to our "City of Hope" and the precious church there that caters to transients like us! I will be there at the end of May with my sister. In the meantime, it is important I help keep her healthy enough so that she is able make the trip. I hope you find answers and treatment. I hope our Louie finds peace and resolution to this sickness that has challenged his little body. Looking forward to seeing our little man headed to the Mayo! Keep us posted.

—Betty Franklin, April 9, 2019

to the family just want you guys know that I have been praying and also the church I go we have add to the pray list I wish I could have you guys a bear hug this is far I can go but I would like say that God Is Loved His Children

—debra robinson, April 9, 2019

Praying for His sweet peace and mercy on your home. We go to church with some friends of yours. The army that God has raised up to love and pray for Louie is absolutely incredible. What an honor to petition the Lord on your behalf! What a testimony of what trusting God looks like♥

—janie cole, April 10, 2019

Praying for Louie and your family. Praying for Louie to have a good day today that God

will grant new mercies everyday. Thankful for your faith and testimony in this very difficult time. You are an inspiration to others in the mist of difficult trials. I am continuing to plead with God for a miracle for Louie. Happy Easter to your family.

—Rista Nichols, April 20, 2019

...LIFE TO DAYS...

April 11, 2019



Life is filled with good days and with bad days. No one is exempt from this reality. While on earth there is so much out of our control and thus life happens. There are days of great joy which may be followed immediately by great sorrow. We often can't map out the mountains and valleys of our day in advance, but how we navigate them says everything about who we are...about our character...about our faith.

Today, Louie had a bad day. A really bad day. Louie had to spend last night in the hospital. His PIC line had sprung a leak which meant we couldn't administer medication or nutrition and it was open to infection. After a trip to the ER, hoping they would just fix it, he was instead admitted. It was fixed this morning, but then because he was having such a bad day (couldn't arouse him and keep him alert...requiring more oxygen than typical...blood pressure low, etc.) we hung out all day in a hospital room. Finally, after meeting with our doctors and medical staff, we discussed whether he should stay in the hospital longer or if we could come home. After much thought and prayer, I asked to come home.

I asked to come home simply because of a philosophy Erik and I have had regarding Louie for the past 15 months. You see when we first started seeing scary decline in Louie's health, we were overwhelmed. We tried to hold it together and find a path that would lead back to normal...back to the mountain top moments...back to routine. After a while of spinning our wheels trying to navigate it on our own, I will never forget the night we knelt to pray together in total desperation. You see, we were in the valley and realized the only way to look was up.

As we prayed, I remember Erik's words like it was yesterday. In the midst of his prayer, he said, "**Lord if we can't add days to Louie's life, help us add life to his days.**" This prayer has become our motto...our driving force. It acknowledges the simple yet profound truth that none of us can determine the number of days we have left on earth. We don't have that power. God alone counts our days as easily as He counts the number of hairs on our head. But what we can control is what we do with the days we are given. We can't change the quantity of days but we can change the quality. We can choose to invest in the things that matter most...to build memories...to add life to days...

Let me share a brief story...but first, a little self-disclosure. I don't like cleaning up messes. I prefer the kids to wear one outfit for the day and for things to stay tidy. So often at our house when the kids ask if they can play in the backyard, my answer is, "yes but stay out of the dirt and don't play in the water!" And many times when those instructions haven't been followed completely, I have found myself quite frustrated and quick to dish out consequences. Plus, because these were my requests and preferences, Erik has been quick to adhere to the same guidelines when asked by the kids to play outside. Well, about a month ago as we were in what we believed to be the very last

days of Louie's life, there was a moment when Erik and I were talking and crying together. We began to talk about regrets...and that is when Erik said it...he said, "I regret not letting Louie play in the dirt more...he loves the dirt and I would give anything to see him in the yard playing in the dirt again." And Erik was right. As we were preparing to say "see you later" to Louie for the final time, we sat in regret that there were not more messes...more times of saying yes...more times of needing a clean set of clothes...more messy houses but happy memories...more adding life to days...

I don't know if you are in the middle of a valley, on the top of a mountain, or somewhere in between. But what I do know, is that we each have a chance to add life to days. We have the opportunity to smile more...to laugh more...to love more. Even in the valleys, we can look up and know that there is a beautiful hope in knowing the one who counts our days...and He gives us the strength to see through a different lens. A lens that adds life even to the days that feel like death. A lens that isn't afraid of the valleys, but instead frees oneself to still love completely. A lens that embraces the dirty moments because of the belief that faith in GOD is enough to sustain...enough to find purpose in the pain...enough to add life and not just count life...

Today we brought Louie home in the midst of his very bad day and with the tiny bit of strength he had, we ate popsicles and snuggled and Louie went to bed moments later with a blue tongue and a smile on his face.

So wherever you are today...say yes! Play in the dirt a little more... Hold the ones you love a little tighter... Be silly a little longer... Look up in the valley or on the mountain, because what I have found is that in adding life to days, the number of days becomes far less important...

Comments

Praying lots of love, light and hugs adding life to each day. ☺☺

—*Suzette Goodman, April 11, 2019*

Love, hugs and prayers.

—*Kim Wilson, April 11, 2019*

Love, hugs and prayers.

—*Kim Wilson, April 11, 2019*

Praying you get sleep tonight!

—Betty Franklin, April 12, 2019

Amen! You are teaching us so much in the midst of your sadness. Thank you for your transparency; for allowing God to take you through this sorrow you are enduring and knowing that somewhere in all this is His purpose. Most of all, thank you for the courage to glorify the One who made us all and counts our days.

—Paula Bush, April 12, 2019

☐☐ Amen

—Braille Braddock, April 12, 2019

That is so true!! Thank you for reminding me, Kristy, what is more important!!! Love you!

—Carol Lybarger, April 12, 2019

I needed this today! Thank you for sharing your heart! I pray every single day for your family.

—Debbie McAnally, April 12, 2019

I'm so sorry Louie had to stay in the hospital, and for you too, praying for days full of life making memories, I love what you said about adding more life to our days, this is so true, tell Louie we Love Him and I think of him as my Hero, I have learned a lot from this absolutely precious young man, in fact I believe he has taught us all how to love and to love big with all our hearts, I love the way Louie Loves Jesus, I can see Jesus all over him and you and Erik, I can't think of 2 more perfect examples of parents than you 2, your children are so blessed to have you for their Mom and Dad and Jesus knew that, and that's why he has blessed with those beautiful children and I congratulate you on the adoption of their older brother, I appreciate the example you set for me and all other parents to follow, we all lose our cool sometimes, and you surely deserve to, I know Jesus is smiling down on you right now and your beautiful family, give Louie and the kiddos hugs and kisses for me, Love you Louie so much ☐☐☐☐☐☐☐☐☐☐

—Joy Stuckey, April 12, 2019

Love you ALL and praying for healing in the name of Jesus!!!

—Kathy Bettis, April 12, 2019

Prayers. That's all I've Got....but when I think about what that means, it's all you need.

Lord, I know I fail to recognize Your essence when I look for answers in earthly places. If these remedies work, it is ONLY by Your Hand. Desperation will drive us to many things, but I deeply desire to be drawn to You! Your Word is full of promises! And You give us strength from Your unending treasure room of it; to face a storm, cling tightly to You, and let You carry us out on the other side. This is indeed a storm for Louie's family. I believe they are hanging on to You! I know that You will not fail them, but we do not know exactly what that means. I pray for peace to remain with them as the stinging rain hits. I ask for the assurance of Your presence, the "I am with you always" to anchor them with stoic hope. And I wonder if You might shine a light in the distance that helps them see the destination is indeed in their trajectory, and Your finger points to it, giving them the comfort of knowing that they aren't running blindly in circles, because YOU are their sense of direction. These crosswinds of adversity do not altar Your course, nor cause You to stumble. And as You said in your Word, "at all times we ought to pray and not lose heart". So we will take comfort in knowing that You are a one-Word prayer away: "Jesus". And in that Name, I voice this prayer to You on behalf of this family within the BIG family, and bring You praise and giving You thanks, AMEN!!!

—Lannece Mayo, April 12, 2019

First, prayers for the whole family! It's absolutely wonderful that in such a difficult time you are being an incredible witness for God!! ♥

—Kari Stanley, April 12, 2019

Praying for all of you!

—Julie Tolman, April 13, 2019

MY PRINCESS

April 15, 2019



We asked Louie what he wanted to dress-up as for Halloween this past year. Without hesitation my sweet 9 year old said, "Prince Charming so I can take MY princess to the ball!" His princess is Selah. He adores both of his sisters but there is a very special bond between him and Selah. Selah immediately followed his request with, "mom can I be a real princess for Louie?"

And so it was...they have spent the last 6+ months frequently dressing up in their Prince Charming and Princess Selah outfits. In their outfits, they walked arm and arm into Louie's Make-A-Wish reveal party. They dressed up in front of Cinderella's Castle at Disney World. They have danced in their costumes singing "Best Friends Forever" more times than I can count. And when Louie was in the hospital too weak to stand, they sat and danced in his bed and he would "spin" her around until they both just giggled.

In that moment I cried as I took video after video of them in his hospital bed. I desperately wanted to grab and hold that moment for Selah's sweet four-year-old self. I don't want her to forget the beautiful gift of the relationship with her brother. Thus, I have prayed over and over again that God would imprint on her heart the love her brother has for her.

As Louie's fine motor skills have declined, I have watched as he has asked his sister to button his shirts. I have seen her tie his shoes and even help him with his mohawk. They just have a longing for each other that is stronger than words.

Walking anticipatory grief is hard enough for me as an adult...but to do so while also shepherding the hearts of other small children is too big a task on many days. But then I look at Selah and the unique bond with her brother and I know that she gets it on a level that even I don't. I remember just before going into the hospital for what we believed would be Louie's last days, I was brushing Selah's hair. As I worked to tame her curls, for a moment her blue eyes caught mine. She looked at me and said, "mom, we will never let go of Louie until Heaven, right?" I paused for a moment to harness the flood of emotions threatening to overtake me. Then I whispered to her, "sweet girl, yes you are right. We will hold tight to Louie until he goes to Heaven and then God will hold Louie." With that she wiped the tears from my eyes, gave me a quick hug, and went back to sit beside her prince.

Today, life with Louie is day to day. On the bad days, Louie wants Selah in bed with him and with linked arms they watch movies. On the good days, they will tell silly stories or laugh at jokes that don't make sense. But to them, it is not about good days or bad days...there is just love. Love that is so beautiful and innocent that it is enough...enough to get through anything...enough to overcome sickness...enough to conquer death.

Can you imagine love that innocent and free? For us as adults, relationships are filled with so much other stuff clouding our view that we often miss the purity of love itself. Yet in Louie and Selah I see a glimpse of what the love of God is like. I see a devotion that goes beyond circumstances and carries each others burdens. I see an excitement to be together not because of what you gain, but because of the togetherness itself. I see a hope that is deeper than this world.

Thus I stand in confident faith that when the day comes, Louie will run into the arms of Jesus. There will be tickling and giggling and dancing on the streets of gold while singing "Ever Be" with the one who perfectly formed Louie's body. And with the same confidence I know that Louie will be eagerly waiting for the moment when his Princess Selah will come running through the gates of Heaven and they will once again spin and dance with each other in eternity... Oh what a glorious day that will be!!!

And until that day comes, I thank the Lord for each opportunity to grab moments through videos and pictures to forever remind Selah of her first prince...and for the opportunity to understand more of God's love through the innocence of a Prince and his Princess...

Photos









Comments

♥♥♥ □□□□ □□

—Laurie Dombrosky, April 15, 2019

Simply precious! □□□□♥

—Cindy McCrotty, April 15, 2019

Oh Kristy that is so beautiful and sweet, in fact it's pure love in the purest form. You are so blessed to have these children Precious Louie and Precious Selah, this just takes my breath away, if we could all Love like these 2 Little Ones what a beautiful world we would

walking in your shoes, and I continue to plead with our Lord for continued strength and courage to walk through each day granted to Louie. Your words today bring tears to my eyes. And yet with the sorrow that originates the tears, I feel they bring a soul cleansing. I have come to believe God awakens Louie each new day to a ministry that is a mystery only Louie and his Father in heaven perceive, - one of which reaches out to all of us who need ministering to through Louie. And the instrument of God's hand is the physical hand of your own body Kristy, that writes and records the message you see being played out before your very eyes. Our world is in need of what Louie can give each of us. And yet, everything I internalize in my mind and heart to build me up and draw me closer to God may not be the same lesson in the heart of another. I believe God is using Louie to manifest within every one of a different message, one unique to our needs. I hope you can understand what I'm trying to say. How long we will need Louie on this earth to continue ministering to the crowds who need him so I guess only God knows. Thank you, Kristy for your faithfulness to continue to reach out to so many of us. My prayers and those of so many others continue as we live and are changed through this mystery of Louie's life.

—Cindy Krueger, April 16, 2019

Cindy, thank you for your words here...I do know exactly what you mean and agree with all of it...it is a beautiful thing what God is doing in and through Louie's life...Thank you for all the support and prayers for us on this journey. It means so much.

—Kristy Schneider, April 19, 2019

What a gift and blessing they are to one another. ☐☐

—Laura Sloate, April 16, 2019

Sacrifice

April 19, 2019

This week Louie has had some great highs...but also some of the lowest moments we have experienced at home medically. He loved throwing out the first pitch at the little league baseball game on Tuesday night. It still brings him smiles to think about and is his favorite topic of conversation. But it was followed by about 36 hours of recovery for his body. His pain increased. He struggled to sustain his oxygen level at a good place and his other vitals were poor. Thus, he spent most of his time in bed, lethargic, and

unable to be maintain any level of alertness.

It is hard to watch 2-3 hours of increased activity wipe him out for so long afterwards. There are moments when I think, is it worth it? Is it worth sacrificing the quality of life afterwards? Selfishly I want to say no it isn't. I want to have every moment to myself...within my control. So I find myself telling him constantly to stay calm and relax and lay down...because when he does, he exerts less energy and the result is I get more moments with him...more time where he is alert. But there is one problem with this view...

...Louie's smile...

Did you see the smile on his face when he threw out the first pitch? If only each of you could have seen the joy and excitement in his eyes as he talked and interacted with the boys on the team. For a moment he was able to forget how hard his life is. For a moment the pain was in the background and what was in front of him felt normal. It was a time where he could just be a silly 9-year-old boy...doing what 9-year-old boys do...play baseball. He was a part of a team of peers that genuinely wanted him there. And his smile revealed clearly that he was right where he needed to be.

So I gladly swallow my selfishness and embrace the sacrifice. In fact, I hope and pray for more moments of sacrifice because that means that my son is still fighting for life and finding the energy to do something that brings him great joy. And what I have found is that the cost of that joy is lost when I see clearly the memory gained.

Too often we let hard trades rob us of the joy gained in the sacrifice. We want so badly for life to be easy...for there to never be hard choices...for there to never be sacrifices. We want to have our cake and eat it too. Louie lives life not seeking the cake for himself, but rather desiring only to share it. His joy is in purely being with people. He sacrifices his comfort for smiles and laughter with others. What if we stopped counting the cost and instead counted the gain?

As I sit here on Good Friday pondering all that my son is teaching me regarding sacrifice, I find my thoughts shifting to THE Son. Jesus walked sacrifice at a depth we never can through His death on the cross. Yet there wasn't a counting the cost, but looking to the gain, that kept Him from calling down a legion of angels to come to His aid on the cross. Jesus wasn't crushed by the weight of the sacrifice because he was too busy looking at the "joy set before Him..."

Hebrews 12:1-2 "Therefore since we are surrounded by such a great cloud of witnesses, let us lay aside every weight, and the sin which so easily entangles, and run with endurance the race set before us, looking unto Jesus, the author and perfecter of our faith, who for the **JOY SET BEFORE HIM** endured the cross, despising shame, and sat

down at the right hand of the throne of God."

The joy set before him is US... It is simple people recognizing that they can't earn their way to Heaven. It is realizing that Jesus, and His beautiful sacrifice on the cross, made a way for us...a way we couldn't possibly create on our own...a way to know God and walk with Him in eternity. Jesus hung on that tree and thought of me...and He thought of you... The joy before Him was greater than the sacrifice upon Him. Jesus chose us. Have you sacrificed your plans, dreams, sins, struggles, strivings, addictions, children, marriage, desires...your everything to the one who has already sacrificed for you? To the one who loves you completely even in your failings? To the one who saw you on that cross and counted you joy? No matter where you have been...no matter where you are now...Jesus loves you. Jesus chose sacrifice for you.

When I look at Louie, his life reminds me that the sacrifices I make, pale in comparison to the one Jesus made for us. Louie reminds me that what is important isn't counting the cost, but being in the moment. Louie reminds me that a sacrifice is only a bad thing, if you refuse to see the smile and joy of what you gained. Louie has nothing to lose in this life...because he knows the One who sacrificed with him in mind. Louie knows that in sacrificing his pain on earth, the gain is eternity in Heaven.

So if Louie wants to, we will go to baseball games...and we will go to his special needs soccer practice...and we will embrace whatever beautiful opportunity is brought before us, because the time we may seemingly sacrifice is redeemed in the smile of the moment...

(If a relationship with God is something you don't understand or you have questions about...please send me a message. Easter isn't about bunnies and chocolate eggs...it is about Jesus and the love he has for you... I would love to talk to you or point you to someone who can. Louie has peace only a relationship with God can bring...and you too can have that peace this Easter weekend...)

Comments

We have followed Louie 's journey since he went to Children's. He and you are such an inspiration to many people. Prayers said for all of you and family. Thanks for your great post and for Louie's smile and faith

—charlesandfreda christian, April 19, 2019

R. C

—Patti Stroud, April 20, 2019

That smile was amazing! God bless you for sharing Louie with all of us. He is on the prayer list at the new church I go to because of your words and him. I pray for a miracle every day for this little angel.

—Wanda Cook, April 20, 2019

Louie's beautiful smile was amazing, I love seeing him out there on the baseball field with the other boys, my heart was so full of joy and love for him it brought tears to my eyes, I am so sorry that he was knocked off his feet afterwards, I pray every day and night faithfully for him and for you and your family. God is using Louie in a special way . I know that Louie is setting the example for all of us to follow . I love that Little Man and he just melts my heart with his smile and love he has for people, it's just so pure and precious. Tell Louie he's my Hero always, sending lots of hugs and kisses, Happy Easter to you all may you be blessed ☺☺☺☺☺☺☺☺☺

—Joy Stuckey, April 20, 2019

Thank you, Kristy, for your incredible words of insight, inspiration, and transformation. You and Louie are knowing and experiencing the Presence of God in this valley of shadows. Thank you for sharing your heart, soul, and little boy with us all. Praise be to God.

—Kay Hardin, April 20, 2019

You are all in my prayers and in my hey. God knew what he was doing when he brought y'all together. May God bless you all.

—Misty Pruett, April 24, 2019

Where Do We Go From Here

April 22, 2019

Today I got a call from the Mayo Clinic. I was told that Louie has been deemed a good candidate for one of their specialized diagnostic programs. This would enable doctors from at least 5-7 subspecialties to take a close look at his history, symptoms, run tests,

evaluate him thoroughly, and ultimately provide a second opinion on if they believe Louie's body can sustain life...basically on if my son will live much longer.

I should be excited about this news. I should be rejoicing and counting the moments until I hear from them on a date for when we can go. I should be making travel plans. I should feel a sense of hope that there may be a path forward...that there may be a treatment that could help Louie live.

And I am...I am so thankful for this possibility....but....

But if I am completely honest, it is overshadowed by how hard much of the last few days have been for Louie...for me...for our family. Social media provides beautiful glimpses into the smiling moments Louie may have, but what it misses is the other 20+ hours of the day that are filled with great struggle. It doesn't capture the way he crashes after the excitement of a new moment dies down. It doesn't display the exhaustion that comes when there are machines beeping in the night seemingly every time I finally fall asleep. It doesn't quantify the hours of time dealing with issues I am untrained to manage or the time on the phone with medical supply companies, insurance representatives, and medical personnel. It doesn't do justice to the fight for life that he is in...that we are in with him.

Thus today, in the midst of the relief provided by the Mayo call that he is accepted into their program, the weight of this road just seemed too heavy. So much of me wants to sit and document for each person reading this the intricacies of today. I want to pour out all the crazy that made it hard...the bath for Louie that requires significant preparation and help from a friend...the service call at bedtime to fix his broken oxygen machine...the beeping TPN pump that is as user friendly as the computer blue screen of death...the demands of a child's homework when they have procrastinated...the crying two year old who doesn't understand why mommy can't lay with her until she falls asleep...the look in Louie's eyes as pain wakes him up from a deep sleep and the rush to get meds to try to get him relief...and this isn't the whole day. It is just a small piece of the last 4 hours of today... If only you knew it all, then there would be no judgement in me wanting to scream and throw my hands up in surrender and run away to a world that makes sense...but wait, does that even exist?

Please hear me LOUDLY that I am not saying any of this to elicit sympathy or pats on the back of encouragement or any form of response. I am not saying this to complain about what life looks like currently...simply to acknowledge that it is hard - just as you have hard places in your life. We have chosen to be very open regarding the ups and downs of Louie's journey. It is a choice that Erik and I have made to honor the beauty of his legacy and allow his light to shine brightly...but also because we believe that the world doesn't just need to see Christians able to talk about a good God when life is easy or "normal." The world needs to see how we respond when the walls are crumbling...when

we want to give up...when the sadness or pain or despair is too great to bear. As a Christian, the world needs to see our weakness in order to know HIS strength.

Tonight as I am so weary...as weary as I have been these past 4 months...I still choose to shout from the mountains - or even moreso in the valleys - I TRUST YOU LORD...I am unable to see what the path forward looks like, but I TRUST YOU LORD...I am disappointed by certain aspects and people on this journey, but I TRUST YOU LORD...today was too exhausting to even begin to fathom tomorrow, but I TRUST YOU LORD...I want there to be an easier road - for my son to be healed immediately, but I TRUST YOU LORD...I struggle to find the words to pray often, but I TRUST YOU LORD... Regardless of the outcome of Louie's story, I TRUST YOU LORD.

Trust in God... It is all I have. It is all that directs the path forward. It is all that will remain when the hype of "Louie" fades away. It is all that keeps me standing. It is my only hope of finding the world that makes sense, because this side of heaven our eyes will always be consumed by the imperfections of life...the sin...the struggle...the pain...the sickness...the hardships. BUT when our trust is in God, we long for Heaven - for that perfect completeness of eternity - the only place where things make sense...

So where do we go from here? Well for me, instead of throwing my hands up to surrender to the pain and defeat of today; I throw my hands up in worship to the only one who is worthy...to the one who loves Louie more than even I can comprehend and is shining SO bright through his smile...to the one who, if it is in HIS plans, will continue to open the door for the Mayo Clinic program to be a gamechanger for Louie's life... Oh Lord, I trust you even now...

And I go to bed with the lyrics of one of my favorite songs on my lips...
"With every heartbeat in my chest
Lord, I surrender all that I have
The days yet to come, the days in the past
I'm giving You all I am
With lifted hands, with lifted hands."

(From With Lifted Hands by Ryan Stevenson)

Comments

Praying. Every day for you all! Thank you for being raw and real!

—Debbie McAnally, April 22, 2019

Praying for Louie and for all of you! I watched as my dad and mom suffered from Cancer the highs and lows and the only thing that got me through was my full trust in God. The song you raise me up carried me through, I would picture God raising me up above all the pain and sorrow and knowing He was with me all the way. I am praying so very hard Kristy!

—*Diane Huggins, April 22, 2019*

Yes, we trust you Lord! Through the tears rolling down my face, we trust you Lord!!!

—*janie cole, April 22, 2019*

Thank you for our honesty. Thank you for your public confession of faith. “God, give Krisry great sleep and rest tonight. Renew her strength. Thank you for your grace in her life. Please use this opportunity at Mayo to heal Louie. Please protect this family. Keep them strong. May your Chutch rally around them. I ask this in Jesus’ name. Amen”

—*Jimmy Carter, April 22, 2019*

Continuing to pray for precious Louie, you, your husband and your entire family! Louie is such a courageous and inspiring young man with so much faith! God Bless Y’all!

—*SONIA PEYTON, April 22, 2019*

You are amazing. Thank you for your posts of inspiration and encouragement. I will continue to pray for your precious family.

—*Betty Franklin, April 22, 2019*

Keeping all of you in my prayers

—*Linda Davis, April 22, 2019*

I pray daily for all your family and the decisions your family has to make. I ask him to give you you the wisdom and courage with the decisions you have to make!!! May he give you peace and comfort in the days to come. Love to all!!!!!!

—*Patti Stroud, April 23, 2019*

Your ministry through your trial is so powerful. We have dear friends with a daughter dealing with brain cancer and just found out her mama may be facing her own chemo (for second time). Your words - today especially- are so helpful to the hurt and confusion we are feeling for our friends. Thank you seems so trivial, but I mean it wholeheartedly.

Standing with you in prayer and surrender ♥

—Danielle Turley, April 23, 2019

Psalm 18:6

"In my distress I called to the Lord ; I cried to my God for help. From his temple he heard my voice; my cry came before him, into his ears."

Reading your post today, brought back to mind this verse that I have on my heart for so many family and friends going through alot. Your family as well. Thank you for sharing!

—Shandra Tipton, April 23, 2019

Your post and your faith in God are an inspiration to many. Continued prayers for each of your family as you care for Louie. God Bless

—charlesandfreda christian, April 23, 2019

Our Christian walk is never easy. There are always high's and lows, easy parts and hard parts. Sharing all the parts helps the rest of us to know that we are not alone. Thank you for choosing to share your and Louie's journey.

—Marla Burger, April 23, 2019

There are no words, I type and delete and type and delete . I wish I didn't understand. Thank you for showing others the real things.. It is so hard.. love you. ♥

—Braille Braddock, April 23, 2019

Praying for Louie and your whole family. I am so glad he got accepted at Mayo. Praying for the details to work out smoothly,

—Rista Nichols, April 23, 2019

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—Rista Nichols, April 23, 2019

I pray for you every nite.

—Paula Vines, April 23, 2019

Oh sweet sister, I love you. I wish I could give you a big hug, a shoulder to cry on, and watch the kids for a couple of hours for you to nap. Although I can't possibly know everything you are going through, I do know the feeling of standing on God's promises and trusting Him completely no matter what. I TRUST YOU GOD is the same thing I said over and over when I lost my baby and walked through the grief of miscarriage. And He is so good to carry us through those times. Stay strong in Him sweet sister. You're doing amazing things for His kingdom. Love you ☺☺

—Kristina Mete, April 23, 2019

Kristy I am so sorry that Louie had such a hard day and that yours was so hard also but your right God is the only one that we can lean on because he will always be there for his children, Jesus is our strength and our Hightower and a very present help in times of trouble and He's a friend that sticketh closer than a brother, my husband Wayne and I are constantly praying for Louie and you and your Beautiful family, I have come to love you and I love Louie so much, he is a beautiful light in a dark world and I am so thankful for him and for you, we all have bad days and in my case my husband Wayne is disabled so we go through some of the same things that you do but the difference being Wayne's a grown man and Precious Louie is a child, but he is very wise for his age , I can see his picture and he just melts my heart and I think what a beautiful child with the wisdom of Jesus that some adults don't even grasp, he is amazing too me , but I have got alot of people praying for Louie and you all, on my husband's side and my side of the family so there is alot of people praying for you and Louie , We know that prayers are powerful and prayers work! I just wanted to let you know that I had read the journal and it touched me in a big way and you and Louie was on my mind and on my heart, God Bless you Little Man and God Bless you Kristy and the rest of your beautiful family!! Hugs and kisses to you both from Wayne and I, Good night and Sweet Dreams and even though I live so far away from you and Louie We will be at the game Saturday night in heart and spirit!! ☺☺☺☺☺

—Joy Stuckey, April 23, 2019

I cannot wrap my brain around your lives right now. Hard is an understatement. Praying rest comes from somewhere for you heart, mind and body. And pain relief and energy for Louie.

—Debbie Hamilton, April 24, 2019

Hi Kristy, I just learned about Louie today via a FB post. I'd like to pray over Louie for his healing over the phone. If this is something you would be interested in, please email me, we can set up a time and exchange contact information. God's blessings on you all ♥
PinkRoses1220@gmail.com

—Robin Romanow, April 25, 2019

Kristy I am so sorry that you and Louie had such a hard day, but you are right, no matter what happens always Trust in Jesus, because he will be there for you , Louie and your family when no one else is, I have felt the way you do quite a few times but I always call on my Precious Lord and my favorite song too listen to is The Crabb Family's Through The Fire and I am immediately at ease as I know Jesus just lifted my burdens and I Praise Him and Always give Him the Glory , I could not imagine going through lifes battles without Jesus, He is our everything and tonight Wayne and I are going to lift you and Louie up in prayer who knows it could turn into Intercessory Prayer my husband has that gift , he is a Prayer Warrior , We Love you and Louie and your adorable family, talk soon !!☺☺☺☺☺☺☺☺☺☺

—Joy Stuckey, April 25, 2019

Kristy, I read each word you write and try to imagine what you are going through. - and if course i can't. I can only say that you are helping me to be a better Christian. I realize i can go to God in love, supplication, anger,as long as I go to Him. I read each word and ask how i would behave in far less challenging situations And I find i would come woefully short of where I should be. So, please know that your words are being read and that I am walking with you. Prayers are coming your way through our church, my family and me. And you are loved.

—Judy Herrick, April 26, 2019

ONE PITCH...

April 27, 2019

Today started with Louie waking up and saying to me, "one pitch!" He was excitedly referring to throwing out the first pitch for the Arkansas Travelers at tonights game. Over and over again today he would ask how long before "my one pitch?" Louie practiced his pitching motion. He told everyone he spoke with this week about his "one pitch." To say he was looking forward to it, is an understatement. In fact, the only time I have seen Louie this excited was at his baptism in January.

When we arrived at the stadium, we were greeted with such kindness by all the Travelers staff. They allowed Louie onto the field before the game so he could meet a few players. Up walked first baseman Evan White. He immediately knelt next to Louie and began talking to him. Quickly they found their common thread...and it wasn't baseball...it was Jesus. Next thing you know, Louie is asking to pray for him. He prayed

for him to "play hard for me..." Evan then began praying over my son. Then Louie ended the conversation by telling Evan that the first thing he wanted to do when he got to Heaven was "play baseball." This sweet conversation was followed by a similar one with Jake Fraley and with one of the team managers. These three men took the time to talk with and pray for my son as he also asked to pray over them.

The conversations with these ballplayers caused me to stop in my tracks. I looked around the stadium and for a moment I no longer saw the crowds, I saw the faces...the people. Each of them with something that drew them to the stadium on this day...maybe it was a boyfriend...maybe a company picnic...maybe it was their job...maybe it was the love of baseball...or maybe it was even my son...but there in that moment I saw that each of them has a story. Each person is fighting their own battles and celebrating their own victories...and yet in a few short minutes, all eyes would be on my son.

As I pushed him in his wheelchair to the field, the applause was thundering and many were on their feet. Oh how I wished that time could stand still as I held Louie up and he giggled, grinning from ear to ear, as he looked straight at his new friend Evan. For that instant, that moment before the "one pitch," everything felt so right...so beautiful...so full of life.

Louie, with all his strength, delivered the best pitch in his power...and the crowd erupted again. As Evan walked to Louie to give him the ball...Louie didn't really care about the ball any longer...what he wanted was to hug his friend Evan. Evan then had a few of the other players join him on the sideline and together they knelt and prayed for my son.

I realized as I stood there with my head bowed and arms resting on my son and a major league baseball player, that Louie's "one pitch" wasn't about baseball at all. It was about Louie's love for God and for people. It was about a faith that can unite strangers and uplift a community. It was about hope in the face of death. It was about living each day for things that matter.

Louie will never play in a "real" baseball game. He will never throw a strike. He won't steal a base or catch a fly ball. But tonight, Louie belonged with the Travelers. He was a part of the team...and I realized that it truly isn't because of anything Louie has done, but all because of his faith in a God that has graciously given him more days to smile...to laugh...to love others.

In the end, Louie will care less about the "one pitch" than he will about the men he met tonight on the field. I guarantee you he will wake up in the morning longing to see and talk to Evan and Jake and those that prayed with him, because Louie gets that baseball is temporal, but people matter. Louie loves people fiercely.

What if all of us learned a little from Louie? What if we looked each other in the eye a little more frequently? What if we treated people with more loving kindness? What if we spoke with less of a filter and more authentically with each other? What if we allowed our hearts to see the good in people before we put our walls up? What if we lived in the instant before the "one pitch"...in the pause where we count blessings in the midst of hardships, and smile, and giggle, and believe with innocence again?

What if you only had "one pitch"...what would you do with it?

Comments

Mrs. Schneider thank you for all your words. You have no Idea how uplifting your journal entries are for me. I'm on my own faith walk learning how to have a closer relationship with Jesus. Thank you for sharing Louie with all of us.

—Carol Frederick, April 27, 2019

Watching your precious son, Louie, throw the first pitch and interact with the ballplayers was such a satisfying, beautiful, and blessed occasion tonight! I continue to pray for Louie and you and your entire family. I pray Louie has a restful night of sleep after his exciting adventure today as well as the rest of the Schneider family! May the peace of Lord be with you all. Amen.

—Susan Anderson, April 27, 2019

My hubby & I were at the Travs game tonight.... & I was one of I'm sure MANY with tears running down my face when I saw some of the players kneel down & pray with your son. As they did that, I was praying for YOU.

Two & a half months ago, my hubby & I held our precious almost 4-month old sweet baby boy up in CVICU at ACH as he took his last breath, was finally made WHOLE & was brought HOME. ☹️☹️ He spent his whole short life there in the BEST hands EVER!! In that moment tonight, God laid you on my heart as I know all too often some of the same struggles you are experiencing as I walked this road not too long ago with our precious son, Brandon Aaron.

Please know you are being covered in prayer, along with your loving Louie & the rest of your family. It was a spur of the moment decision we made tonight to come to the game.... & now I know why - God wanted us to see Louie!! Keep holding on to HIS peace & keep shining bright!! God is using you ALL in mighty MIGHTY ways.... & used yall to minister to my heart tonight. ♥️☹️

—Brittany Carmichael, April 27, 2019

Thank you Brittany for sharing this with me....and thank you most of all for your prayers. You have walked a hard path as a mother and I will be praying for you as I am certain your heart is still healing. Thank you for understanding and seeing me in the midst of all of this... And think...before long, our boys will be playing together in Heaven completely whole!

—*Kristy Schneider, April 29, 2019*

AMEN!!!! You can tell Louie that Brandon will be the one crawling/running to those pearly gates to hug & welcome him when he gets HOME & will be SOOO excited to show him all around!!♥☐☐

Continued prayers!!

—*Brittany Carmichael, May 4, 2019*

I was anticipating this journal entry! And wow! I surely wasn't disappointed! That Louie! I saw him (via Christie's FB video) immediately engaging with people! I watched as God became the main focus in a world of baseball and baseball fans. I saw a loving mama get a heart-full and a stadium-full get a glimpse of the Main Thing. And now your words about it; powerful! Louie doesn't just have a message to tell; He LIVES the message of Jesus and You aptly interpret it! I love your question, "what if we had "one pitch", what would we do with it? Reminds me of the quote (whose author I do not either know or remember):

"Only one life, 'twill soon be past...only what's done in Christ will last."

One pitch.

Thank you for sharing your heart, Kristy. ♥

—*Lannece Mayo, April 28, 2019*

Thank you for these very kind and encouraging words.

—*Kristy Schneider, April 29, 2019*

What beautiful and amazing words Kristy, and all you said has me thinking about myself and my husband, Louie has had the most profound effect on us and so have you . I am so thankful that Louie had such a wonderful day filled with many wonderful blessings, people and experiences , I can feel his beautiful Love for the Lord through you words and through his gorgeous smile and beautiful eyes , Love you always Louie ☐☐☐☐☐

—*Joy Stuckey, April 28, 2019*

You are so blessed to have a son like Louie who is not afraid to share Jesus. Oh that we

should all have his faith, what could be accomplished for God's kingdom

—Paula Vines, April 28, 2019

Louie is such a blessing to everyone he meets....he is truly a gift from God!! Many of us will never meet him here on earth, but he has blessed us all. Louie, you are a hero!!

—Joey Daniel, April 28, 2019

Thank you for a beautiful challenge and perspective, Gods love spilling out of you & Louie is contagious! Praying for y'all.

—Valerie Frith, April 29, 2019

Love you Louie. Praying for God to heal your bofy♥♥♥♥♥♥♥♥

—Kathy Bettis, April 30, 2019

Working on something special for Louie. Hope to get it in the mail today or tomorrow. God's healing and sustaining blessings to you all. □□□□□□□□□□□□□□□□

—Cindy Krueger, April 30, 2019

10 Second Turnaround

May 2, 2019

A few days ago I spoke with a kind nurse at the Mayo Clinic regarding Louie. She works for the program that had accepted him and we were talking to further discuss his needs and ideally schedule the visit to Minnesota. However, the more we talked, the more we both realized that the program she is with is not the program he needs most. While it would likely provide some answers and support, it would not give us the help we need to sustain life longer and they could not schedule him until July. The door is by no means closed at Mayo, but they are needing more time for a different set of doctors to evaluate the case and set up the plan. They assured me we would hear from the complex care diagnostic team within the next few days.

We remain hopeful that the Mayo Clinic will provide a breakthrough for Louie. However, at the end of the call there was a heavy wave of disappointment in realizing that we are

back to waiting. Waiting is such a part of life. We wait for a returned phone call. We wait for our turn to check out at the store. We wait for the right person to marry. We wait to hear back regarding a job interview. We wait for test results. We wait for the light to turn green. We wait...

In fact, I read a study recently that said that the average person throughout their lifetime spends FIVE YEARS waiting in lines and SIX MONTHS of that is waiting at traffic lights. Waiting is part of life and therefore something that we get accustomed to whether we like it or not.

Yet, this waiting feels very different. It is not a waiting that is inconvenient like when you wait in traffic. The waiting we are doing now, is life or death for my son. I can't control the waiting but I am learning quite a bit in it. One of the simplest and yet most profound things I am learning is that it only takes a moment and a few words to encourage the heart of another person and make a difference in their day.

For example, Louie had an appointment recently. As we were about to leave the appointment, a nurse intentionally approached us to say that she had been following Louie's story and that she was praying for him. That day was a hard day for many reasons...that day my heart was so weary and burdened...I felt isolated and alone...and that day, those few words, that intentional action encouraged me deeply. The sincerity in her eyes resonated with me and I wanted to cry and hug her and tell her how much I needed those few words in that moment. You see what took her 10 seconds was a great reminder to me that God is watching over us. God has people praying for my son and our family that I may never meet. God has not left us alone to fumble through this hard place. He is with us and so many others are standing, united, praying for Louie and our family. The 10 second encounter with this nurse truly turned around my day...it gave me a sense of togetherness.

There are many other examples where God has taken Louie's story and used it to touch the heart of someone. Consistently at difficult junctures we find a stranger or a friend stepping into our path for a moment to encourage us. Each time I walk away from the encounter - whether it was in person, in a message, in a text, in a phone call, or in a letter - and find myself saying "Thank you Lord for sending someone to be your voice, your words, or your hands today. Thank you that I am not alone."

I firmly believe there is not much that is more debilitating than loneliness. It keeps one paralyzed and stuck in an inward battle that can't be won independently. Loneliness can feel so big that even with all the knowledge you may have in your head that says "God is with you," it feels so trite to contemplate those words because you long for someone with skin on to see you and step into your world if even just for a moment. Loneliness clouds our judgement and fills our world with gray. And the hardest part is you can be surrounded by a sea of people and still be desperately lonely. It is not the quantity of

people around that dictates the depth of loneliness...it is the quality of the people.

We pass lonely people every day. Chances are that you know people well who are wrestling with feeling alone. Chances are when you are going about your day, there are people you interact with who internally are crying in loneliness through the casual smile they may offer.

I thought a lot recently about a few groups of people I know battle loneliness because we have walked it personally. I thought about other dear families I know with special needs children and how their daily lives will never look "normal" compared to the American dream. Trying to navigate a world made for "normal" when you will never be "normal" is isolating and often feels so lonely. Then, I couldn't help but think of some foster and adoptive families I am close with that are wrestling with big issues with their children and every day is a struggle. It can feel so lonely to be fighting for kids with behavior issues and feeling the stares of others but you can't and won't explain their history or share that you are giving your all to love a child you didn't birth. And there are so many other reasons...and sometimes no reason at all for loneliness...BUT...

What if we all decided to be encouragers? What if we decided that today we would find something nice to say to each person we encountered? What if we gave a person the benefit of the doubt and when we saw a glimmer of hard, we took 10 SECONDS to reach out and say I am thinking of you...praying for you...here for you? What if we, like that sweet nurse, looked someone in the eye with sincerity for a moment...just the look that says "I see you and you don't have to say a word...you are not alone."

You can make a difference in someone's day with 10 seconds of kindness. Will you do it today? Will you leave a person feeling better than before they interacted you?

Comments

Thank you! I will.

—Jimmy Carter, May 2, 2019

Continuing to pray for all of you. Thank you for the reminder that we all can make a difference. Love and hugs ☺☺☺☺☺

—Linda Davis, May 2, 2019

Awe, sweet Kristy, you are such an encouraging lady! We pray for you all every day, much love and prayers!

—*Julie Bryant, May 2, 2019*

I wish I could hug you personally, and bring a smile to Louie too, but I can and do pray to you all. Thank God for the miracle of Louie and all the blessings that his life is shining out into the world. I pray for strength, comfort and healing for all of you!

—*Joey Daniel, May 2, 2019*

Thank you for sharing. This truly touched me today
Sending prayers for Louie and your family.

—*Jana Lippe, May 2, 2019*

You are a blessing. Thank you for making me rethink my actions daily. I pray for you and your family every day, with that hope that things will change for your Louie. Your testimony is making a difference in so many lives, I just know it. It has mine.

—*Ellen Davis, May 2, 2019*

Your words spoke directly to my heart. I don't understand your loneliness because I haven't "walked in your shoes", but I have fostered and adopted 2 beautiful children and the loneliness can be overwhelming. No one could understand what you are going through unless they are in your home living through it, but the meals, kind words, hugs, prayers, smiles, and listening ears are so very helpful. I am praying for you and your son. Thank you for ministering to my heart through your pain. Thank you for allowing the Lord to work through you. You and your son are world-changers!

—*Tiffny Stewart, May 2, 2019*

Praying for you, Louie, and your family. Praying for open doors, perfect provision for your every need, healing, wisdom, comfort, peace, courage, strength, and joy for the enduring race ahead. You and your family are an encouragement and inspiration to myself and others. Praying that God will show up and show off at just the right times so that everyone will know it was Him who can take credit and receive the glory and that in the meantime that He will keep you all covered under His wing and you'll feel safe and cared for and prayed over.

—*Haley Crellin, May 2, 2019*

You are such an inspiration to me. I truly needed to read this today. Praying for all of you. God bless!

—Dena George, May 2, 2019

Thank you. You speak so eloquently with truth. God has his hand on you.

—Noel Hutcheson, May 2, 2019

"The joy of the Lord is my strength" is playing in my head this morning. I pray this for you all today.♥Doesn't mean we have to be happy all the time! But pull on Him!

—Linda N Jackson, May 2, 2019

Well said and so very true. We have to be His hands and feet!

—Barbata McCreight, May 2, 2019

Each time you post your words reach out to so many people in various situations that are vastly different from your son's. God speaks through you in your post to so many. Thank you for letting your light shine!! I am continuing to pray for Louie here in South Carolina.

—Sharon Neal, May 2, 2019

Your post and Louie are truly an inspiration to many. Prayers for Each of your family. 1Peter 5:7. "Casting all your cares upon him for he careth for you." God Bless.

—charlesandfreda christian, May 2, 2019

God uses you to encourage my heart. Thank you for sharing your journey with us. Praying hard for Louie and your family!

—Lynette Place, May 3, 2019

It is amazing, in your own loneliness, you have helped so many others. I don't know if it helps you to know that we are reading your words and listening to the pain you share. Please know that we are following you on this unbelievable journey and sharing the path with you.

—Judy Herrick, May 7, 2019

The Mayo Clinic

May 7, 2019

The past week has brought more hard days than good days. Louie has needed oxygen more than ever before and at higher rates. His blood pressure is dipping quite low...even for him. His energy is declining. He is sleeping more. His pain has increased. We have adjusted and added some medication. We are taking it a day at a time...well actually, a moment at a time...

The next part of the update I have wrestled with whether or not to share... Up to this point, I have shared very openly with the world pieces of our journey. If I am honest, I have gotten some negative feedback for doing so. Yet, I also see how God is using his story...his struggle...our perspective to encourage people and leave them wanting to be better. I realize this miracle begins with how Louie lives. I want to be better when I am around him. I want to never meet a stranger. I want to see past exteriors to ask each person I meet, "what you doing?" and truly want to know the answer. I want to not be focused on stuff but care about people more...and not just people I know well, but all people. I want to apologize quickly and sincerely. I want to forgive without judgment. I want to have the innocence of a child again..the gift of God's eyes...the heart of Louie.

Do you know not one time has Louie ever been doing something that he wanted to do and not stop it immediately when a person walked in the room. He stopes because he values people so highly he wants to talk with them more. Yet, I was so convicted today when one of my girls came up to me to tell me something and I asked her to wait while mommy sent an important email - and then I listened to her without looking up from my screen. Doesn't my daughter deserve better than a distracted mother? Even if I can justify the importance of what I was doing in that moment, doesn't a child, or any person for that matter, have more value than emails or texts or games or whatever "good" thing we fill time with and convince ourselves we are doing okay...doing what we have to do? Yes, there are times when a child should wait and what we are doing can't...but if we are authentic with each other, the vast majority would admit that there are times our devices take the place of face to face conversations in a way that is not honoring to others...even to our children and family.

Anyway, I digress...that was free processing from my own moment of conviction...back to the update. After the wrestling, I am opting to share the newest info with you because we need prayers. We need people storming Heaven's gates on behalf of Louie. We need people holding our arms up, now more than ever, because we are so tired physically and thus even spiritually weary.

Yesterday afternoon I spoke with someone in scheduling with the Mayo Clinic. (FYI: Last

week I was told that they were just verifying some scheduling things with some specialists and we should receive information on when we can come early this week.) So as I initiated the conversation with the scheduling team yesterday, I was told very flatly, "it looks like the reviewing doctor has denied the referral." The breath left my lungs. I proceeded to ask what she meant. She said that the note indicates that "the reviewing Pediatrician feels they would do the same things as Arkansas is already doing." Before I could stop myself, I blurted out, "The same thing as Arkansas? They have sent us home to die!! They have said they don't have the expertise but feel that you do. Without your help, my son dies. So what do you mean the referral is being denied?" I talked in circles with this scheduling lady who didn't seem real interested in helping me figure out who I could talk to...so with a promise to hear back from her supervisor, I got off the phone with her.

Immediately I called a very kind nurse at Mayo Clinic that I had spoken with previously. I told her that I needed her help connecting with the right person. At this point, I could no longer contain the tears as I explained that I wasn't sure the right people had the right information. I explained that we were needing a second opinion that hopefully provides a treatment plan to move forward and improve the health of my son. I explained that if the right people have reviewed the correct information and there is nothing to be done, then that is something I will have to be okay with...but until I know for sure that is the case, I must keep fighting for Louie...for his life. The nurse definitely understood and agreed completely that there is a strong likelihood that they hadn't had the right people review the right information. At this point, the nurse places me on hold...

As I wait... find myself staring out the window and the only phrase being repeated over and over again in my heart is "My hope is NOT found in medicine." It was all I could think. I was trying to breath. It was all that consumed my thoughts..."My hope is not found in medicine." And with the tears streaming down my cheeks, I uttered simple words, "Lord, give me hope." I realized in that moment the feeling threatening to consume me was one of panicked desperation. It was a feeling that made the air too thick to breath...and the grief too much in the forefront...especially when in the background I hear Louie's oxygen machine and a sudden burst of soft laughter from him as he watches a movie with his sister. This can't be the end...this can't happen. My thoughts try not to contemplate the despair that will inevitably come if the Mayo Clinic rejects the referral for my son. I hold to the truth, "My hope is not found in medicine."

After a few minutes, the nurse comes back on the line and tells me that she feels the best course of action is for her to send a message straight to the doctor and ask that she contact me directly. She says "it is time to get the middle men out of it and let you talk to her and discuss the situation. She needs to hear from you where Louie is and what you are hoping to obtain from a trip to the Mayo Clinic." I thanked her and let her know that it would be an honor to talk to and advocate for Louie, straight to the one making the decisions, since that will provide the assurance that they understand.

I have to make them understand...

Then today I waited for the phone call, but it didn't come. So now I write... I do so to ask you to join me in praying that Dr. Jones will call very soon and that God will give me a clear and concise way to communicate the necessary information to her. Pray that I know what to say and ask. And more than all that...pray boldly that even now God will be moving in her heart and the hearts of the specialists and medical professionals that would be involved in any way with Louie's care. Pray that she is able to have clear eyes to see the exact program Louie needs and with what doctors. Pray for a hope for Louie. Pray for a yes...

And as the waiting continues, Lord may we all be reminded that our hope doesn't rest in people or man-made things like medicine...may the hymn resonate with our soul and calm our fears..."My hope is built on nothing less than Jesus Christ, my righteousness; I dare not trust the sweetest frame, but wholly lean on Jesus' name... On Christ, the solid Rock, I stand; all other ground is sinking sand, all other ground is sinking sand."

If I am completely honest, there were many moments today when I found my feet sinking in sand as I placed my trust in people - waiting for a phone call as if that was my only hope...but in the stillness of the night I cry out to the Great Physician - Jehovah Rapha - the God who heals and renew my hope...I proclaim my trust in Him regardless of the outcome of this battle. God has already proclaimed victory...He has won the war.

Comments

"Father, I ask that You make a way for Louie to get to Mayo. Psalm 124:8 says 'Our help is in the name of the LORD who made heaven and earth.' Father, You are our help. You are our hope. We desperately need You to intervene in this situation for Louie. Please intervene. May Louie find favor with Mayo. We confess that You are the author and sustainer of life. Every breath is a gift from You. Pour your grace and mercy out on this precious family. Sustain them. Go before them. We ask this all in the powerful name of Jesus and for His glory. May He continue to be magnified in and through this. Amen."

—*Jimmy Carter, May 7, 2019*

I am agreeing with you in prayer for your needs and answers.

I lay here reading this outpouring of your heart. And it reminds me of the times I have waited for answers and phone calls from doctors for my daughter. She has a chronic illness that no doctor can figure out.

My heart really goes out to you. It is so hard to lose sight of who we should have faith in

while we are waiting for those phone calls.

You asked God to give you hope...and He did! Praying for you all. Even his sister. It's hard for their siblings , too.

You sharing this tonight has reminded me to keep my eyes on the Lord. Not so much on the doctors. Bless you.

—*Tonya Pinkerton, May 8, 2019*

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—*Tonya Pinkerton, May 8, 2019*

Prayers. ♥

—*Linda N Jackson, May 8, 2019*

Dear lord in heaven please watch over Louie and give him a miracle. Bless this family with a call from the Mayo and the Doctor in charge. Louie is truly your child and he proves it daily without effort. He lives his life knowing and trusting you. Bless your child with healing hands as only you can.

—*Wanda Cook, May 8, 2019*

I am so sorry you are having such a difficult time getting through to the right people and the doctor. Praying you get the phone call from the doctor today! Please know you are in my thoughts and prayers. Praying for a better day for Louie and you and the rest of your family. Thank you for your transparency through your walk with God and struggle to get Louie another chance with the doctors at Mayo.

—*Rista Nichols, May 8, 2019*

Our sovereign God is seldom early but NEVER late. That is a truth in which we raised our children. As David lay prostrate before God, I know he was pleading every minute and CRYING out to God for HIS intervention. I encourage you because you, Louie's parents,

are his greatest advocate. I encourage you to keep boldly crying out to God and doctors until our mighty God reveals HIS answer. I pray for HIS glorification, your comfort and Louie's successful healing! Amen. Your family is a testimony of faith for us all.

—Ken Lawson, May 8, 2019

In my prayers daily.

—Paula Vines, May 8, 2019

Prayers for you that you can receive the answer the doctor gives you no matter what it is. God bless you and your family as you travel this very hard and rough road.

—Doris Perkins, May 8, 2019

My prayers are with you, as my Mother would be storming the gates of heaven for their child. We have come to love Louie very much. My granddaughter has kept him in her prayers.

—Donna Lemons, May 8, 2019

Father God I come to you as humble as I know how. I am asking you today to just wrap your arms around Louie and his whole family. They need you and they can't make it without you. I ask you to move in a mighty way right now. Lord they need answers from on high. I am asking you right now to bless them with the blessings they stand in need of. Make a way for him to get the medical attention he needs. In Jesus name I pray Amen!

—Jo Butler, May 8, 2019

I pray for Louie & your family daily. I stand with you confirming our Hope is built on Jesus. So many love y'all & are praying for you. God has you in His arms. Sue(Merritt's MIL)

—Sue Johnston, May 8, 2019

My heart breaks for you .As a single father of 2 sons one being 6 I just could not be as strong as you and especially Louie.I cry every time I watch the videos of Louie especially the ride to the hospital. I pray that they will find a treatment for him FAST.We have one of the best children's hospital in the world here in Fort Myers Florida Golisano Children's Hospital maybe they can help.He is a brave young man and you are great parents and I pray for Louie

—paul MONTGOMERY, May 8, 2019

I too waited all day yesterday from my doctor at mayo in minnesota.i live in alexander,ark.I have been a patient there for the past 2 years.No call all day,today I called back to send out another request.Mistakes happen maybe message got lost.Call back today,tomorrow,keep on til they return your call.prayers continued for Louie and his family.

—*Mary Keelwy, May 8, 2019*

Sending prayers up for you all!! I wear my love like Louie shirt all the time. Prayers for strength, healing, comfort and quick answers!

—*Anna Hederman, May 8, 2019*

My thoughts and prayers are with Louie, and your complete family. I pray the lord wraps his arms around you all.

—*Teddy Goodman, May 8, 2019*

My heart is overflowing with so many unspoken emotions. It will be turned to non- stop, continuous prayer throughout this day and the days ahead. Jesus pray to our Abba Father with words too deep for us to understand concerning Louie's life and future.

—*Cindy Krueger, May 8, 2019*

Still praying. Love and hugs to all of you.☺☺☺☺☺☺☺

—*Linda Davis, May 8, 2019*

I am currently at Mayo Clinic with my sister who is receiving treatment. Is there anything we can do for you from here? We have just finished praying for you, for Louie, for Dr. Jones. Please do not hesitate to call on me. Stay Louie Strong! Louie is a beacon of light and hope for all who hear his story. You can get my number from Sam. I will personally visit the Pediatric unit tomorrow if needed! Love your sweet family.

—*Betty Franklin, May 8, 2019*

Thank you so much for the very sweet and kind offer. I just saw your message. I hope that your time at Mayo with your sister has gone well. I will be praying for your sister!

—*Kristy Schneider, May 11, 2019*

You and your family live up the hill from

Us. I am praying fervently for a miracle. For not only the phone call, but that God steps in, in a mighty way and provides the means to heal Louie.

—*Summer Scott, May 8, 2019*

You and your family live up the hill from

Us. I am praying fervently for a miracle. For not only the phone call, but that God steps in, in a mighty way and provides the means to heal Louie.

—*Summer Scott, May 8, 2019*

I love meeting neighbors! Thank you for the prayers and support! Hope we cross paths in the neighborhood.

—*Kristy Schneider, May 11, 2019*

I am so sorry that you had a rough couple of days, Yes absolutely our hope is in the Lord, He is where our help comes from, we have got to trust in the Lord with all our hearts and he will never fail us , Lean not into our on understanding but lean on Jesus because He will never fail us. He is a Friend that sticketh closer than a brother, he will never leave us or forsake us and that is His promise to us . He had never failed me on one single promise that he's made me. You hold on to The Lords Unchanging Hand and I promise you everything will work out for you and your family and especially "LOUIE " , Wayne and I are perfect examples of Gods Love, Mercy, and Grace . I am going to get a prayer chain going for Louie and you all too. God has got you and your family and especially Louie in the palm of his hand holding you up and I know that there is alot of people lifting you and your family up in prayer and now there is going to be more ☺☺☺☺ Sending Hugs and kisses to Louie and you all too , Love you always Sister in Christ ♥♥♥

—*Joy Stuckey, May 8, 2019*

PRAYING ☺☺☺☺

—*Tacarra Wright, May 8, 2019*

Sweet mama; I cannot imagine what you are going through. I know Who does! If you didn't know Jesus too, I'm not sure I could bear to keep up with this plight you are treading in. But with You, I know you have Hope. You are anchored in the Rock. Your storm is lengthy; Your God is timeless. You have love to give your family, and you know that came from a Source that does not run dry. Your faith is strong, but it has certainly been exercised!!!

“Heavenly Father, Lord of all things, Lord over all people, powers, and principalities; THANK YOU that nothing can separate us from the Love You have for us in Christ Jesus,

Your Son/Our Lord!!!! What a privilege that we can carry everything to You in prayer!! Anything!!! I pray for Kristy right now for a blanket of peace over her through Your Spirit. Not just a feeling....a real knowledge that lets her breathe in Your vitality and brings up her "oxygen levels". I ask that You bring her a booster shot of Hope....that the phone will ring and there will be a doctor that you have prepared to have listening ears, wisdom, and innovative ideas. What else would You have me ask for, my Father? I want to pray in accordance with Your desires. Yes....I do pray that Your Kingdom will see growth because of Louie's journey! Eternal matters are hard for us to grasp, but they grace us with the ability to endure, so thank You for that reminder. I will be eager to see how You bless Louie and Kristy and their family, hopefully soon! Thank You for hearing this prayer! Thank You for covering our nastiness with Your blood. We pray these things in the Name of Jesus Christ who bought us our Salvation, Amen!!!"

—Lannece Mayo, May 11, 2019

In Jesus Precious Name Amen ☐☐☐☐☐☐

—Joy Stuckey, May 11, 2019

I PRAY To Jehovah God through his Beloved Son Jesus, that he will preform a miracle to help Louie & his Dear Family Please Jehovah Help this Sweet Kindhearted boy he has been dealt w/problems only You Jehovah can Fix, please help the Dr.'s figure out the BEST plan for Louie keep him in your Loving Arms & Thoughts as only you can, please Jesus, when you saw Lazarus's your friend die & his family in Sheer Anguish, your spirt Groaned & resurrected him, please Help Louie & his Mom to endure & to see you work with them in evidence of your Great love for all mankind, But for your Genuine Love for Children as your apostles held back the kids YOU TOLD them Let the Little ones Come PLEASE Be W/Louie in that same way! I Love you heavenly Father Jehovah may your Kingdom soon come to restore Louie to a Very Healthy state as you said NO Resident will say I am sick may your Power & Glory be bestowed on this young Sweet Boy Louie in the name of your Dear Son Jesus AMEN <3

—Cindy Richey, June 5, 2019

Medical Update & Message for Moms

May 11, 2019

Many of you have joined me in praying for Dr. Jones at the Mayo Clinic who is reviewing

Louie's case. She called me Wednesday morning when I was having a rare moment out of the house...I was actually in Walmart with my two girls. I made a bee-line for the toddler section of the store because it is in the back and not typically busy. I told my girls the call was important and to talk to and play with each other. So there we were in the toddler sock section of Walmart as Dr. Jones begins to tell me why the referral was being denied. She explained that they felt there wasn't anything they would do different with the information they had received, and they were concerned that Louie would not be able to endure a trip to Minnesota.

As I began to pour out information on Louie's medical journey, highlighting the last 5 months, Dr. Jones became more and more interested. She stated that they had not received a request from cardiology in Arkansas and had not realized there was such a strong cardiovascular component. She said their cardiology team hadn't even reviewed the record at all. I was able to articulate the biggest needs and questions we have and what we hope to gain from a Mayo visit. She expressed concern over the logistics of getting to Minnesota and I assured her that we feel strongly it is worth the risk and that we had already started exploring options. The conversation ended with me pleading with her to give my son a chance... I told her boldly that there were many people praying for her and that our hope is that she would be an advocate for my son - for his life. She assured me that with the new information she would follow up with cardiology and have neurology as well look over everything again. She stated she would get back to me as soon as possible and hopefully by the end of the week.

As we ended the conversation, my last words to her on the phone were, "I hope to meet you face to face very soon!" I could tell in the pause, that she was taken aback by the statement. I believe it was likely because of the weight of what her decision holds, but also because in understanding the process, most of the time you will not actually have appointments with the reviewing physician when you go. But I meant my words. I pray fervently that I get to meet her...that I get to hug her neck and thank her...that she gets to see Louie's smile and that it affirms in her that she made the right call - to say yes...to fight for my son's life. Please join me in praying that she can't get Louie off her mind until she says "yes, we want to see and help Louie..."

As we hung up the phone, I wiped my eyes and admired my girls. They were sweetly giggling in the buggy in the sock section for the entire 24 minute conversation. I was so thankful for how well they did, that I bought them both new socks!!

Now, here I sit on Saturday night, still waiting to hear back from Dr. Jones...still praying...still hoping. But in the meantime it has been a rough few days for Louie. He saw a number of his doctors in Arkansas on Thursday including cardiology and electrophysiology. They decided to lower the pacing rate on his pacemaker. Theoretically it would help his heart not be weakened by the pacing and allow his heart to regulate better itself. However, in the 48 hours after the change we saw Louie's body struggle.

He was only awake about 10 of the 48 hours after the change. His blood pressure began to drop even lower than its "normal low." In fact, last night was the lowest I have seen it....for hours it was hovering at 61/26 (give or take a number or two).

After talking with a number of doctors and with hospice, his electrophysiologist arranged for the pacemaker company to come to the house and readjust the pacemaker back to where it was set originally. Thankfully, he is resting tonight back at his "normal low." Hopefully, this will allow for his body to recover a bit and have a better day tomorrow.

Tomorrow... Mother's Day...

It is a day filled with as many different emotions as there are people and seasons of life. A day of joy for most and filled with breakfast in bed and hopefully a little pampering. But also a day for many filled with tears of longing or grieving. I have been in both of those places. I celebrated Mother's Day in beautiful ways, and yet I will also always remember the sting of infertility on many Mother's Days. And this year, Mother's Day brings new feelings...

There is a gratitude that I have another opportunity to hear ALL my children tell me they love me...something I didn't think would happen this year. But there is also great fear over where we are and what is to come. As a mother you see your own limitations...your own failings...you know them even though you cover them well to others.

I know for me, right now I am failing in many ways as a mother. I can't be everything that my children need right now. It is not a pity party; it is simply truth. It is my reality. I can't care for Louie the way he needs and get Peter to and from school. I can't play with and interact with my girls the way I would like and still get to every appointment. And the lists just keep building. The burden is too great. As a mother I spin my wheels, give my all, and still have moments I wish I could take back at the end of the day...words I wish I had left unsaid...harshness that I wish had been gentleness...busyness that I wish had been stillness with a child.

But then I realize that this describes all of us as mothers. As I sit and have a moment of self-reflection...a moment where I want to throw up my hands in defeat because I don't know how much longer I can manage this pace...a moment where I choose instead to allow God's love to cover me and engulf me with his grace...that is when I realize my plight may look different but the hard of it as a mother is the same for all of us. We all carry a great longing to be excellent in motherhood so the fruit of it is reflected in our children. And the longing to be excellent brings with it a desire to be "Mother of the Year"...but every day we fail in some way. So the weight can feel so heavy when we look at the struggles our children endure.

I write this tonight in no way to get a pat on the back from anyone saying that I am doing

a good job, etc....that is not what I need...that is not my heart. My heart is simply to acknowledge what many of us feel as moms but don't express...our inadequacies...our fears...our regrets...our moments of drowning. We have all had those days...sometimes they come often. But as frequently as they come, it is not greater than the love God has for us nor the love we have for our children. That love is what prods us forward even when we have no strength (or sleep for that matter). That love is what keeps us wiping bottoms, feeding everyone first, running ourselves (and our minivans/SUV's) to empty...all because we are moms and we would die for our children.

If you are having a rough season with a child...if you are struggling to find yourself in the midst of the busyness of the family...if you are feeling judged as a mom...if you are scared, hopeless, discouraged, alone, grieving, or sitting in regret today, know that behind the smiles, every one of us has been or is there too...so don't give up. You are not alone. You are seen. You are loved. And God's grace is greater. Within the burden we will carry, is also the tremendous love and sacrifice we pour out upon our children. So as we say to moms tomorrow, "Happy Mother's Day," may we also be saying, "I know it's hard sometimes, but we can do this together!"

Comments

"Father, Your Word tells us that You are able to direct the king's heart like a water channel. Therefore, we ask You to direct Dr. Jones' heart and the decision of the powers that be at Mayo to allow Louie to go to Mayo. We ask this in Jesus' name. Amen."

—*Jimmy Carter, May 12, 2019*

Happy Mother's Day! You have such a way with words that only I wish I had. Thanks again for sharing. You are a very special mom no doubt. God picked you to be those children's mom for a reason. I'd be the first to admit that I don't think I would be as strong as you are. Bless you lady and many prayers for you all.

—*Wanda Cook, May 12, 2019*

HAPPY MOTHERS DAY! You just keep doing what you are doing! You, God and Louie got this! Just know God is in the midst of all your struggles. In his word it says "he will never leave you nor forsake you". God Bless you and your family. Stay #LouieStrong! ☺☺☺☺☺☺☺☺☺☺

—*Jo Butler, May 12, 2019*

Praying for a good Mothers Day for you! I have moved to Rochester from Searcy. I am here if I can help. Please let me know if there is anything you need. I can help you with info about hotel or transportation or anything else you need. Praying you are here at

Mayo soon. I am a friend of Suzette's.

—*Rista Nichols, May 12, 2019*

Thank you so much for the offer. We don't know anyone in the state of Minnesota, so if it all works out I will let you know and would love any tips you have.

—*Kristy Schneider, May 12, 2019*

Thinking of you and your family today and praying that Louie gets his appointment at Mayo. Happy Mothers Day.

—*Parthenia (Tena) Taylor, May 12, 2019*

Prayers for all doctors involved in making the right decisions to get Louie to Mayo!! Happy Mother's Day blessings for you and your family!

—*Cathy Perkins, May 12, 2019*

□□□□□□□□□□

—*Vicki Barney, May 12, 2019*

Beautifully said and I agree completely, Praying for you Kristy ♥♥ and praying you will hear good news from Dr.Jones and it will be what you want to hear , give Louie hugs and kisses for me please □□□□□□□□

—*Joy Stuckey, May 12, 2019*

I hear ya, sister!!! I've felt like a failure a many a time!!! But someday as a grandma, your kids will trust you with theirs, and if nothing else reassures you that you haven't failed the whole motherhood thing, that will do it!!! ♥
And PRAISE GOD for your answered prayer! He is SOOOOOOOOOOOOOOOO good!!!!!!

—*Lannece Mayo, May 13, 2019*

I've been following your story for a while. I remember Louie from our days at Peds but don't think I ever met you. You described motherhood so perfectly and reading this today encouraged me. You have every right to throw a pity party but instead you're using this channel to encourage others, and that is inspiring. I will continue to pray for Louie and your family.

—*Stacy Peterson, May 14, 2019*

Kristy; I do know in many ways what you are saying, I raised 3 special needs children all very close in age all adopted. My youngest son took more attention it was very difficult even when my children started school I would be called to the school at any given moment for any one of them. I many times felt like a mother failure not knowing which way to turn. We are all mothers and we all understand and give all we have to our children. All we can do is our very best and you truly have done that as hard as it is. You continue to be in my prayers as well as all of your family. May God continue to give you the strength all of you need. You truly are an inspiration!

—*Diane Huggins, May 15, 2019*

Louie's Birthday Wish

May 15, 2019

It was 5 days ago that I wrote an update asking for prayers for Dr. Jones and those at the Mayo Clinic reviewing Louie's case. I hoped this update today would be about praising God for good news, answered prayers, and a date to travel to Mayo. Unfortunately this is not the case. I haven't heard back from Dr. Jones or anyone from Minnesota. When I called to follow up, I had to leave a message. More waiting. More hard days. More uncertainty.

If I had to summarize last week with one word, it would be discouragement. It all culminated on Mother's Day when I realized that Louie was not doing well enough for us all to be able to attend church together - something I had been looking forward to doing all week. Instead I found myself at home, cleaning off my desk, taking care of my son, and listening to worship music as loud as my charging dock would allow. What started as a pity party, soon shifted...as the words of the songs flowed over me, I found myself holding back tears with every song...and then not holding them back at all.

I was overwhelmed with emotion. It took me a minute to capture what the emotion was. It was gratitude. Gratitude towards a God who continues to love me in all the ugliness of my sin...who continues to sustain and breathe life into my son...who continues to provide for us in amazing ways through both strangers and friends... To sum it up...it is a GOD WHO CONTINUES!

Right now, as I gaze at the beautiful flowers sent to me for Mother's Day from a LouieStrong supporter I have never met, or as I look at my pantry stocked full because of people we casually know through our son's school showed up with groceries, or as I pull

out the calendar of all the people driving my oldest son to and from school this week...I am completely in awe of a GOD WHO CONTINUES to see us, love us, and provide for us. The encouragement we have received from the community and people we didn't know previously, has opened my eyes to the intricate provisions of a good God...and each word or act of encouragement from friend or stranger has lifted my spirit and held me up on days I had nothing left to give. And it is all because of a God who continues to guide our steps and sustain the life of our son.

There was a time when I didn't think there was a chance on earth that Louie would live to see his 10th birthday...but the chance wasn't on earth...it is a chance provided only by the Giver of Life...by the GOD WHO CONTINUES to have a purpose and plan for my son. So here we sit 12 days away from him turning 10. Each day we count as a miracle...

As a family, over the past week or two, we have started to talk with him about what he wants for his birthday and all that typical stuff you do in planning a birthday...but Louie isn't typical... He doesn't want the newest electronics or toys or anything like that. Stuff isn't what matters to Louie...in fact I had to really press him to get him to name any actual item he wanted. Instead, Louie asked to visit the fire and police stations. Louie mentioned wanting challenge coins from every state. But then his big request is what blew me away...

Louie said what he really wanted was to "celebrate with all my people." Louie is certainly an extravert and LOVES people. I assumed what he meant by "all my people" was his local law enforcement friends, sweet nursing friends, and a few peers...but I was very wrong. This is the conversation that ensued:

Me: "Louie what do you mean "all my people"? Who is your people?"

Louie: "My people...LouieStrong!"

Me: "Baby "your people" live all over the state, country and world so we can't really have a party with them or anything like that. There are so many people that love you and support you but many live far away. Do you understand that?"

Louie: "Yes. LouieStrong love from there....all over." (and he motioned with his hand)

Me: "Yes baby they love you."

Louie: "No. Love ALL other."

Me: "Baby are you saying that for your birthday you want "your people" to love each other?"

Louie: "Yes, love! And no cake. Popsicles!" (He can't eat anything by mouth but can have an occasional popsicle.)

I left that conversation smiling and yet completely humbled. I can get so wrapped up in what is right around me that it is overwhelming...and here my son is always thinking of others. It is who he is. Louie lights up when he is around people - ALL people. He makes everyone he meets feel loved and cared for. He will treat the mailman with the same

value and care as he did the famous musician he met last week. Louie doesn't see status, he sees people. He leaves you better. As I ponder how to honor his request, I realize it is just about being more like the attributes he imitates.

May 27th, Memorial Day, Louie turns 10. I want to ask for your help to make his birthday wish come true. On Memorial Day, what if each one of us went out of our way to perform an act of kindness, or to express love or appreciation to someone, or to buy a meal for a stranger, or to encourage a laborer, or to bake cookies for first responders, or _____ (you fill in the blank)? What if we went to bed that night knowing we left someone better because of our words or deeds? What if we loved each other well...loved different...loved intentionally that day? I truly believe there would be no greater joy for Louie than to know people were impacted by his life and his love!

So here is where you come in.... Let's spread the word and make Louie's birthday wish come true... Write it on the calendar now - "LOVE LIKE LOUIE DAY" and tell everyone you know to do some kind or loving act that day in his honor. And if possible, snap a picture or write about it on facebook and tag Love Like Louie, or tag LouieStrong or tag me (or tag all three if you are an overachiever!). I will make sure Louie sees every one, and he will rejoice because it is GOD WHO CONTINUES to use his life to make the world a better place. So let's celebrate with Louie!!!

Comments

Amen

—*Summer Scott, May 15, 2019*

Oh I am SOOOOOO in!! What an awesome way to celebrate Louie's birthday! Actually what an awesome way to LIVE!!! Yes, I will definitely find someone to serve or bless or whatever God calls me to do!!!!

—*Barbata McCreight, May 15, 2019*

Count me in and thank Louie for having such a BIG heart and love for God and others.

—*Janean Hardister, May 15, 2019*

Gavin and I will do that! #LoveLike Louie. We so enjoyed the visit. To God be all the Glory!

—Jo Butler, May 16, 2019

Count me in.

—Nancy Hignite, May 16, 2019

Will be paying your love of people forward on May 27th for your 10th birthday sweetheart!! Love you Louie!!♥

—Cathy Perkins, May 16, 2019

What a special little boy you have and I continue to pray for him. And, what a special request by him for his 10th birthday. I will endeavor to do what Louie has requested for his birthday, not just that day but every day. May God give you and your family His special grace during this time.

—Rosanne Ramer, May 16, 2019

Already on my calendar! I can't wait!!

—Debbie McAnally, May 16, 2019

Awesome! Making a note! Love you Louie. God bless you and your family

—Louann Smith Harasym, May 16, 2019

Got it on my calendar, Louie you are such a inspiration to us all!! This world needs more big hearts like yours!

—Lana Foster, May 16, 2019

Kristy I have read every single one of your post and the all have touched me in a big way, you are an amazing and inspiration to us all, but this has brought me too my knees , I am going to do everything I can to make Louie's Birthday wish come true, Louie is one special Little Man and he never fails to amaze me you either. Your so right we do serve a God that continues to provide for us and carry us through the hard places , you tell Louie we are in and we are praying fervently for him and for you and your family, it is a miracle that God has sustained Louie and I am so thankful, I pray God's strength to cover you in the hard and ugly days In Jesus Precious Name Amen ♥♥♥♥

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—Joy Stuckey, May 16, 2019

I love this idea!!!! I know that the incredible God we serve has a smile as we all think of such kindness taking place for the love of His beloved little boy! Your God is alive and more than well! And your faith is contagious! God is busy for you; I can see it in your posts. I see it n the extended days Louie has seen. I see it in the people who minister to you in different ways. I see it in your answered prayers. And He won't be manipulated by us; what kind of God would that be? A powerless being he would be, leaving us hopeless! Thank you for reflecting Him to the world and to your family! So hang in there, precious one! You are being held. "Lord, We are intrigued by You and Your mysterious ways! How You love us; sinners that You extended grace to redeem!!! Help us see better with our eyes of faith! I continue to ask You, (The God Who continues) to bring answers to Kristy and her husband. Sustain Louie and bring him health! We thank You for the amazing things You are doing!!! We ask these things in your name, Jesus Christ, amen ."

—Lannece Mayo, May 17, 2019

I am all in. On LOVE LIKE LOUIE DAY I will make contact with a friend who has Parkinsons. She is homebound.

Please tell Louie that Debbie Hamilton from Conway wishes him all God's very best for his birthday. Praying that he feels great. Happy 10th, Louie!

—Debbie Hamilton, May 23, 2019

Louie: I just read this post. What a precious heart you have. You inspire me! I will for sure reach out to a stranger this week in love and it will be because of your birthday wish. Thank you for spreading kindness and joy. Happy Birthday!

—Laura Watson, June 1, 2019

MAYO HERE WE COME!!!

May 19, 2019

We stormed heaven with our prayers and God has heard them... He is making a way... I wish I had the time to explain the details of what has occurred the past few days. Let me sum it up by saying that there were mistakes made in the referral to Mayo initially. As I realized all of this, I was beyond upset. I am watching my son struggle while paperwork and simple communication is standing in the way of him receiving additional care.

Then I reached out for help to our complex care team at ACH. Without hesitation they stepped in and advocated for Louie. Within 24 hours, I received a call that the cardiovascular team at Mayo has an appointment for Louie on May 28th!!! So currently we are working on the GREAT number of logistics that must be ironed out in order for us to actually make the trip a reality. Please be praying for the logistics of care at home for Erik and our other three kids...then also for Louie and I as we prepare for Minnesota. I believe God is in the details, and it is evident that He is already at work putting the pieces in place...

As I stare at my to do list this morning, which has grown exponentially with the Mayo trip happening so quickly, I can't seem to focus. I am still pondering my most recent conversation with Louie. Last night as I was putting Louie to bed, I had to apologize...well, if I am honest, I didn't have to, but I chose to. You see, earlier in the day I had caught him messing with his PICC line. His PICC line is life sustaining for him and thus messing with it is something that can be dangerous on many levels. Louie knows to leave it alone. In that moment, I totally lost my cool. I raised my voice. I yelled at my son...yelled at my son on hospice. I can tell you that it was because I was exhausted, which is true. I can tell you he deserved it for the wrong choice he made, which is true. I can tell you all the reasons I was justified in yelling at him...and they may

all be true...but it doesn't make it right. And the guilt I felt immediately told me it wasn't right.

Throughout the next few hours I knew I needed to apologize. I needed to make it right. I wanted to apologize because in my heart I knew that I yelled not to correct him but because of the fear his actions stirred in me and the inconvenience a broken PICC line would bring. I had yelled to get his attention, not to cultivate his heart and help him choose right. I had yelled because it was the easiest way to get a response not because it was the right way.

So as I knelt next to Louie's bed, I looked into his eyes and I told him I was sorry and that I loved him...but that he can't mess with his PICC line. The more I talked to him about it, the more I realized I was apologizing as I justified my actions. I was basically saying, I wouldn't have yelled if you hadn't made your wrong choice. In doing so, I cheapened my apology. I wasn't taking responsibility without condition, I was explaining my actions based on his sin. I was trying to turn my apology into a lesson for Louie, instead of it being a pure reflection of MY heart taking responsibility for MY actions.

In the middle of my talking, Louie cupped my chin in his hands and gave me kisses on my nose, cheeks and lips. He interrupted me to say, "Love you mommy...no more sad...love you." I paused and then simply said, "baby please forgive me." Louie responded without hesitation, "Did mommy." And that was it. Did. Past tense. Louie had already released me from my sin. Louie had already let it go. Louie didn't need a speech, he only needed my presence still there with him.

So I smiled and kissed him and told him I want to not only LOVE LIKE LOUIE, I want to FORGIVE LIKE LOUIE! He smiled and said, "Birthday! LOVE LIKE LOUIE DAY!" And we spent the next few minutes giggling about ideas to spread love and smiles on his birthday. Then off to sleep Louie went. No grudges. No anger. No fear. No resentment. Just peace. Beautiful peace brought by forgiveness.

I challenge each of you to continue contemplating how you can LOVE LIKE LOUIE on MAY 27th...his 10th birthday. Maybe you need to apologize, not to elicit a response, but to find peace yourself. Maybe your act of love is to elevate a relationship by initiating restoration. Whatever act of love and kindness you choose, may it leave someone else better and your heart free to love bigger...

Comments

Thank you Lord Jesus for the best news ever! Khristy, first and foremost your a human just like all of us... Most of us have had those moments when caring for someone that we love have spoke harsh to them when exhausted. I know I have. I yelled at my elder mom

for playing with her port. And like you, immediately felt like crap. I know you hear this all the time, but it's true, YOU dear lady are a wonderful mom. Louie and Peter are blessed to have received such amazing parents.

—*Wanda Cook, May 19, 2019*

Rejoicing with you at this great news!! And humbled by your son once again. I have lost my temper with Isaiah too when he's been messing with his central line and medicine pump. Sigh. Praying for you and all of your family. Much love friend!!

—*Charis Lau, May 19, 2019*

SO EXCITED FOR YOU! PRAISE THE LORD!

—*Jimmy Carter, May 19, 2019*

This is wonderful news! My prayers are with you. Thank you for sharing today and giving us this challenge to celebrate Louie's day with love, encouragement to others and sharing.

—*Ellen Davis, May 19, 2019*

After having just returned last Wednesday, from Mayo Clinic in Rochester, Minnesota I can confirm how amazing this wonderful place is.... when I left Arkansas I had kinda lost HOPE. After being sick for so long, and having heard so many times how difficult my situation had become, I was hesitant to think this trip would be any different. Just let me say, I was so wrong. I received healing at this place, and restored HOPE with has greatly increased my Faith. I pray you all find the same for Louie. If you need any tips and pointers, feel free to reach out to me. I'm on FB as Glenda Hickman-Gore. ♥

—*Glenda Gore, May 19, 2019*

Praise the Lord!! Prayers continue for Louie his team of physicians and his beautiful family.

—*Stephanie Edmondson, May 19, 2019*

Praising God and rejoicing in the good news! Prayers continued for Louie to stay strong for the trip and for your strength. It will be exhausting for you on your own at the Mayo Clinic (City of Hope). Know that the Rochester Church of Christ is small but mighty and have been instrumental in my own personal experiences. The House of Compassion is accommodating and so is Kahler Apache Hotel. Hopefully you are hooked up with a Ronald McDonald House but if not, keep those two places previously mentioned in your

go to notes. The Mayo is 4 miles of connected tunnels and you never have to go outside if you do not want. If you look lost people stop immediately to guide you. Stay strong ... stay safe ... God is good!

—*Betty Franklin, May 19, 2019*

Praying for All of you during this time. How a child like faith can change situations. Thank you for sharing and inspiring.

—*Janean Hardister, May 19, 2019*

Praise God with joy and laughter!! Get ready Minnesota Louie is coming your way!!☺☺

—*Janice Calaway, May 19, 2019*

I think we're all guilty of making that kind of apology...at least, I know I am. Thanks for sharing your story and setting an example for us when we falter in that way. Continuing to pray for y'all.

—*Cheryl Golden, May 19, 2019*

PRAISE GOD!!!

—*Lynette Place, May 19, 2019*

As I sit here with tears running down my face, I not only pray for Louie and all concerned in his care (I.e; the family and caregivers at home) but I pray to have the kind of faith Louie does. Forgiveness first and foremost. Thank you for sharing.

—*Sharon Stewart, May 19, 2019*

Oh my! Excited beyond measure at the good news. And touched and moved as always by Louie's example!

—*Elaine H, May 19, 2019*

Faith ♥ and Prayer ☺☺ move Mountains ☺☺

—*Dawn Lawson, May 19, 2019*

Beautifully said and I believe that all of us could find a lesson in this and handle situations a little bit different than the way we handle them in the first place, Thank you

for sharing this Kristy , I just know Jesus is smiling down on you and Louie. I know you made my day and it helped me so much . You are so blessed to have those precious children, their all very special in their on way , Louie just happens to be the one getting the attention because of his illness and his amazing Love for Jesus and his amazing Love for people. I love you Louie and Kristy and Wayne and I are constantly lifting you all up in prayer ☺☺☺☺♥♥♥

—Joy Stuckey, May 20, 2019

So thankful to God for the wonderful news! So proud of you for your perseverance with the Mayo Clinic. God has given you strength beyond measure. We will continue to pray for God to lead both you and the Mayo Clinic team. Praying also for your family and all those helping with their care. Stay strong! Give Louie our love and let him know we pray for you all daily.
Thank you Louie for always showing us Love like Louie!!

—Debra Worsham, May 20, 2019

I'm still praying ☺ ☺☺☺♥☺☺☺♥☺☺☺

—Vicki Barney, May 21, 2019

Sending love and prayers for you and prayers for the doctors to have the wisdom to help heal your body. You continue to inspire and shed God's glory. I hope you have a great birthday and safe travels!

—Jana Barnett, May 21, 2019

Absolutely amazing that we continue to get lessons from this Incredibly beautiful child. God has a plan. I have no idea what it is but this child is conduit to learning what God wants from all of us; love unconditionally, trust implicitly, believe in the goodness of God. I am humbled.

—Judy Herrick, May 22, 2019

Heading to Give Kids the World to volunteer in honor of Louie's birthday! I hope Louie had the best birthday he could possibly have,! Sending love and compassion to your whole family!

—Jennifer Cardonick Walker, May 27, 2019

THE TOASTER OVEN

May 23, 2019

TRUE STORY: A while back, our toaster oven broke. It wouldn't turn on. It wouldn't try to work. It was done. My husband, being the great engineer that he is, began to take it apart in hopes of figuring out the problem and fixing it. He spent hours working on. Then he put it back together and the moment of truth arrived. We watched in anticipation as Erik reached out and pressed the start button...and...nothing. Nada. It was still just as broken...just as dead...

As Erik was literally about to unplug it and take it to the garage, Louie entered the kitchen. In his famous Louie words, he said, "what you doing?" Erik explained that the toaster oven wasn't working. Louie IMMEDIATELY responded by reaching over to Erik and grabbing his arm. He said "Daddy I sorry" and he began to pray. There in the kitchen, Louie bowed his head and prayed, "God toaster oven dead...no more dead...help toaster oven...A-men!" Erik was about to unplug it...but there was Louie...waiting in joyful expectation. So Erik paused and hit the start button...

Without hesitation the toaster oven came on! Erik and I stared at each other as Louie performed a little happy dance and said repeatedly "God fix!" I have no explanation for why our toaster oven is working today other than my son prayed for it. Just as I have no explanation for why my son is still alive, other than so many people have prayed faithfully for him. We have begged God for his life and here Louie is defying the odds.

In saying yes to Mayo, we didn't realize the complexities of the logistics that would occur. This week has been filled with phone calls, texts, and emails needed for making arrangements so the next few weeks can operate smoothly. There are many people filling in the gaps both at home and for the Mayo trip itself. The way God is working to put the pieces in place has left me in awe of how intimately involved in details He is. There are a number of stories I wish I had time to tell... But let me suffice it to say, because of great people God is using, Louie and I have received the gift of an air ambulance ride to Mayo...because of great people God is using, my daughter will have a gluten free cake for her 3rd birthday even though I will not be here to celebrate with her...because of great people God is using we don't feel alone, we feel surrounded and held on this hard road. There are so many stories...and they are ALL ROOTED IN ANSWERED PRAYERS.

At this moment, the GREATEST NEED we have is for God's people to stand in faithful prayer for us. We firmly believe that God hears and answers our prayers... Thus, we want to share very specific prayer needs and humbly ask that you lift us up with the kind

of faith that can heal a toaster oven:

- • Pray for the logistics of travel to work out smooth and for us to get there on time and without any difficulties.
- • Pray for the hospice providers (here and at Mayo) to be able to coordinate a plan ASAP to ensure he will have access to his medications and TPNs while we are outpatient.
- • Pray specifically for the doctors involved in Louie's care. **We are specifically praying that they will see him at his WORST medically so they understand the complexities and see the needs first hand.** Some of the doctors we will be seeing are: Dr. Van Dorn, Dr. Jones, Dr. Tran, and Dr. Starnes. Please pray for the Lord to give them open eyes and great insight. Pray for GI to step into this mix of specialists very soon as well.
- • **Please also pray that they will be willing to put him inpatient to initiate treatment immediately. Pray for wisdom for them to know what steps to take. Pray for a path that provides Louie a longer life!**
- • Finally, pray for things at home to operate well, especially with our three children. Pray for every logistic at home to be ironed out easily.

Thank you for believing with us...for praying for us...for not ceasing to care about Louie and our family. Thank you for faithfully reading, commenting, sending messages, and reaching out to help us feel connected and loved so well. Believe with us that just as Louie declared "God fix" when the toaster oven worked, that we too will all declare "God fix" when we see the miracle He performs in and through Louie's life! God isn't done with our little boy....so please don't stop praying...

Comments

I never stop praying, Louie, you Kristy and your entire family is an inspiration! God is good he has brought you to this and He will see you though it, good times hard times, heartbreaking times, "God Fix" He will! Prayers Rise!

—*Diane Huggins, May 23, 2019*

I have some GOD FIX experiences so I know the awe and wonder and joy. So happy God gave you that! He is good. Louie is pure joy. Praying God's Master Touch on every tiny detail of your lives. And the big ones. Praying for your hearts and minds. Sending love.

—*Debbie Hamilton, May 23, 2019*

Dear lord in heaven, you have shown us all what the power of prayer can do. Now lord please show us a miracle for Louie. Give the doctors the knowledge to know exactly what to do to keep Louie around for many years to come. He has been your angel on earth and he has shown many of us what can happen if you truly believe and trust in Jesus. Keep Kristy and Louie safe on their travels. Amen

—*Wanda Cook, May 23, 2019*

WOW WOW WOW Love that the toaster oven is fixed just with a simple prayer..... Simple as in Louie didn't need to know how to fix it. he just needed to know a guy that knows a guy that can..... Praying a simple prayer for you and your family..... God your will

—*Myra Ferrell, May 23, 2019*

Prayers for you all as you prepare for this journey. I pray that what Louie is about to face will be helpful and painless for him. Quality of life is far more important than quantity. We've followed your journey and have prayed and will continue to pray for you. Give Louie our love. By the way, thanks so much for sharing the toaster story. It just confirms that our God is in the small details of our lives too.

—*Doris Perkins, May 23, 2019*

Bless the faith of a child of God! Toaster fixed, travel in place, seems to me like God is answering a lot of prayers for Louie. So....we'll keep saying them and thanking God for his grace. Louie has touched a lot of lives with his strength and his love..not to mention his faith. I know he's touched mine. If he's walking with God, his path is cleared for miracles that only God can provide. And mom, you are too. Never forget that, even in despair and uncertainty, God is with you.

—*joyce johnson, May 23, 2019*

If God can fix a toaster then God can also fix Louie. Praise be to God for fixing Louie because I believe he is fixing this child even now as plans are in place to go to Mayo next week. I believe this is part of His plan and He will fix Louie when the time is right. God be with you and your family through this next step.

—*Maurie Keys, May 23, 2019*

Praying for everything to fall into place and for the doctors to be able to ascertain exactly what Louie needs! Praying also for peace for all of you throughout this whole

process.

—*Barbata McCreight, May 23, 2019*

Absolutely Kristy we will storm the gates of Heaven for you and your family and for the drs that God will feel them with the knowledge they need to help our precious Louie we are going to lift you and Louie up and everyone else to . We will pray for a safe and smooth trip for you and Louie on the air ambulance, we Love y'all so much, y'all have become a part of our family and maybe one day we can meet face to face. I have you and Louie on alot of prayer list , so there is alot of people praying for y'all here in Texas . Y'all are always in our thoughts and prayers and will always be, we're trusting Jesus for Louie's complete healing in his precious little body . He is a inspiration to us all and you are too.

—*Joy Stuckey, May 23, 2019*

Prayers for Louie, your family, and all the medical personnel that will come in touch with you and Louie.

—*Cindy Gordy, May 23, 2019*

I brought your prayer requests to our Lord! I know He is faithful to answer! Thank you for sharing your story about the toaster. We all need Louie's kind of faith! ☐☐

—*Cherlyn Varnes, May 24, 2019*

In complete agreement with all your prayers!!

—*Debbie McAnally, May 27, 2019*

HOLDING HANDS

May 28, 2019



This morning I woke up at 2:48am...two minutes before my alarm clock was scheduled to go off. The day had finally come...the day we head to the Mayo Clinic. With tired eyes we hit the road and were escorted by dear friends (who happen to have lights and sirens on their vehicles) to the Saline County Airport. There we met and hugged many first responders from Bryant who have become so special to our family...and onto the medical jet we went.

The crew was fantastic. The flight fairly smooth. And we made it in plenty of time to get to the hotel, drop off luggage, and head over to Mayo. Today Louie had two heart tests, his pacemaker interrogated, a chest x-ray, lab work, and met with the cardiologist. (Did I mention that each one of these things were in a different area of the facility and a few in a different building? Walking...lots of walking...anyway...) We were there from 8am to 4pm. In the end, I liked the thoroughness of the cardiologist and I am praying with great fervor that she will see with clear eyes what is going on with Louie and find a path to help him from a cardiovascular standpoint. Please continue praying for Dr. Van Dorn because she is a big part of the puzzle for Louie.

As I sit in reflection this evening, I am so thankful for all the people that made today possible. I am beyond grateful for every prayer uttered on our behalf. But tonight, I stare in sweet adoration at my Louie as he sleeps. It was a big day...an exhausting day...a day filled with unknown people, places and experiences. I saw brief moments of apprehension in him at times today...but it never stayed long. Louie, in the special way he copes, connected with people and prayed to God.

Before our jet left the ground, Louie had grabbed the hand of the precious flight nurse and held on tight during take off...he muttered an innocent prayer and didn't let go... Louie was anxious and he knew he needed to hold on tight...he needed to find something, someone to help him feel grounded. For just about the entire 2.5 hour flight, she held his hand. She gazed at him as he rested. He never let her hand go. Her kindness comforted my heart. And his determination to hold on in the face of the unfamiliar challenged me... It challenges me to let down my own pride and reach out to the hands that know more than I do...

Then later between appointments Louie was tired and struggling a bit to grasp all that was happening. Mayo is a big and busy place. We stumbled upon a woman playing the piano and other "well seasoned" individuals were singing (okay, it was a senior citizen choir)!! As we paused to listen, Louie would wave and blow kisses at ladies at least 65 years older than he is. Then up next to us rolled a man named Jim and his daughter Rhonda from the Mankato, Minnesota area. Louie immediately noticed Jim was wearing oxygen. Louie reached over and touched Jim's arm and said, "you like me" and smiled from ear to ear. They held hands and listened to the music. They smiled and giggled

together. Louie prayed for Jim. They had such a special time. I believe that Louie and Jim forgot for a moment where they were...they were just two guys spending tender time together...time that I will never forget...I will never forget because age is a just a number...love surpasses years....love stops time for just an instant to hold the hand of a stranger. (The only regret I have is not finding out Jim's last name or contact info so Louie could send him a card...Louie has asked about Jim multiple times this afternoon and evening.)

All in all, today was a good day. I am striving to stay rooted in faith and hope. I know God has brought us here...He made a way...and He is not finished with Louie yet. So please continue to hold us up in prayer as we walk each day. Tonight (or even tomorrow), please be praying for:

- The unplanned genetics appointment we will have tomorrow morning. Pray for the doctor to provide a fresh new perspective. Pray for a breakthrough idea.
- Pray for Dr. Van Dorn to see clearly and be invested in Louie. Pray that she can't get him off her mind and that God brings her to some insight previously missed.
- Pray for rest for Louie and I...

I can't express enough how valuable your prayers are to us...to Louie. Thank you for continuing to pray for us...

Photos







Comments

Always saying a prayer for you guys! For answers and a plan to get Louie well.

—*Wanda Cook, May 28, 2019*

I.m so thankful you and Louie had a smooth trip and I will continue to pray for Louie and you and his drs also, that they will find answers for Louie and you all, God is able, he is the Almighty Physician, He has got this and he has Louie and you in the palm of his hand holding you always ☺☺☺☺☺

—*Joy Stuckey, May 28, 2019*

Praying

—*Valerie Frith, May 28, 2019*

Prayers for each of you

—*paula allen, May 28, 2019*

Praying you get some answers and true solutions for Louie! Maybe you will run across Jim again! ♥☺☺☺☺☺☺

—*Laurie Dombrosky, May 28, 2019*

So thankful the trip went well and Louis continued shining!! All my prayers for you and

Louis and for all those working on his case. Lord, guide, enlighten and inspire all the Dr's and staff.

—*Joey Daniel, May 28, 2019*

So glad the flight went well and the process has started for Louie. Just praying that these doctors will see the hidden and will be able to do something to help Louie. Love to you both.

—*Doris Perkins, May 28, 2019*

Prayers for Louie and his family that all the medical personnel you come in contact with will be led by God to find positive answers for you. Prayers that Louie will meet his friend again.

—*Cindy Gordy, May 28, 2019*

Prayers for Louie and Family on this journey ! Also that you get some answers to find out anything they can for this special boy♥

—*Dodie Miller, May 28, 2019*

These pictures are priceless! Praying for you all is the least I can do as you have done so much for me

—*Sylvia Leach, May 28, 2019*

So glad that you are there and hopefully getting answers to questions about Louie that others haven't found. It is amazing how Louie can make the best of every situation. He brings out the good in everyone. Hope that he gets to see his friend again. Praying ☐☐ for you to find answers and that Louie meets many more friends.

—*Laurie Young-Staver, May 28, 2019*

Sleep well Kristy♥

—*Janice Calaway, May 28, 2019*

We will be praying. Reading how Louie didn't hesitate to pray for others is powerful. I know that God still answers prayers, but I believe there is something special about a innocent child's prayers. God bless you and that precious child.

—*Angela Hill, May 28, 2019*

Dearest Louie. ,

Thank you for being such a bright spot in my day. I love the updates your mom posts and, like so many other, I so appreciate you letting her share your journey. I am praying for you sweet one. Your smile is so infectious and I look forward to seeing it often. Mayo is full of amazing medical staff and resources. I pray the Great Physician and Healer will bless you with all you need. I hope you'll be able to find a little fun in each day.

—*Laura Neal, May 28, 2019*

Prayers and all my love to Louie and you! I have payed all day today.

—*Diane Huggins, May 28, 2019*

I've though about y'all all day -continuing to pray!!

—*Debbie McAnally, May 28, 2019*

I've though about y'all all day -continuing to pray!!

—*Debbie McAnally, May 28, 2019*

I've though about y'all all day -continuing to pray!!

—*Debbie McAnally, May 28, 2019*

Hugs and prayers to you all... thanks for the upbeat reports☺☺ I love to see faith in action and how he faces the challenge head on and holds the flight nurse's hand... so heartwarming, too, to see him reach out to others and befriend them. And then to be concerned about others and pray for them. Louie, you are so awesome!!!

—*Debbie Hauser, May 28, 2019*

The story about Louie and the older man almost brought me to tears! Everyone at THV11 is rooting for you Louie throughout your journey in Minnesota. You're in a great place!
<3 Melissa from THV

—*Melissa Zygowicz, May 29, 2019*

Many prayers were obviously answered positively for your first day. Thank you for updating us! Will continue this attitude of prayer for you guys! Seeing the people in the photos is just a reminder of how intricately God has designed each of our lives to intermingle with specific people at His appointed times and designated places. Such details that emphatically let us know that our God cares about us and is sovereign over

ALL things!!!! Isn't He wonderful, amazing, merciful, splendid, personable, inexhaustible, indescribable, majestic and much, much, much-to-no-end-more than we can imagine? And invites us to keep knowing Him more! Enjoy!!!! Our prayers are with you! ♥

—Lannece Mayo, May 29, 2019

God is answering prayers! Louie has a purpose and God's will be done! We love you all more than you could ever imagine ♥ He brings special strangers in to show us his presence- I'm seeing it here too ☺♥Hugs from Philadelphia!!!

—Jennifer Tarvin, May 29, 2019

Continued prayers for all. Sending some sunshine and love from Arkansas

—Myra Ferrell, May 29, 2019

Prayers for Louie. It's got to be hard for anyone to go through such an ordeal but we see it everyday. Love to Louie and Gods Blessings he gets good treatment.

—Marilyn Alsleben, May 29, 2019

Hi Kristy! It's Ronda and Jim. We are here in Rochester again today. Would you and Louie have time to meet at the piano ? ♥

—Ronda Hennek, May 29, 2019

Louie and Kristy I live in Beaufort South Carolina and worked many years with your Aunt Lavone who has always kept me informed. I teach a women's Sunday school class and share with them each week. I am touched by the faith and strength you both have. You help me to grow in my faith!! God is truly working in many lives as doors keep opening. What a loving and awesome God He is. Carol

—Carol Myers, May 29, 2019

May God's comforting hand remain on you and your family throughout this journey. Praying that you and Louie rest very well tonight. Praying for Dr. Van Dorn and all the medical team you may encounter on still another leg of your journey,. May God provide the continued strength you each need.

—Nancy Skinner, May 29, 2019

How beautiful to see all of the different people that are helping you. What a testimony to God's faithfulness. Thank you for sharing these pictures so we can get a taste of your

journey. You are so strong and we are continuing to pray for strength, healing, rest, and peace. All day Monday I thought of Louie on his birthday.

—*Anna Hederman, May 29, 2019*

Louie and Kristy you are being held in my prayers tonight. I have known Jim and Ronda for over 40 years. You have met 2 amazing people. Those two along with the rest of their Family are absolutely awesome. Hugs and prayers are being said for all of you along with all who are struggling with health issues. May God keep his loving arms around you all and his powerful hands guiding the hands of the Medical teams. God Bless you.

—*Carol Brady, May 29, 2019*

Louie , I just want you to know that Jim is my uncle and Ronda my cousin. You could not have 2 better people in your corner. Jim and Ronda always carry my aunt Pat with them at all times. I would call Pat a saint as she lived a life of service to others. I will add you to my prayers and just know you are in good hands.

—*Lisa Cumiskey, May 30, 2019*

LOUIE'S PRIORITY

May 29, 2019



Day 2 of appointments at Mayo was calmer than day 1. We spent the morning with multiple people in the genetics department. Each person listened intently, showed great care for Louie, and the main geneticist had some intriguing thoughts on what his body may be doing. In the end, they enrolled him in a research program that we hope over time yields helpful information. Plus, I am praying fervently that Dr. Lanpher will advocate for Louie. He had some ideas that I think may be helpful and I pray the team will put great weight to into his ideas.

After meeting with genetics and giving blood, Louie was able to have some sweet time with 3 local FBI agents. They came and brought smiles to my boy in the lobby of the hospital. Louie was quick to show them his FBI tatoo and make all of us laugh. I am so thankful that there is a special law enforcement comradery that embraces my son even outside of Arkansas. It is nice to have friendly faces in a state where we started out knowing no one.

BUT the HIGHLIGHT of the day was hands down what happened a bit later. Louie and I were standing in line when I got a message from someone saying she had a friend in Mankato that knew Jim and Ronda. She was able to get my number to them and send Ronda my post from yesterday. When Ronda called me a few minutes later and told me that they were back at Mayo, my heart lept for joy. When I told Louie, he said, "my friends here!!! I love them!!!" We then planned to connect at noon near the piano where we had first met them yesterday.

We spent almost an hour talking with them. Louie even FaceTimed with Ronda's husband and baby dwarf goat! It was such a special time. I watched them interact. There is such a genuine joy in Louie and care that he shows for Jim. I couldn't help but think maybe my view is too limited. I came to Mayo with the weight of Louie's life in the balance. I realize that what we are seeking is a long-shot...for something to extend and improve Louie's life....the reality of our purpose here is never far from my mind.

But not Louie. Louie's priority is not to extend life or for there to be answers. Louie's innocent priority is to love people and bring them joy. So as I watched him with Jim and Ronda...as his laughter filled the space between us...as his eyes danced with joy...I realized I want his priority to be mine. I want to be less inwardly focused and more outwardly attentive. I want to smile as much as he does. I want to leave worry behind and laugh more freely. I want to have what Louie and Jim have - an unlikely friendship that leaves imprints on the heart.

PRAYER REQUESTS FOR TOMORROW:

1. That Dr. Jones will fall in love with Louie and want to dig in more thoroughly than ever before. I pray that she will hear without preceieved ideas...and that God will give her

great insight to anything that is being missed. I believe that Dr. Jones will be one of the greatest influencers to what happens from here - so please pray for her to champion Louie's cause.

2. That his kidney ultrasound will show the severity of his kidney and bladder stones...and that Dr. Tran will have ideas that are out of the box to improve the stones and possibly understand more completely why they are forming.

3. That Dr. Grothe with GI will take great interest in Louie's case. We pray that he will want to jump in head first and give Louie the most complete GI work-up possible so we know if his GI system will ever be operational again.

Photos



Comments

Hooray! God is so good! Praying with you all ☺☺

—Noel Hutcheson, May 29, 2019

We prayed for Louie at Church tonight and I pray always for Louie, you and your entire family! Trusting that God will guide these doctors in knowing what to do for Louie's sake, God is Love and God's love shows through Louie.

—Diane Huggins, May 29, 2019

I am so happy for you and for sweet Louie, his connection with people is so precious and sweet. I know Jesus is smiling down on Louie, Thankful that drs are really dealing with Louie and we are praying for God too guide them to finding a answer for Louie and most of all you , continued prayers going up for you and and the rest of the family and of course Louie ☺☺☺☺☺☺☺

—Joy Stuckey, May 29, 2019

I pray for your family every nite. I just started getting careing bridge recently. I went back yesterday and read the early posts. I now have specific things to pray for. I did not actually know what was wrong with louie,was just praying because Santa Pete asked for it. God has blessed you and he does perform miracles. Louie is proof

—Paula Vines, May 29, 2019

Praying for your family always! Stay strong Louie !☺☺☺☺☺☺☺

—Dodie Miller, May 29, 2019

How precious this young man is!! Oh what we can learn from his great heart filled with love. Praying in agreement with you! May God amaze you each day.

—Valerie Frith, May 29, 2019

Standing in prayer with you on everything!!!

—Joey Daniel, May 29, 2019



—*janie cole, May 29, 2019*

Praying with you that our Lord, the Great Physician, will give these doctors and nurses at Mayo special insight into Louie's medical needs and be able to help him have the best possible chance at life. God's blessings on your entire family.

—*Polly Gan, May 29, 2019*

Praying in total agreement with your prayer requests. God is in control just rest in that. I hope you rest physically and feel energized everyday.
Doris Perkins

—*Doris Perkins, May 30, 2019*

Your prayers are my prayers! God love is so prevalent in Louie! Your heart as a mother and a Child of God, is a testimony of faith and perseverance! I 100% claim in the name of Jesus that breakthrough is coming! Believing by faith God is with you and Louie! ♥

—*Bridgette Wallace, May 31, 2019*

Your prayers are my prayers! God love is so prevalent in Louie! Your heart as a mother and a Child of God, is a testimony of faith and perseverance! I 100% claim in the name of Jesus that breakthrough is coming! Believing by faith God is with you and Louie! ♥

—*Bridgette Wallace, May 31, 2019*

Praying for Dr's wisdom ,and Louie's healing. Prayer is powerful.

—*susie bush, May 31, 2019*

Still praying for Louie. Thank you for journaling after what must be exhausting days. My church is praying for Louie and for all concerned with this. I appreciate you. Love and prayers through Christ, Sharon Stewart

—*Sharon Stewart, May 31, 2019*

I am so happy that you and Louie are experiencing what we call Minnesota Nice! Our continued prayers to you and Louie. I live about 3 1/2 hours north of Rochester and I wish I could be there to sit with you while you wait. Louie, thank you for being such an inspiration!

—*Laura Schieffert, May 31, 2019*

Officer Louie

May 31, 2019



Mayo Day 4:

If you are keeping score, I get a negative point for not posting an update yesterday...it was a super long and exhausting day. Yesterday we had an ultrasound, two additional tests, and three doctors appointments. We were in appointments for 9 solid hours. Today we only had blood work and two appointments. All in all, the doctors are fantastic and really seem invested in helping Louie. They each do their exams, gather information, order additional tests, and then will make recommendations. Next week we will begin to get the specifics of a plan for moving forward. Until then we are striving to enjoy each day and praying for hope to reign...

I want to take a minute to share what occurred today because it is pretty amazing. First off, I had my groceries picked up by the FBI...that alone is pretty cool... In fact, just saying it outloud makes me smile and giggle a little! The FBI agents we have met here are incredible people and they have stepped into our journey to be friends while we are in Minnesota. In doing so, they contacted Rochester PD and shared with them Louie's love for law enforcement. We were then contacted by a Lieutenant from the police department. He explained that some officers wanted to meet him and they were planning a surprise for Louie.

And a surprise it was!!! Lieutenant Turk and Agent Brian escorted us to a meeting room at the hotel. The room was lined with officers, city officials, and the media. The next thing we know the police chief was telling Louie how brave he is and how he is the kind of guy that he likes to hire. The mayor then stepped forward and read an official proclamation naming Louie an officer for the day. He was then sworn in by a city official as an officer of the Rochester Police Force. The police chief then put his badge on him and they shook hands. Louie was so happy...giggling with joy. Then other specialities within the police force stepped forward to give Louie various gifts. He met a K-9 and a member of the special ops team and others.

As I stood back watching all of this, there were tears in my eyes. I am not one to cry easily but this moment challenged my composure. It wasn't the gifts or honors; it was the people that blew me away. It was the fact that we are strangers to this community and in that moment they were wrapping us up in their arms and saying we are here for you. We are your family here. They were investing in my son, and Louie looked at each of them as if they were his long time friends. It was pure and genuine. The entire experience just reminded me of hope...of goodness...of love.

As the event ended today Louie asked to pray for his "police friends." The beautiful thing was that they all immediately bowed their head. But, Louie didn't want to pray with them at a distance. He wanted them near. He waved them close...he grabbed their hands...he told them to close their eyes...and my sweet boy prayed over them. There in

that room I think most caught the spirit that makes Louie special. Here was a boy from Arkansas seeking treatment...seeking life...praying over grown men and women in uniform. In that moment, I had a thought I had never contemplated before...I can't think of the last time Louie has prayed for himself. I truly can't. But I can tell you of the names of 3 strangers he prayed for at various points today. I can describe the look in the officers' eyes as Louie finished praying over them. I pray over him each night. But his prayers are always about others. His eyes and thoughts always on others. What a God honoring way to live and see the world. Oh to be more like Louie...

PRAYER REQUESTS MOVING FORWARD:

1. For the remaining consult and two tests that are needed but having difficulty getting scheduled to open up early next week. Please pray that there are no shows and just favor given so that we can get them done ideally on Monday or Tuesday morning.
2. For the doctors and medical team to continue to talk about and contemplate Louie's case. Pray for a consensus regarding treatment and that they will be willing to initiate treatment immediately. Pray for there to be a clear path they are willing to pursue and for Louie to be on their minds constantly.
3. For a relaxing weekend as we explore downtown Rochester and recover from a super busy few days.
4. For God to receive immense glory through our time in Rochester!

Photos







Comments

Continued prayers for all ☺☺

—Cindy Gordy, May 31, 2019

Words cannot describe the warmth that fills my heart for sweet Louie. If we could all be like him the world would not be in the mess it's in. Praise the P D who are loving Louie☺☺

—Paula Vines, May 31, 2019

Thank you for sharing Louie's journey. I am amazed each time I read your updates at how God is using Louie to touch so many lives. Louie is such an incredible young man and you are an inspiration. Prayers for you, Louie, and all those touched by your sweet son.

—Shelley Ennis Ruth, May 31, 2019

Your blue family keeps growing and I just love it!! I miss that kiddo so much, I'm in constant prayers with you for the Dr.s and nurses to work on his behalf. God has plans for Louie!! #louiestrong #lovelikelouie #thankyoujesus #praybig #lovebig #pinkhandcuffs ☺☺☺☺

—Jennifer Tarvin, May 31, 2019

God's blessings are new every day. I don't believe I am alone when I say our country is so confused, discouraged, even angry that to have the ongoing outpouring of sincere love shown to Louie and your precious family is truly a balm to our hearts and souls. Pray on Louie. Like Winston says, we NEED you!

—Cindy Krueger, May 31, 2019

Oh my goodness that's so amazing!! Prayers for you all!!

—Paula McGinty, May 31, 2019

Louie makes me smile, Louie touches my heart so deep and your words Kristy just are so beautiful and from the heart. Praying for Louie , you and the entire family.

—*Diane Huggins, May 31, 2019*

God is so good. Tell Louie we are praying for him and the doctors that are working on his case. Love to you all.

—*Doris Perkins, May 31, 2019*

You are bright light...keep shining Louis, you are touching so many!!! Prayers for you every minute of the day!! <3 <3

—*Joey Daniel, May 31, 2019*

Louie may be a young boy doing God's work, but he is a Mighty, strong. Powerful man in the Kingdom of God.

Don't worry that he don't pray from himself , we all have that covered. God bless you

—*Angela Hill, May 31, 2019*

Hi Kristy and Louie, my prayers are with you, Ronda and our family are standing in the gap for your complete healing and restoration!! Louie you are a mighty young man and God is using you to touch so many people with his peace and love. It was so nice to face time you and we are looking forward to seeing you on Sunday.

—*Mike Hennek, May 31, 2019*

How amazing!! The officials tried to honor him and Louie was the one who truly did the honoring!! He Honored God by loving his neighbors as himself. What a beautiful display of love. I am praying in agreement with you all. God bless you all

—*Valerie Frith, June 1, 2019*

Dear lord please see that these doctors see a clear way to help your child. This little angel has touched so many lives and helped us (me) turn to you for answers. He has helped me realize you are the answer to all things.

—*Wanda Cook, June 1, 2019*

After reading your story, you and your family will be in my thoughts and prayers. Louie's team of doctors, nurses and helpers will be in my thoughts and prayers. You are special people. Louie has a huge heart and amazing spirit. Mayo Clinic is amazing. It seems you've just witnessed and experienced our "Minnesota Nice." Welcome to Minnesota and God bless you all.

—Vikki Smith, June 1, 2019

As I read this I'm thinking, "Isn't God amazing!" I'm encouraged by the love poured out on you and Louie, and I'm challenged by Louie's love for others. Thank you for sharing specifics on how to pray. It helps so much. Love to you and Louie and your family!

—Ellie Williams, June 1, 2019

What a wonderful day spent with what sounds like such caring people! The heart Louie has for others is something special! Praying for this precious child!

—Sheila Fitts, June 1, 2019

My sweet sweet Louie-

WELCOME TO MINNESOTA!!! You're in my home state!!!!

Your tenderness towards others is a true reflection of who Jesus is. He made you to show others what he is truly like. I am so proud of you. Praying over you right now! Can't wait to see you next. Love you tons buddy! I know you're in good hands♥

—Martha Perrel, June 2, 2019

We talked about you just yesterday Martha! Thank you for the kind and encouraging words. We have missed you the last few times we have been up at the hospital. I hope that you are doing well and that popsicles with Louie are in your near future!!!

—Kristy Schneider, June 2, 2019

You don't know me, but I saw you both as I was eating my breakfast in between appointments at the clinic last Friday. It breaks my heart to see all those affected by the brokenness of our earthly bodies, but especially when it is kids (and their parents). I remember as you passed thinking that Louie looked like a really neat kid, probably because of his stylish haircut. ☐☐ But I now understand that he stood out to me because of the real Joy he embodies. I was recently diagnosed with a terminal illness and am also praying for cure to be found. But I have decided that with whatever days God gives me on this earth I will strive to point towards Him, his amazing goodness, and the unshakeable hope we can find in him, even as we face death. After seeing your story on the news I was curious to hear your story and I am blown away by how you and Louie are being used so tremendously to bring glory to God through such hard circumstances. I pray I can be more like Louie and have his childlike faith. You have also encouraged me to a better mother, so thank you for your openness and sharing your son's story. You are

truly an inspiration to so many on being a disciple of Christ. To God be the Glory!

—*Sara Brouwer, June 2, 2019*

Thank you so much Sara for sharing this with me. I hope that if you are back at Mayo in the days to come that our paths will cross again...but that this time we will be able to talk and hug and find hope in the joy Louie radiates...joy from Jesus. I will be praying for you... Thank you again for sharing and know that you will be on our hearts and in our prayers.

—*Kristy Schneider, June 2, 2019*

I will most definitely introduce myself in person if I see you again at Mayo! Lord willing I won't have to be back until June 21. And I pray that God will grant positive outcomes from all the many tests you are both enduring this week, and grace and peace as await the results.

—*Sara Brouwer, June 4, 2019*

THE TOP 10

June 2, 2019



The past 6 days have been busy...hard...lonely at times...and filled with the gravity of the life and death battle Louie is in. The past 6 months have been the most challenging of my life. There have been so many tears...so many sleepless nights...so many medications, beeping machines, medical supplies, therapists, doctors, and the list just goes on.

But not today.

Today was different. Today was special. Today renewed my spirit as strangers who had become acquaintances, became family. Remember the story of Jim and Ronda and the way God worked to connect us after we met them our first day?? Well, the story doesn't stop. Today the story grew...

Ronda and her husband drove almost 1.5 hours each way to pick up Louie and I so we could spend the day with them. We were able to attend their church...have our son prayed over...then spend the rest of the day at their home. Since there is not enough time to even begin to explain all that we did in the hours we were there, I made a top 10 list of my favorite moments today (and it could easily be a top 25 list because it was that amazing):

10. Clean clothes! Having a place to do laundry that didn't require quarters.
9. Louie's giggles as he dangled his feet in the swimming pool and resisted the urge to take a swim.
8. Having the church pray over Louie.
7. Louie kissing the baby dwarf goat Winnie.
6. Louie holding hands with Ronda across my lap during the church service.
5. Seeing a tiny baby deer curled up sleeping as we explored the trails on their land.
4. Hearing the joy in Louie as he rode the bucket lift on Mike's truck.
3. Having Mike and Ronda help me with Louie's bath and medical stuff. It was beautiful to see their willingness to jump in and join the medical world with me and support us in such a tangible way.
2. Louie charming the ladies....he ended the day with not just one girlfriend, but FOUR girlfriends!
1. Louie's face when Jim walked in the room! It was priceless to see the love Louie has for him!

Overall, it was a day I can't describe because the love and experience was too great. There just aren't words. The love was so big that for a time I forgot. I forgot about the hard. I forgot about the pain of watching my son fight. I forgot about all the appointments, what if's, emotions, doctors...all of it...I forgot and simply watched. I watched my son giggle and laugh with people who have chosen to step into this

journey with us. I watched as Louie experienced things for the first time. I watched as selflessly and tenderly others served us, cared for us, and held my son up (both literally and figuratively). Mike and Ronda opened their home, but their ENTIRE family opened their hearts to us, and for that we are forever changed.

PRAYER REQUESTS FOR MONDAY:

1. For God's favor. We have one appointment with a doctor tomorrow but we have 4 other things (consultations, tests, etc) that the doctors want us to have while we are here but there were not appointments available this week. Thus we will be a "checker" tomorrow for these. To be a checker, it basically means we will be sitting in the waiting room and hoping/praying that they have a cancelation, no show, or way to squeeze him in. Please pray for God to make all 4 of these possible Monday or first thing Tuesday morning.
2. For the doctors to continue to work hard on Louie's case and to be coordinating a plan. Please pray for a plan that will involve treatment we can start immediately up here and will provide a path forward that includes answers and treatment opportunities.
3. For my sweet Liana to have a great 3rd birthday tomorrow...and for my heart as I am missing a birthday for one of my kids for the first time.

Photos







Comments

God is so good! Thankful He has provided you with “family” there to love on you and Louie and give you a respite while you are away from your home and those you love!

♥□□□□□□□

—Laurie Dombrosky, June 2, 2019

Thank you lord for giving Kristy and Louie a home and family away from home. For the love they are being shown. It's rally easy to fall in love with this family. Lord we pray that more answers come tomorrow and they get the appointments they need taken care of. Keep them safe on their journey through all this. Amen

—Wanda Cook, June 2, 2019

Lord thank you for a wonderful day for Louie and Kristy with new family members in Minnesota. Please touch Kristy's heart in a special way since she will be missing Lianna's birthday party tomorrow. Father please make a way for appointments to open up tomorrow that Louie is in need of. We are so thankful for all things you are doing in Louie's life and we give You all the glory and praise. Thank You especially for the gift of Louie and his family's willingness to share him with all of us. In Jesus most holy name I pray. Amen

—Suzette Goodman, June 2, 2019

God provides family every where.happy you got to relax a little and louie got to laugh

—Paula Vines, June 2, 2019

God is good. At our lowest He will bring us up. Kristy I know tha God has put this family here to help you through the troubles while you are away from home. May God lead the Doctors to find a treatment plan that both extends Louie's life and adds to the quality of his life.

We miss you but know you are in His hands during this time.

Love and kisses to you both.

—Maurie Keys, June 2, 2019

Prayers tonight as I go to bed and prayers tomorrow for God to answer prayers on behalf of you and Louie. Love you Bod Bless I just love that Louie!

—Diane Huggins, June 2, 2019

Thank you for your comments and pictures. You are such a thoughtful, articulate and caring mother. I wanted you and your son to know the Gonda Singers sing again

tomorrow at ten thirty Under the big steps in the Gonda We will sing happy birthday to your daughter and some songs for Louie See you then we hope. Jane b

—Jane Belau, June 2, 2019

I just saw this message....when are you there singing again??? He loved you guys and wanted to dance with you!

—Kristy Schneider, June 4, 2019

If you are able, please send me the reply through facebook or messenger....I see it faster that way. My facebook is Kristy Tyler-Schneider. And I will try to be checking here more frequently to see if you were able to respond.

—Kristy Schneider, June 4, 2019

Praying as always for Louie, Mom and all concerned. I'm so glad you got a much needed break yesterday. Louie, you are such a thoughtful, selfless person. God must be so proud of you, your Mom and your new friends. Praying for the best for you and yours.

—Sharon Stewart, June 3, 2019

Praying for openings today for Louie. And for answers and excellent results. So glad y'all enjoyed a day out.

—Doris Perkins, June 3, 2019

Happy birthday Leanna from the Gonda singers

—Jane Belau, June 3, 2019

Kristi I need your email address to sendcsingscctthank youb

—Jane Belau, June 3, 2019

Thanks be to God for all the wonderful people he has placed in your journey and blessings to them for their kindness. Continued prayers for you and Louie.

—Cindy Gordy, June 3, 2019

3am Friends

June 4, 2019

There are people in our lives that are friends...even good friends. And then there are the 3am friends. The rare relationships that are available, truly available at all hours of need. The people who give more than lip service to being there...the ones who actually are.

When you walk a long health crisis, some get weary of walking it with you. When you walk a long health crisis, asking for help gets harder and harder while the weariness and loneliness only increases. When you walk a long health crisis, it stifles your ability to give and invest in others the way your heart desires, making friendships more challenging. So, often times, when you walk a long health crisis, the support comes from unexpected places...from people you didn't know were 3am friends.

When I met Ronda and Jim by the piano at Mayo last week, I knew they were special people. As Louie and I spent Sunday at their home with their family, I was so touched by their gentleness and love for my son. I have been drawn to the way they genuinely care for our family even after just getting to know them for a week. But last night...I discovered the friendship is even deeper... I discovered they are 3am friends.

Last night Louie was only allowed to sleep 4 hours in order to complete a sleep deprived EEG today. For reference, these days Louie sleeps about 14 hours on average a night. And for greater reference, I struggle with less than about 6 hours of sleep a night. I was dreading last night. I was dreading trying to keep him and myself awake...and knowing that I needed enough brain function this afternoon to meet with a few very important doctors.

I simply mentioned to Ronda yesterday evening in a text that we would be up most of the night. Just a mention. Within about five minutes I had a call from her and Mike. They said that Mike would be at the hotel at 3:30am to take a shift of keeping Louie awake so I could get a little extra rest. I was floored. 3am friends. People I have known a week, who without being asked, stepped in to make my load lighter...and Louie's night so much smoother.

Today I have contemplated multiple times, why would people I have only known a week be 3am friends to me? And the answer I come back to again and again is easy and hard all at the same time....the answer is Jesus. Jesus is recorded in John 15:13 as saying "Greater love has no man than this, to lay down his life for a friend." To sacrifice one's comfort for the sake of a friend...to change one's plans to help another...to give generously of time, talent, or financially to meet the need of another expecting nothing

in return...it is simple...it honors God. It is being Jesus. It is being a 3am friend.

I am ending tonight thankful for my 3am friends and praying that I can be that same caliber friend to those in my life. Circumstances may make it hard to literally be present at 3am with someone, but that doesn't let me or anyone else off the hook. To be like Jesus, is to love that selflessly. Lord help me be present and available for those in my life...to be a 3am friend.

MEDICAL UPDATE

Louie continues to be seen by a number of specialists and still has a few tests and appointments left to go. We will be here until the middle of next week at a minimum. He is tolerating it all so well and we are learning more and more each day about his body. (I will share more specifics of what we are learning early next week when the team gives us a more comprehensive plan for what is to come.) In the meantime, please continue to pray for the doctors to have wisdom and clarity on how to proceed. Pray they will know what needs done here and what can be done back home. Please pray that the heart monitor test we are about to embark on will yield a better understanding of how his heart is struggling due to the autonomic dysfunction. And finally, pray that we are able to get in to pulmonology THIS WEEK (ideally tomorrow)!!!

Thank you all for continuing to follow our journey and provide us with such kindness and encouragement.

Comments

Continuing to pray everyday for Louie, you and your family. It's amazing how god puts people where we need them when we need them. Thank you lord for all your angels on earth.

—Wanda Cook, June 4, 2019

Continued prayers for you, Louie, and your family; all the medical personnel you meet with; and blessings again to 3am friends.

—Cindy Gordy, June 4, 2019

Wow, how God is truly meeting your every need! So thankful for Mike and Ronda and the way they have come along side of you and Louie to be the hands and feet of Jesus! God is so amazing! Praying you get some good results from the tests and the medical team there at Mayo! ♥□□□□□□□□□□□□

—Laurie Dombrosky, June 4, 2019

The word “Inspirational” doesn’t justice. Your story and Louie’s make me strive to be a better person in every way. I pray for y’all continuously.

—Eva Edens, June 4, 2019

I pray for you every night to have strength. God sends things when we are truly in need and he sent you 3am friends. We serve a beyond description God

—Paula Vines, June 4, 2019

Always thankful for those friends who are friends no matter what time of day and you are right Jesus hears our cries and answers them. I am so thankful for your 3 AM friends if I was closer I would be there for you to.

—Diane Huggins, June 4, 2019

So thankful that God has put Mike and Rhonda in your lives!☺☺ Continued prayers that the doctors come up with a plan to give sweet Louie a better quality of life! ☺☺☺

—Cathy Perkins, June 4, 2019

Wonderful blessings in these special people who are 3am friends! Continued prayers for you all

—Sheila Fitts, June 4, 2019

Wow!!! God provides the 3am Friends exactly when we need them. I can’t be there physically, but I can pray at 3am for Louie and you. Love you both!!!

—Kathy Bettis, June 5, 2019

God provides what we need. Continually praying for you all.

—Noel Hutcheson, June 5, 2019

Continued prayers

—Myra Ferrell, June 5, 2019

That is amazing, those kind of friends are few and far between, and such a precious

blessing, I am so thankful for those kind of friends and especially for You and Louie. God knows what we need when we need it and he is always on time every time. We are continuing fervent prayers for Louie and the drs that God will lead to get answers for Louie and you all , God is able and he is the Almighty Physician and we're trusting in Him for all things. Sending Love and Hugs to you and Precious Louie ☺☺☺☺☺☺♥♥♥

—Joy Stuckey, June 5, 2019

I know about Louie and you all's challenges through my daughter officers Jennifer Tarvin and husband Paul, know that prayers are sent your way daily from VA. God bless

—Dave Mayberry, June 5, 2019

Thankful that you have 3am friends where you are - where they are needed. God provides. Continuing to pray for Louie, you, your helping hands, the doctors and medical team and your family at home. Love and hugs ☺☺☺☺

—Linda Davis, June 5, 2019

Sending love to you and Louie! I heard you stopped by! I'm back at my desk and I can meet you. ♥

—Danielle Teal, June 5, 2019

I hope you got the note and stuff we left you. Hopefully we can swing by again some time to say hi if that is okay with you? Louie was bummed you weren't there.

—Kristy Schneider, June 5, 2019

I hope you got the note and stuff we left you. Hopefully we can swing by again some time to say hi if that is okay with you? Louie was bummed you weren't there.

—Kristy Schneider, June 5, 2019

You don't know me but I live near the Twin Cities in MN and I saw a post the Rochester PD had about Louie. I went to his Caring Bridge site and read his entire story yesterday. What an amazing boy he is! I have such a good feeling about his prognosis. Please know that I will be thinking about your family and Louie and sending positive energy your way. That boy is destined for great things!

—Alexis Cimaglio, June 6, 2019

Love and prayers to ALL! God is Great and his will is Perfect!

—Heidi Beck, June 6, 2019

Plaid Pants

June 7, 2019

Today was discouraging for me in many ways. I won't go into all the medical details, at least not until after we meet with our final doctors next week at Mayo, but suffice it to say the appointments today didn't go the way I hoped for them to go.

As I left the appointment, I was upset...the kind of upset that you feel deep inside...the kind that threatens to come pouring out but you swallow hard to keep the emotion at bay. I walked through the halls of the clinic, along the streets of Rochester, through the hotel lobby....I walked and I smiled. I spoke with kindness when strangers spoke to Louie (which happens all the time). I never let the tears out. I never let my voice crack. I walked and I smiled.

As I was walking and smiling, Louie initiated a conversation with a gentleman on the bridge over the river. Louie asked about him being in a walking cast. And Louie commented on his stylish spring colored plaid pants. As we stood and visited we learned the man's name was Kevin. Kevin and Louie chatted and laughed and enjoyed each other's company for quite a bit. Then Kevin invited us to come to meet his friend John. John owns an antique shop near our hotel and Kevin was on his way there. We agreed to swing by after our walk.

A little later we walked by and saw John and Kevin sitting outside the store. They greeted Louie with great excitement. They had special toys for Louie including a fun whistle. They laughed and giggled with Louie as he interacted with them and blew the whistle. We talked with them for quite a while. In doing so, we learned that Kevin, the man in plaid pants is a district judge here in Rochester.

When I think of judges, I think of men in suits and ties...I think of men you address formally as judge all the time. I don't think of plaid pants. Kevin didn't fit the mold of what a judge looked like to me as he sat playing and talking with Louie. I realized that I have a preconceived idea of what judge or person in authority looks like and in doing so I have missed the humanity in them. I have missed seeing the person because all I noticed was the plaid pants.

Then I wondered how many times I assume because someone is smiling, that they are happy and okay. I let the exterior tell the story instead of asking for the interior truth. I was guilty today of hiding behind a smile...and for secretly wishing someone could see through it to hold the hurt with me just for a moment. But the facade was easier than the tears. I wonder how many people I passed today were hiding behind the illusion of a smile just to survive the moment....hiding behind plaid pants.

I am so thankful for a God who sees us in our entirety and loves us anyway. A God who counts the tears we aren't brave enough to cry. A God who knows our hiding places and pursues us in them. A God who doesn't need our smiles or plaid pants because He knows what is behind them. A God who says we are enough because He is enough.

There is no hiding. There are no illusions. There is simply this truth, God is love and He loves you. He loves me. He loves us in plaid pants or in suits. He loves us with smiles or in tears. He loves.

So tonight as I eagerly await for my family to arrive in Rochester, I am thankful for Kevin and his plaid pants and what they taught me today...but more than that, I am challenged to love others more like God loves me. I want to see behind the smiles and ask people how they are really doing...and want the raw answer. I want to love as I see Louie love. (Today Louie interacted with a judge and a homeless man exactly the same.) And, I want the courage to not hide behind smiles but embrace that we all cry...we all hurt...we all need each other to walk this crazy hard life...and we all need God's love to bring beauty from ashes...

Comments

You truly are in my deepest prayers and I ask God to always hold you close and give you the strength you need! I never met you personally but I love you and your family very much!

—*Diane Huggins, June 7, 2019*

Your testimony is amazing as always. I am always in awe at the amount of people that think I do not care or do not want to hear their story ... truth is I would not ask if I didn't care. If you ever just want to vent you can call me

—*Sylvia Leach, June 7, 2019*

Oh Kristy, this breaks my heart. I wish I could hug your neck, just know I'm doing it from here. I'm asking the Lord to hug you tight, to hold you and give your heart a moment to catch up. I'm so sorry you didn't hear the words you had hoped for, but we know WHO is

still in control. Hold your family tight, draw strength from their presence as you draw the greatest strength from God the Father. I love you sweet friend and am praying without ceasing. ♥

—Cindy McCrotty, June 7, 2019

Oh dear friend, I just want to give you a great big hug. Be there to let those tears fall safely, and all those thoughts and emotions too hard to let out. You and your amazing family are bringing such glory to God. This is such an unimaginably hard path, but He is clearly with you and He is using it in so many ways. Thank you for constantly showing us Jesus. Love you

—Kristina Mete, June 7, 2019

I'm so sorry for answers that didn't come as hoped. Praying for you and your family . Thank you for sharing your innermost feelings and glorifying God.

—Sam Bartolotta, June 7, 2019

Such beautifully written words to remind us of what really matters! You are walking through such difficulties and you are an encouragement to me! Your Louie is an amazing encouragement to me and I've never met either of you. I thank you for your posts, for your honesty, for your heart. I pray for you, for Louie, and for the answers to your questions and medical needs. May you feel God's arms holding you close tonight!

—Sheila Fitts, June 7, 2019

Kristy, John Kruesel and Judge Kevin Lund are two great citizens of our city. I'm glad you and Louie met them. If you would share your EMail address with me I will send you the songs we sang for Louie and Lianna. The Gonda singers sing again Monday morning at ten thirty under the big steps in the Gonda. You are invited to join us if you can. You seem to be doing very well in meeting the best here. God bless you and your family. Have a great weekend with the family. Best wishes Jane

—Jane Belau, June 7, 2019

Kristy, John Kruesel and Judge Kevin Lund are two great citizens of our city. I'm glad you and Louie met them. If you would share your EMail address with me I will send you the songs we sang for Louie and Lianna. The Gonda singers sing again Monday morning at ten thirty under the big steps in the Gonda. You are invited to join us if you can. You seem to be doing very well in meeting the best here. God bless you and your family. Have a great weekend with the family. Best wishes Jane

—Jane Belau, June 7, 2019

Im so touched by Louie, and your honesty. Thank you for sharing. We will be praying.

—Angela Hill, June 7, 2019

Hiding seems easier for most of us... Prayers...

—Valerie Frith, June 7, 2019

I am so moved by your words. I live in Bryant and have been praying for Louie, you, and your entire family for months. I cry with every post and I am so glad God has brought these people to you while you have been at Mayo. I pray that you and your family have a good visit this weekend and you get more answers on Monday. God bless you all.

—Amy Birge, June 7, 2019

Beautifully said - we all love our masks - praying that Jesus will help me to see through the masks and into the soul of people I meet.

—Debbie McAnally, June 7, 2019

Even in your darkest times, there is a Presence that is evident in your journey. You possibly don't realize that He interjects His thoughts between the lines of your journal entries to the reader, and provokes us to contemplate how He marvelously orchestrates events and circumstances continually to accomplish His will. These reminders bring us to an awareness of His activity and compels us to worship and bring Him glory. I can't help thinking about the smile you reluctantly wore, and how you pulled it out of the "closet" and put it on like a pair of "plaid pants". I think not wearing your smile would have put you in danger of becoming "faceless" and ignored. No one is happy to engage in conversation with a crest-fallen face. So I tend to think your smile was more an open door than one you hid behind. "Lord, thank You for speaking to us through Kristy! You are more than we can fathom in every way!!! Your love is endless, as is your mercy and power! Your ways are incredible and nothing about You is ordinary. I pray that you awe us and bring awesome results to this family; to Louie. We love You and appreciate the friendship we enjoy with You and we give ourselves to You anew.. in Jesus Name, Amen".
♥♥♥♥ You are loved!!!!!!,-

—Lannece Mayo, June 8, 2019

I love this for so many reasons! This message and your wonderful words resonate with me right now on so many levels. As I sit at the airport about to leave.....my face and heart don't match ♥☐☐ Cant wait to hug all of you!

—Jennifer Tarvin, June 8, 2019

Your post was definitely good for thought. I pray that you will soon have the support you need. Continued for Louie and you.

—Cindy Gordy, June 8, 2019

I am so sorry for your really bad day. I've had days I just had to put on a smile over tears as well. It's such a lonely feeling, not knowing who you can trust with your pain. I hope you have a few people you can trust with whole heart. Praying for you

—Jennifer Nunley, June 8, 2019

If Words Could Heal

June 10, 2019

In 12 hours we will be sitting in front of a cardiologist...a woman I have met only once. Yet, she will carry in her words the weight of the future for Louie. Her decisions will deeply impact our son...our family...our path. Her wisdom, knowledge, and willingness to take a risk will determine the next steps for Louie's life.

I am nervous yet I have peace. I am scared yet I have hope. There is such a vast array of emotions...some too big for words. Words for me are an outlet...words are something I am good at...words help me process through the crevices of life that threaten my sure footing.

However, today as I walked through Mayo with Louie and our family, I was acutely aware of the weight, the heaviness, that one carries when they deeply love someone that is sick. I talked with countless people who are at Mayo for unique medical reasons. Each of them clinging to hope and longing for good news. Each of them carrying a weight which they long to lay down. The loved ones that are with them would give anything to make the path easier...to take on more weight themselves, if it would mean an lighter load for the one they love.

I watched and talked to individuals. Families. Couples. Friends. Parents. Children. I saw them all today. All holding the weight. All reaching for more. All here seeing doctors and getting tests...

Why?

Because the desire for each person here is to be healed...to be whole...to be well...to have more time...less pain...and hope restored. As a society we are quick to offer words to those suffering or struggling. We are slow sometimes to offer prayers. We want our words to heal the wounds. Yet, even the best speaker, the most profound writer, the most knowledgeable linguist, can't heal with words. If our human words could heal, there would be no Mayo Clinic...no medical insurance companies...no doctors... If our words could heal, we would be walking Heaven on earth - since Heaven is the only place where we are truly whole, complete, without sickness, without death - completely healed.

As I looked in the eyes of so many today, I found it easy to say, "I will be praying for you." But found it more complex to stop in the moment and look them in the eye and ask "May I pray for you right now?"

But then why do we pray for healing if my human words can't bring healing? Why do we pray for the sick...for the one needing a diagnosis or good prognosis, if my human words can't bring healing? Do we pray because the words carry some power to make it better? Do we pray or say we will pray simply because it is the easy way to make the hard moment feel more comfortable? Do we pray for an outcome or because of a relationship?

When you contemplate the essence of these questions, they are hard ones...especially in the midst of any form of suffering or struggle. But the truth is, my words (even those said in the form of a prayer) do not have the power to determine life and death. My words do not hold the power to alleviate fears. My words do not carry the power to heal.

I know of only one who has healed with his words...and his name is Jesus. Jesus spoke healing and life into people. Jesus gave sight to the blind. Jesus restored health. Yet every single person Jesus healed on earth still died. 100% of them. Maybe the goal was never to avoid sickness, pain, and death, but to live believing Philippians 1:6, "He who began a good work in you will be faithful to the day of completion."

If we live believing that God began our life...that He began the work in us, then we can live with the hope that He will be faithful until the day of completion. The day of eternal healing. This is not to say that God is not capable of healing on this earth...I believe he can and does. But even that physical healing would only be for a time. We all still will die. Instead, believing that God is at work in us, means that my hope is not stuck in the outcome of the moment, but in the person of Jesus. So I pray for healing not because the outcome is the goal, but because a deepening relationship with the one who holds the power to heal with words, is the goal. And I pray because the person carrying the

weight needs to know they aren't alone. They need to know we are willing to carry it to. They need to know there is a place where the weight is laid down eternally because of Jesus.

So as I wait to see the cardiologist tomorrow...which is now in 11 hours... I wait knowing that words can't heal my son...but God can and will in His way and in His time. I wait - praying, believing, and hoping that others will be praying to...not to heal but to share the weight and lay it at the feet of the one who can.

Comments

Thank you. Your words point us to Christ who can heal and will ultimately heal and put the ultimate enemy, death, under His feet. But thanks be to God who gives us the victory through our Lord Jesus Christ. I am praying for Louie.

—*Jimmy Carter, June 10, 2019*

Praying for the necessary medical treatment for Louie's healing!☺☺☺☺

—*Cathy Perkins, June 10, 2019*

Dear Lord, please, we ask that you heal Louie!

—*Nancy Headdings, June 11, 2019*

Agreeing with your prayers!!

—*Debbie McAnally, June 11, 2019*

Such powerful Truth... praying for you all today!

—*Valerie Frith, June 11, 2019*

Continued prayers

—*Myra Ferrell, June 11, 2019*

Lord, thank you for going before them into today. Prepare the heart of this doctor, direct her thoughts, knit together her ideas. Trusting you is so hard when the answer is potentially no, but no is nearly impossible to bear if we think humans have gotten in the easy. Allow no human to get in the way of your will today, Lord.

—Jennifer Nunley, June 11, 2019

I am praying for you today. Feel Gods arms around you as you go through this day. I Love You, Erik and your sweet family.

—La Vone Cording, June 11, 2019

Prayers for the desire of your heart to be granted by the One that knows Louie best. My love to you and Louie both.

—Doris Perkins, June 11, 2019

Dear Jesus, please be with Kristy, Louie and the Doctor today. That the outlook be a good one. That you will show us a miracle for this child of yours. That you hear our prayers and there is a clear path to start the healing. I believe you put this child on earth to do your will. He has done your will and showed us what a loving god you are. He has shown us also how we should live. Through him I have returned to what I lost so long ago. Please lord, heal this child.

—Wanda Cook, June 11, 2019

Profound words. Your faith inspires so many. May God continue to be ever present with you today. Come, Holy Spirit.

—Sugar Bostick, June 11, 2019

I m praying deeply for you as a family!

—Sue Lewis, June 11, 2019

Continued prayers for all of you ☺☺.

—Cindy Gordy, June 11, 2019

♥♥♥♥ Amen!!

—Brittany Carmichael, June 11, 2019

Today

June 11, 2019

Today.

Today we met with two brilliant doctors.

Today we discussed so much regarding Louie's health, prognosis, and overall plan.

Today we heard how there is no textbook to aid in understanding Louie's body.

Today the doctors spoke with caution regarding his prognosis.

Today we were told that any diagnosis would really be made up because there will likely never be an exact understanding as to what is causing his symptoms...or how to fix it.

ALSO...

Today Louie felt crummy and slept much of the day.

Today Louie was flirting dangerously close to an infection in his PICC line.

BUT...

Today Louie started a new heart medication with close monitoring.

Today Louie was also given IV antibiotics to fight the infection near his PICC line.

AND MOST IMPORTANTLY...

Today Louie is alive.

Today Louie kissed his siblings and laughed with them.

Today Louie snuggled with friends and prayed for a man in the elevator.

Today brought a glimmer of hope.

BECAUSE...

Today we go to bed thanking God for a doctor willing to think outside of the box and try something to help Louie's body.

Today Louie carried no worry or fear about what is to come.

Today we made the most of what we had and lived it without regret.

Today God's presence brought peace to every moment.

Today we felt the prayers and knew God was present.

Today is a day the Lord has made and we will rejoice and be glad in it (Psalm 118:24).

What is your story for today?

Comments

Thank God for all things! Outside the box, family, prayers, love and like you said thank you lord for Louie still being here! Still praying these doctors will find the answers!

—*Wanda Cook, June 11, 2019*

Praise the Lord!

—*Jimmy Carter, June 11, 2019*

I have checked back here often today to see if there was an update from your appointments. I have prayed for your whole family, for answers, for peace of mind, for comfort for all of you!

—*Chris Logan, June 11, 2019*

Thankful for today. Praying for Louie and his team. Love and hugs

—*Linda Davis, June 11, 2019*

Thank God for Louie's life, Thank God for you Kristy, both of you a true inspiration of God's love and strength! Today I worked hard for our group and our wounded Officers, today I crocheted for our wounded Officers, Today I thanked God for all of our Law Enforcement and today like every day I prayed for their safety and for Louie's health and strength for you Kristy! Today I was strong in the Lord because He brought me to our mission for wounded Officers and he brought me to know Louie and to love like Louie! May God be with you all!

—*Diane Huggins, June 11, 2019*

Thank you for sharing this Diane. I am so thankful for what you do to encourage so many....like us.

—*Kristy Schneider, June 12, 2019*

Thank you for continuing to share Louie's story. He is a precious inspiration. Prayers continuing for your family and everyone involved in Louie's care.

—*Leigh Russell, June 11, 2019*

Today.....TO GOD BE ALL THE GLORY! LOVE YOU FAMILY!

—*Jo Butler, June 11, 2019*

Praise God, Praise God, Praise God!!!

Today I prayed for your family.

Today i prayed for the doctors you would see.

Today I scanned 5 very sick babies and was part of giving their families hard news.

Today I scanned 3 healthy babies and was part of giving really great news and celebrating with their families.

Today I held my babies and prayed.

Right now...today....I am celebrating the glimpse of hope Louie was givin and celebrating a brave doctor!!!

—Lynette Place, June 11, 2019

I am so thankful for who you are and what you do. I love that I know you pray for the babies you scan and God is with you even in the very hard moments. Thank you for sharing this!

—Kristy Schneider, June 12, 2019

Thank you, friend!

—Lynette Place, June 13, 2019

Hallelujah and praise the Lord!!! What wonderful news. Praying fir the meds to take care of Louie. PTL !!

—Doris Perkins, June 12, 2019

Today I woke up like I have every day since I met Louie....running to my computer to read your posts.

Today I prayed for my little buddy Louie.

Today I thanked god for the opportunity to meet a real hero.

Today I will look forward to the good news that you will post tomorrow.

Today I am happy to hear Louie is with his siblings.

Today I will protect and serve knowing Louie has my back!

Trooper Louie

—Dan Lewis, June 12, 2019

I LOVE THIS SO MUCH! Thank you Dan for sharing!

—Kristy Schneider, June 12, 2019

Today I'm reminded of what real faith looks like, Today I stand amazed at a child battling giants with no fear, Today I worship & praise God for how He speaks to us, Today I am thankful I can lift up "family" that I've never met & know that Our Daddy hears and Cares. Today I am humbled.

—*Valerie Frith, June 12, 2019*

I pray every night for your family. I pray for God to heal louie whatever way he wants, for you to have strength to get through, for louie to keep influencing and inspiring people. God is answering my prayers and those of others. Blessings on you.

—*Paula Vines, June 12, 2019*

Today...I am so grateful for answered prayers.

—*Angelena Van Don, June 12, 2019*

Today I thank God that there are doctors who listen to the patients, the parents (in this case) and the patient's body. Today I thank God for the happy tears I shed as I pray for Louie and his family. I see the blessings Louie passes on as he prays for other people. I see the blessings that you pass on to those of us who read your daily posts. I pray that God showers you all with many blessings today and in the future.

—*Sharon Stewart, June 14, 2019*

I am so sorry that the drs can't seem to find a diagnosis for Louie and you, but the Lord knows he knows it all and I will continue to pray without ceasing for Louie and your beautiful family, Louie is very special but so are you and your beautiful family , your

—*Joy Stuckey, June 15, 2019*

PANIC

June 14, 2019



This morning I got ready for the day while Louie slept. He had slept all night without waking up in pain...which means it was a really good night. He had been asleep for about 13 hours, when I couldn't wait any longer...it was time to get him up and ready for his appointment. As I turned on a soft light and began to roll him over, I saw it. Blood. Lots of it. All in the bed was blood. Immediately I felt it...

Panic.

My heart began to race. I started saying his name trying to wake him up. I scanned his body looking for the source of the blood. All the while, panic was right there under the surface waiting to take hold...panic was causing the fear to be so great it couldn't be contained. And I looked down at the bloody mess and my sleeping son and I paused...for a moment I paused in the panic...

Now as I sit at the end of the day...a very long day...thinking back over the moments of panic this morning, I am contemplating the way panic took such a grip on me so quickly. I think about the fear that was forcing the panic to grow. The more I think, the more I am convinced that panic either paralyzes or propels...

When the feelings are big, when the panic sets in, it can cause a person to be paralyzed and stuck completely in the moment, in the emotions, in the fear or sadness or whatever is the driver of the panic. When that happens, I think panic wins. It wins because it pushes us deeper into ourselves instead of propelling us forward to action. I believe that when we refuse to be paralyzed by panic or other big emotions, then we can be propelled to act. When we act, we find our footing again even if the circumstances don't change. When we act, we can be guided by God to find the source of the panic. When we act, we can see beyond ourselves. When we act, hope is waiting just around the corner...not necessarily to change the moment, but to propel us to the one who can.

Back to this morning...

Panic was big...and I paused. But thankfully I didn't sit paralyzed. I actually uttered outloud, "Lord help me" and the pauses ended...it was replaced by a panic that propelled me to act. I found the source of the blood. Louie's PICC line had broken and thus the bed was filled with a mixture of blood and TPN (his nutrition that runs overnight). He was weak from a combination of dehydration and blood loss, but he was okay.

I was able to get him to the doctor's office and they promptly sent him to the Emergency Room. We spent the entire day there (10+ hours). He went under anesthesia with precautions in place for his heart and they were able to replace the PICC line. He had

difficulty waking up from the anesthesia and spent about 4 hours in the recovery room...

Tonight, he is resting well in his bed with his new and improved PICC line and nutrients running. I am hopeful for a better day tomorrow. In the meantime, I hope panic is an emotions I can forget for a while...but if it must surface, I pray it propels...

Comments

Thank you lord for calming and helping Kristy thru her time of need. Thank you also lord for keeping Louie safe in your arms and keeping him here.

—*Wanda Cook, June 14, 2019*

On my what a way to start a day. I'm glad you had the strength to pull you self out of panic and act. This proves you are stronger than you think. God carries you through. You are in my prayers

—*Paula Vines, June 14, 2019*

I had great panic while reading this my hand over my mouth, my head shaking no no I am so thankful when I read the rest but praying hard for Louie, this is so hard on him and you. Kristy you are in my deepest prayers along with that dear little Deputy Louie.

—*Diane Huggins, June 14, 2019*

Sending love to you and Louie ♥

—*Danielle Teal, June 14, 2019*

I cannot begin to imagine the terror you felt!!! Covering you and Louie in prayers for rest and recuperation!! Thank you Lord for watching over them!!

—*Joey Daniel, June 14, 2019*

Such timely words.

My continued prayers and thoughts over your family ☺☺☺

—*Julie Martindale, June 14, 2019*

Oh so scary!! Praying for you both! So glad he is resting and hope you can too!

—Anna Hederman, June 14, 2019

I cannot even imagine! 🙏praying for you and Louie!

—Sheila Fitts, June 14, 2019

Oh how scary. Praise God he is resting. Prayers for a restful night and better Saturday.

—Carol Frederick, June 14, 2019

I can't imagine what you felt at that moment. Glad you could survive your moments of panic. Glad God could calm your spirit enough to propel you into action. Glad Louie was resting last night. Praying you were able to get some rest, too. Continuing to pray for Team Louie. Hugs

—Linda Davis, June 15, 2019

God Bless You and precious Louie! I know it was a horrible scare and a very long today for you! Praying you both were able to rest and that today will be a much better day for you both! Sending hugs and love! ❤️🙏

—SONIA PEYTON, June 15, 2019

Thinking of you and your family.

—Parthenia (Tena) Taylor, June 16, 2019

Arkansas Bound

June 16, 2019



Tonight is our last sleep in Rochester. My thoughts and emotions are racing. I was a bit apprehensive about coming to an unfamiliar city, especially with Louie's complicated health situation. The obstacles that we had to overcome just to get here were big. But through it all, God made a way.

When we arrived, we were embraced by "Minnesota Nice." We were made to feel at home in our hotel. We were provided for in ways I never imagined and by people we didn't know. The loneliness faded as the unfamiliar environment became a foundation for us. In the process of three weeks, Louie spent time with the mayor, police chief, city officials, FBI, district judge, community leaders...and also with the homeless, laborers, delivery drivers, and any average person who would pause, give a high five, and tell Louie their name. Everyone that talked with Louie left with a smile...

There were very special relationships formed with Jim, Ronda and Mike...and their entire family. They will forever be our second family. The way they have loved us, leaves my eyes wet. They don't give lip service to caring...they give action. They have taught me that there is beauty in living to be an answered prayer to someone else.

Then there is Pasquale who loved and encouraged Louie more than words can ever describe. He invested such time and energy in our family. I never imagined a craving for pizza would end in a changed perspective. Through Pasquale I have learned what generous living is all about...and it isn't money, it is extravagant care for people...for seeing needs and meeting them...for letting them in your heart...

Then there was Pam...who drove 7 hours (3.5 each way) to remind Louie that his Make-A-Wish wasn't a thing of the past...but instead there are wishes and promises to look forward to in the future. There are carousels yet to be ridden.

And we can't forget the staff at our hotel. They have become friends who genuinely care for our family...people who connected with Louie and recognize that the joy in him is special.

As we prepare to leave, we will miss the faces that have become so familiar. We also leave cautiously hopeful that because of the amazing medical expertise at Mayo, Louie will have the opportunity to return to Rochester and continue treatment in the months to come.

For those wanting more medical details...Louie has been started on a heart medication called Digoxin. The hope is it will work to stabilize his heart rhythm and rate allowing his heart to work more efficiently. The result would then be his heart not having to work so hard and his blood pressure and heart rate improving. If this happens, we will then be

able to work on a plan to address some other significant medical needs (which would occur both in Arkansas and some in Rochester). Time will tell. But the good news is we have doctors here that are committed to Louie and working to find a plan that keeps his smile around for as long as God wills it.

So as we leave Rochester tomorrow morning, our prayer is that it is only a "see you later!" We pray that God sustains and works in Louie to heal his body. We pray that he comes back in the near future to again brighten the city of Rochester and thank every person who has encouraged us here. We leave grateful and hopeful...

Photos









Comments

Prayers continue for Louie and for you! Your posts are so encouraging and such a blessing! Louie sounds like such an amazing example of what we all should strive to be.

♥Thank you for sharing your heart!

—*Sheila Fitts, June 16, 2019*

God is working effortlessly to show us what he can do through Louie. He is showing us that if we believe and pray with our whole heart and we truly believe, his will, will be done and miracles can happen. I believe this more than I ever have. Safe travels home. We love you guys.

—*Wanda Cook, June 16, 2019*

No matter where God takes you, my prayers rise!

—*Diane Huggins, June 16, 2019*

How amazing! Thank you again for sharing your experience. May God bless you and continue to walk with you through this incredible story. I do hope you gain strength in knowing the many of us are walking with you.

—*Judy Herrick, June 16, 2019*

Thank you Kristy for this beautiful message today . I pray this seed of hope grows through the will and cultivation of God's hand. Blessed be the name of the Lord. Love to all the Schneider's.

—*Cindy Krueger, June 16, 2019*

Keep spreading the Love Louie!♥

—*Linda Jackson, June 16, 2019*

Safe trip home,treasure memories
and keeping making them. Prayers going up daily. Trying to love like louie☺☺

—*Paula Vines, June 16, 2019*

Love and hugs friend! Praying continually!

—*Heather Holman, June 16, 2019*

Safe travels home. We will continue to keep Louie and your family in our prayers. Hugs from Rochester

—Jill Wilson, June 17, 2019



—Valerie Frith, June 17, 2019

Yeah! I'm so glad you guys are on your way home~ God will sustain, he has already answered so many prayers, opened so many doors and he has big plans for Louie
♥️♥️♥️♥️#louiestrong #lovelikelouie #lovebig #praybig

—Jennifer Tarvin, June 17, 2019

Continuing to pray for Louie and family daily. 🙏🙏🙏🙏

—Dave Mayberry, June 17, 2019

God is so good and faithful. Keep smiling and blessing those around you Louie as we continue to pray for healing and joy and peace in your lives.

—Doris Perkins, June 17, 2019

We are praying for you all!!!

—Melissa Plummer, June 17, 2019

Continued prayers for all of you 🙏

—Cindy Gordy, June 17, 2019

I have been "absent" and just catching up on your news today. So grateful for your Mayo experience and the Mayo family God provided. Prayers over Louie's treatment plan.

—Debbie Hamilton, June 27, 2019

TERMINAL

June 20, 2019

Terminal.

It is defined by Webster as "leading ultimately to death : FATAL...approaching or close to death."

Over the course of the last week I have had two different people, in different scenarios, ask if Louie is "terminal." I have to be honest...when it comes to my son, I struggle with this word. I struggle with the definition. I struggle with the question.

It is not a struggle that the question is asked...in fact, I respect VERY much that someone would ask the hard and uncomfortable questions. The struggle is what is beneath the question...what is in the words left unsaid. The core of the question is really, is Louie about to die? This is where I struggle.

As I process the last 6 months, the word terminal has carried a new meaning...a new fear. December 19th, Louie's heart stopped three times in the PICU at Cincinnati Children's Hospital. It was the scariest time of my life as medical professionals ran into the room as alarms you never want to hear were going off. I didn't sleep for days as I was terrified of what was next.

In January, in the PICU of Arkansas Children's Hospital, his heart rate was stabilized with a pacemaker but his body continued to struggle. Doctors sat us down and began to use terms like comfort care, hospice, and terminal. The hardest part is that there was still no concrete clear diagnosis...all they told us was that his body "can't maintain life" and we needed to "do what is right because living in the PICU is no way to live or die." We were sent home with doctors telling us to expect only "a few hours to a few days" for his life expectancy...

Terminal.

So we connected with hospice and prayed a lot. We had no idea what was coming. We tried to prepare our kids. We tried to prepare ourselves and Louie. But when the definition of terminal includes "FATAL," I am convinced you can never really be prepared. I believe that in the vast majority of situations the grief is still bigger than the relief from suffering. So we poured into Louie and our family and our faith...and waited... The days were very rough but Louie lived.

We rejoiced that he was alive but the definition of terminal was still never far from our mind because behind the moments of smiling, were very big and real medical struggles. He remained very sick and baffling doctors with the way his symptoms were presenting themselves. Each day was a struggle...each day a miracle...

So fast forward to March when finally everything had declined to a point that there was very little quality of life. Louie had great peace about his life ending. He talked nonstop about his faith and desire to see Jesus. Terminal was a word that again came to the

forefront as Louie went back to the hospital for what we believed to be the last time. Louie then went 9 days without fluids or nutrients. He had an occasionally popsicle that drained out his stomach...but otherwise there was no intake. He should have significantly declined. He should have died. He was terminal.

Yet for reasons doctors still can't explain, 9 days of no nutrients, left Louie smiling and loving life. He was more alert, in less pain, vital signs improved and he looked better than he had in months. Doctors couldn't believe it. We couldn't believe it. After 9 days, the doctors asked us if we wanted to try to reintroduce fluids and give his body one last shot as they pursued other opinions from other experts around the nation. They had never seen anything like this. But we trusted God and not medicine...and we knew God was working. We knew he wasn't done with Louie. The definition of terminal was knocking on the door but Louie hadn't opened it. We prayed for wisdom...for a path...for doctors who would step in and fight for him.

We limped along. He spent five weeks in the hospital before we were told Mayo would only see him as an outpatient. Thus, we brought our sweet boy home on hospice again. Still so many questions. So much that can't be explained. So much pain. So many hard days. But alive.

Finally as God opened the door for Mayo, we were thrilled. Would we be able to remove the word terminal from our mindset? Would we get a definitive diagnosis? Would we get doctors willing to hunker down in the trenches with us to fight for his life? Would we find hope?

Three weeks. So many tests. At least 10 doctors.

At the end of it, there is still no definitive diagnosis. At the end of it, there are still so many questions and areas of uncertainty. At the end of it, we have doctors we have placed our faith in as his medical providers. At the end of it, we have some medication and other changes we are hoping will provide better quality of life and of course we pray extend his life. But at the end of it, Louie is still sick...very sick. Louie is still on hospice. Louie is still by definition ("leading ultimately to death : FATAL...approaching or close to death") terminal...

But then the more I process it, the more I believe we all are. We all have the same prognosis. Each of us currently alive, will one day have their heart stop. Each of us will take a last breath. Each of us will tell someone we love them for the last time. Each of us will experience the same fate...death. Terminal.

So when I am asked if Louie is terminal, there are so many thoughts and feelings that it stirs in me. His life is already such a miracle...each day is a miracle. And am I ready for my son to die - absolutely not. Do I think he will live another week, or month, or 6

months - only the Lord knows. Even the doctors are hesitant to provide any definitive prognosis at this point.

So when I am asked if Louie is terminal, ultimately, all I know to do is say, "we all are!" We all should strive to live each moment in a way that honors life and love and the Lord because we are all terminal. We have no guarantees, except that our physical body will die. Maybe the better question should be, because we are terminal, are we living a life of honor so that when our day comes, we are ready to meet Jesus?"

Louie is still fighting to live each and every day...but when the time comes and he closes his eyes on earth for the last time, one thing I am confident of is that the word terminal will carry no meaning...the word eternal will. Louie is ready...are you?

Comments

What a powerful read. I wish I could express my words and thoughts as you do. You manage to bring to light so many things and it always makes me think about life in general. I can't express how thankful to God I am for bringing you and Louie into our world. Louie has shown so many of us what it means to live life one day at a time and how to love effortlessly, and you for your words of wisdom. Thank you again for sharing your family and your words with us. Prayers everyday for you all.

—*Wanda Cook, June 20, 2019*

Kristy, your words and thoughts seem to reflect standing on Holy ground. You have expressed the poetry of life to death in such a thought provoking way. Thank you once again for living in the trenches of life and bringing to us the unseen beauty.

—*Cindy Krueger, June 20, 2019*

Again you capture my heart with your words. Still praying for that sweet boy! And God's Oman. And your family.....

—*Debbie McAnally, June 20, 2019*

Perfectly said. Love to you and Louie and your precious family. May God continue to perform miracles in your lives.

—*Doris Perkins, June 20, 2019*

Blessings. We pray for your every precious moment.

—*Mary Donovan, June 20, 2019*

I remember when I met you and your family, on the Subway level of Mayo, tucked next to the stairs in the atrium. We were all there to listen to the guy playing the piano and stuck around for the singers. Louie, as always, was dressed to the nines and was sporting a huge smile. What a charmer! In between songs you mentioned Louie had already been on hospice twice. Honestly, I couldn't believe it. I can see Louie and I getting into some serious hijinks if we are left to our own devices! I've had some trouble readjusting to life after Mayo, coming back with no diagnosis. That said, I wouldn't trade that experience for the world. For one, I wouldn't have met you and your family. As my doctor here in KC has said, the longer we live, the more medical breakthroughs we'll see. Let me know if there's anything we can do from afar...

—*Tracy Johnson, June 21, 2019*

So very true Tracy! I am so thankful our paths crossed! And so true regarding breakthroughs the longer we are alive....

—*Kristy Schneider, June 25, 2019*

Truth. Powerful truth. ♥

—*Valerie Frith, June 21, 2019*

Still praying for your Louie and your family. I am sure that you have heard the expression "there is something worse than death". When we approach death without Jesus, yes there is "something worse than death" and that is death eternally. BUT, for those of us who belong to Jesus, as Louie does, earthly death only brings eternal life with Jesus forever. No more hospitals, no more doctors, no more suffering, no more, no more.....BUT a life forever living and praising our Lord and Savior, Jesus Christ and free from everything this earthly body suffers. May God sustain Louie and your entire family with the mercy and grace that only He gives.

—*Rosanne Ramer, June 21, 2019*

Beautiful post. You have a gift with words. Praying for you all.

—*Noel Hutcheson, June 21, 2019*

I hear your words from a Mothers heart. My daughter was diagnosed with cancer when she was five. She relapsed twice and was sent home on "terminal". We had all of the same questions and found the same answer that we are all headed for a life beyond this

one.

Hang on to each day, God's plan for our daughter was for many more days, she's 39 now. I pray for Louie to totally live to fulfill what God has planned for him and y'all.

—Carole Craig, June 21, 2019

Your so right Kristy we all are terminal , but are we all ready for eternal life with the Lord, I strive everyday too be the best I can that is pleasing too the Lord, only He knows when our time is up , Louie is such a awesome example of how Jesus uses us , Louie I am positive he is the apple of the Lords Eye , and I believe we all do our very best to be the apple of the Lords Eye, but Louie is not ashamed of his Jesus and he is not afraid of telling people about his Lord and that is the kind of child of God I long to be , don't get me wrong I am not ashamed of my Lord Jesus what so ever, but precious Louie puts it out there and is feeled with a joy while witnessing or telling his testimony and oh my goodness does he have a testimony and he will be rewarded for it. I could go before Louie goes , only He knows when our time is up, so I don't see Louie as terminal at all , I see a little boy that is very sick but Jesus is carrying him in a mighty way , I see a little boy that has my heart in the palm of his hand , oh how blessed you and your family are too have such a precious, sweet child in your beautiful family. He is so easy to love and I just want too hug him so tight and feel Gods glory on me from him , I know you and your husband have been through it taking care of him but I see the Love you have for him and I just know when it's your child you will do anything that's possible too help him , I know I did . Just wanted to tell you this , I read your post and it touched me deeply, Continued prayers for you and your family ☐☐☐☐☐☐

—Joy Stuckey, June 21, 2019

I prayed for you just now!!! In fact I had a long post written for you and a prayer written out for you and which I was just about to say amen and my phone rang... A call I needed to take, so I answered it and of course I lost my entire post to you. But God heard every word and I just hope you can feel him giving you strength and encouragement since I was basically praying the last part of Romans, chapter 8. God is good!!!! ♥♥♥♥♥♥

—Lannece Mayo, June 21, 2019

I'm ready!!! Someday I shall see Louie there!!! Love me some Louie!!!!

—Patti Stroud, June 21, 2019

I learned of Louie at session 3 of Uplift. After reading your post, I am moved by your faith and words encouraging everyone to spend whatever time we have honoring God. I hope to have your strength when needed.

—Shane Ware, June 22, 2019

I prefer to think of terminal as a noun in Louis' case. Such as an airline or train terminal. It's not the end of anything, but a continuation or new beginning to bring us to our final destination. As Christians, of course, that final destination is our journey to Heaven to spend eternity with Jesus, when our work on this earth is done to His satisfaction. My personal opinion is that Louie is a long way from being finished here. God gifted Louie with the ability to reach others with Jesus love that few people have or use. And Louie does that very, very well. There are countless people in this world that need to hear of Jesus unconditional love and plan of salvation. They need to hear it from people like Louie. So far in his young life, I believe Louie has reached more people for Christ than many of the great evangelists of the world. He also meets them where they are and what they do. I am so thankful Jesus chose your family for Louie. We all love that kiddo. Thanks for being there for him. We adopted 3 kids from foster care some years ago. 2 of them were special needs older kids. The oldest, who was 7, was born drug and alcohol affected, We lost him in a tragic bicycle accident later, so I can feel a little of your pain as well. The one thing that kept us going through this was we knew he had Jesus in his heart and his absence would be only temporary. Today at our little country church on the Oregon coast, I showed our congregation the gallery on this site and read a couple of your beautiful posts. There were lots of wet eyes, mine included. Our pastor then prayed for Louie, his family, medical staff, and all his friends from all over. Expect good things to happen very soon. Remember.....PBPGINFWMY.....Please Be Patient God Is Not Finished With Me Yet.

—dan albertsen, June 23, 2019

Wrestling

June 26, 2019

Let me preface this journal entry by saying that it is probably more for me than anyone else...in fact, most of the entries are really just my processings to make sense of this challenging road. This one in particular though, is less about a medical update on Louie and more about my heart. It is raw and real... It is not me wanting or needing any response... It is simply what I am learning and I believe is making me a better person... I hope as people we can be vulnerable, not for selfish-gain, but simply to see each other, encourage each other, and make each other better people.

Mayo was eye opening for me in many ways. I saw a medical system that is far superior to any I have encountered before. I saw doctors listen intently and never give up until a plan was formed. I saw a community of strangers embrace my son. I saw more clearly the impact a single smile or act of kindness can have on a person. And most of all, I saw Jesus. I saw Jesus comfort my broken heart over reflections of what this lengthy crisis has meant to some dear friendships...I saw Jesus bring glimmers of hope into view when evaluating Louie's health...I saw Jesus use Louie to lift the spirits of others even on the days he didn't feel well... To sum it up, I found that with the distance separating me from the familiar, I saw many things more clearly.

But that also meant I felt things more deeply. I felt deep grief over friendships changed...I felt great sadness over the way life is no longer in the realm of "normal". I felt immense fear over the unknown path forward. I felt hugely inadequate to care for all the needs of my family just due to geography alone. But on the otherhand, I felt significant relief that God made a way for the rest of the family to visit. I felt supported and loved by those who stepped in to encourage us - sometimes with a simple comment or message - and some by blessing us with meals or aiding with our hotel costs. Overall, I felt great insight into who I am, who Louie is, who my "people" are, and who God is.

We have now been home about 10 days. And truthfully, they have been mostly hard days...not always because of Louie's acute health struggles, but because we are trying to piece together life in the midst of a short term crisis that has become a long term one.

I am learning that in long term crisis situations, there are new challenges. They are lonely and isolating places. There is weariness in the needfulness. There are griefs you didn't know you would need to grieve. And you realize that grief isn't just about death. Grief is present when you sit with any loss in life...which can come with a friendship, a job, a pet, a diagnosis, an accident...the list is endless...and sometimes the grief can be too.

I also have seen that a long term crisis can cause confusion between people and presence. There is an assumption that often hides in the shadows. The assumption is that if a person seems to have people in their life, then they have the emotional support and care they need...that their personal needs are met. But having people doesn't necessarily equate to presence. Presence is about authenticity...Presence is about getting into the trenches to hold the arms up of someone who is weary and too weak to ask...Presence is a quiet proding saying I am here, even when there isn't the energy for response...Presence is wrestling with and for another person...Presence is a rare and beautiful gift that is often brought about by one's own victory over silent sufferings. In other words, when you walk a crisis you learn how to love in one. You learn the value of presence.

I was talking with a friend this week and we discussed wrestling with God. As we used

that term, I found my mind contemplating two types of wrestling I see practically. One is the sport of wrestling which is about competition, domination, and victory. Then there is the wrestling that I saw recently with my kids (and husband) at the swimming pool. They were laughing and splashing and pushing and giggling and simply wrestling with each other. This second type of wrestling is what I hope we talk about when we say we are wrestling with God. This type of wrestling means there is a closeness in proximity and a mutual enjoyment. This type of wrestling leaves you wanting more because it is rooted in presence. In this type of wrestling the goal isn't winning but the goal is a deepening connection.

I may not understand why God has laid the path as he has for Louie and our family. I admit there are days of intense wrestling with God. A lot has happened in the last 10 days alone that have complicated our lives so much and stirred such emotion... But in the end, I know that even after agonizing days like today - a day that carried lots of tears and fears - proximity with God is where I want to be - even if it looks like wrestling.

Comments

Thank you for being so transparent. You are a channel of God's grace to fellow pilgrims. We continue to pray for Louie, you, and your wonderful family.

—*Jimmy Carter, June 26, 2019*

Thank you for writing so boldly about the journey u are going thro with sweet Louie and your family. God has given u a true gift and I thank you for sharing it with so many. I for one am learning so much about God thro you and Louie. Prayers going out for u sweet sister in Christ!!!!

—*Judy Coates, June 27, 2019*

Nothing is as powerful as Truth ♥

—*Valerie Frith, June 27, 2019*

What an AMAZING testimony. Thank you for your kindness in sharing it, I am still taking tiny steps in the path God has laid out for my life, It carries a lot of the same emotions you are experiencing and they are difficult. Praying for you and your family daily.

—*Myra Ferrell, June 27, 2019*

Thank you for this post. The 'changed friendships' jumped out at me. Asking God to be

God over those friendships....to move and illuminate and heal.

Praying for solutions. For emotional rest. For help.

—*Debbie Hamilton, June 27, 2019*

Continuing to pray for Louie, you, your family and the medical team caring for all of you.
Hugs

—*Linda Davis, June 27, 2019*

My health condition isn't anything like Louie's, but I understand the post-Mayo blues. Returning to regular life is a very, very tough transition. You have friends in KC, should you ever need a shoulder or an ear. I've been thinking my goofy dog should start a pen pal correspondence with your kids...she's a pretty good writer, for a dog.

—*Tracy Johnson, June 27, 2019*

YES!!! Your dog absolutely should write my kids. They would love it!

—*Kristy Schneider, June 29, 2019*

Continued prayers for all ☐☐

—*Cindy Gordy, June 27, 2019*

I'm thankful for you, that God has given you the ability to put so much into words for others to understand! Through your words, someone may see a situation near them in a new way, and reach out to help the one who needs help so much, but can't even ask for it.

Many people are touched by a tragic or unique situation and jump in to help, then when it becomes chronic, they fade away. But God never leaves us, or we couldn't keep taking another step! Thank you for expressing our ♥.

—*Deann Wagner, June 27, 2019*

I wished lived closer to you. I would be sitting beside you in a heartbeat. I would be learning to Louie's care to give you a break! You are both amazing people! ♥

—*Callie Neves, June 27, 2019*

As I read and re-read every journal entry since February 14; I pray, I grieve, I laugh, I 'listen', and I am encouraged and challenged. I see and hear God through the eyes of

Louie and the gift of words through your journal. Louie's sweet and honest love for all people and above all for Jesus and his questions "What are you doing? " and "What are you doing tomorrow?" are food for thought. And in every entry I 'see' how Big, Personal, Relational, Miraculous, Tender, and Suffucient our God is through the stories of this journey that call me to 'live' in the moments of each day with being present, authentic, sensitive to the unspoken needs of others, prayerful and with an honest heart with God and others.

Your steadfast faith, though disappointments, victories, and dark nights are a testimony of choosing to hold fast to the One who holds you!! Every journal has many nuggets of Truth. Most recent I want to apply is "Proximty to God is where I want to be, even if it looks like wrestling".

Lifting you to God tonight to touch your raw and weary heart with fresh hope and encouragement.

—*Trisha Norton, June 28, 2019*

This is amazing. And you are amazing. Your words have immensely spoken to me with every entry. Praying HARD for your family today!

—*Debbie McAnally, June 29, 2019*

Beautifully said , and I know how you feel, I wish I had a way with words like you do , you are an amazing woman Kristy and I don't believe anyone would disagree with me on that , your journals give me so much strength and they help me to understand why we are given battles to see our strength and hold on to our faith, your words come from a place deep inside you as a mother and I applaud you for that , Thank you for your encouraging words , Love you always ☺☺☺☺☺

—*Joy Stuckey, June 29, 2019*

You are always, every day in my thoughts and prayers!

—*Diane Huggins, July 2, 2019*

July 3rd and Rocks

July 3, 2019

Six years can feel like an eternity. Or six years can pass in a flash. Today, as I contemplate July 3, 2013, it feels...well...unrecognizable.

Six years ago today I woke up and got ready like any other day. Six years ago today Erik kissed me as he left for work like he always does. Six years ago today I sat at my dining room table wondering if I was ready for what the day would bring. Six years ago today I picked up a dear friend and drove to Pine Bluff. Six years ago today I loaded a few tattered black trash bags into my truck...but that wasn't all I loaded... Six years ago today I loaded two little boys ages 4 and 5 into my truck and I drove them home.

Home...

In the few short years of their lives, Peter and Louie had lived in many houses, but on July 3, 2013 they were home. After the devastating instability and neglect they had experienced at the hands of those who were supposed to protect them, trust had to be earned. It took intentional work to show my boys - to prove to them - that a home is more than an address. A home is a place where your presence matters and where there is security that breeds confidence. A home is a place of love, forgiveness, and hope.

But a home is also the place where we are vulnerable enough to be ourselves...which if we are brave enough to admit it, can be ugly. Home is where the guards are down...the make-up is off...and the energy to hold it all together isn't always present. Home is where we are comfortable, even in the discomfort of our own skin.

I remember soon after the boys were home, there was a day when Louie fussed and cried on and off ALL DAY. At this point in his life, Louie had very few words and couldn't communicate his needs well. I remember checking his temperature...calling my mom for advice...trying to get him to eat more thinking he was hungry...all to no avail. I did everything I could think of but the cranky continued...and by cranky I mean screaming, crying, flopping on the floor refusing to get up. By bath time, I was so done. The kind of done as a parent, where you tune it all out, have nothing left to give, and bedtime can't come quick enough because you don't know if you can manage one more fit...one more meltdown...one more moment of screaming...one more.....rock????

There it was. A tiny pebble. It rolled out on the floor from Louie's shoe as I was getting him undressed for the bath. The rock couldn't have been more than a quarter of an inch big. Oh but the power it had!! As I picked it up I looked at Louie. Through the tears a smile erupted. A calm overtook him and the screaming stopped. I stood kneeling in front of him and holding this tiny rock in my hand...and Louie slowly got up from the ground and hugged me. The kind of hug that communicated far more than words could.

Then I cried. My son was uncomfortable and hurting all day. Yet here I was upset and frustrated for him being so uncooperative, when he simply needed help. He needed me but couldn't articulate it.

As I think about the imprint of that moment, I realize that as adults we often have a rock in our shoe. We have something that is rubbing us the wrong way...something small that is stealing our joy and stressing our relationships. We may not know how to articulate it but the feelings are real and big. We long for someone to have the kindness to take off our shoe...someone to see the hurt or anger or disappointment or fear or betrayal that we feel every step. Healing is only possible when the shoe comes off and the rock is exposed.

So here I sit next to Louie six years later in our home. This time I am not taking off his shoe, I am holding a bag for him to throw up in. It is a day where he feels poorly. But as I look into his eyes, I pause with the deep realization that the rock is in my shoe tonight. I have allowed the hard and the hurts of the past few months to build and justify the selfishness in my own heart. I have spoken harshly. I have judged unfairly. I have hidden behind written words to keep from being vulnerable with my own inadequacies face-to-face. I have sacrificed moments because I didn't have the strength or insight to take off my own shoe. Those closest to me, those in my own home, I am confident saw the rumblings of the "fit"...heard the "screaming"...wondered when "bedtime" would come.

It is no fun to be around someone living with a rock in their shoe.

But tonight as I administer medication and pray for my sweet boy to feel better, I notice him watching me. As his green eyes hold my gaze for a moment where neither of us have words...that is when I am fully aware that metaphorically, Louie is taking off my shoe. We may have given the boys a home, but they have given us hope and the bravery to admit our own failings. These six years may not have looked like a picture perfect story to anyone on the outside and definitely not on the inside, but in our home we have found the ability to embrace grace as we reach out to remove each other's shoes...to expose the rock - the tiny but powerful things that has caused such distress...and to believe it can be better. For me, this process reveals the hope that even though the storm hasn't cleared - and it may not - that I don't have to be controlled by the rock in my shoe any longer. I can dare to stand without it.

Comments

Wow your words are so powerful!!! What a good lesson it has taught me. I am thankful God chose you and Eric to be the parents of Peter and Louie!! You have given them a

loving and caring home and life. You have taught them how to love like Jesus nothing can be more important than that. Thank you for always sharing these thoughts with us. I'm still praying for Louie's healing and praying his new heart medicine has made a difference. And I continue to pray that the Doctors at Mayo and Children's Hospital keep Louie on their minds to miraculously come up with answers and solutions to Louie's disease. God bless you tonight and always as you continue this fight for Louie's life.

—*Judy Coates, July 3, 2019*

This is amazing!! Thank you for sharing! Hope Louie feels better! Still praying for you all!

—*Leslie Nanny, July 4, 2019*

Thank you for giving of yourself. I never imagined when you agreed to take in the boys what your world would become. You have been an inspiration

—*Kelly Braton, July 4, 2019*

No words, only tears... rock in my shoes as well. Thank you

—*Valerie Frith, July 4, 2019*



—*Linda Jackson, July 4, 2019*

Praying for all the rock bearing moments you and your sweet family endure. You've been told, I'm sure a thousand times, your family is inspiring. You opened your hearts and home to two children who would not have been given these years without you. Those of us who admire all you're doing, are united in prayers for strength to endure and peace in knowing you're only human.

—*Emily Davis, July 4, 2019*

Beautifully written!! In the midst of all you are going through, you are still encouraging and inspiring others. Thank you! Prayers for you all.

—*Anna Hederman, July 4, 2019*

I so enjoy your 'open letters' which you share so boldly with us. They encourage me to be a better person, to be thankful for life, and to pray more for others. What a lovely gift!

—*Polly Gan, July 4, 2019*

Such beautiful words Kristy ,I am so sorry Louie is not feeling well and I am lifting y'all up in prayer everyday and I wanted to tell y'all Happy 4th of July from Wayne and I, tell Louie he still has my heart, Kristy you should write a book and if you do I will definitely buy a copy, God Bless You ☺☺☺☺☺☺☺♥♥

—Joy Stuckey, July 4, 2019

Continuing to keep Team Louie in my prayers. Praying that Louie feels better. Wonderful words of inspiration, Kristy.

—Linda Davis, July 4, 2019

I pray that you will be able to keep the rocks from your shoe.

—Cindy Gordy, July 7, 2019

It's Not Fair

July 9, 2019

A year ago my son was literally skipping his way through a special needs summer camp program. Louie was an active, walking, talking, playful 9-year-old. He loved to eat chicken burgers (which took us months to realize actually meant hamburgers). He needed supplemental formula to get enough calories for life, but he was present at every meal. His seizures were fairly well controlled. Louie was the epitome of life...even with some medical challenges.

A year ago my son wasn't bound to a wheelchair as his primary means of mobility. He wasn't requiring IV medication and TPN nutrition. Louie wasn't asleep more than awake. He wasn't on oxygen support at all. He wasn't needing 4 medical supply companies, two pharmacies, 6 therapists, and a list of doctors that is well over 20 strong.

A year ago looked so different. A year ago routine was possible. A year ago we planned our week and knew every part of it was feasible without hesitation. A year ago Louie's body was showing signs of struggle but not in a manner that impacted every aspect of his life...our lives...our family.

It's not fair.

It is a three word statement that carries strong sentiments and I have heard countless times over the past 7 months. It's not fair that children are sick. It's not fair that every day people suffer and die. It's not fair that Louie's heart and body act in ways far outside the norm causing his quality of life to be vastly different from others his age. It's not fair that we have had to travel multiple states to get answers and a plan for Louie. It's not fair that routine is impossible and each day carries fear. It's not fair that Louie's life teeters somewhere on the continuum between life and death...and while we are thankful for life, death is a reality that we never anticipated for our child. It's just not fair.

It's not fair that my children have been to a hospital more than a shopping mall or playground this year. It's not fair that my three-year-old prays every night for her brother to "be all better"....while my five-year-old prays for Louie to "walk with me again without a wheelchair"...while my eleven-year-old has had to come to terms with how fragile life is while his friends are playing video games. It's not fair.

Or is it?

Fair. According to the Mirriam-Webster Dictionary, means marked by impartiality; implies a proper balance of conflicting interests...just...equitable...conforming with the established rules.

So when we say that _____ isn't fair... Are we saying that hardship, whatever it is from, is causing things to be out of balance? Are we saying that there is partiality...that some are punished or suffering when others aren't? Are we saying the rules have been violated? But what are the rules? What are we striving after in life? Who determines fairness?

As I have sat and wrestled with the statement, it's not fair, I have found my thoughts drifting to Jesus. We cannot have a Savior without the saving. The saving came with suffering and pain and tears and heartache. To find the Savior, we have to acknowledge the saving of the cross...a brutal and awful way to kill a man...to kill Jesus.

It's not fair. It's not fair that Jesus, a man without sin, had to die...and in such a horrific way. Yet you and I, who are filled with sin, are offered grace. Is it fair?

You see we don't talk about fairness when we are blessed. We don't talk about fairness when we receive mercy, forgiveness, grace...total unmerited favor. I believe we talk about fair when what we mean is easy. We want fairness when it means no sickness or suffering. We long for life to be fair when we think we have a better plan. We want fairness when the days are hard and we cry out for relief...for hope...for healing.

But praise be to God that in those moments, we don't have a God offering fairness. He is not waiting to condemn us or steal a loved one or mock our pain. He is a God who rolled

away the stone and revealed a plan far greater than the pain of the cross. He is a God who offers grace upon grace without end. He is a God who can heal in ways that surpass anything this earth can comprehend. He is a God who loves without needing it reciprocated.

Life on earth was never meant to be fair...it can't be... So to say "it's not fair" will always be true this side of Heaven. But what will also, always, and unequivocally be true, is that God is unfairly loving us each and every day...filling life with grace that is greater than all our sin...never looking away...never leaving a promise unanswered... He is greater. He is good. He sees for us beyond the temporal pain and junk of this world to an eternal hope.

So maybe instead of hovering in a mindset of "it's not fair," we should focus on presence...presence with God and presence with those suffering. Trite reminders bring little comfort, but presence can change perspective. Instead of saying, "it's not fair" let's choose to say, "I am here."

Comments

I ran across an article a few weeks ago written by a man dying of cancer, and it's sentiments were nearly identical. Praise God we don't get what is fair. Rather the grace and hope of eternal life bought for us is offered so freely. How wonderful! Thanks for that reminder again tonight in the struggles and weaknesses of this earthly life.

—Sara Brouwer, July 9, 2019

Words well written and I am guilty of saying that more than I can remember since my husband got hurt on his job at the young age of 38 because a supervisor wouldn't listened to him about the problem and my husband paid the price and the first words out of my mouth was it's just not fair the supervisor should have listened, but that has been almost 20 yrs ago and we had to find a new normal, in fact we've had to find a new normal 2 times in our life , but when I read your journal it resonated with me on a special level, but like you we turned to Jesus and he is our saving grace, I am so thankful for God's grace because without it I don't know where we would be especially after we lost Kamisha in Iraq . God is so good and he is always here for us and our ugly sin . I am so thankful for Jesus because I know what He has brought us through just like He is with Louie and your precious family. He will never leave us or forsake us no matter what, and I sometimes wonder what have I done to deserve that kind of Love and Grace and then I hit my knees and He shows me why, we are His children and we were made in His image so like any father He loves us unconditionally. I appreciate your journal Kristy and the saying it's just not fair is something I believe everyone has said from time to time.

Wayne and I are continuing praying for Louie and you as well as your beautiful family, life never turns out the way we plan because God has the plan for our lives first . You are the strongest woman I have ever seen , God gave you your life with them precious babies because He knew you was strong enough for it . He will never put more on us than what we can bear . He might let us bend some but He will never let us break , Love too Louie and you and your family ☺☺☺☺☺

—Joy Stuckey, July 9, 2019

Thank you for sharing your words and pieces of your journey. It is an encouragement to me.

—Kristy Schneider, July 9, 2019



—Linda Jackson, July 9, 2019

I am 62 years old and wish that I had half of the knowledge that you have. It seems that every time you write a new post it hits so close to home for me. I have learned so much from your posts. I am a Christian but I wished I was only half the Christian that you are!!! I pray for Louie and for your family and that you could get the answers for Louie's health.

—Laurie Young-Staver, July 9, 2019

Wow! Thank you for putting this in perspective!

—Leslie Nanny, July 9, 2019

Absolutely beautiful. Thank you so much.

—Jennifer Nunley, July 9, 2019



—Valerie Frith, July 10, 2019

Beautifully written, Kristy. Perhaps you should consider taking all your Caring Bridge letters and have them published as daily devotions especially for caretakers of loved ones. I believe the word “GRACE “ is the strongest and most meaningful word in the Bible and in life. I “found” that word and dissected it several years ago when I had my own spiritual mountain to climb. The word “unmerited” love and forgiveness changed my life and put everything in order for me. I pray for all of you every day. My love to your

sweet family.

—Cindy Krueger, July 10, 2019

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—Cindy Krueger, July 10, 2019

You Just Have to Laugh...

July 11, 2019

Today. Goodness. Where to even begin... It was a day packed with appointments, and very little wiggle room for life. But life happens anyway...regardless of the schedule. So I thought I would take a moment to decompress this evening and share with you the wildest day of failings and funnies that we have experienced in quite a while.

For perspective, you must know that the day started at 1am...and 4am...and 7am...and every 3 hours thereafter with holding down a screaming and kicking three-year-old to administer pain medication for her tonsillectomy. As I am holding her down to give meds, she is often screaming, “I miss my tonsils! I want my tonsils back!” This super awesome adventure at three hour intervals forms the framework for the day.

Today we had multiple appointments that were challenging, but got accomplished. There was swim lessons, occupational therapy for two kids, and speech therapy all before 12:30pm. I was feeling pretty good in spite of the packed schedule. Then the real fun began...

Louie had an appointment with his PCP. So I wrangled the tonsil missing three-year-old to give her the 1pm dose of meds and then snuck out the door for the appointment. On the way, I got to thinking about how many hours I have actually slept since the tonsils were removed. Due to the intense calculating this required, my multi-tasking skills failed....resulting in watching the clinic pass right on by...yep, I missed the exit for the

doctor's office.

So now I am having to detour to get to the appointment knowing I will be a little late...which for me is awful...I HATE to be late. So I call and confess my failure to exit to the very kind receptionist and get there as quick as I can manage. The appointment is fairly uneventful.

As I am loading Louie back into the van afterwards, which is not as easy as it sounds, I pick him up out of his wheelchair and place his feet on the step of the van. At that point his eyes got real big and he says "uh oh." At the exact same moment I see it...his GJ drain tubes are caught on the wheelchair. As I immediately make a grab for them while trying to steady Louie, it was like a slow motion train wreck as his entire GJ tube comes sliding out of his stomach and falls to the ground under the van.

My heart sinks... Louie looks at me and says, "I no do that!" I sighed deeply and tell him it is not his fault, it is mine.

As I load the wheelchair, I begin making phone calls. I am so frustrated with myself because I just didn't have time for a trip to the hospital. I call our friends at Interventional Radiology and they instruct me to drive straight to the hospital...so off we go. But on the way I am frantically making arrangements for my other kids. I am making sure the friend staying with the girls can stay longer. I am calling to get a ride home for Peter from his summer program...and I am trying to get a hold of my husband. Oh the logistics brought on by an unfortunate encounter between the ground and a feeding tube... Lord help me...

Then somehow...for some reason...only because of God's great grace, I glance down as I am driving. AND PANIC ENSUED... The display, ever so kindly reveals, 5 miles to empty.... I am blazing down I-30 to the hospital with my son and his barf bag in the backseat and before I can even form a plan it is 4 miles to empty. I am in a part of town I never stop...and you never want to stop. I don't have a clue where to go. All the while my son is in the backseat saying, "mom I angry at you...you rip my tube out!"

Let's just go ahead and say mother of the year is definitely off the table at this point, as I am planning the speech I will provide to the kind people I hope will stop to help me...in hopes that I can convince them that they don't need to call DHS or the mental health team when I am stranded without gas on the side of the highway with my disabled son who would be telling everyone that I just "ripped out" his tube and we need to go the hospital. Then I realized as I am sweating out the last few miles to the gas station, that the only thing I can really do at this point is laugh.

Laugh because, well, what else can I do. Oh and did I mention that through all this I am like dehydrated thirsty...the kind of thirsty that is overwhelming and you smack your lips

and feel like you are in a desert. I am looking everywhere in my van for my water bottle...I always have a water bottle...but instead in its place...in the cup holder...is bug spray. Yep bug spray. Not helpful in this moment at all...

Then just when I think we will be on the evening news, I see the gas station. I sit at red lights not able to get there fast enough. I envision pushing my van the last little way there. But by the favor of the Lord, I pull up to the pump with ZERO to empty now on the display.

Relief... But considering how I picked the slowest gas pump in the city, in an "interesting" neighborhood where there are more people on foot than in cars at the gas station, and I am needing to get to the hospital before the IR team leaves for the day, half a tank will have to do. So I book it the rest of the way to the hospital.

And once there, sure enough, Louie, in quite the animated fashion, proceeds to notify everyone that will talk to him that "mom ripped out my tube" and he does it with sound effects and all. Super awesome, mom fail, kind of day. And then my husband finally returns my calls and says, "Hi honey, how is your day?" And I just had to laugh...

But don't we all have those days. Days when we just need to get in bed and start again. Days where it's laugh or cry...or even laugh AND cry! Days where nothing goes quite right. Days where the struggle is mostly caused by you and decisions you have made. Today I was there. Today I failed more than I succeeded. Today I wanted another chance at the day...a chance to snuggle the fussy three-year-old a little bit more (and bribe more effectively to get her to take her meds)...a chance to read with the five-year-old...a chance to sit and listen to the eleven-year-old until there were no more words...a chance to do it right with Louie - not just with his tube but with greater patience in the hard moments and more efficiency in the good ones...a chance to not count the hours of sleep I lack, but instead count the moments of joy around me.

It is all about perspective. So I end the day laughing at myself...laughing as I psych myself up to give meds to the very sad tonsil missing three-year old and laughing at the ridiculous moments of today...but beneath the laughter there is deep gratitude. I am grateful that laughter brings perspective for me as I choose to not take myself so seriously. I am grateful for the reminder that we all muck it up sometimes. But most of all, I am grateful for a chance to look forward to tomorrow - believing it will be better...

Comments

Here's to more laughter, even through tears! None of us can do everything perfectly so we might as well strive to see the humor in a bad situation when we can.

—Cindy Gordy, July 11, 2019

You are mother of the year! Through the tough times is when God shows us the laughter because He knows it gets us through to the next day! You are always in my prayers! God bless you!

—Diane Huggins, July 11, 2019

Oh I love how real this is! Thanks for sharing!

—Debbie McAnally, July 11, 2019

Yup, we all have these days! How great that you can indeed gain from them. You are a super mom. Good bless you through all these, uh, tests of fortitude.

—Judy Herrick, July 12, 2019

Oh Mercy!!! What a day! Made me tired just reading this! Praying for a calmer less taxing day today! What a beautiful attitude tho! God bless you all

—Valerie Frith, July 12, 2019

Bless your heart!☺☺ What a day. You are an awesome mom! Thank you for sharing this. You are always so encouraging. Louie and your family are always in our thoughts and prayers. Today is going to be a great day! ☺☺☺☺☺

—Dena George, July 12, 2019

Wow. I am tired just from reading about your day. God be with you as you face another challenging day. And another and another...

Life is full of challenges and you meet them head on all the time. I can't help but think back to the time before you had the boys and the girls and think even the hard days are good days because you love your kids so well. Just like God loves us all. We do the best we can and laugh at our missteps.

What a wonderful day you had with all your children.

Maurie

—Maurie Keys, July 12, 2019

Bless your heart! They say laughter is the best medicine, I am glad you laughed. You are a great Mom, and I am not sure, no I know I couldn't do what you do. I hope your weekend is filled with more laughter, minus the mishaps.

—*Ellen Davis, July 12, 2019*

Thank you for sharing your chaos. Keep up the good work and keep finding humor in the chaos. As you well know laughter brings healing. Prayers for you and your family.

—*Doris Perkins, July 12, 2019*

Wow can relate in so many ways. Tears of I am there are in my eyes now. Keep sharing still praying

—*Robert Veldkamp, July 12, 2019*

Just so you don't have to stress as much next time. Most vehicles have about 2 gallons of gas left when the miles hit 0. Compare a fill up at almost 0, to what your manual says the gas tank is. On most cars, that means you have at least 50 more miles before it is truly empty. The reason is, that the gauge in the tank is a floating ball, which the bottom half of hits the bottom of the tank still surrounded by gas. I, myself, try not to push it past using 1 of those gallons, but that should, at least, get you to the hospital.

—*Sean Orme, July 13, 2019*

Hi Kristy,

You don't know me from Adam. I only know of your family through my Sunday School teacher whose daughter who lives in Arkansas heard of Louie and started sharing your posts.

I read each of your posts hanging on to every word, meditating and praying for Louie and you as God speaks his truth into your life and you pen what's been revealed to you. I find myself sharing with friends and family many of your posts. I was especially gripped by "If Words Could Heal" and why we pray for others and the comfort of letting them know you are in the fight with them.

I said all that to say this. There are people you don't and will most likely never meet this side of heaven that is in the fight with you lifting up your son and family to the one who has the power to heal. In your valley through your words know the character and truth of our God is being shared and lives are being impacted. Prayers for healing...Prayers for Understanding...Prayers for Strength..Prayers for Joy and Laughter

—*Mark Giglia, July 13, 2019*

Your writings are such a blessing to my soul! I love reading the transparency of your life. Thank you for being real - and sharing it!

—Paula Bush, July 14, 2019

"You Happy?"

July 15, 2019

Today was complicated. My youngest little one is in the hospital so I have spent the last few nights here with her. The logistics to manage Louie's medical needs and be in the hospital with her is exhausting...at times frustrating...and in honesty, borderline overwhelming.

Today required a lot of detail work to ensure that all the needs of my children were met and appointments attended. At one point today, I had to take Louie to an appointment with a doctor we have waited months to see. I didn't want to leave my daughter but I knew this was an appointment that required my presence. So it was one of those moments where your heart longs so badly to be in two places...so you struggle to be completely present in one.

At this appointment, a resident is the one who comes in to ask the initial questions and gather medical history. It often irritates me because I end up having to go over it all again with the doctor because to say Louie's medical history is complex is an understatement. It takes over an hour to answer his questions and provide a basic overview of Louie's health and medical issues. The resident then leaves the room to "go update the doctor" and assures me the doctor will be in shortly.

I sit there and think... I think of my little girl and how I wish I could be with her. I review in my mind and in my calendar all the things I need to get done. I contemplate how much time away from home I have spent this year in hospitals and clinics. Then I look down and my watch is kind enough to remind me of how little sleep I have had.

Just then I look up at Louie who I didn't realize was watching me...studying me. If you have spent time with Louie you know there are a handful of questions and phrases he says repeatedly. He asks things like "What you doing today?" and "What that?" when pointing to something someone is wearing that is unknown to him. He will read your emotions and respond to them with amazing precision. He will be the first to notice and ask, "bad day?" or "you okay?"

Today in that moment, Louie caught my eye as I looked up at him. With great purpose, he locked eyes with me, and very intently he asked me something I don't recall him ever asking me or anyone else before. He simply said, "you happy?"

I couldn't find words to say.

Tired. Scared. Hopeful. Disappointed. Regretful. Worried. Peaceful. Relief. So many emotions flooded my heart but happy wasn't one of them.

I didn't respond initially. I just looked at him. As I tried to process how to respond, he asked again, "mommy you happy?"

I still couldn't find words.

Yet in actuality, there were plenty of words if my husband or a friend had asked the question...plenty of words because then I could unleash all the ramblings going on in my head. I could express the exhaustion and the things I wish were different. I could explain my shortcomings and how I want to be better. I could celebrate the small victories and grieve the hard places. I could pour out the fears and embrace the joys.

If a peer were to ask you if you are happy, there would be a natural pause to determine if the moment and relationship allows for authentic response...if it does, then you release...in doing so, you can find connection...you can recharge by being real and deepen in trust. But this moment was different...it caught me by surprise. It wasn't a peer asking me, it was a child...my child.

As I kept my eyes on my son, I realized that buried in the simplicity of his words, was the true question, "are you happy **with me**?" What my sweet boy wanted to know is how I felt about him. In all the stress I carry, I can be slow to affirm and lost in my thoughts and busyness. What he needed from me in that moment was to know I was pleased and happy with him.

Thankfully I realized this and I responded with, "baby you are my son. You make me happy. You bring me joy. I love you." His face lit up and you could see the relief.

After the appointment, I returned to my daughter's side and things calmed a bit. I thought about the exchange between Louie and I in the doctor's office. The more I thought, the more I hurt that my son had to ask...that there was a part of him doubting how I felt towards him. He was seeking encouragement and acknowledgement from me because even though my presence with him is strong, my words don't always reflect my love for him. My silence spoke what I never intended...

Then I thought about how many times the same thing happens in marriage and friendships. We get so wrapped up in the daily grind of life that we don't spend time speaking love and kindness. We forget the importance of speaking words to affirm and build up another person...words to remind someone of their place of importance in our life. We act as if saying something kind once is enough...but it isn't. We are simply humans who fail often in this walk of life...and we need each other to pull us up, to encourage us, and to point us to Jesus. We need to be reminded that we are loved...cherished...cared for...adored...valued...affirmed...and not alone.

I am thankful for Louie reminding me to be more intentional with my words. I am thankful that I had the opportunity to speak love into him. I am thankful that tonight I made a list of 3 people close to me that I want to intentionally encourage. In doing so, I am actually amazed at the joy and happiness it brings me just to think of speaking goodness and love over someone else.

Who do you need to encourage today? What person in your life is looking to you and asking with their eyes, "are you happy with me?" Will you answer them?

Comments

God Bless you all, I can't imagine being to town between your children, I see one very strong woman here who yes is tried , worried, stressed, nervous, but still is able to carry through no matter how tough it gets. You are a total inspiration to your family, to your friends and to those of us who have never met you in person, but care deeply about your entire family. We are all a part of the family of God ! I pray for all of you daily, nightly...Love one another thus says the Savior and I do love all of you!

—*Diane Huggins, July 15, 2019*

My goodness - I needed this! I'm so guilty of the same! Thank you for sharing so deep!

—*Debbie McAnally, July 15, 2019*

Wow. This really hit home. Thank you. You and Louie are both such inspirations. Your raw honesty and his unwavering love for everyone, it never ceases to bring tears to my eyes.

You and your family are always in our prayers. God bless you all.

—*Dawn Lawson, July 15, 2019*

Wow! Thank you for sharing this! ♥

—Dena George, July 15, 2019

Your words have spoken so much to my heart this evening! Praying for you all!

—Julie Tolman, July 15, 2019

Thank you for sharing this I failed at this tonight. My son sat with me tonight, I kept working. He talked with me and I answered him. Several times I had to ask him what he said again, because I could tell I didn't answer how I should have, several of my answers were "yahs" he said "never mind". Mom fail. Every day is a gift, I need to be in the moment. Thank you for always being honest, for sharing Louie, his honesty and all the love you all have for Jesus! Praying for you family!

—Dawn Reed, July 15, 2019

Prayers of comfort and healing. You are a warrior, mama.

—Jill Wilson, July 15, 2019

Louie.....he, and you sure pull a soul down deep, where the pressure is on and that what's important takes on clarity. When I resurface, I am going to let some people know I'm happy with them.
Also, I'm sending up just a little prayer of thanks for that brief, calm moment you had! ♥

—Lannece Mayo, July 16, 2019

In my opinion Louie will live because there is no one with his perspective of people and God needs his insight to make people see things properly.

—Paula Vines, July 16, 2019

As usual, your words are food for thought. Thank you. Please try to schedule in some time for yourself to sleep or at least rest.

—Cindy Gordy, July 16, 2019

I love this. You both amaze me. I'm so sorry your daughter is in the hospital and I hope she gets to return home soon.

—Jennifer Nunley, July 16, 2019

Oh how I needed this!

—Debbie Hamilton, July 22, 2019

Family Time

July 21, 2019

Today was a pretty good day for Louie overall. He had some increase in pain later in the day but his spirit was sweet and playful when he was awake. Many people have been asking if the medication and plan from Mayo is working... Honestly, we aren't sure. We see some positive signs but we also see some concerning signs. His heart rate and blood pressure seem to be a little bit better but his energy and alertness have declined.

As a family we have determined our goal...and it is constant. Our goal is simply to love Louie like Louie loves others...and to leave the rest to God. Personally, the more I focus on this...the more I have peace in the unknown. The more I can sleep with unanswered questions. The more my heart is open to take little risks to show people Jesus.

For the past for months, our family has forged a new daily tradition. Each night we have family time. Most days, family time happens after Louie is asleep because he is down for the night around dinner time. This actually works out really well because it is a way we can connect with our other three kids...and it provides them focused time with us that is completely theirs...

During family time, we sit in our living room with no distractions and look each other in the eye. Family time may include a number of things but there are a few non-negotiables. We always go around and tell our favorite parts of the day. We always take turns sharing a specific prayer request. We always sing a song or hymn...or three!! And we always end in prayer.

When we pray, it is a tender time when each person in the family has a turn to pray for their specific prayer request and anything else on their mind. Even Liana, our 3-year-old, faithfully lifts up sweet and innocent prayers before the Lord.

About 99% of the time, Liana states her prayer request is for "Louie to feel all better." This is always followed by Selah who prays for "Louie to be able to walk again a long, long way without a wheelchair and we can dance." Peter will most often pray for a situation he has encountered that day. Erik and I will chime in with a prayer request as well. Then we pray...each of us...one by one youngest to oldest...

This is what we do...how we pray...each and every night. My favorite is the bold and beautiful prayers from our children who love their brother fiercely.

Tonight my thoughts are on a mini family time that occurred earlier today. I was giving Louie all of his medications for the night and getting him ready for bed and we started talking...we had our own little family time...just the two of us. I asked him all the same questions we would go over as a family later in the evening. Louie stated his favorite part of the day was going to church (something he hasn't felt well enough to do for quite a while). He talked about how much he loved the worship and how pretty it was. He told me he liked giving so many high fives and knowing "they were happy to see me!"

Then we talked more about the rest of the day. We sang an old hymn together that he picked - "In the Garden." Then I asked Louie what he wanted to pray for tonight. Louie reached out and took my hand and immediately said, "Mr. David (man in our church who has constantly invested in our family)...he in hospital...sick...I pray for him." Then Louie bowed his head and uttered the sweetest prayer between him and the Lord just for Mr. David.

Tonight I can't get this off my mind because while so many are praying for Louie, including his siblings, Louie is praying for others. He doesn't ask for the pain to go away...he doesn't ask to be able to eat again or not have drain lines and PICC lines and TPN and medications...he doesn't ask for more time to be awake...he doesn't ask to walk and run again. Louie doesn't see his needs in the forefront. He sees others first. He lives this way not just when he prays, but in everyday interaction.

I, on the other hand, go to bed with my own complaints for the day fresh on my mind. I lay there and as I drift into prayer, honestly, most of my prayers are about me...my shortcomings...my desires...my confessed sin...my hopes for tomorrow... The common thread often is me. Yet what if I spent less time with my own stuff at the forefront and allowed others to occupy that spot? What if in my time alone with the Lord I focused a little less on me and a little more on others? What would the result be in my day?

The more I think and dwell on this, I am convinced that one thing is for certain...God knows my heart and my needs and when I spend time praying for another person, it is never a wasted moment...never a wasted prayer. It is heard. It is received. It is held by God in Heaven, as a precious treasure knowing that His children are loving each other enough to pray for each other...to surrender their own place of designated importance and allowing someone else to be lifted up.

Now I am not saying it is wrong or bad to pray for oneself...only to point out that there is a great many around us that need us to be in their corner lifting them up...some of them too weak or weary to pray themselves. I believe there is great power that comes when we spend time formulating our prayers not by looking in the mirror (yet there is a time

and place for that), but in looking around us...looking at our neighbors...our families...our churches...our country...our leaders...our world...but also the checker at the grocery store...the babysitter...the house cleaner...the tire man...the bite squad driver...and whoever else God places in one's path.

Ultimately, hearts softened and willing to pray for others – even those who haven't asked for prayers – are hearts God is molding to look more like His. Tonight, I too will pray for Mr. David and a few other moms I know with children fighting for lives...and in doing so, I find myself so thankful for Louie...thankful for the way he teaches me to love...thankful for family time...

Comments

I pray unceasingly for your whole family including the extended ones who do or don't understand Louie and the daily struggles as you and yours live out your lives.

I appreciate very much your posts. I look forward to them and how I learn to better walk my Christian walk through your eyes.

I have a soft spot for special needs people of all ages. It is my belief that Louie is a modern day David. He has been chosen by God to swing his love sling at all who enter his path. It doesn't matter whether they want to or not, no one leaves unaffected or uninfected.

Thank you for writing these journal passages. God give you and your family the strength and tenacity as you walk this walk.

—*Sharon Stewart, July 21, 2019*

Awesome journal Kristy, yes I find myself praying for Louie and you and your family and also I pray alot for my husband because he is disabled and it's terribly hard on him and me too , Louie taught me a valuable lesson also sometimes it's better too pray for others in our lives and not so much for our selves. When we are as low as we feel we can get , if we can muster the strength too hit our knees and pray for someone else, Jesus will open the windows of heaven and pour out a blessing on us. That's when I really get blessed most , it maybe spiritual blessing, physical blessing or a prayer answered. I am always thankful and grateful. Lord Bless you Kristy, your an amazing Lady ♥♥♥

—*Joy Stuckey, July 22, 2019*

RISK

July 28, 2019

Authenticity isn't easy. In fact, it is hard...very hard. It is hard because inherent within the concept of being authentic, is a scary...intimidating...overwhelming...4-letter word...risk. Risk is always present when the walls go down...when the real and the raw come to the surface.

Authenticity is a risk because we are flawed people in a sin-filled world. It is a risk because our hope is that others hold the same values as we do...and when they don't, we can be hurt, judged, exploited, and discouraged. Our hearts can be broken. Our intentions can be questioned. Our reputations marred without merit.

Yet on the other hand there is a tremendous relief...a beauty that comes when one is open and honest. There is growth and goodness that comes in being heard and understood. It is a fundamental hope that we all possess because authenticity results in connection...in joint struggle for the purpose of joint gain. It is iron sharpening iron at its greatest.

Risk. Authenticity. Trust. When does one take the chance to be authentic? When does one run and hide? When do the wounds become enough to silence the risk...to silence the authenticity?

When authenticity brings wounds, the natural inclination is to remove the risk...to close up...to be done with trust. But if we are honest, the truth is, we have each probably been on both ends of the risk spectrum at various times. We have likely wounded someone with words or deeds, possibly even unintentionally...but wounded nonetheless when they trusted us. On the other hand, we have likely all had our trust betrayed.

When we do the betraying...if the relationship holds value to us, we work hard to restore it. We own our mistakes. We seek forgiveness. We choose repentance. On the other hand, when we have been betrayed, we have a different impasse. We must decide if we can give forgive and move on...and truly the basis of that decision is made in our heart regardless of the other person.

Forgiveness is what we choose to offer out of an overflow of the forgiveness God has showered upon us... Forgiveness was never meant to be contingent on the confession of another. Forgiveness was never meant to require certain actions or words from someone else. The core of forgiveness is found in one's own heart...not based on anyone else.

Do we learn from the actions of others and allow that to change our response to a person? Absolutely. So if you take a risk and a person wounds you...and there is no repentance... Then you may change your trust in that person and whether you choose to take risks with them in the future, but you are still called to forgive...even if they never ask. Forgiveness isn't for them...it's for you...for your conscience before the Lord.

Overall, wounds reduce the likelihood that we will risk again. The hurts strip us of the willingness to be authentic. They make it hard...really hard...to trust again...which is why authenticity is such a risk.

Circumstances recently have led me to contemplate these things. I have had trust betrayed in a big way on this journey where I have taken a risk to be authentic. It feels violating to have that risk result in such betrayal. It wounds in a way that leaves the door open for me to run and hide and refuse authenticity again...and I have contemplated this path...I have considered closing up shop when it comes to taking the risk to share honestly because the pain is real and runs deep.

But then I remember a few truths...

- God loves people...all people...even those that hurt us. We are all people prone to mess up. We pass judgements that are wrong. We muck up relationships. We are messy people fumbling through life. We wound and are wounded. But God loves regardless...and to honor Him, I am called to love regardless as well. If I run from authenticity because I am wounded, I miss the opportunity to love well in the midst of the pain. I miss the chance to grow and reveal a God who is still present in the tough, unfair, hard, places of life.
- To be silent let's fear win. Fear keeps us quiet and often withdrawn from authenticity. Fear paralyzes and makes risk seem impossible. For me, I have battled fear in many ways over the course of my life...and I don't want to return to a place of being trapped and controlled by fear. To be in that place cripples freedom...hinders love...and robs joy. Fear reduces confidence and my confidence is not in who I am, but in WHOSE I am...
- Further, I know in whom I believe and He is able (2 Timothy 1:12). Exodus 14:14 "You need only to be still, the Lord will fight for you." The opinions that matter to me ultimately are that of the Lord and my husband. I have a God who sees my actions, and knows my thoughts and intentions, and forgives my sins, and loves me completely. God has called me to worship and honor Him. He is my judge. He protects my heart, my family, and my reputation. I know where I stand with the Lord...and my husband respects, love, adores, and is proud of who I am as a wife, mother, and person. These two places, the Lord and my husband, know my victories and defeats and choose me...and I submit back to them both

as my place of accountability, and leadership...they lead me...they are secure...they are my place of safety because they know all and fight for me still. They give me the courage to stand and stare risk in the face...

When I sit with these truths and I contemplate authenticity, I recognize that as I forgive...which I am intentionally choosing to do regardless of if it is ever requested of me or not...in doing so, I move towards peace. (By the way, forgiveness never comes by accident. You don't stumble upon it. It is totally and completely an intentional and often painful path that involves continually choosing mercy.) For me, while authenticity still feels raw, forgiveness breeds the hope found in Jesus.

I challenge each person reading to sit with the Lord and process your places of authenticity, of woundedness, of fear, and of beauty. Approach the places of brokenness head on...one-on-one seek restoration in a manner that reveals value in accordance to Matthew 5:23-24, whether you are the one who caused the division or not. Evaluate your fears and remember that God's perfect love casts out fear (1 John 4:18). And ultimately "Above all, love each other deeply, because love covers over a multitude of sins" (1 Peter 4:8) God's heart is for us to be reconciled to each other and live in the light as He is the light.

So to the one who has brought about this contemplation of risk through their judgements of me...I say simply I love you...I forgive you...and I hope for the opportunity to process these things with you one day. Until then, I will continue to prayerfully and consistently seek God and honor my husband in determining when and how to take the risk to be authentic again...knowing that the most breath-takingly beautiful places of growth come through authenticity.

**"...But I am not ashamed, for I know whom I have believed, and I am convinced that he is able to guard until that day what has been entrusted to me."
2 Timothy 1:12**

PLEASE NOTE: Details aren't important...affirmation towards me is not the purpose at all...my hope is simply that we all examine our hearts and relationships and live out love before the Lord and those around us. Authenticity is a risk, but without it, nothing is real.

Comments

Kristy, the Lord uses you in a mighty way. I needed this tonight. Love and prayers!

Emma's Gigi

—*Donna Lemons, July 28, 2019*

Powerful, exactly what I needed to read.

—*Shanna Burks, July 28, 2019*

Kristy, you have know idea how much this Risk story will help me in my thinking! We've all had terrible horrible things to happen to us in our married lives and trust has been the hardest thing for me to get back. I trusted and then something else goes wrong and took away my trust again. I was so naive all my life! I've been the type that gave everyone the benefit of the doubt but when I lost trust a second time, it makes me afraid to trust again! Thank you so much for writing such a great devotional! I'm saving it to read and study! Praying for you and all of your family! Praying for Your son always!!!! Thanks so very much!!!

—*Dorothy Chaffin, July 28, 2019*

It is iron sharpening iron at the greatest. I love that Kristy. And our forgiveness is not contingent on another's confession is spiritually poetic. You really must consider, at some point putting all these letters to your people into a book of devotions. They are pure, they are real, and God's wisdom in your heart falls on waiting and needy ears. I love you and your family, Kristy, even though we have never met face to face and my prayers continue for all of you. I understand this risk you speak of and the indescribable pain with the desire to claim up, pull back, and for me, to nurse my wounds. The truth is we live in a world daily progressing toward destroying any who hold a different view from "the beloved self", and we won't stop until we have our way, our say, and the other is ground out of existence. I pray God will lift your soul to the "heavenlies" today for some extra love and rest. Give Louie a hug for me as well as the rest of the children.

—*Cindy Krueger, July 29, 2019*

What you have said is so true. Trust is something that when it is destroyed it is very hard to rebuild. And you are reluctant to do it. But I have thoroughly enjoyed the things you have been sharing and I believe God will and does use them to help others. Just keep sharing and being yourself and don't worry about what others think or say. We are still keeping Louie and your family in our prayers. Just keep us posted on our special guy.

—*Doris Perkins, July 29, 2019*

This is so inspiring to me Kristy, I love the way you use words , Thank you for for posting this it is just what I need to hear right now at this point. I am going to sit with the Lord and bear my heart and soul too him , I know I don't have to because he already knows

me inside and out as does my husband and he does whatever he can too protect me from being hurt , getting my heart broken and anything that will bring me sadness, Wayne is my best friend but he knows that my Jesus always comes first. I feel like along as I have the Lord beside me and Wayne on the other side I will make it through hurt , pain and a broken heart. I appreciate you so so much. I love your journal it speaks volumes to me. Give them precious babies huggs and kisses for me, I am still continually praying for Louie and you and the rest of your family. Love y'all bunches ☺☺☺☺☺☺

—Joy Stuckey, August 5, 2019

This is so inspiring to me Kristy, I love the way you use words , Thank you for for posting this it is just what I need to hear right now at this point. I am going to sit with the Lord and bear my heart and soul too him , I know I don't have to because he already knows me inside and out as does my husband and he does whatever he can too protect me from being hurt , getting my heart broken and anything that will bring me sadness, Wayne is my best friend but he knows that my Jesus always comes first. I feel like along as I have the Lord beside me and Wayne on the other side I will make it through hurt , pain and a broken heart. I appreciate you so so much. I love your journal it speaks volumes to me. Give them precious babies huggs and kisses for me, I am still continually praying for Louie and you and the rest of your family. Love y'all bunches ☺☺☺☺☺☺

—Joy Stuckey, August 5, 2019

Mismatched Shoes and Uno

August 3, 2019



We have a saying in our house when it comes to competitive games and activities...the saying goes like this, "We win with gratitude and we lose with gratitude." It is something I started saying to teach my children the joy of competing without the outcome dictating the overwhelming emotional response. In other words, there is beauty in the gift of being able to compete and give one's best that runs deeper than if you win or lose.

Some call it having good sportsmanship. But for me, it is simply choosing to say people matter over competitions. It is about celebrating that giving one's best is enough, regardless of how it stacks up in comparison to others. It is also about turning from the heart's natural bent towards pride. It is about understanding that gratitude yields humility.

As a parent, and honestly just as a human, we tend to see life as a competition. We live in comparisons. We chalk up our worth to whether things are going well or poorly...what we have or don't have...whether we are "winning" or "losing."

Anyone who knows me, knows my competitive spirit especially when it comes to sports...or board games...or cards...or bowling...or marbles...or...well anything. I was taught early on that you work hard, give your best, and you always strive to win. This attitude helped me be successful in athletics, academics, and even professionally prior to staying home to raise my children. Yet it has been important for me to teach my children that we are not defined by our successes...we are defined by our effort. Our effort reveals our character. Our effort reflects our beliefs. Ultimately for me, I pray that in all things my effort points to Jesus.

Yesterday two things happened that stirred my heart and brought me to thinking much more about this subject...

Yesterday morning Liana had a make-up swim lesson. There is a whole lot to do to get 4 kids ready and out the door first thing in the morning - especially factoring in the logistics of Louie's care. Thus, I felt accomplished as we left the driveway on time. We arrived at swim lessons and I got Liana ready. In doing so, I went to take off her sandals...that is when I saw it...two sandals...two right sandals...two matching right sandals of different sizes... Liana was wearing one right sandal that was hers and one right sandal that was Selah's. My first thought was, "Ugh, what a parenting fail!" Then in slight embarrassment, I uttered to her swim instructor who noticed the shoes, "Well, I am really winning today!" It was that awkward, slightly humorous moment, when your hope to be viewed as "put together" becomes an illusion.

Fast forward to yesterday afternoon... I was playing a game of Uno with my four kids around Louie's bed. The first game, Selah smoked us...everyone had at least 4 cards in

their hand when she won. Louie immediately, and without hesitation, threw his arms around his sister and proclaimed with great enthusiasm, "Good job Selah! You did good job!" He hugged and kissed her but didn't stop there. He threw his arms around Liana and said, "You not win, but you do great!" This was followed by a high fives to Peter. Then to me he said with the biggest Louie smile, "Mom, you do good! Good dealing cards!" So my son lost the game, but yet he was more excited than even Selah who had won. His reaction to losing was so pure and beautiful. He was genuinely proud of his sister and he lost with great gratitude. The fact that he played the game and we were together was more important than the outcome.

As I have contemplated those two moments from yesterday, I find myself in a familiar spot...wanting to respond more like Louie...wanting to find the confidence to worry less about the outcome and more about the process...wanting to cherish each moment no matter whose victory it is.

Go back to the two right sandals...

I have reflected long and hard on the statements I thought and made. "Ugh, what a parenting fail!" "Well, I am really winning today!" They are simple statements that as a parent we have probably all said...or thought. Yet even just in jest, it suggests that the winning and losing for me as a parent is rooted in the performance of my child - in this case my daughter getting the correct shoes when asked. Furthermore, it implies that the evaluation of my parenting is seen in the compliance of my child. None of this is truth.

We pour into our children and we long for them to grow into Christ-following, healthy, happy, loving, kind, and well-rounded adults. But no matter the age of our children, they still have their own will that makes decisions. No matter how competent we are as a parent, our child will still throw fits. No matter how loving we are as a parent, our child will still hurt someone else's feelings. No matter how organized we are, we will still forget something they need. No matter how much we invest to teach and guide them towards truth, they will still sin...they will still cause us to worry...they will still have times when their will and desire is stronger than our hopes for them.

Does that mean we have failed in parenting? Do the wins and losses of a child dictate the heart of the parent? When we stop looking at life through eyes of competition and comparison (which go hand in hand), we are able to find gratitude in all things. We can lose a moment and still be thankful...thankful for our children...thankful for the chance to be parents...thankful for opportunities to improve...thankful for grace...thankful for the fact that we have more than we need...thankful for a child who can throw a fit, let us down, pick out mismatched shoes and still have life in front of them.

The more I think of the scene yesterday at the pool, the more I want to go back to the

moment I found the mismatched sandals on Liana's feet...the more I want to have said in that moment, "baby great job getting your shoes on when I asked...I love you!" and given her a hug while chuckling inside...for gratitude makes each moment not about you, but about others. Louie reminded me of that over a game of Uno.

Comments

Love this so much!

—*Debbie McAnally, August 3, 2019*

Oh Kristy, I am so blessed by each of your posts. I just don't have the words for it. I truly believe the Holy Spirit is mightily at work in and through you. Thank you for sharing as you do. Much love and many prayers. ☺☺☺☺☺

—*Kristina Mete, August 3, 2019*

Love you friend. Thank you for the encouraging words... I pray God uses my life, Louie's life and this journey to bring him great glory.

—*Kristy Schneider, August 7, 2019*

You and Louie give me so much inspiration in how you view and deal with things...thank you for being such a blessing!

—*Joey Daniel, August 3, 2019*

Thank you so much! As a parent of a 51 and 53 year old, this lesson is even more important now than when they were growing up.

—*Judy Herrick, August 6, 2019*

This was a precious reminder to my heart today. Thank you!!

—*Lynette Place, August 10, 2019*

Highs and Lows

August 11, 2019

I have said often that Louie has good days and he has bad days. This is quite true. Everyday is different. There are days when he feels well and makes great memories. He will play with his siblings and ultimately a "talent show" or "dance party" will ALWAYS erupt. Louie will sing or play an instrument while the others dance and everyone giggles in great delight. Then there are days where he feels so poorly that he will sleep or lay without moving the vast majority of the day. He won't talk or feel like playing. He will flash a smile if the moment is right, but otherwise he simply rests. The hardest part is the fact that you can't predict which day is coming next. Thus each morning we wake up and we hope and pray for a good day.

We live in an age where we can snap a picture all the time...and we do. There are no longer barriers such as needing to remember a camera or running out of film. Our phone is rarely out of reach. When you realize how fragile life is, your pictures look different...and they come more frequent. You want to hold tight to each and every moment. You take pictures so the memories are solidified.

The problem with a picture is that it captures only that tiny moment...not everything that may be surrounding it. We can then filter and zoom and edit in ways that manipulate the authenticity of a moment to the point that it is no longer recognizable to those that were there. Then that picture can be posted. It may or may not be truth. It may or may not offer insight into a moment. But once it is posted, it is there for the world to judge.

But no one wants to be judged. Yet we all are judged every day. Judged by the things we post or don't post...say or don't say...do or don't do. When the audience becomes greater, the judgement becomes harsher. We then must question our purpose. Words can't come back. Judgement can't easily be erased. We all judge and are judged each time we open social media...with each post we make...with each pause in the scrolling...

The past seven months have been filled with many lows and some beautiful highs for Louie and our family. There have been times where online you saw him smiling in a moment, and yet, that may have been the only smile of the day. It may have been a day where his body struggled and he was in pain. Social media is deceptive because a person can't be defined by a moment...but we often judge a person in the moment.

I began this caring bridge journey in order to allow others to understand our path a little more and know how to pray for my son and our family. I found it to be a place of processing for me and within it I have shared vulnerably. To do so has been risky...yet it has brought about great encouragement, support, and love...well, mostly. The authenticity has also yielded some judgement and loss.

Yet in the end, I know who I am and more importantly whose I am. I know what opinions I value and the character with which we lead our family. My husband is the strength of our family. My children are amazing and resilient. They showed it so perfectly yesterday with the triathlon. My children never complained when the race wasn't able to take place as planned due to severe thunderstorms.

My children didn't say a negative word when friends were helping to run them into the building so they wouldn't get drenched. My children held hands most of the morning. They walked together. They played together. They laughed together. They cheered together. They made memories together.

It was a day filled with moments that can't adequately be captured with a photo or with words...you had to be there. You had to have the perspective of seeing twenty or so special needs kids competing in a way that was more about each other than about winning. You had to know that each child had a story that was hard. Each family had a journey that wasn't easy. But with lots of grace and great determination, there was also a moment when medals were placed around the necks...when tears were threatening to stream down faces...when a moment wasn't enough to hold what was taking place - oh it was so much deeper - so much beauty - so much to be thankful for. There was so much a camera couldn't capture but the hearts of those present did.

Then each one of those families, mine included, left that special moment to return to a life that is filled with highs and lows. Louie enjoyed the triathlon immensely but it wiped his little body out. The sacrifice for Saturday morning came in sleeping about 18 or so hours afterwards. It was a trade. Then our air conditioner went out at our house today bringing more challenging obstacles to overcome. But when you just look at the pictures, the videos, the moments, you miss the rest of the story. It is easy to smile and scroll and put forward only the foot you want others to see.

However, for each of us, the moments are only pieces...snapshots of a day with highs and lows...ups and downs. As we were putting our kids to bed tonight in our very warm house, I was talking with our girls about why it was so hot and that they didn't need their blankets tonight. My five year old left me speechless when she said matter-of-factly, "mom, I don't mind the hot. I wouldn't know cold if I didn't know hot."

What wisdom! Without lows we wouldn't know the value of the highs. Without the hard places and tears, we wouldn't be able to grasp the depth of joy in the good times. Without the defeat, victory loses some of its power.

Friends, we all know that there are highs and lows for each of us. The moments are not indicative of the whole story. Thus, when we are tempted to judge, even just for a moment, may we stop ourselves and close the app instead...turn from the temptation to decide what one's life must be like from snapshots...from tiny moments. May we pick up the phone and talk to a person instead. May we initiate a time for coffee to get to know one's heart not just the public moments. May we base our thoughts on truth that only comes from having the whole picture...the whole story...from valuing people over "likes" and "shares". May we be bold enough to ask the questions instead of judging, and graceful enough to receive the answers.

Because ultimately the only one that is worthy to judge is Jesus and His death has offered each of us grace. Why can't we do that more? For the truth isn't solely in the highs and lows; it is in the character, heart, and integrity of a person.

Comments

I am sitting here with tears. I wish everyone could have seen your family yesterday. The girls walking beside Louie either holding his hand or on to the chair. Your husband pushing him and Peter to really close by. I wish I had gotten a picture of the hugs they gave each other at the end of the swim. My thoughts after leaving was quickly turned to praying for Louie to have a good night and day after. God bless you for letting me part of your journey yesterday.

—*Wanda Cook, August 11, 2019*

I always look forward to your postings. Sharing your insight is truly a blessing and always speaks to my heart. Keeping you and your family in my prayers.

—*Polly Gan, August 11, 2019*

Your postings are inspirational but yet I know in my heart how hard it has to be in this time of heartbreak and trials watching your precious son and family struggle daily with the ups and downs. The only judge we have is Jesus and he truly is looking down and watching over your family. He is our greatest strength and He guides our way. I have come to love your family and pray for you genuinely . May God be with you day after day and I know He is. God Bless you all!

—*Diane Huggins, August 12, 2019*

Very well said!!! Hugs and prayers...
Keep on being awesome☺☺

—*Debbie Hauser, August 12, 2019*

Wow... your posts shed such a light of perspective and ALWAYS point others back to Christ. Thank you for allowing God to use you in this way and being truly authentic. THIS is what the body of Christ needs!

—*Karen Thompson, August 12, 2019*

Prayers for strength and power continually in your sweet family's life. Thanks for sharing.

—*Doris Perkins, August 12, 2019*

I met you in CBS. I love your authentcity..we have followed Louie 's journey for awhile

now. My husband prays for that little Louie boy each morning and asks me what is happening. Our path is chemo for my husband every month to keep him alive. This is our fourth year what I'm getting to is our conversation always falls to God's time. My husband is 82 and has not met God's time. I can understand it's hard but God is there in good and bad moments God is using Louie to show your families strength. You keep posting those hard truths and the fun times . They are actually touching someone's heart. Mine

—*Mary Wilson, August 12, 2019*

Thank you so much for so much for the kind and encouraging words. I remember you from CBS!!!! I will be praying for your husband and I am so thankful we don't have to figure out the when's...we just have to strive for obedience on this earth - longing for what is to come!

—*Kristy Schneider, August 12, 2019*

Keeping you and all of Team Louie in my prayers. Always find myself looking for your posts and updates. You are an amazing woman and so humbly sharing God's love and strength with all of us. Hugs and prayers.

—*Linda Davis, August 12, 2019*

Good food for thought and contemplation. Hope today is a good one!

—*Cindy Gordy, August 14, 2019*

Continued prayers for Louie and the family

—*Sue Henson, August 15, 2019*

Prayers for Louie

August 16, 2019

I know I often write a lot about small things that happen and my processings of them. In all honesty, I write as much for me as I do for those reading it. I typically keep the medical information fairly vague primarily because it is just so complex. But tonight is different. Tonight I write to ask for you to pray specifically for Louie.

I am a firm believer in praying boldly and specifically. I know God hears and understands our every prayer, and the words that make up our prayers are not the driver - our hearts are. God longs for us to pour out the yearnings, the desires, the thoughts, the fears, the questions...all that is in our hearts. He wants it articulated...for it to be laid out before Him. He can take it. He already knows it. He is God.

I believe there is such a beauty in praying specifically...in crying out to the Lord not with vague requests, but with concrete ones. He may not answer as quickly or as clearly or as we would want Him to at all. But truthfully, prayer is not about the "results," it is about the surrender. It is about surrendering our will and our hearts to the one who holds life. It is about trusting and believing in something so much greater than ourselves...in the one who made man out of dust and who will be there in the end to say "well done my good and faithful servant." God is able...able to handle our hurts in prayer, our concerns in prayer, our longings in prayer, and our victories in prayer. He is our only hope... He is why we pray.

Thus, I come to ask for prayers, specific ones, for my little guy. Louie has not been feeling well overall the past couple of weeks. He spent quite a while in cardiology yesterday for routine appointments. We received some good news regarding his heart functioning. It appears the new medication prescribed at Mayo is helping his heart be more efficient, and thus it has improved his heart's output. For this we are thankful.

However, we also had something come up on his pacemaker interrogation that was quite abnormal and definitely warranted concern. Two of our doctors discussed it together and determined that we need to investigate the concern a bit further. They ordered additional lab work and he was sent home on a halter monitor to capture more data.

Please be praying for the following:

1. The halter monitor to yield the insight needed to determine what, if any, steps need to be taken to improve his cardiac health and protect his life.
2. Wisdom for the doctors here and at Mayo as they will continue to work hand-in-hand to strive to sustain (and ideally improve) Louie's quality and quantity of life.
3. For the Lord to help us know as parents how and when to advocate for our son...especially regarding quality of life.
4. For a small outpatient procedure to go smooth next week...for there to be no complications.

Thank you so much for praying for Louie and our family. It is such an encouragement to us when we know that we are not alone and there are others praying. Thank you for the comments, cards, messages, and words of encouragement we have received the last few months. We read and cherish each one. As the body of Christ, may there be greater unity as we humble ourselves and seek to love others in the most beautiful way...on our knees.

Comments

My prayers rise and believe God will hear us all to answer the prayers above!

—*Diane Huggins, August 16, 2019*

Prayers for a perfect heart for Our Louie. May God lessen the pain and give Louie comfort. God please let the monitor show exactly what is going on and the procedure go well next week. In Jesus Holy Name.

—*Doris Perkins, August 17, 2019*

Your words on prayer really spoke to me tonight. Though we never met, I remember Louie from when my son went to Peds. Praying with you for your specific requests. Thank you so much for sharing God's love in such a difficult time.

—*Stacy Peterson, August 17, 2019*

Agreed with you!

—*Valerie Frith, August 17, 2019*

But truthfully, prayer is not about the "results," it is about the surrender. It is about surrendering our will and our hearts to the one who holds life. It is about trusting and believing in something so much greater than ourselves...in the one who made man out of dust and who will be there in the end to say "well done my good and faithful servant." — These words are so true. Thinking of Jesus surrendering in the garden. Prayers continue for your precious son who is teaching me about life, love, and death through your words.

—*Teresa Siegel, August 17, 2019*

Oh, Kristy...we will be praying diligently for all of those outcomes. Your strength through the storm has reminded me often to keep on truckin' through my much easier issues. I will cross Emma the Dog's toes, too, since she only has been taught to sit, stay, and give high fives. Need to work on her ability to "pray". Love and hugs from KC...

—*Tracy Johnson, August 17, 2019*

Praying as always!!

—Debbie McAnally, August 17, 2019

Continuing to pray for Team Louie. I can't imagine the emotions y'all feel on a daily basis. And then there are all the decisions that have to be made. Yes, I will continue to pray for all of you. I continue to pray for wisdom for the doctors treating Louie. I continue to pray for compassionate nurses who work with the doctors, Louie, and Louie's family. I will be praying for next week's procedure to go smoothly and reveal what needs to be done next. I am praying that the halter monitor reveals what the doctors need to know to help Louie. I am thanking God that the trip to Mayo has led to the medication that is helping Louie. Loving all of you, I lift you up to Jesus to carry you through this valley.

—Linda Davis, August 17, 2019

Soooo many profound truths here (and quotables ;-)) --thank you for sharing your reflections & reminders on prayer (and the posture of our hearts, not the content of the words or the results...). Definitely praying for Louie and the points you laid out!

—Laura H, August 17, 2019

I am so sorry that Louie hasn't been feeling as well, but I will definitely be on my knees pleading the blood for Precious Louie and you all too, Louie and your precious family has become a family that we pray for every night and day. I know you Kristy and your husband carry a heavy load, but I also know like you that we serve a great big God and there is nothing too big or too small for Him, He can handle it and He will on His time. We will be praying for all of your request in Jesus Precious Name and He will answer, Lord Bless you Kristy and your family and Precious Louie, give Louie lots of hugs and kisses for me. He is a precious inspiration to me and my husband Wayne ☺☺☺☺♥♥♥♥

—Joy Stuckey, August 17, 2019

Thank you Joy

—Kristy Schneider, August 17, 2019

I will be keeping you and your little one Louie in my prayers. Prayers for your peace and comfort Louie's quality of life and for wisdom for all of his medical team as they try to take care of him.

—Marilyn Weeden, August 17, 2019

Think of this precious boy and the whole family. Love to hear he doing better in some areas. Hope and pray the other obstacles will subside. Love and prayers he is a cutie

—Dorothy Morlan, August 18, 2019

Continued prayers for Louie and family. May God Bless you richly as you care for him and your other children. Look forward to each of your updates

—charlesandfreda christian, August 18, 2019

Specifically praying for the needs you mentioned. God is listening and knows the needs of your heart. May you be blessed beyond measure and your precious son.

—Linda Duncan, August 28, 2019

Prayers unceasingly for all concerned. Bless you all

—Sharon Stewart, September 17, 2019

1,440...

August 20, 2019

1,440. That is the number of minutes in a day. In one 24 hour period of time we have 1,440 minutes to form, to shape, to choose what is important. 1,440 seems like such a big number. Yet, we blink and the day is over...and we often find ourselves laying in bed trying to figure out where the day went.

Today for me was a super busy day...well...when you have four kids, most days are pretty busy! Today I proceeded through my to do list without much thought. I taught my girls a few things, got everyone to their school or appointments on time. I squeezed in a quick run to the library. Collected my children from their various daily adventures. Kissed my husband when he made it home from work. Then fed everyone, ran a quick errand, and looked forward to a quiet evening.

By 6:30pm, the evening routine was in motion. Children were getting dressed for bed. Homework was getting completed. I was in the midst of giving medication and tucking Louie in for the night. That is when I noticed it.

Louie has a number of dressings covering various tubes or things on his body. There are a few of them that are very important - like life or death important. Earlier in the day he

had messed with one of the really important dressings because he said it itched. I had reminded him of how important it was to leave it alone. As I was putting him to bed, it was evident that he had done so again...but this time much worse.

Ugh... My heart sunk and immediately I felt the emotion rise. It was that moment where you don't know if you want to scream or to cry but something is about to come out...the emotion is too big to hold back. We have all been there. Do you allow the disappointment to turn to sadness or to anger? Oh how anger and sadness are such close relatives when the lump forms in your throat.

For me...today...in that moment...what came next was I raised my voice. I told him among other things, that I was disappointed in him for messing with the dressing which can really hurt him. I let the anger come out of my mouth. It was anger directed appropriately and righteously justified and certainly within the bounds of a safe expression of anger...but it was still anger. It was still rooted in sadness. It was still seeping out from layers of fear.

The truth is that if I was walking out the depths of my faith, that moment would have looked different. If I was surrendering daily to the fact that God has this plan lined out for us, and He is totally and completely in control, then the anger would have been replaced by loving grace. But the truth is I struggle, sometimes on a daily basis, to stay completely rooted in that surrender. In other words, I totally and wholeheartedly believe that God has Louie's life and our family in His hands. He is the author of life. He is the perfecter of our faith. God is in control always. He never allows a minute of the 1,440 in a day to pass without knowing it thoroughly and dictating it entirely. Yet, His love allows our will to decide how fully we surrender our hearts in the moments when we are pressed...when things are hard...when they don't go as planned...when we are exhausted or overwhelmed...

However, when we surrender, we can respond not out of the big-ness of our human emotions, but out of the fruit of the spirit inside of us. We can offer a response that is congruent with HIM even when the lump is in the throat...and the anger threatens to release...and the tears are filling the eyes. We don't have to allow our emotions to control us. We can instead allow truth and peace and love to overtake. It doesn't happen easily, but with a surrendered spirit, it is possible. It is beautiful. It should be the God-honoring goal for each of us.

Back to side of Louie's bed. I let out my words of anger. I roughly pull out medical supplies I needed from drawers - shutting them a little harder than necessary. I let the lump rise in my throat as I did. Then I paused next to his bed knowing this is not who I want to be. At that moment, Louie reached his arm towards me. I am still angry but I allow his hand to pull my head towards his. He kisses my cheek. And I surrender.

Lord I surrender. I confessed to Louie that I was wrong for being so upset and was so sorry for raising my voice. I sat in bed with him, my head touching his, and prayed for God to forgive me and heal my unbelief. I asked God to help me to trust Him so fully that when the lump rises and the choice between sadness and anger threatens, that I will have the courage to look up and see the third option...God's hand reaching down extending grace. Grace to me and grace to whoever else is involved in that moment. Grace that is greater than all my sin...and their sin. Grace that commands the moment and brings hope and perspective even in the storm.

In the end, from the outside looking in, I had a busy, but good day. 1,435 minutes were pretty good...productive...lived without regret...and filled with moments of knowing that I am immensely blessed. Then there were 5 minutes. 5 minutes I wish I could get back. 5 minutes that threaten to define my day. The kind of 5 minutes I often lay in bed at night redoing over and over again in my mind.

Tonight I want to lay in bed having surrendered completely to God's grace. Grace that doesn't take back the words I spoke in anger, but offers full and total forgiveness for them. Grace that doesn't mask the anger, but grace that eradicates it with the freedom that comes in trusting in the death of Jesus on the cross as enough to cover my sin. Maybe instead of wishing for the 5 minutes back, I should surrender to the idea of 5 more minutes with Jesus tomorrow. Maybe if I surrender more intentionally, tomorrow will be filled with greater patience, deeper joy, and lasting hope...not that circumstances are magically different; but that in surrender, 1,440 minutes of the day can be lived in grace...and grace doesn't return void...especially when the grace God is longing for you to offer is towards yourself.

Comments

Continuing to keep you in my prayers.

—*Linda Davis, August 20, 2019*

Thank you so much for writing this entry for me to read. It reminded me of what happened at the end of my day yesterday too. I was in a hurry trying to wash the dishes last night because I had a million things to do before going to bed. My three year daughter likes to pull up a chair and “help” me wash dishes now. She got in my way and started to make a mess with the water. I got upset and scolded her. She hung her head down. I felt bad because I normally let her play next to me. I know she is trying to copy what I do, but I was in a hurry this time. Your journal entry reminded of how to have patience with her. God has a plan each day for us. How we choose to follow it is up to us. Have a blessed day today!

—Kristy Whitmire, August 21, 2019

I know that you are upset that you were upset that you became upset set with Louie. Please remember that God knows that none of us is perfect. Louie knows that you, as well as he, aren't perfect but he and God know that you try your best. You will try your best again today and know that it will be a good day even if it isn't a perfect day. Continue in love.

—Cindy Gordy, August 21, 2019



—Valerie Frith, August 21, 2019

Storms

August 30, 2019

This week I have struggled to write. There is so much I want to say and express, but the hesitations at authenticity have been numerous. I want to update openly about Louie and how he is doing medically...about the highs and the lows we have experienced this week. I want to ask for specific prayers. I want to be vulnerable about the path forward. However, if I am honest, I am scared to do so.

We have moved into a season of long term crisis, which has brought challenges I never anticipated. The feelings have been big....the road rocky...the judgement real...the background noise threatening to drown out the peace.

The circumstances we are walking are unique, but I am certain most reading this can relate at some level to the battle for one's mind and emotions in the hard seasons of life. The feelings can be so overwhelming. The thoughts don't cease to race. Then to complicate it all, Satan really likes to kick us when we are down. It is what he does best. It often serves to paralyze us to the truth.

The past few weeks I have sat in this struggle...a struggle of wanting to be authentic and acknowledge the mountains and the valleys...a struggle of wanting people willing to stand with me on the high places and cry with me in the low places...a struggle in trying to look forward just a few steps with hope...a struggle to trust fully, laugh freely, and give grace completely.

As I have struggled, it is as if my feet have been stuck in cement. I can't get traction to move. The longer I am stuck, the harder it becomes to stand. The weight increases. Recently, in desperation, I found myself on my knees very late one night. As I poured out to the Lord in prayer, one word came flooding in...it penetrated my heart deeply...the word was WORSHIP.

Music and worship have been a large part of life since becoming a Christian. I have aided in leading worship through playing instruments (piano or drums) in many seasons of life. In fact when I look back at each and every pivotal moment in my life over the past 25 years, I can tell you the exact songs that God used to reveal Himself to me or to encourage me...the songs that resonated and brought me hope...the songs that were on repeat day after day after day.

Music is powerful. I believe it is powerful because of the way it connects our thoughts to our feelings. Lyrics can become battle cries, victory dances, anthems of hope, or laments in despair. Music can bind people and their unique stories together. Music can articulate feelings in ways our words may fail.

And then there is worship...a beautiful opportunity for music to connect our heart more deeply to God's. Worship is so much more than just music. What makes worship powerful is not our singing...it's not whether or not a person raises their hands...it's not the type of song (hymn vs. contemporary music)...it's not how talented the worship leaders are...it's not if you sing loudly or not at all...it's not even the words at all. Worship is powerful because of the interchange that occurs with God as we surrender our heart and our will to His. When we praise Him without reservation...when we acknowledge Him as God and God alone...when we seek Him in surrender...worship occurs because of who HE is.

Zephaniah 3:17 says, "The Lord your God is with you, He is mighty to save. He will take great delight in you; He will quiet you with his love, and rejoice over you with singing." Worship is possible only because the God who made the universe is singing back over us. Imagine that for a moment. God sings over you...like a parent singing over the baby in their arms...singing comfort and love and emotions far too intense to articulate. God is quieting our spirit. He is taking delight in us, not because of what we have done, but because of who He is. It is the exchange of our surrender and God singing His love over us that makes worship so impacting.

For me personally, in the past few weeks of struggle, I have failed to worship. Music has rarely played. I have sought solitude instead of the Savior. I know the power of music, but I haven't initiated it in a while. I didn't intentionally take it out of my life...but I also didn't intentionally seek it. Life will fill your mind with so much noise that without seeking worship intentionally, it won't happen. For me, it wasn't happening.

Then a dear college friend of mine posted a song called “My Testimony” that her teenage daughter (Selah Kurtz) had written and recorded. I wanted to support her, so I downloaded the song. As it started to play, it was as if I had the wind knocked out of me. Her voice is captivating but it was the lyrics that spoke deeply to me. Here is a portion of the song...

“You calm and keep me quiet,

Your love is drowning out the noise.

And the echo of the quiet is sweeping over me,

And the thunder of the silence is speaking your peace.

When my voice is gone,

The storm of your love rages on.

When I cannot sing,

The words you speak bring me to my knees.

Redeemed my heart will sing,

Proclaiming this broken melody.

This is my testimony.”

As the song played, it was as if I realized how loud the noise had been. I began to long for the quiet...to long for stillness before the Lord...to long for my heart to calm in worship and for God to sing over me.

As I processed the lyrics, I found myself stuck on the following lines, “And the thunder of the silence is speaking your peace. When my voice is gone, the storm of your love rages on.” How can thunder speak peace? I thought of my little girls and how storms, especially those at night, yield so much fear they run to our bedroom trembling and need our presence to relax...to feel confident...to rest...to sleep in the storm.

In that moment, I realized there are two types of storms. There are the storms of life that bring destruction and fear. The storms that leave us trembling, hurting, confused, and anxious. They are the types of storms that come because we are human and live in a fallen world. These storms will always threaten our peace and leave wounds. And often these are the storms we never saw coming. We went to bed ok, and the next thing you know our world is upside down...the wind, the rain, the lightening so intense we can barely see in front of us. Then the storm passes but the damage is great and overwhelming.

Our response in these storms can either be to buckle down and tackle it on our own, or to run to Jesus like my little girls in the night. We can try to hold it together, to be strong, to manage the destruction; or we can sit in the arms of the One who saw the storm coming and sings softly over us...the One who knows the fears and hurts before they are spoken...the one whose presence is comforts in the darkness and He never abandons us.

But there is a second kind of storm that I feel this song is truly talking about. There is a kind of storm that is orchestrated by God himself to bring healing, cleansing, and calm. It is the kind of storm that regardless of how hard the season is, there can be peace and hope because the feelings aren't rooted in things of this earth, they are rooted in a longing for Heaven...they are rooted in Jesus. It is the kind of storm that pours rain into the desert...rain that drenches the dry soil of our heart with beautiful healing rain. No judgement for the dryness, only peace that brings hope again...hope that the drought has ended. It's the kind of storm that draws you outside to stand and let the water run over you as it cleanses so completely. It replaces fear with love and strength and peace. It is the storm found when our humanity collides with God Himself and the result is worship...pure worship...the God of all creation meeting us in our hard places and singing over us.

It is then that the words God speaks, will bring us to our knees...because then and only then, can my response be, “Redeemed my heart will sing. This broken melody. This is my testimony.”

As I look at Louie and how our lives have changed so drastically over the past 8 months, I am thankful for the storm – the second kind of storm...the soft thunder of God's voice...the cleansing rain. I don't have answers and I may wish life looked different, but I have all I need...a redeemed heart proclaiming the brokenness of this world and the

healing love of God. This is my testimony.

Here is the link to the song if you would like to hear it yourself...
<https://music.apple.com/us/album/my-testimony-single/1476734894>

Comments

I hope you are keeping these post in a journal . Beautifully written words to the Lord.
Thank you for sharing

—*Sam Bartolotta, August 30, 2019*

Kristy; I have been wondering how our little Deputy Louie is doing, how your family is doing. I never cease to look up at his picture above me as I work and pray for him. Sometimes we just need the silence when we feel so empty and drained. I have been there when nothing seemed to help then a song comes along and truly lifts us up and makes us realize God is there, a song I love so much
<https://www.youtube.com/watch?v=g1rYmj1AN44&feature=share> The song that your friends teenage daughter wrote is so beautiful and meaningful. I know how hard it is to stay strong and it's ok to want the silence for it is then we hear the voice of our Lord speaking. He is with you and Louie, I love you all so much!

—*Diane Huggins, August 30, 2019*

I pray God's song continues to flow over you.

—*Cindy Gordy, August 30, 2019*



—*Barbata McCreight, August 30, 2019*

Amen, amen, and amen! May God continue to strengthen you and fill your heart with worship as you walk through the life He has given. You are a blessing to me and so many others.

—Linda Castello, August 30, 2019

I'm glad He has sent refreshing storms your way! It's sweet to know He is singing over you and bringing peace to your spirit. Thank you for the reminder to just worship our Heavenly Father, King Of Kong's, and Lord of lords. He is worthy. Prayers for your family!

—Lannece Mayo, August 31, 2019

Very Powerful & authentic words... that has the power to speak to every heart. God pour your song over this beautiful family and soothe the weary heart & soul.

—Valerie Frith, September 1, 2019

Kristy this is so profound and you touch me in the mightiest ways with your words and transparency with your feelings , I am so sorry I haven't been on here for some of the same reasons you talked about, I have been struggling with certain matters in my life , but I never fail to get on my knees on pray for you and precious LOUIE and your beautiful family. You are so blessed to have the strength that God has blessed you with .Your family is so blessed to have a Mommy and Wife that is so strong they know they can depend on without waver , that's a gift from God . Your children are so blessed to have you and I thank God for you and the inspiration you have been too me and alot of women that have children or not . I know you have Gods favor upon you in a mighty way. No matter what my husband and I never fail to pray for y'all. We love y'all and don't really know y'all except for fb and Caring Bridge , one day I hope we get to meet face to face. Oh I wanted too let you know I have a drs. appt. with a speacialist from your Alma Mater Baylor on the 20th. Pray everything goes well. I will go for now, give the kids hugs and kisses for me ☺☺☺☺☺☺☺

—Joy Stuckey, September 7, 2019

Medicine and Grace

September 8, 2019

You would think that medicine and overall health is pretty straight forward. You would think that it is black and white. You would think that a degree or a license covers all you need to know. You would think that training is enough to close the gaps when the moments of gray arise.

However, if there is anything I have learned over the past 9 months, it is that the body is so complex that only it's Creator, God Himself, is able to understand the intricacies within each of us. We are more than just a jumble of cells that have come together. I have fat thumbs, brown hair, and allergies I wish I could do without. My girls have blue eyes. My boys tan instead of burn. My husband dreams of running to work. Each of us is unique. Each of us created purposefully. Each of us looking like our Maker.

Louie is no different, yet he is completely different. His medical file is thicker than most...His list of medical issues is long. But, the truth remains, Louie was created by God - intentionally. There was no accident. So as medicine has struggled to understand his body at times, I have found peace in not having to have the answers because I know I can't change the course God has planned for him. Instead, I choose to trust and worship a God who loves my son more than I can even fathom.

AND...I have come to realize that God has also created amazing medical personnel to walk alongside us on this challenging road. After spending half of the week with Louie in the hospital, it has brought me to reflect on the people who have provided him intricate, complex, routine, intense, and delicate care over the past 9 months.

We have had some of the best nurses the world has to offer. People that see beyond medical charts to the needs of a child and the heart of parents struggling to understand. We have had doctors cry with us. We have had child life specialists go above and beyond to bring smiles where there is only pain. We have had an IR team keep us grounded when circumstances were challenging. We have had medical professionals hold our hands, lift our chins, and provide us care when hope was hard to find.

There are so many medical folks I could list by name. So many that have made our journey easier. So many that have seen us at our worst and still believed in us, in our son, and in hope. Hospitals and medical journeys can be overwhelming and threaten to consume one's spirit. They can cause you to doubt yourself and feel like you are a little crazy sometimes - or a lot crazy. Then there are times when you may not see eye to eye with your medical provider. Times when you feel wronged or angry at the care, or lack thereof, that you feel you or your loved one has received. Times that make you question competencies.

After spending so much time immersed in the medical world, I have come to fully believe that in the heart of everyone in the field - even those hard to deal with - there is good. There is a person. There is a real person who is fighting their own battles, and walking their own mountains and valleys. There is a person desiring to make a difference and do what is right even on their hardest days. There is a person needing grace the same way I do.

So today, I choose to be thankful that Louie has improved and we are home. But I am

also very thankful for the men and women in the medical field who have devoted their lives to caring for others. Thankful for a path we don't have to walk alone. Thankful for the answers I don't have to find. Thankful for people who do really hard things...deal with difficult people...sit with crying families...hug hurting parents when the moment overwhelms...and then they go home to deal with their own stuff.

Friends, can you join me in offering grace, love, and gratitude to those in the medical profession today? Can you send a note or text of appreciation? Can you offer a prayer of protection over them? Can you see them as people, not perfect, but trying to give their best in hard places? Can you offer forgiveness not asked for, kindness that may go unseen, and hope that their best will be enough for the needs of those they care for today?

To all in the medical field who have personally cared for Louie and our family in any way, thank you...from the bottom of my heart...from the depths of my prayers...thank you. The gift you have given to my family is more than I can repay. My greatest prayer is that God will give you wisdom for another day...and that you will have the grace to offer back to people and families like ours...people who like you, are trying to navigate this wild journey of life the best they know how. We need each other. We need the Lord. May the gratitude and kindness overtake all differences and give us the courage to press on.

Comments

Amen!

—*Wanda Cook, September 8, 2019*

God bless all of those who give of themselves everyday, yet still carrying their own personal responsibilities. ♥♥ And, God bless Louie, and all of the family. Have a wonderful day. ♥♥□□□□□□□□

—*Candy Gates, September 9, 2019*

Kristy, you are spot on about people in the medical field. They deserve so much more appreciation than they ever get especially from these hospitals. Their jobs are so hard in every way imaginable. And they too are carrying burdens of their own. God bless them for showing up and doing their best with what they are given to work with which is not much sometimes. I borrowed part of your post to share on FB so maybe these people will get some much needed recognition from their employers for a hard job that has been done well.

—Doris Perkins, September 9, 2019

Amen!

—Gigi Parker, September 9, 2019

Amen!

—Robin Hall Guadagnini, September 9, 2019

My daughter is an RN at UAMS. Thank you for this post. Prayers for Louie. Prayers for you and the family and the medical team. Asking God for fresh strength.

—Debbie Hamilton, September 10, 2019

Still praying for Louie and all of you. God bless.

—Dena George, September 19, 2019

AMEN....God is GOOD

—Tacarra Wright, September 30, 2019

Wonderful, prayers continue for all!

—Kathy Carlton, September 30, 2019

Continuing to pray for all of you. Love and hugs

—Linda Davis, October 14, 2019

Continuing to pray for all of you! Louis is an encouragement to everyone. He is a testament to what true love for our Lord and Savior should look like in all of us. Please continue to keep us updated. Your Journals are encouragement to us as well. Love, Prayers, Hugs!

—Brenda Bradley, October 17, 2019

Continuing prayers for precious Louie and your beautiful family, and your words are so profound and deep , I stand with you in lifting all in the medical field up in prayer. I know we all need prayer in this world we live in today. Prayers going up for everyone ☺☺☺☺

—Joy Stuckey, November 12, 2019

Thoughts and Well Wishes

I am going to think about you every day. I hope you are feeling better. Tell your brothers and sisters hello for me. Keep your spirit up. GOD bless you.

— *Parthenia (Tena) Taylor, February 19, 2019*

Hope you are feeling good today. Just wanted you to know that I am thinking of you today. Did you ever get cards from every state? Wishing you lots of love.

— *Laurie Young-Staver, February 20, 2019*

Just wanting to tell you I hope that you are feeling better today. I hope with the sun coming out today it brightened up your day a little. Keeping you in my prayers and sending you love from my heart.

— *Laurie Young-Staver, February 23, 2019*

Hoping and praying that your last journey on this side of heaven is peaceful and pain-free, your story has touched me deeply. Thank you for your love, friend.

— *David Brooks, February 28, 2019*

My heart hurts so much for your family. I see my boy in you Louie. He's had a rough go of it too - GI, neuro, genetics, feeding tubes, hospitals all over the county, and no answers. Your bravery and the bravery of your mom and dad have made me braver. You've strengthened my faith; you've reminded me that no matter my son's outcome there is a God who loves and protects him when I can't. Thank you for sharing your story with the world; it has inspired many. I am praying for you all.

— *Josh Bryant, March 1, 2019*

Sending my prayers and positive thoughts to Louie and his precious family. God bless you at this special time.

Know how much Louie's precious life has touched so many for Christ. What a special family you are and you are truly so special to so many. God bless Louie and I pray as he meets Jesus he will be whole and well again in the presence of our Lord. Much love.

— *Linda Duncan, March 2, 2019*

Hi Louie, my name is Joy and I seen you on FB and I thought you have got too be the sweetest boy I have ever seen ,your smile is precious and the way you love Jesus just humbles me to the core , I know Jesus is smiling down on you right now Sweetheart , your are in my thoughts and prayers and my husbands too, we are praying for your family also , God is so good, we see and feel his wonderful blessings everyday , just know that you have touched and blessed so many people with your unshakable faith and such a pure humble heart ,I know you have me ,I am so thankful for you and how you have touched our lives, I will send you another message later????

— *Joy Stuckey, March 3, 2019*

God's power is amazing! Jesus cured the lame, the blind, the lepers. We must remember to in all trails consider it joy. What a blessing Louie's journey is. Praying for family strength and peace.

— *Louann Smith Harasym, March 4, 2019*

????????????

— *Don-Marilyn Matzig, March 7, 2019*

Dear Louie, Love your smile! Love your beautiful heart you have for Jesus! Wish I Could give you a big hug! I'm praying daily for you buddy and your beautiful family.
Love you! Debra Worsham

— *Debra Worsham, March 7, 2019*

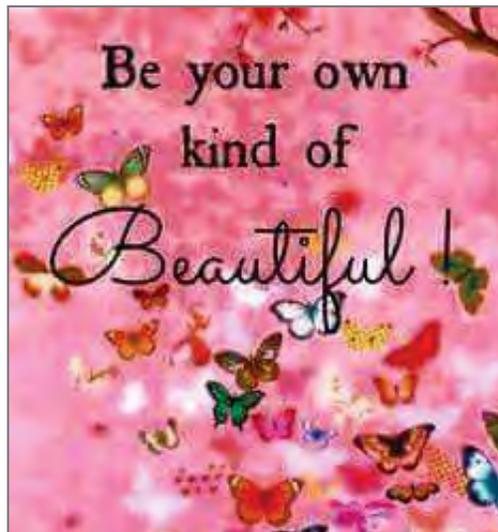
I love and miss you, Louie! Thinking about you always and praying for a miracle. Regardless of what happens, you will always have a very special place in my heart. Stay strong and keep spreading the love of Jesus! I am

so proud of your bravery and faith!!!

— *Elisa Brown, March 8, 2019*

Hello Louie, I was thinking about you, I love your mohawk very much, your such a handsome young man , my husband and I are steadily lifting you and your family up in prayer , I am saving all your videos, they are very special too me , you will forever be in my heart and soul, we Love you so so much ,you enjoy your family and friends and the rest of us will enjoy you ,you are so precious, I am so blessed to have got to get to know you through our phones, tell Mama to take care of herself we're praying for her, I will write you again soon,Love you always Sweetie ???

— *Joy Stuckey, March 13, 2019*





**GOD WILL SHOW UP
IN YOUR SITUATION**

- On Time!
- On Point!
- On Purpose!

Good morning

— *Joy Stuckey, March 13, 2019*

We are still praying for you and Sweet Louie, I have been in that same position with the small room and Jesus always worked it out for me and my husband , I am so sorry that Louie had such a bad time, I pray for him and the peace that surrounds him and you , it's only natural that you need to let some things out when you can, and I understand that completely, I went through that with my husband, he caught pneumonia in 2003 and spent a week in ICU the drs couldn't guarantee me anything so I know what you are going through, but no matter what we are going to continually lift y'all up in prayer ???

— *Joy Stuckey, March 15, 2019*

Hey Louie, how are you doing this morning? Know that you are always in my thoughts and prayers and so is your Mama, I saw your new coin that is awesome, your so precious to us all ,I am so thankful that I have had the chance too share your life and mine together ,God works in mysterious ways, he is an Awesome God , I can see and feel him when I look in your beautiful eyes and smile, that smile of yours is enough to lift me and my husband up in a big way , see my husband Wayne is sick too so I understand how you feel and how your Mama feels , well I wanted to wish you St. Patricks Day , Love you always ???

— *Joy Stuckey, March 17, 2019*



— Joy Stuckey, March 20, 2019

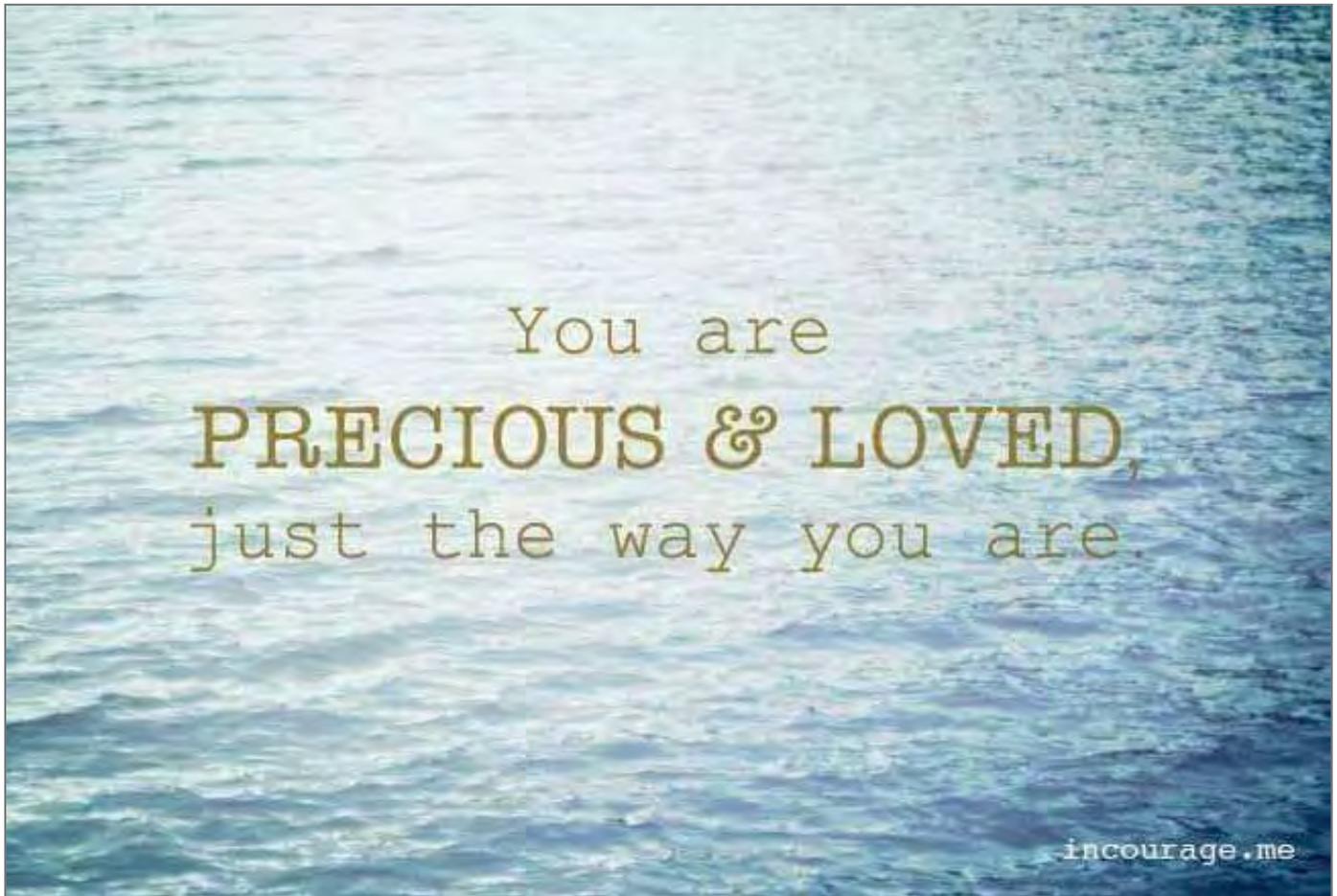
**Whether you're happy,
sad, lonely, far away,
mad or blue, this little
hug is meant for you.
Send me on to someone
you know, to see how
far this hug can go.**

~Leana Haasbroek



**You
are
VERY
Special**

— Joy Stuckey, March 20, 2019



— Joy Stuckey, March 21, 2019

Thinking of you this evening.

— Angelena Van Don, March 22, 2019

Keeping you and your family in my thoughts and prayers, Louie??
You are an inspiration to many people, myself included!!

— *Vicki Barney, March 23, 2019*

Please tell Louie that deputies with the Galveston County Sheriff's Office and police officers from many surrounding agencies are praying for him, for y'all, and for a successful trip to Houston. Let him know we are putting together a little something for him -- he is a hero in our eyes. Much love and strength to you.

Deputy Crystal Robinson
Galveston County Sheriff's Office

— *Crystal Robinson, March 25, 2019*

Hello Sweet Louie, I have been praying for you and I am not going to stop till Jesus answers my prayers, you are a light in this dark world we live in, I think about you constantly, that beautiful smile and your gorgeous green eyes just draw me in and you are wearing the light of Jesus all over you , what a blessing you are too all of us following you and your Mama , you have a awesome Mom ,I really admire her strength and courage and yours too, I have been praying and asking Jesus to help me too be more like you , I want child like faith and inner strength as strong as yours, I am working on it with Jesus and so is my husband Wayne, we have come to love you and your family even though we haven't formerly met , but maybe By The Grace of God, we will get to do that. I know I would just fall in love with you , you're an amazing little boy ,we are praying for a miracle from God for you, but it's all in God's hands and we have too trust in him no matter what, well I was just wanted to let you know that I was thinking about you and wanted you to know that we are praying without ceasing , that comes from the bible, when you want God too answer a prayer, we pray without ceasing ,check on you tomorrow ,Lord Bless You Sweetie and your Mom ???

— *Joy Stuckey, March 26, 2019*



— Joy Stuckey, March 26, 2019

Faith, Hope

& Love, but the
greatest of these is



LOVE

1 Corinthians 13:13

BibleVerseImages.com

— *Joy Stuckey, March 26, 2019*

So blessed to have been able to meet you and your family, my thoughts and prayers are with you and I'm sending love from Florida.

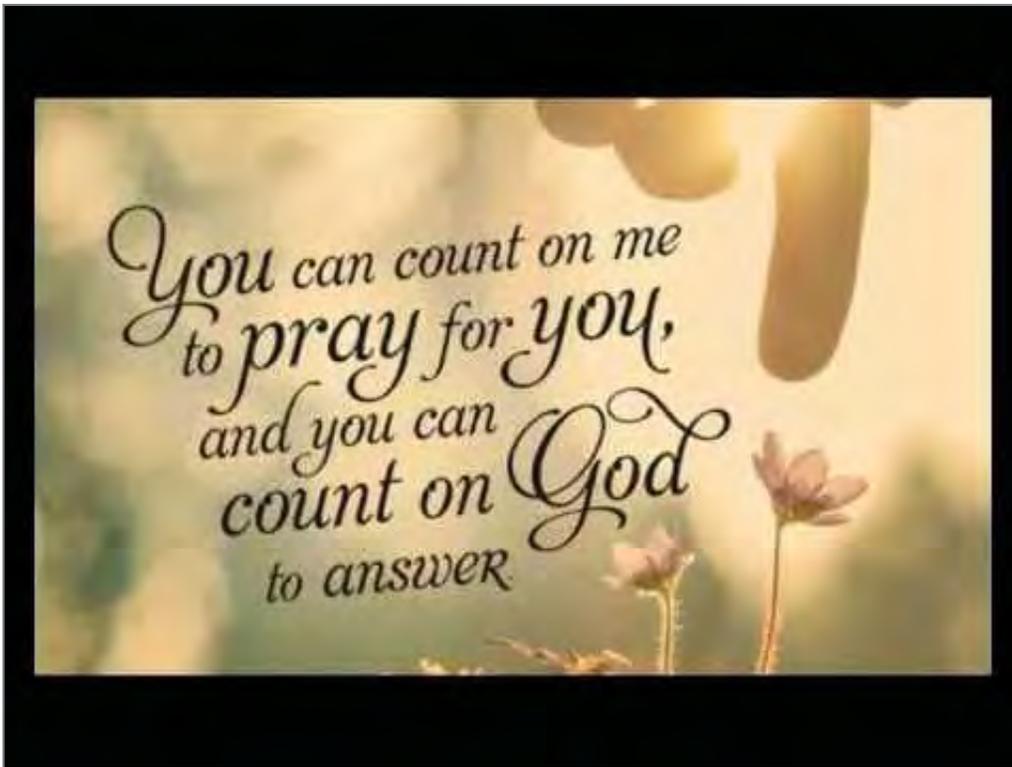
— *Jennifer Cardonick Walker, March 27, 2019*

Thoughts n prayers are with you n your family today saw you on the news the other night love your smile

— *Judy Ford, March 28, 2019*

It's just a bit past 2 in the morning. I can't sleep, so I am offering up prayers now for you, sweet Louie, and for your amazing mommy and family. May the peace of the Lord be with you all. Amen.

— *Susan Anderson, March 30, 2019*



— Joy Stuckey, April 1, 2019

Praying for Louie and all of your family. I just read your update and will be praying for Mayo appointments to be set up quickly.

— Rista Nichols, April 3, 2019

Will continue lifting your family up in prayers daily. Thank you for sharing Louie and your incredible trust in Christ with each of us. May he cradle you all in his arms and give you the kind of peace, joy and strength that only comes from him.

Love to sweet Louie!

— Debra Worsham, April 3, 2019

Just wanting to say Hi to Louie and hope that he feels better today. Loved the story you told. It was so inspiring. I have never thought about making the use of the time and things you do in a day the way you described it. I am going to do this for my grand children and myself. Thanks for bringing to light the way God

wants us to spend the time we have making memories !!! Bless you all.

— *Laurie Young-Staver, April 12, 2019*

Prayers and super happy wishes from Shreveport, LA! You are so inspiring, Louie!! We love you!!

I am O negative and CMV negative. I am happy to donate blood to Louie if it will be of any help!

— *James Monk, April 15, 2019*

Praying for Louie! Praying for comfort and strength for the parents

— *Sheila Houser, April 27, 2019*

Praying for Louie daily. Praying all goes smoothly on your flight to Rochester. We will be back in Rochester on the 30th. Kristy I would love to help if there is anything we can do. We can run errands, give you rides, bring you supplies literally anything you need. We will be moving into our rental house on the 1st and we are only 4 miles from Mayo. My phone number is 501-230-8850. Praying for all of your family and I am so thankful all the prayers worked and you are on your way to Mayo next week!

Love,

Rista

— *Rista Nichols, May 23, 2019*

What an amazing young man you are raising. I will say a prayer for him that the outstanding doctors at the mayo find a cure for what is ailing him. You are in great hands at that facility.

If you are in Rochester for a while longer, would it be possible to bring some drawings to him from my son? I'm sure he would love to put a smile on boys face.

Best of luck for you and your family. Prayers for all.

— *Ammie Murphy, June 1, 2019*

So glad to hear that you are lucky to have the 3am friends to help you. Praying for all of the Drs to find a plan for Louie. You are such a strong person. Louie is so lucky to have you as a mom. Tell Louie HI from Arkansas and we will be glad when he gets to come back home.

— *Laurie Young-Staver, June 4, 2019*

Louie and family,,

The emotions that anyone going through this type of process knows that they are physically and emotionally draining. I have been there with my family working with my health issues as well. I appreciate the fact that you know you are being guided by God's hand to where you are at. The lives that you and your family are touching will reach far beyond what you may know. I pray that as you walk this unwelcome path you are comforted and realize we are where we are for His purpose. Continue to share your story as it is a blessing to be able to share your walk.

I pray for answers and healing may take place. I will continue to pray for your safety, health and well being in the days ahead. Blessings going forward each and everyday and everyone you meet.

— *RObert Veldkamp, June 7, 2019*

Praying for you and hopeful test results at the Clinic will give you the answers you need to help Louie. Seems not a day goes by that I don't have you all close in thoughts and prayers. He has taught all of us so much and reminds me to stop and live in the moment, appreciating all the beauty in each one of us. He is truly a remarkable young man as is your family.

— *Meg Hartle-Swimelar, June 9, 2019*

Today is a clean slate. Today I praise our Abba Father for Louie and your family. Today, as everyday I am awed by Louie's precious ministry. Today I'm thankful for your beautiful words of ministry, Kristy. Today I will use the example of Christ in Louie's life to guide me. Today I will stretch and exercise my faith on behalf of those whose spirits are being trampled and broken; God have mercy.

— *Cindy Krueger, June 12, 2019*

As I sit here this morning praying for you my mind is a little bit of everywhere. I have a congenital heart defect, on my second pacemaker. It's a defect passed on to my children and grandchildren. I have some understanding of the issues when I pray. I also find myself praying from a sense of loss. In 2017 I had to say goodbye to one of my grandchildren. From my heart to yours, please know that I am always praying.

— *Angelena Van Don, June 15, 2019*

Prayers for Louie and his family. May God bless us within your beautiful smiles for years to come. God be with you m

— *Tina Saenger, June 18, 2019*

I hope u continue therapy and help with making everything easier for y'all and trusting in the good lord for the decision that can be made for us anytime. The affected ppl and good natured fun and positive attitude and prayers can be better medicine along with great outlook on life and family and friends. People that care unconditionally and prayers will guide you the way you are wanted by our lord and savior. Call or txt me and I'll see if I can get some razorback football players to join in a game with us 501-504-9520, Id love to let ya meet some razorback football players!!!

— *David Spillers, July 17, 2019*

Louie I continue to pray for you and your family

— *Vada Harris, October 15, 2019*

Louie I continue to pray for you and your family. We have not heard from you in a while. Praying that is a good sign.

— *Vada Harris, October 16, 2019*

Hi Kristy & family,

Thinking of all of you and hoping everyone is well. Hope your family had a fun Halloween. I look at last years

picture and smile.

Love, Judy & Ed

— *Judy Kramer, November 1, 2019*

Louie praying for you!! Hoping you are doing better. We love Louie??????

— *Vada Harris, November 2, 2019*

Continuing to pray for you Louie and for your family.

— *Sue Henson, November 2, 2019*

How is everything going?? Prayers sent everyday.

— *Rena Smith, November 3, 2019*

Louie and Family, I have been missing pictures of you and your adventures. We still have brownies in our freezer for the family. I think we will eat them and make some fresh!?

— *Terri Morris, November 3, 2019*

I have been thinking about all of you. Haven't seen a up date in a while. Keeping prayers coming your way.

— *shawndra oglesby, November 3, 2019*

I have not heard from you in a while. On going prayers for you and your family. ???

— *Rachel Waddle, November 3, 2019*

Tributes

You have touched me Louie. Prayers continue for strength. Love from Knoxville TN! I know you have a special angel watching over you.

—*Stahr Family, February 14, 2019*

May God bless you! You are in my prayers!

—*Peggy Moser, February 15, 2019*

Keep fighting Louie. We love you and think about you a lot. Hope you are getting lots of cards.

—*Tena and Larry, February 19, 2019*

I will say a prayer for you !! God love you, little boy !!!

—*Curt Davis, February 20, 2019*

My cousin tagged me in your story on the Project Zero page. I'm so thankful she did. It gives my heart stir when I see your smiling face. Stay strong Louie. I look forward to your updates. Bunches of love and many, many prayers sent to you!

—*Your New Friend, Genie Handley, Houston Tx, February 21, 2019*

Praying for Louie and family.

—*In Christ's Love, Diane, February 28, 2019*

—*Stephen J Lemley, March 3, 2019*

—*Loran Sullivan, March 4, 2019*

Praying for you sweet Louie and your family

—*Morgan Salinas, March 4, 2019*

Louie, I have a 9 year old grandson named James. James and I love you very much because have reminded us about how wonderful Jesus is. We are thanking Jesus and your family for letting us get to know you. You are awesome!

—*Susan Anderson, March 6, 2019*

Louie fills my heart with so much joy! I don't personally know him but I love him so much and can't imagine now not knowing him and following him. I wish whoever is reading this will give him a hug and kiss for me and whisper Christ's love for me

—*Charlie Chambers, March 9, 2019*

We are praying for you guys and thinking of you and sweet Louie.

—*Cristi and David Wean, March 9, 2019*

Loving thoughts to Loving Louie

—*Susan Anderson, March 12, 2019*

Stay Strong For Louie

—*Someone Who Cares, March 12, 2019*

—*Diane Walker, March 14, 2019*

We pray for Louie and we pray for you. Can't even imagine this journey you are on and the strength it takes to continue. Only with God's grace. We too believe in miracles and know that nothing is impossible with God. May He bless you and keep you all.

—*Connie and Michael, March 14, 2019*

I love you Louie and his family! God is amazing!

—*Charlie Chambers, March 15, 2019*

—*Amber Johnson, March 23, 2019*

God Bless all the Louie's and their parents who give so much of the themselves in the name of Love!

—*Bob & Laura Owens, April 12, 2019*

Prayers and blessings

—*Mike Dorr, April 12, 2019*

Blessed Easter to you and your family. Christ has Risen and is walking hand in hand with you and your family . We love you and pray without ceasing for all of you.

—Love, Judy & Ed, April 21, 2019

Happy Easter Blessings to Louie and the entire Schneider Family. May the peace of the Lord be with you always!

—Ronald Anderson, April 21, 2019

Louie and your gift of writing and sharing his story are such an inspiration and encouragement to me and others! Cheering for you guys all the way! Love you and your sweet family so much! Gina Brown

—Watching And Praying From Afar, Your Friend And Sister In The Lord, Gina, April 29, 2019

—Jennifer Crimeni, May 2, 2019

I'm in. Thanks for providing opportunity for everyone to show support.

—Betty Guhman, May 16, 2019

You're in my prayers

—Robert Reeder, May 17, 2019

Thank you for sharing the stories of Louie's sweet spirit. God is so good. May his goodness show through us all more and more!

—*Theresa, May 19, 2019*

Thanks for sharing Louie's 'Holding Hands' story, which safely delivered him to Mayo. Blessings in Abundance!

—*Toni & Richard Mattson, May 29, 2019*

Louie.....we got your back dude! Glad you got to meet Kevin and John in Rochester! Two of the men we should all try to be more like! God Bless you and your family!

—*Tim , Missy and Trevor Simmons, June 8, 2019*

—*Lori Determan, June 11, 2019*

My heartfelt prayers are being offered to our God, the Great Physician on Louie's behalf every day. God bless and keep your family!

—*Polly Gan, June 12, 2019*

Thank you for sharing Louie's and truly your family's story with us. Believing God is using you to bring hope and encouragement and deepen the faith of each person reading.

—*AnneMarie, June 12, 2019*

Louie you are my hero! God Bless You!

—*ERIC, KIM & CHRISTIAN TINNER, June 12, 2019*

Luv your comments, it is so true. We don't know what tomorrow will bring for any of us. But I know like Louie, who holds tomorrow. Thank you for this reminder. My prayers are with you. Donna Lemons Emma's Gigi

—*Gigi, June 20, 2019*

Praying for the perfect strength of God to keep you moving forward IN HIS WILL!!!

—*Cindy Gray, July 1, 2019*

—*Jen Linck, July 22, 2019*

ARKANSAS COURT OF APPEALS

DIVISION III
No. CV-20-111

KRISTY SCHNEIDER AND
ERIK SCHNEIDER

APPELLANTS

V.

ARKANSAS DEPARTMENT OF
HUMAN SERVICES AND MINOR
CHILD

APPELLEES

Opinion Delivered: September 30, 2020

APPEAL FROM THE SALINE
COUNTY CIRCUIT COURT
[NO. 63JV-19-271]

HONORABLE GARY ARNOLD,
JUDGE

AFFIRMED

WAYMOND M. BROWN, Judge

Appellants Kristy and Erik Schneider appeal the December 3, 2019 adjudication order by the Saline County Circuit Court finding that their son, L.S., was dependent-neglected due to abuse (Munchausen syndrome by proxy), neglect, and parental unfitness. Appellants argue first that the DHS/Children’s Hospital interpretation of “Munchausen Syndrome by Proxy, also known as factitious illness by proxy” accepted by the circuit court is at odds with both the statutory requirement and the definitions accepted within the medical profession. The application of this ad hoc definition also violates constitutional guarantees. This misapplication fatally taints the allegations against both parties. Next, they contend that the circuit court’s posthearing attempt to redefine the allegations violates rules

**EXHIBIT
B**

of procedure, constitutional requirements, and the court's own pretrial guarantees. Finally, they argue that the circuit court's findings of facts are clearly erroneous. We affirm.¹

Appellants adopted L.S. in Pope County in September 2014. L.S. has been diagnosed with a chromosomal abnormality, cognitive learning delay, seizure disorder, reflux, rumination, and heart rate variability with a pacemaker. These medical conditions required him to be seen and treated by several doctors at different clinics. In December 2018, he was admitted to Cincinnati Children's Hospital for testing. He was eventually placed in the pediatric intensive care unit (PICU) there due to issues with his heart rate and blood pressure. He was subsequently transferred to the PICU at Arkansas Children's Hospital (ACH) between late 2018 to early 2019. While in PICU, he received feeding through a feeding tube, known as a total parenteral nutrition (TPN). He also received a pacemaker due to ongoing issues with his heart rate and blood pressure. An epinephrine drip (EPI) was used at ACH to maintain L.S.'s heart function. Because the EPI was ineffective, ACH suggested that it be removed, and appellants were informed that no one knew what the outcome from removing the EPI would be. L.S. was discharged home on TPN on January 11, 2019, with hospice services in place. L.S. remained on TPN and was prescribed fentanyl and morphine.

Appellants concluded after meeting with ACH's palliative-care team that L.S.'s TPN would be withdrawn so that his natural death would occur. At the end of February 2019 L.S. returned to ACH for what was believed to be his final days alive. There was a send-

¹This case was orally argued on September 16, 2020.

off parade for him, which included first responders from numerous agencies since it was reported that he wanted to see as many first responders as he could before he died. L.S. was taken off the TPN for nine days and appeared to look better than he had in months. Appellants decided to put L.S. back on TPN, and he stayed in the hospital for about a month. After his dismissal, he made several public appearances at baseball games, parades, etc.

L.S. was seen at the Mayo Clinic in Rochester, Minnesota, between May 28, 2019, and June 14, 2019. While at Mayo, he was seen by doctors in complex care, neurology, cardiology, GI, pulmonology, nephrology, urology, genetics, and pain management. He was placed on a new heart medicine, Digoxin, before he left Mayo. Mayo did not believe that L.S. was a candidate for hospice care at the time of his dismissal. It was anticipated that he would slowly wean off his pain medications; however, that did not take place until sometime in August. On August 9, Dr. Travis Ayers placed an order to have a port placed in L.S.'s chest. Dr. Spencer Lewis placed L.S.'s port on August 19, 2019, pursuant to Dr. Ayers's order.²

L.S. was readmitted to ACH on September 4 due to a possible infection of his port. He was discharged on September 6. DHS received a hotline report on July 20 concerning all the Schneider children, except P.S. The allegation was that Kristy was causing the children to be sick. DHS made contact with her on July 23 and went over the allegations. DHS spoke with L.S. at school on September 3 and 9. They also talked to P.S. on

²The port was subsequently removed in November, after approximately three months.

September 9. DHS spoke with school personnel on September 3 and sometime after September 9. A new hotline report was received on September 11 alleging that Kristy was misrepresenting the severity of L.S.'s condition, which was causing him unnecessary medical care, and interfering with knowing how to care for him. It was also alleged that Kristy was misrepresenting L.S.'s pain and providing false information between his different medical providers. DHS removed L.S. from appellants' custody that same day.

A petition for dependency-neglect was filed on September 13. It alleged that L.S. was dependent-neglected and at substantial risk of serious harm as a result of abuse, neglect, and parental unfitness. The supporting affidavit laid out additional facts and indicated that L.S. was removed because the caretaker was unwilling or unable to meet his needs for food, clothing, shelter and/or medical or mental healthcare. It also stated L.S. was removed because the caretaker failed to protect L.S. from serious physical or threatened harm. The medical affidavit of Dr. Karen Farst was also included with the petition. She stated that the misrepresentations by Kristy were making it impossible to accurately assess L.S.'s current condition and make accurate care and treatment plans. She further stated that his medical conditions placed him at substantial risk for complications if he is not provided an accurate treatment and care plan. The probable-cause hearing took place on September 18, and in the order entered on October 31, the court found that probable cause existed for DHS to remove L.S. and that the issues that led to removal still existed, making it necessary for L.S. to remain in DHS's custody.

The adjudication hearing took place November 14, 15, 20, and 21. Testimony and exhibits consisted of thousands of pages. At the conclusion of the hearing, the court

instructed the parties to submit proposed findings of fact and conclusions of law, which everyone did. Appellants filed objections to both DHS's and the ad litem's proposed findings and conclusions. The court filed an order on December 3 granting DHS's motion.

The order stated in pertinent part:

3. The Court finds by a preponderance of the evidence that the juvenile is dependent-neglected and that the allegations in the petition are true and correct. The Court grants the request of the Department that the pleadings conform with the proof. The Court finds the juvenile was at substantial risk of serious harm from abuse, neglect, and parental unfitness, as alleged in the Department's Petition for Dependency Neglect, pursuant to Ark Code Ann. §9-27-303 (18)(A)(ii); §9-27-303 (18)(A)(v); §9-27-303(18)(A)(vi). Specifically, as to abuse by mother, subjecting a child to Munchausen syndrome by proxy, also known as factitious illness by proxy (now also known as Pediatric Condition Falsification), when reported and confirmed by medical personnel or a medical facility. With regard to neglect by mother and father, the parents' failure or refusal to provide the necessary nutrition and medical treatment for the juvenile's well-being. Specifically, as to parental unfitness by mother and father, a fit parent would not exaggerate or misrepresent symptoms to medical professionals and a fit parent would not acquiesce to another caregiver's false reporting. The dependency neglect finding is based on the evidence presented at the hearing, which included the testimony of six medical providers, five of whom were qualified as experts in their fields, and medical records. This evidence established that [L.S.] has been portrayed by Kristy Schneider as being in significant and persistent pain even though this is not corroborated by medical providers. These representations resulted in the child being subjected to high doses of narcotics (including fentanyl, Ativan and morphine), an unnecessary medical procedure, and being denied nutrition, all of which threatened the child's health and potentially his life. Evidence also established that within days of being placed in DHS custody, [L.S.] transformed from a wheelchair-bound child on artificial nutrition, to an ambulatory child, able to eat normal food by mouth. The Court is exercising its discretion under ARCP 15(b) to amend the pleadings to conform to the proof with regard to specific findings based on testimony and evidence presented in this hearing.

4. The Court makes the following findings of fact:

- a. [L.S.], dob: 5-27-2009, was adopted by Kristy & Erik Schneider in 2014.
- b. [L.S.] has been diagnosed with a chromosomal abnormality, cognitive learning delay, seizure disorder, reflux, rumination, and heart rate variability treated with a pacemaker.

c. The Court finds Dr. Aime Jones, a physician at the Mayo Clinic in Rochester, Minnesota, to be an expert in the fields of pediatrics and complex care, and finds her testimony to be very credible. The Court notes that she testified via teleconferencing. Dr. Jones testified that she first learned of [L.S.] due to a family-initiated request for consultation, and she first saw him on May 30, 2019 when [L.S.] and his mother came to the Mayo Clinic. At initial evaluation, Dr. Jones found it interesting that medical outcomes were unusual based on the history provided. Ms. Schneider described severe pain for [L.S.] that were not observed in clinic. Dr. Jones asked Ms. Schneider to bring [L.S.] to clinic when he was in severe pain so they could evaluate; she never did so. Dr. Jones reported that a Pain Specialist documented that [L.S.] pointed to his stomach and said he was in pain, but the staff found that the child was in no distress. Dr. Jones stated that doctors treating children heavily rely on parents' descriptions of their children's pain and symptoms when deciding what treatments are warranted. Dr. Jones said that the Mayo team felt strongly that a careful wean of narcotics was needed in order to determine [L.S.'s] baseline medical conditions. She also reported that Ms. Schneider had taken [L.S.] to the Mayo emergency room because his PICC line had broken, and she had requested the insertion of a port in the ER, but that request was denied. Dr. Jones explained that a port is a surgically placed line in the chest, and that it was not necessary in [L.S.'s] situation, and would subject him to risks of blood clots and infection. Dr. Jones denied that [L.S.] had been diagnosed with dysautonomia, a dysfunction of the nerves that regulate nonvoluntary body functions such as heart rate, blood pressure, etc.

Dr. Jones testified that she had conversations with [L.S.'s] primary care physician in Arkansas, Dr. Meghan Repp. Dr. Jones said that it is common practice for Mayo to communicate with a patient's primary care physician, as this fosters continuity of care. Dr. Jones told Dr. Repp that she had some concerns about Ms. Schneider's representations of [L.S.'s] pain and had concerns her reports were not accurate. Dr. Jones informed Dr. Repp that Ms. Schneider endorsed and requested a port, but that Mayo did not support or agree with have a port placed in [L.S.]. Dr. Jones stated she confirmed this with the other doctors at Mayo. Dr. Jones stated Mayo's recommendation against a port was documented in her medical notes. As well, Dr. Jones testified that Ms. Schneider requested a referral for hospice, but Mayo did not agree that a hospice referral was warranted and declined her request. Dr. Jones testified that Mayo did not tell Ms. Schneider [L.S.'s] gut was broken or that [L.S.] had a poor prognosis. Mayo Clinic did not recommend that [L.S.] return to Mayo Clinic before trying oral feeds.

Dr. Jones said that although the Mayo Cardiology Department had discussed future appointments for [L.S.], the GI department did not have any scheduled appointments. In fact, Mayo recommended to Ms. Schneider that they contact Cincinnati Children's Hospital for requests for GI appointments due to

Cincinnati's expertise in pediatric GI. Dr. Jones testified that Dr. Repp asked her if Mayo recommend that [L.S.] had to be stable on digoxin before starting his narcotics wean, and Dr. Jones told her this wasn't accurate; rather, Mayo recommended starting the narcotics wean immediately. Dr. Jones informed Mrs. Schneider that if chronic pain was an issue for [L.S.], she recommended he see a psychologist or their TENS unit. Dr. Jones mentioned that Ms. Schneider had contacted Mayo since September 11, 2019, the date that [L.S.] was placed in the custody of the Arkansas Department of Human Services, to try and schedule a return appointment for him.

Dr. Meg[han] Repp testified that she has been [L.S.'s] primary care physician since April 2018. The Court finds Dr. Meghan Repp to be an expert in pediatric medicine and finds her testimony to be very credible. Dr. Repp testified that she relies on caregiver reporting and that if she is provided misinformation it could result in an inappropriate treatment plan for a patient. Dr. Repp started having concerns over the first 3-4 visits. Specifically, Ms. Schneider showed Dr. Repp a photo of [L.S.'s] GJ site which appeared red and possibly infected. When Dr. Repp examined [L.S.] in person the next day, the site did not appear infected and Dr. Repp found this to be unusual. Ms. Schneider, on more than one occasion, reported to Dr. Repp that [L.S.] had swelling and vital sign abnormality-specifically low blood pressure and heart rate. Dr. Repp never found swelling on [L.S.] upon examination, and had the school nurse check his blood pressure and heart rate on multiple occasions and those reports were normal. Dr. Repp had concerns that [L.S.] was malnourished and recommended that Ms. Schneider try to increase either the number of calories or the rate of [L.S.'s] feeds. Dr. Repp recommended she try this through either his GJ tube or through oral feeds. Ms. Schneider consistently reported that when she tried to increase the calories or rate of feeds it would cause abdominal pain and distention. Dr. Repp found this unusual because she was recommending small changes that typically do not cause any pain. Dr. Repp provided support to the Schneider family when they made the decision to admit L.S. to the hospital and have his TPN nutrition stopped in March of 2019. Dr. Repp testified that she was never under the impression that the Schneiders felt pressured by ACH to withdraw the TPN. Dr. Repp testified that she thinks the reason [L.S.'s] health improved while he was at the hospital for his TPN withdraw was because the hospital was allowing him to drink liquids and eat popsicles upon request. During a home visit prior to his hospital admission, Dr. Repp saw [L.S.] ask his mother for a popsicle. Despite the doctor's encouragement, he was not given a popsicle during her visit. Dr. Repp spoke with Ms. Schneider after the TPN withdraw was stopped, and found it odd that she made the comment that [L.S.] "did a bad job of dying."

Dr. Repp testified at length about her concerns regarding Ms. Schneider's reports of pain for [L.S.]. She examined [L.S.] 23 times, and only on 2 examinations did she observe abdominal pain. On those 2 exams, the pain was

not severe and [L.S.] was able to be distracted from the pain. Dr. Repp stated that Ms. Schneider continued to report abdominal pain and distention in the months leading up to [L.S.] entering foster care. Dr. Repp testified that she had very specific concerns regarding Ms. Schneider's report of pain on August 28, 2019. Ms. Schneider contacted Dr. Repp's office and reported significant pain, to the point it was recommended she take [L.S.] to the ER if she is truly unable to control his pain. Dr. Repp's medical note states that Ms. Schneider reported "he has been off his fentanyl and morphine for 2 weeks now, and ever since getting below 50 mcg per day of fentanyl, he's crying out about abdominal pain during the day and night." "She also states 'we are at our breaking point.'" After checking the next day, Dr. Repp learned that [L.S.] was not taken to the ER to have his pain evaluated. Similarly, Ms. Schneider contacted Dr. Repp's office on September 3, 2019 with concerns that his port site was infected. Dr. Repp testified that a port site infection could be very dangerous, and it was recommended that she take [L.S.] to the ER to have the site evaluated. Dr. Repp learned that [L.S.] was not taken to the ER, rather he was on a float the Saline County parade the evening of September 3, 2019. He was taken to the ER later the next day.

Dr. Repp testified that she had several conversations with Ms. Schneider after she returned from the Mayo clinic in June 2019. Dr. Repp obtained the records from Mayo prior to meeting with Ms. Schneider. Ms. Schneider also provided Dr. Repp with Mayo records, but Ms. Schneider omitted the record regarding pain management and recommending the narcotics wean. Dr. Repp was concerned that Ms. Schneider failed to mention, at all, that Mayo recommended weaning [L.S.'s] narcotics. Dr. Repp's concerns regarding the narcotics wean were documented in detail in her medical records. Ms. Schneider informed Dr. Repp that Mayo recommended [L.S.] should be stable on his digoxin prior to starting the narcotics wean. Dr. Repp found this unusual, and when she contacted Mayo she learned this was not their recommendation. Ms. Schneider informed Dr. Repp that Mayo, specifically Dr. Jones, recommended [L.S.] have a port placed for his TPN feeds. Dr. Repp found this very unusual because it was her understanding they were going to try and move away from TPN and get [L.S.] back on feeds. Ms. Schneider informed Dr. Repp that Mayo said [L.S.'s] gut was broken. Ms. Schneider informed Dr. Repp that once [L.S.] was weaned from his narcotics, he was to return to Mayo for further gut testing, and shouldn't try oral feeds prior to the gut testing. Dr. Repp told Ms. Schneider that she would confirm this with Dr. Jones, at which point Ms. Schneider stated that maybe it wasn't actually Dr. Jones who made the recommendation for a port, but a nurse named Amy. Dr. Repp contacted Dr. Jones who informed her that no one at Mayo recommended a port, and in fact they strongly disagreed with [L.S.] receiving a port. Dr. Repp also checked with Mayo clinic who informed her that [L.S.] did not have any future GI appointments at Mayo, and they had recommended she return to Cincinnati Children's Hospital for any future gut

motility testing. Dr. Repp testified at length about her concerns that Ms. Schneider was resistant to weaning [L.S.'s] narcotics. Dr. Repp testified that Arkansas Children's Hospitalist, Palliative Care, and Mayo Clinic had all discussed weaning narcotics, and ultimately it was only at the insistence of Arkansas Children's Hospital (ACH) that the wean was initiated. ACH recommended admitting [L.S.] to the hospital for the wean, but ultimately allowed Mr. and Ms. Schneider to do the wean at home. Dr. Repp also recommended that [L.S.] see a psychologist to help him deal with pain control but Ms. Schneider did not want to pursue this treatment because she herself was a therapist and could handle [L.S.]. Dr. Repp testified that she has had training in child abuse pediatrics, but that is not her specialty, and she relied on both her training and communication with the child abuse pediatrician at Arkansas Children's Hospital (Dr. Karen Farst) regarding how to handle [L.S.'s] care. Dr. Repp testified that her training was clear in cases of suspected Munchausen's by Proxy cases that the doctors must start collaborating with each other prior to questioning the caregiver about their suspicions. Dr. Repp testified that earlier this spring [L.S.] was small, appeared malnourished, was quiet and kind, often in a wheelchair and on oxygen. She has seen him 3 times since he entered foster care and he had gained approximately 7 lbs, was walking and jumping, and was not on oxygen. In addition to her concerns regarding the discrepancies in Ms. Schneider's reporting of symptoms and Dr. Repp's examination of [L.S.], Dr. Repp also had concerns regarding the Schneider family interactions. Specifically, she attended a farewell party for [L.S.] at ACH, followed by a private Baptism ceremony at Arkansas Children's Hospital therapy pool. These events were scheduled after the decision was made to remove TPN and the expected outcome was [L.S.'s] death. Dr. Repp was concerned that [L.S.] was notably upset at the baptism, and neither Mr. nor Ms. Schneider comforted [L.S.] at all, although at one point his brother did approach him and comfort him. Dr. Repp testified that she agrees with Dr. Farst's pediatric diagnosis for [L.S.], Munchausen's by Proxy.

Dr. Karen Farst, director of the Team for Children at Risk (hereafter TCAR) at Arkansas Children's Hospital, also testified at the hearing and was qualified as an expert in the fields of pediatrics and child abuse pediatrics. The Court finds her testimony to be credible. She stated that after reviewing [L.S.'s] medical records from various providers, talking with his doctors and the Arkansas Department of Human Services, and after [L.S.'s] transformation after he was separated from his parents, she concluded that [L.S.] was a victim of Munchausen by Proxy, which also is known as Pediatric Condition Falsification or Medical Child Abuse. She emphasized that as a pediatrician, she can make this diagnosis and that it is not a mental health diagnosis of the parents. She was first asked to review [L.S.'s] medical case in January 2018, because there were concerns by his treating physicians that that his symptoms were being exaggerated by the parent. She reviewed his chart and talked with his doctors and declined to make a report at that time. Dr. Farst was consulted again in April 2019 for continuing concerns

that Mrs. Schneider was exaggerating or misrepresenting [L.S.'s] symptoms, but no report was recommended. At that point, the family's plan was to seek additional opinions regarding [L.S.'s] condition from other providers outside Arkansas. After Texas Children's and Dallas declined to see [L.S.], Mayo agreed to see him outpatient in May 2019. Dr. Farst said TCAR wanted input from other providers before making a decision regarding whether a report to the hotline was needed. In making her report regarding suspicion of Munchausen by Proxy, Dr. Farst primarily focused on the time period of May 2019 to present. Records indicated that [L.S.] was seen at outpatient clinics at Mayo for about two weeks in late May and early June 2019. [L.S.] saw a multitude of doctors at Mayo, and there was consistency in reports from those doctors that Mrs. Schneider's accounts regarding [L.S.'s] symptoms did not match what the doctors were seeing. Mayo instructed Mrs. Schneider to begin to wean narcotics to see how intestines were working. Once [L.S.] returned to Arkansas, the parents did wean Fentanyl at home, but continued to describe [L.S.'s] quality of life as poor due to pain. Ms. Schneider told doctors at Arkansas Children's Hospital that Mayo wanted to see [L.S.] back and to finish testing, although Dr. Repp, [L.S.'s] PCP, later found this to be untrue. Ms. Schneider insisted to the Palliative Care Team at ACH that Mayo wanted him to have a port for longer term Total Parenteral Nutrition or TPN, which is intravenous feeding, rather than continuing to use his PICC (peripherally inserted central catheter) line. Based on Ms. Schneider's assertions, a Port was placed on August 19, 2019. Ms. Schneider continues to tell Dr. Repp that [L.S.'s] quality of life is poor if he is on less than 50 micrograms of fentanyl. On August 27, 2019, DHS contacted Dr. Farst, because the hotline had received reports from the community, with concerns about [L.S.'s] wellbeing.

Farst reported that [L.S.] was admitted to ACH for a possible port infection on September 4, 2019, and Mrs. Schneider continued to insist that [L.S.] was in terrible stomach pain and that if his Gastrojejunostomy Tubes were clamped, he had distension of his stomach and increased pain. Because of these assertions, she argued against weaning him from Ativan, another narcotic. While [L.S.] was hospitalized, a multi-provider meeting was held at ACH to discuss concerns about [L.S.'s] condition and the parents' possible misrepresentations of his condition. Palliative care staff recommend[ed] that [L.S.] begin to wean from the Ativan while in the hospital; parents were resistant to this directive, and he was discharged on September 6, 2019, with instructions to wean at home. On September 11, 2019, Palliative Care called mom to check on [L.S.], and Mrs. Schneider told them that he was in significant pain and that it was not the time to wean the Ativan. That day, a hotline report was made due to concerns about Mrs. Schneider continuing to exaggerate symptoms, and [L.S.] was admitted to the hospital in DHS custody.

Dr. Farst explained that separating him from his parents while in the hospital was a definitive way to determine his health baseline and to determine his true condition. After being in the hospital starting on September 11, 2019, [L.S.] made a profound transformation in the first two days. He was admitted to the hospital in a wheelchair, on oxygen, allegedly in profound pain, receiving TPN feeds and nothing by mouth and with GJ tubes. Dr. Farst reported that [L.S.] initially stated that his abdominal pain was 10 out of 10 on the pain scale, but his smile and demeanor belied that report. He was not showing any guarding or tensing of his abdominal muscles when he reported pain. Medical staff clamped his J-G Tubes and fed him macaroni and cheese, to his delight and without any side effects. By the time of discharge on October 4, 2019, [L.S.] was out of the wheelchair, eating solid foods exclusively, off oxygen, and receiving all his medications orally. His J-G tube was removed after discharge, on November 5, 2019. He progressed from the fifth percentile in weight to the twentieth percentile. Dr. Farst stated that given the parents' history of exaggerating and misrepresenting [L.S.'s] symptoms, triangulating between [L.S.'s] numerous medical providers, and his transformation once in DHS custody, she had concluded that he suffered from Munchausen by Proxy (also known as pediatric condition falsification or child medical abuse.)

Dr. Farst was questioned by parent counsel regarding the validity of her diagnosis of Munchausen by Proxy, given that she was not a mental health provider and didn't use the Diagnostic and Statistical Manual of Mental Health Disorders to make her diagnosis. She explained that as a pediatrician, she was making the diagnosis on the child rather than the parent, and that her diagnosis was consistent with the medical literature on the issue, including the Squires article that was introduced as Attorney ad Litem Exhibit number 1. Dr. Farst also noted that to her knowledge the mother was the primary caregiver of [L.S.] in the home, although the father was present in the home.

Dr. Carrie Brown, a palliative and complex care physician at Arkansas Children's Hospital, was qualified as an expert in palliative care and complex care. The Court finds Dr. Brown's testimony to be credible. Dr. Brown testified that she first started treating [L.S.] around January 2018 due to his complex medical issues. Dr. Brown was approached by a locum GI physician in 2018 who expressed concerns about Ms. Schneider accurately reporting [L.S.'s] symptoms. As a result, Dr. Brown had conversation with Ms. Schneider about the importance of accurately reporting symptoms and not exaggerating any issues. Dr. Brown believed Ms. Schneider thereafter and thought her reporting was accurate. Dr. Brown set aside what the locum doctor told her. Dr. Brown testified that she was trained to believe the caregiver when they describe their child's symptoms and condition. In March 2019 [L.S.] was at home on hospice care. Dr. Brown, Mr. and Ms. Schneider, and other medical professionals were all involved in conversations about admitting [L.S.] to the hospital to stop his

TPN nutrition. Dr. Brown testified that the expected outcome of withdrawing his nutrition would be death. Dr. Brown stated that based on the reports given by the Schneiders regarding symptoms and quality of life, ACH agreed this decision was an option for the family. Dr. Brown stated that Mr. Schneider was present at these meetings and agreed with Ms. Schneider's reporting and comments. In spring 2019, Dr. Brown made the referral for [L.S.] to go to Mayo clinic. When [L.S.] returned, the issues that Dr. Brown personally addressed were urology, pain, and the narcotics wean. Ms. Schneider reported that Mayo recommended start[ing] the narcotics wean once [L.S.] was stable on his digoxin, in about 1-2 weeks. Ms. Schneider reported that once the narcotics wean was complete, [L.S.] was to return to Mayo clinic for gut motility testing. Based on this information, Dr. Brown recommended finishing the narcotic wean and then sending [L.S.] back to Mayo. Ms. Schneider reported that [L.S.] could not tolerate anything in his G-tube without it causing distress. Dr. Brown has seen this in other patients, and believed Ms. Schneider's report despite the fact that she had not observed [L.S.] in distress. Dr. Brown also confirmed that [L.S.] did report pain himself, although she was not sure if he was actually in pain. [L.S.] was admitted to the hospital September 4-6 for a possible port infection. The Ativan wean was discussed at the hospital at this time, and ACH recommended weaning the Ativan at the hospital. Mr. and Ms. Schneider felt like ACH did not trust them, and wanted to do the Ativan wean at home. [L.S.] was discharged with Ativan wean instructions. Dr. Brown called Ms. Schneider on September 11, 2019 to find out how the Ativan wean was going. Ms. Schneider reported that it was not going well and [L.S.] was still having significant pain, not tolerating the Ativan wean, and Ms. Schneider stated it was not discussed about why the Ativan was being weaned right now. Ms. Schneider stated that Mr. Schneider wanted to go to the Administration because communication had stopped. Dr. Brown later learned that Ms. Schneider had filed a grievance against her, but she did not know about the grievance when she placed the phone call on September 11, 2019. Dr. Brown has not treated [L.S.] since she found out about the grievance.

Lynn Dees, a pediatric APRN under Dr. Carrie Brown at ACH, testified that she first met [L.S.] around January 2018. The Court finds Lynn Dees testimony to be credible. Lynn Dees testified that she became close with Ms. Schneider during the course of treating [L.S.], and she was involved in the conversations about the narcotic wean after the Mayo visit in May-June 2019. Ms. Schneider reported that the narcotic wean was progressing, but that [L.S.'s] pain was worsening. In a medical note dated August 3, 2019, Ms. Schneider reported to Lynn Dees that Mayo told her the plan was to go back in the next 4 months or so to try and test [L.S.'s] GI system. The note reads "I know they will test his gut again, but there truly didn't seem to be much optimism because the system was broken even before this all began in December." The note also reads "we are certainly on TPN for the foreseeable future-until we return to Mayo and get more information-and thus we hope we could transition to a port as soon as

possible.” Lynn Dees testified that Ms. Schneider stated Mayo first brought up the port to her, and this was also reflected in Lynn Dees medical notes. Lynn Dees contacted the pediatric GI doctor at ACH to let him know that Ms. Schneider was requesting a port, and that the palliative care team’s understanding was that [L.S.] was to return to Mayo once he was off narcotics to pursue GI motility testing. Lynn Dees testified that Ms. Schneider reported if she clamped the bags attached to [L.S.’s] GJ tubes, it would create abdominal distention.

Dr. Travis Ayers testified and was found to be an expert in the field of pediatric gastroenterology. The Court finds Dr. Ayers to be a credible witness. Dr. Ayers stated that he first met [L.S.] about a year ago and still cares for him today. Dr. Ayers testified that after [L.S.] was seen at Cincinnati Children’s Hospital, he oversaw [L.S.’s] TPN orders. Dr. Ayers explained that [L.S.] currently has reflux and rumination, but that the rumination is being addressed by [L.S.’s] psychologist, Dr. Brandi Whitaker. Dr. Ayers emphasized that, as a pediatric gastroenterologist, he relies on the parents’ reporting of symptoms when making decisions. He stated that every time he saw [L.S.] and his mother, Ms. Schneider would tell him that, “We know his gut doesn’t work.” After [L.S.] returned from the Mayo Clinic, Mrs. Schneider reported that Dr. Spencer Lewis, an interventional radiologist, wanted to place a port. Thereafter, on August 9, 2019, Dr. Ayers placed the order for the port.

Dr. Ayers stated that there was always a suspicion that [L.S.] could tolerate oral feeds. When [L.S.] was admitted to ACH on September 11, 2019, Ayers told the staff to clamp his G-J tubes. [L.S.] didn’t have abdominal pain from the tubes being clamped, so Dr. Ayers authorized oral feeds for him. Dr. Ayers stated that [L.S.] would eat “macaroni and cheese until he was blue in the face.” Eating was clearly giving him pleasure and there were no side effects. Dr. Ayers ordered a slow withdrawal of the TPN. Dr. Ayers reported that [L.S.] is significantly better. He was jumping around the room, excited about eating, and talking nonstop. Ayers indicated that [L.S.’s] port was removed on November 18, 2019.

Dr. Spencer Lewis, an interventional radiologist with Arkansas Children’s Hospital, was called as a witness by defendant, and the Court finds him to be a credible witness. Dr. Lewis testified that he placed [L.S.’s] port on August 19, 2019, pursuant to an order by Dr. Ayers. Dr. Lewis explained that a port is placed under the skin and can last years. The port is placed under general anesthesia and the surgery usually takes about 1 to 1 ½ hours. He stated that if TPN was needed for a long time, then the port is appropriate. He said that the port could have been placed by either radiology or by general surgery. Dr. Lewis stated that he was aware that the port had been removed recently.

5. The Court finds that the father, Eric Schneider, contributed to the dependency-neglect of the juvenile. Father is a caregiver of the juvenile and lived

in the home. By his own description, Mr. Schneider is the “leader of the house,” and stated that he makes the final decisions on major issues in the family. He participated in the meeting where it was determined that TPN would be withdrawn, participated in the decision to have a port placed in the juvenile, and met with the cardiologist at Mayo Clinic, and by his own testimony does not think that his wife misrepresented or exaggerated any symptoms of [L.S.]. He testified that he was frustrated with ACH in September 2019 because he felt they were not treating [L.S.’s] gut problems or working with the family on his Ativan wean. Upon further questioning Mr. Schneider acknowledged that once [L.S.] entered foster care, the only change in [L.S.’s] treatment was to clamp his tubes and later feed [L.S.] food. Mr. Schneider is not a fit parent who can meet the juvenile’s medical, emotional, and physical needs. He has not demonstrated that he can protect his child from unnecessary medical treatment. Mr. Schneider’s reliance upon *Young v. Ark. Dept. of Human Servs.*, 2018 Ark. App. 270, is misplaced as *Young* is distinguishable from this matter. Here, Mr. Schneider, by his own testimony, participated in decisions that ultimately affected the medical treatment of his son.

6. Defendants’ argument at this hearing is that the juvenile’s change in medical condition was based on the fact that he completed his narcotics wean shortly before entering foster care, and that is the basis for his recovery. The Court finds this argument implausible, based on the testimony presented at this hearing. The Court finds that the parents’ misrepresentation of the juvenile’s medical condition, to multiple doctors over an extended period of time, resulted in unnecessary medical treatment and procedures. Most notably, the juvenile had a port placed in his chest. This is a surgery that was done under general anesthesia—the juvenile later had to have the port removed under general anesthesia once he was placed in foster care

7. Counsel for Ms. Schneider argues that the Department has not met its burden with regard to his client, because a mental health provider has not diagnosed her with Munchausen by Proxy. However, the statute in question, Ark. Code Ann. § 9-27-303 (3)(A) vii (j) defines abuse as “Any of the following intentional or knowing acts, with or without physical injury...(j)Subjecting a child to Munchausen syndrome by proxy, also known as factitious illness by proxy, when reported and confirmed by medical personnel or a medical facility.” The statute does not require that a mental health professional make the diagnosis; it only requires that the conditions be reported and confirmed by medical personnel, and Dr. Farst meets this condition. (See also *Parker v. Ark. Dept. of Human Servs.*, 380 S.W.3d 471 (2011).)

Kristy filed a notice of appeal on December 9. She also filed a notice of objection of the court’s amendment to allegations and motion for vacation of the adjudication order.

In the motion, she challenged the sufficiency of the evidence to support dependency-neglect

based on Munchausen syndrome by proxy, she contended that her due process was violated when the court made the posttrial amendments, and she also claimed the court's amendment violated Arkansas Rule of Civil Procedure 15(b). She asked the court to vacate its adjudication order. Erik filed a notice of appeal and objection that same day. His objection was almost identical to Kristy's objection. DHS and the ad litem filed a joint response to the motions and objections on December 23. The court filed orders on December 31 denying appellants' motions for vacation of the adjudication order. It stated that the petition alleged abuse, neglect, and parental unfitness and the evidence at trial supported the petition for dependency-neglect, but provided more detail and illustrations than what had been initially pled. It said that it allowed appellee to amend its pleadings to conform to the evidence and that appellants did not object or move for a continuance. It further found that appellants failed to allege or even demonstrate how they were prejudiced by this amendment. Kristy filed a supplemental notice of appeal on January 6, 2019, to include the court's December 31 order. Erik's supplemental notice of appeal was filed on January 7. This appeal followed.

Adjudication hearings are held to determine whether the allegations in a petition are substantiated by the proof.³ Dependency-neglect allegations must be proved by a preponderance of the evidence.⁴ In dependency-neglect cases, the standard of review on appeal is de novo, but we do not reverse the circuit court's findings unless they are clearly

³Ark. Code Ann. § 9-27-327(a)(1)(A) (Supp. 2019).

⁴Ark. Code Ann. § 9-27-325(h)(2)(A)(ii).

erroneous or clearly against the preponderance of the evidence.⁵ A finding is clearly erroneous when, although there is evidence to support it, the reviewing court on the entire evidence is left with a definite and firm conviction that a mistake has been made.⁶ In reviewing a dependency-neglect adjudication, we defer to the circuit court’s evaluation of the credibility of the witnesses.⁷

Arkansas Code Annotated section 9-27-303(18)(A) defines a “dependent-neglected juvenile” as any juvenile who is at substantial risk of serious harm as a result of abuse, neglect, parental unfitness, along with other acts or omissions. Abuse has been defined as intentionally or knowingly “[s]ubjecting a child to Munchausen syndrome by proxy, also known as factitious illness by proxy, when reported and confirmed by medical personnel or a medical facility.”⁸ The statute does not require that actual physical injury occur. Neglect is defined as the failure or refusal to provide the necessary food, clothing, shelter, or medical treatment necessary for the juvenile’s well-being; as well as the failure to take reasonable action to protect the juvenile from abuse, neglect, or parental unfitness when the existence of this condition was known or should have been known.⁹ There is no statutory definition for parental unfitness.

⁵*Ward v. Ark. Dep’t of Human Servs.*, 2018 Ark. App. 376, 553 S.W.3d 761.

⁶*Id.*

⁷*Id.*

⁸Ark. Code Ann. § 9-27-303(3)(A)(vii)(j).

⁹Ark. Code Ann. § 9-27-303(36)(A)(ii)–(iii).

Appellants' first point on appeal is actually several different points rolled into one. Appellants first challenge the definition of Munchausen syndrome by proxy as explained to the court by Dr. Farst. Dr. Farst explained that the term has evolved to include several instances of child abuse implemented directly or indirectly by the caregiver. She stated that as a pediatrician, her focus was on the abuse suffered by the child, not on the caregiver. Appellants' argument regarding Dr. Farst's testimony centers on the fact that she did not rely on the DSM¹⁰ or any other psychological or psychiatric diagnosis in relation to Kristy. According to appellants, this is at odds with both the statute and definition accepted within the medical profession. Based on the statutory language found above, there is no requirement that Kristy has to be diagnosed with Munchausen syndrome by proxy before a child can be found to be dependent-neglected based on it. To the extent that appellants claim that Dr. Farst's diagnosis had to be in line with the DSM before a diagnosis could be made, there is no indication in the statute that DSM has been adopted as authority for this statute. As written, the statute requires only that the diagnosis be reported and confirmed by medical facility or medical personnel. Here, Dr. Farst met this requirement. Additionally, Dr. Meghan Repp stated that the literature now tells medical professional to recognize the implications of Munchausen syndrome by proxy from the child's perspective. She further stated that when she uses the terms, she "really means what is happening to the child, not what the psychological diagnosis is of the parent." Dr. Repp testified that words like "child medical abuse" and "pediatric condition falsification" are synonymous with Munchausen syndrome by proxy. She indicated that although she did not make the

¹⁰Diagnostic and Statistical Manual of Mental Disorders.

diagnosis in this case, she agrees with Dr. Farst's diagnosis. The court heard each side's position, including appellants' insistence that Munchausen syndrome by proxy had to be based on a diagnosis of Kristy. In the end, the court found that no such diagnosis is required. We cannot say that this finding is clearly erroneous.

Appellants also contend that Dr. Farst's testimony disregarded the statutory requirement that a child be intentionally or knowingly subjected to Munchausen syndrome by proxy. However, regardless of the standard Dr. Farst chose to use during her testimony, the court was presented with the statutory language and was aware of the requirement that in order for Kristy's actions to be considered abuse, they had to be intentional or knowing. Although the court did not specifically find that Kristy's actions of misrepresentations were intentional or knowing, in the absence of a showing to the contrary, this court must presume that a court acted properly and made the findings necessary to support its judgment.¹¹ Here, there was ample of testimony where the court could conclude that Kristy's actions of misrepresenting information to the medical professionals were done either intentionally, knowingly, or both.

Appellants ask this court to overturn *Parker v. Arkansas Department of Human Services*,¹² to the extent it stands for the proposition that Munchausen syndrome by proxy can be found despite the absence of a diagnosis of the caretaker. However, we decline this invitation. The statute has no such requirement and *Parker* is in line with the statute. Appellant argues

¹¹*Pelayo v. Sims*, 2020 Ark. App. 258, 600 S.W.3d 114.

¹²2011 Ark. App. 18, 381 S.W.3d 471.

that a diagnosis of the caretaker is required by the DSM, but as stated earlier, there is no indication that the legislature intended for it to be the authority for this particular statute.

Appellants also contend that Dr. Farst's testimony and definition regarding Munchausen syndrome by proxy have constitutional ramifications. Appellants mentioned these constitutional challenges in their proposed findings of facts and conclusions of law, but the court never ruled on the issues. As a matter of fact, the adjudication order is silent on appellants' constitutional issues. It is well settled that to preserve arguments for appeal, even constitutional ones, the appellant must obtain a ruling below.¹³ In their reply, appellants equate the court's grant of appellees' petition as overruling all of appellants' objections, including their constitutional ones. However, granting a petition and obtaining a ruling are not one in the same, and appellants have failed to cite this court to any legal authority which states otherwise.

We hold that the circuit court correctly found that L.S. was dependent-neglected as a result of abuse (Kristy subjecting him to Munchausen syndrome by proxy), neglect (by appellants due to their failure or refusal to provide the necessary nutrition and medical treatment to L.S.), and parental unfitness (a fit parent would not exaggerate or misrepresent symptoms to medical providers and a fit parent would not acquiesce to another caregiver's false reporting). Based on the evidence, the court correctly found that Erik played a role in L.S.'s dependency-neglect status. Therefore, we affirm the court's dependency-neglect findings as against both appellants.

¹³*Chacon v. Ark. Dep't of Human Servs.*, 2020 Ark. App. 277, 600 S.W.3d 131.

Next, appellants argue that the circuit court's posthearing attempt to redefine the allegations violates rules of procedure, constitutional requirements, and the court's own pretrial guarantees. This argument has no merit. When DHS filed its affidavit, it alleged that L.S. was dependent-neglected due to abuse, neglect, and parental unfitness. The court granted DHS's petition based on abuse, neglect, and parental unfitness. In the order denying appellants' motion to vacate the adjudication order, the court indicated that the reasons for dependency-neglect did not change, but that the evidence adduced at the hearing elaborated more on what was initially pled. Although the court said that it granted DHS's request to amend the pleadings to reflect the evidence, no amendment was necessary because DHS had already stated its theory for dependency-neglect against appellants and stood on its petition and supporting affidavit.

To the extent that an amendment was necessary, the court was within its bounds to grant the amendment. Arkansas Rule of Civil Procedure 15(b) governs the amendment of pleadings to conform to the evidence and states that pleadings can be amended at any time, including after judgment. If a party objects to the amendment, the court may still allow the amendment in its discretion. The court may also grant a continuance to allow the objecting party to meet such evidence. Here, DHS moved to have the pleadings conform to the evidence after it concluded its case and Kristy moved for dismissal. Kristy objected to the amendment based on improper notice. The court did not rule on the pleadings until the adjudication order. The circuit court stated that it was using its discretion to allow the amendment, which it is permitted to do. Although a court may allow an objecting party a continuance, it is not required to do so. A circuit court's decision regarding the amendment

of pleadings to conform to the evidence will not be reversed absent a manifest abuse of discretion,¹⁴ and the party seeking reversal on that ground must show the manifest abuse.¹⁵ Prejudice from the circuit court's ruling must also be demonstrated.¹⁶ Both appellants have failed to demonstrate how they would have presented their cases differently had they known that the court would allow DHS to amend its pleadings. Thus, we hold that there was no abuse of discretion in allowing the amendment.

In an earlier hearing, the court informed DHS that it had to notify appellants what theory it was basing its petition for dependency-neglect on. DHS stated that it was standing by its petition and supporting affidavit. The court in turn told DHS that it would be limited to what it had indicated to the attorneys it was going to prove. Here, as the court suggested in its December 31 order, the allegations against appellants did not change, those allegations were just elaborated upon during the hearing. Thus, there were no due-process violations as appellants were fully aware that DHS sought to have the court declare L.S. dependent-neglected as a result of abuse, neglect, and parental unfitness.

Finally, appellants argue that the court's findings of facts are clearly erroneous. It appears that appellants want this court to reweigh the evidence in their favor. Under our standard of review, we do not act as a super fact-finder, and it is not reversible error for the circuit court to weigh the evidence differently than how appellants ask the evidence to be

¹⁴*Ison Props., LLC v. Wood*, 85 Ark. App. 443, 156 S.W.3d 742 (2004).

¹⁵*Hickman v. Kralicek Realty & Constr. Co.*, 84 Ark. App. 61, 66, 129 S.W.3d 317, 320 (2003).

¹⁶*Honeycutt v. Honeycutt*, 2017 Ark. App. 113, 516 S.W.3d 750.

weighed.¹⁷ The circuit court's findings are supported by the record. Accordingly, we affirm.

Affirmed.

ABRAMSON and SWITZER, JJ., agree.

¹⁷*Allen v. Ark. Dep't of Human Servs.*, 2018 Ark. App. 136, 540 S.W.3d 742.



**EXHIBIT
C**



City of Alexander Fire / Rescue

February 27, 2019 · 🌐



Tomorrow morning, Alexander 🚒 Fire and Police 🚓 Dept. also many other Fire 🚒, EMS 🚑, Police 🚓 Agencies will stand together as LOUIE travels to Children's Hospital. Louie, who is battling a medical condition, doesn't have much time left on earth. As many know, he has become a warrior for many and loves the Fire, EMS & Police.

His last wish as he rides to Children's Hospital is to see as many Fire, EMS, Police Officers.

So, that is EXACTY what we all are going to do. Tomorrow at 9:30, members of Alexander Fire & Police and other agencies will set up at Vimy Ridge and the South Service Road to give Louie his greatest send off that we can do.

Last thing I want to leave you with is from Louie. I Can Not Wait to See Jesus! Wow. He knows his time here is almost done, but what waits as he leaves this earth is more amazing than we can ever imagine. God bless you Louie 🇺🇸 🚒 🚑 🚓

**EXHIBIT
D**

**9913-DEPARTMENT OF PUBLIC SAFETY
FISCAL YEAR 2021
AS ENACTED BY ACT 97 OF 2020**

The mission of the Arkansas State Police is to protect human life and property in the state of Arkansas by providing the highest quality of law enforcement services to the public. Their vision is to be the premier law enforcement agency of the state, by developing the skills of our members through efficient and effective management of agency resources to deliver the highest level of service to the public.

TOTAL APPROPRIATION

Appropriation- Shared Services		2019-2020	2020-2021
		Authorized	Legislative
Z07	LESO Program - Cash	\$0	\$40,000
Z08	LESO Program	\$0	\$83,867
Z33	Fire Prevention Commission Grants	\$0	\$30,000
Z36	Crime Victims Reparation Program	\$0	\$1,975,368
Z49	Department of Public Safety	\$0	\$196,013
Z52	Crime Victims Reparations Board/Federal	\$0	\$1,040,763
Total		\$0	\$3,366,011

Appropriation- State Police		2019-2020	2020-2021
		Authorized	Legislative
1FD	Highway Safety Program - State	\$189,000	\$194,000
1FJ	Highway Safety Program - Federal	\$24,771,244	\$24,776,210
2EG	Homeland Security-Federal	\$1,028,748	\$1,028,748
345	Automated Fingerprint Identification System (AFIS)	\$2,497,544	\$2,489,344
519	ASP-Operations	\$98,349,087	\$99,327,495
521	Various Federal Programs	\$701,760	\$701,760
524	Confiscated Funds Transfer	\$1,667,412	\$2,058,212
526	Criminal Background Checks	\$4,616,594	\$5,036,715
9KA	AR Wireless Information Network (AWIN)	\$7,357,888	\$0
F97	CHCL Cash Fund	\$0	\$0
U78	ADFA Bond Loan - Agency Construction	\$150,000	\$150,000
Total		\$141,329,277	\$135,762,484

EXHIBIT

E

Appropriation- Law Enforcement Training	2019-2020	2020-2021
	Authorized	Legislative

172	Law Enforcement Standards-Operations	\$3,891,655	\$3,892,146
86M	911 Training & Education	\$264,779	\$264,779
F63	Fallen Law Enforcement Officers	\$25,000	\$25,000
V52	Fallen Law Enforcement Officers (GR)	\$75,000	\$75,000
X55	Law Enforcement Training Program	\$300,000	\$300,000
Y90	Special Training - Cash	\$380,000	\$380,000
Total		\$4,936,434	\$4,936,925

Appropriation- ACIC		2019-2020	2020-2021
		Authorized	Legislative
171	ACIC - Operations	\$7,405,474	\$7,407,696
739	Sex/Child Offender Registration	\$60,000	\$60,000
86Z	Scrap Metal Logbook	\$150,000	\$150,000
944	Systems Conf-Cash in Treasury	\$60,000	\$60,000
Total		\$7,675,474	\$7,677,696

Appropriation- State Crime Lab		2019-2020	2020-2021
		Authorized	Legislative
1ED	Crime Lab-Federal	\$1,839,400	\$1,839,400
1VM	Equipment	\$1,000,000	\$1,000,000
498	Crime Lab State	\$12,790,333	\$12,797,627
788	DNA Special	\$1,252,270	\$1,252,270
Total		\$16,882,003	\$16,889,297

FUNDING SOURCES

Funding Sources- Shared Services		2018-2019	
		Actual	%
Fund Balance	4000005	\$0	0.00
General Revenue	4000010	\$0	0.00
Federal Revenue	4000020	\$0	0.00
Cash Fund	4000045	\$0	0.00
Intra-agency Fund Transfer	4000317	\$0	0.00
State Administration of Justice	4000470	\$0	0.00
Total Funds		\$0	0.00

Excess Appropriation/(Funding)	\$0	
Grand Total	\$0	

Funding Sources-State Police		%
Fund Balance	4000005	17.59
General Revenue	4000010	47.58
Federal Revenue	4000020	10.04
Special Revenue	4000030	18.07
Other Sources	4000045	6.71
Total Funds		100.00
Excess Appropriation/(Funding)		
Grand Total		

Funding Sources- ALETA		2018-2019 Actual	%
Fund Balance	4000005	\$283,702	6.58
General Revenue	4000010	\$3,248,559	75.38
Special Revenue	4000030	\$5,606	0.13
Cash Fund	4000045	\$264,396	6.13
Performance Fund	4000055	\$273,176	6.34
Inter-agency Fund Transfer	4000316	\$28,500	0.66
Miscellaneous Transfers	4000355	\$200,337	4.65
Other	4000370	\$5,367	0.12
Total Funds		\$4,309,643	100.00
Excess Appropriation/(Funding)		(\$280,026)	
Grand Total		\$4,029,617	

Funding Sources- ACIC		2018-2019 Actual	%
Fund Balance	4000005	\$8,394,339	63.10
General Revenue	4000010	\$1,005,006	7.55
Special Revenue	4000030	\$3,613,401	27.16
Cash Fund	4000045	\$46,923	0.35

M & R Sales	4000340	\$2,125	0.02
Miscellaneous Transfers	4000355	\$36,377	0.27
Transfer State Admn of Justice	4000570	\$55,570	0.42
Various Program Support	4000730	\$150,000	1.13
Total Funds		\$13,303,741	100.00

Funding Sources- State Crime Lab		2018-2019 Actual	%
Fund Balance	4000005	\$2,293,181	12.73
General Revenue	4000010	\$8,764,099	48.64
Federal Revenue	4000020	\$2,821,372	15.66
Special Revenue	4000030	\$3,674,570	20.39
Performance Fund	4000055	\$105,000	0.58
Inter-agency Fund Transfer	4000316	\$32,066	0.18
M & R Sales	4000340	\$2,314	0.01
Transfer State Admn of Justice	4000570	\$326,960	1.81
Total Funds		\$18,019,562	100.00
Excess Appropriation/(Funding)		(\$1,997,774)	
Grand Total		\$16,021,788	

CHANGE LEVEL REQUESTS

LESO Program - Cash (Appropriation Z07)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5900046	Law Enforcement Safety Program	\$0	\$40,000	\$40,000
Total		\$0	\$40,000	\$40,000

- Leso Program- Cash was transferred from the Department of Education - Career Education because of Act 910

LESO Program (Appropriation Z08)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5010000	Regular Salaries	\$0	\$52,227	\$52,227
5010003	Personal Services Matching	\$0	\$16,640	\$16,640

5020002	Operating Expenses	\$0	\$15,000	\$15,000
Total		\$0	\$83,867	\$83,867

- Leso Program was transferred from Department of Education - Career Education because of Act 910

Fire Prevention Commission Grants (Appropriation Z33)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5900046	Fire Prevention Commission Grants Program	\$0	\$30,000	\$30,000
Total		\$0	\$30,000	\$30,000

- Fire Prevention Commission was transferred from DFA- Disbursing Officer due to Act 910

Crime Victims Reparation Program (Appropriation Z36)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5010000	Regular Salaries	\$0	\$339,497	\$339,497
5010003	Personal Services Matching	\$0	\$95,807	\$95,807
5020002	Operating Expenses	\$0	\$37,419	\$37,419
5050009	Conference & Travel Expenses	\$0	\$1,100	\$1,100
5060010	Professional Fees	\$0	\$1,545	\$1,545
5110015	Claims	\$0	\$1,500,000	\$1,500,000
Total		\$0	\$1,975,368	\$1,975,368

- Crime Victims Reparation Program was transferred from the Office of the Attorney General due to Act 910

Department of Public Safety (Appropriation Z49)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5010000	Regular Salaries	\$0	\$155,916	\$155,916
5010003	Personal Services Matching	\$0	\$40,097	\$40,097
Total		\$0	\$196,013	\$196,013

- Appropriation Z49, Department of Public Safety, was created through Act 910 and establishes the cabinet-level position.

Crime Victims Reparations Board/Federal (Appropriation Z52)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5010000	Regular Salaries	\$0	\$25,920	\$25,920
5010003	Personal Services Matching	\$0	\$9,843	\$9,843
5020002	Operating Expenses	\$0	\$5,000	\$5,000
5110015	Claims	\$0	\$1,000,000	\$1,000,000
Total		\$0	\$1,040,763	\$1,040,763

- Crime Victims Reparations Board was transferred from Office of the Attorney General

Highway Safety Program - State (Appropriation 1FD)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5100004	Grants and Aid	\$185,000	\$190,000	\$5,000
Total		\$189,000	\$194,000	\$5,000

- Grants and Aid was increased to anticipate additional awards.

Highway Safety Program - Federal (Appropriation 1FJ)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5010000	Regular Salaries	\$605,015	\$605,115	\$100
5010003	Personal Services Matching	\$563,536	\$568,402	\$4,866
Total		\$24,771,244	\$24,776,210	\$4,966

- Regular Salaries and Personal Services Matching change levels were increased due to career service payments.

Automated Fingerprint Identification System (AFIS) (Appropriation 345)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative(Amended)	Change Level
5020002	Operating Expenses	\$930,944	\$2,430,944	\$1,500,000
5050009	Conference & Travel Expenses	\$8,400	\$8,400	\$0

5120011	Capital Outlay	\$1,550,000	\$50,000	(1,000,000)
Total		\$2,497,544	\$2,489,344	(\$8,200)

- Capital Outlay costs were decreased due to a one-time cost in FY 20 for software upgrades.
- **Per Governor's Letter 2**, \$1,500,000 will be reallocated from the Capital Outlay line item into the Operating Expenses line item within the Arkansas State Police- Automated Fingerprint Identification System

ASP-Operations (Appropriation 519)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative(Amended)	Change Level
5010000	Regular Salaries	\$54,154,551	\$54,924,312	\$769,761
5010003	Personal Services Matching	\$29,393,694	\$30,138,744	\$745,050
5020002	Operating Expenses	\$13,480,832	\$13,447,514	(\$33,318)
5050009	Conference & Travel Expenses	\$176,575	\$173,275	(\$3,300)
5060010	Professional Fees	\$88,327	\$257,777	\$169,450
5120011	Capital Outlay	\$720,273	\$885,500	\$165,227
Total		\$98,349,087	\$99,327,495	\$978,408

- Regular Salaries and Personal Services Matching change levels were increased due to career service payments.
- Operating Expenses were decreased due to a one-time cost in FY 20 for increased utility, fuel costs and IT expenses.
- Conference & Travel Expenses were decreased to align with agency training needs.
- Professional Fees were increased for FY 21 officer promotional testing.
- Capital Outlay costs were decreased due to a one-time cost in FY 20 to upgrade a concealed handgun carry filing system, replacement of canines and other items.
- **Per Governor's Letter 2**, adds \$650,000 appropriation in Arkansas State Police- Operations to the Capital Outlay line item.
- **Per Governor's Letter 3**, \$246,608 will be transferred from other divisions for ASP-Operations regular salaries and personal service matching
- **Per Governor's Letter 3**, four (4) positions will be transferred to the ASP-Operations appropriation

Confiscated Funds Transfer (Appropriation 524)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5020002	Operating Expenses	\$610,900	\$561,700	(\$49,200)

5120011	Capital Outlay	\$560,000	\$1,000,000	\$440,000
Total		\$1,667,412	\$2,058,212	\$390,800

- Operating Expenses were decreased to better align with anticipated revenues
- Capital outlay costs were increased to cover costs for crime scene scanners and wheel alignment systems

Criminal Background Checks (Appropriation 526)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5010003	Personal Services Matching	\$234,296	\$239,132	\$4,836
5020002	Operating Expenses	\$3,295,160	\$3,525,160	\$230,000
5050009	Conference & Travel Expenses	\$17,415	\$8,700	(\$8,715)
5120011	Capital Outlay	\$696,000	\$890,000	\$194,000
Total		\$4,616,594	\$5,036,715	\$420,121

- Personal Services Matching levels were increased due to career service payments
- Operating Expenses were increased to replace in-car cameras and mobile AFIS
- Conference and Travel Expenses were decreased in the current FY due to a one-time costs in the previous FY 20 for new ID Bureau staff training
- Capital Outlay costs were increased to replace software and replace office equipment

AR Wireless Information Network (AWIN) (Appropriation 9KA)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5020002	Operating Expenses	\$7,357,888	\$0	(\$7,357,888)
Total		\$7,357,888	\$0	(\$7,357,888)

- AWIN was transferred to Emergency Management due to Act 702

Law Enforcement Standards-Operations (Appropriation 172)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5010000	Regular Salaries	\$2,267,298	\$2,267,698	\$400
5010003	Personal Services Matching	\$795,001	\$795,092	\$91
Total		\$3,891,655	\$3,892,146	\$491

- Regular Salaries and Personal Services Matching Levels were increased due to career service payments.

ACIC - Operations (Appropriation 171)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5010000	Regular Salaries	\$2,965,785	\$2,967,585	\$1,800
5010003	Personal Services Matching	\$1,062,613	\$1,063,035	\$422
Total		\$7,405,474	\$7,407,696	\$2,222

- Regular Salaries and Personal Services Matching Levels were increased due to career service payments.
- **Per Governor's Letter 3**, \$62,146 will be transferred to ACIC - Operations for regular salaries and personal services matching.
- **Per Governor's Letter 3**, one (1) position was transferred to ACIC - Operations

Crime Lab State (Appropriation 498)

Commitment Item		2019-2020	2020-2021	
		Authorized	Legislative	Change Level
5010000	Regular Salaries	\$8,022,791	\$8,026,891	\$4,100
5010003	Personal Services Matching	\$2,564,518	\$2,567,712	\$3,194
Total		\$12,790,333	\$12,797,627	\$7,294

- Regular Salaries and Personal Services Matching Levels were increased due to career service payments.

Transferred/discontinued appropriations

AWIN- (\$7,357, 888)

POSITIONS

Total Authorized Positions FY2021: 1,379

Total Authorized Positions FY2020: 1367

Increase / (Decrease): 12 (State Police)

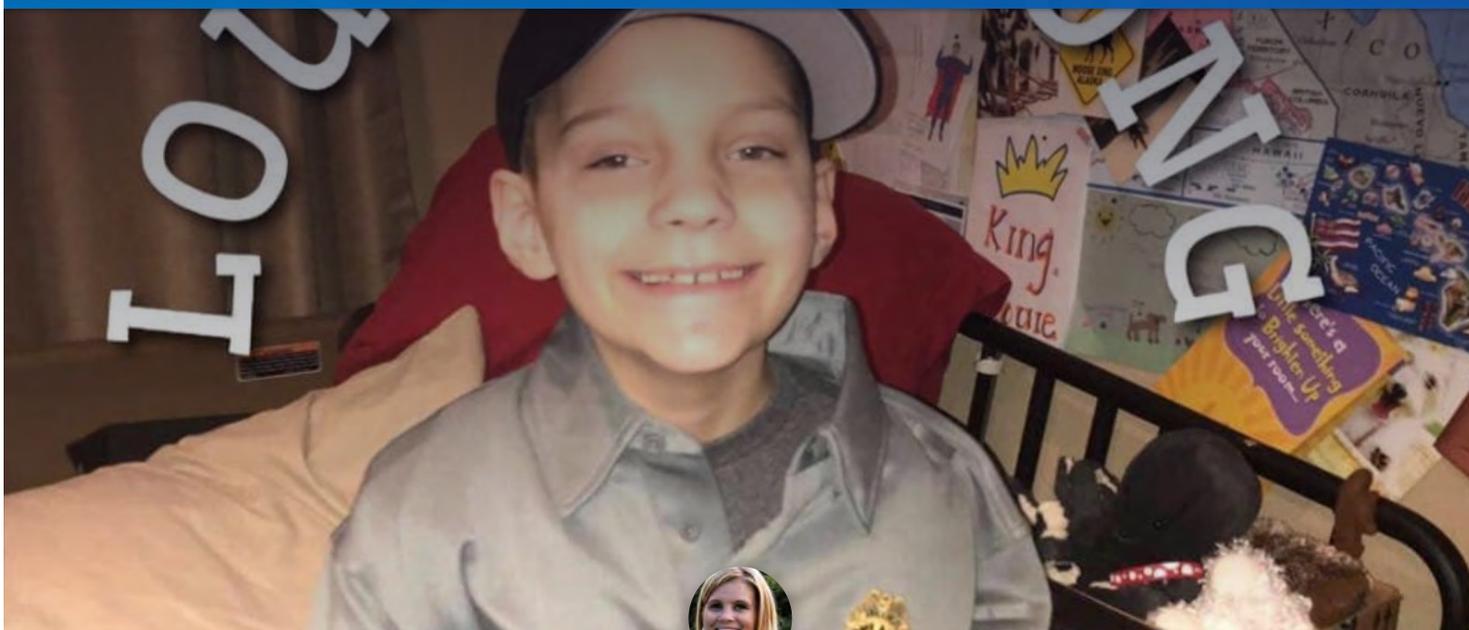
Extra Help Positions FY2020: 20

SPECIAL LANGUAGE REVISIONS

Allows upon approval by ALC or JBC, the department to transfer funds, appropriation and positions related to shared services. These transfers are limited to services provided for multiple divisions of the department. A report of these transfers shall be included in budget manuals presented to the General Assembly.

Pool Ended

Log Out



Lovin on Louie

Organized by Chrystal Baker

Pool Ended

\$10,395.00

Collected

RAISED IN 307 DAYS

\$2,713.00 was pledged by Chrystal

About this pool

After hearing Louie's amazing story of love and faith through adversity, several people have inquired about helping his family monetarily.

We all know that medical care for a terminal illness can be a financial burden and so many people have recognized that and offered to help.

**EXHIBIT
F**

If you are not familiar with Louie Schneider, do yourself a favor and learn about him here:

Pool Ended

**This pool is administered by Adam & Chrystal Baker and approved by the Schneider family. 100% of the money donated will be provided to the family for expenses incurred during this journey. While anonymous donations are welcome, the Schneiders ask that everyone leave their name so personal notes can be sent. Let us know where you are from too!

[Show less](#)

109 contributions so far

- | | | |
|---|---|----------|
|  | <p>Kathy Kumpe
On 8/6/19
Praying for you!</p> | \$10.00 |
|  | <p>Morgan Wilkins
On 7/5/19</p> | \$500.00 |
|  | <p>Anonymous
On 5/26/19
Hope this helps out with upcoming expenses at Mayo Clinic. Prayers for Louie and family.</p> | \$385.00 |
|  | <p>Melissa DetrickDouglas
On 5/24/19
Keeping you in our thoughts, hearts, and prayers.</p> | \$100.00 |
|  | <p>Susan Anderson
On 5/23/19
Already praying for the specific prayer requests! May God bless and protect Louie and the entire Schneider family throughout the MAYO experience. 🙏❤️</p> | \$100.00 |
|  | <p>Heather Bennings
On 5/23/19
Always in our prayers!</p> | \$15.00 |

Pool Ended

David Cranford

To help with Mayo Clinic expenses. We love you all.



Anna Hallum

On 4/8/19

\$100.00

Louie you will forever be in my prayers.



SW

Shavonne Waltman

On 4/8/19

\$20.00

. 🙏🙏❤️❤️❤️❤️ Sent your way. May god bless you



TN

Tracy Nelson

On 4/8/19

\$50.00

Gods blessings and prayers from St. Louis



CK

Crazy kings kingdom

On 4/8/19

\$100.00

#louiestrong



KB

Katherine Balser

On 4/8/19

\$25.00

Payers for you sweet boy



KB

Katherine Balser

On 4/8/19

\$50.00

Prayers for little man and the while family May the world be blessed with more people to have an attitude like louie



HM

Heather Mariani

On 4/8/19

\$100.00

Lots of love, hugs and prayers! Your smile is a ray of Sunshine and you are SO inspirational <3

Bold and Elegant Paparazzi Pool Ended \$10.00



Brittany Jones

On 4/7/19

\$10.00



David Cranford

On 3/29/19

\$200.00

We love you, Louie! You are an inspiration to people all over the world!



theresa mabray

On 3/28/19

\$20.00



Anonymous

On 3/28/19

\$42.00



Project Zero

On 3/28/19

\$100.00

Thank you Project Zero supporters!



Anonymous

On 3/28/19

\$20.00



Shanna Hastings

On 3/28/19

\$30.00

We are in awe of your strength and joy, Louie! God has created such a big plan for you and you have impacted the lives of so many with your testimony of faith! We are continuously praying for your sweet family! ♡
Shane & Shanna Hastings, PCSO

Ter Crawford

Pool Ended

\$50.00

Louie, we live close to you. Your faith, courage, kindness and love is an inspiration to everyone! You are such a strong young man and we love you! You only see the positive in everything and that is truly something everyone should do!



Angela Robertstone

On 3/14/19

\$150.00

Our prayers go out to Louie and your family. We don't know him personally but have prayed everyday for him and believe that miracles can happen, for him. This is something my youngest son wanted to do for him and spread our love for him. Can't wait to pass these out at his bday party and to all our baseball family. You got this Louie! We all believe in you!!



MARY PREATOR

On 3/12/19

\$255.00

#LouieStrong Stickers



TR

Teresa Ridgeway

On 3/11/19

\$20.00



PZ

Project Zero

On 3/10/19

\$105.00

Thank you friends for purchasing #louiestrong stickers!!!



SH

samantha hodgson

On 3/10/19

\$5.00

#louiestrong.



NW

Nathan Wadkins

On 3/9/19

\$20.00



KH

Katrina Heath

On 3/9/19

\$25.00

Timothy Preator

Pool Ended

\$20.00

Louie you have touched many people across this country ! A true fighter you are ! We love you little buddy



Anonymous

On 3/8/19

\$500.00

So inspired by Louie and his family. Praying for comfort and peace for all involved. My husband and I felt strongly that we were supposed to help your family financially. We hope this makes a little dent in what you will need for all of the medical expenses. Katy and Kevin Niehaus



susan dardeen

On 3/8/19

\$20.00

I wish I could add some zeros to my tiny drop. I will never have the words to explain how my heart and life are forever changed by your story. Forever love!



Heather Thomason

On 3/7/19

\$25.00

Impressed by your incredible strength. Keep fighting the good fight! ♡



Mark Ridgeway

On 3/7/19

\$20.00



Project Zero

On 3/7/19

\$665.00

Sticker sales through Project Zero's merch store! Thank you all so much for supporting our Louie! ♡



Chris Williams

On 3/6/19

\$50.00

Louie, your faith and courage are an inspiration for me!!

Jerry Wegerman

Pool Ended

\$50.00

Louie I am 6'3" and 280 pounds and I wish I was as strong as you are young man. Keep your head up and fight on. I love your positive attitude!!

PB

Patti Brady

On 3/6/19

\$50.00

God bless you, Louie, such a precious and strong little boy. You are loved.

JW

Jill Woodard

On 3/5/19

\$100.00

Praying for you and your family!



Jordan Malone

On 3/5/19

\$50.00

Striving to be like Louie every day!

DN

DEBBIE NANCE

On 3/5/19

\$50.00



Patricia Parr

On 3/4/19

\$50.00

Such an inspiration to us all. Faith of a child.

NH

Nestor A Hernandez

On 3/4/19

\$20.00



John Crabtree

On 3/3/19

\$50.00

Prayers up for Louie and his family.

Mollie Harbert

Pool Ended

\$20.00

Louie, we will continue to pray for you and your family everyday. You are a brave and beautiful soul!

GG

Grannys Gifts

On 3/3/19

\$100.00

God bless you Louie! You have stolen our hearts.

CL

Charles Loetscher

On 3/3/19

\$25.00

Prayers from my family to urs!! Keep smiling Louie#Godswithyou



Anonymous

On 3/3/19

\$250.00

From your Arkansas Pulaski County Sheriff's Office friends. God bless and strengthen you all.

KK

Kathy Kumpe

On 3/3/19

\$50.00

Louie, thank you for being an example of strength & joy for us. Family, we are praying for you to be surrounded with peace & love. #Louiestrong



Anonymous

On 3/3/19

\$100.00

"Never will we be struck except by what Allah has decreed for us; He is our protector. And upon Allah let the believers rely." Quran 9-51 May God be there for you. A Police Officer from Egypt

GM

God's Smile Ministries

On 3/2/19

\$20.00

Louie, you are a bright light in a world full of darkness. May God hold you tightly in His arms and use your life to bring others to Him. I have never met you, but Adam and Crystal are my friends, so we love you through those friendships. You are one brave boy! When your day comes, Run to Jesus! Henry & Yyuvone Heidelberger Conway, AR


 Krystal Watson

Pool Ended

\$50.00

WE LOVE YOU LOUIE!!!! PRAYING FOR YOU AND YOUR FAMILY.


 RK

Rebecca Kincannon

On 3/2/19

\$25.00

Love you Louie. I am so glad I was able to help with your forever home.


 JB

Jessica Bragg

On 3/2/19

\$20.00

We love you Louie! Praying big for you and your sweet family! You are the bravest, strongest, and coolest kiddo I know!



Anonymous

On 3/2/19

\$20.00

God bless your family, I know that your son will be dancing with Jesus in heaven no more pain no more tears only joy forevermore!


 SA

Shannon Atkins

On 3/2/19

\$50.00

So very inspired by his faith and strength! Love and prayers for the days ahead.


 KE

Khristy Earnhart

On 3/2/19

\$50.00

Payers for the whole family!!



Anonymous

On 3/2/19

\$20.00

Thank you for showing us what true faith and strength is, Louie.



Brenda Ramsey

On 3/2/19

\$10.00

Louie has shown us all what true faith is!!! I can see joy on his face.

shelly atkins

Pool Ended

\$10.00

from a #FFmom and a #LEOmom, both my sons have helped in Louis' journeys and I am so proud to call them sons. I pray Louis final journey is beautiful and peaceful. God Bless.

RT

richard thomas

On 3/2/19

\$10.00

Stay strong buddy we love you!



stephanie ruesga

On 3/2/19

\$10.00

You are A Brave Young Man.



Emily Henry

On 3/2/19

\$25.00

Prayers for strength & peace ..

CM

christina mcbride

On 3/2/19

\$50.00

.. ..

DB

Dea Brumley

On 3/2/19

\$10.00

Praying for peace and love to surround your family in the coming days.

KL

Kimberly Lamb

On 3/2/19

\$10.00

Sending prayers.

KH

Krystal Hopkins

On 3/2/19

\$30.00

Peace surrounding every friend and family in this little angels life. We cry because they leave, we rejoice for the fact he will never experience pain. Now you live the rest of your lives as he is walking beside you and love like crazy

Margaret

Pool Ended

\$20.00

Louie, you're so brave and strong.. You are an inspiration to us all... We all love you Louie..

LA

Lakan Agustin

On 3/2/19

\$20.00

What a beautiful family, and what a beautiful soul Louie is. My heart goes out to you all.

AG

Amber Gonzales

On 3/1/19

\$20.00

He's such a strong, brave young man! A. Gonzales Woodruff County Dispatch & A. Gonzales McCrory Police Dept. and family.

SV

Scott Viadock

On 3/1/19

\$10.00

Harding, Exeter Township Police. Stay Strong Brother



Brittany Jones

On 3/1/19

\$10.00

SP

Susan Pomtree

On 3/1/19

\$50.00

Louie is so amazing. In his life he has had an incredible impact on those around him. I know there are many first responders who will never forget him. God bless him and your family! I will always smile when I think about his plan to "tickle Jesus".



Anonymous

On 3/1/19

\$10.00

Bless we've all been with this story, Thank you for letting us be apart.

TB

traci berry

On 3/1/19

\$50.00

Anonymous Pool Ended \$20.00



Anonymous
On 3/1/19

\$50.00



Kathy Cragun
On 3/1/19

\$50.00

Louie, Thanks for sharing your smile & love for everyone. Your faith is an inspiration & testimony to all. Prayers of comfort & love for your family.



Heather Mendoza
On 3/1/19

\$15.00

You are an amazing boy. ❤️



Jana Franks
On 3/1/19

\$100.00

Thinking of You and your family at this difficult time. Peace be with you.



Anonymous
On 3/1/19

\$25.00



Lisa Phillips
On 3/1/19

\$30.00

So happy Louie loves the Lord and what a great witness he is to so many!!! Prayers for him to be comfortable, at peace and happy! Prayers for comfort & strength for his family now and for the days ahead. 🙏



JERRY ODOM
On 3/1/19

\$50.00

Praying for the family!

Tom Cordell
Pool Ended \$50.00



Deniece Byers

On 3/1/19

\$35.00

Blessings and prayers for Louie and his family from TN.



Alaina Mitchell

On 3/1/19

\$40.00

Prayers for Louie and His family! So glad he knows Jesus!!



Timothy Evans

On 3/1/19

\$50.00

Such an inspiration and strong little boy! Thank you Louie!



Jeff Scott

On 3/1/19

\$75.00



Jedidiah Sawyer

On 3/1/19

\$250.00

Louie is so very brave & strong, such an inspiration! You all have been and will continue to be in my prayers. #Louiestrong



Caleb Miller

On 3/1/19

\$50.00



Nick Ramsey

On 3/1/19

\$100.00

Was an honor to get to know this young man. He said he will have our "6". Thank you Louie! Thank you Schneider family for letting us be apart of his and your lives! God Bless. Love y'all!

simon young

Pool Ended

\$20.00

For 4 stickers to support Louie and family



Anonymous

On 3/1/19

\$50.00



Anonymous

On 3/1/19

\$20.00



Anonymous

On 3/1/19

\$20.00

May God bless Louie and his family!



SS

Stephanie Sims

On 3/1/19

\$50.00

Will be praying for you!



BL

Bevin Lewis

On 3/1/19

\$50.00

God bless your entire family. -Will, Bevin, Gage and Gia Lewis



DB

Dan Brown

On 3/1/19

\$20.00



BB

Beth Bakalekos

On 3/1/19

\$40.00

What a courageous family. It's amazing what this baby has taught so many of us.



CH

Claire Hurlburt

On 3/1/19

\$20.00

..

John Baker

Pool Ended

\$100.00

How I do love me some Louie! ❤️ ..

AL

Anna Long

On 3/1/19

\$10.00

Praying for Louie and his family-

KZ

Kristin Zolten

On 3/1/19

\$50.00

Love and blessings to you!



Anonymous

On 3/1/19

\$50.00

We sent a card from AZ and have prayed for this precious boy and his family constantly! We are amazed and encouraged by the faith of this little boy and his sweet family. God bless you!



Anonymous

On 3/1/19

\$50.00

CB

carrie Bowen

On 3/1/19

\$75.00

Praying for this beautiful family

LT

Leigh Taylor

On 3/1/19

\$50.00

Praying for Louie and his precious family. I don't know you, but I used to live in Arkansas. Louie, your story has reminded me of the great things Jesus has done and can do. You are such a special guy loved by many all over the world.

LB

Leslie Bass

On 3/1/19

\$25.00

Share this pool
Pool Ended

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