

In the Face of the Unknown

September 2016

We live in a time of great uncertainty. The world as we know it seems to be changing and whether we focus our concerns on international affairs, global climate change, or the upcoming presidential election, most of us are led to wonder – what is the world coming to? As we watch the news and follow social media, most of us would likely agree that our response as a society is one of both fear and anger and this seems to be getting us nowhere. Fear over the unknown causes many of us to resist the inevitable change and to cling to what we feel is rightfully ours. It draws our focus inward.

As I have reflected on this, I am once again humbled by many of the families we serve at Joe's Kids. From the moment their child is diagnosed with a delay, our families are faced with uncertainties. Despite constantly evolving genetic testing, some will spend years seeking a diagnosis. Diagnosed or not, our parents will find themselves constantly asking, "What does the future hold for my child? How will they function in school, in the community, as an adult? Who will care for them when I am gone?" For those with serious, complicating medical issues, our parents wonder what the next week or even the next 24 hours will hold. They become their child's greatest advocate, researcher, and defender. They spend hours researching on the internet searching for answers, searching for cures.

Is there fear? Yes. Is there anger? Sometimes. Does this draw their focus inward? **NO**. They put their best foot forward every day in an effort to do what is right for their child and there is little time for "me." They are part of a small community of parents, all working for the same cause – to help their child reach their full potential. And though their burden is heavy, they are the first to reach out and support others, to offer a shoulder to cry on and to encourage each other along the way. In the face of adversity, they choose to look outward, to make the best future for their child and to support others trying to do the same.

Rebecca

Sophia Long

6/1/10 - 8/18/16

We are heartbroken for the Long family as we all grieve the loss of Sophia. Her sweet smiles and joyful presence at the clinic will be greatly missed by our staff, volunteers and families. We may have lost an angel, but heaven has gained one. There is peace in knowing that Sophia knows no limits as she runs, jumps, dances and sings in the presence of our heavenly Father.

In lieu of flowers or gifts, the Longs have asked friends and family to consider supporting Joe's Kids in loving memory of Sophia. We are honored that in the midst of great heartache and loss, this family is choosing to support other special kids at the clinic. Please keep the Long family in your thoughts and prayers in the months ahead.



JOE'S KIDS Superstar



Lilly is a ball of energy... the kind of little girl that never stops moving and has an infectious smile and laugh! In 2011 when Lilly was 18 months old, she was diagnosed with Rhabdomyosarcoma. Life took a drastic change. She completed her 24 weeks of chemotherapy at Riley Children's Hospital, however, some of the side effects of the chemo effected Lilly's balance, muscle tone and fine motor skills. This required her to begin Physical and Occupational Therapy. Once she aged out of First Steps, we were looking for a local option for Lilly to receive her therapy services. Unfortunately the closest options were either Goshen or Fort Wayne. Thankfully, after only a few months of traveling out of town, we were referred to Joe's Kids which provided a local option for Lilly to receive therapy.

When Lilly began therapy at Joe's Kids, she received Physical Therapy. Lilly loved her sessions and playing upstairs with all of the fun "toys" and equipment. Her balance and muscle tone greatly improved, and she was able to walk and even run with more confidence! She went from having to "slide" down and crawl up the stairs to taking each step one at a time. Joe's Kids also connected us with a specialist for orthotics to improve Lilly's gait even more. She went from being an unbalanced, shaky little girl to walking with confidence and keeping up with her peers in "normal" activities.

Lilly also receives Occupational Therapy at Joe's Kids. She loves spending time with Miss Laura and playing every week. Her favorite activities are finding the beads in the thera-putty and "playing" on the scooter boards. While these activities are challenging for her, she has come so far in the time she has received services at Joe's Kids. Her fine motor skills are now closer to children her age. The patience and dedication that Miss Laura has shown with Lilly is amazing... you can tell that she truly cares and wants her to succeed and meet her goals!



This past year Lilly has also received Speech Therapy from Miss Amber. I appreciate that all of the therapists work together at Joe's Kids and make suggestions to help the kids reach their full potential. While communicating with Lilly in OT, it was discovered that she would benefit from speech therapy, too. She loves her sessions and Miss Amber works to keep her on task and pushes her to reach her goals!

We are so fortunate to have Joe's Kids in our community. The entire staff is so welcoming and truly care about our kids. It has been amazing to watch Lilly grow and "graduate" from physical therapy and reach goals in her other areas. I know that Lilly would not have come as far as she has without the amazing therapists at Joe's Kids!

- Angie Jarrett
Lilly's mom