

Hope Votes

June 2017

LETTER FROM A HOPEKIDS FAMILY

Dear Friend of HopeKids.

I have been meaning to share with you what a difference you have made in our family since last spring, but life got in the way and I haven't had a moment. Please know that my delay in sharing does not diminish the appreciation we have for you.

Last summer, there was a HopeKids event at HopeRides Ranch. My five-year-old daughter, Victoria, loves, loves, loves horseback riding. We have been unable to afford the cost of therapeutic riding in the last year, so we jumped at the opportunity to have a day with her favorite activity in the entire universe. Little did I know that opportunity would be a complete game changer for my daughter's future.

While at the event, we met a teen with the same disorder that Victoria has. After the surprise that someone else had the same uncommon diagnosis settled, the young lady and her mom began to share some invaluable information they have learned in managing the issues the disorder brings.

They shared resources, personal experiences, and lots of stories of "I wish I had known ... when I/my daughter was Victoria's age." I was no less than overwhelmed and near tears.

I got home and immediately got to work. I contacted physical therapists who had been personally recommended and set up evaluations. Pretty intensive therapy began, and Victoria is leaps and bounds ahead of where she was when we started--specifically because of the knowledge and understanding the therapists had with my daughter's issues. If I had not gotten the recommendations I did, I likely would not have pursued therapy again--thinking there was nothing really that could be done to help her.

We have put her school team on alert regarding some other potential issues, and her individualized education program is set up to incorporate them as they may arise. We already jumped on some speech/articulation issues before they progressed because they were on our radar from meeting the other family. The early identification has allowed early intervention before things got much worse and were unfixable.

l also agreed to some interventions, like the use of a power wheelchair in school, that I had been resisting before meeting this other family. Allowing my daughter this seemingly overwhelming (and obnoxiously pink!!) assistive device has entirely reshaped her ability to benefit from academic experiences.

I don't say this lightly, and I am not prone to hyperbole in general: I can say with full confidence that HopeKids has changed my daughter's life in ways that I could have never imagined.

A few months ago, we went snow tubing on a flash "spots still available!" text alert. Victoria had a blast! Because of her increased strength and endurance--that have been accomplished due to that chance encounter with another HopeKid and her family--Victoria was able to stick it out and enjoy repeated trips down the hill without collapsing in exhaustion.

Thank you. Thank you. Thank you. Thank you.

Anne Lawson









"There are so many moments that pull you back to the darkness, and you start to believe that life will never be normal. And then you get out of that darkness, even for a moment; an hour; a day. Hope is all that keeps propelling you forward."

David and Casie Katzer have never taken their kids' health for granted. Casie's pregnancies were difficult, and the birth of both boys felt like a miracle. Little did they know there was cancer ravaging the body of their youngest son—even while he was in the womb.

The scope of Hudson Katzer's world was primarily the inside of his hospital room. His diagnosis came at 9 months old: a time when infants are starting to crawl. Instead, Hudson seemed to be losing mobility. After a trip to the emergency room, and scans at 11:30 pm, his parents first saw the gutwrenching pictures of a tumor, which had been causing paralysis.

"The tumor was neuroblastoma," Casie said. "They were going to remove only 20% of the tumor, because it was so wrapped around his spine."

Hudson's treatment included 16 rounds of chemo, 20 rounds of radiation, a stem cell transplant, and antibody therapy. They lived at Children's Mercy Hospital for three years. Last August, Hudson's treatment was finally complete.

"You can't sugarcoat the cancer experience. It was hell. The hardest things we've ever done, and our darkest days."

Casie accepts that it's taken years to mentally heal and memories of the physical and mental anguish are still vivid. Yet, she has an appreciation for the word, "hope."

-Casie Katzer, Hudson's mom

"There are so many moments that pull you back to the darkness, and you start to believe that life will never be normal," Casie said. "And then you get out of that darkness, even for a moment; an hour; a day. Hope is all that keeps propelling you forward. It gives you a sense of what life was before, and what life can be again."

The Katzers are the third family to join HopeKids Kansas City. They attended their first event with other HopeKids families at LEGOLAND on May 11. Casie believes the hope that is fundamental in the HopeKids community is exactly what families who have a child with a life-threatening medical condition need when everything is desperate, and the only instinct is survival.

"An event at LEGOLAND is priceless," Casie said. "From having the facility be closed to the general public so families don't have to worry about crowds and germs, to allowing the siblings to participate and for once, not feel left out. There's nothing like HopeKids here in Kansas City; nothing to provide an escape from the darkness."

HopeKids Kansas City recently launched and is currently enrolling families who have a child with a life-threatening medical condition, with plans to serve more than 150 families by the end of 2017.















HOPEKIDS KANSAS CITY PHOTO ALBUM

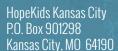
LEGOLAND Discovery Center Kansas City

On Friday, May 12, LEGOLAND Discovery Center Kansas City hosted three HopeKids families for a "sneak peek" of their brand new exhibit, Train Station Adventure. Our HopeKids families had the entire place to themselves for two hours to play in the new exhibit and kick-off our first HopeKids KC event.

In addition, two of our HopeKids, Hudson and Phoebe, got to join the Greater Kansas City Chamber of Commerce in the official ribbon cutting for the new LEGOLAND exhibit.

As HopeKids Kansas City grows, we continue to welcome new families, and offer additional events over the coming months.

- 1. Phoebe, age 12, and Hudson, age 5, build the very first trains at the new Train Station Adventure.
- 2. Hudson, age 5, and HopeKids Volunteer, Ray, race cars and build trains.
- 3. Phoebe and Hudson join the Greater Kansas City Chamber of Commerce for the ribbon-cutting ceremony for Train Station Adventure.
- 4. The Schondelmeyer family enjoys LEGOLAND Discovery Center.
- 5. Phoebe and Executive Director Kerrie Bryant play with one of the new Train Station Adventure exhibits.
- 6. Nathan, age 12, enjoys building trains, racing cars and more at his very first HopeKids event.



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