

## August 2016 Minnesota HopeNotes

## **MY HOPEKIDS JOURNEY:** A YEAR IN THE LIFE OF THE BOWEN FAMILY

The Bowen family joined HopeKids in March 2015. Christopher is 7 with PAVMs -- abnormal communications between pulmonary arteries and veins. The journal entries below were written by Christopher's mom. Kaylene and are just a sample from the 39 events they have attended.

March 9, 2015: Our application was approved, and I registered for HopeKids today. Christopher is not in treatment, so we want to do as much as possible. I cried when I viewed the calendar because it's given me hope where I didn't really have it. I signed up for *Peter Rabbit*, KidMania, the Shrine Circus and the HopeFlick: Home. [Joining HopeKids] is opening up a world to my kids that I never thought I would be able to give them.

March 13, 2015: It was priceless to sit for an hour and half and watch my kid laugh at our first HopeKids event, Peter Rabbit. Christopher didn't worry about anything, and nothing was hurting him. I also met another HopeKids mom who understands my life.

March 20, 2015: I took the kids to KidMania with HopeKids. Christopher was NPO (cannot take food or liquids by mouth) so my other two played while I just sat and held him. We found out today that Christopher didn't qualify to get the lung transplant. While Alexis and Caleb yelled, "Mommy look, Mommy look," I held onto Christopher and prayed that this is not the last month with my son.

March 28, 2015: We received our HopeKids t-shirts in the mail. Christopher ripped open the package and started

handing out t-shirts: "Mommy, this is for you, and this is for Daddy. This is for Bubba, and this is for Lexi." It was like Christmas. We wore our shirts to the kids' first circus ever and I snapped the cutest picture.

> May 31, 2015: Christopher loves baseball. It's the only sport he's been able to play. Before the 'kids night out' at the baseball game today, we met the players, played games and ate ice cream. The excitement wore on Christopher, and he took a nap from the third to the seventh innings but he was so excited to run the bases. In the car he said, "Mom, this is the best day ever."

July 23, 2015: Christopher realized while roller skating that he wasn't the only one with a feeding tube, a bald head, a port, or wearing a mask. He opened up and felt comfortable because he was finally like everybody else. I can tell him 'it's okay to be different' but he wants to look like the kid to the left and the right of him. We want to identify with him, but we'll never understand. Tonight, he was comfortable in his own skin.

August 29, 2015: NFL tickets!! It's kind of like winning the lottery. Christopher bought a jersey to wear to the game with the \$63 he had saved. He slept some during the game, but I know he'll remember seeing the players on the field, meeting the mascot and taking pictures in front of the stadium. I don't think the people who donated the tickets realize what it means to us. We would never be able to afford an NFL football game. I won't forget this one.

**December 12, 2015:** Everybody thought we were going for a nice dinner but I surprised them with the ballet. I call it "culturization". My family thinks I'm crazy and I made the word up. I told them, "Let's try it!" They actually liked the ballet.

March 5, 2016: We saw Zootopia today. My daughter knows that when we're wearing the HopeKids t-shirts, we're going to be doing something fun. Her favorite thing is the movies because they bring her peace and normalcy. They give her something to look forward to instead of being Mommy's helper and taking care of her baby brother. One day a month she gets to watch a movie and just be 12-year-old Alexis.



- RTNERS
- Minnesota Twins
- Minnesota Zoo
- KTIS
- Tradition Companies
- Minnetonka Power Squadron
- Hennepin Theatre Trust
- Stages Theatre

- Feed My Starving Children
- Chick-fil-A
- Tix for Tots
- The Smith Family
- Elko Speedway
- Minnesota Lynx
- Minnesota Twins

- Chanhassen Dinner Theatre
- Como Town
- Edinborough Park
- Minnesota Wild
- Merrill Community Arts Center
- USSA
- Libby Cameron



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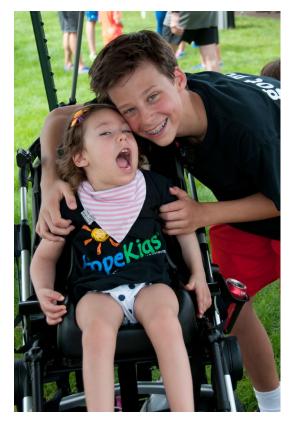




## MINNESOTA HOPEDAY PROGRAM



Left: "Kids Fun Run" starting line at the 8th Annual Suburban Adventure presented by Tradition Companies and Spirit of Brandjten Farm on June 11. Below (Left to Right): HopeKid Charlie, 4, poses with her brother at Suburban Adventure: HopeKid Talitha, 13, fishing with the Twins at Lake Harriet: HopeKid Serenity, 6, and Kaylee, 4, enjoy the Lake Minnetonka boating and island picnic event.









## MEET NOLAN

Nolan is a 6-year-old kindergartener who loves hockey. He is functionally non-verbal but his excitement is undeniable as he watches hockey games with both arms in the air and yells, "HOCKEY!"

Nolan started to have seizures at 4 months old and had a portion of his brain removed with hopes that surgery would help control his seizures. Nothing has ever come easy for Nolan, but he goes through life with a big smile on his face. Nolan's family has attended 23 HopeKids events, including several hockey games, since joining HopeKids in September 2015.

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