

# HopeNotes

## *imagine* HOPE here.

"Whenever anyone asks me what HopeKids does for families I show them this picture and say, 'This is what they do.' There is nothing more amazing than seeing that look on your child's face."

Cassandra Lambert treasures each look of wonder she spots on her son, Johnathan. Last year, he spent 115 days in the hospital because of his mitochondrial deletion syndrome.

"Your mitochondria converts everything you eat and drink into energy," Cassandra explained. "It's like your battery. The DNA of his mitochondria is broken. All the processes [in his body] are deleting themselves."

At age 6, Johnathan recalls a time when he was able to run and play and when he could eat food. In spite of the deterioration, Johnathan remains upbeat.

"He's so big in his personality and the love he gives," Cassandra said. "There's a lot of pride in watching him as he deals with these things. He handles himself with such love and joy."

As a single mom of three, and like many parents who have a child with a lifethreatening medical condition, having a job is out of the question. Along with financial stress, Cassandra felt a cloud of guilt because she has so little time with Johnathan's siblings, JJ and Lilly. Extended hospital stays mean someone else tucks the older kids in at night.

"After Johnathan was discharged from the hospital, we were finally reunited, but there was nothing to look forward to," Cassandra said. "I would save all our money in a year for a weekend camping trip. That's all we could manage."

#### WHAT IS YOUR CHRISTMAS WISH?

"I am praying our HopeKid learns "no" and "why" - every parents nightmare words. For us, it lets us know his little brain is processing information correctly."

"Praying for a cure to POTS and our daughter can return to school soon. She is sad to be at home."

"A cause/treatment for our sons nonstop pain."

"Praying to be home and that our sweet boy can enjoy something by mouth."

"I wish my son does not remember any of this!"

"A cure for my daughter's perineurioma and for my other daughter to not loose her vision."



Cassandra recalls the despair she had felt when JJ requested a birthday at Legoland. It was out the question financially. Amazingly, a Legoland event appeared on the HopeKids calendar the week of his birthday.

"It really felt like his birthday celebration," Cassandra said. "The events always seem to work out with what the kids really wanted to do,"

Since joining HopeKids, the family has attended numerous events, giving them access to a wider variety of family activities than they could have dreamed. The harsh realities of Johnathan's syndrome are always there but Cassandra likens it to a long, dark tunnel.

"When I think of the hope, the hope is the bright spots along the way. I don't even know how to explain what it means for us to have things to look forward to when we used to never have anything to look forward to. It's strengthened our bond as a family, and made such a difference in everybody's outlook on life."



*The Lambert Family* (*L to R*): J.J., Lilly, Cassandra, and Jonathan

Winter 2017

"My Christmas miracle wish is for all children to be cured no child should ever have to suffer... #cureCF"

"A cure or even a treatment for Sanfilippo. For my son to not be regressing and dying before our eyes."

"An end to suffering for all of these children. Our kids deserve more joy than pain."

"For all the parents to suffer less."

"That the doctors keep spiraling through all her systems and keep doing their best to keep her happy and healthy for as long as we can get."

"No GI pain and sleep."

"Wishing for sleep and comfort from chronic pain."





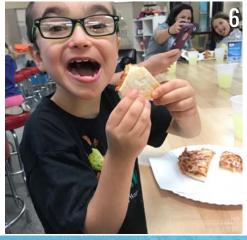
















#### HOPEKIDS MINNESOTA PHOTO ALBUM

Snapshots captured at September, October, and November HopeDay Events

- 1. HopeKid Anders rock climbs at Vertical Endeavors in St. Paul.
- 2. HopeKid Evan is a super hero in his new cape while inpatient at Children's St. Paul.
- 3. HopeKid Kate enjoys Spookley the Square Pumpkin at Stages Theatre.
- 4. HopeKid Lydia and HopeKid Jackson are best buds during the PHS Fall Festival.
- 5. HopeKid Olivia poses with Goldy at the Gopher Hockey game.
- 6. HopeKid Sam cooks way cool food at the Way Cool Cooking School.
- 7. Nothing says fall like the corn pit at Dehn's Pumpkins in Dayton, MN.

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- 8. Tristan meets the cast of *Singing in the Rain* at University of Northwestern St. Paul.
- 9. Zip lining at Kerfoot Canopy Tours was above and beyond our expectations.
- 10. HopeKids families had a wonderful time exploring the Minnetonka Orchards HopeCommunity event.
- HopeKids imagined hope during the Imagine Dragons concert in our HopeSuite at Xcel Energy Center.
- 12. HopeKid Caleb and his family enjoy a Wild Game in the HopeSuite at Xcel Energy Center.



Minnesota Lynx **Game Day Memories Tickets for Kids** Minnesota Twins University of Northwestern Theatre Hennepin Theatre Trust **Stages Theatre** Minnesota Wild Sever's Corn Maze **Gopher Athletics** KTIS Northrop Auditorium Sky Zone Microsoft - MOA Store Minnesota Timberwolves **Tradition Capital Bank Vertical Endeavors** GameWorks **City of New Brighton** Mann Theatres Pediatric Home Service





### MEET CHRISTIAN

Christian is a very happy and active 7-year-old, who was born prematurely at 24 weeks gestation. He was diagnosed with cerebral palsy at birth and had his first major seizure with convulsions in December 2015. Christian's nickname is "Braveheart" because of his time in NICU when his vital signs would drop extremely low but his heartbeat remained strong.

"HopeKids has benefited our family in many ways such as being able to meet and share with other families who live and have a similar lifestyle as ours and understanding the challenges that we face. We benefited from networking with other HopeKids families on shared information for medical providers, therapists, healthcare, schools and more." - Theresa, Christian's mom

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