

Squeezing a childhood into a few months

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Kaz Novak, the Hamilton Spectator

Family filling life of dying tot

February 11, 2009

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THE HAMILTON SPECTATOR

(Feb 11, 2009)

kari patterson cries in the shower where her children can't see her.

Then she picks herself up and sets about making memories that will last long after her two-year-old son, Tucker, is gone.

He is dying of a genetic disorder called Leigh's disease, which affects the central nervous system causing progressive degeneration of motor functions. He's not expected to live past the age of three.

His parents have to cram an entire childhood into the next year.

They can't get help from the Make-a-Wish Foundation of Canada because Tucker is too young -- you have to be at least three to get a dream come true.

So Patterson and her husband, Dave, grant Tucker's wishes with the help of fundraising done mostly in Waterdown where they live.

They've taken Tucker, his fraternal twin, Avery, and four-year-old sister, Tori, to Disney World and to a Toronto Maple Leafs game. Next up is the Toronto Raptors and indoor waterpark Great Wolf Lodge.

"You walk down the street and you see dads playing catch or street hockey with their sons and Tucker won't get to do that," said Patterson. "I won't even get to take him to school. Instead we've planned his funeral and purchased a plot."

But the Pattersons have big plans for Tucker to help change the world, or at least his small corner of it.

They are raising money in his name to fund research at McMaster University Medical Centre into a relatively unknown group of diseases that affect about one in 2,500 children. Hamilton's Dr. Mark Tarnopolsky is the only physician in Canada to dedicate his entire practice to mitochondrial diseases.

Mitochondria are essentially the powerhouses of cells, mixing the food we eat and the oxygen we breathe to create energy. Genetic mutations cause mitochondria to malfunction so the cells run out of gas. Nerve cells in the brain and muscles are particularly damaged by mitochondrial dysfunction because they require a lot of energy.

Leigh's disease is a rare mitochondrial disorder and, like the others, it has no cure.

"When you have kids, you promise to take care of them and not let anything hurt them, but I can't do that for Tucker," said his mom. "So I changed my promise to letting everyone know about this terrible disease that is going to take him away from us. Maybe there is an up-and-coming doctor who will see this and go out and find a cure."

Tarnopolsky is trying to be that doctor. In the next three months, Hamilton will test Triacetyluridine, a drug that holds promise for treating mitochondrial disease. Only 30 adults are in the study, but Tarnopolsky hopes it's a start.

It will likely come too late for Tucker. But it could make a world of difference for his sisters. So far, it appears they don't have Leigh's disease -- the onset is generally age one to three. But there is a chance they carry it and could pass it on.

Both of Tucker's parents have the mutated gene. Neither of them knew and there are no health problems in their families that would have given them a clue.

They met on an Air Canada plane in July 2001. Dave is a firefighter at Pearson International Airport and Kari is a Peel Regional Police officer who was on duty at the airport. Dave was tending to a medical emergency on the plane and having trouble with other passengers blocking the aisle. All of a sudden, he heard a woman bellow orders for everyone to go back to their seats.

They were married May 17, 2003, and had Tori nearly two years later.

Next came the twins July 5, 2006, born six weeks early. They each had a short stay in McMaster's neonatal intensive care unit but were thought to be in perfect health when they went home. For nine months, they each met their milestones.

"We had a jumperoo and Tucker was jumping so high we thought he was going to go airborne," remembers his mom. "He had so much strength."

But suddenly the spit-up doctors thought was reflux turned to projectile vomiting. He was refusing to eat and stopped gaining weight. While his twin sister had long slept through the night, Tucker was still waking every hour. He had abnormal hair growth on his legs and back.

A battery of tests turned up nothing and he seemed a happy toddler so doctors didn't make him a high priority for an MRI. He was put on a two-year waiting list in November 2007. By May, he'd lost his pincer grip and his mom asked to see an eye doctor thinking his sight was the problem.

When he turned two, it was clear something was very wrong. He was regressing. He couldn't sit up or crawl and he weighed the same as he did when he was one year old. The final straw was when an eye doctor discovered degeneration of his optic nerve fibres.

Tucker finally got an MRI on July 30, 2008, and the results were worse than anything his parents could have imagined.

"I thought we'd have a child with special needs," said his mom. "I never thought we'd have a terminally ill child."

To cope, Tucker's mom threw herself into raising awareness through her website and blog, tuckerstime.com.

She also started fundraising. First it was to help raise money for the medical bills such as Tucker's wheelchair. Next it was for the family to build memories with Tucker. Now, it's for research at McMaster. A fundraiser last week brought in about \$5,000.

She's given up her hopes of hockey practices, soccer tournaments and baseball games with her son.

But Patterson holds tight to the dream that his short life will have big meaning. "I hope I live to see it so I know we made a difference. It's the only way I can help my son."

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