



Tucker's time

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August 15, 2008 is a date that will forever be etched in the minds of young parents Kari and Dave Patterson: that was the day the Waterdown couple learned that their two-year-old son, Tucker David Patterson, has a rare and fatal disease known as Leigh's syndrome.

The disease, which has robbed their little boy's strength and balance, is caused by problems in the mitochondria—the tiny structures that are the 'power stations' in every cell. It has no cure and treatment is limited. Those afflicted with this rare inherited neurometabolic disorder die within one to three years after onset.

The news that their son—a twin to sister, Avery, and young brother to three-year-old Tori—has a fatal disease hit his parents like a thunderbolt. Yet, they had known for months that something was wrong.

Tucker didn't develop as quickly as his twin sister; at first, the differences were negligible but later, they became more marked. He was "failing to thrive," Kari said, alluding to the medical terminology used to describe Tucker's lack of development, characterized by a lack of motor skills or movement.

"He was 17 months old before he started to crawl," she added. He didn't crawl on his knees, but rather used his arms and "scooted around the house on his bum," usually traveling backwards.

In addition, there were several early signs that something was amiss. At seven to eight months of age, abnormal hair growth occurred on his legs. He couldn't sit up and his gross motor skills were impaired. The abnormal hair growth spread to the base of his back and up his spine.

His mother noticed that he was "always spitting," but between the ages of six and nine months, he had regular episodes of projectile vomiting. In the spring of 2007, after seeing his pediatrician, Dr. Ramsay MacNay, and undergoing tests, he was put on medication for reflux. He was weaned off the medication three months later when the vomiting stopped. But in August, the vomiting reoccurred and he was put back on medication.

Eventually, Tucker stopped eating altogether and his weight began to fall. After another visit to Dr. MacNay, he was referred in November 2007 to a gastro-intestinal specialist, Dr. Bob Issenman at McMaster Children's Hospital. Shortly after being seen by the specialist, he began to vomit six times daily. He was admitted to McMaster for a week and underwent a round of tests, including a barium swallow, ultrasound, and genetic testing. An endoscopy determined he had severe reflux.

In November, he was put on a two-year wait list for an MRI of his brain and spine. Still, there was no answer as to what was causing Tucker's problems. From January through March, he was put on a drug study and the vomiting ceased. In February, "he was labelled as globally developmentally delayed," his mother said. "I



FAMILY:Tucker Patterson, surrounded by his family: mom, Kari, dad, Dave, sister Tori (left) and twin sister, Avery.



Two-year-old Tucker Patterson has Leigh's syndrome, which occurs once in every 500,000 births. There is no cure.

knew it was more than that and I needed answers.”

After taking a three-day workshop on how to advocate for a child with special needs, she became more determined to find the answers that had so far eluded her and her husband. Tucker continued to experience other problems. In April his mother saw reason to question his eyesight and in May, he contracted “a bug” that caused him to scream and vomit every hour. He was taken to hospital, treated for dehydration and put on intravenous (IV). He was discharged but continued to vomit at home and was taken back to McMaster Hospital where he was admitted. Tucker was so exhausted by the ordeal that he slept 22 hours a day during his weeklong hospital stay.

Because of all the problems he experienced in May, he was put on the semi-urgent list for the MRI. But it wasn't until late July that he got the diagnostic test after he had stopped eating and drinking in June and lost more than a pound between July 11 and 23. For his parents, his weight was a constant worry as he would often plateau at 9.7 kilograms (21 pounds) and then his weight would fail.

Also in July, Tucker had an appointment with Dr. Isaza, an ophthalmologist at McMaster. She tested him for optical atrophy and told his parents that it could be caused by one of three things, a birth defect, a mass or tumour.

After months of trips to doctors' offices, countless tests and standing by helplessly as her son's condition deteriorated, Kari said, “My world started to crumble.”

Finally, an MRI of Tucker's brain, spine and eye orbitals was done. Muscle and skin biopsies were also taken. Dr. Mark Tarnopolsky, a world leader in researching neuromuscular and neurometabolic disorders at McMaster, told the Pattersons that Tucker's problems were the result of a mitochondrial disorder, but they still had to determine which specific strain of the disease it was.

A feeding tube was put into Tucker's stomach so he could be treated with “a mitochondrial cocktail” of vitamins and enzymes twice a day and fed a liquid diet for 10 to 12 hours a night. During his three-week stay in hospital, he contracted C. diff, a bacterium that causes severe diarrhea, and was put in isolation. It was shortly after this turn of events that the Pattersons were called into a conference room at the hospital and told that their son lacks mitochondrial complex IV activity. The news was shattering.

“It was good to know (finally)” what was causing Tucker's problems, his mother said. “But that was not what I wanted to hear.” She had been researching mitochondrial diseases on the Internet and she knew that the diagnosis meant her young son's life would end within a few years.

“The tears fell,” she said. “I knew he has one to three years (of life) from onset, and onset was a year ago.”

She and her husband, a full-time firefighter at the Pearson International Airport and a volunteer firefighter at the Waterdown station, have decided to meet future challenges a day at a time. “We're living each day as a gift and trying to cram a lifetime of memories into whatever is left (for Tucker),” Kari said.

The Pattersons are eager to celebrate Tucker's life, give friends and coworkers an opportunity to see him “at his best” and also raise awareness of Leigh's syndrome, a disease that strikes one in every 500,000 children. So they've planned a fundraising party, “by invitation only” for about 150 guests for Sunday, September 21. The festivities, to be held at a Brampton banquet hall, will include a barbecue, face painting for the children, a silent auction and 50/50 draw.

Tara DeBruin, another Waterdown mother of twins, who met Kari two years ago while attending a meeting for Bay Area Mothers of Multiples, is helping contact local businesses for donations for the auction. Anyone wanting to make a donation is asked to contact the Patterson by e-mail at kari@tuckerstime.com. For more information, visit the website at www.tuckerstime.com.

Kari also has access to a supply of green plastic wristbands that many people like to wear as a show of support for those with mitochondrial disease. Anyone wanting to get a wristband is asked to contact her by e-mail.

Donations from area residents wanting to help the Pattersons with the extra costs of medical equipment and

care for Tucker can be made in trust at the TD Canada Trust. Donations should be made to Kari or Dave Patterson, in trust to Tucker Patterson, Branch # 3810 and Account # 6324471. No charitable tax receipts are available.

While Ontario's health insurance plan (OHIP) covers 75 per cent of Tucker's health care costs, specialized equipment comes at a high price: stroller, \$4,000-\$5,000; ponywalker (an assistive walking device), \$2,000-\$3,000; feeding pump, \$600-\$1,000; and braces (foot orthotics), \$1,800. Sterilized water, gauze and pediasure (Tucker's liquid diet) also add to the costs.

The McMaster Children's Hospital has a website that provides opportunities for those wanting to make a contribution toward researching a cure for Leigh's syndrome. Donors can go online at www.mackids.ca, scroll down to "How your donations help" and then to, "Tribute/Memorial Giving" where they can make their donation "in honour of Tucker Patterson." Sponsors can be anonymous or have a card sent to Tucker's parents. Donations of \$20 or more are eligible for a charitable tax receipt.

Patterson recommends two websites for those wanting to learn more about Leigh's syndrome: www.umdf.org and www.neuro.wustl.edu/neuromuscular.

The Pattersons have both learned a lot about mitochondrial disease in the last two years, and while Tucker has been a big focus in their lives, they haven't forgotten how important it is to do things as a family. They're looking forward to a trip to Florida in October when they'll visit Disneyland and re-discover through the eyes of their children, the wonderment of the make-believe world.

In the meantime, they are making plans for another fundraiser in the spring and Kari is thinking about organizing a walk to bring more public awareness to mitochondrial diseases that affect children. But all that can wait until after Disneyland; there is after all, in everyone's life, a time to play and a time to work. The Pattersons can appreciate that better than most.



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