



# Faces of Mito

## Meet Walter Bransonroach

Sharing a joyful life with his family.



Getting an early and accurate diagnosis can be the difference between a life fighting to survive and one filled with adventures and joy.

It was when Walter was approaching his first birthday that Erin felt that something was wrong with her son. He wasn't meeting the developmental milestone of other children his age and his lips would turn blue when he cried. Getting the proper diagnosis was hard – really hard.

Erin says she brushed off the early signs that something was wrong. At 12 months, he couldn't sit up and had no words. We kept telling ourselves that boys develop more slowly. We thought he'd catch up.

When Walter didn't pass an auditory test, the real search for answers began. "The first diagnosis we were given was cerebral palsy," says Erin. "I remember being angry and feeling like we'd been brushed off after a very short consult. I was convinced the diagnosis was wrong. Although I did not believe my son had cerebral palsy," adds Erin, "I did know that he needed help."

Walter was referred to KidsAbility, a wonderful organization in Guelph, Ontario

that helps kids reach their communication, social, physical and behavioral goals. A physiotherapist who worked with Walter, said that she too believed the initial diagnosis was wrong. She suggested he be seen by a developmental pediatrician at McMaster Children's Hospital in Hamilton, Ontario.

Erin agreed to the consult which led to a series of tests, diagnosis by Dr. Mark Tarnopolsky, and the rewriting of Walter's future. After blood work, a muscle biopsy, MRI, CT and genome sequencing, it was confirmed that Walter had Leigh syndrome resulting from a spontaneous mitochondrial DNA mutation. He was two-and-a-half years old.

Erin headed back to her computer to gather more information after the second diagnosis. What she read, scared her. "It didn't take long to learn," Erin recalls, "that Leigh's was one of the really bad mitochondrial diseases."

Symptoms of Leigh syndrome usually begin to appear between three and 24 months when the central nervous system



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*Walter is one of four children in a busy house that is full of energy. He is pictured left with his Mom and Dad, Erin and AJ, sisters, Petra and Sylvie, and little brother Marvin.*

begins to weaken. This includes the brain, spinal cord, and optic nerve. The illness can cause deterioration of motor skills, loss of appetite, vomiting, irritability, onset of seizures, generalized weakness, lack of muscle tone, and/or episodes of lactic acidosis which can affect lung and kidney function. Most children with Leigh's do not live long.

Walter and his parents were determined to beat the odds. "In some ways," says Erin, "we feel like we lucked out. At the time of his diagnosis, Walter was not in metabolic crisis and had no lesions in his brain. It is quite unusual to be diagnosed before the disease progresses to that point. We are so thankful that, to this day, he has not experienced metabolic crisis and his brain remains lesion-free." When reflecting on the past, Erin says that the biggest piece of advice she has for other parents is to trust your gut and push for answers.

Dr. Tarnopolsky started Walter on a mito cocktail comprised of CoQ10, alpha lipoic acid, vitamins E and D, creatine, monohydrate and lots of iron. Within six months, Walter was walking and talking and has continued to advance ever since.

Life is good but not easy for Walter, who is now eight years old. He has braces to help him walk and sometimes needs to use a walker. He struggles with fine motor skills and lacks muscle control in his mouth, so he speaks slowly. And, when Walter gets sick with common colds or ailments, it takes him much longer to recover.

Erin says Walter has to work hard and tires easily. Because his body has less energy, he has to prioritize where he spends that energy. He knows that if he doesn't, he will crash.

Erin believes that her son, now in grade 3, will have a wonderful future ahead of him. She credits Walter's phenomenal success to an early diagnosis, the proper treatment and a strong spirit.

"We are so grateful Walter has been given the care he needs," says Erin. "When we first got the diagnosis of mitochondrial disease, we didn't know if he would make it to high school. I now know he has a future. He will have a job, be a contributing member of society, and continue to make people smile."

**MitoCanada** focuses its energy on creating a world where all lives are powered by healthy mitochondria. We use our collective energy to reduce the devastating impact of mitochondrial disease by creating MitoCommunities that are empowered, inspired and connected.

[MitoCanada.org](http://MitoCanada.org).