



# Faces of Mito

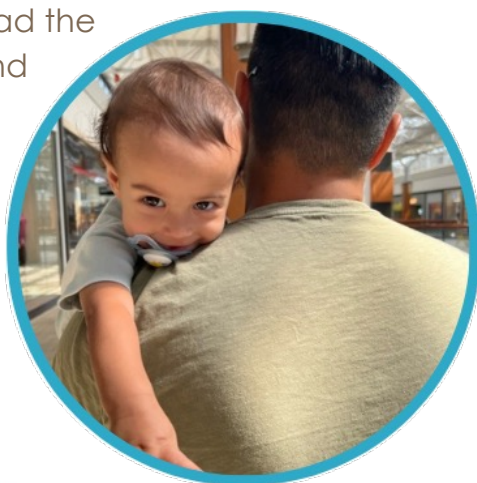
## Remembering Charlie: The Leitis family shares their story



Before they knew what mitochondrial disease was, Dani and Ivars Leitis had what they considered to be the perfect family. Their daughter, Riley, was thrilled to have become a big sister at the age of seven, and baby Charlie (born June 4, 2021) was reaching all his milestones. "Everything in our lives was going well," says Ivars. "We didn't have everything, but we had it all."

"We had no clue that Charlie was silently fighting a battle that would lead to a devastating loss," says Dani.

Charlie was big on snuggles and loved being held. "His favourite place was intently watching the world over Ivars' left shoulder," says Dani. "He had the greatest smile and laugh and big beautiful eyes. He was always watching what was going on around him."



Charlie loved to make music, hum along to songs, play with his toys and the family's dog Dusty, and scoot down the hall to his big sister's room to see her. "The way Charlie's face lit up for Riley was filled with pure love," says Dani. Riley loved to give him piggyback rides, which were guaranteed to make him smile or laugh.

While Charlie was a happy, playful toddler, he faced challenges from the start. "He was very demanding in his first year as he was extremely fussy," says Dani. "He struggled with breastfeeding. He seemed to get tired, as though it was a lot of work, and we ended up having to supplement with formula. We noticed he sometimes made a gurgling noise when he was breathing, but we were told that he just had underdeveloped vocal cords because he was premature. He had a 'slight nystagmus' we were told, which is involuntary eye movement. He also had what we thought were breath-holding spells. He'd cry so hard he'd stop breathing.

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As it continued to progress, he'd go completely stiff – arching his back, his hands and toes would curl up and he looked like all the muscles in his body were seizing." A visit to the family doctor sent Charlie into one of these spells. Witnessing it in person, the doctor became concerned that Charlie may be having seizures and referred him to a pediatrician. This would be the first time a pediatrician would dismiss concerns without any testing.

"Charlie started to seem a lot better after his first birthday," says Dani. "The gurgle was gone and the breath-holding spells had nearly stopped. He continued meeting his milestones. But somewhere after the 16-month mark, we started noticing that Charlie was losing weight. He had been walking with support since 10 months but wouldn't progress. He also wasn't using his words anymore. It happened so quickly." The family doctor once again put in referrals for pediatricians, but it wouldn't be until 19 months – January 2023, with desperate pleas from the family doctor – that two more pediatricians would finally accept Charlie as a patient.

The family's concerns were mostly dismissed by the first pediatrician they saw and they were told to check back in four months. Unfortunately, Charlie didn't have four months.

Unsatisfied, the family moved on to a third pediatrician. She ordered blood work, tests, and referrals, including a dietitian and an occupational therapist (OT) who would support the family at home. The OT noticed that Charlie slouched a lot in his highchair, causing fatigue, and that his oral muscles were taking a long time to fire at the beginning of a meal. They switched from a highchair to a booster chair, added dietitian-provided supplements, and incorporated special foods to wake up his muscles, along with unlimited amounts of his favourite foods – chicken nuggets, chocolate chip panettone, and chocolate milk – to increase calories. Charlie started gaining weight quickly. "He was even napping less," says Dani. "We started noticing him figuring out new ways to move and engage with things and people."



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The Leitis' optimism was high until March of 2023, when Charlie came down with COVID. Although he appeared to have recovered from the virus, he had a lingering cough and the gurgling was back. After a particularly difficult morning with his cough, the Leitis family took Charlie to McMaster Children's Hospital for the first time. Charlie was prescribed a steroid inhaler in addition to a rescue inhaler he was already on, and they were sent on their way.

Charlie appeared to start recovering and relief was setting in until late one evening he started choking more on his fluids at dinner. That night, Dani and Ivars were woken multiple times to Charlie screaming in his sleep, much like he was having a night terror – something his sister had experienced as a toddler.

The next morning, Charlie was not himself. "He had no interest in food," Dani recalls. "He wouldn't settle to nap and his breathing seemed weird. His eyelids were heavy and he was staring blankly at me."



**Charlie's Leigh syndrome was due to a gene deletion, making it an exceptionally rare case.**

Dani took Charlie to the hospital, and Ivars met her there. Charlie was admitted right away. His oxygen was just 39%. Doctors were perplexed as he was not presenting like anyone with such low oxygen. Charlie would eventually be intubated. During this process, concerns arose that he may have suffered a seizure, but it was never confirmed.

Charlie spent two weeks in the hospital while doctors and specialists tried to determine the cause of his distress. His lungs were full of fluid, causing his left lung to collapse and bringing focus there, until an MRI test showed that his brain stem (which controls the lungs, speech, swallowing, eye movement, and more) was covered in lesions. With the damage to the brain stem, they couldn't save his lung.

Charlie never came home. He earned his angel wings on April 10, 2023. The beloved little boy passed away in the arms of his mom, dad, and sister, two months short of turning two.

Months later, his family received Charlie's official diagnosis of Leigh syndrome, a rare and fatal genetic mitochondrial disease with no cure. Charlie's Leigh syndrome was due to a gene deletion, making it an exceptionally rare case.

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When asked if there's anything they know now that they wish they'd known before, the Leitis family found it a difficult question. Charlie lived a normal life for a toddler. The family went to Sauble Beach, Santa's Village, Canada's Wonderland, Niagara Falls, and a Blue Jays game. Charlie took a music class, spent life at a dance studio, and saw Riley dance in two recitals. "These are all things that we wouldn't have felt safe doing had we known he was immunocompromised," says Dani. "We often wonder whether we could have better protected him had we known sooner, but in us not knowing, Charlie was able to enjoy a better quality of life."



"We want to continue Charlie's life by sharing his story," says Ivars, "and we hope that sharing his story makes a difference in the life of another child. Our hope is that through his story and better awareness, health care specialists will see the signs and symptoms sooner."



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