



# Faces of Mito

## Bright smiles and unwavering optimism: Dave and Victoria's journey through adversity



Victoria Mosher has a superpower. Wherever she goes, she brightens people's day with her positivity and bright smile. Victoria's sweet, affectionate nature and relentless optimism are undeniable despite the immense adversity she's encountered throughout her life. Diagnosed with mitochondrial disease and autism, Victoria is non-verbal, relies on a G-tube for sustenance, takes a daily cocktail of supplements to ensure adequate nutrition, and faces physical challenges due to muscle weakness.

### A shocking diagnosis

At 15 months old, Victoria had a high fever. Her parents took her to Credit Valley Hospital just to be safe, as she was a bit small for her age. "Within an hour or two, things went really badly," says her dad, Dave, of Burlington, Ont. "She crashed. The doctors told her mother and me that we should call our parents and bring in support, which is code for 'this isn't going to end well.'"

Victoria's blood work showed lactic acidosis – the accumulation of lactic acid in the blood, signalling a potential metabolic problem – and she was whisked to SickKids by ambulance. It was a harrowing experience. Doctors stabilized Victoria but she went into a week-long coma and when she woke up, she had a brain injury.

"She could no longer control her movements. She had to get a G-tube because she couldn't swallow," says Dave.

"It was about as awful as can be. But I've never met

somebody more determined than Victoria." Putting forth immense effort, Victoria learned how to sit, then scoot, then crawl. Despite her newly-impaired motor skills,

Victoria eventually learned to walk.

"It took years, but she did it," says Dave.



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Doctors mapped Victoria's DNA and figured out the genetic mutation she had. It took about four years before the family finally had a diagnosis: thiamine metabolism dysfunction syndrome type 4.

## Giving back

"When Victoria first got diagnosed, it was pretty scary," says Dave. "As a parent, I felt helpless. And I felt like I owed the system for saving her life – which the SickKids medical team truly did, by diagnosing and treating her properly. That indebtedness to the health system motivated me to get into healthcare, which I now work in."

This sense of earnestness, sincerity, and dedication perfectly highlights the type of person Dave is: a compassionate, grateful, and resilient individual who's driven by a sense of purpose to make a positive impact in healthcare and who chose to be inspired by his daughter's journey with a rare disease rather than allowing himself to be overwhelmed by despair or adversity. That's not to say there haven't been any hardships, of course.



## An indomitable spirit

Because she has autism, Victoria loves routine. She splits her time between her mother and her father's homes. Victoria, her mother's, and Dave's daily schedule involves structured activities intertwined with caregiving responsibilities. Victoria's specialized care needs – including constant supervision and seven daily G-tube feeds – complicate even simple tasks like mowing the lawn. "She needs careful supervision, so cannot be left on her own," says Dave.



Although Victoria has graduated from high school, three times a week she participates in a day program which offers recreational opportunities for people with autism. "There's a bit of a tendency for people with autism to be inwardly focused," says Dave. "We want Victoria to be interacting with people and having adventures and new experiences. The day program gets her out in the world."

At home, Victoria loves playing with puppets and stuffed animals, playing games on her iPad, and going on car rides and errands with her mom or dad. She's also a huge fan of listening to music and watching music videos. "She loves all kinds of music," says Dave. Victoria is perfectly content listening to her dad's music – whether it's Elvis Costello or the Rolling Stones – and she also enjoys pop music, rapper Pitbull, and whichever artist was featured most recently on *Sesame Street*. When she's in the car and music isn't playing, she reaches for the screen, eager to start it up.

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## Getting to know Victoria

“When you’ve got a child with special needs, you worry that people will look at them as a collection of their disabilities,” says Dave. “Victoria is so amazing as a person, and everybody who spends time with her just falls in love with her. When she graduated high school, all her teachers were sad that she was leaving because she’s so unrelentingly positive and happy and affectionate.”

While Victoria is incredibly loveable, Dave notes that it can be hard for people to get to know her. “Because she’s non-verbal and doesn’t write, she doesn’t really have a good way to communicate,” he says. “It’s hard to get to know her unless you spend time with her.”

Despite not speaking, Victoria communicates non-verbally. “She’ll show me what she wants,” says Dave. “For example, if the internet goes down and she’s playing with her iPad, she’ll come running to get me, take my hand, and pull me over to the iPad to show that the internet’s not working. Or if we’re at somebody’s house and she wants to leave, she’ll come and get me and hold my hand and walk me to the door. If that doesn’t work, she’ll bring me the car keys, and then her shoes, until I have a pile of things around me that represent leaving.”

Even when things don’t go her way, Victoria’s steadfast positivity and cheerful outlook on life remain intact. “I try to learn that from her,” says Dave. “She was just in the hospital recently, and they’re poking her to give her an IV and drawing blood. Those things hurt. But five minutes later, Victoria is laughing and smiling, being her cheerful self. Things just bounce off her. She always maintains her positive disposition. I only wish I could do that, too, sometimes.”



## Advocating for support and understanding

Dave rejects sympathy in favour of understanding and appreciation, highlighting the need for improved diagnostic processes and respite care. “It’s not easy to get a proper mitochondrial disease diagnosis,” he says. “One thing the MitoCommunity needs is for it to be easier to diagnose patients because getting a diagnosis is crucial. The second thing the community needs is respite. People living with mito need a lot of care. Having some sort of respite program where they’d be safe for a week at a camp, so caregivers could go on a trip to re-energize themselves, would be really helpful.”

One thing the MitoCommunity doesn’t need, according to Dave, is sympathy. “I’m so proud of Victoria,” he says. “I don’t want people feeling sorry for her.”

## Looking forward to the future

At nearly 22 years of age, Victoria should have the whole world ahead of her. But because of her diagnoses and complex medical needs, Dave worries about her future. “She requires 100% care,” he says. “As I and her mother get older, who will be there to provide that care?”

Despite his fears, Dave remains hopeful for a fulfilling future for Victoria outside their insular world, filled with new experiences. “I want to make sure that she’s out and meeting new people and developing relationships and having experiences,” he says. “That’s important.”

Having a child with mito has impacted Dave’s life in many ways, but most importantly, it has brought him immense happiness. “Seeing Victoria happy and playful brings me great pleasure,” he says. “I wish more people could get to know her and experience the joy that she can bring.”

If you’re a patient, parent, or loved one seeking support, MitoCanada can help.

Visit [www.mitocanada.org/support](http://www.mitocanada.org/support) to access a variety of support resources. Or, reach out to us at: [info@mitocanada.org](mailto:info@mitocanada.org)



**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.