



Faces of Mito

Life with Evan: MitoCanada's co-founder, Blaine Penny, shares his family's story



I'm Evan's dad. I'm also Julia's dad, Sarah's husband, an endurance junkie, MitoCanada's co-founder, and the CEO of a digital health company called Lumii. Today, though, I want to tell you about my son Evan and what it's like to be his dad.

Evan was the happiest little boy. We're a super active family, so when he was young we were always hiking, skiing, and playing outside together. He loved that. And he was really cheeky. He had this coy sense of humour and a glint in his eye.

I wish we'd known that Evan had dysfunctional mitochondria and was at a high risk of developing a mitochondrial disease. If we'd known, it would have changed our whole approach to his exposure to stressors. Hindsight is 20/20.

Evan's disease onset was sudden. When he was four, Evan woke up one day with stomach pain. Doctors suspected appendicitis and recommended surgery. Unfortunately, surgery and anesthetic are pretty major stressors.

During the surgery, Evan suffered a significant brain injury. He was initially diagnosed with acute disseminated encephalomyelitis (ADEM), which is a neurological disorder characterized by brief but widespread inflammation in the brain and spinal cord that damages the myelin. Overnight, Evan became non-verbal and needed to be tube-fed. Nine out of ten kids would fully recover from this, so we didn't panic – we thought we were dealing with an acute brain injury, and that we'd see a lot of improvement. But when Evan didn't improve and started developing seizures, his clinical team realized something more was going on.



It took us a while to accept that he wasn't going to improve – that he'd be in a wheelchair and need to be tube-fed probably for life.

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It was such an abrupt, jarring change. It turned our lives completely upside down. And there was a massive amount of grief. We lost a lot of the Evan we knew and loved, and we also mourned the loss of this whole life that we had envisioned for him, that we'd thought was ahead of us. Suddenly, the future looked so different from what we'd imagined – for Evan and for all of us.

It took about a year of testing for Evan to get a clinical diagnosis of mitochondrial disease. Fifteen years later, we still don't know the underlying genetic cause for his disease (even after completing DNA sequencing three times).

Life with mito has been tough for Evan. Not being able to communicate has been a massive challenge and source of frustration. He's dealt with chronic pain and many surgeries over the years. Evan's muscles are always turned on and he suffers from chronic seizures, so he's on a lot of medications, which have a lot of side effects.

"We co-founded MitoCanada to help build awareness, increase education, and advance research"



It has also been a challenge navigating Evan's care. When he was little, he was almost like a baby. We could just pick him up and move him around – it was fairly easy physically. But as he got older and heavier, that became more and more challenging. It was hard on our backs, lifting him in and out of the car or wherever. Eventually, it came to a point where we could no longer do it. We've had to shoulder the costs of adaptive devices, wheelchair-accessible vehicles, and a wheelchair-accessible home.



Despite the challenges, we always reminded ourselves that Evan was still with us. He could still smile and we could tell that he had quality of life. Sarah and I are optimistic people. We're really just focused on the here and now, and on trying to give Evan the best life that we can, because we don't know how long it's going to last.

When Evan was first diagnosed, we quickly realized that there was nowhere to turn in Canada to find support with navigating the mitochondrial disease health care journey, connecting with others, or learning about mito. At a United Mitochondrial Disease Foundation conference in the U.S., I met several other Canadian families. We said, "Hey, we need to do something back in Canada." So we co-founded MitoCanada to help build awareness, increase education, and advance research and clinical knowledge while also preventing mitochondrial diseases from manifesting in others. We became a registered charity in 2010, and the rest is history.

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Co-founding MitoCanada helped me on a personal level, too. When Evan got sick, I felt helpless that I couldn't do more for my child. Starting the organization made me feel less helpless and knowing that we could potentially help others was also uplifting.

Evan is 19 years old now. He loves music, getting outside for walks, and watching shows and movies on his iPad. He's a huge fan of *Frozen*! And he still has that glint in his eye and his sense of humour – I see it in the books he enjoys, like the *Pigeon* book series by Mo Willems. Seeing Evan smile brings us so much joy.

The last few years have probably been Evan's most comfortable and best years. He recently graduated high school, which he loved. He made some great connections with his teachers and classmates – he has a way with people, and is super expressive and engaging in communicating through his eyes. The transition from pediatric to adult care has gone smoothly, which is fantastic and better than we expected.



Another big change was Evan moving into a group home about 16 months ago. It's been a big change for everyone and great for him. He has three adult roommates so he has some amazing social stimulation and interaction. He's doing really well!

And now for the first time, our house is our own. We had so many caregivers and nurses coming and going over the years, looking after Evan, that there was basically no privacy in our home. Now, we're spending more time together as a family and enjoying more quality time with our daughter Julia, who's in grade 12. Fortunately, Evan only lives a 10-minute drive away so we can pop over to visit him anytime.

Here are some of my takeaways from my story and life with Evan. Never give up advocating for yourself or a loved one. Sarah and I were relentless in trying to find answers for Evan – and for every problem, truly, there's a solution. Also – look after your mitochondrial health. The best way to do that is through exercising and living as healthy a lifestyle as possible. And finally, find community. I'm so grateful for MitoCanada and our MitoCommunity. The people who rally around this cause have been unbelievable and we've done some incredible work as an organization.

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.