



Faces of Mito

Aiden Procyshyn



One of the happiest kids you'll ever meet!

"Aiden is one of the happiest kids you'll ever meet," says his Mom, Bonnie Procyshyn. "My eldest son is easy going and has the greatest smile. Preferring people to toys, Aiden loves to connect and interact with others."

When Aiden was born, Bonnie and her husband, Andrei, were told that his newborn screening showed some abnormal results. Despite not receiving a diagnosis for many months, the family was connected with a metabolic specialist. Aiden underwent many tests, but, as is so often the case, none were conclusive.

When Aiden was 6 months old, Bonnie started noticing developmental delays. He wasn't hitting basic milestones, like sitting up. At nine months, he had no interest in solid foods and was hospitalized for

concerns about his failure to thrive.

Aiden started having seizures around his first birthday. This precipitated a switch in focus from a metabolic care team to a

neurological one.

Whole Genome Sequencing (WGS) was ordered shortly thereafter. The results indicated that Aiden had Leigh's Syndrome, a debilitating mitochondrial disease. He was 15 months old at this time. Bonnie and Andrei were told it was unlikely their son would see his fifth birthday.

"Aiden's cells can't generate enough energy for him to function the way he'd like to," says Bonnie. This means frequent naps, sensitivity to heat, and delays in movement and speech.

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Aiden's mito is *de novo*, which means it is the result of a random genetic mutation that could not have been predicted. 97% of his cells are affected.

We don't know what we don't know

Before Aiden was born, Bonnie didn't think about an unfamiliar illness gripping her child. "When you think about starting a family, you may hope for a boy or girl," she says, "but you really just want a healthy child – that's what's important."

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After the possibility of a mitochondrial disorder was first mentioned by Aiden's doctors, Bonnie and Andrei headed to the internet for information. Not knowing anything about mito, they wanted to learn all they could so they would understand how to help their son. In hindsight, Bonnie says that was a mistake. They found nothing but bad news and worst-case scenarios. It was scary and upsetting. Every change they saw in Aiden was concerning and they couldn't help thinking the worst.

"Understanding your child's diagnosis and their needs is critical," says Bonnie. "As parents of children with mito, we need to learn a new vocabulary and integrate ourselves as part of the healthcare team."

This can seem impossible when you are reeling from a child's devastating diagnosis. And, although it is important to be given hope and to understand that the worst-case scenario is not always how it goes, Bonnie asserts that the facts and brutal honesty are what parents really need in order to actively participate in and advocate for the care of their children.

Living Everyday with Mito

Bonnie is a strong, energetic, empathetic mom and a dedicated CPA (Chartered Professional Accountant) who enjoys her career. She loves her two boys but concedes that life is challenging. She admits to being chronically tired and rarely being able to find time for herself.

The world is not designed for children with special needs. Planning a fun, family day trip, means concerns about safety, the need to pack special equipment, finding accessible activities and washrooms in the community, all while still having time and energy to enjoy the event.

Two of the biggest challenges for the Procyshyns are i) mobility and ii) time, especially as Aiden grows.

Now approximately 40 pounds, he is getting difficult to lift. They do have an electronic lift in their home, but find it cumbersome and time consuming to use.

Getting through everyday routines, like breakfast before heading out the door to daycare and work in the morning also takes extra time because of Aiden's needs. Having someone come and help would be welcomed,

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but it is expensive and difficult to find someone willing to work for short periods of time each day.

Aiden is attending daycare rather than doing half days in kindergarten. Fortunately, their daycare has been fantastic and is next to a centre that offers support for children with special needs. Aiden receives physical, occupational and speech therapy from his amazing team.

Aiden also has Landon, his younger brother. The pair love being together. "Landon has compassion that is amazing to witness," says Bonnie. "He brings Aiden toys, sings him songs, and can sense the rare occasions when Aiden is frustrated."

Play is work for kids and Aiden and Landon have found the perfect workspace. They love playing in a bouncy castle that remained in the family basement after a birthday party! It helps Aiden move more and more independently. It's also fun, soft, safe, surrounded by walls, and offers unintentional benefits like building core and grip strength.

All of the people, activities and devices Aiden has in his life are helping him break through barriers and defy the odds. He is thriving despite his diagnosis and is starting to support weight in his legs, can lift himself up to kneel, which means he can grab things for himself, and he can use a pommel walker with a harness that supports him to get around at home and at daycare.

Looking Forward to the Future

Aiden and his family are living with challenges that few can understand. Although endless questions remain unanswered, Bonnie refuses to be discouraged. She knows every child is unique and this applies to Aiden. Her son will soon be a sensational six-year-old. He will be starting school next year in a stimulating environment where he will be surrounded by other kids and have the opportunity to develop into a stronger, more independent boy. While Bonnie and Andrei aren't sure what Aiden's long-term future will look like, they are loving life and the time they spend together.

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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.