



Faces of Mito

Meet survivor Zach Seymour

Passionately advocating for others



Zach Seymour is an expert at living with mitochondrial disease. He doesn't have mito himself, but both his mother **and** brother do.

When Zach was 12, he was running the household. He was doing the family's cleaning, helping raise his younger brother, and leaning on his grandparents to help balance everything.

No diagnosis also meant no treatment, relief, support, or hope.

During this time, Zach's Mom was suffering from chronic fatigue and sleeping for 14 hours a day. As a single mother of two, she worked at several jobs to try to make ends meet -- when she could.

She suspected mitochondrial disease but was unable to convince doctors in their small, rural town that this was a possibility. It was demoralizing, frustrating, and debilitating, as this lack of willingness to consider mito left them without a diagnosis. No diagnosis also meant no treatment, relief, support, or hope.

Outsiders were unaware of the incredible challenges Zach and his family faced. The handsome young man did very well in school, he was captain of several sports teams, and, he didn't complain or ask for help.

As a teenager, Zach felt he and his family were living in some strange

sort of limbo. His brother also developed chronic fatigue. They knew that what they were experiencing wasn't normal but there was no infrastructure in place to put them on the radar. Zach tried constantly to advocate for his family but was unsuccessful at getting them the care and support they needed.

When Zach was 16, he started experiencing similar symptoms to his mom and younger sibling. He was exhausted, often light-headed, and nauseous. He suffered from debilitating headaches and had trouble concentrating. His athletic abilities declined and his grades dropped. His hands started to tremble. He suffered from depression.

Zach believed he too had developed mitochondrial disease.

Zach believed he had developed mito. He had not. Zach had a 5.5 cm brain tumour which would be diagnosed three years later.

During the summer following his first year of university, Zach was rushed to a hospital in a major urban centre where he endured a 14-hour surgery to remove the brain tumor. Over the next weeks and months, he fought – and won – many battles. He had to learn to walk and talk again. He needed to regain the 30 pounds and the significant athletic muscle he'd lost. He was not the same person.

You'd think this experience would dampen his spirits but Zach says, "I felt like I was handed this golden opportunity. The monkey on my back was gone. I needed to start from ground zero but ...



I was healthy for the first time in my life. I knew that I was capable of so much and would not only beat this but live to help others."

And, helping others is just what Zach is doing as the newest addition to MitoCanada's board of directors. He says he's excited to be part of the mito community and eager to help the organization grow, increase awareness of the challenges mito patients face every day, and improve the lives of people living with mito.

This has already started with his mom and brother, who were finally diagnosed with mito. Zach supports them both. His brother is going to university. It is a slow process as he needs special accommodations such as extra time for exams, flexible deadlines, and time to rest when his muscles are weak. Zach says his brother is smart and determined but reluctantly accepts that he will need to find a non-conventional way to live as the traditional 9 to 5 routine is not an option. Zach's brother also accepts that the individual he chooses to share his life with will also share some of his limitations.



Zach wants to help those with mito exercise their intellect and capitalize on their creativity, so they can **live healthy, fulsome lives.**

"I am so thankful that my journey had an end date," asserts Zach. "I am able to function way above normal and now I can give back to others." While his family used to struggle with feelings of isolation and hopelessness, Zach says, "my experience has motivated us all to find solutions. My commitment to MitoCanada will help us uncover those solutions."

Determined to help create a world where there are treatments that can help everyone with mito, Zach wants the mito community to be healthier so they have the strength to complete the education they need to contribute, work to support themselves, and enjoy life.

Zach's family continues to search for therapies that will resolve their symptoms. They both take a mito cocktail, exercise when they can, and are involved in a couple of clinical trials.

Zach remembers what it was like to go undiagnosed. "The affects of my illness will stay with me for the rest of my life," he says. "It still makes me angry and anxious when I reflect back on the time my health concerns were ignored and I was labeled by teachers and coaches as lazy and wasting my talent and potential."

Learning through painful personal experience, Zach asserts that when you can't advocate for yourself, you get left behind. He wonders how those with less ability, knowledge and support than his strong and clever mother can be expected to advocate for themselves. He sympathizes for those who know they are capable of so much but are held back by something they can't control.

As a former patient and patient advocate, Zach says that people need to keep telling their stories. He also emphasized that healthcare professionals need to truly listen to what patients have to say and empathize rather than jumping to a diagnosis before having the full picture.

Today, as a litigation lawyer, Zach proudly advocates for others. He says he wants to help those with mito regain – or experience for the first time -- the ability to exercise their intellect, capitalize on their creativity, and feel like they can live healthy, fulsome lives.

While we are truly sorry that Zach and his family have been through so much, we are excited and thankful that this incredible survivor has chosen to share his passion, compassion, expertise and energy with MitoCanada.