

## Fundraiser launched to help Bolton teen with complex disorder



By Joshua Santos

A GoFundMe has been launched to help a Caledon teenager battling with a rare and complex illness.

Jarred Fosbury, 16, was diagnosed with Hyperadrenergic Postural Orthostatic Tachycardia Syndrome (POTS) with mild Ehlers Danlos Syndrome.

"It's been very difficult," said his mother, Kimberly Fosbury. "It's been a lot of ER trips, a lot of doctor's appointments, a lot of anxiety and stress, not knowing what's happening. We just got the diagnosis at the end of the first week of February

Jarred was experiencing symptoms over the past seven and a half months. He had tachycardia ? rapid heart rate and brachycardia ? low heart rate. He has headaches, nausea, extreme fatigue, tingling and numbness in his face and limbs, joint pain, blurred vision, weight loss, muscle twitching, an inability to regulate body temperature and hot hand and cold hand.

"This condition has been very debilitating for Jarred," said Fosbury. "He has spent most of the past seven months in bed, unable to go to school, visit or hang out with friends, or go to the dentist and other such appointments. This illness has taken a real toll on our entire family as well."

Her husband called a POTS specialist in Hamilton and they won't even see him until he turns 18, which prompted their decision to go south of the border.

The GoFundMe campaign has raised \$6,065 of a goal of \$25,000. It was raised by 62 people in two days. Fosbury said funds will be used to cover some of Jarred's treatment costs.

"It's very overwhelming," said Fosbury, emotionally. "It's amazing that so many people care about him and so many people want to help him and they just want him to get better."

"What really touches me is when I see some of Jarred's friends; they're high school kids and donating \$25 or \$50 and it's very touching."

She said people suggested the idea of her starting an online campaign after she contacted MPP Sylvia Jones' office for help.

?They were supposed to send me some paperwork to apply to OHIP,? said Fosbury. ?I haven't received anything yet and the timelines are tight. I contacted my health insurance company and they don't cover anything out of country. Then I went to the bank, to get a loan and the best they can do for me was to increase my credit limit on my credit card.?

?As much as I don't want to ask people for money, my son has been suffering for eight months and he needs treatment and this is the only way we can do it.?

Jarred's mood differs each day. Fosbury said he had a few bad days, with a lot of tachycardia, migraines, headaches, nausea and was unable to eat.

He would however have days where he has a few more hours of sleep, headache isn't as bad and is able to do some online courses.

?We just don't day to day,? said Fosbury. ?There are times when he can walk to the car to go to a doctor's appointment, there are other times where has to be carried and use a wheelchair.?

The family tries to keep a record of all of his symptoms to detect any triggers, but it's all random. They plan to travel during March Break to see a specialist, but that may be postponed until July.

?It's a bit of a waiting game right now,? said Fosbury. ?I don't expect it there will be an issue but I'm a teacher and I have march break. If we were to get everything in, they're going to treat him twice a day, but they need to start on the seventh, and because of his illness he can't fly. I anticipate it's going to be a very difficult trip down.?

She said her husband may have to drive with her son and then she will meet with them after she takes an airplane down.

The family is trying to have Jarred attend the Neurologic Wellness Institute in Wood Dale, Ill., USA.

On the GoFundMe page, Dr. George Michalopoulos said there would be no guarantees but he thought he could help. He had some success with similar patients. Fosbury felt positive after talking with him. She heard of him by watching some testimonials on YouTube.

?There was a young girl, the same age as Jarred who sounded very, very similar and two months after treatment, she was back to playing competitive soccer,? said Fosbury.

She didn't want her son to be bedridden and wait two years if she can help it. She went to different websites, did a lot of research and started looking on YouTube ever since POTS was suggested.

She searched up Michalopoulos' credentials and information on the clinic. She then called and left messages with six practitioners in Ontario to get their opinions before investing into the American health centre.

?One in London and one just outside Waterloo got back to me and actually talked to me on the phone for quite a while and asked a lot of questions,? said Fosbury. ?They both said given Jarred's type of POTS and severity of POTS, that this was the man to go see, Dr. Michalopoulos.?

Fosbury said Jarred's symptoms started appearing in July, 2018. Jarred woke up early one morning not feeling well. He tried going to sleep but couldn't. When he tried getting out of bed, his heart felt like it stopped for a few seconds, then started beating hard and fast.

?He thought he was having a heart attack, so he called 911,? said Fosbury. ?His limbs and his lips started to seize so he moaned and kicked his bed post to wake us up. By the time I flew out of bed and down the hall, my husband already had Jarred propped up against him, but was unable to keep his hand on Jarred's chest as his heart was beating so hard and so fast. The paramedics didn't want to take him to the hospital because they said it was just a panic attack and that he was fine. We insisted, so they took him to the smaller hospital to the north of us where they monitored him, did bloodwork, and sent him home after a few hours.?

She said Jarred's heart would skip beats, double beat and then race high.

After attending the Hospital for Sick Children, the family was referred to a pediatric cardiologist. They were then referred to an endocrinologist, Dr. Verbeeten who proposed a diagnosis of POTS.

?The problem is Jarred's kind of POTS,? said Fosbury. ?A lot of people with POTS are functional. It's only about 25 per cent that are debilitated like Jarred. He's also in a very small group where his particular type of POTS, his heartrate also drops too low because cardiologist said a lot of times the treatment is beta blockers, but because his heart rate drops too low, they can't give him beta blockers. So essentially, there's nothing they can do for him.?

They would see their family doctor, a pediatrician, a pediatric cardiologist, neurologist, endocrinologist, two psychiatrists, a psychologist and two naturopathic doctors. The doctors will then consult with each other and concluded POTS.

Fosbury was told it's one of those illness that they don't come to a diagnosis until they ruled everything else out.

?Jarred just wants his life back,? said Fosbury. ?He wants to be able to go to school and see his friends. One thing I miss more than anything is his singing. He has a beautiful, rich singing voice, and from the time he was 11 months old, his vocal chords never stopped. If he wasn't talking, he was singing. Now, he can't do either for long. He gets out of breath, his chest gets tight, and he has an episode. Jarred wants to sing and play his guitar again.?

Jarred is a member of Humberview Robotics Alpha Dogs team working as a programmer and a member of the Bolton Wanders Soccer Club.

To visit the campaign or donate visit <https://www.gofundme.com/5xjrr-jarred039s-road-to-recovery>.