This page was exported from - Caledon Citizen
Export date: Fri Mar 29 9:21:05 2024 / +0000 GMT

Fundraiser planned for baby Nixxon?s battle with spinal muscular atrophy

By Mike Pickford

A young Caledon boy, just six months old, is fighting for his life in Toronto's Hospital for Sick Children after being diagnosed with a rare neuromuscular disorder.

Now, friends of the family are preparing to host a fundraiser next week as they bid to help little Nixxon Ciappara and his parents, Tyler and Victoria.

It has been a heart-wrenching few months for the Ciappara family. Happiness at the birth of the couple's first child soon turned to concern and sorrow when a routine three-month checkup signalled Nixxon was showing signs of spinal muscular atrophy (SMA), a disorder that causes progressive muscle-wasting and often leads to an early death. When he was officially diagnosed late last month, all that concern and sorrow turned into grit and determination as the steadfast Ciapparas entered fight mode.

Nixxon was admitted to Sick Kids, where doctors expect he will stay for the next couple of months at least. Victoria, already on maternity leave from her position at The Millcroft Inn and Spa, moved into a Ronald McDonald house in downtown Toronto so she could be there for her son around the clock. Tyler, a tow truck operator, has since done the same.

Unfortunately, even when disaster strikes, life doesn't come to a complete standstill. With bills to pay and very little money coming in, the couple were left to worry about more than just their little boy's health. And so, up stepped Crystal McHughan and a host of other family friends to offer some assistance.

A GoFundMe page was set up Sept. 17 and has so far raised $12,475 ?more than double the original goal of $6,000. A fundraiser has been scheduled to take place this coming Monday (Oct. 16) at Boston Pizza in Orangeville from 6 to 9 p.m., where organizers hope to raise ?as much as possible? to help the family through this tough time. There will be a silent auction with numerous prizes up for grabs, while Boston Pizza will donate 10 per cent of all food sales over the course of the evening to the Ciapparas.

?As parents, you should never, ever have to worry about money when your child is fighting in the hospital, so we want to help take some of that stress away and allow Victoria and Tyler to focus on Nixxon and Nixxon only,? McHughan told the Citizen. ?If people can come out and show them that they're not alone, that would be fantastic. It's times like these that you really need the help, support and love of your family, friends and community to help you through.?

There are four types of SMA, Type 1 being worst-case scenario and primarily affecting newborn babies, and Type 4, which typically forms in adulthood, being base case.

Nixxon was diagnosed with Type 2, usually onset in children between six and 18 months. In most cases, children with this type are not able to stand and walk, but can maintain a sitting position. Body muscles are weakened and the respiratory system is troubled throughout a patient's life. While life expectancy is somewhat reduced, most people with SMA Type 2 live well into adulthood.

Nixxon has been receiving a new drug designed to fight SMA called Nusinersen. While it is designed to help those suffering with Type 1 SMA, it can also be used to help those suffering with Type 2. He is the first child at Sick Kids to receive this drug while under respiratory distress. He has already received two injections, with a further two planned over the coming month. Doctors are hoping the drug will give Nixxon the necessary support he needs to fight.

?Nixxon is a strong kid. He's been through a lot so far in his young life and it really isn't fair, but Victoria tells me he stills seems to be happy, he's still smiling every day and there's lots of fight left in him,? McHughan said. ?We're just hoping to lessen the burden a little bit on the financial side so they can focus on the important thing, which is helping Nixxon through this fight.?