

## NEWS LOCAL

### Tuffing out the stigma behaviours



By Zach Mueller, Fort Saskatchewan Record  
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Shaun and Cristina Fehr pose with their two daughters, Hayden (left) and Norah (right). Zach Mueller/Sherwood Park News/Postmedia Network.

Inspired by their daughter's courage and strength, one local family is trying to tear down the stigma surrounding people with special needs.

On April 16, 2014, Cristina and Shaun Fehr welcomed Hayden into the world — a beautiful baby girl who was born with a rare genetic condition.

Three years later, after countless trips to the hospital, the Fehr's have decided to start Tuff Sprout — a company dedicated to changing the way people think about the special needs community.

"One of the reasons we wanted to start Tuff Sprout was to spread awareness, as well as to advocate for our daughter and other kids that we've met along the way," Cristina said.

The Fehr's plan to launch their company with a campaign at the Stollery Children's Hospital in Edmonton. While they are still trying to figure out the exact dates, they are aiming for five days at the beginning of August.

"Our main campaign is going to be centred on our empowerment blanket," Cristina said. "People will be able to buy one for a child going through extraordinary circumstances, and a portion of that purchase will be donated to the Stollery."

During the campaign, the Fehr's intend to set up a booth in Edmonton, where the blankets will be available for \$55. In addition to that, people will also be able to pre-order a blanket online.

Delivery of the blankets will be randomized, in the sense that the Fehr's will deliver them to the hospital and leave it to the staff to distribute them to children.

"We can't release the names of any children who need blankets to the general public because of the patient confidentiality clause," Cristina explained. "So, we're thinking about including a few pre-written messages that a purchaser can choose from, which will then be delivered in a card to the child."

The company will also be selling Tuff Sprout silicone awareness bracelets for \$5 throughout the campaign.

"We've included the bracelets for people who may want to help our cause but don't want to spend \$55 on a blanket," Cristina noted.

As opposed to making a general donation to the Stollery, Tuff Sprout will allocate 20 per cent of the net profits toward specific medical equipment for the hospital, according to Cristina.

"We've been working closely with the Stollery Foundation and they have said that we can try to save up for (new equipment) for the hospital," she explained. "It's really nice because it's applicable to Hayden and the struggles that she's undergone."

Hayden was born with a microdeletion on chromosome 21, which means that a portion of it is missing. In fact, she's the only known living person to suffer from the deletion break points that she does.

In May 2015, just after turning one, she experienced her first seizure and spent four days at the Stollery.

"At that time, the genetics staff told us that she would probably have epilepsy due to one of the genes that's missing," Cristina noted.

Four months later, Hayden ended up having a status seizure, which is an epileptic seizure that lasts for more than five minutes.

"She had to be airlifted and incubated because she had aspirated and developed pneumonia," Cristina recalled. "She was essentially sedated for a week after that."

Then, just last year, Hayden started seizing multiple times a day. As a result, she was repeatedly admitted into the Pediatric Intensive Care Unit (PICU) at the Stollery for a two and a half month period.

"It got to a point where she was having upwards of 80 seizures a day and the doctors had no idea how to stop them," Cristina noted. "They said it might come down to having to put her into a coma for a month and turn off all of her brain activity."

Although they managed to avoid that scenario, Hayden still has seizures and has to deal with a number of other challenges, too.

She has a low platelet disorder called thrombocytopenia and is at high-risk for developing acute myeloid leukemia. She has also endured a gastrostomy tube surgery for her feeding issues and suffers from a moderate intellectual disability.

Even so, Cristina said that Hayden is very happy and active on a daily basis.

"We just take it one day at a time and try to enjoy the present because nothing is guaranteed in this life and that's especially true for her."

More than anything, Cristina said she has learned the value of patience from being a mother of a child with special needs.

"I've had to be patient with my daughter at times, but the whole experience has also taught me to have patience with the rest of society," she added. "My husband and I have found that there's a certain stigma around individuals with special needs."

"I think it's still one of those topics that makes a lot of people in the general public feel uncomfortable and they don't know how to act or react what's going on."

That's where Tuff Sprout comes into the picture again.

Aside from raising awareness, the organization will also provide Hayden with a place to thrive in the future.

"No one has that crystal ball to let us see our daughter's future, so we want to make things as secure and inclusive for her as possible," Cristina said.

"A lot of companies are hesitant to hire people with special needs, so we're trying to create an environment where we can include Hayden in our lives and provide her with a place to work, grow and flourish."

Eventually, the Fehr's look to offer employment opportunities for other people in similar circumstances, as well.

Likewise, Cristina said that they intend to run the same campaign at different hospitals through the Children's Miracle Network on an annual basis.

"We hope that parents and their children will gain a sense of empowerment from it," she explained. "Being a hospital family ourselves, we know that it can be very isolating and depressing at times."

"We want to create an atmosphere where families feel comfortable sharing their stories without the fear of people pitying them or thinking that their child is less than somebody else."

In fact, the Tuff Sprout website has an entire section dedicated to those stories, where people can submit and share their own.

For more information, including updates on the campaign, visit [www.tuffsprout.com](http://www.tuffsprout.com) or check out their Facebook page.

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