

Petition fights for mom with rare disorder

Alberta urged to cover costs of medication

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While training to do the Run for the Cure, Carrie Stogryn, 52, was alarmed when she began having severe head and neck pain and unusual shortness of breath.

As her symptoms began to worsen, she checked in to the University of Alberta Hospital last year on Thanksgiving Day. After a month of blood transfusions, suggestions of removing her spleen, and four cancer treatments, she was told she had an rare disease called Atypical Hemolytic Uremic Syndrome (aHUS) — the first adult patient in Edmonton to have the diagnosis.

"They came in and basically said, 'Well, this is what you have, we don't know what it is. We're going to have to look it up online. You're the first patient,'" said Stogryn. "And that was the most shocking thing. I thought it was the end of my life."

Two of Stogryn's daughters, Sydney and Leslie, presented a petition with more than 4,500 signatures to Health Minister Fred Horne on Friday at the legislature building.

With the help of one of their teachers at Harry Ainlay High School, they began a petition in early December and received more than



LARRY WONG/EDMONTON JOURNAL
Health Minister Fred Horne receives a petition Friday from Harry Ainlay High School students calling for coverage for a drug for a rare disease called aHUS.

2,000 signatures in just three days.

"I started thinking a lot about what my life would be like if I lived without my mom and I started thinking that I should try to do something about it," said Grade 12 student Sydney Stogryn, 17.

Carrie Stogryn was told that Soliris, a medication

found to be helpful with aHUS patients, was not covered for her disease in most provinces in Canada — including Alberta.

The petition was presented in the hopes of receiving public funding for the medication. She said it would not cure her disease but would "turn off" her symptoms and

trick her body into thinking it's OK. After speaking with Horne, she has high hopes. "He seemed positive," she said.

She said the treatment for aHUS depends on an individual's size and weight, but can run up to \$500,000 a year. Without this treatment, the prognosis is not good

and patients will likely receive dialysis within the first year. Complications can include blood clotting, vascular problems, heart disease, neurological problems, and strokes.

She has not been able to work full-time since first developing symptoms, but said that the past two weeks have

been the best she's had since last October.

After handing in this first round of petitions, Carrie Stogryn and her family have continued to canvas neighborhoods for more signatures and said that she will not give up.

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