

Students petition for drug

Harry Ainlay high schoolers gather signatures after parent falls ill with rare blood disorder

Doug Johnson
Edmonton Examiner

Carrie Stogryn fell ill last fall and became a number in the very small data set surrounding Atypical hemolytic uremic syndrome (aHUS).

The rare blood disorder progressively damages the body's major organs, leading to heart attack, stroke, kidney failure and, if left untreated, death.

"Basically, your body thinks your own blood is an intruder and it starts creating lots of clotting trying to kill this intruder off as it would with something unhealthy," said Stogryn, a mother of five and local business owner.

There are about five known cases of the disease in Alberta, and around 50 in Canada.

There is a treatment for aHUS, a drug Health Canada approved for other disorders in 2013 called Soliris.

In short, the drug tricks the body into thinking that everything is alright, so it stops attacking its own blood cells.

"It just starts working on its merry way," Stogryn said.

Soliris needs to be injected intravenously indefinitely, unless a new treatment comes along.

Luckily for Stogryn, her specialist prescribed her the treatment, but, despite Soliris being approved for treating another disorder called Paroxysmal nocturnal hemoglobinuria, it is not available through public funding.

Stogryn chalks this up to a lack of data on aHUS, and urges Alberta to look at the statistics on the disease on an international level.

When Stogryn fell ill, her daughter, a student at Harry Ainlay high school, and her classmates took to action.

At the time, they were studying democracy in their social studies class, and were encouraged by



PHOTO SUPPLIED

Carrie Stogryn, left, with supporters after delivering 4,591 petition signatures to their MLA, Health Minister Fred Horne. The petitions urge the Alberta government to fund Soliris, a life-saving drug.

Stogryn's plight to gather support for funding Soliris for aHUS treatment.

The students got over 4,500 signatures on a petition to publicly fund the drug's use, and last Fri-

day they presented the document to Alberta Health Minister Fred Horne.