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STAFF PHOTO/SUSIE KOCKERSCHIEDT

Runners in the 10th annual Angus Glen Half Marathon head out under an early season snowfall Saturday as they raise funds targeted for Markham Stouffville Hospital's Stollery Family Centre for Children and Childbirth. See more photographs at yorkregion.com

Woman, family struggle for lifesaving drug

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As a mom to three boys, Johann Kerlow always tried to maintain an active lifestyle. Skiing, in particular, is one of her favourites. In between volunteering her time around the

community and caring for her family, Kerlow loved to get out to the slopes.

Little did the Markham resident know, her life would change dramatically this past July.

After a successful left knee replacement almost a year ago, Kerlow began to notice her

right knee was beginning to give out. On July 16, the day after surgery, her health began to steadily decline. Her blood and platelet counts fell dramatically.

Soon after, the 57-year-old was placed

See **DRUG**, page 17.





Johann Kerlow has spent her fair share of being hooked up to machines at hospital. Government funding will allow her to get a needed drug for six months.

Drug \$500K per year

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on dialysis, as her kidneys slowly began to fail. Eventually she was diagnosed at Toronto General Hospital with an incredibly rare genetic condition called atypical Hemolytic Uremic Syndrome – or aHUS, currently only affecting between 60 and 90 Canadians.

The aggressive disease attacks the body's major internal organs, potentially leading to a heart attack, kidney failure, stroke or death.

Since her diagnosis, Kerlow has been receiving weekly transfusions of plasma. "When things were critical, I was getting 18 dosages in one sitting. Recently it's been down to 10," she explained.

When Kerlow and her family first spoke with the Economist & Sun in early October, they were hoping she would be able to receive a potentially life-changing treatment called Soliris – the only drug at present that can keep aHUS at bay and improve Kerlow's quality of life.

According to aHUS Canada vice chair Michael Eygenraam, the Canadian government says it does not have enough data from Canadian patients to support funding.

Soliris costs upwards of \$500,000 for a year's worth of treatment.

Petitions were signed, government representatives were contacted and family and friends of Kerlow pushed day and night for the treatment to become available.

Then, near the end of October, they received word six months' worth of the treatment would be funded through the Ontario Trillium Foundation. Though Johann has already experienced severe trauma to her internal organs, husband Tom is hopeful.

"We are extremely grateful for access to this drug through the ministry of health and we're hoping it will work and that there hasn't been irreparable damage," he said. "After the six months, Trillium will re-assess her condition and determine whether or not she will get more funding for it."

He added Kerlow and the family owe a lot to local MPP Michael Chan, as well as Kerlow's hematologist.

Though receiving the drug has been a small step toward a normal life for Kerlow, there is still the threat of it affecting her three sons — one of whom has already battled aHUS and kidney failure.

"My mom is one of the toughest people I know and is the glue to our family," said son Jeff. "We're doing everything we can to get the government aware of this. Down the road we may have a need for the drug for myself, my mom and my brothers."

Kerlow's other two sons will soon be tested for aHUS.

The family hopes enough awareness will be raised in order for the government to fund Soliris.

"I'm not the only one suffering from this," said Kerlow. "There are other people in Canada that need this drug and I want them to have access to it. We deserve it."

For more, visit www.ahuscanada.org