

Life-saving drug funded — for 6 months

It costs \$500K a year. Johann Kerlow may need Soliris for the rest of her life, but so far OHIP will cover only six months' worth

Johann Kerlow was an active community volunteer and passionate skier who almost never relied on medication. Then, this past summer, her organs suddenly started to fail.

Following routine knee surgery, Kerlow, 57, fell ill. Her blood and platelet counts were dropping and her kidneys were getting weak, but it wasn't immediately clear what was attacking her body. She was taken to Toronto General Hospital, where the diagnosis was delivered: atypical Hemolytic Uremic Syndrome (aHUS), a potentially life-threatening blood disease that attacks the major organs and affects just 60 to 90 Canadians a year.

"They had me hooked up to dialysis and plasma exchange,

and my life was turned upside down," said Kerlow, a mother to three sons who lives in Markham.

The one drug Kerlow and her hematologist believed would ease her suffering was Soliris, which is approved by Health Canada for the treatment of aHUS but not funded by the Ontario government. The medication, made by Alexion Pharmaceuticals, costs about \$500,000 a year. The provincial government does, however, cover the drug for the treatment of another rare blood disease.

Kerlow then became the latest Ontarian with a rare illness to speak out against the lack of access to expensive and potentially life-saving medication.

After going to her local MPP and other politicians, and after her doctor appealed to the health ministry, Kerlow was finally granted funding about two weeks ago for a six-month supply of Soliris. While she's feeling better and grateful for the funding, she wonders why the government would tempor-

Why is it so costly?

A spokeswoman for the drug company, Catherine London, said Soliris is expensive because of several factors, including "the severity and extreme rarity of PNH and aHUS, the life-transforming impact that Soliris has for patients, the enormous costs and risks of developing Soliris as an ultra-orphan therapy, (and) the costs associated with manufacturing this biopharmaceutical product."

arily cover a drug she expects she'll need for life — and why they won't do the same for anyone else with aHUS.

"We're lobbying for everyone (affected) in Ontario to get it," she said. "It's a miracle drug. We really need it. It's the only thing that works for aHUS."

She's also fighting for her three adult-aged sons, who may have inherited the genetic disease. Her middle son, Jeff, has shown symptoms of aHUS in the past and received a kidney



Nurse Susan Cousins preps Johann Kerlow for her first infusion of Soliris at her home. Kerlow has a rare disease and needs access to Soliris for life. RICK MADONIK/TORSTAR NEWS SERVICE

transplant several years ago.

Gabe De Roche, a spokesman for Health Minister Eric Hoskins, said he couldn't comment on Kerlow's case, but said in situations where a final funding decision has not been made for a particular drug, requests for access will be considered on a case-by-case basis.

"The request must be for a drug therapy that is directly

related to the clinical condition that has resulted in the hospitalization and that drug in question is under review by the ministry," he wrote in an email. "Interim drug funding will be limited to a maximum six-month approval and will be reassessed as appropriate considering the patient's clinical condition."

De Roche said Soliris is not

permanently funded for aHUS because of "unresolved concerns regarding diagnostic criteria, appropriate use, lack of long term efficacy and safety data, high cost, and uncertainty in cost-effectiveness." He said Connecticut-based Alexion submitted additional information this past June, which the Ministry of Health is reviewing.

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