FLYING GIANT

World's longest aircraft draws a crowd as it touches down at Pearson Airport, **GT3**

GTA GREATER TO

RICK MADONIK/TORONTO STAR

Johann Kerlow was diagnosed with a potentially life-threatening blood disease following a routine knee surgery.

Province agrees to six months of funding for a lifelong medical fight

Markham woman with rare disease says drug costs $500,000 a year

JACQUES GALLANT
STAFF REPORTER

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 for a six-month supply of Soliris about two weeks ago.

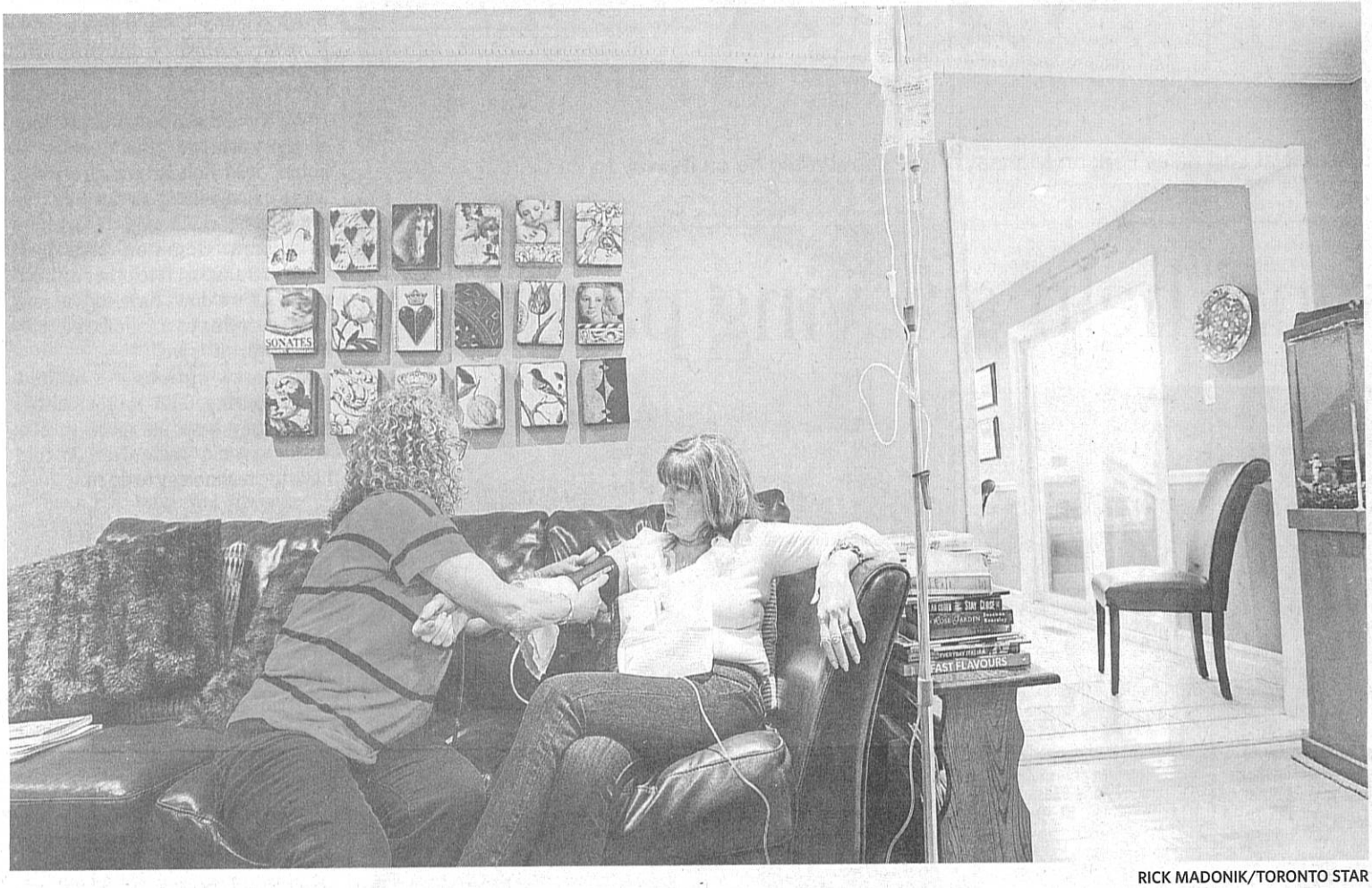
While she's feeling better and grateful for the funding, she wonders why the government would temporarily cover a drug she expects she'll need for life — and why they won't do the same for anyone else with aHUS.

"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 sons, who may have inherited the genetic disease.

DRUG continued on **GT4**



RICK MADONIK/TORONTO STAR

Nurse Susan Cousins checks the vital signs of Johann Kerlow, who is undergoing an infusion of Soliris.

Funding approved on case-by-case basis

DRUG from GT1

Her middle son, Jeff, has shown symptoms of aHUS in the past and received a kidney 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 for people hospitalized for life-, limb- or organ-threatening complications.

"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.

Progressive Conservative health critic Christine Elliott said she doesn't find the ministry's reasoning satisfactory.

"It just adds anxiety for people suffering from these rare diseases," she said. "Obviously, there's a need to fund these drugs for rare diseases so that people don't have to resort to political pressure and running to the media in order to get the services they so desperately need."

Provincial premiers banded together in 2011 to bulk-buy Soliris for the treatment of paroxysmal nocturnal hemoglobinuria (PNH), another rare blood disease, but under the terms of the agreement, they are not allowed to discuss the reduced price they are getting from Alexion.

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, the costs associated with manufacturing this biopharmaceutical product, and the additional costs of supporting the PNH and aHUS communities by investing in patient registries, disease education and other programs to help ensure that patients with these devastating diseases receive optimal care."

Johann Kerlow is lobbying to have the Soliris drug available for everyone affected in Ontario

The disease activates part of the immune system called the complement system, causing it to attack good cells, said Michael Eygenraam, vice-chair of aHUS Canada.

While treatments such as dialysis and plasma exchange treat some of the symptoms, Soliris stops the complement system from getting out of control. His association estimates there are 25 to 30 Ontarians living with aHUS.

Kerlow is now back at home, where she receives a weekly dose of Soliris from a nurse.

She still spends about 15 hours a week in hospital undergoing dialysis and has a feeding tube in her nose, but she is no longer receiving plasma exchange. She says she's feeling more energized and her blood pressure has gone down.

"I'm staying positive, and hoping that this will eventually be just a distant nightmare," she said.

With files from Robert Benzie and Rob Ferguson