

Brampton man with rare disease says Queen's Park funding needs clarity

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A Brampton man with an ultra rare disorder says Queen's Park decision to fund the life-saving drug Soliris on "interim basis" for patients with atypical hemolytic uremic syndrome (aHUS), though welcome, is shrouded in lot of unknowns and may not benefit all.

Last week, Michael Eygenraam, 50, and other patients with aHUS held a press conference at Queen's Park before question period. Afterwards, Ontario Health Minister Eric Hoskins announced the government would fund the drug for patients that met certain clinical criteria, which means payment will be decided on a case-by-case basis.

aHus is a rare genetic condition which can cause neurological problems, seizures and severely high blood pressure, leading to damage to the body's vital organs, including the heart, kidneys and brain. In Canada, there are some 100 aHUS patients. Soliris costs around \$500,000 per year for patients and is unaffordable for the average person, said Eygenraam.

The Brampton man and others said they greeted the minister's announcement with "cautious optimism" and will do so until such a



Michael Eygenraam seen here with his wife Margriet. The Brampton man has an ultra rare disease called aHUS whose only pharmaceutical cure is drug called Soliris which is unaffordable for the average patient and costs \$500,000/per year. Last week, Queen's Park announced funding for the drug, but Michael says the government's criteria of who's eligible is very "restrictive."

time when there's a clear understanding around the criteria.

"A temporary funding announcement is a significant first step towards reaching the long-term, permanent funding solution we urgently seek, as we feel it demonstrates that the ministry of health and long-term care sees the value in the strong clinical data supporting the efficacy and safety of Soliris," he said.

"aHUS Canada will continue to seek clarity from the ministry on the interim funding criteria,

and importantly, collaborate with government to ensure all aHUS patients, whose physicians determine (if patients) can benefit from this life-saving treatment, can receive timely access to Soliris."

In conversations with the decisions makers that determine the criteria, Eygenraam has found the conditions for patients to qualify for Soliris funding are restrictive and so many may not benefit.

"There will be very few patients that will actually get access to Soliris," he said, adding he's currently in

remission. "You actually have to be in a life-and-death situation before you can get it."

Until last week, Quebec was the only province that covered the drug.

Eygenraam began showing symptoms of aHUS in 2002, but it was eight years before he would receive the right diagnosis. In 2002, the Brampton man lost his kidneys as a result of it and attempts at a transplant failed. The father of two continues to be on hemodialysis five times a week and the disease leaves him with extreme fatigue and pain.

"The treatments available in the province currently are not effective," he said. "We (patients) have been waiting a long time for the government to make a decision on funding the only pharmaceutical treatment (Soliris) for the disease we have."

In patients diagnosed with aHUS, the body's complement system – a network of proteins and enzymes that interact with one another to protect the body against foreign bodies – fails to shut off and cannot distinguish between the healthy cells and the invasive ones.

For more information, visit www.ahuscanada.org and join the group on Facebook at www.facebook.com/ahus.canada.