

# Local man urges province to fund life-saving drug

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All Michael Eygenraam wants is a chance to live a 'normal' life. But, without the medication he needs, the outlook is grim for the Brampton resident and others in Ontario suffering from an extremely rare genetic condition called atypical Hemolytic Uremic Syndrome (aHUS).

This is the story he took to Queen's Park yesterday, when he urged the province to publicly fund the cost of Soliris — the drug that could save Eygenraam's life.

"I am asking the Ontario government for a real chance at a normal life," said Eygenraam, 49, noting that Feb. 27 is "Rare Disease Day 2014."

"We're hoping that the MPPs we speak to understand our frustration, and under-

stand what we think needs to be done to change things," he said.

It's estimated only 60-90 Canadians suffer from aHUS, a disease that progressively damages the body's major organs.

It's a condition that can lead to heart attack, stroke, kidney failure and death. There is clinical evidence supporting the use of Soliris in treating aHUS — but the

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## Fighting for drug funding for rare kidney condition

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the government won't fund the drug.

The process for approving pharmaceuticals to treat ultra-rare conditions is flawed, said Eygenraam. He took that message to a senior policy advisor in the Ministry of Health during his visit to Queen's Park.

"I'm doing this on behalf of all patients in Canada," said the father of two.

Eygenraam first fell ill in 2002; six months later, he lost his kidneys. At the time, he was unknowingly misdiagnosed with a disease similar to aHUS.

In 2005, his wife Margriet donated one of her kidneys. The transplant failed.

In 2010, doctors confirmed aHUS diagnosis, which explained the failed transplant five years prior.

He's been on hemodialysis five times a week for the last 12 years, just to get by. It's a 10-hour process that leaves him confined to his home.

Without another kidney, however, he must continue to do 10 hours of hemodialysis. He'll continue to be at elevated risk for heart attack and stroke, and will go on suffering from symptoms of extreme fatigue and pain.

But Eygenraam's name won't appear on any transplant lists; without a treatment that will manage his disease, he's not a candidate for receiving the organ.

"Until I'm on a treatment that will control my disease... any donated kidney would fail again," said Eygenraam, who now sits on aHUS Canada's board as vice-chair.

Soliris is the first and only drug, he said, that offers any hope — and despite Health Canada's approval to use Soliris as treatment for aHUS, access is restricted because Ontario won't fund it.

Paying out of pocket isn't an option, either. It's estimated to cost roughly \$400,000 a year to treat one patient.

However, those in Ontario living from another rare disorder, paroxysmal nocturnal hemoglobinuria (PNH), have full access to the treatment. Another argument, said Eygenraam, proving the system is flawed.

Two years ago, 12-year-old Joshua DeBortoli of Vaughn was diagnosed with aHUS, and suffered kidney failure and life-threatening symptoms. He was enrolled in a clinical trial for Soliris, and his health dramatically improved.

His kidney function has since been restored — as has his quality of life.

"Why can't the government see these results," Eygenraam said, adding all the clinical evidence — evidence like DeBortoli's case — is promising for aHUS sufferers. "We expect more from the health system."