

RUSSIAN ROULETTE OF DRUG PROGRAMS

Convoluted approval process leaves patients fighting for their lives



The random nature of this province's drug approval process picks winners and losers from patients looking for costly, life-saving drugs.

Patients with certain diseases are able to get funding for certain drugs, while others who are prescribed the same drug by their physicians for a different disease are turned down.

Michael Eygenraam, 49, was diagnosed with atypical Hemolytic Uremic Syndrome (aHUS), a rare, devastating genetic blood disease.

It's triggered by a number of factors and causes the body's antibodies to fight one another.

In his case, it caused kidney failure and he now undergoes eight hours of dialysis five times a week.

In 2006, his wife, Margriet, donated one of her kidneys to him.

Sadly, though, the medication that was supposed to stop his body rejecting the new kidney actually triggered an attack of the disease — destroying the new kidney within two weeks.

Eygenraam's only hope is a new drug, Solaris.

While it was approved 22 months ago by Health Canada, so far this province's convoluted drug financing process hasn't approved it for OHIP funding.

It costs about \$500,000 per patient each year.

"The government doesn't have a very good handle on how effective the medication is," Eygenraam told me in a phone interview from his Brampton home Tuesday.

While Solaris is approved



Michael Eygenraam, with wife Margriet, needs Solaris to stay alive, but OHIP won't cover it. Joshua DeBortoli, right, is receiving it — paid for on compassionate grounds by the drug manufacturer.



for treatment of another disease, aHUS patients can't get it paid for by OHIP.

"We don't have \$500,000 sitting around," said Margriet, who works part-time as a cleaner and volunteers for the aHUS association, trying to get funding for the drug.

The first sign Joshua DeBortoli, 13, had the disease

was when he turned yellow. Mom Sonia remembers rushing him to the Hospital for Sick Children in Toronto.

"He was intubated. He had internal bleeding. He had kidney failure for 2½ weeks," she said.

He's now on Solaris — paid for on compassionate grounds by the drug manufacturer.

He has full function in his kidneys.

He's back at school, healthy, playing — and has an excellent prognosis.

"We want the government to fund the drug, but when we've been in discussion with them, I'm not sure they understand that you can't put someone on it tentatively

and then take them off of it," she said. "It doesn't work that way because it's a chronic disease."

Joshua has been on it for two years now.

"We don't have \$500,000 sitting around"

Margriet Eygenraam on the cost of the drug needed to keep her husband alive

There are fewer than 100 aHUS patients across Canada.

Tory MPP Michael Harris has been advocating for Solaris funding on behalf of aHUS patients.

"There's nothing more sad as an MPP than friends and family in your constituency office who come in and are begging you to help their dying loved ones," he says. "I hate to call it picking winners and losers, but it is."

John Haslam, general manager of Alexion — the company that manufactures Solaris — says the drug is paid for in Quebec and in 40 countries around the world, including Britain and France, which have rigorous evaluation methods.

He called it "life transformative."

It would cost \$8 million to \$10 million to fund it in this province.

"If we talk about the

Canada Health Act, it really should be there for everyone," Haslam said. "Patients with rare diseases shouldn't be left behind."

In an e-mailed statement, Health Minister Eric Hoskins said the government "took the politics" out of drug funding, making sure approvals were based on the "best available evidence."

Hoskins said all drugs are thoroughly reviewed and evaluated by an expert committee.

"The committee is composed of patient representatives, physicians, pharmacists and an economist," he said.

The government is still reviewing additional information from Alexion and has a "compassionate review program," which looks at emergency situations.

Look, we all understand health dollars are stretched to the limit.

But if it's your life and your health at stake, surely every request deserves a compassionate response.

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