



CANADAEAST NEWS SERVICE/CINDY WILSON PHOTO

Asking for help: Mark Brennan, a Saint John radio show host, is one of about 90 Canadians who suffers from a rare and fatal blood disease. He's awaiting a provincial government decision to see if an expensive drug that controls the disorder will be included in a catastrophic drug plan.

Prescription to live: \$500,000 per year

Coverage | Port city man says New Brunswickers need financial aid

By JENNIFER PRITCHETT
Canadaeast News Service

SAINT JOHN — Mark Brennan is one of fewer than 90 Canadians who suffer from an ultra-rare, progressive and fatal bone marrow disorder.

He spends about an hour and a half every two weeks hooked up to an intravenous needle that feeds him a drug designed to prevent blood clots, kidney failure, crippling fatigue and, ultimately, to keep him alive.

The only problem is, the drug costs about \$500,000 a year and isn't covered by the New Brunswick government.

"Without it, there is no life — (my) life would be crap until it's over," said Brennan, 40.

The deep-voiced, affable Saint John radio host suffers from Paroxysmal Nocturnal Haemoglobinuria, or PNH, a disease that affects the blood and major organs.

It destroys red blood cells through a process called haemolysis, which can lead to life-threatening blood clots, kidney disease, pulmonary hypertension and other life-threatening consequences.

Until the drug Soliris was approved for use in Canada in 2009, there was no effective treatment for the debilitating disease. A bone marrow transplant is the only cure, but a match has to be found.

Brennan is receiving the expensive Soliris treatment for free on a compassionate basis from the drug manufacturer, but he doesn't know when the company might stop providing him with it so he constantly worries about what he'll do when that happens.

"I don't know how long I have ... If it wasn't for Soliris, God knows if I'd be here or not," he said. "Death's door is more like it."

After his diagnosis in 2004, Brennan battled through five years without adequate treatment while his condition got progressively worse. He was becoming jaundiced, his skin and eye whites were turning yellow, he was having joint pain so bad he could barely walk and his kidneys were failing. He was about to be put on dialysis.

When his doctor told him in 2009 about a new drug, Soliris, that had recently been approved for use in Canada, he was elated. Then he found out the treatment would cost about a half-million dollars a year.

He almost didn't ask to receive the drug because of the cost.

"None of us can afford it. Even if we won the lottery, we couldn't afford it,"

he said.

When the drug company started providing him with the drug in November 2009, he saw improvements to his health almost immediately.

One of the tell-tale signs of PNH is dark urine and within a few hours, his "Coca-Cola-coloured" urine had returned to yellow for the first time in years.

"I almost cried," he said.

For him, it was a sign he was moving in the right direction. Over the coming days, his condition gradually improved. His skin was no longer a yellow colour, his kidney function stabilized without dialysis and his joint pain went away.

In the absence of a nationwide drug program, Brennan is among a growing number of Canadians suffering from rare diseases who are fighting for access to the life-saving medicine they require.

"Soliris is my only hope to survive," he said. "I'm living proof that it works. I mean look at me now. I feel fantastic."

New Brunswick is one of only two provinces in Canada — Prince Edward Island is the other — that doesn't have a catastrophic drug plan to cover costly prescription drugs for serious diseases.

While the provincial Conservatives committed to implementing the plan in the first year of its mandate, it remains unknown when it will happen.

Brennan has written to provincial Health Minister Madeleine Dube to urge the New Brunswick government to add Soliris to the list of drugs it will include in the catastrophic drug program the province has said it will bring into effect.

She responded earlier this year in a letter to him in which she wrote, "Please be assured that improving drug coverage is a priority and we will be moving on this commitment as quickly as possible." She didn't pro-

vide a time frame for when it would be implemented, nor did she indicate whether Soliris would be included in the plan.

This week, Health Department spokeswoman Tracey Burkhardt said New Brunswick is waiting to see the outcome of discussions that Ontario is having with the manufacturer of Soliris before reconsidering whether it will be included in the existing New Brunswick Prescription Drug Program.

"Ontario is leading discussions with the manufacturer on behalf of other provincial drug plans regarding the price of Soliris," she said in a statement. "When these discussions are concluded, the benefit status of Soliris will be reconsidered."

Barry Katsof, president of the Canadian Association of PNH Patients, said governments in Canada have to address the fact that people with rare diseases require access to often expensive drugs and people shouldn't be discriminated against on that basis.

"Canada has a charter of rights and it's very clear that every citizen of the country is equal to every other citizen and has the same rights to treatment without prejudice," he said in a phone interview from Toronto.

Katsof, who also suffers from PNH, said it's unfair that cholesterol-lowering drugs are readily available through government health plans across the country when some life-saving drugs are not. It's particularly baffling, he said, that both high cholesterol and PNH carry a risk of blood clots, but governments typically provide drug coverage only for those managing high cholesterol.

"Why are patients with PNH not given access to medication when the medication has been proven and written up by world-leading medical journals to save lives?" he said.

With files from Chris Morris