



This photo of Johann Kerlow, left, was taken on October 4, 2014, two weeks before she was prescribed Soliris, an expensive, life-saving drug. Now at home, she walks daily and is learning to do her own dialysis. The province is paying for her Soliris until April 16, 2015. With Johann is her husband Tom Kerlow, and Ann Bilodeau of Kitchener, her friend who is lobbying the province to continue to cover the cost of the drug.

aHUS patients and their families to lobby Queen's Park to cover cost of life-saving drug

BY ANDREA HALL

It's one of the most expensive medical drugs in the world – but one Kitchener woman says it works miracles.

Ann Bilodeau is pushing the province to cover the cost of Soliris for patients of aHUS, an extremely rare blood disease that affects 60-90 Canadians.

Soliris is approved by Health Canada to treat aHUS, but can cost \$500,000 a year, and in Ontario the bill goes to the patient, not the province. So when Bilodeau's close friend was diagnosed with aHUS, she started campaigning.

"Probably the worst feeling in the world is when you are watching one of your dearest friends literally die in front of you," she said, "and knowing that in that hospital they carried Soliris but she couldn't get it. Because of money."

Bilodeau lives in Kitchener with her husband. It was through him that she met Johann Kerlow more than 30 years ago. Kerlow, an active mother of three, lives in Markham and went in for elective knee surgery over the summer. What should have been a fairly common procedure became a nightmare.

"The next few days, my kidneys were shutting down, all my blood work was out of whack, they just had no idea what was wrong with me," said Kerlow.

She was moved to Toronto General Hospital, where hematologist Dr. David Barth eventually diagnosed her. She spent much of the next three months in hospital.

"I could barely shower, from the top of my head to my toes I was just totally exhausted, I was in a wheelchair," she said. "And for seven hours a day I was on machines."

Those machines kept her alive, conducting plasma exchange and dialysis.

"I still get goosebumps looking at the suffering that this woman has gone through," said Bilodeau. She started contacting local MPPs, pleading the case to get Soliris covered.

"One of the things that I felt terrible about from the very beginning is the distance between where I live and the family lived," said Bilodeau. She visited often, but wasn't able to provide the same daily support as friends and family who lived in Kerlow's community.

"All I kept thinking of is, what can I do to have some kind of impact?"

Bilodeau found support from local MPPs of all parties – Liberal Daiene Vernile, NDP Catherine Fife and Conservative Michael Harris took immediate action.

"New drugs are coming on the market all the time, medical advancements continue to happen," said Harris, adding it isn't the first time someone with a rare disease has sought help from Queen's Park. "There really should be a provincial strategy for funding life-saving drugs."

Harris says that in the long run, some drugs, though pricey, may ultimately save the healthcare system money.

Bilodeau agrees. She said a bigger picture is needed when considering the treatment of aHUS – daily dialysis, plasma transfusion, blood pressure medication, and hospital stays can all be required for treatment without Soliris.

For now Kerlow is out of hospital. In mid-October she was granted six months of Soliris injections under the province's Compassionate Review Policy, and said the change is unbelievable.

"I went from 2% energy to 110%."

She still requires dialysis three times a week, but is hoping Soliris will eventually make that unnecessary. And she's still pushing for coverage for everyone with aHUS, which can be genetic.

"I have three boys, there is a 50% chance that they could have it," said Kerlow. "So we do have to fight for the drug."

Soliris has been approved for coverage in Quebec, and in Ontario for another blood disease, PNH. Kerlow says in that case the process was similar – one woman got temporary coverage under the Compassionate Review Policy and pushed until it was covered permanently for everyone. Both she and Bilodeau are hopeful the same thing will happen for aHUS.

"There's a due process and we certainly understand that," said Bilodeau. "But in the meantime she is absolute proof that this drug saves lives."

The next step is a lobby day at Queen's Park, happening February 25. Friends and family are invited to Question Period, and some aHUS patients will also be present, but Kerlow will be on dialysis and unable to attend.