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The
Bradford Times

www.bradfordtimes.ca

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The quest for Soliris

By Lindsay Bray, Intern

There are many life-saving drugs out there. Those made for rare diseases tend to be more expensive than commonly-used drugs that have a potentially larger market.

This can make it harder for people with those rare diseases to find the cure or even treatment they need.

Michael Eygenraam, age 49, knows this all too well.

In 2011, he was diagnosed with atypical Hemolytic Uremic Syndrome (aHUS), a very rare and life-threatening

for treatment of a different disease, Paroxysmal nocturnal hemoglobinuria (PNH) - another rare, genetic blood disorder. The provincial government believes that there is more evidence that Soliris improves the health of PNH patients, than aHUS patients.

Health Canada has approved Soliris for the treatment of aHUS - the only approved treatment - but the province hasn't followed. Eygenraam is unable to get funding for the drug, and paying for it by himself is extremely hard. The cost is \$500,000 per year.

genetic blood disease. It attacks part of the immune system, leaving it always active and working against both healthy and unhealthy cells. This can cause blood vessel damage, clotting, and major organ failure, which can lead to heart attack, stroke, kidney failure, and even death.

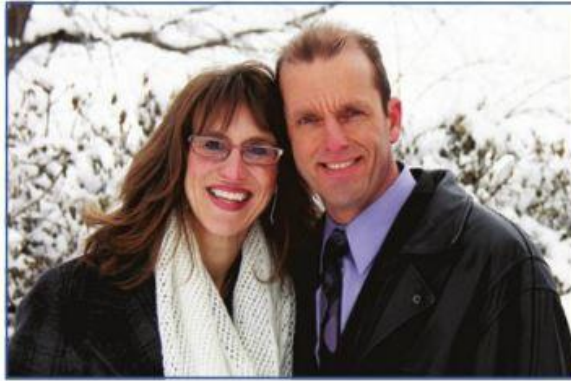
For Eygenraam, the disease has caused kidney failure, and he now goes through dialysis for eight hours, five times a week in order to stay alive. He also suffers severe fatigue and pain.

In 2006, he was donated a kidney by his wife, Margriet Eygenraam. But at the time, Eygenraam had been diagnosed with a different disease; if he had been correctly diagnosed, he never would have had the transplant, since aHUS is known to be responsible for transplant failure. The new kidney was destroyed within weeks.

Eygenraam now has no other options. He needs the new drug, Soliris.

“Without the drug, I won’t be allowed to have another transplant. So I’ll have to deal with dialyses for the rest of my life,” Eygenraam said in a phone interview.

Ontario has approved the use of Soliris



Cost is the reason the Ontario government has chosen not to list the drug for aHUS. They have yet to accept just how effective the drug really is, and how necessary it is for some people.

“To not treat people with a known treatment, we feel, is not ethical,” stated Eygenraam, especially for a disease as serious as aHUS.

The health budget is limited, and dollars are stretched sometimes as far as they can go; no-one is questioning that. But when it comes to a fight for your life, the cost shouldn’t matter. Soliris is “expensive, but affordable,” Eygenraam said.

He is now on aHUS Canada’s board as Vice-Chair, working to “support patients in any way we can.” aHUS Canada, formed in November of 2012, is a non-profit organization, supported by corporations and private donors. Their mission is to support the patients and families living with aHUS - and get them the drug they need to survive.

To learn more about aHUS see www.ahuscanada.org

Submitted photo: Michael and Margriet Eygenraam.