



atypical
Hemolytic
Uremic
Syndrome

Supporting patients and families
living with aHUS

PATIENT GROUP URGES ONTARIO TO MAKE SAVING LIVES A PRIORITY

- Election candidates commit to continue advocating for publicly funded access to Soliris for Ontarians living with life-threatening ultra-rare disease -

TORONTO, ON – June 10, 2014 – Ahead of the Ontario election on June 12, aHUS Canada board members attended All-Candidates Meetings in Whitby-Oshawa, Brampton West and Vaughan to secure the support of the ridings' electoral candidates. Speaking with PC health critic, Christine Elliott, and Liberal candidates Vic Dhillon and Steven Del Duca, as well as PC candidates Randeep Sandhu and Peter Meffe, aHUS Canada confirmed their commitment to continue advocating for publicly funded access to Soliris® (eculizumab), the first and only pharmaceutical treatment option for children and adults living with atypical Hemolytic Uremic Syndrome (aHUS).

“We are very encouraged by Ms. Elliott’s commitment to working on a new strategy for drugs for rare diseases. In fact, she told us that she looks forward to continuing to work with the aHUS community. She pointed out that there is no point in developing drugs for rare diseases if they cannot be accessed by the patients who need them,” said aHUS Canada Vice-Chair Michael Eygenraam. “We are also grateful for the support of Mr. Dhillon, who was my MPP, for writing to the Minister of Health on our behalf, as well as Mr. Sandhu, who believes that the Ontario Public Drug Program should not discriminate against rare diseases.”

Eygenraam is one of the 60 to 90 children and adults in Canada affected by this very rare, chronic and life-threatening genetic condition, which leaves a part of the immune system uncontrolled and always active. As a result, the immune system attacks the body’s unhealthy and healthy cells which can cause blood vessel damage, abnormal blood clotting^{i,ii} and progressive damage to the major organs, leading to heart attack, stroke, kidney failure and death.ⁱⁱⁱ

Studies have shown that Soliris is highly effective in controlling aHUS and improving patients’ quality of life.^{iv} Unlike supportive plasma therapies, Soliris has the potential to change the course of the disease, to repair and restore kidney function in some patients^{iii,iv,v} and, for the first time, offers a real opportunity for transplant in those aHUS patients on chronic dialysis.^{iv}

“The highly credible New England Journal of Medicine published a study of 37 patients at different stages of aHUS which suggests Soliris is a necessary treatment. It's going to be hard to get better evidence than that,” said Dr. William Clark, a London, Ontario-based nephrologist and medical advisor to aHUS Canada. “These patients need Soliris to survive, and provincial governments have a responsibility to provide optimal care for the population as a whole, including those with rare diseases. Treating the small number of patients with aHUS wouldn't threaten the financial supply of the health care system.”

In March of 2013, Soliris was approved by Health Canada as safe and effective for use in children and adults with aHUS, based on a strong body of clinical evidence. Since then, additional studies have been published in leading peer-reviewed journals, such as the New England Journal of Medicine, reinforcing international expert consensus supporting the use of Soliris as the new standard of care for children and adults with aHUS. Unfortunately, the Ontario government has continued to restrict access to this life-saving treatment by refusing to fund it. Unless they were part of the clinical trial that led to its approval in Canada – like aHUS board member Sonia Giroto’s son, Josh DeBortoli – only those patients with private drug coverage or who can pay out-of-pocket have the opportunity to access Soliris.

“At the Vaughan all candidates meeting last week, Mr. Del Duca confirmed that he will continue to support and advocate for funding for rare diseases, and that he believes that the process for reviewing drugs for rare diseases needs to change. Mr. Meffe also committed his support to all constituents living with any disease,” said aHUS Canada Treasurer, Sonia Giroto. “Ultimately, we are hopeful that, if elected, either candidate will do everything they can to help ensure immediate, publicly funded access to life-saving treatments like Soliris for the children and adults in this province who so desperately need it.”

About aHUS Canada

aHUS Canada was formed in November 2012 to support Canadian patients and families living with aHUS. In addition to establishing a Canadian aHUS community, the group is committed to building public awareness and understanding of aHUS and advocating for the best possible care and treatment for patients. For more information, please visit www.ahuscanada.org.

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