

Media Advisory

Thousands of Ontarians support ultra-rare disease group's plea for public funding of life-saving drug

On Wednesday, February 25, 2015, patients with atypical Hemolytic Uremic Syndrome (aHUS), their family members and supporters will bring their voices to the Legislative Assembly of Ontario. They bring with them thousands of Ontarians' signatures on a petition showing support for their plea. The Ontario aHUS community is gathering not only to mark Rare Disease Day (February 28, 2015), but also to convince the government to reach an immediate, long-term solution which would allow patients to access the life-saving treatment they need to save their organs, limbs and lives.

aHUS is an ultra-rare, chronic and life-threatening condition that can only be effectively treated by Soliris (eculizumab). Soliris was approved by Health Canada in 2013 as the first and only pharmaceutical treatment for aHUS, and it has shown greater efficacy than plasma therapy in the management of the disease. Studies show that Soliris can allow patients to discontinue plasma and dialysis therapies, and lead to a significant improvement in kidney function and control of the disease. Soliris has even opened up the possibility of kidney transplantation in patients whose organs were destroyed by the disease.

Yet, despite being recognized as the new standard of care for aHUS by international specialists, and being funded by numerous governments around the world, the drug is still not funded by the Ontario Public Drug Programs for patients in need.

Who: **Michael Eygenraam, aHUS patient and Vice-Chair, aHUS Canada (Brampton, ON)**
 Margriet Eygenraam, caregiver and Secretary, aHUS Canada (Brampton, ON)
 Joshua DeBortoli, aHUS patient on Soliris (Vaughan, ON)
 Sonia Giroto, mother to Joshua and Treasurer, aHUS Canada (Vaughan, ON)

Where: **Legislative Assembly of Ontario**
 Media Studio, Legislative Building, Queen's Park
 Toronto, Ontario

When: **Wednesday, February 25, 2015**
 9 a.m. – 9:30 a.m. News Conference

The individuals listed above and other aHUS patients will be available to speak with media after the news conference, and later in the day following Question Period. Dr. Nigel Rawson (Ph.D.), a pharmaceutical policy researcher, will also be available during and after the news conference.

For further information, to confirm attendance or to book an interview, please contact:

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