



HAE Canada Newsletter

December 2018: by Paige, HAE Canada Youth member

The HAE Canada Team has been busy these past few months. In May, some HAE Canada members participated in the HAEi 2018 Global Walk where many Canadians put their best foot forward into walking for a cause. Canada came out on top with over 9,000,000 steps! Congratulations Canada!

At the Global Conference in Vienna, Austria we launched our own HAE Canada Youngsters Program helping more youth like me feel at home and empowered with their diagnosis. We are grateful that HAEi Youngsters launched their website and magazine where any HAE youth wishing to submit something to either platform can now do so. Here is the link for the website and more information about the magazine is found on its amazingly inspiring pages. <https://haei.org/youngsters/>

In addition to attending the Global Conference 2018, some HAE Canada Board of Director members were lucky enough to have a tour of the CSL Marburg Plant (May 2018), and a tour of the Shire Vienna Manufacturing Facility (May 2018). These pharmaceutical companies were the generous sponsors of the HAE Global Conference this year. The tour helped the HAE Canada board members get a look into the other side of the needle, you could say.

We are also very proud to announce that Health Canada has approved TAKHZYRO™ (lanadelumab injection), a first-of-its kind monoclonal antibody treatment for the prevention of Hereditary Angioedema (HAE) attacks. This is the first step in the approval process for new drugs in Canada.

HAE Canada had the privilege of being involved in the Canadian Society of Allergy and Clinical Immunology (CSACI) Conference held in Halifax, Nova Scotia from the 12th to the 16th of September. Many specialists representing all regions of Canada who treat HAE patients were in attendance. Others in attendance included allied health professionals, medical students, Immunology Fellows and Pharma representatives.

Dr. Jonathan Bernstein, an Allergist and Immunologist from the US delivered a presentation on the different types of HAE and the current research on new treatments carried out in the US and on Genetics. Dr. Gina Lacuesta, Allergist and Immunologist in Halifax, Nova Scotia spoke about the pathophysiology of HAE, the various blood components that play a roll in the condition and the current treatments available in Canada. The change they are promoting within their local medical communities is encouraging to HAE patients and their families.

Their presentations increased awareness of advances in ongoing drug trials. It is hoped these drugs will be available for the HAE Canada community. It was amazing to get to meet many physicians and the Pharma representatives who visited the booth and appreciate their keen interest in the HAE condition that my family and I struggle through daily.

HAE Canada, CSL Bering, Shire and other companies held booths alongside one another during this conference. We were lucky to have our President, two other Board members, and

helpful HAE Canada volunteers support the booth. HAE Canada's main goal for supporting a booth was to spread the message to physicians about our organization and ask them to help spread the word about HAE Canada and to encourage any patients with HAE to join our organization.

Four HAE Canada posters were presented at the conference that were based on data of the HAE Canada National Report Card Survey issued by HAE Canada to our membership in 2017-2018. Several conference participants viewed the HAE Canada posters. Questions were answered by those who developed the posters.

By offering information at the booth, it gave me the chance to meet face to face with specialists or other medical personal who may or may not have HAE patients. This allowed me as a patient to share information brochures as well as my personal experience of living with HAE. I was also able to provide them with direction on how to get more HAE information to further their understanding for themselves and or their patients.

I visited a couple of pharma booths and reviewed a few very informative audio visual tools for patients. These audio visual programs show how important it is for others to learn more about treating HAE and how the quality of life for myself and my fellow HAE patients are impacted by our condition.

In addition to attending the CSACI Scientific Meeting, two board members and a HAE Canada member attended the recent Science for Rare Warriors: Rare Disease Knowledge Translation Conference in October in Toronto. The conference was hosted by the Rare Disease Review which is a medical and health policy journal that translates current rare disease research into informative reports that anyone can understand. Those who attended found the conference helpful as it taught the basics of

medical science, and how to break down complex medical information.

One final, but important, item we'd like to share is that in the fall, HAE Canada President, Jacquie Badiou, traveled to St. John's to meet with Deputy Minister of Health and Community Services, John Abbott and Ms Jamie O'Dea, Director of Pharmaceutical Services to discuss treatments for HAE patients in Newfoundland and Labrador. During their meeting they discussed the importance of providing all available treatments to HAE patients across Canada. We have been informed of the wonderful news that Newfoundland & Labrador has added Icatibant (Firazyr 10mg/ml solution) to the province's benefit list. We would like to thank Deputy Minister John Abbott, for the attention he and his government gave to this very important step towards equal access for all Canadians with Type 1 and 2 HAE. We are pleased to announce that Firazyr is now available from coast to coast – a fantastic way to end 2018.
