



HAE Canada Newsletter

May 2021

Canadian HAE patients have more to celebrate since our last newsletter.



After years of discussions and negotiations, we are excited to share that all eligible HAE patients across Canada are now able to access HAEGARDA, CSL Behring's subcutaneous C1-INH prophylaxis therapy for adolescents and adults, through Canadian Blood Services (CBS). Listing HAEGARDA on this federal formulary ensures equitable access for Canadian HAE patients. Thank you to the teams at CSL Behring and CBS who worked hard to ensure this treatment is available to Canadian patients. HAE Canada is proud to have played a major role advocating for access to HAEGARDA in Canada.

TAKHZYRO Available to More Patients

Since our last newsletter, additional jurisdictions have added Takeda's lanadelumab (TAKHZYRO), a subcutaneous

monoclonal antibody inhibitor of plasma kallikrein, to their formularies. We are thankful to Takeda for successfully negotiating with five additional provincial governments, as well as the Non-Insured Health Benefits (NIHB) for First Nations and Inuit Program, for access to TAKHZYRO. We are on the road to equitable access to TAKHZYRO for eligible HAE patients across Canada.

We are thrilled to share that our second abstract of 2021, this one titled: *HAE in Canada: Preliminary Demographic and Treatment Results* from the Second National Survey has been accepted at the 2021 EAACI Hybrid Congress. Once again, we need to thank Dr. Suzanne Kelly of Red Maple Trials who always does an amazing job developing our abstracts, and we are always grateful for assistance provided by our Board of Directors and Advocacy Committee.

Our Patient Information Update

On May 15th, HAE Canada hosted a virtual Patient Information Update for our membership. Panelist, Jacquie Badiou, President, presented on HAE Canada's latest news and initiatives, and fellow panelist Daphne Dumbrille, HAEC COO, kept the meeting on task. We were grateful to have a

fantastic line-up of expert speakers, which included:

- Dr. Chrystyna Kalicinsky, MD, FRCPC, Allergist/Immunologist,
- Dr. Sylvain Grenier, Director, Plasma Derived Products Formulary Program at CBS
- Anthony Castaldo, CEO & President of HAEA and HAEi
- Kim Speiss, RN, Regional Director, Manitoba & Saskatchewan

Dr. Kalicinsky spoke about HAE and the different treatment options available to Canadian patients, while Dr. Grenier spoke specifically about accessing treatment through CBS. Tony Castaldo discussed HAE treatments on the horizon, and Kim Speiss spoke about her patient journey. Members were grateful for the opportunity to have their pre-submitted questions answered by the different speakers. We would like to thank our wonderful speakers who generously took time out of their busy Saturdays to help ensure our members remain informed.

During our Patient Update we announced that we are soon launching our HAE Day 2021 initiative: the HAE Canada Cafe. This members-only online forum will allow our members to connect with other patients and caregivers to share stories and experiences in a supportive environment. We will also allow members to ask medical questions that will be answered by different HAE specialists from across Canada. We are excited to offer this platform to the HAE Canada membership.


For the past five years, Jacquie Badiou has met with various stakeholders, including the Canadian Heart and Stroke Foundation, to work toward getting HAE added to the Airway Management section of the Advanced Cardiovascular Life Support (ACLS)

/ Pediatric Advanced Life Support (PALS) curriculum. This important initiative would ensure that first responders and front-line healthcare workers are educated on HAE and would learn the special treatment precautions necessary for HAE patients presenting with a laryngeal attack. We are grateful that recently, Canadian physicians, including Drs. David Barnes, Susan Wasserman and Paul Keith, and US physician Dr. Marc Riedl and Anthony Castaldo, HAEi and HAEA, CEO & President, volunteered their time to develop a PICO question to submit to the International Liaison Committee on Resuscitation (ILCOR). This is the first step, asking for a systemic review. While we have come far, we still have more steps to complete on this project. We will be sure to provide additional updates on this important initiative in upcoming newsletters.

A Very Successful HAE Global Walk

The 2021 HAE Global Walk illustrates why we are so proud of our amazingly engaged Canadian HAE community. Our membership, including the HAE Canada Board of Directors, continuously entered their steps to ensure Canada remained in the lead for a third time. Teams from our energetic sponsors, specifically, CSL Behring and Takeda Canada, as well as our contracted workers, especially our health policy consultant, Bob Bick, also logged many steps for Canada. We could not be prouder of the Canadian community who finds the time to keep HAE awareness alive. Thank you to all who participated, we appreciate the engagement and enthusiasm for this amazing initiative.



	Steps	Activities	Participants
Denmark	12,000,000	501	500
United States	14,235,735	162	371
Sweden	16,347,730	53	127
Canada 	24,347,107	718	1,223



Lorraine
Pacific Reg Director

