



HAE Canada Newsletter

August 2020 by the HAE Canada Team

You wouldn't know it based on the temperatures outside, but summer is quickly wrapping up. Seems like ages ago we were venturing outside to go on much needed walks (and runs, bike rides, swims etc.), then logging our steps into HAEi's 2020 Virtual Global Walk website. We know many Canadians put their walking shoes on and participated in this amazing awareness campaign because Canada logged the most steps; allowing Canada to win the Global Walk! Canada logged an impressive **7,748,272** steps because of participation from many across the country.



Thank you to all our members who not only added their steps, but, went one step *further* and asked their friends and families to also get involved. Not only did our membership add steps, but also our extended HAE community enthusiastically participated. Teams from our two major sponsors, CSL

Behring and Takeda, added many steps on a regular basis, as did healthcare providers who work with HAE patients. Thank you for the time and energy all Canadians put into the Virtual Global Walk. We are so proud of our engaged HAE community here in Canada.

In the spring, HAE Canada realized many Canadians needed current information regarding accessing new HAE treatments in Canada. We decided the best way to share reliable information was to host a virtual Patient Information Update. On June 29th, four panelists came together online including, Jacquie Badiou, President and Daphne Dumbrille, COO from HAE Canada, as well as Dr. Sylvain Grenier, Director, Plasma Protein Products Formulary, Canadian Blood Services (CBS) and Dr. Bruce Ritchie, MD, FRCPC, Professor, Division of Hematology, Dept. of Medicine at University of Alberta.

Dr. Grenier and Dr. Ritchie each provided interesting presentations to educate and inform our membership on different topics related to accessing HAE treatments, and they also graciously answered pre-submitted questions from our members. Jacquie's presentation updated participants on latest news and the great initiatives that HAE Canada has been working on, while Daphne's moderating kept the meeting on track and moving along. It was a wonderful,

interactive event and we want to thank our panelists for providing their perspectives and expertise to our members. Their time was greatly appreciated. A recording of the Patient Update is available for viewing on our website's "Past Events" page: <https://haecanada.org/past-events/>. We are already looking forward to our next planned Patient Information Updates in Manitoba, Saskatchewan and Ontario which will be scheduled once we are safe to gather in person.

We were excited and honoured to participate in two virtual conferences in June. HAE Canada submitted a slide show presentation to HAEi's 2020 HAE Global Conference titled: *Fear of Attacks Reduces Quality of Life for Canadian HAE Patients* and a poster to EAACI's Digital Congress titled: *Real-world data of Canadians living with HAE: Need for Innovative, Newer Prophylactic and Subcutaneous Treatments*.

Thank you

to everyone who worked on creating and developing these documents, specifically, Dr. Suzanne Kelley at Red Maple Trials and members of our dedicated Advocacy Committee who always step up to the plate to help with these documents. Jacquie did an amazing job providing the voice recordings for each of these presentations. We appreciate all the help we receive to ensure each project is a success. We are proud to report that our poster was awarded a Five Star Rating by Dr. Marcus Maurer at the EAACI Digital Congress. Please view both submissions on our website's Abstract & Posters page: <https://haecanada.org/national-report-card-abstracts-posters/>.

In June HAE Canada's Governance Committee completed the necessary and important task of updating HAE Canada's Bylaws. A huge thank you to our Board members, Anne Rowe (chair) and Tina McGrath, who worked extremely hard to ensure the bylaws remain accurate and follow all required standards. The Governance Committee also attended multiple webinars held by the Canadian Organization for Rare Disorders (CORD) to remain up to date on the current situation with the Patented Medicine Prices Review Board (PMPRB). We are grateful for the work CORD is doing to prevent the PMPRB from introducing new guidelines which will prevent treatments for rare disorders from coming to Canada.

Over the summer months HAE Canada had a fantastic team working on our next major survey which will gather important data to create our second National Report Card. This team included Bob Bick, policy consultant, Maggie Dow, our summer student, as well as Dr. Suzanne Kelly from Red Maple Trials (RMT). Our president, Jacquie, regularly provided the team with guidance and feedback to ensure this survey will be a success. Thank you to the HAE specialists, CADTH staff and others who reviewed the questionnaire to reflect our Canadian Healthcare System. We look forward to gaining valuable insight and perspectives from HAE patients and their caregivers from across Canada. The National Report Card will be a vital tool used to help bring new treatments to HAE patients in Canada.

HAE Canada collaborated with the Canadian HAE Network (CHAEN) on two Quality of Life abstracts, titled *Assessment of HAE-specific quality of life and proximity to acute therapy* and *Prodromes and attack triggers in Canadian HAE patients*. We are happy to report these two abstracts have been

accepted by the World Allergy Organization's online JSA/WAO Joint Congress 2020. Congratulations to CHAEN, HAEC's Regional Directors and all who worked on these important abstracts.

Recently we learned encouraging news that *the Institut national d'excellence en santé et en services sociaux* (INESSS) has reevaluated lanadelumab (Takhzyro) and soon HAE patients in Quebec will have access to Takhzyro through Hema Quebec. To help INESSS make an informed decision, in December 2019 HAE Canada submitted Patient Input for Lanadelumab (Takhzyro): Drug Evaluation Questionnaire for Patient and Caregiver Associations and Groups. This document references HAE Canada's submission to the Canadian Agency for Drugs and Technologies in Health (CADTH) Common Drug Review (CDR) Pharmacoeconomic review report – Lanadelumab (Takhzyro). All documents can be found on our website: <https://haecanada.org/hae-canada-patient-submissions/> Thank you to our Advocacy Committee, consultants, Bob and Suzanne, staff member Daphne and our tireless president, Jacquie, who diligently worked on this important patient submission.

To help keep the drug prices affordable, the pan-Canadian Pharmaceutical Alliance (pCPA) conducts joint negotiations with the provinces, territories and the federal government for brand name and generic drugs in Canada. Jacquie and our VP, Tina McGrath, have been working with Takeda regarding access to Takhzyro and we are anxiously awaiting pCPA's decision on when and how lanadelumab (Takhzyro) will be available to HAE patients outside of Quebec.

Thank you once again to Jacquie, who over the summer, regularly met with CBS and CSL Behring to discuss when and how patients outside Quebec will access HAEGARDA, a subQ prophylaxis treatment. We are able to report that we expect the treatment to be available through CBS this fall.

Finally, we would like to thank our diligent and dedicated treasurer, Richard Badiou. Over the past year, Richard has been leading the development of the Canadian Angioedema Scholarship Program (CASP) Foundation, and we are confident the research funded by CASP will contribute to positive changes in the HAE community.

We hope all are well and staying safe.