



# HAE Canada Newsletter

June 2020 by the HAE Canada Team

Organizations across the globe have adjusted and regrouped due to the COVID-19 pandemic, and HAE Canada is no exception. It is hard to believe we are in the third month of the quarantine, but we are grateful we are still able to move forward with our projects and initiatives from the comforts of home.

Between encouraging the Canadian HAE community to participate in HAEi's Virtual Global Walk and helping our members navigate around COVID-19, HAE Canada continued to work on abstracts and posters to present at international conferences. We are fortunate that our poster, titled "Real world data of Canadians living with HAE: Need for innovative, newer, prophylactic and subcutaneous medications", will be presented at the European Academy of Allergy & Clinical Immunology (EAACI)'s Digital Congress 2020, and a slide show, of the same title, will be presented at the 2020 HAE Global Conference. We are amazed at the creativity and ingenuity used to make these conferences available virtually after they were cancelled due to COVID-19.

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Speaking of the Virtual Global Walk, we would like to say how proud we are of the Canadian HAE community. We have been leading the way from right from the start of the Global Walk, and we hope to gain the coveted title for a second time. Thank you Canada – your steps are encouraging and appreciated!

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An exciting piece of news we would like to share is our partnership with HAEi to create our new and improved website. Our website, while still fully managed and run by HAEC, is now being hosted by HAEi and we couldn't be happier with the outcome: a stunning new website. Working with Ole Frølich, HAEi's Enterprise Technology Manager, was a pleasure; his guidance and expertise, not to mention his patience, were invaluable. Thank you HAEi. Please take a look at our site at [haecanada.org](http://haecanada.org), where you can also find the newly updated 2019 – 2024 HAEC Strategic Plan.



We cannot mention HAEi without thanking the HAEi Team for the amazing job they did on the Virtual 2020 HAE Global Conference. The website was easy to navigate and the content was interesting, informative and fun to learn. The hard work and energy that went into developing the virtual conference was greatly appreciated; despite COVID, we had a fantastic conference experience.

We are also pleased to report that HAE Canada now has more to offer when young Canadian HAE patients join the HAEC Child & Youth Program. There are two age groups, 0 to 13, and 14 to 25 years old. The younger children will be connected with child-focused resources, such as exercise books; however, both age groups will be provided with information on new treatments, clinical trials and given an opportunity to connect with other youth with HAE, to name but a few. We are looking forward to further supporting the young HAE patients in Canada.

Unfortunately, COVID forced us to postpone a planned HAE Canada Patient Information Update in Winnipeg, Manitoba, where Dr. Chrystyna Kalicinsky offered to discuss current and upcoming treatments with members in the area. We are looking forward to re-scheduling once gatherings are permitted again.

Fortunately, on May 9<sup>th</sup> we were able to host a *virtual* Patient Information Update to HAEC members who live in the Edmonton, Alberta, area. We would like to say thank you to Dr. Bruce Ritchie who kindly spent his Saturday morning with us, explaining the latest and upcoming treatments, as well as answering member's questions. We all enjoyed and benefited from the presentation. Thank you,

also, to our amazing Regional Director Pacific, Lorraine Coumont, who connected with most members before the event to ensure they were aware of the event and helped them join online. The Update was a success and we have already started to plan another for our membership.



*Dr. Bruce Ritchie presenting at the 2018 HAE Global Conference in Vienna.*

For the rest of the spring, HAE Canada will focus on initiatives aimed at helping ensure Canadians are given access to new and improved treatments. A few projects are planned, including one where we will be asking our members to participate in a survey that will ultimately provide data for our second National Report Card. We are looking forward to connecting with our engaged HAE community to complete these important projects.