



# HAE Canada Newsletter

June 2022

## Health Canada approves ORLADEYO

We are starting this newsletter with exciting news: Canadian HAE patients are one step closer to gaining access to the first oral HAE treatment. Health Canada has recently approved BioCryst's treatment, ORLADEYO® (berotralstat), for the routine prevention of HAE attacks in patients 12 years and older. HAE Canada will continue to help bring this oral treatment to Canada and we are looking forward to hearing the results from the patient and clinician submissions that we provided to the Canadian Agency for Drugs and Technologies in Health (CADTH).

This spring HAE Canada worked with Takeda Canada on multiple projects that amplified the patient voice to different audiences:

- In February, HAE Canada President, Jacquie Badiou, was part of a panel at a Rare Disease Day event. The event gave Takeda employees a better perspective and appreciation for how rare diseases impact a person's life.
- In March, Board member Kim Speiss, along with a volunteer, participated in a panel discussion for healthcare providers in Saskatchewan. They each shared their patient journeys and advised on unmet needs for HAE patients in Saskatchewan.
- In April, alongside Drs. Marcus Maurer and Stephen Betschel, Jacquie participated in the HAExpert Panel Discussion to

healthcare providers (HCP). The event aimed to educate HCPs on treatment options while providing a patient's perspective.

- A recording was shown at the HAExpert event of HAE Canada member, Anne, sharing her patient story. She described her childhood before she was diagnosed, her journey to receive a proper diagnosis and she ended by discussing how she lives her life to the fullest as a patient receiving proper treatment today. We want to extend our sincere gratitude to Anne for sharing her inspiring story.

HAE Canada was asked by HAEi to recruit members to complete CSL Behring's Patient Reported Outcome (PRO) Online Survey. Recognizing the importance of gathering real world evidence through surveys, HAE Canada was happy to help. We are grateful to our members who completed this survey and provided the Canadian patient's experience with long term prophylactic therapy.

## EAACI Hybrid Congress 2022

*Common origins of allergy and chronic inflammatory diseases - One Health approach*

We are both excited and proud to report that HAE Canada is presenting a poster (virtually) at the European Academy of Allergy & Clinical Immunology (EAACI)'s Hybrid Congress in Prague titled "Type I/II HAE: Treatment and attack frequency improvements between 2017 and

2020 based on data from the Canadian national patient surveys". A huge thank you goes to Dr. Suzanne Kelly from Red Maple Trials who always does a fantastic job analyzing data and creating our abstracts. Thanks also to our Advocacy Committee and the HAE specialists who reviewed both our documents. We will be sure to post the abstract and poster on our website after it is presented at the conference in July. Our third abstract of 2022 was recently submitted for consideration at the next Annual Scientific Meeting for the Canadian Society of Allergy and Clinical Immunology (CSACI).



We recognize the importance of having a Canadian representative on the HAEi Youngsters Advocacy Group and we were thrilled when asked to be interviewed to express our reasons why. Over Zoom, the Canadian representative, Jacob Collins, expertly asked Jacquie and COO, Daphne Dumbrille, why it is important to have a Canadian part of HAEi's Youngsters community and why the youth voice is necessary to advocacy, and specifically to HAE Canada. Jacob did a fantastic job, and we are very proud to be part of this initiative. The interview will be part of their blog series and the recording is posted in our members-only HAE Canada Café portal.

The Canadian Organization for Rare Disorders (CORD) held their first in-person conference since March 2020! Daphne and HAEC Treasurer, Carmen Craciun, attended the conference titled "Building Canada's Smart Rare Disease and Rare



Drug System 2022". The goal of the conference was to bring together key stakeholders to discuss the importance of a holistic and comprehensive Rare Disease & Rare Drug System in Canada. The jam-packed agenda covered topics ranging from the importance of genetic testing to why it is essential that Canada's system considers a patient's full needs and not just their access to treatment. CORD invited a wide variety of panelists to discuss these topics, such as representatives from government and industry. Physicians and patients presented on their experiences of working and living with rare diseases. Daphne participated on a panel discussion titled "Patient Engagement and Patient Empowerment".

The end of COVID restrictions meant Jacquie was able to travel to Ottawa to meet with our sponsors who live in the city. During her visit, she and Daphne had productive meetings with representatives from BioCryst, CSL Behring Canada and Takeda Canada. HAE Canada is fortunate to have support from amazing companies.



Once again, HAEi hit it out of the park with their hae day :-) Global Walk initiative. We loved watching the numbers climb as participants from across the world contributed their steps. Canada respectfully finished fifth for the number of steps, but we ranked first in the number of participants, clocking in at 911 participants! Thank you to all Canadians, including our members, their friends and family, HAE physicians and their staff and the pharmaceutical companies in Canada who took the time to Step Up for the Global HAE Movement. Congratulations to the United States for their first-place finish.

It was a great spring, and we are looking forward to an even better summer!

