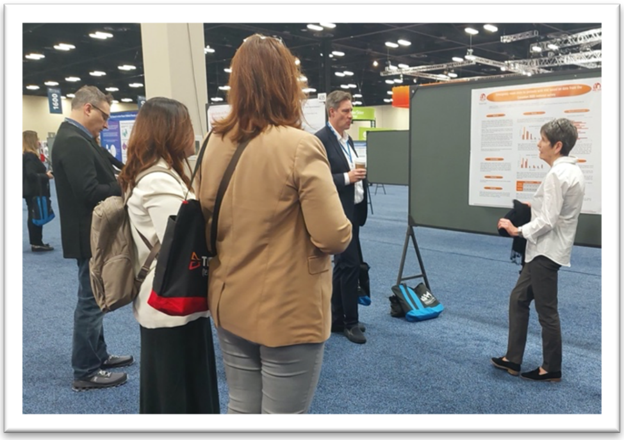
HAE Canada Newsletter

June 2023

American Academy of Allergy Asthma & Immunology
ANNUAL MEETING
SAN ANTONIO, TX · FEBRUARY 24–27, 2023

The first event of the year was the 2023 American Academy of Allergy, Asthma & Immunology (AAAAI) Annual Meeting in San Antonio, Texas. Thank you to Suzanne Kelly of Red Maple Trials who presented our poster on our behalf, titled *"Emergency room visits by patients with HAE based on data from the Canadian 2020 national survey"*. As one of the authors, she did an amazing job. We have learned that the event was a great success, and we were excited knowing there were many posters showcasing the latest HAE research. As always, we want to extend our thanks to the co-authors, as well as our Advocacy Committee, for their collaboration and support on the abstract and poster.



We are thrilled to share that the Canadian Agency for Drugs and Technologies in Heath (CADTH) recently announced that they are recommending the oral treatment ORLADEYO (berotralstat), for reimbursement. This is a significant accomplishment as Canadian patients are now one step closer to accessing this oral treatment. As mentioned in the previous newsletter, HAE Canada provided the patient perspective through CADTH's patient submission process. At first, CADTH decided not to recommend reimbursement, however, this decision was reversed after further advocacy work and an additional submission from HAE Canada. Overturning a CADTH decision and getting a funding recommendation changed is a landmark event. We would not have achieved this in Canada without the extraordinary effort, expertise and time invested by Jacquie Badiou, HAEC Past President & Advocacy Committee Chair, with the assistance of Tony and Herik Balle-Boysen of HAEi. We want to extend a huge thank you to Jacquie, and also to the team at HAEi and the Advocacy Committee who assisted Jacquie with this amazing accomplishment. Thank you also to Daphne Dumbrille, COO, and Kim Speiss, Regional Director Central, who helped ensure HAE Canada was given a seat at the table at the reconsideration meeting with CADTH.

Rare Disease Day 2023

To celebrate Rare Disease Day, HAEC's President, Michelle Cooper, attended a Breakfast Reception in Toronto that was organized and hosted by the Canadian Organization for Rare Disorders (CORD). There were many attendees and a wide variety of speakers including Durhane Wong-Rieger (CEO, CORD), multiple Ontario Members of Provincial Parliament (MPPs), Rute Fernandes (GM Takeda Canada), patient advocate representative and a physician from Toronto's Sick Kids hospital. The speakers discussed how the Ontario government and health sector stakeholders need to collaborate to develop a rare disease strategy that allows patients to equitably access new therapies.

Michelle with Durhane Wong-Rieger (CORD)

Rare Disease Drug Strategy

The Toronto Rare Disease Day event set the stage for the March 22 announcement from the Canadian federal government: *up to $1.5 billion over three years will be provided to implement the Rare Disease Drug Strategy*. Working with patient advocacy groups across Canada, CORD consulted with multiple key stakeholders to develop a strategy that will meet the patient's needs, while remaining fiscally responsible in Canada's public healthcare system. Over her years as President, Jacquie, while collaborating with Tony Castaldo, and Daphne provided insight and input to CORD in a variety of ways, from participating on a panel to filling out a survey, to help ensure this strategy will benefit rare disease patients in Canada. Thanks to this advocacy work from Jacquie, Daphne and others in the CORD family, the strategy not only aims to provide better access to therapies, but it will invest in infrastructure to facilitate faster diagnosis and on-going patient monitoring. HAE Canada is proud to be part of CORD and grateful to finally have a Strategy that will help patients in Canada with a rare disease.

Action Day on Parliament Hill

Michelle was lucky to spend Monday, March 27 attending CORD's Action Day on Parliament Hill where she, along with other patient advocacy group representatives, met with Members of Parliament, Senators, and other government officials. They discussed how rare diseases impact Canadians families and communities, and what can the federal government do to provide much needed support. Following the day on the Hill, Michelle and Daphne attended CORD's spring conference in Ottawa (while Jacquie participated virtually) titled *Delivering on Canada's Rare Disease Investment*. Experts from across Canada, including physicians, patient group representatives, and government and pharmaceutical representatives, presented throughout the two-day conference discussing how to optimize the newly announced Rare Disease Drug Strategy in Canada. By the end of the conference people were feeling hopeful and energized. We are proud to have a long-standing relationship with CORD, participating in Action Days and many conferences and webinars with current and previous board members.

Action Day: second from left, MP Chris Lewis; fourth from left, Michelle

Patient Voice feature

To honour Rare Disease Day 2023, Kim Speiss, shared her patient journey in Patient Voice, an online publication that helps amplify the patient voice to help decrease the stigma many patients with a rare disease face. HAE Canada is proud to have an HAE patient featured in Canada's Rare Voices 2023. Thank you, Kim, for generously sharing your story.

Honouring HAE Day

HAE Canada started celebrating hae day :-) slightly early by hosting a hybrid **Patient Information Update on April 29th in Edmonton, Alberta.** This was our first in person event since the start of COVID and it goes without saying - we were absolutely *thrilled* to bring people together. Pacific Regional Director, Kerstyn Lane, expertly organized this event that brought in members from the area to hear about the latest news from the HAE community. Attendees enjoyed a variety of presentations, specifically from:

- HAEi's Tony Castaldo who discussed HAEi's roll internationally,
- Jacquie who introduced Michelle as the new President,
- Michelle who provided an update on the latest HAE Canada events and accomplishments,
- Kerstyn who kept everyone's full attention while she generously shared her incredible patient story,
- Dr. Bruce Ritchie, who kindly joined us remotely from his holiday in Spain, discussed HAE patient's care in Edmonton and treatment options, and
- Dr. Adil Adatia who presented on how HAE causes swelling, how to effectively treat attacks, the role of genetic testing and current and upcoming treatments.

Michelle and Kerstyn Lane in Edmonton

Dr. Adil Adatia

Daphne moderated the Q&A session at the end while Heather Dow worked behind the scenes on Zoom to allow members from across the country to join the meeting virtually. We are very pleased to have many in attendance on a Saturday afternoon. Thank you to Dr. Ritchie, Dr. Adatia and Tony for taking time out of your weekends to spend it with us. We are very lucky to have such dedicated physicians in Canada who volunteer their time to ensure patients are well informed. At the end of the event, we encouraged everyone, both in Edmonton and across Canada, to engage in an activity and add their "steps" to the Global Activity Challenge.

Michelle, Jacquie, Kerstyn, Kim and Daphne had the pleasure of spending May 16th with HAEi's Tony Casteldo and Henrik Balle-Boysen in Ottawa. All were in Ottawa to attend the [Canadian Agency for Drugs and Technologies in Health (CADTH) Symposium] to learn about important advocacy topics; from the importance of collecting real world evidence (RWE) to how to accelerate access to new health technologies.

It was wonderful to spend HAE Day with Tony and Henrik – we all added our steps to earn the designated May 16th hae day :-) badge.

At CADTH conference in Ottawa: Kerstyn, Kim Speiss and Daphne

Jacquie, Kerstyn, Daphne, Michelle and Kim

HAEC Board of Directors: Kerstyn, Kim, Carmen Craciun, Jacquie, Michelle – and Daphne