



# HAE Canada Newsletter

November 2022



As the season ends, we must start with the most impactful event from fall 2022: the HAEi Global Leadership Workshop in Frankfurt. We'd like to deeply thank the HAEi team for giving

HAE Canada's leadership the opportunity to participate in such a worthwhile experience. HAEi did a phenomenal job of bringing organizations from across the globe to meet, learn, reflect, and share. Thanks to the engaging and meaningful presentations, we are excited to put the tools we learned into practice. Not only did we learn, but we proudly presented our poster titled: *HAE with normal C1 esterase inhibitor (HAE<sub>n</sub>C1INH): Diagnosis, treatment and attack frequency from the 2020 Canadian patient survey* in the Workshop's Scientific Track. We returned to Canada energized, motivated and grateful for having such an engaged and well-informed international umbrella organization.



## Patient Information Update

Soon after returning to Canada, HAE Canada hosted a Patient Information Update in Hamilton, Ontario. We hoped to welcome our members in person, however, rising COVID numbers forced us to hold the Update virtually once again. After COO, Daphne Dumbille, highlighted key initiatives and items from HAE Canada, the Ontario Regional Director, Michelle Cooper, presented about the Global Leadership Workshop.



Michelle was followed by patients Jordyn and Danielle who generously shared the journey they have both taken as HAE patients. We all appreciated hearing what they have experienced as patients with a rare disease, and how they have become who they are today after receiving their diagnosis and treatment.



Dr. Paul Keith, an allergist and immunologist from Hamilton, shared a very informative presentation on the current HAE treatments in Canada while also explaining the importance of patients participating in clinical trials here in Canada. Lastly, Dr. Keith was joined (virtually) by Dr. Sylvain Grenier from Canadian Blood Services and they each answered pre-submitted and live questions from attendees. Thank you to our members who attended the Update on November 5<sup>th</sup>, and a special thank you to our presenters and speakers; their time and expertise are always gratefully appreciated.



## 2022 AGM

Directly after the Patient Update, we hosted our 2022 Annual General Meeting. Thank you to Heather Dow for chairing this important event. Thanks to our engaged membership, we held a successful meeting that voted in our 2022-2023 Board of Directors, who then elected the executive positions as follows:

- **Jacque Badiou:** *Director at Large / Past President*
- **Michelle Cooper:** *Ontario Regional Director: President*
- **Carmen Craciun:** *Director at Large / Treasurer & Secretary*
- **Kirsten Lane:** *Pacific Regional Director / Vice President*
- **Martine Paquette:** *Quebec Regional Director*
- **Dwayne Semple:** *Atlantic Regional Director*
- **Kim Speiss:** *Central Regional Director*

We are thrilled to announce that Michelle Cooper has generously agreed to take on the President position. The President position is a natural next step for Michelle as she has been part of the HAEC Board since 2020 as the Ontario Regional Director, in 2021 she became Vice President and has remained on the Advocacy Committee throughout. With Michelle's work

experience as a nurse, an assistant professor and a certified leadership coach, the Board remains in good hands. We are lucky to have her at the helm, and we are confident she will be amazing in her new position.

She has some HUGE boots to fill! After 12 years as President, Jacquie Badiou decided transition from the President position to the Past President position. To say we are grateful for her guidance and leadership is an understatement. Each year she dedicated countless hours to guide HAEC Canada and with her extensive public health experience as a nurse and administrator, she helped HAEC become the well-organized and respected patient advocacy group it is today. Jacquie will remain a very active member of our Board of Directors, providing mentorship to Michelle and increasing her advocacy work internationally. On behalf of the entire HAEC membership and Board of Directors, we want to profusely thank Jacquie for her unwavering commitment to help HAE patients and their caregivers in Canada.

Tina McGrath, who sat on the Board since 2018, decided not to renew her term as a Board member. We are grateful for her dedicated years as the Ontario Regional Director and as a member of the Governance Committee. Her work experience in marketing, banking, and at the Canadian Cancer Society served her well when she worked on HAEC's Imagine Canada Application and revising the By-Laws and Five-Year Strategic Plan. We appreciated her sharing her story to bring awareness of HAE in the emergency department. We are grateful she will remain as one of our Regional Director Assistants for Ontario.

Thank you to our returning Board members who are not only a joy to work with, but also bring new perspectives and knowledge to the table.

## CORD Conference

Michelle and Daphne attended the Canadian Organization for Rare Disorders' (CORD) Fall conference in Toronto titled *Planning for Proof-of-Concept Programs to Transform Vision to Reality*. Canada is committed to setting up a federal Rare Disease Drug Strategy to provide

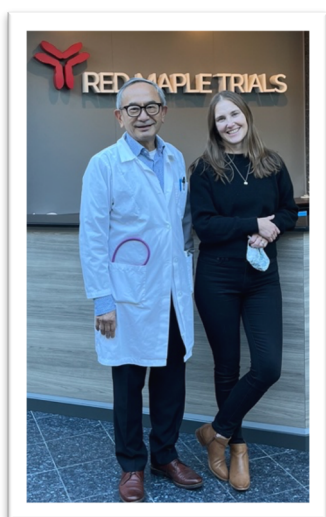
Canadian patients access to treatments. The conference discussed the key elements of what makes up an effective and economical Rare Disease Drug Program. The two days covered a vast number of topics, including genome screening and sequencing, what role patients can play in establishing the Drug Strategy and why it is important to invest in Canadian research. The two days were packed full of useful and interesting information, and it was great connecting with others in the rare disease community.

## First ACARE Centre in Canada

The CORD conference discussed the importance of establishing Centres of Excellence in Canada for rare diseases, which brings us to our next topic: Angioedema Centers of Reference and Excellence



(ACARE). As per the [ACARE website](#), the centres are a joint initiative between HAE International (HAEi) and the Global Allergy and Asthma European Network (GA²LEN), *"with the aim of developing and accrediting an interactive network of centers of reference and excellence in*



*angioedema management"*. We are proud to say that Yang Medicine, headed by Dr. William Yang in Ottawa, was designated as the first ACARE in Canada. For many years, Dr. Yang has been a tremendous support to HAE Canada, while providing wonderful care to his HAE patients. He is dedicated and passionate about

his work, making this designation from HAE International and GA²LEN, very well deserved. We are very proud of Dr. Yang and hope his clinic will be the first of many ACARE centres in Canada.

As mentioned in a previous newsletter, ORLADEYO® (berotralstat), was approved by Health Canada. HAE Canada has been working with the manufacturer, BioCryst, to help support a positive recommendation from the Canadian Agency for Drugs and Technologies in Health (CADTH). This is an important step in Canada because for provinces and territories to fund a treatment, the treatment first needs a positive CADTH recommendation. Thank you to HAEi Board members, Tony Castaldo and Herik Balle Boysen for providing input to the patient feedback to CADTH; their contribution certainly made an impact. We hope CADTH will announce their decision early in the new year.

HAE Canada wants to help not-yet-diagnosed and diagnosed HAE Canadian patients who present at the Emergency Department during an attack. We are reaching out to stakeholders to accomplish key strategies, such as having HAE added to the Advanced Cardiac Life Support (ACLS) supportive text and adding HAE to first aid training materials. Fortunately, we have assistance from Canadian physicians, Drs. Susan Waserman, Paul Keith, Allan DeCaen and David Barnes, American physician Dr. Marc Riedl, HAEi's Tony Castaldo, HAEC Board members Jacquie Badiou and Dwayne Semple, and Kim Speiss contributed in Dwayne's absence. With their help we are confident HAE will become better recognized by emergency health providers.

We will end this newsletter with the great news that our recent abstract titled *"Emergency room visits by patients with HAE based on data from the Canadian 2020 national survey"* has been accepted to American Academy of Allergy, Asthma & Immunology (AAAAI)'s 2023 Annual Meeting. Thank you to Dr. Suzanne Kelly from Red Maple Trials, and to the contributing authors, for developing this abstract. We are excited to share our data at this prominent event.