

November 2023



NEWSLETTER

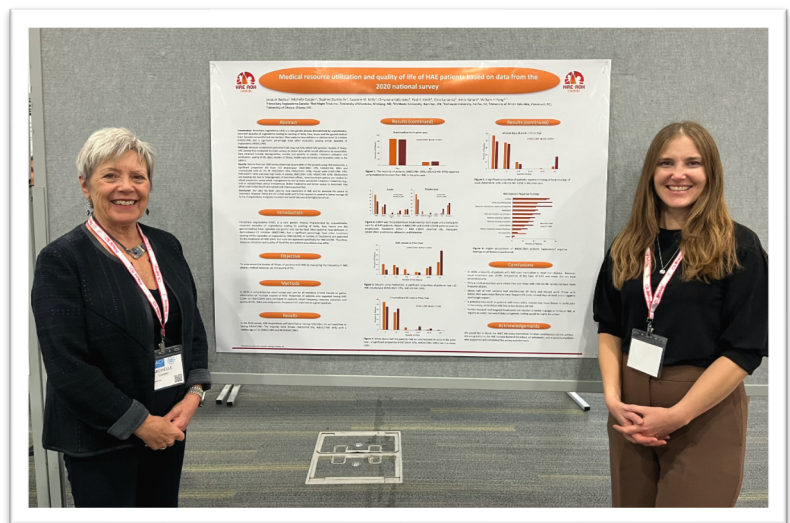
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In October, HAE Canada President, Michelle Cooper, along with COO, Daphne Dumbrille, were given the opportunity to attend BioCryst's first annual Patient Community Open House at their Discovery Center of Excellence Labs in Birmingham, Alabama. The open house brought Michelle and Daphne to their Lab where they were treated to a guided tour, complete with a virtual reality experience to explain the molecules developed right there in the lab. Meeting BioCryst's staff, including the leadership team and scientists, allowed them to learn first-hand how BioCryst's patient centred research truly drives the company.

CSACI | CAAIF | CASP

In October, Michelle and the Atlantic Regional Director (Interim), joined Daphne in Ottawa, to attend the **Canadian Society of Allergy and Clinical Immunology (CSACI)'s** Annual Scientific Meeting. Past President, Jacquie Badiou, attended by taking advantage of the virtual option. HAE Canada presented a poster titled "*Medical resource utilization and quality of life of HAE patients based on data from the 2020 national survey*". During the conference, Michelle and Daphne were able to meet with fellow



Michelle and Daphne presenting the HAE Canada poster at CSACI's Annual Scientific Meeting in Ottawa

attendees, including representatives of some of HAE Canada's sponsors, as well as members of the Canadian HAE Network (CHAEN).

While in Ottawa for CSACI, HAE Canada board members and partners were pleased to attend the **Canadian Allergy, Asthma and Immunology Foundation (CAAIF)** fundraising gala at a table sponsored by the **Canadian Angioedema Scholarship Program (CASP)** foundation. CASP was founded by HAEC's Past President, Jacquie Badiou, along with Past Treasurer, Richard Badiou, and aims to fund research to find a cure for HAE and related angioedema. By attending CAAIF, we helped celebrate the first CAAIF-CASP HAE Research Grant. This grant was awarded to Dr. Stephen Betschel to help fund the Canadian Physicians HAE Practice Pattern survey, designed to better understand how physicians manage their HAE patients and learn of any potential care gaps.

PATIENT UPDATE IN WINNIPEG



Michelle, Stacy, and Kim at the Winnipeg Patient Information Update

On November 4th, HAE Canada hosted our second hybrid Patient Information Update. Patients, caregivers, family members, two HAEC Board members, Michelle and Kim Speiss (Central Regional Director) and Daphne gathered in Winnipeg to learn and meet fellow members of the HAE community. Kim began by presenting on HAE Canada's latest news and upcoming

projects, and she then handed the microphone over to Stacy who did an amazing job sharing her incredible patient journey. Attendees were treated to informative and helpful presentations from two local physicians. Dr. Nestor Cisneros discussed HAE and the burden of illness, while also explaining the different available treatment options. Dr. Chrystyna Kalicinsky updated attendees on the latest clinical trials in Canada and the crucial research on HAE that is happening right here in Canada. Thank you to our members who

joined us either in person (over 30 members!) or virtually; as well as our sponsor reps who were also able to attend.

Thank you especially to our presenters who took the time out of their very busy schedules to spend the afternoon with us. We are extremely grateful that they shared their expertise and knowledge at our Patient Update. Finally, thank you to Heather Dow for providing IT support and allowing members across Canada to join us virtually

Dr. Chrystyna Kalicinsky & Dr. Nestor Cisneros presenting at the Winnipeg Patient Update



NEW ACARE CLINIC IN EDMONTON

Many HAE patients across the globe are fortunate to have access to **Angioedema Centers of Reference and Excellence (ACARE)**; a network of clinics dedicated to educating medical professionals on angioedema. We are excited to report that the University of Alberta Hospital / Kaye Edmonton Clinic run by Dr. Bruce Ritchie and Dr. Adil Adatia recently received full accreditation status. Reviewers particularly noted the following strengths:

- a multidisciplinary team (physicians, nurses, social workers, and dentists),
- real-time blood product tracking,
- research productivity, and
- the electronic health system ConnectCare with myAHS direct patient connectivity.

It is clear Drs. Ritchie and Adatia are part of a committed and dedicated team who provide excellent care to their HAE patients. Congratulations to these amazing physicians.

2023 AGM

For HAE Canada, fall means it's time for our Annual General Meeting (AGM). On November 14th, thanks to our wonderfully engaged membership, we held a successful virtual meeting that voted in our 2023-2024 Board of Directors. After the AGM, the Board then elected the executive positions as follows:

- Michelle Cooper: Ontario Regional Director / President
- Carmen Craciun: Director at Large/Treasurer & Secretary
- Kerstyn Lane: Pacific Regional Director / Vice President
- Jacquie Badiou: Director at Large / Past President
- Martine Paquette: Quebec Regional Director
- Kim Speiss: Central Regional Director

We are extremely pleased that these Board members are returning to lend HAE Canada their time, expertise, and enthusiasm to help ensure the success of our upcoming projects and events. Thank you to the Board for your dedication to HAE Canada, your contributions are invaluable.

I AM NUMBER 12

HAE Canada is honoured to be part of the I Am Number 12 campaign, organized and funded by Takeda Canada. This campaign brings together and elevates the voices of 12 individuals, or Changemakers, with different rare diseases from across Canada. The campaign includes patient journeys and beautiful portraits of each Changemaker in their hometowns. The campaign aims to increase awareness and highlight the importance of incorporating the Rare Disease Drug Strategy in Canada.



Photo of Kerstyn Lane's campaign portrait, displayed at the Toronto launch



We are extremely proud of Kerstyn Lane, HAEC's Pacific Regional Director and VP, who volunteered to be one of the campaign's Changemakers. Her powerful story is a wonderful contribution to this worthwhile campaign.

Michelle was fortunate to attend the official launch of the campaign in Toronto on November 20th, 2023. Politicians from all political parties expressed support for a rare disease strategy and there is currently a private members bill being tabled for the Province of Ontario to support its implementation.

Michelle had the opportunity to meet the Parliamentary Assistant to the Minister of Health, Dawn Gallagher Murphy MPP and will be following up with her about reimbursement and access to medication for HAE patients in Ontario.

CORD

Michelle and Kim attended the **Canadian Organization for Rare Disorders (CORD)**'s Fall Conference in person in Calgary, Alberta, on November 29-30, 2023. The theme of this conference was implementing a community created Rare Disease Network and Drug Strategy across Canada. HAE Canada has been an active participant in CORD's advocacy efforts to implement a Rare Disease strategy.

REFLECTIONS & HOPES

To end this final newsletter of the year, we thought we would reflect on 2023.

Our top three highlights are:

1. Two successful hybrid Patient Information Updates - it was amazing meeting our members in person after a few years of only offering virtual Updates.
2. In May in Ottawa, the HAE Canada Board of Directors had the first board retreat since COVID. While in Ottawa, they were fortunate to have HAEi's Tony Castaldo and Henrik

Balle Boysen join them while attending the Canadian Agency for Drugs and Technologies in Health (CADTH) Symposium.

3. A boom in our membership - partly due to patients and family members interested in attending our Patient Updates and applying to the HAE Regional Conference in Panama City.

We hope 2024 will bring:

- equal access across Canada to treatment for HAE patients with normal C1-INH and acquired angioedema.
- standardized age testing for children who are at risk of having HAE.
- Access to reimbursement for Orladeyo across Canada
- Inclusion of treatment recommendations for acquired and normal C1 INH patients in the Canadian Hereditary Angioedema Guidelines.
- Greater awareness in ER departments to recognize and appropriately treat HAE attacks. Specifically, that they listen to the patients and follow their treatment plans.
- Beginning implementation of a rare disease network and drug strategy coast to coast.
- More rapid approvals of new therapies for HAE.
- Access to more drug therapies for Pediatric patients.

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