

March 2024



# NEWSLETTER

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The HAE Canada Board of Directors began 2024 thinking about the next five years. In January we had the first of five meetings to plan our next Five-Year Strategic Plan. We are keen to plan new projects, set goals and update our mission and vision. We will continue to work on this over the next few months, and we are excited to begin this important task.

## RARE DISEASE DAY

Rare Disease Day is celebrated each February, and to honour this international event, HAE Canada Board members, Kerstyn Lane and Carmen Craciun, along with staff member, Daphne Dumbrille, attended the [Canadian Organization for Rare Disorders \(CORD\)](#) Rare Disease Day Summit in Ottawa (February 28-29). HAE Canada joined others in the rare disease space to learn about many issues, such as how Canada can speed up access to drugs and why the government needs to move faster and launch the promised National Strategy for Drugs for Rare Diseases.



On Thursday, February 29th, CORD invited HAEC, along with other patient organizations and some Members of Parliament (MPs), to attend the "Breakfast on the Hill." CORD took this opportunity to share patient stories and stress the importance of implementing the National Strategy for Drugs for Rare Diseases. Following the reception, we marched to Parliament Hill to further raise awareness for Rare Disease Day and in support of the [Fight for Our Lives campaign](#).



## LIGHT UP FOR RARE

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Throughout the year, the [Rare Disease Day](#) organization is "raising awareness and generating change for the 300 million people worldwide living with a rare disease, their families and carers." One of their initiatives is the [Light Up For Rare](#) campaign which encourages people to arrange for local monuments to be lit up in the Rare Disease Day colours at 7:00pm (local time) on February 28th or 29th (on a leap year). HAE Canada's Kim Speiss (Central Regional Director) wanted her city to Light Up so she reached out to the City of Winnipeg in Manitoba and to have lights shine on the Esplanade Riel Footbridge - and they said yes. This Global Chain of Lights campaign not only illuminates the world, but also spreads awareness for everyone living with a rare disease.

*Kim and Jacquie Badiou at  
the Esplanade Riel  
Footbridge in Winnipeg*



## ADVOCACY

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Access to new treatments can take a very long time, and the wait in Canada is especially long. According to [Innovative Medicines Canada](#), Canadian patients can wait up to two years for access to approved new medicines through public drug plans. HAE patients in Canada are experiencing the frustration firsthand as they wait for access to berotralstat (Orladeyo). Berotralstat was approved for reimbursement back in March 2023, and price negotiations between the pan-Canadian Pharmaceutical Alliance ([pCPA](#)) and the manufacturer should have been complete 40 business days later, but patients are still waiting. HAE Canada sent letters to the pCPA, and the manufacturer, urging them to accelerate negotiations so patients can gain access to this oral treatment. We now understand negotiations were finally initiated by the pCPA in January 2024, so we are hopeful the process will move at an accelerated pace.

## HAEI REGIONAL CONFERENCE: AMERICAS

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We had the amazing opportunity to attend the HAEi Regional Conference Americas from March 15 to 17. Patients, caregivers, leadership teams, physicians and industry representatives met just outside Panama City to learn and connect with one another. Thanks to HAE International's travel grants, over 30 HAE Canada members joined HAEC Board and staff members in Panama. Knowing there



was going to be over 600 people at the conference, we hosted an informal Meet & Greet on Friday afternoon to allow our members to get to know one another before the busy schedule began. It was amazing to spend valuable time with our fantastic members - in person!



The conference officially began on Friday evening with a keynote presentation and an official welcome from HAEi. Day Two's schedule was jam packed with presentations from HAEi, physicians, member organizations and patients. There is no need to provide full details about the conference's content here since it is expertly summarized in [HAEi's Global Perspective Magazine](#), but we do need to say how we are all incredibly grateful that we were given the opportunity to experience this worthwhile event.





*Michelle presenting the HAEC poster at the Global Conference*



Canada was lucky to have two people present at the conference. Anne from Ontario thoughtfully and kindly told her patient journey. She spoke from the heart and her presentation touched all in the room. We are grateful for Anne's dedication to advocacy and openness to share her perspective. We are also proud of Michelle Cooper, HAEC President, who represented HAE Canada extremely well on two panels during the Patient and

Caregiver Track, one titled "The Americas Member Organizations' Panel Discussion" and the other titled "The Path to Success in the Americas." Michelle was kept busy as she also attended the Scientific Track to present our poster titled "HAE attacks in Canadian patients with HAE: Triggers and treatment based on data from the 2020 national survey". Thank you, Michelle and Anne, for making us proud!

*Anne sharing her patient story at the conference*



We want to extend a huge thank you to HAEi for expertly bringing everyone together for this incredible experience. The conference illustrates just how lucky HAE patients across the globe are to have a well-informed, engaged and organized international organization.

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