



HAE Canada Newsletter

June 2019: by the HAE Canada Team

Summer is fast approaching and HAE Canada has had a busy spring. Things kicked off with the HAE Canada Director at Large, Anne Rowe and Ontario Regional Director, Tina McGrath, attending the Network of Rare Blood Disorder Organizations (NRBDO) Spring Forum in Toronto in April. It was an informative and busy weekend discussing many issues, particularly around the importance of a patient registry.

In April, on behalf of HAE Canada, an enthusiastic member of our Advocacy Committee attended the Canadian Agency for Drugs and Technology and Health (CADTH)'s conference: Supporting Health System Transformation in Edmonton, Alberta. It was a valuable three days spent learning about best practices and new ideas from everyone from the pharmaceutical industry to government representatives.

In May, a member of HAE Canada's Advocacy Committee, along with Tina McGrath, attended the Canadian Organization for Rare Disorders (CORD) Conference titled "A Rare International Dialogue" in Toronto. The 3-day conference was jam packed with dialogue and deliberation on all things rare: from research and policy to action and better outcomes. We appreciated the opportunity to attend this important conference.

HAE Day was celebrated by many Canadian footprints making their mark. In Ottawa, CSL Behring hosted a lunch and learn about HAE for employees, followed by the staff taking a walk among the historic buildings of downtown Ottawa – adding an impressive 250,000 steps to HAEi's Global Walk. The learning continued the

following week when HAE Canada office staff, Daphne, attended an additional HAE lunch and



learn with CSL staff. They all enjoyed an informative HAE presentation from a prominent HAE specialist, touching on subjects from the history of HAE to treatment options. There is always more to learn about HAE and we appreciate it when people are willing to listen.

In another part of Ontario, to celebrate HAE Day, Tina travelled to Toronto and spent the morning with Takeda staff at Takeda's offices, where she enjoyed lunch, including a wonderful macaron



tree! She shared her patient journey and

participated in a question and answer panel discussion to help educate the staff on HAE. After the discussion, a group of 40 walked the streets of downtown Toronto on behalf of HAE – adding to the many other Canadian steps for HAEi's Global Walk.

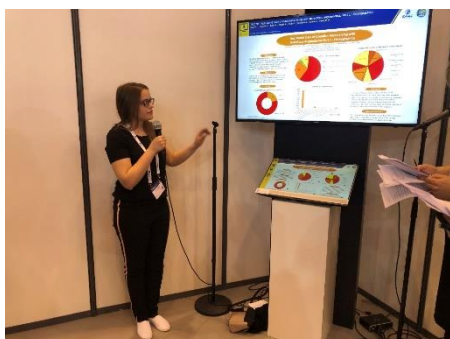
HAE Canada is truly grateful for the time and effort both CSL and Takeda put in marking HAE Day in a productive and worthy way.

On the other side of our large country, HAE Canada's Pacific Regional Director, Lorraine Coumont, attended the Rare Disease Foundation's Rare Finds Gala in Vancouver.



Money raised at this wonderful event goes toward important and valuable research grants. HAE Canada is proud to attend this event that raised approximately \$80,000.

HAE Canada was lucky to have our Real World Data posters and abstracts, that were developed from data collected during HAE Canada's National Report Card, presented by Jodi Valois, Clinical Practice Team Lead at Ottawa's Yang



Medicine at the 2019 European Academy of Allergy and Clinical Immunology (EAACI) Congress in Lisbon, Portugal. This important global event allows specialists in the field of Allergy and Immunology share discoveries, knowledge and latest trends with colleagues and peers from around the world. HAE Canada wants to thank Jodi for expertly presenting Canadian data at this international conference.

Not only have we actively attended relevant conferences and meetings, HAE Canada is also busy preparing a patient submission for the Common Drug Review (CDR) process at the Canadian Agency for Drugs and Technology and Health (CADTH) in support of the new treatment, Takhzyro. We would like to thank our Advocacy Committee from coast to coast for the many hours spent working on this submission. We also like to thank the presidents from the international HAE organizations for their quick responses and contributions to help HAE Canada with this submission. We are blessed to have such a dedicated international HAE team that is willing and able to share their advice and knowledge.

We are truly grateful to all Canadian HAE patients who participated in our survey which will provide information and data to support this patient submission. We are hoping the valuable perspectives that were gathered will ultimately help ensure this new treatment becomes available to all Canadians.