



HAE Canada Newsletter

May 2018: by Paige Gunderson, HAE Canada Youth Member

Greetings from HAE Canada! We are proud to say that our Board members have been very active advocating for HAE by attending many functions these last few months. In March, Jacquie, along with two members and staff attended the Canadian Organization for Rare Disorders (CORD)'s Rare Disease Day Conference and participated in Action Day on Parliament Hill to mark Rare Disease Day in Ottawa. A few



weeks after the conference, Jacquie, along with fellow Board members, Richard, Ken and Linda, travelled to Toronto to attend the Network of Rare Blood Disorder Organization (NRBDO)'s Spring Forum. Also in April, HAE Canada

organized and hosted a successful and informative Patient Event in Hamilton which was well attended. In Halifax, Board member Kari, along with a fellow HAE Canada member, attended the Canadian Agency for Drugs and Technologies in Health (CADTH) Symposium: Supporting Appropriate, Affordable and Accessible Care. Across the country, HAE Canada member, Lorraine attended the Rare Disease Foundation "Feast for the Senses", in Vancouver in April. Lorraine also travelled to Edmonton in May to attend a Patient Update Event that was hosted in conjunction with the Canadian Immunodeficiencies Patient Organization (CIPO). Also in May, Jacquie and Richard were fortunate to visit the newly renovated Manitoba Clinic and attend the Blue Skies Gala.

As I write, there are over 30 Canadians making their way to the HAE 2018 Global Conference in Vienna, Austria. We are pleased and proud so many Canadians had the opportunity to attend this event. Many people around the world energetically logged their steps for HAE Day with the HAE Global Walk and Canada is in the lead with most steps recorded.

We are recruiting for clinical trials for youth and adult HAE patients with Type 1 and Type 2, which is exciting news for future treatments in Canada. We are also in the process of preparing to offer a youth membership, which we have not had thus far.