



HAE Canada Newsletter

December 2017 by Jessica Howlett, Social Communication Coordinator

At HAE Canada we have evolved so much over the past few months. All of our board members have been extremely busy forging relationships with Health Organizations and Medical Groups throughout Canada. In September, HAE Canada President Jacquie Badiou, Directors Richard Badiou and Bob Simon, and HAE Canada member Judy Simon represented Canada at the 2017 US National Patient Summit in Minnesota, USA. Vice-President Ken Howlett and Regional Director Anne Rowe were no less busy, attending the Association des Patients Immunodéficients du Québec (APIQ) - Journée Éducative AOH in Montreal, Quebec. In October, Bob attended the Saskatchewan Society of Medical Laboratory Technologists (SSMLT) Conference in Regina, SK., along with Physician Dr. Andrea Fong, where they presented an overview of HAE, the importance of efficient access to HAE treatments, and a patient perspective of HAE. Later that month, Anne, Ken and Linda Howlett (Regional Director) attended the Canadian Society of Allergy and Clinical Immunology (CSACI) Annual Scientific Meeting in Toronto.

In November, we held our HAE Canada 2017 AGM and Patient Event in Toronto. This was a wonderful opportunity for our HAE Canada family to come together, interact and learn more about our rare disease. Also in November, Jacquie, Richard, Ken and Linda attended the Canadian Organization for Rare Diseases (CORD) conference. The following weekend they were guests for an elegant evening at Canadian Immunodeficiencies Patient Organization's 20th Anniversary Gala and Excellence Awards. Lastly they participated in the Network of Rare Blood Disorder Organizations (NRBDO) Comprehensive Care Symposium.

Canada's network of physician HAE specialists (CHAEN) continues to foster the development of HAE learning and international collaboration. In 2017 CHAEN implemented an elective program for residents registered in a Canadian Clinical Immunology and Allergy

Program for a three week observer elective at the US HAEA Angioedema Center at the University of California, San Diego. Dr. Lisa Fu of the University of Toronto was selected from the applicants and attended earlier this year.

Our HAE Canada Survey concluded in September. This survey is going to be an excellent tool in allowing us to better serve the needs of our HAE Canada family members by ensuring we are abreast of the needs of our membership, enabling us at HAE Canada to provide ongoing support and advocacy now and in the future. We are grateful for the positive response and participation we received from our HAE Canada members.

At the end of the summer I was appointed Social Communication Coordinator and I have been working hard to increase our online presence through social media platforms like Facebook, Instagram, and Twitter. For the first time in HAE Canada history, our Annual AGM and Patient Education Day was broadcast live throughout the day via Facebook and will also be available later on the HAE Canada website. At the event, we also unveiled our Navigating the ER Tool Kit, a project spearheaded by HAE Canada board member Linda Howlett in collaboration with the Woodstock General Hospital. We have also made some changes to our HAE Canada website, in an effort to provide better and more current information for a more user-friendly experience.

HAE Canada founding member and long-time Regional Director Atlantic, Anne Rowe has decided to step down from her Director's position with HAE Canada.

During her time with HAE Canada, Anne has been instrumental in connecting all our HAE Family across Canada, as well as fostering HAE education and awareness in Canada. Without her influence we would not be the organization we are today.

In her absence, we are pleased to welcome our new HAE Canada Regional Director Atlantic, Kari Feere and look forward to all the skills Kari brings to our team. At HAE Canada we know that our organization will only continue to improve and grow, and we look forward to everything the future holds for us and our HAE Canada family.