



HAE Canada Newsletter

September 2021

Over the summer we received the news that our abstract titled “Hereditary angioedema in Canada: Changes in medication use and untreated attacks between the 2017 and 2020 surveys” was accepted to the Canadian Society of Allergy and Clinical Immunology (CSACI)’s Annual 2021 Scientific Virtual Meeting. The abstract drew from data collected from HAE Canada’s National Report Card surveys and we are thrilled we will share this information at the annual meeting in October 2021. A huge thank you goes to Dr. Suzanne Kelly at Red Maple Trials who always produces top quality abstracts on behalf of HAE Canada. We are grateful HAE specialists across Canada who contributed their expertise to the abstract. Thanks also to our Advocacy Committee who reviewed the abstract. We have a great team in Canada to help us submit quality abstracts and we appreciate the assistance we receive.

We ❤️ Volunteers

The HAE Canada understands the importance of staying connected with volunteers who selflessly offer their support when needed. While in British Columbia, the HAE Canada President, Jacquie Badiou, was fortunate to connect with volunteers Karen Wakita, an Emergency Department nurse, Jacob Collins, the Canadian representative

on **HAEi’s Youth Advisory Group** and the Pacific Regional Director, Lorraine Coumont. Together they discussed future HAE Canada goals and projects over a lovely lunch.



Seated left to right: Lorraine Coumont, Karen Wakita, Jacob Collins & Jacquie Badiou

Jacob enjoys being involved with HAEi’s Youth Advisory Group and we are very proud to report that Jacob helped facilitate the upcoming HAEi Youngsters Online Meet Up: *Back to School on September 11th*. During the Meet Up, the group discussed how to have a successful and safe return to school after experiencing extreme disruptions due to COVID. It was an interesting and helpful discussion for young HAE patients across the globe. We encourage all young Canadian HAE patients to join HAEi Youngsters; they are an enthusiastic group of well-informed

young people who always welcome new members to their group.

Our Board will be busy this fall connecting with our membership to share HAE Canada projects. Our Regional Directors and volunteers will encourage further participation in our 2020 National Report Card Survey, and let people know about the HAE Canada Café, an online members-only forum, that will be launched this fall. Also, we will be asking members with HAE normal C1 their interest in genome sequencing, which we hope will ultimately lead to better diagnosis and access to effective, accessible treatments.

ORLADEYO Approval

At the end of August, we learned that ORLADEYO (berotralstat) was accepted for review by Health Canada. ORLADEYO is an oral treatment used daily to prevent HAE attacks in patients 12 years old and older.

HAE Canada is thrilled to receive this news as it is the first step towards Canadian patients gaining access to this new treatment.

CASP Foundation

After over a year in the making, the Canadian Angioedema Scholarship Program (CASP) Foundation has launched thanks to the hard work and dedication of the CASP Board of Directors. The CASP Foundation was established to fund research to help find a cure for HAE and related angioedema in Canada and will begin initiating partnerships for potential research projects.