



HAE Canada Newsletter

**By Jacquie Badiou (President and Regional Director, Quebec) & Daphne Dumbrille (COO)
February 2021**

We made it through 2020 and excited to welcome 2021! Despite dealing with COVID and all that it throws at us, thankfully we have some great achievements to share.



In our last newsletter we mentioned that we launched our 2020 National Report Card survey to our membership; we are thrilled to report we had a

fantastic participation rate.

Thank You

We want to thank our tireless Board members and volunteers, Lorraine Coumont, Michelle Cooper, Suzanna LeVatte MacDonald, Tina McGrath, Anne Rowe, Tamara Phillips and Kim Speiss, who got on their phones and computers to contact our members to ask they fill out this important survey. Their huge efforts were greatly appreciated. We also need to thank our engaged and dedicated members who took the time to carefully fill out this survey to provide the important data that will ultimately be used to understand patient product use, symptoms and needs so we may continue to advocate for improved access to treatments for Canadians living with HAE.

In November 2020, we were proud to learn that our abstract titled: *Real World Data of Canadian Adults living with Angioedema – Health Economic Burden* was accepted as a poster presentation to the 2021 AAAAI Virtual Annual Meeting in February. We are very fortunate to have a talented team to help develop our abstracts. Once again, Dr. Suzanne Kelly of Red Maple Trials was key in developing this abstract and poster, and our Advocacy Committee and Board members provided helpful assistance.

Our AGM

Also, in November, we held our Annual General Meeting when we successfully passed our updated Bylaws and welcomed three new Board members: Carmen Craciun (Director at Large), Michelle Cooper (Regional Director: Ontario) and Suzanna LeVatte-MacDonald (Regional Director: Atlantic). We are excited to work with our new Board members who will bring enthusiasm and their own expertise to the Board. We also said goodbye and thank you to three outgoing Board members: Richard Badiou, Anne Rowe and Kari Feere whose contributions over these past years have been greatly appreciated. Richard spent many years as Treasurer, ensuring HAE Canada's finances are properly kept in order in accordance with all rules and regulations. We are grateful Richard will remain on our Finance Committee. Anne Rowe is also leaving our Board; however, thankfully she will remain on our Governance Committee. Anne has been with HAE Canada from the start and has spent many years ensuring we adhere to all proper governance rules, while sharing her nursing

knowledge with the rest of the Board. Her years devoted to HAE Canada are truly appreciated. Kari has provided support to the Atlantic members for the past few years and her kindness was appreciated. We are thankful that three Board members have agreed to remain with HAE Canada for another year: Jacquie Badiou (President), Tina McGrath (VP) and Lorraine Coumont (Pacific Regional Director).

For the past few years, staff at Takeda Canada have been diligently working towards providing HAE patients in Canada with lanadelumab (TAKHZYRO®). We are thrilled to report that this hard work and dedication is paying off because eligible HAE patients in both Alberta and New Brunswick now have access to lanadelumab through their provincial drug plans. We are confident other provinces will soon follow. It has been a long journey to arrive where we are today, and we are proud we helped advocate to arrive at this point in the road.

In February, Jacquie Badiou, HAEC's President, participated in Health Canada's virtual meeting titled: "National Strategy on High-Cost Drugs for Rare Diseases" to help provide input into how best to create a national strategy on high-cost drugs for rare diseases. HAE Canada is encouraged and excited that long awaited attention is going towards learning how to provide patients with rare diseases access to important treatments in Canada.

We continue to hope people are staying safe and coping to make it through what we hope to be the final stretch of this COVID pandemic.