



HAE Canada Newsletter

February 2022

Welcome to our new Board members

Our first big piece of news to share is the HAE Canada team has blossomed to eight Board of Director members. At the 2021 Annual General Meeting on December 7th, we thanked our outgoing Board members, and welcomed new Regional Directors to the Board who will bring their own expertise to the Board:

Kerstyn Lane (Pacific)
Martine Paquette (Quebec)
Dwayne Semple (Atlantic)
Kim Speiss (Central)

For the past year, Kerstyn has been a member of our Governance Committee and we are thrilled she has agreed to continue in this roll and will work towards accreditation with Imagine Canada. Martine is a returning Board member from Quebec, and we are grateful she will bring her knowledge and experience (& energy!) back to the table. Dwayne, an experienced paramedic, will assist with our ongoing project to have HAE added to the ACLS/PALS course. Kim, a member of our Advocacy Committee for the past four years, will focus on our HAE Canada Café.

We are grateful our experienced Board members remain on the team:

Jacque Badiou (President)
Michelle Cooper (VP & RD: Ontario)
Carmen Craciun (Treasurer & Secretary)
Tina McGrath (Director at Large)

We are lucky to have new, fantastic people join us at HAE Canada. Daphne Dumbrille, our COO, is excited and looking forward to working on upcoming projects with the new team.



AAAAI American Academy of Allergy Asthma & Immunology
ANNUAL MEETING
PHOENIX, AZ - FEBRUARY 25-28, 2022

HAE Canada President, Jacque Badiou, is heading to Phoenix, Arizona, to present our poster titled "*HAE with normal C1-INH: Treatment and attack frequency based on data from the Canadian 2020 national survey*", at the 2022 American Academy of Asthma & Immunology (AAAAI)'s Annual Meeting in February. This will be her first in-person event representing HAE Canada since the start of COVID and her packed agenda shows how excited everyone is to finally meet in person once again.



Over the past few months, HAE Canada has been collaborating on a few projects with Canadian Blood Services (CBS), the national organization that provides blood-derived HAE treatments to Canadian patients. One project is regarding CBS's procurement process for their plasma-derived products to be listed on the CBS formulary. We are proud to report that a HAE Canada Board member is part of the Request for Proposals (RFP) committee. This Board member will represent the concerns of HAE patients while providing support and advice to CBS throughout the process. We trust

CBS is in good hands and look forward to learning the outcome of this very thorough and extensive process.

Also, CBS invited Jacquie to be one of the founding members of the CBS Patient Engagement Forum, a new initiative to improve how CBS connects, listens to, and collaborates with patient organizations. This is an amazing accomplishment. We are both privileged and proud to be part of these important projects with CBS and would like to thank Daphne and past Board members who were instrumental in making this happen.

Helping HAE patients gain access to new treatments is always a top priority for HAE Canada. To illustrate how effective new treatments are, patients and clinicians need to have the ability to share their experiences. That is why we have hired a health policy consultant to complete the patient and clinician submissions for the Common Drug Review (CDR) for the Canadian Agency for Drugs and

Technology and Health (CADTH) in support of the new oral treatment, ORLADEYO (berotralstat). Our aim in completing these submissions is to bring Canadian patients one step closer to accessing ORLADEYO. We want to thank our Advocacy Committee, HAE Canada members and the physicians who contributed to these submissions by sharing their real-life experiences and knowledge.

To ensure our members remain engaged and connected, HAE Canada hosts Patient Information Updates throughout the year. Our next update will be from Saskatchewan; however, it will be virtual and open to our entire membership. Dates and details will be shared with our membership very soon. We look forward to hosting this event “from” beautiful Saskatchewan.