



HAE Canada Newsletter

November 2021

When fall hit, HAE Canada hit the ground running.



Our first task of the fall season was to present our poster titled, "*Hereditary angioedema in Canada:*

Changes in medication use and untreated attacks between the 2017 and 2020 surveys" at the Canadian Society of Allergy and Clinical Immunology (CSACI)'s Annual 2021 Scientific Virtual Meeting. It was a great conference, and we were proud to present at this well-respected annual meeting.

We are thrilled that our abstract titled "*HAE with normal C1-INH: Treatment and attack frequency based on data from the Canadian 2020 national survey*", has been selected for a poster presentation at the 2022 American Academy of Asthma & Immunology (AAAAI)'s Annual Meeting in February 2022. We would like to once again thank Suzanne Kelly of Red Maple Trials who did a fabulous job developing this abstract. We also need thank the HAE specialists across Canada who contributed their expertise to this abstract, as well as the HAE Canada Advocacy Committee.

Regional Director Assistants

Since HAE Canada is always growing, we are grateful to have the support of our volunteers. We officially welcomed new people to the HAE Canada team: Regional Director Assistants (RDAs). When we need to contact our members individually for certain projects, or to gather updated information, helpful RDAs will lend us their support. Each province has at least one RDA and we want to thank everyone for their commitment and assistance.

Our Virtual Patient Information Update

On Saturday, November 20th, HAE Canada hosted a Patient Information Update. We were hoping to host in-person Updates in London and Sudbury, Ontario, however, COVID is still preventing us from gathering. We remain grateful for the option to host virtual events, especially since this allows us to connect with members across Canada. The day stayed on task with Daphne Dumbrille, HAEC's COO, and fellow panelist Michelle Cooper, the Ontario Regional Director who kept her eyes on the questions

and comments. To start, the participants enjoyed two interesting and informative presentations by HAE specialists from the London area:

- **Dr. Harold Kim**, MD, FRCPC, Allergy & Clinical Immunology, and
- **Dr. Samira Jeimy**, MD, PHD, FRCPC, Allergy & Clinical Immunology

Dr. Kim informed us about the available treatments for Ontario HAE patients, and how specifically to access these products, and Dr. Jeimy shared her presentation titled HAE and Pregnancy: ten things I want patients to know. Next, Michelle Cooper kindly opened-up and shared her patient journey and how she became involved with HAE Canada. Jacquie Badiou, President, followed Michelle with a presentation asking three HAEi representatives, about their early patient days and how they became involved with HAEi. These representatives included:

- **Anthony Castaldo** (President & CEO),
- **Fiona Wardman** (Treasurer & Chief Regional Patient Advocate) and
- **Henrik Balle Boysen** (Executive VP & COO)

We also learned about Treatments on the Horizon from Anthony Castaldo and the day ended with a Question & Answer session with our already mentioned guests, plus:

- **Dr. William Yang**, MD, FRCPC, FAAAAI,
- **Dr. Sylvain Grenier**, CD, B Pharm, PharmD, FFIP, FOPQ, Director, Canadian Blood Services.

All in all, it was a wonderful event, and we are extremely grateful to all our invited guests; they were fantastic.

Thank you to all our guests and speakers for taking the time to help inform Canadian HAE patients.

HAE Canada will remain busy with different projects in the next few months, for instance, our Governance Committee is preparing for the Annual General Meeting on December 7th. We are excited to examine the excellent Real-World Evidence from our Canadian membership that has been gathered in our 2020 National Report Card survey.