



HAE Canada Newsletter

September 2023

IMAGINE
CANADA

A few years ago, Past President, Jacquie Badiou, realized that

HAEC would benefit from gaining accreditation from Imagine Canada, a national organization that helps not-for-profits become and remain effective, accountable, and productive. Since then, she, along with past volunteers from the Governance Committee, Board member Kerstyn Lane and staff member, Daphne Dumbrille, have worked closely with Heather Dow from Events and Management Plus to demonstrate to Imagine Canada that HAEC fulfills the necessary requirements for accreditation, such as excellence in Board governance and financial accountability. We are extremely proud to report that our hard work has paid off and we have officially received accreditation. Special thank yous go to Heather, Kerstyn, Jacquie, Daphne, Michelle and our treasurer, Carmen Craciun, for working diligently to achieve this goal. HAE Canada has always remained accountable to our members; and thanks to Imagine Canada's accreditation, it's now official.

Patient Stories

We are excited by our latest addition to our website: [Patient Stories](#). We hope many viewers will relate to these amazing stories highlighting how HAE patients can lead happy, fulfilling lives. Recognizing that patients with HAE often feel alone, we understand that many HAE patients have some negative feelings. We hope these stories will help alleviate these negative feelings and show that HAE patients are not alone; there are others who have similar struggles and are leading a fulfilled life. We are extremely grateful

to Jordyn, Shannon and Kim for opening their doors and hearts to share their experiences, and to let others know that having a rare disease does not define who you are.

Our abstract titled "*Medical resource utilization and quality of life of HAE patients based on data from the 2020 national survey*" was recently accepted by the Canadian Society of Allergy and Clinical Immunology (CSACI)'s Annual Scientific meeting. Michelle, Jacquie and Daphne are looking forward to attending CSACI's meeting in Ottawa in October and showcasing the abstract's data at the poster presentation. Thank you to Suzanne Kelly from Red Maple Trials for her work developing this abstract, along with fellow authors and members of the HAEC Advocacy Committee.

In March 2023, the Canadian federal government announced they plan to provide up to \$1.5 billion over three years to implement the Rare Disease Drug Strategy. To better understand and keep well informed of the progress the government is making on this strategy, HAEC Board members have attended webinars and conferences hosted by the Canadian Organization for Rare Disorders (CORD) that focuses on this much anticipated strategy. We will continue to advocate towards implementing this strategy and participating in CORD's events to ensure our voices are heard.

Our Upcoming Projects

Our Board is looking forward to some big projects coming up, specifically developing our next Five-Year Strategic Plan and designing our next National Report Card survey. We also plan

to attend multiple national and international conferences to remain up to date in the current treatment and rare disease landscape. We are getting excited to attend the HAEi Regional Conference in Panama City in March 2024 and judging by the number of new HAE Canada members, it's clear there is a lot of interest in this upcoming event.

We are grateful for the work our Regional Directors are doing with the HAEC members to keep everyone engaged and well informed. Our next Patient Information Update on November 4th will take place in Winnipeg, Manitoba, and we will be offering a virtual option for members who do not live in the Winnipeg area.