



HAE Canada Newsletter

March 2020 by the HAE Canada Team

It has been a few months since our last HAE Canada Newsletter, but not due to a lack of exciting news to report - it's hard to know where to begin.

We would like to start with an important announcement – we are pleased and proud to report that the new treatment, Takhzyro (lanadelumab), received a positive recommendation from the Canadian Agency for Drugs and Technology and Health (CADTH). This recommendation was supported by the patient submission HAE Canada provided, which illustrated the importance of this treatment to Canadians with HAE. Special thank you to our engaged Advocacy Committee and Robert Bick, Health Policy Consultant. This positive recommendation means Takhzyro is one step closer to becoming available to HAE patients across Canada. HAE Canada continues to work hard advocating for the provinces and territories to add Takhzyro to their drug plans. You can find a copy of the “Patient Group Input Submission” on CADTH’s website: <https://www.cadth.ca/lanadelumab>.

Fall 2019 was busy for the Regional Directors who organized and held Patient Update Events in their areas. Members from across the country attended events in Halifax, Ottawa, Calgary and Vancouver to not only connect with other HAE patients, but to also learn about a variety of HAE related issues. Each Regional Director arranged for professionals to speak on these issues, such

as, accessing new upcoming HAE treatments in Canada. The Patient Events are always a positive and energizing experience for everyone – the HAE Canada Board enjoys meeting new members and reconnecting with those we have



met along the way. Thank you to all these

Regional Directors and especially Lorraine Coumont, Pacific Regional Director, for organizing two of these events and the upcoming event in Winnipeg.

Tina McGrath, HAE Canada’s Ontario Regional Director and VP, along with, Daphne Dumbrille, from the HAE Canada office, attended the 2019 Canadian Society of Allergy and Clinical Immunology (CSACI) Annual Scientific Meeting in Montreal, in October. A poster was presented by Dr. William Yang on behalf of HAE Canada titled: Real World Data of Canadians Living with HAE: Attributes of New Medications. The poster was well received and generated many discussions surrounding the importance of providing

Canadians with a variety of effective, current and convenient treatments.



HAE Canada understands the importance of partnering with different rare diseases in Canada. To help remain up-to-date, HAE Canada Treasurer, Richard Badiou, President and Quebec Regional Director, Jacquie Badiou, a volunteer, Tina and contracted workers Heather Dow and Daphne were happy to attend the Canadian Organization for Rare Disorders (CORD) Access to Innovation Opportunities for Cell & Gene Therapies Conference 2019, in Toronto in November. Presenters discussed many topics, from cellular and gene therapies to personalized healthcare in Canada. It was an incredibly informative and interesting conference and we appreciated the opportunity to attend.



In December, Daphne presented on behalf of the HAE Canada Board of Directors at the Canadian Blood Services (CBS) Open Board Meeting. She respectfully requested that CBS work toward fast-

tracking products that have been approved by Health Canada, specifically HAEGARDA and Takhzyro, and asked CBS to consider adding them both to the CBS formulary, which would further improve the care of HAE patients. Soon after this presentation, Jacquie and Richard, with a fellow Board member, volunteers, clinicians, health policy experts, government officials and CADTH representatives travelled to Toronto to attend CBS's HAE Forum. The Forum aimed to engage all stakeholders in an open and honest discussion to analyze various key issues surrounding HAE treatment options, namely C1 esterase inhibitor (C1-INH) products. Over the two days, many topics were discussed, such as patient's perspectives and access, as well as trends in



utilization. All discussions aimed to provide an understanding of the increase in demand for C1-INH products. HAE Canada would like to thank CBS for hosting this important and valuable Forum that will hopefully see HAEGARDA, a C1-INH product, added to the CBS formulary; giving equal access to all Canadian HAE patients.

In January, Daphne, along with a HAE Canada volunteer, attended the Patented Medicine Prices Review Board (PMPRB) Forum organized by CORD. The PMPRB is an independent Canadian agency mandated to keep the costs of patented drugs low. The goal of the Forum was to educate attendees of the impacts the PMPRB's proposed changes to drug pricing regulations will have on treatments for rare diseases. HAE Canada appreciated the opportunity to attend and learn about this complex issue and supports CORD in trying to ensure the proposed changes will not prevent Canadian patients from accessing treatments.

The start of March brought Board members and contracted workers to Ottawa to attend CORD's conference "Bringing Canada's Rare Disease Strategy to Life". There participants learned about CORD's "Fight for our Lives" campaign which highlights the PMPRB's changes and encourages everyone to send an email to their MP asking them to stop the PMPRB's changes. To learn about the campaign, please visit: www.fightfourlives.ca.

We are indeed excited for what lies ahead for 2020.