



# HAE Canada Newsletter

September 2019 by the HAE Canada Team

## A Great Summer for HAE Canada

Summers are always too short and 2019 was no exception. July was particularly eventful for two HAE Canada Youth members, Paige and Makayla, who were fortunate to attend HAEi's Youngster's Summer Camp in Atlanta, Georgia. Their experience is best heard from their perspectives:



**Paige:** *This July I attended a Youth Advocacy Workshop held in Atlanta, Georgia. This was my second Youngster's Camp and of course it was nice to see everyone again and get to meet all the new faces. It's amazing to see how our little community*

*is growing at a rapid rate. We had the most new comers at this year's conference which was fantastic. We were split into groups and got to choose a topic that we as a group thought was important to us. My group chose a brochure for hospital staff to have a more improved Emergency Department experience. Collectively we put together a presentation about our idea to share with the rest of the Youngsters. Everyone's ideas were very inspiring to listen to. I have aged out this year so hopefully other Canadian youth will apply to attend next time round. Many of us keep in touch since becoming good friends through this outstanding family.*

**Makayla:** *I was not feeling the best when I got to Atlanta, but I was so excited to see everyone I tried my best to push through. I love being able to see all*



*of the familiar faces and getting to meet new people my age. I am an introverted person so talking to a lot of people makes me nervous. That being said, sitting in a room full of people my own age that are also patients and caregivers, not just*

*adults all older than me, is calming in a way. Not needing to explain yourself to everyone, knowing they all understand; it is indescribable. I am more than grateful I was chosen to be able to attend this workshop. Being able to go to these events brings the community together more and for youth like me they make the world a little less lonely knowing there are people out there going through the same things as I do. I hope that I get to attend the next conference at the Global summit next year to see everyone again. Thank you HAEi and HAE Canada for this opportunity.*



Thank you, Paige and Makayla, for representing Canada so well at the fantastic HAEi Youngster's Camp; HAE Canada is very proud of our youth members.

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HAE Canada is pleased to announce the completion of the patient submission for the Common Drug Review (CDR) for the Canadian Agency for Drugs and Technology and Health (CADTH) in support of the new treatment, Takhzyro. The submission, which HAE Canada is hoping will help ensure this new treatment becomes available to all Canadians, is now currently under CADTH review. You can find a copy of the "Patient Group Input Submission" on their website: <https://www.cadth.ca/lanadelumab>. Our appreciation and gratitude continues to all who contributed to this valuable and important project.

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Over the summer, HAE Canada was happy to assist the Canadian HAE Network (CHAEN), an organization of physicians who treat HAE patients, by distributing their Quality of Life survey to our membership. Our Regional Directors enjoyed speaking with their members about the importance of the survey and were pleased at how many members participated in the survey. We would like to thank everyone who took the time to fill out the survey; their invaluable assistance was appreciated. We are excited to share the results once they are made available to us.

In August, the HAE Canada team was honoured to attend the 40 Year Anniversary Celebration of C1 Inhibitor Therapy in Marburg, Germany, where they presented our Real World Data posters. HAE Canada is very appreciative of all of the HAE specialists, both globally and in Canada, who gave informative presentations on a wide variety of issues. We would like to extend a special thank you to HAEA's President Tony Castaldo for his very moving talk on the patient perspective. The HAE Canada team enjoyed the tour of the CSL Behring facility where they witnessed the facility staff's pride, knowing they



are improving the lives of HAE patients across the globe. HAE Canada wishes to thank the CSL Behring global staff who organized the plant tour, as well as the Canadian CSL Behring team who treated the HAE Canada team so very well.

While in Ottawa in September, Jacquie Badiou, HAE Canada President, Anne Rowe, Board member and a participant in the patient / physician group since 2003, along with Daphne Dumbrille, from the HAE Canada office in Ottawa, attended a meeting at the Canadian Blood Services (CBS)'s Ottawa headquarters to discuss the upcoming subcutaneous long-term prophylactics, HAEGARDA and Takhzyro. Also while in Ottawa, the HAE Canada team was honoured to attend the CSL Behring Boardroom dedication in memory of Joseph Andolfatto, who in his life showed compassion and support to Canadian HAE patients. Joseph is missed by all who were lucky to know him.

It was an indeed a busy summer for HAE Canada, and we are excited to continue to support and represent Canada's HAE patients into the lovely fall season. HAE Canada is happy to announce that starting this November, HAE Canada will be holding Patient Events in Ottawa, Calgary, Vancouver and Halifax. Once the details are finalized, updates will be found on the HAEC website:

<https://www.haecanada.net/category/blog/events/>