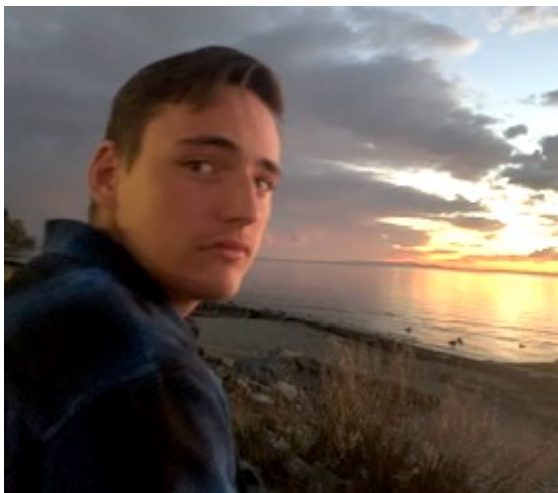




# HAE Canada Newsletter

*November 2020 by the HAE Canada Team*

We are kicking off this article with an exciting announcement: Canada now has a representative on the [HAEi Youth Advisory Group](#). We would like to formally introduce Jacob Collins who lives on Canada's west coast, in beautiful British Columbia. We are thrilled a Canadian will help this fantastic group connect young HAE patients, who will ultimately grow the global HAE community. We are confident that Jacob, who hopes to become a nurse one day, will be a positive and helpful addition to the team. We would like to thank Nevena Tsutsumanov, HAEi's Operations Manager, for inviting a young Canadian to join the Youth Advisory Group. The group is in great hands with Nevena at the helm.



*Jacob Collins: Canadian rep on the HAEi Youth Advisory Group*

We are also happy to share that HAE Canada associates, between ages 0 and 8, are now able to join the Brady Club, an online safe space created for children diagnosed with HAE. We are grateful that HAEA has opened registration to Canadian children associates so they can better understand and cope with their disease in a fun, interactive way. We would like to extend a special thank you to Lisa Facciolla, HAEA's Patient Advocate / Children & Youth Programs. Lisa was amazing to work with and we appreciated all the work she did to facilitate Canadians joining the Club.

Canadian HAE patients are one step closer to gaining equal access to treatments across Canada. Takeda Canada completed negotiations for TAKHZYRO (lanadelumab injection) with the pan-Canadian Pharmaceutical Alliance (pCPA), a negotiating body that helps keep drug prices affordable in Canada. This means that Takeda Canada is now able to start working with different payers across Canada to implement public funding of TAKHZYRO for eligible HAE patients. We are very excited about this new development and grateful of the time and energy spent by our President, Jacquie Badiou, VP, Tina McGrath, along with Takeda's staff, that helped to allow this to happen.

As mentioned in our last newsletter, Jacquie Badiou, along with our talented contract

workers, Bob Bick and Dr. Suzanne Kelly, along with summer intern Maggie Dao, worked hard on our second National Report Card survey over the summer. We are happy to share this survey was launched and our members across Canada will have a few months to complete this important survey. The data will allow HAE Canada to understand patient product use, symptoms and needs so we may continue to advocate for improved access to new safe, and effective, therapies and treatments for Canadians living with HAE, as well as retain access to current treatments. We look forward to sharing the results.

HAE Canada recently had the privilege of attending the 75<sup>th</sup> Annual Canadian Society of Allergy and Clinical Immunology (CSACI)'s Scientific Meeting. Three Board members, Jacquie Badiou, Anne Rowe, Lorraine Coumont and staff, Daphne Dumbrille, joined other participants online to view interesting and informative sessions. One

presentation that was particularly interesting was by Dr. Hilary Longhurst of the UK, titled, "Practical Management of Immune diseases – HAE Guidelines and Management with and without COVID-19". HAE Canada submitted a virtual "booth" that provided participants with HAE Canada's various handouts on HAE. It was wonderful to have an effective way to digitally share HAE information to the Canadian and international participants.

As we enter into the winter season, HAE Canada will continue to stay busy with different projects and events, including organizing another virtual patient information update and attending our Annual General Meeting.

We are certainly grateful we are able to continue to function as an organization during these COVID-19 times, and grateful there is a vaccine so we can soon be social once again.