



# HAE Canada Newsletter

*March 2019: by Paige, HAE Canada Youth member*

**HAE Canada** was pleased to be part of the celebration in Ottawa to recognize International Rare Disease Day 2019. On February 28th, HAE Canada's Volunteer Coordinator, Daphne, joined a large group of supporters for a flag raising ceremony on Parliament Hill, followed by a catered reception; thankfully, indoors. Attendees of the event enjoyed speeches from different people, including, David Cox, the Executive Director of the Rare Disease Foundation, Maureen



Smith, the Secretary of the Board for the Canadian Organization for Rare Disorders (CORD) as well as from Members of Parliament from Canada's four major political parties. Each speaker gave their perspective on the importance of recognizing rare diseases in Canada. The event, organized by the Rare Disease Foundation, hoped to not only recognize International Rare Disease Day, but also to encourage the federal government to implement Canada's Rare Disease Strategy, including adopting a federal Orphan Drug Regulatory Framework. Events such as these are a great reminder that many dedicated organizations and individuals work hard each day for Canadians with rare diseases and we are proud to be part of this community.

HAE Canada President, Jacquie Badiou and HAE Canada Treasurer, Richard Badiou, along with two volunteers, attended the American Academy of

Allergy, Asthma & Immunology (AAAAI) Annual Meeting in San Francisco, California, from February 22 to 25, 2019. Jodi Valois, a representative from Yang Medicine in Ottawa, joined them to present four posters developed from data collected from our National Report Card, specifically Demographics, Attack Profile, Treatment Utilization and Treatment Satisfaction. Not only did HAE Canada share our important research, but also helped raise awareness of our rare disease at this important annual event.

We have exciting news from the newly established Youngsters side of HAE Canada. Makayla Gunderson and myself, Paige Gunderson, were chosen through the Youngster volunteers and accepted to travel to Atlanta, Georgia to attend the HAEi Youngsters Camp 2019 in the hot summer month of July. I am happy I will reunite with my sister Makayla, who will be coming from the opposite side of the country, to learn and reconnect with the HAE youth community once again. We hope to bring back new ideas and initiatives which will help us develop our Youngsters program and strengthen our volunteering skills gained through volunteering with HAEC over the past two years.

With the HAEi Youngsters website and magazine launched from the Vienna, Austria, Global Conference, I am quite electrified to see what we youngsters have in store for the bright future. With the HAE Canada Youngsters program kicking off here we are also excited to see what adventures will come with that. Look out world, we HAE Youngsters are diving head first into our futures, with each other at our backs.

Stay tuned for news on our upcoming HAE Day here in Canada!