



HAE Canada Newsletter

February 2018: by Paige Gunderson, HAE Canada Youth Member

These are the highlights HAE Canada has been involved with, in amazing 2018 thus far.

Some of our provinces held celebrations for **Rare Disease Day** on February, 28, 2018. Canada has been participating in this special day since 2008. Globally, it is the eleventh International Rare Disease Day with hundreds of patient organizations from countries and regions around the world participating in various local events. This year's theme was "Research". This benefits not only my family, but many other people dealing with HAE and other rare diseases. As we can all appreciate, research is essential to further understand how to improve medications, treatments and above all **Quality of Life**. In honour of Rare Disease Day, a



video was posted on the HAE Canada website of Ken Howlett, HAE Canada's Vice President, describing his life with HAE. To further mark Rare Disease Day, Ken, along with his wife, Linda Howlett, HAE

Canada's Secretary, attended Question Period at Ontario's Legislative Assembly in support of the Canadian Organization for Rare Diseases (CORD)'s presentation to Members of the Provincial Parliament (MPPs).

One big thing we are all excited about is the up and coming 2018 HAE Global Conference, hosted this year in Vienna, Austria, from May 17 – 20, 2018. At least 27 participants from all over Canada are gearing up to go and represent our wonderful

country at the Global Conference this year. We will be sporting red and white HAE Canada shirts, so keep your eyes open for us.



While on a personal holiday in California in February, one of our Regional Directors, Bob Simon, had the

opportunity to tour the US HAEA Angioedema Center at UC San Diego. While on tour, he learned what the centre has to offer, including their care for patients with angioedema, state-of-the-art diagnostic tests and techniques, therapeutic modalities, patient support programs, and research. Pictured with Bob is Patient Representative Ms. Michelle Martinez.

For the last 3 ½ years a member of CHAEN, Dr. Amin Kanani and HAE Canada's President Jacquie Badiou were involved in advocating the British Columbia (BC) Provincial Government for approval of funding for patients in BC to gain access to Firazyr (icatibant injection). A positive recommendation was recently obtained to provide coverage, which is fantastic news!

Check out our website, our Facebook page, Twitter & Instagram accounts to follow along on our journey through this year's achievements and progress. Our official Twitter account was launched in February (@HAE_Canada). We are also aiming to re-launch our newly updated website for HAE Awareness Day on May 16th. Stay tuned for more of our social media update.