

WFH national haemophilia organisation training

Shauna Adams attended the World Federation of Hemophilia (WFH) global national member organization (GNMO) training at the WFH World Congress in May 2022. She participated as a Youth Delegate, representing HFA. She spoke to Suzanne O'Callaghan at HFA about her experience.

Suzanne: Where was GNMO Training held?

Shauna: GNMO Training was held in conjunction with the WFH World Congress this year, at the Palais de Congress in Montreal. Some sessions were held at the hotel nearby where the GNMO participants were staying, so we were all in close quarters. We were located within walking distance of old Montreal, with lots of unique architecture and access to the local cuisine.



Chateau Ramezay Museum Montreal

Suzanne: What was different about GNMO Training this year?

Shauna: Feedback from previous congresses indicated that there was a level of disconnect from the GNMO training to the congress itself, so this

year WFH trialed a new delivery method where the GNMO training occurred in conjunction with the Congress. Participants were provided with a suggested schedule of Congress sessions to attend that complemented their training. This kept the group together throughout the week and really allowed us to solidify our new connections.

There was a big focus on reconnecting as a group in person for the first time since the pandemic began. Some of our peers were unable to make it through the current visa processing system, so as a result we received a mixed method delivery of both virtual and online sessions. With a few technical bumps along the way, for the most part the technology enhanced the experience for those attending in person, along with access to simultaneous interpreting services. With a group from such a variety of different countries, the interpreting service meant that those who did not speak the language of the presenter could remain engaged with the presentations in real time. It also allowed people to ask questions in their native language to be translated back to the presenter.

I attended the Congress as a Youth Delegate, and the opportunity to meet and network with other young people in the community was invaluable. I was also able to meet some delegates in person for the first time whom I had connected with online some time ago – a common experience across the board with the travel restrictions we have been facing recently.

Suzanne: Did any sessions stand out for you?

Shauna: We had the opportunity to meet over lunch with all the Asia Pacific NMOs, chaired by our regional manager Guada. I heard about everyone's current priorities, and we took the time to touch base after a few years of no face-to-face contact. As a Youth Delegate this was a new experience for me, though there were several other new faces in the

group too. I look forward to meeting with this group again and explore collaboration opportunities in the future.

I really enjoyed the ‘Ask the Experts’ session as part of the GMNO training, where four delegates from Malaysia, Panama, India and South Africa spoke about unique challenges in each of their locations. The strong leadership shown by each of the speakers and the way they have all overcome adversity was really inspiring.

Suzanne: What was the most memorable aspect of the World Congress?

Shauna: Attending the first Women’s Networking Event chaired by Dawn Rotellini. We celebrated the achievements of women who have been making a significant contribution to the bleeding disorders community, including our own Susie Cooper from HFWA. The Susan Skinner Memorial Award recipients were introduced and presented with their awards by Susan’s son. It was really interesting to hear about how the landscape has changed since Susan started advocating for safe treatment for her sons.

It was lovely to see such a huge focus on women with bleeding disorders throughout the whole Congress, with an entire stream of sessions addressing topics around genetic testing, taboo topics, and increasing awareness for treatment of women with bleeding disorders. There was a real shift from talking about women simply as carriers, as we have in the past, to opening the scope to carriers, women with haemophilia and VWD, mothers of children with bleeding disorders and women with other rare bleeding disorders. Many experiences were explored, and all were presented equally.

Suzanne: What did you like about the social aspects of Congress?

Shauna: It was great to meet with people socially face-to-face for the first time for quite a while. I met people who are doing amazing things for our community which has really inspired me to think about what more I can do after a period where we were really all just trying to get through the post pandemic ‘normal’. There was a lot to see in Montreal. I love to sightsee via the food options so I sampled a lot of the local cuisine – including sampling many bagels! It was great to network with other Youth Delegates and talk about ideas for the function of WFH in the future.



Shauna at the WFH General Assembly

Suzanne: What were the take home messages?

Shauna: We had a big focus on the WFH mission: **Treatment for all.** It was a timely reminder as we move into the world of exciting new long-life products and gene therapy to remember those who may not yet have access to reliable sources of what some of us may consider bare minimum treatment options. The pandemic has really highlighted the disparity in our community where some have had to prioritise treatment for COVID-19, or transportation and supplies were redirected to other areas.

Suzanne: Why do you think the World Congress is important?

Shauna: Congress brings us all together and provides an opportunity to refocus on what is important, what our priorities are as we transition into an age with gene therapy and long-life products. For those of us who are fortunate to receive world class treatment, it is important to understand the challenges of the global community and consider how we can support the WFH mission of Treatment for all.

Shauna Adams was funded by HFA and WFH to attend the WFH World Congress.

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Shauna Adams is HFACT Secretary and an Australian community member with VWD.

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