



EHC Youth Leadership Workshop Alumni Event

25-27 January 2019, Amsterdam, the Netherlands

By Charles Kinney, EHC Communications Officer

For this week's EHC Now! we report on the first edition of the Youth Leadership Workshop Alumni event that took place in Amsterdam over the weekend.

Amsterdam provided the backdrop for the EHC Youth Leadership Workshop Alumni Event held 25-27 January, 2019. With over 30+ participants from all over the EHC network, the EHC Youth Leadership Alumni Workshop Event proved to be a successful continuation and celebration of five years of youth training and advocacy. The event was aimed to build, assist and encourage participation and engagement in NMOs for the youth and to focus on expanding the participants' knowledge and skills in terms of advocacy for patients with haemophilia and related blood disorders around Europe. The theme of the event was **WWWVHW (who, what, when, where, how and why)**. The intensive three-day event, always high energy with the EHC Youth Leadership Alumni, was not only a "hands-on" workshop for the EHC advocate membership to gain more knowledge about being an effective advocate, but an opportunity to network and continue to build a community for young people with bleeding disorders in Europe.

The event focused on practical and pragmatic exercises building on the five-year history of EHC Youth Leadership Workshop.

Under the leadership of EHC's Fiona Brennan, the event opened with Valentin Brabete from Romania leading a session about lifelong learning developed by the Alternative University in Bucharest. This was followed by an informative and highly useful session by EHC CEO Amanda Bok and the UK Haemophilia Society's Board of Trustees Chair, Clive Smith, using an excerpt from Martin Luther King Jr.'s *I Have a Dream* speech, combining the power of advocacy with the power of speech. Clive highlighted that credibility is the byword, 'whatever it is they need to know, make sure it is the truth – you want to be accurate, reliable, understandable and actionable.' The session also emphasised that by using and understanding rhetorical devices your audiences and participants can advance their message.

Amanda demonstrated that by providing proof (facts) through data (here's the literature!) and a paper trail, you can gain equal-footing stating 'data is a universal language, everyone can use it, everyone can understand it.' Amanda also led a very popular communications style exercise to use for finding the best spokesperson, which focused our attention on how to communicate effectively with people with different and sometimes opposing communication styles to achieve your goal. Communication is advocacy and advocacy is an art. Clive Smith and EHC Steering Committee member Thomas Sannié, spoke about real-world experiences in NMOs and critically examined where we can improve but also how the training can be applied to refine and analyse our advocacy skills.

Women have also stepped up and are taking a bigger role in advocacy than ever. Olivia Romero-Lux spoke about NMO updates. Naja Skouw-Rasmussen from the Danish Haemophilia Society stressed that, "Women can and should take a bigger role in advocacy. Women need to be informed and be concrete in their solutions in women's bleeding disorders. Stronger advocacy and participation in your NMO is the way forward."

Some of the main take-aways participants were offered to advance their advocacy skills were the importance of preparedness, providing proof by collecting data and using the literature, offering viable solutions and the importance of sustaining long-term relationships both internally and externally. Last but perhaps most importantly, all external advocacy requires internal advocacy. The NMO was referred to as a living organism; we need to be flexible and adaptable and continue to grow together.

Reactions from participants were highly positive. In addition to the next steps in advocacy, participants gained practical, real-life experience from roleplaying situations experienced by advocates. These included both internal and external advocacy issues, constructive discussions inside NMOs, engaged discussions with Ministries of Health and an intensive session of what to do with the press. Robbert-Jan T'Hoën from the NVHP said of the roleplaying experience, "When you sit you see, but when you do you learn."

Facilitator Stefan Radovanovic from the Serbian Haemophilia Society said, "It's good to see how far we've come. When we started, this was relatively new for us. We understand what advocacy is and we want to go further."

It's not an understatement to say that the Youth Leadership Workshop Alumni are the future. When asked what he gained from the experience, Youth Leadership Alumni member Alex Teinburg, from the Estonian Haemophilia Society said, "Confidence. Practical experience, like body language and English-language clues from experienced advocates like Clive Smith, give us more tools we need for greater participation."

The next Youth Leadership Workshop will take place on April 5 – 7, 2019 in Amsterdam.