



EHC NOW!

EHC 2018 Conference highlights and looking towards the year ahead



Interviews taken by Laura Savini, EHC Public Policy Officer

Following the EHC 2018 Conference, we asked some of our Steering Committee members to tell us what were their highlights of the conference and what they were most looking forward to in the coming year?

Naja Skouw-Rasmussen



Some of the Programme committee members for the EHC Conference on Women and Rare Bleeding Disorders

For me the highlight of the conference and of the work ahead is **the increased visibility and focus on women with rare bleeding disorders**. During the conference we had the women's booth and a full session focusing on women. In the margins of the conference we met with the EHC Committee on Women and Bleeding Disorders as well as the organising committee for the **EHC Conference for Women and Bleeding Disorders** taking place next year on 24-26 May 2019. The work of the committee and the conference are two things that I am looking forward to as well as the development of a **movie on Women with Bleeding Disorders in Europe, which will be available in 2019**. Keep an eye on EHC social media for more information on all of these!

Minette van der Ven

I was thrilled to be **elected VP Finance** and become even more involved in this community. I also echo Naja's sentiment with regard to the increased work on Women with Bleeding Disorders. I am looking forward to familiarising myself with all the practical aspects of the day-to-day management of the EHC and I hope I will be able to **make meaningful contributions to ensure the running of the consortium is even smoother**. Finally, I am really looking forward to supporting the whole



The new EHC Steering Committee (Minette van der Ven is fourth from the left)

community and to **bringing my experience and dedication wherever they are needed!**

Michael van der Linde

For me the highlight of the weekend was the **cycling to the conference** and the **youth debate**. I really believe that it is important to continue to highlight the benefits of physical therapy and an active lifestyle, which are beneficial for everyone and in particular for those with bleeding disorders. We need to continue to spread the message that there is a way to practice sport safely, even when access to treatment is not optimal. This can be done together with both haematologists and physiotherapists who play a key role in comprehensive haemophilia care. This is why I was delighted that Pfizer donated its symposia to the EHC so that we could partner with the European Association for Haemophilia and Allied Disorders (EAHAD) to really stress the **benefits of physiotherapy**. I believe this was a successful symposium with an important message.



The #thisway campaign cyclists arriving in Brussels

With this conference I also conclude my role on the EHC Youth Committee and I am very proud of the work this committee has achieved and each year I am amazed by the talent, energy and motivation of youth volunteers from across Europe. There is no better place to demonstrate this than the Youth Debate, a symposium donated by Sobi to the EHC. This year the performances on the

debate were stellar and this truly shows that training youth is worth all the resources, time and energy that the EHC has been investing in it in the past few years.

This coming year I will continue to look ahead at the EHC youth-related activities, which will now include the **Youth Fellowship Programme**, the **Youth Leadership Workshop** and **the work of the new Youth Committee**. I am excited to see the youth activities grow, this is a real investment into the future of the European bleeding disorders community.

Brian O'Mahony

For me **the record attendance at the EHC Conference** (with over 375 delegates!) is a true statement of the good work that the EHC volunteers and the staff are doing throughout the year. I was pleased to see the sessions being very well attended, in particular on **novel therapies**. There is a real sense of excitement in the community for what is coming and this will be discussed in depth in the **Workshop on New Technologies in Haemophilia Care** that the EHC will hold later in November. We also received very positive feedback on our new **newsletter on novel haemophilia therapies**. The committee managing this publication has met in the margins of the conference and they will publish two short updates at the end of

this year and in February 2019 before publishing a fully revised long-version of the newsletter in July 2019 after the ISTH Congress.



Brian O'Mahony as Inhibitox, the inhibitor superhero

For the year ahead, I am also looking forward to continuing the work to **support the inhibitor community both through the European Inhibitor Network and the Inhibitor Summit**. This often-overlooked part of the community needs all the support it can get, in particular at a time when exciting novel therapies for inhibitors are coming to European markets; we need to ensure that our inhibitor community will be able to access these novel therapies.

Finally, the year ahead will be very important our **PARTNERS programme (Procurement of Affordable Replacement Therapies – Network of European Relevant Stakeholders)**. We are going to mark the one-year anniversary of the programme during our next **Round Table of Stakeholders on 'Switching from standard therapies, where do novel therapies fit in?'** taking place on 20 November in the European Parliament. Dr Cristian Busoi will be hosting the Round Table, which is fitting seeing he was one of the Members of the European Parliament (MEPs) that supported the launch of PARTNERS almost a year ago. We will also continue our advocacy work with governments in the PARTNERS programme to promote sustainable purchase of adequate levels of haemophilia therapies as well as the organisation of comprehensive haemophilia care. For this, we are delighted to be partnering with our colleagues at EAHAD. Finally during the Conference we announced that Roche officially joined PARTNERS, we are really excited about this and we are hoping that this will contribute to better access to treatment for people with inhibitors in PARTNERS countries.

Olivia Romero-Lux

I want to echo a few things that were already mentioned, such as the work for women with rare bleeding disorders and the importance of physical activity. In this regard, **I am hoping that we will be able in the future to build-in ahead of each conference some kind of activity to highlight the importance of the practice of sport and physical activity.**

I also very much enjoyed the talk by Alison Dougall on **oral health** and I am hoping that the EHC could increase its activities in this area as I think that there are still many misconceptions and taboos surrounding oral health in people with bleeding disorders.

Finally, meeting the community is always such a pleasure and really energising for continuing the work of the Steering Committee. It is an opportunity to 'take the temperature' on what our NMOs are doing and what topics are at the heart of our members' concerns. I think that the EHC should also definitely look at what it can do for people with **Von Willebrand Disease**. However, nothing is set yet, so stay tuned for more updates.

Radoslaw Kaczmarek, Miguel Crato, Thomas Sannié and Alain Weill (ex-officio) were not available for quotes.