

EHC NOW! 
Compilation Newsletter

January – June 2019

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EHC NOW!



EHC Half-Year Progress Report 2019

EHC Now! will take a summer break, the newsletter will be on hiatus for July and August and we will resume our activities on 4 September. However, before taking a break, we give you here below a summary of our activities for the first half of the year

January

The year started with the much anticipated [Youth Leadership Alumni event](#), which was held in Amsterdam on 25-27 January. This event brought together alumni from the past five Youth Leadership Workshops to provide extra training in advocacy for young volunteers. EHC continued with its 'Happy ½ Hour' initiative (read about it on pg 5) and kicked off the year with a talk with Dr. Maria Elisa Mancuso about [surgery](#) in people with haemophilia and inhibitors.

February

[EHC staff and volunteers attended and presented at the Conference of the European Association for Haemophilia and Allied Disorders \(EAHAD\) #EAHAD2019](#) conference held in Prague. This conference provides participants with an opportunity to learn more about developments in clinical practice in the area of comprehensive care of haemophilia. The EHC published the second issue of the [Novel Treatments Review in Haemophilia and Other Bleeding Disorders](#). In February, the EHC also launched the first instalment of [EHConversations](#) with its premiere series on gene therapy, the first major piece of patient-focused discussion and education on gene therapy and haemophilia. Read more and view all the videos on page 5. EHC and EAHAD launched the video on the [European Principles of Inhibitor Management](#) (see more on pg 5). The EHC Inhibitor Working Group met in Lisbon for productive and informative meeting. The EHC also held its first Round Table of Stakeholders of the year on [The Future of Comprehensive Care and Outcomes](#). The event was held at the European Parliament and a full account of the event can be read on pg 11. Finally, the European Inhibitor Network held its second 'Happy ½ Hour' with [psychotherapist Nicola Dunn](#).

March

EHC celebrates International Women's Day with a [video production on women and science](#). The Youth Fellowship Programme announces its [first major project with Ireland, Hungary and Serbia](#). EHC revamps its [website](#). EHC CEO concludes productive meetings in North Macedonia with North Macedonian NMO in advance of the EHC 2019 Conference in Skopje, October 4-6. EHC staff attended the International Plasma Protein Congress (IPPC). This event is organised by the Plasma Protein Therapeutics Association (PPTA) and discusses latest news from the pharmaceutical industry manufacturing plasma-derived medicinal products. Finally, 'Happy ½ Hour' discusses [home treatment and self-infusion](#) with paediatric haematologist Dr. Beatrice Nolan and haematology nurse Ms. Mary Kavanagh, both from Our Lady's Children's Hospital in Crumlin, Ireland.

April

EHC honours [World Haemophilia Day](#) (read the full report on pg 13) and launches #EHCelebrate, the 30th anniversary of the founding of the European Haemophilia Consortium, with the [Every Day is a Winding Road Campaign](#), where members of the community can send e-cards and videos. EHC creates new logo for 30th anniversary from designer Marion Brauer and launches new animated explainer video in English, Russian, French and Spanish, [What is EHC?](#) EHC participates in a successful campaign on #WorldHealthDay with the European Patients' Forum to call on the EU to deliver #HealthForAll. The [2019 Youth Leadership Workshop is held in Amsterdam](#), read the full account of this event on pg 7. EHC CEO Amanda Bok [speaks at the World Orphan Drug Congress](#) in Maryland, USA. Finally, 'Happy ½ Hour' discusses employment issues and the bleeding disorders community with Specialist Training Provider in the Disability Sector Traci Marshall-Dowling.

May

EHC publishes in the *Haemophilia Journal* the results of its 2018 survey on [Barriers and challenges faced by women with congenital bleeding disorders in Europe: Results of a patient survey](#). The 'Happy 1/2 Hour' with an expert in haemophilia care in May focused on [parenting a child with inhibitors](#). EHC holds its First European Women and Bleeding Disorders Conference, held on May 24 -26 (read the full report on pg 16), where the movie '[Women and Bleeding Disorders](#)' is premiered. EHC volunteers attended the International Workshop on Surveillance and Screening of Blood-borne Pathogens organised jointly by the International Plasma Fractionation Association (IPFA) and the Paul-Ehrlich-Institute, the German regulatory agency in charge of assessing the quality and safety of blood and biologics. Finally, EHC Membership Officer, Jo Eerens, travelled to and met with the EHC Ukrainian NMO.

June

The month of June was a busy month packed with activities ahead of the summer break. EHC held two events: on 11 June, the EHC held its second [Round Table of Stakeholders on Pain Management in Haemophilia](#); while on 20-23 June, the EHC held its [Leadership Conference](#). Both events were held in Brussels. During the Leadership Conference, EHC launched the second instalment of EHConversations with a video on [living with hepatitis C and haemophilia](#). EHC also published its [PARTNERS programme report](#). Meanwhile EHC CEO Amanda Bok was featured on the US podcast '[Blood Stream](#)' to talk about the European bleeding disorders community and EHC activities. EHC staff and volunteers were also present at the European Symposium, Wildbad Kreuth, an initiative of the University of Munich, the European Directorate for the Quality of Medicines and Healthcare and the Rudolf Max Foundation. This event gathered experts in haemophilia and blood safety from across Europe to prepare recommendations on the management of haemophilia and other rare bleeding disorders. The recommendations developed during this event will be presented to the Council of Europe to adopt as a formal resolution. EHC staff and volunteers were also in attendance at the Congress of the European Haematology Association. EHC CEO, Amanda Bok, [spoke](#) and moderated sessions of the advocacy stream. Finally, EHC Membership Officer, Jo Eerens attended the [official launch](#) of the Maltese Haemophilia Association. This association will now take steps to become a member of the World Federation of Hemophilia and EHC.

EHC launch *EHConversations*

In 2019 EHC launched a new series of short, informative and patient-centred videos called '*EHConversations*.' The first series looked at gene therapy and gave viewers more information on:

- [What is gene therapy?](#)
- [An overview of gene therapy trials in haemophilia A and B](#)
- [How does a clinical trial in gene therapy for haemophilia works?](#)
- [Safety in gene therapy and,](#)
- [Gene therapy: A patient's perspective.](#)

The second series '[Living with hepatitis C and haemophilia in Europe](#)' looked at the impact of the HCV contamination in people with haemophilia in Europe. The video is part of our advocacy campaign calling on European governments to eradicate HCV from the haemophilia population. Although the video focuses primarily on haemophilia, many patients affected by other rare bleeding disorders were also impacted by the contamination and should be offered curative treatments with direct-acting antivirals.

The production of the gene therapy videos was made possible thanks to educational grants from BioMarin, Pfizer, Spark and UniQure.

EHC launch *European Principles of Inhibitor Management Video*

The EHC developed and published a video describing the European Principles of Inhibitor Management, which were published in late 2018.

In April 2018, an [original article](#) outlining the European Principles of Inhibitor Management was published in *Orphanet Journal of Rare Diseases*. These principles are the culmination of two years of collaborative work by patients and multidisciplinary healthcare professionals from both EHC and the European Association for Haemophilia and Allied Disorders (EAHAD). The EHC developed a [video](#) outlining these principles as an advocacy tool for its National Member Organisations (NMOs).

Since the publication of the principles new treatment options have become available in Europe and the principles are currently being revised to reflect this situations.

The European Principles of Inhibitor Management video is an activity of the European Inhibitor Network, whose work is supported financially by Roche, Sanofi Genzyme and Shire

European Inhibitor Network: Happy ½ Hour with an expert in haemophilia care

Since 2018, the EHC has been holding a monthly half-hour live conversations with an expert in inhibitor care. The principles are simple, participants register in advance and log-in to a live but closed video conference with an expert in inhibitor care. Typically, the expert will give a short presentation followed by Q&A with the audience. Following the conversation, the content of the session is recorded on an article published on the EHC Inhibitor Website. So far, the 'Happy ½ hour' has featured experts in venous access, dental care, physiotherapy, surgery, psychosocial issues, home treatment and self-infusion and parenting a child with inhibitors. Find all of the past sessions and more information on upcoming new events [here](#). This is an initiative of the [European Inhibitor Network](#).

The Happy ½ hour is an activity of the European Inhibitor Network, whose work is supported financially by Roche, Sanofi Genzyme and Shire

EHC Launch our first Youth Fellowship Project

The Youth Fellowship Programme started in 2018 and in 2019, we were delighted to announce our first project.

The EHC works hard to invest in patient advocacy and developing leadership skills for the future. For this reason we have built a comprehensive youth leadership strategy, which actively encourages and includes the training and participation of young members of our community throughout EHC programmes and events. As part of this strategy, we are delighted to announce our first Youth Fellowship Project!

The first Youth Fellowship Project will be organised by three of our Youth Alumni from Hungary, Ireland and Serbia. The purpose of this project is to encourage our youth to get involved in their National Member Organisation (NMO), not just in camps and activities, but in the governance of the NMO and in the decision-making process. The team will also focus on the benefits of working together with other NMOs and stakeholders at a European level. The Youth Fellowship Project team, comprised of Karola Diosi, Donal Mc Cann and Nikola Kumovic acknowledged that, as a community, we need to encourage our youth to expand their view of the NMO from a two-dimensional approach. The team aims to empower and encourage the youth to be involved in their NMO at an organisational and at board level, where they can shape the future direction of the NMO, while also educating their peers on the importance of collaboration at a European level. The team focuses on highlighting that in a rare disease community, it is vital to create European wide engagement, friendships and professional relationships to encourage active participation in NMOs at a European level.

The team is planning to visit each of the three NMOs to attend a planned event, where they will be offered a space to facilitate an interactive workshop. They will actively encourage and

challenge the youth and members of the NMO, to expand their focus and understand the importance of youth collaboration for the future strength of the NMO. The project will take place throughout 2019. We are excited to see the results and impact of this worthwhile project and wish the project team the best of luck and thank them for their motivation and collaboration!

Watch their announcement video [here](#).

The Youth Fellowship Programme is made possible thanks to the kind financial contribution of BioMarin and Sanofi Genzyme.

Youth Fellowship Programme - Update

In this week's EHC Now! we get an update on the Youth Fellowship Programme and the work of our first collaboration between Ireland, Hungary and Serbia.

With the summer months amongst us, it is perhaps a time to rest and rejuvenate for some, but for others it can be a time for new ideas and new learning. Following the success of our recent Women with Bleeding Disorders Conference – we, and indeed our community, experienced first-hand how important all groups in our inclusive community are and also how successful and motivated the entire community a small group with a big idea can be!

It is in this spirit that this week our EHC Now! focuses on the importance of our youth members across Europe. We want to bring you an update on our first Youth Fellowship Project work that is being done by three of our Youth Leadership Alumni from Ireland, Hungary and Serbia. Donal, Karola and Nikola will focus on encouraging youth in their respective NMOs to step up and become actively involved in their NMOs and to get them thinking about how to become effective advocates. The first NMO visit takes place in August in Hungary and the team will host a series of workshops with groups of youth. Watch their promotional video [here](#) and we will be following their visits and reporting back to the community so watch this space! The EHC has, and will continue to, invest in patient advocacy and strive to develop and train effective, educated and skilled leaders for our community for the future. With our Leadership Conference taking place this weekend, it is also timely to highlight the importance of our community working together with our leaders, our youth, our volunteers and our staff.

Tomorrow's leaders are today's youth and it is for this reason we have built a comprehensive youth leadership strategy, which actively encourages and includes the training and participation of young members of our community throughout EHC programmes and events. The latest and most ambitious part of this youth leadership strategy is the Youth Fellowship Programme, which embraces and encourages our youth to get working together in cross-border collaboration while serving the interests of our community.

We have already had some ambitious applications, and we are truly encouraged and excited for the type of projects along with the motivation and enthusiasm our youth have to be active

members of our European community. We would also like to encourage our National Member Organisations to consider applying for this worthwhile programme to offer our young leaders real hands-on experience while at the same time contributing in the right way to the European community.

We are all aware of how much important work remains to be done for our NMOs. It is hoped that the Youth Fellowship Programme can help our NMOs and youth work collectively towards achieving some of this work, while also benefitting more than one country. Importantly, the projects will not over-lap but complement existing work being done by the NMO in the European patient community.

For further information on the Youth Fellowship Programme, the application process or indeed for any queries please contact [Fiona Brennan](#) or see our [FAQ!](#)

We look forward to working with our future community leaders on these projects!

The Youth Fellowship Programme is made possible thanks to the kind financial contribution of BioMarin and Sanofi Genzyme.

EHC Youth Leadership Workshop



For the sixth year in a row, the EHC was delighted to host its Youth Leadership Workshop.

It's appropriate that the Youth Leadership Workshop concluded on World Health Day (April 7). Healthcare is a universal right and EHC is part of the global effort to ensure that all patients, regardless of their nationality, economic background or health status, receive the care they deserve. The Youth Leadership Workshop aims to train the next generation of volunteers and leaders of the European haemophilia community. The future leaders of our community gathered together in Amsterdam on April 5 – 7 to gain tools and information which we hope will help to encourage greater participation in their NMOs and their community. Representatives from Albania, Austria, Bulgaria, Croatia, France, Kyrgyzstan, Northern

Ireland, North Macedonia, Romania, Serbia and the United Kingdom, all aged under 30, who have made the decision to be advocates and continue their lifelong process of developing and fine-tuning advocacy skills. Kyrgyzstan's Aizat Aidarbekova, who resides in Kyrgyzstan, but is also part of the international Korean community, said, "This work goes beyond borders. I came to Amsterdam to learn as much as I can. I've listened to other peoples' experience with their care when they younger. This information has been invaluable when sometimes it's difficult to get information inside your country."

Led by EHC's Community Programmes Officer Fiona Brennan, the 2019 Youth Leadership Workshop is a vital component of EHC's aim to empower and build young advocates and leaders in our community. After a group introduction and agreement session led by EHC Youth Ambassadors Valentin Brabete from Romania and Stefan Radovanovic from Serbia, EHC CEO Amanda Bok talked about our collective community and our patients and NMOs representing the voice of over 90,000 patients in Europe. Amanda also talked about patient centricity and how patients should not only be part of this sometimes abstract concept, but steer it through governance and participation. The main focus of the first day of the workshop was governance – governance enables our community to be credible and credibility is key and maintaining constructive and positive relationships with industry, regulatory institutions, national patient organisations, health care providers and other patient organisations which reflects our unity. Austria's Christian Berner said, "We are fighting together for a better future. I can go back to my NMO with a better understanding and stronger international network." Advocacy is about lifetime participation, accountability, transparency and inclusion. While we may have disagreements, advocacy is about unity and agreement. Youth Committee Clive Smith, Steering Committee Olivia Romero Lux, Youth Ambassador Stefan Radovanovic and Fiona Brennan led an open and honest discussion about advocacy, empowerment, and good NMO governance, followed by breaking into group and strategic planning.

Saturday's sessions were heavily participant-focused with active group work and feedback. Fiona led a session on engaging and retaining volunteers, followed by Clive who discussed the importance of successful youth engagement through project planning. Both sessions used real-world case studies and situations that the participants might encounter at their NMOs. As always, the role-playing sessions were lively, particularly for women with bleeding disorders, an often-overlooked group of our community. Our community is much greater than the sum of our borders and our genders. Macedonia's Marija Aloa Vera Drzmanoska, who has created a public-awareness art campaign in North Macedonia, said, "For me, these programmes raise awareness on all parts of our community, including women. That I am able to support my friends and community is the best part of this weekend."

Steering Committee Olivia Romero Lux conducted an in-depth and exhaustive discussion on the process of medicines from discovery to market authorisation. This session was complimented by interactive discussions on patient engagement with external sessions and the role of patients, regulators and industry. The second day of the workshop concluded with a moderated discussion with representatives of the pharmaceutical industry.

On Sunday, Clive opened the morning with an interactive discussion about strategic planning. Fiona, Valentin, Stefan and Charles Kinney led ambassador exercises, where teams found real-

world solutions to four possible challenges in NMOs. Finally, we concluded with more role-playing about volunteering and engagement. Northern Ireland's William McKeown said, "This workshop was on-the-button for relevancy. For any aspiring leader, the workshop was not only well-presented but full of ideas. My expectations were surpassed." There were several recurring themes over the course of the workshop namely the importance of good governance and the principles that guide good governance, the importance and inclusion of all stakeholders and decision-makers in the collective focus of the patient organisation and how to work effectively with these stakeholders to ensure a collective, cohesive and inclusive organisation for patients now and into the future.

We would like to thank this year's youth participants for their motivation, enthusiasm and engagement – the future of our NMOs in Europe is bright. For more information on youth related activities please see our newly rebuilt [Youth section](#).

The Youth Leadership Workshop was sponsored by BioMarin, CSL Behring and Takeda.

EHC Physical Activity Grants and #thisway campaign

Back in the 1970's haemophilia patients were advised to avoid exercising to minimise the risk of bleeding. The consequences of limited physical activity such as obesity and loss of bone density were, however, quite damaging and in the long term caused more bleeds.

Today, five decades later, the tables have turned and physical activity is seen as an essential component of wellbeing for people with haemophilia and other bleeding disorders, and is being actively promoted for its benefits in terms of joint health, coordination, general fitness, body weight and self-esteem:

- Strong and flexible muscles provide better support to the joints, preventing bleeds and joint damage;
- Regular exercise boosts energy and reduces fatigue;
- Feeling fit greatly contributes to psychological wellbeing;
- Healthy body weight reduces the stress placed on the joints, thus reducing the risk of bleeds;
- Improved balance and coordination can help joints and muscles work better together, which again helps in reducing bleeds;
- Exercising in a group provides the feeling of normality and inclusion which is important for people with rare conditions.

To promote the importance of physical activity for people with bleeding disorders, the EHC launched its **#thisway** campaign, inspired by and continuing the BloodRelatives campaign of the Dutch Haemophilia Society in 2017. Between the launch of the campaign in July and EHC Conference in October 3,457 kilometres were tracked during the EHC 2018 **#thisway** campaign by everyone who took part in it.

Being a competitive bunch of people, we directly set out on a new challenge – **#thisway** to **#EHC2019!** At this point, we have almost tracked 200km in the four activities that have taken place! Unfortunately, this is far from enough as we would like to beat last year's number! Join

us #thisway to #EHC2019 and track the kilometres of your physical activity and submit the count to us to let us add to the overall number together as a community.

What's more, if you would like to promote physical activity within your NMO, the EHC has something to offer. Apply for EHC Physical Activity Grant and kick-off a physiotherapy or physical activity project in your NMO. Find out more [EHC Grants](#).

The Future of Comprehensive Care and Outcomes in Haemophilia – Round Table

The first Round Table of 2019 took place in February at the European Parliament and was graciously hosted by the honourable members of European Parliament (MEPs) Gesine Meissner (Germany/ ALDE) and Norica Nicolai (Romania/ ALDE). The event was the opportunity to discuss the future of comprehensive care in haemophilia in a changing landscape.

Evelien Mauser-Bunschoten, UMC Utrecht and members of the EHC Medical and Scientific Advisory Group (MASAG), set the scene with a compelling speech about what is comprehensive care and the Dutch experience with it. In '*Setting the Scene: haemophilia treatment paradigm shift – how will novel therapies impact the role of comprehensive care centres (CCCs)*,' Dr. Mauser-Bunschoten stressed that in the future, specialised haemophilia centres will be needed more, not less, as their expertise will be needed to address several challenges arising out of the complexity both of rare bleeding disorders themselves as well as of the introduction of novel therapies. Amongst these challenges, she highlighted the ageing of patients and the complexity of their multi-specialist management, including of comorbidities not previously seen in haemophilia (which accompany today's increased life expectancy).

EHC Medical Advisory Group (MAG) member Prof. Johannes Oldenburg, University of Bonn, followed with '*Haemophilia treatment outcomes: raising the bar in the rise of novel treatments*.' While prophylaxis remains the gold standard for therapy there is a need for novel therapies. Prof. Oldenburg outlined the potential of true personalisation of haemophilia treatment with novel therapies, underscoring the important role of comprehensive care centres in the delivery of such personalisation of treatment and care.

Sébastien Lobet, Chair of the Physiotherapy Committee at the European Association for Haemophilia and Allied Disorders' (EAHAD), and member of Cliniques Universitaires St Luc, highlighted the importance of a multidisciplinary approach and individualisation in the provision of haemophilia care. To illustrate his point, he underscored the discrepancy between the structural condition of joints and their functionality, highlighting that novel therapies may improve joint function and mobility, but the underlying damage to joint structures from previous bleeds will remain unimproved and may indeed continue to deteriorate despite mobility gains. For this reason, even in a world of novel therapies, the close evaluation of patients and sensitive diagnostic tools made possible by CCCs will remain

vital to monitor the true health status of patients and to be in a position to respond quickly if needed.

Anna Griesheimer, staff person from the Deutsche Hämophilie Gesellschaft (DHG), the EHC's German National Member Organisation, raised the alarm on a proposed law in Germany during her talk on '*The role of comprehensive care centres in the distribution of treatment.*' This draft law – '*Gesetz für mehr Sicherheit in der Arzneimittelversorgung*' – was introduced in November 2018 and if passed would come into effect before the summer of 2019. While the intention behind the law was to make pricing more transparent and homogenous, Ms. Griesheimer highlighted the many ways in which this proposed law, if enacted, would in fact be detrimental and negligent in the haemophilia space, including:

- 1) Effectively limit patient visits to haemophilia treatment centres and CCCs, which would lead to the weakening of these centres and therefore to the endangerment of safety and traceability of treatment products, quality of treatment, safeguarding of documentation and erosion of scientific research, training and development. Ms. Griesheimer reminded audience members that the move to distribute haemophilia treatments through treatment centres was the direct result of the contamination of blood-based treatment products with HIV and hepatitis C in the 1980s and early 1990s and that by reversing this protection, the proposed law would create gaps in patient monitoring and gaps in traceability and therefore threaten the current reliable and safe system. In the eyes of the patients, such a move would be grossly negligent on the part of the government.
- 2) Very likely lead to increases in morbidity and mortality as haemophilia is a rare disease that can be life-threatening and for both reasons requires specialised treatment and medical expertise. Adequate treatment of haemophilia and its frequent co-morbidities (including HIV, hepatitis C and orthopaedic problems) is only possible in CCCs. Additionally, the introduction of novel products with their completely new modes of action should take place exclusively through CCCs as is the joint position of the EHC and EAHAD. Not doing so would lead to expert clinicians losing full control, oversight and documentation abilities, which would also lead to the erosion of data reporting into the national registry and overall quality and safety controls will become more difficult.
- 3) Finally, all of the above will lead to the loss of national expertise as, up until present, the centralisation of treatment through CCCs has ensured that expert healthcare providers are retained and able to grow their expertise through seeing a sufficient number of patients regularly. Regular interaction with patients is also a pre-condition for conducting scientific research and observational studies and, as is true for all rare diseases, good data collection is essential for the continued study and improvement of treatment protocols.

Ms. Griesheimer concluded her talk with a call to preserve the current model that works, and works very well, namely to maintain the distribution of haemophilia treatment products via haemophilia treatment centres, such as CCCs. Concerns about transparency may be addressed in other ways, she suggested, and cited one proposed strategy, namely to ensure that contracts between haemophilia centres and national health insurers are established.

It was certainly a ‘comprehensive’ Round Table of which the key takeaways include that, while it may seem that there are viable alternatives, the long-term effects of circumventing or reducing Comprehensive Care Centres would lead to increased costs and negative outcomes. “*We'll (certainly) need the European Union and others to further strengthen our hard-built, highly expert Comprehensive Care Centres in a world of post-novel therapies,*” Amanda Bok tweeted, and further reflected on the irony that, “*On one hand, we are building (European Reference Networks) ERNs to centralise European expertise in rare diseases, but on the other hand in haemophilia, which has trail-blazed this centralisation in comprehensive care centres, we're fighting to keep them.*”

MEP Meissner closed the meeting with words of gratitude for having learned many new angles to this complex disease state and flagging her support for the continued role of CCCs in Europe. She reiterated European Union Health and Food Safety Commissioner Vytenis Andriukaitis’ position that by working together and exchanging views on rare diseases, European expertise can be a world leader. It will take a partnership approach, but one thing today’s Round Table made clear is that the partners are there, and ready.

The full report of the event and additional information can be found [online here](#).

World Haemophilia Day: Celebrating 30 years of EHC

Officially, World Haemophilia Day is April 17. This is the birthday of World Haemophilia Foundation founder, Frank Schnabel. EHC celebrates this event a day earlier to accommodate a world-wide week of activity.

On April 16 from Dublin, members of our community gathered to honour not only World Haemophilia Day but also to officially launch EHC’s 30th anniversary Every Day is a Winding Road #EHCElebrate campaign.

EHC President Brian O’Mahony opened our World Haemophilia Day celebrations and 30th anniversary, reflecting that hope and history may rhyme as we honour our past and forge towards our future. He looked back at how both the community and the EHC as an organisation changed and grew in the past thirty years. Brian noted that the focus of the community’s activities shifted from a focus on the safety of treatment products to the inclusion of all patients (such as people with inhibitors, women with rare bleeding disorders and other bleeding disorders) within the community and the activities of the EHC. As for the EHC, the organization has grown and is growing in staff, activities and volunteer engagement.

Professor Wolfgang Schramm outlined how through the Wild Bad Kreuth initiatives, experts from across Europe came together to ensure that the tragedies of the 1980s HIV and HCV contaminations would never be repeated by developing safety standards for plasma-derived treatment products. He also showed the long collaborative process to develop clinical protocols for the treatment of haemophilia and the determination of prophylaxis as the gold standard of treatment.

EHC MAG Chair Professor Peyvandi outlined the positive experience of working with patient organisations such as the EHC and outlined the achievements of joint work between clinicians and patients. This work has included the development of certification standards for European haemophilia treatment centres, advocacy efforts with the EMA on the guideline for the development of coagulation FVIII, data collection and the development and dissemination of scientific and medical information through the EHC scientific conference, the EHC Workshop on Novel Technologies in Haemophilia Care and the EHC New Product Review (NPR) publication. Professor Peyvandi also noted the great efforts made by the EHC to promote eradication of HCV in the haemophilia community, something that she sees realistically happening by 2022.

Dr Radoslaw Kaczmarek dramatically quoted Irish-born Yeats in describing the EHC not waiting “*to strike till the iron is hot; but make it hot by striking*”. Radoslaw spoke about the revolution in treatment in haemophilia. He also described the development of the European principles of haemophilia care and their subsequent launch at the European Parliament in 2009 as one of the most significant achievements of the EHC.

EHC Steering Committee member Ms. Naja Skouw-Rasmussen from Denmark warned against complacency and called for continued efforts to not only improve access to care but to ensure that current achievements are maintained. She warned that growing cost-containment measures on national health care systems coupled with anti-European sentiments and a growing populist movement across Europe are a threat to access to health care and treatment that should not be ignored or underestimated. She concluded by noting that it is key to ensure that innovation is not only seen in haemophilia but also other rare bleeding disorders, calling for no one to be left behind.

Mr. Jim O’Leary, member of the inhibitor working group, underscored the importance of the work carried out by the EHC to empower the inhibitor community. For him, the biggest challenge that will be faced by the EHC in the coming years is an ageing population, which will be confronted for the first time to age-related co-morbidities. For him, the challenge will be to ensure timely access not only to haemophilia care but other medical specialties. Another challenge will be to ensure continued adequate care for people moving to care homes.

For Mr. Thomas Sannié from France, the future challenge of the EHC will be to continue to provide education and support to patients. The challenge will be also to be more inclusive not only of other rare bleeding disorders but also of other severities such as people with mild and moderate haemophilia.

The event continued with a panel discussion in which patients and clinicians outlined and discussed their perceived future challenges. Mr. Adam Sumera, Vice-President of the Polish NMO, noted how in many NMOs the main issue is to recruit and retain young volunteers to stay involved in the activities of the society, in particular as treatment levels improve. EHC CEO Amanda Bok pointed out that this is why the EHC has been focusing in the past few years on training youth and ensuring that young volunteers are engaged within their NMO. For her, it will be essential to develop a new framework in which these volunteers will be able to make their voice heard and given the opportunity to be passionate, active and grow into the leaders of tomorrow.

Panellists noted that the strengths of the EHC lies in its partnership and its ability to work with diverse stakeholders who are key players in the haemophilia landscape.

What message would you give to a newly elected ministry of health as a patient representative? produced clearer roads to advocacy. “*Reflect on what your predecessor didn’t do, listen to patients and their needs and finally, collaborate with their representatives to improve care.*” EHC CEO Amanda Bok unequivocally agreed, “*We will need to redefine how we advocate. We need to create a framework that inspires people and that gives them a space to flourish.*”

Panellists reiterated that adequately caring for an ageing population will be the main challenge in the next 30 years. In this regard, comprehensive care centres will need to reconsider the services they offer. Furthermore, panellists outlined how telemedicine may provide solutions to ensure that patients access timely specialised care, in particular when living far away from the treatment centre or within care homes.

Finally, discussions looked at novel treatments and how it will be crucial to ensure that data on the long-term effects of these novel products is collected. What endpoints should be collected? How can data be shared in the current legislative framework? Also are current Quality of Life measurements still reflecting accurately the efficacy of treatment. “*We are at an historic low in joint bleeds,*” noted EHC PARTNERS consultant, “*This measurement is no longer enough to adequately evaluate haemophilia treatments, we need new QoL tools to incentivize treatment improvements.*” “*However,*” noted Thomas Sannié noted, “*joint bleeds still happen! We need to ensure that novel treatments will prevent all bleeds and protect joints for a life-time for all patients. This will be real progress!*”

Watch photos from the event [online here](#).

Extensive Reporting from the First European Women and Bleeding Disorders (WBD) Conference

The EHC Women with Bleeding Disorders Conference which took place in Frankfurt, Germany on May 24th – 26 bringing together a group of over 150 people to discuss, for the first time, issues faced by women with bleeding disorders in Europe.

It was an idea that was long overdue: a conference, discussion and information-sharing platform for women with bleeding disorders. Abounding with misconceptions, general disregard and a lack of information, women with bleeding disorders have been sadly ignored and underrepresented in our communities. The First European Women and Bleeding Disorders (WBD) Conference, May 24-26, 2019 in Frankfurt, Germany, was an unqualified success. With over 30 countries, including representatives from the United States and Canada and partner organisations World Federation of Hemophilia (WFH) and National Hemophilia Foundation (NHF), the event went far beyond European borders. EHC CEO Amanda Bok opened the conference, establishing a safe and dynamic space for all participants. Prior to the event, Ms. Bok said, *"When we conceived the WBD conference, we took a leap of faith. Build it and they will come, we thought. Now it's here, and there is palpable excitement. For participants, it is finally something about them, something many of them thought would never happen."*

Day One

Naja Skouw-Rasmussen, Member of the EHC Steering Committee and Chair of the EHC WBD Committee, presented **Women and bleeding disorder in Europe: Results from EHC Survey** about women and bleeding disorders in Europe. The survey had a high response rate of 709 responses from 27 of the 46 EHC National Member Organisations (NMOs) members, and 15 responses from medical professionals. The survey was translated into numerous languages, including Russian, Dutch, French, Danish and Latvian. Questions included such topics as physical activity, active life, romantic and social life, and reproductive life. Alarmingly, between 40 to 70% of different groups, regardless of the severity of disorder, reported *my bleeding disorder impacts my desire or ability to have children*. Without a doubt, menstruation is the primary concern of participants, including how to talk about it, how to bring menstruation into the public arena without shame and how to help other women. It is almost inconceivable to many that women with bleeding disorders may endure needing to change their pads 40 times a day, or needing blood transfusions to get through a period, and this happens 12 times a year or more. The presentation included an overview of the status of treatment and the work and progress of NMOs. Education and frank discussion about treatment and understanding women's issues must involve a massive rethink about how we discuss and think about menstruation. Ms. Skouw-Rasmussen succinctly but perfectly said, *"We need to talk about it like every other bleed in our community."*

Dr. Michelle Lavin, Clinical Lead for coagulation haematology research at the Irish Centre for Vascular Biology at the Royal College of Surgeons in Ireland, presented the enlightening but alarming **Overview of rare bleeding disorders in women**. The main perception in nearly all societies is that bleeding disorders are a male issue. Where is the primary diagnosis point for

women? Treatment centres or gynecologists? Dr. Lavin presented shocking statistics of the current situation of women with bleeding disorders in Europe. Bleeding disorders of varying severity may affect as many as 4.5 million women in Europe. Of those numbers, the numbers of women being diagnosed is very low or even non-existent in some places. As Dr. Lavin pointed out, every patient with haemophilia has a mother. They are certainly not being picked up or detected. Dr. Lavin said, "*Diagnosis of von Willebrand disease in women (the most common bleeding disorder in women) is appalling.*" Dr. Lavin reinforced that, while diagnosis is relatively higher in some countries (85% in the Netherlands and 605 in Ireland), there is still incredible squeamishness about talking about menstruation. Dr. Lavin said we need to link websites and to create culturally-appropriate content. Last, and this may be true for nearly all patient organisations: patients should not only be involved in the data collection process of a survey but in the design of the survey. Dr. Lavin led an engaging question and answer session. Dr. Alison Dougall, Assistant Professor Dublin Dental University Hospital, reminded participants that the second primary sign of a bleeding disorders is gum bleeding. Unless women are alerted and specifically asked, this condition is often ignored. Dr. Dougall said, "*Healthy gums don't bleed.*" We should be asking "*how long gums bleed after brushing teeth*" as a sign of a bleeding disorder."

Dr. Eugenia Biguzzi, Haematologist at the Centro Emofilia e Trombosi A. Bianchi Bonomi in Milan followed with **Haemophilia – inheritance and carrier detection** and **RBD – transmission, inheritance and detection**. Dr. Biguzzi gave an informative presentation using the royal houses of Europe to illustrate and define bleeding disorders. The father will transmit the Y chromosome to sons without effect but the daughters will receive the X chromosome and be a carrier. The mother will transmit the chromosome to the son guaranteeing the condition, and with a 50% chance of transmission to a daughter. Why are there sporadic cases of haemophilia? Because gene mutations occur spontaneously and frequently. Everyone probably has mutations in any given gene. Genetic counselling involves obstetric/gynaecologists, haematologists and clinical genetics experts. The aims of genetic counselling are to inform a couple of their genetic risk, present care and treatment as well as reproductive options, and explain subsequent choices if the foetus is affected. Genetic counselling is preferable in pre-conception but in reality, usually happens after conception. Dr. Biguzzi presented an innovative way to understand DNA mutations through sentence patterning.

Dr. Karin van Galen, UMC Utrecht, spoke about **von Willebrand disease (VWD) – transmission, inheritance and detection**. How do we detect VWD? This is done through examination of bleeding history and laboratory assessment. Dr. van Galen's discussion included the pros (may help in subtyping, congenital vs. acquired) versus the cons (not diagnostic) of genetic testing. Dr. Razin Kadir, consultant obstetrician and gynaecologist at the Royal Free London hospital NHDS Foundation Trust, spoke about the importance and difficulties of **Prenatal diagnosis (PND) and testing** and the difficulties of reproductive choice and decision making, especially in reference to different cultural and religious considerations. Dr. Kadir discussed results of a PND survey and the revealing number that, in carriers considering their reproductive choices, over 50% decided not to have a child or more children. This number was borne out in EHC's survey. A quarter of patients terminated pregnancy. Additionally, the original PND method is invasive and sometimes risky resulting in foetal loss. Just over 20% of carriers of haemophilia used the procedure, versus over 70% with Down's syndrome. Yet there is hope. There is also a non-invasive PND procedure: free foetal DNA in

maternal plasma (detection of Y-chromosome-specific sequence (SRY)). This technique resulted in a dramatic overall uptake of PND. The question and answer discussion involved active participation discussing real-life experiences and the reality of most situations involving WBD and their reproductive choices, PND and child birth. Dr. Kadir said, "When we compare how long it has taken us to get this First Conference on Women and Bleeding Disorders, we still have a long way to go and must do our best." There was also discussion about the General Data Protection Regulation (GDPR), which has had a negative impact on access to information. Privacy rights sometimes do not allow for a greater sharing of information.

The World Federation of Hemophilia (WFH)'s Luisa Durante's **Raising awareness globally for women with inherited bleeding disorders** provided real-life experience of WBD initiatives in Honduras, Malaysia, Colombia, Botswana, Nicaragua and Bangladesh. Swedish Haemophilia Society's Anna Tollwé, Slovakia's NMO Vice-President MD. Martin Sedmina, Latvia Haemophilia Society President Baiba Ziemele and Slovakia's Alexandra Vaskova presented their experiences. Dr. Sedmina discussed the NMO's experience with WBD and its plan to create a women's committee (does your NMO have a women's committee?). Ms. Vaskova gave a **personal experience of a WBD in our society** and summer camps in Slovakia. Ms. Ziemele spoke about her experiences and difficulties in Latvia. Though small, the Latvian NMO and its website has 15,000 hits a year, proving that the demand for information and for a corresponding website and social media platform is a powerful weapon. Ms. Ziemele said, "Health is a human right, but it still took 10 years for me to receive adequate treatment." Ms. Tollwé gave an eye-opening presentation about the creation and difficulties of the Swedish NMO's women's committee. Even in liberal societies there can be initial resistance to discussion and better treatment for WBD. There was an audience-grabbing video showing how many girls with bleeding disorders suffer in silence (www.blodarsjuk.nu).

Day Two

Dr. Michelle Lavin chaired a panel discussion on **Preparing for menarche: Developing a treatment and management plan for heavy periods – including treatment options and how to approach and prepare for adolescence** with Dr. Rezan Kadir, Dr. Roseline d'Oiron (Clinician Investigator at the Reference Centre for Haemophilia and Other Congenital Rare Bleeding Disorders, Congenital Platelets Disorders and von Willebrand disease at Bicêtre Hospital AP-HP – Paris XI University), Anna Tollwé, Debra Pollard (Lead Nurse at Royal Free London NHS Foundation Trust) and Dr. Sylvia von Mackensen (Senior Scientist, University Medical Centre Hamburg).

The discussion started with frank comments on preparing young girls and speaking openly. A key point was reminding young women that they are not the problem; they have a disease that is causing the problem. Open discussion followed about what to expect and what language to use, for example the terms contraception, which might be alarming to parents, versus hormonal treatment to make lives better and reduce bleedings. Speakers discussed possible tools (e.g. the pill) and that one solution does not fit everyone. Panelists also discussed potential counter benefits, like hormonal difficulties and additional bleeding. The discussion progressed to adolescents and giving appropriate information about future pregnancies. With 1/3 of carriers having low-factor levels, testing is crucial. Bleeding may be the result of polyps, for example. Changes in bleeding patterns need to be assessed and understood. Outcomes of patient assessments may take up to two years, which may be a financial and time drain on patients. Dr. Lavin stressed, "*We need standardisation of data*

collection.” Dr. Lavin then brought up the design of such data collection. Patient panelists underscored that both males and females with VWD face recognition problems. Dr. Lavin affirmed the importance of information and said, “*Haemostasis is not just haemophilia.*” It was suggested haemophilia treatment centres might be renamed haemostasis treatment centers. Ill-health is not just physical. Heavy menstrual bleeding is also a quality of life issue. Dr. Lavin brought up the ridiculousness of making female athletes wear white and the psychosocial effects of such behavior. Doctors stressing possible solutions, NMO support and breaking taboos are essential. Ms. Pollard said, “*The impact of heavy menstrual bleeding (HMB) can be extremely isolating.*” The question and answer follow-up led to discussions about menopause and the stigma of early loss of menstrual cycles. Treatment centres and NMOs should and must have open access and healthcare professionals should be working in unison.

Other gynaecological issues in WBD was hosted by the Netherlands’ Evelyn Grimberg and Portugal’s Ana Pastor. Dr. Angelika Bartorova, Medical Director of the National Haemophilia Centre and Haemostasis and Thrombosis Unit of the Department of Haematology and Transfusion Medicine, University Hospital, Bratislava, presented extensive scientific discussion about bleeding in surgery, including treatment options for Rare Bleeding Disorders (RBD) and the do’s and don’ts for surgery. Dr. van Galen presented case studies, focusing on mid-cycle pain, possible hormonal ovulation suppression and timely treatment with clotting factor correction in cases where patients desire pregnancy. Dr. Mackensen discussed the impact of bleeding disorders on women’s health-related quality of life (HRQoL). Psychosocial programmes should be created, expanded and supported. Dr. Ioannis Tsimpanakos, consultant in obstetrics and gynaecology from the Royal Free London NHS Foundation Trust, presented **Management of pelvic pain in women with bleeding disorders**, discussing chronic vs. acute pain, and non-hormonal pharmacological management. Dr. Tsimpanakos said, “We need to educate doctors.” Ms. Grimberg presented experiences about preparing for surgery. Almost given painkillers with blood thinners, Evelyn learned and expressed that preparing yourself is crucial.

Two breakout sessions followed: **Fertility and pregnancy in bleeding disorders** with moderators Dr. Roseline d’Oiron, Dr. Rezan Kadir and Norway’s Marie Lahn Rømcke This breakout session was as open discussion in which participants were able to freely discuss any issues surrounding fertility and pregnancy in women affected by bleeding disorders. **Support from your NMO and peer-to-peer support** followed with moderators Evelyn Grimberg and France’s Yannick Collé: This breakout session showcased examples on how to build a peer support group and how to utilise your NMO to raise awareness about and provide support to women with bleeding disorders. There was a very useful practical exercise on how to create a women’s committee in your NMO.

EHC Steering Committee Member and AFH’s Olivia Romero-Lux chaired **Non-gynaecological issues in women with bleeding disorders.** The session started with Detection & management of iron deficiency and anaemia in WBDs with Dr. Biguzzi. Dr. Biguzzi stressed the importance of sharing information with the patient. Oral therapy in low doses for non-anaemic patient (better absorption), and of course a higher rate in anaemic patients, which may cause stomach issues and other unwanted side-effects. Intravenous therapy has dramatically improved (requiring fewer injections). Recommendations included eating well, listening to

your body and checking haemoglobin levels. Oral care in WBD with Dr. Alison Dougall stressed that dental health is mandatory for overall holistic health. People with haemophilia are five times more likely to have gingivitis and there is nearly no data about women with bleeding disorders and dental health. Dr. Dougall led a popular session about smiling and understanding societal perceptions while also offering practical solutions.

Women and Bleeding Disorders Premiere

For many, the Saturday night screening of "[Women and Bleeding Disorders](#)" was the highlight of the conference. Directed and produced by director Goran Kapetanovic, who previously collaborated with the EHC on "Haemophilia Stories" and "Inhibitor Stories," the film echoed the general mood of the conference. Through all the science, difficult subject matter and understandably deep emotion, a true sense of camaraderie and the feeling that something special was happening permeated Day Two.

Day Three

Sunday's sessions started with the **Impact of bleeding disorders on quality of life** (QoL) with Naja Skouw-Rasmussen. After a discussion of the tools to evaluate quality of life, there was a comparison of male vs. female experience of bleeding disorders. There was an analogy comparing QoL between patients with HIV and female patients with bleeding disorders with regard to both cohort's uncertainty about the future. Support from family and friends, your NMO and healthcare professionals (and to properly and adequately involve your healthcare professional) also has a dramatic effect on QoL. When considering QoL, Ms. Skouw-Rasmussen said, "*You must consider what QoL is for you. What kind of limitations do you set for yourself because of the bleeding disorder?*"

Psycho-social issues with Debra Pollard started with a heart-warming moment of praise for the conference, a feeling that was expressed over and over again by participants. Ms. Pollard expressed the reality that many mothers and families with members with bleeding disorders feel when she said, "*We all want to hug our children. What happens when you pick up your baby who has a severe bleeding disorder? You are afraid you will leave a bruise. That has an immense psycho-social impact on a mother and a family.*" The holistic and emotionally-realistic presentation included spiritual health and a checklist of difficult psych-social issues: being believed, fighting for care, mother's instincts, physical health affecting mental/emotional health, sexuality and relationships, and even guilt. This was echoed by participants, many of whom stressed that the sense of guilt was one of the primary issues faced by WBD.

Two breakout sessions followed: One was on **Management of labour, delivery and neonatal care** with moderators Dr. Rezan Kadir and Dr. Angelika Batorova. This breakout session was an open discussion in which participants were able to freely discuss any issues related to the management of labour, delivery and neonatal care in women affected by bleeding disorders. The other session was on **Support from the haemophilia treatment centre** with moderators Debra Pollard and Liora Tevet (Director of Aleh, the Israalil Haemophilia Association). In this breakout session, moderators explored how to build dialogue with and ensure that women with bleeding disorders are recognised by local haemophilia treatment centres. This breakout session was an open discussion in which participants were able to freely engage with moderators and other participants.

Recurring themes of the First European Women and Bleeding Disorders Conference included: having no diagnosis or under-diagnosis, the general lack of knowledge/information, and the need for much more effort by all bleeding disorder organisations, treatment centres and NMOs to ensure awareness, education and appropriate advocacy tools. If there was a primary takeaway from the conference, it was the establishment of an anthem for women with bleeding disorders: you are not alone. The sense of excitement, progress, empowerment and finally being heard and listened to was immeasurable: stronger, together. The future is looking a little bit brighter. Hungarian participant and EHC Youth Leadership alumni Karola Diosi said, "This is the place I have to be."

Find the complete event and programme [here](#) and consult more [photos](#) and [impressions](#) from the event here.

The Conference received platinum-level sponsorship from CSL Behring and silver-level sponsorship from Novo Nordisk. Takeda contributed financially towards the "Women and Bleeding Disorders" documentary.



Discussion on Women with Bleeding Disorders on Dutch National TV

Women with Bleeding Disorders was featured in a segment aired on Dutch National TV.

European Haemophilia Consortium (EHC) Women and Bleeding Disorders Committee member and Youth Leadership alumni Evelyn Grimberg took to the Dutch airwaves to discuss women and bleeding disorders. The nationally-syndicated show highlighted the reality that women with bleeding disorders, even in countries with advanced medical systems like the Netherlands, are often undiagnosed or under-diagnosed. The European Haemophilia Consortium and the EHC Women and Bleeding Disorders (WBD) Committee are leading the way to not only reach this part of our community but to lead, encourage and provide a safe atmosphere for discussion.

Evelyn Grimberg and Karin van Galen (haematologist). Ms. Van Galen works at UMC Utrecht at the van Creveldkliniek. Her focus is on women and bleeding disorders. Ms. Van Galen initiated the Women and Bleeding Disorder Committee of the European Association for Haemophilia and Allied Disorders (EAHAD). She also assisted with the European Haemophilia Consortium survey on women (first publication came out this week).

Evelyn told us '*What we wanted to do was to bring more attention to heavy blood loss during menstrual cycles and under-diagnosis of bleeding disorders. Karin briefly explained what a bleeding disorder is and where the problem can be. She also expressed that for women it is substantially more difficult because every month they have a bleeding when they have their period. Karin also listed other symptoms like nose bleeds, bruising and bleeding after surgery / visiting the dentist.*'

Evelyn then explained that she spoke about her personal experience and the challenges she faces, including changing clothes often, low blood levels, being hospitalised and blood transfusions.

Evelyn said '*We focused on the fact that unless there are symptoms, diagnoses are often delayed. However, symptoms do not always appear together. These symptoms may include gum problems at the dentist, heavy periods, nose bleeds and so on. Sadly, in our society, a heavy period is a subject that is not easy to talk about. Also, this is not always recognised as an issue by women themselves, because it is unidentified as their mother or sisters have the same issues. What is heavy blood loss? When do you bleed too much? We talked about the menstruation score card where you can screen yourself for a possible bleeding disorder.*'

One primary question of the presenter included how often do we see this? Karin said that 1 in 100 women has a bleeding disorder, and that having heavy blood loss during a period happens quite often in women. Karin also said that 1 out of 5 women who go to the gynaecologist with heavy blood loss has a bleeding disorder.

To view the interview in its entirety (in Dutch) click [here](#).

Calendar of Events

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| September 6-8 | Workshop on Tenders and Procurement
Istanbul, Turkey |
| October 3 | Pre-Conference Workshop on the European Inhibitor Network
Skopje, North Macedonia |
| October 4 | EHC Annual General Assembly
Skopje, North Macedonia |
| October 4-6 | EHC 2019 Conference
Skopje, North Macedonia |
| November 22-24 | Workshop on New Technologies in Haemophilia Care
Athens, Greece |
| Nov 8 – Dec 1 | Inhibitor Summit
Barretstown, Ireland |
| December 3 | Round Table of Stakeholders on 'Markets and Access'
Brussels, Belgium |