



# EHC Conference 2022- Programme

6-9 October 2022

Scandic Hotel, Copenhagen and online

## Thursday 6 October 2022

9.00 - 17.00

**European Rare and Inhibitor Network (ERIN) Training Session**  
*Building an Expertise from Knowledge to Action*

Open to EHC NMO volunteers only  
Registration required

10.00 - 17.15

**von Willebrand Platform Community Workshop**  
*From Guidelines and Principles to Reality*

Open to EHC NMO volunteers only  
Registration required

18.00 - 21.30

**EHC Committees and Working Groups Networking Events (followed by dinner)**

Open to EHC volunteers only  
Registration required

## Friday 7 October 2022

8.30 - 17.15

**EHC Conference**

Open to all

17.30 - 19.30

**EHC General Assembly**

Open to EHC NMOs and patients

17.30 - 19.30

**EHC Nurses Workshop on Sexual Health and Intimacy**

Open to nurses only  
Registration required

## Saturday 8 October 2022

8.30 - 17.15

**EHC Conference**

Open to all

## Sunday 9 October 2022

8.30 - 12.45

**EHC Conference**

Open to all

8.30 - 9.30	<p><b>Quality of Life: The Danish Experience</b> <i>Chaired by Jacob Andersen and Lone Hvitfeldt Poulsen</i></p> <p>Conference Opening - <i>Magnus Heunicke</i> Survey on quality of life - <i>Eva Funding</i> Apps to track quality of life: The Danish Experience - <i>Lone Hvitfeldt Poulsen</i></p>	
9.45 - 10.45	<p><b>Shared-Decision-Making and Education</b> <i>Chaired by Jacob Andersen and Thomas Sannié</i></p> <p>Shared-decision-making in practice - <i>Kate Khair</i> Shared decision-making in physiotherapy: Local physiotherapy vs HTC - <i>Merel Timmer</i> A patient perspective - <i>Lars Münter</i></p>	
10.45 - 11.15	<p><b>Coffee break</b> Meet our Exhibitors, learn about the <b>EHC Think Tank</b> at the EHC stand and visit the EHC exhibition 'Open the Door to Another Reality.'</p>	
11.15 - 12.15	<p><b>Mild and Moderate Bleeding Disorders</b> <i>Chaired by Julia Rauscher and Karin Fijnvandraat</i></p> <p>What will future mild patients need? - <i>Jo Eerens</i> Addressing mild patients in the clinic - <i>Sophie Susen</i> The work of the European Haematology Association (EHA) on mild bleeding disorders - <i>Francesco Rodeghiero (presenting remotely)</i></p>	
12.15 - 12.45	<p><b>Lunch</b></p>	
12.45 - 13.30	<p><b>Takeda Symposium</b> <i>Living with a Rare Bleeding Disorder: Overcoming Mental and Physical Pain</i></p>	
13.45 - 14.30	<p><b>Sobi Symposium</b> <i>Informed Decision-Making: Jointly Balancing the Needs for Today and the Future</i></p>	
14.30 - 15.00	<p><b>Coffee break</b> Meet our Exhibitors, learn about the <b>EHC Women and Bleeding Disorders</b> activities at the EHC stand and visit the EHC exhibition 'Open the Door to Another Reality.'</p>	
15.00 - 16.00	<p><b>Women and Bleeding Disorders</b> <i>Chaired by Evelyn Grimberg and Roseline d'Oiron</i></p> <p>Impact of gynaecological bleeds on fertility - <i>Rumana Islam (presenting remotely)</i> Patient perspectives - <i>Marion Bräuer</i> <i>Women and Bleeding Disorders: Focus on novel therapeutic approaches - Bernd Jilma</i></p>	
16.15 - 17.15	<p><b>Von Willebrand Disease</b> <i>Chaired by Sophie Susen and Eva Funding</i></p> <p>Stepping stones and challenges that remain - where can we support the data - <i>Sophie Susen</i> From guidelines and principles of care to reality: Implementation in clinical care - <i>Mike Makris</i> The importance of the comprehensive care team - <i>Sunjeev Maini and Greta Mulders</i></p>	
17.30 - 19.30	<p><b>EHC General Assembly</b></p> <p><i>Open to EHC NMOs and patients ONLY</i></p>	<p><b>EHC Nurses Workshop on Sexual Health and Intimacy</b></p> <p><i>Open to nurses ONLY</i></p>
19.45 - 21.30	<p><b>Welcome dinner</b> <i>Scandic Hotel Copenhagen</i></p>	

8.30 - 9.30	<p><b>An Update on Clinical Practices in Replacement and Non-replacement Therapies</b> <b>Chaired by Ilmar Kruis and Carmen Escuriola-Ettinghausen</b></p> <p>State of the art clinical practices with replacement and non-replacement therapies - <i>Robert Klamroth (presenting remotely)</i> Patient perspectives - <i>Nathan Doyle and Eke Hullegie</i></p>
9.45 - 10.45	<p><b>An Update on Haemophilia Gene Therapy</b> <b>Chaired by Declan Noone and Nanda Uitslager</b></p> <p>Latest developments in haemophilia gene therapy - <i>Flora Peyvandi</i> Haemophilia gene therapy then and now - <i>Jack Grehan</i></p>
10.45 - 11.15	<p><b>Coffee break</b></p> <p>Meet our Exhibitors, learn about the EHC activities on <b>Inhibitors and Rare Bleeding Disorders</b> at the EHC stand and visit the EHC exhibition 'Open the Door to Another Reality.'</p>
11.15 - 12.15	<p><b>Maintaining Liver Health</b> <b>Chaired by Clive Smith and Evelyn Mauser-Bunschoten</b></p> <p>Recommendations on maintaining liver health post HCV clearance - <i>Vincenzo LaMura</i> Liver health in a world of gene therapy - <i>Johannes Oldenburg</i> Roles and (new) responsibilities for patient organisations - <i>Brian O'Mahony</i></p>
12.15 - 12.45	<p><b>Lunch</b></p>
12.45 - 13.30	<p><b>BioMarin Symposium</b> <b>Ageing with a Bleeding Disorder</b></p>
13.45 - 14.30	<p><b>Pfizer Symposium</b> <b>Expanding patient access to innovative therapies: Health system challenges for new innovative therapies and learnings on novel methods to support patient access</b></p>
14.30 - 15.00	<p><b>Coffee break</b></p> <p>Meet our Exhibitors, learn about the EHC <b>Youth</b> activities at the EHC stand and visit the EHC exhibition 'Open the Door to Another Reality.'</p>
15.00 - 16.00	<p><b>Treatment Centres and Youth Debates</b> <b>Chaired by Miguel Crato and Ana Boban</b></p> <p>Developing an audit for the EUHANET certification of haemophilia treatment centres - <i>Fariba Baghaei</i> Youth Debates With advancing therapies, reductions in bleeds, better joints and outcomes - should we focus on developing centres of excellence or invest in telemedicine? <i>Dominik Cepic in favour of telemedicine and Admir Mehic in favour of centres of excellence</i> <i>Centres of Excellence are home to expertise, but local centres is home to a life-long relationship with healthcare providers. What is more important - trust or expertise?</i> <i>Anya Ganeva in favour of expertise and Conor Birkett in favour of trust</i></p>
16.15 - 17.15	<p><b>SLAMS</b> <b>Chaired by Declan Noone and Peter Kampmann</b></p> <p>On comprehensive care <i>Joint health - Roberta Gualtierotti</i> <i>The carousel polyclinic model - Greta Mulders</i></p> <p>On treatment <i>Advances in Glanzmann Thrombasthenia - Kate Khair</i> <i>Clinical applications of a-tamers in bleeding disorders - Berndt Jilma (presenting remotely)</i></p> <p>On patient organisations <i>Pre-clinical emergency care in haemophilia - Martin Sedmina</i> <i>Accessibility of physiotherapy outside the haemophilia treatment centre - Dan McIntyre</i></p>
19.00 - 19.30	<p><b>Departure and transport</b></p>
19.45 - 00.00	<p><b>Conference dinner</b> <b>Marriott Hotel Copenhagen</b></p>



**8.30 - 9.45**      ***Reporting and monitoring mechanisms for existing and novel therapies in rare bleeding disorders***

***Chaired by Amanda Bok and Marie Louise Schougaard Christiansen***

How should novel therapies be monitored? - *Mike Makris*

Regulatory changes for advanced medicinal products - *Anja Schiel*

WFH World Gene Therapy Registry - *Glenn Pierce*

Roles and responsibilities for patient organisations - *Miguel Crato*

**10.00 - 10.45**

**CSL Behring Symposium**

**Psycho-social Learnings from COVID**

**10.45 - 11.15**

**Coffee break**

Meet our Exhibitors, learn about the EHC von Willebrand activities at the EHC stand and visit the EHC exhibition 'Open the Door to Another Reality.'

**11.15 - 12.00**

**Novo Nordisk Symposium**

**Advancing Treatment and Care for all Rare Bleeding Disorders**

**12.15 - 12.45**

**Closing session**

***Chaired by Declan Noone and Jacob Andersen***