



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

Quality of Life: The Danish Experience

Chaired by Jacob Andersen and Lone Hvitfeldt Poulsen

Conference Opening - *Magnus Heunicke*

Survey on quality of life - *Eva Funding*

Apps to track quality of life: The Danish Experience - *Lone Hvitfeldt Poulsen*

9.45 - 10.45

Shared-Decision-Making and Education

Chaired by Jacob Andersen and Thomas Sannié

Shared-decision-making in practice - *Kate Khair*

A case study in physiotherapy - *Merel Timmer*

A patient perspective - *Lars Münter*

10.45 - 11.15

Coffee break

Meet our Exhibitors, learn about the **EHC Think Tank** at the EHC stand and visit the EHC exhibition 'Open a Door to a New Reality.'

11.15 - 12.15

Mild and Moderate Bleeding Disorders

Chaired by Julia Rauscher and Karin Fijnvandraat

What will future mild patients need? - *Jo Eerens*

Addressing mild patients in the clinic - *Sophie Susen*

The work of the European Haematology Association (EHA) on mild bleeding disorders - *Francesco Rodeghiero (presenting remotely)*

12.15 - 12.45

Lunch

12.45 - 13.30

Takeda Symposium

Living with a Rare Bleeding Disorder: Overcoming Mental and Physical Pain

13.45 - 14.30

Sobi Symposium

Informed Decision-Making: Jointly Balancing the Needs for Today and the Future

14.30 - 15.00

Coffee break

Meet our Exhibitors, learn about the **EHC Women and Bleeding Disorders** activities at the EHC stand and visit the EHC exhibition 'Open a Door to a New Reality.'

15.00 - 16.00

Women and Bleeding Disorders

Chaired by Evelyn Grimberg and Roseline d'Oiron

Impact of gynaecological bleeds on fertility - *Rumana Islam (presenting remotely)*

Patient perspectives - *Marion Bräuer*

Women and Bleeding Disorders: Focus on novel therapeutic approaches - *Bernd Jilma*

16.15 - 17.15

Von Willebrand Disease

Chaired by Sophie Susen and Eva Funding

Guidelines for the management of von Willebrand Disease - *Manon Degenaar-Dujardin*

From guidelines and principles of care to reality: Implementation in clinical care - *Mike Makris*

The importance of the comprehensive care team - *Sunjeev Maini and Greta Mulders*

17.30 - 19.30

EHC General Assembly

Open to EHC NMOs and patients ONLY

EHC Nurses Workshop on Sexual Health and Intimacy

Open to nurses ONLY

19.45 - 21.30

Welcome dinner

Scandic Hotel Copenhagen

8.30 - 9.30	<p>An Update on Clinical Practices in Replacement and Non-replacement Therapies Chaired by Ilmar Kruis and Carmen Escuriola-Ettinghausen</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>An Update on Haemophilia Gene Therapy Chaired by Declan Noone and Nanda Uitslager</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>Coffee break</p> <p>Meet our Exhibitors, learn about the EHC activities on Inhibitors and Rare Bleeding Disorders at the EHC stand and visit the EHC exhibition 'Open a Door to a New Reality.'</p>
11.15 - 12.15	<p>Maintaining Liver Health Chaired by Clive Smith and Evelyn Mauser-Bunschoten</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>Lunch</p>
12.45 - 13.30	<p>BioMarin Symposium Ageing with a Bleeding Disorder</p>
13.45 - 14.30	<p>Pfizer Symposium Expanding patient access to innovative therapies: Health system challenges for new innovative therapies and learnings on novel methods to support patient access</p>
14.30 - 15.00	<p>Coffee break</p> <p>Meet our Exhibitors, learn about the EHC Youth activities at the EHC stand and visit the EHC exhibition 'Open a Door to a New Reality.'</p>
15.00 - 16.00	<p>Treatment Centres and Youth Debates Chaired by Miguel Crato and Ana Boban</p> <p>Developing an audit for the EUHANET certification of haemophilia treatment centres - <i>Fariba Baghaei</i> Youth Debates <i>Dominik Cepik and Admir Mehic</i> <i>Anya Ganeva and Conor Birkett</i></p>
16.15 - 17.15	<p>SLAMS Chaired by Declan Noone and Peter Kampmann</p> <p>On comprehensive care <i>Joint health - Roberta Gualtierotti</i> The carousel polyclinic model - <i>Greta Mulders</i></p> <p>On treatment Advances in Glanzmann Thrombasthenia - <i>Kate Khair</i> Clinical applications of a-tamers in bleeding disorders - <i>Berndt Jilma (presenting remotely)</i></p> <p>On patient organisations Pre-clinical emergency care in haemophilia - <i>Martin Sedmina</i> Accessibility of physiotherapy outside the haemophilia treatment centre - <i>Dan McIntyre</i></p>
19.00 - 19.30	<p>Departure and transport</p>
19.45 - 00.00	<p>Conference dinner Marriott Hotel Copenhagen</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 a Door to a New 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