



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*

Shared decision-making in physiotherapy: Local physiotherapy vs HTC - *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 the Door to Another 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 (presenting remotely)*

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 the Door to Another 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 (presenting remotely)*

16.15 - 17.15

Von Willebrand Disease

Chaired by Sophie Susen and Eva Funding

Stepping stones and challenges that remain - where can we support the data - *Sophie Susen (presenting remotely)*

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>Dominik Cepic 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>Brian O'Mahony</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 the Door to Another 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 (presenting remotely)</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 the Door to Another 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 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>SLAMS Chaired by Declan Noone and Peter Kampmann</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 aptamers 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 - Jim O'Leary</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* (presenting remotely)

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