

EHC WBD Conference 2022

19-22 May 2022 – Pullman Basel Europe, Basel, Switzerland and online

Thursday 19 May		Friday 20 May		Saturday 21 May		Sunday 22 May	
		Focus on QoL		Focus on patient life cycle		Focus on comprehensive care	
		08.00-12.15	<i>Registrations</i>	09.00-10.30	Session 2 Women's issues at different stages of their lives	09.00-10.00	Session 5 Focus on musculoskeletal health
		12.15-12.45	Conference opening Principles of Care for Women and Bleeding Disorders	10.30-11.00	<i>Break</i>	10.00-10.15	<i>AV Break</i>
		12.45-13.00	<i>AV Break</i>			10.15-11.15	Session 6 Focus on fertility
		13.00-14.00	Session 1 Monitoring for the improvement of quality of life	11.00-13.00	Peer-to-peer sessions <i>On-site participants only</i>	11.15-11.30	<i>Break</i>
		14.00-14.30	<i>Break</i>			11.30-12.00	Session 7 Focus on iron deficiency
		14.30-16.00	Breakout sessions Management of bleeding disorders in WBD Practical tips for patients and clinicians	13.00-14.30	<i>Lunch</i>	12.00-12.15	<i>Break</i>
		16.00-16.30	<i>Break</i>	14.30-16.00	Session 3 Ageing and bleeding disorders	12.15-13.15	Session 8 Advocacy session
		16.30-17.45	CSL Behring Symposium Cinderella: The glass slipper meets the glass ceiling	16.00-16.30	<i>Break</i>	13.15-13.30	Conference closure
		16.30-17.45	CSL Behring Symposium Cinderella: The glass slipper meets the glass ceiling	16.30-17.30	Session 4 Psychosocial issues		
		17.45-19.15	<i>Break</i>	17.30-18.30	<i>Break</i>		
14.00 – 18.00	<i>Registrations</i>	19.15-19.45	Cocktail talks	18.30-19.30	Screening of the 'Mulheres' movie		
				19.30-19.45	<i>Break</i>		
19.30 – 21.30	<i>Welcome dinner</i>	19.45-21.45	<i>Dinner</i>	19.45-20.15	<i>Transfer to restaurant</i>		
				20.15-22.15	<i>Dinner and transfer back to hotel</i>		

Friday 20 May	
Focus on Quality of Life	
08.00-12.00	<i>Registrations</i>
12.15-12.45	<p>Conference opening Principles of Care on Women and Girls with Bleeding Disorders</p> <p>12.15-12.20 Opening speech <i>Evelyn Grimberg</i></p> <p>12.20-12.40 Panel discussions on the importance of the PoC in WBD <i>Declan Noone, Naja Skouw-Rasmussen, Evelyn Grimberg and Debra Pollard</i></p> <p>12.40-12.45 Q&A and closing <i>Evelyn Grimberg</i></p>
12.45-13.00	<i>AV break</i>
13.00-14.00	<p>Session 1 – Joint EHC-EAHAD Session Monitoring for the improvement of quality of life</p> <p>13.00-13.05 Welcome and introduction to the session <i>Diana Lighezan</i></p> <p>13.05-13.20 Where are the women and girls with bleeding disorders? <i>Declan Noone</i></p> <p>13.20-13.35 What can we do when we lose contact with WGBD? <i>Roseline d’Oiron</i></p> <p>13.35-13.55 Q&A and panel discussion <i>Diana Lighezan, Declan Noone and Roseline d’Oiron</i></p> <p>13.55-14.00 Closing <i>Diana Lighezan</i></p>
14.00-14.30	<i>Break</i>
14.30-16.00	<p>Breakout sessions Management of bleeding disorders in WBD Practical tips for patients and clinicians</p> <p><u>Tips for a better management of bleeding disorders in the everyday life</u> <i>For onsite delegates only!</i></p> <p>14.30-14.35 Welcome and introduction Manon Degenaar-Dujardin</p> <p>14.35-14.45 How to collect data for yourself? Priyanka Raheja</p> <p>14.45-15.10 What is normal and when to seek medical support? Joint patient-clinician talk Priyanka Raheja & Evelyn & Anna</p> <p>15.10-15.50 Advice from a lifestyle coach – coping strategies for everyday challenges Svetoslava Stoyanova</p> <p>15.50-15.55 Q&A All</p> <p>15.55-16.00 Closure</p> <p><u>Models for improving the care of women and bleeding disorders</u></p> <p>14.30-14.35 Welcome and introduction <i>Naja Skouw-Rasmussen</i></p> <p>14.35-15.05 How to make multidisciplinary teams work: Case studies and best practices <i>Eva Funding (virtual speaker) on the collaboration between children and adult services to improve transition of female patients with bleeding disorders</i></p>

	<p><i>Rezan Kadir and Keith Gomez (virtual speaker) on a joint haematological-gynaecological clinic</i></p> <p>15.05-15.25 Improving pathways for WBD patients <i>Ana Boban (virtual speaker)</i></p> <p>15.25-15.45 Working with patient organisations: a conversation Beatrice Nolan & Cristina Catarino (virtual speaker)</p> <p>15.45-16.00 Q&A and closure Naja Skouw-Rasmussen</p>
16.00-16.30	<i>Break</i>
16.30-17.45	<p>CSL Behring Symposium - Cinderella: The Glass slipper meets the glass ceiling</p> <p>16.30-16.35 Welcome and introduction <i>Manon Degenaar-Dujardin</i></p> <p>16.35-17.20 The Cinderella study – The experience of women with a diagnosed bleeding disorder: Improving the understanding of their unmet needs <i>Debra Pollard and Kate Khair</i></p> <p>17.20-17.40 Discussions with the audience: which steps to take to serve the unmet needs of women with bleeding disorders? <i>Discussions moderated by Manon Degenaar-Dujardin</i></p> <p>17.40-17.45 Key take-aways and meeting closure <i>Manon Degenaar Dujardin</i></p>
17.45-19.15	<i>Break</i>
19.15-19.45	<p>Cocktail talks</p> <p>Welcome and introduction <i>Laura Savini</i></p> <ol style="list-style-type: none"> 1. Report from the breakout sessions <i>Zita Gacser and Kristine Jansone</i> 2. Introducing EHCucate <i>Daria Mironova</i> 3. Sister, you're not alone: A podcast on women and bleeding disorders <i>Maia Meier (pre-recorded video)</i>
19.45-21.45	<i>Dinner in the hotel</i>

Saturday 21 May

Focus on patient life cycle

09.00-10.30	<p>Session 2 Women's issues at different stages of their lives</p> <p>09.00-09.05 Welcome and introduction <i>Tatjana Markovic</i></p> <p>09.05-09.25 Heavy menstrual bleeds and other gynaecological bleeds <i>Rezan Kadir</i></p> <p>09.25-09.45 Sexual health and intimacy for women with bleeding disorders <i>Nanda Uitslager</i></p> <p>09.45-10.05 Family planning – How does genetic counselling work and key considerations <i>Omid Seidizadeh</i></p> <p>10.05-10.20 Q&A</p> <p>10.20-10.30 Closing and announcing peer-to-peer sessions <i>Tatjana Markovic</i></p>
10.30-11.00	<i>Break</i>
11.00-13.00	<p>Peer-to-peer sessions <i>For on-site patient representatives and healthcare professionals only.</i></p> <p><i>On-site participants are split in four groups for P2P 30' discussions on the topics of:</i></p> <ul style="list-style-type: none"> • <i>Preparing for menarche w Rezan Kadir, Beatrice Nolan, Debra Pollard and Evelyn Grimberg;</i> • <i>Sexual health and intimacy w Nanda Uitslager and Marion Bräuer;</i> • <i>Family planning w Omid Seidizadeh, Priyanka Raheja and Anna Tollwé;</i> • <i>Ageing and WBD w Roseline d'Oiron, Sheila Radhakrishnan and Yannick Collé.</i> <p><i>Every group will have an opportunity to discuss each topic.</i></p>
13.00-14.30	<i>Lunch</i>
14.30-16.00	<p>Session 3 Ageing and bleeding disorders</p> <p>14.30-14.35 Welcome and introduction <i>Yannick Collé</i></p> <p>14.35-15.00 Talking about menopause <i>Sheila Radhakrishnan</i></p> <p>15.00-15.10 Q&A</p> <p>15.10-15.30 Changes in bleeding phenotypes with age <i>Roseline d'Oiron</i></p> <p>15.30-15.55 Panel discussion on how to tackle changes around menopause <i>All and Rezan Kadir</i></p> <p>15.55-16.00 Closing <i>Yannick Collé</i></p>
16.00-16.30	<i>Break</i>
16.30-17.30	<p>Session 4 Psychosocial issues</p> <p>16.30-16.35 Welcome and introduction Evelyn Grimberg and Tatjan Markovic</p> <p>16.35-16.50 Outlining the psychosocial issues and themes that emerged from the peer-to-peer sessions Fiona Brennan and Kristine Jansone</p>

	16.50-17.15 Discussions between a psychologist and patient representatives Dr Jelisaveta Todorovic, Connie Montgomery and Anna Tollwé 17.15-17.25 Q&A 17.25-17.30 Closure Evelyn Grimberg & Tatjana Markovic
17.30-18.30	<i>Break</i>
18.30-19.30	<i>Screening of the 'Mulheres' movie Introduction by Anna Rita Tavares</i>
19.30-19.45	<i>Break</i>
19.45-21.45	<i>Dinner</i>

Sunday 22 May

Focus on comprehensive care

09.00-10.00	Session 5 Focus on musculoskeletal health 09.00-09.05 Welcome and introduction <i>Katja Peltoniemi</i> 09.05-09.20 Taking care of your teeth with a bleeding disorder <i>Alison Dougall</i> 09.20-09.45 Taking care of your joints <i>Laurent Frenzel</i> 09.45-10.00 Q&A and closing <i>Katja Peltoniemi</i>
10.00-10.15	<i>Break</i>
10.15-11.15	Session 6 Focus on fertility – for onsite delegates only. 10.15-10.20 Welcome and introduction Anna Tollwé 10.20-10.40 Personal stories on WBD and infertility Diana Lighezan 10.40-10.55 Panel discussions Moderated by Evelyn Grimberg Anna Tollwé, Diana Lighezan and Marion Bräuer 10.55-11.10 Q&A + sharing Moderated by Anna Tollwé 11.10-11.15 Closing Anna Tollwé
11.15-11.30	<i>Break</i>
11.30-12.00	Session 7 Focus on iron deficiency 11.30-11.35 Welcome and introduction <i>Marion Bräuer</i> 11.35-11.55 Talk on iron deficiency in WBD Anna Boban 11.55-12.00 Q&A and closure
12.00-12.15	<i>Break</i>
12.15-13.15	Session 8 Advocacy and take-aways 12.15-12.20 Welcome and introduction <i>Declan Noone</i> 12.20-12.35 Advocacy 101 <i>Tatjana Markovic</i> 12.35-12.45 Examples of WBD Campaigns from across Europe <i>Yannick Collé and Evelyn Grimberg</i>

	<p>12.45-12.55 EHC offered advocacy resources: Leadership Conference and Youth Leadership Conference <i>Kristine Jansone and Fiona Brennan</i></p> <p>12.55-13.05 Q&A</p> <p>13.05-13.15 Practical exercise</p>
13.15-13.30	<p>Conference closure <i>Chair: Diana Lighezan</i></p> <p><i>Take-aways and closing messages: Declan Noone, Evelyn Grimber and Manon Degenaar</i></p>