

# EHC Women and RBD Conference 2019

24-26 May 2019

Le Meridien Hotel

Frankfurt, Germany

Draft Programme

Friday 24 May 2019	
08.00 – 12.00	Exhibition, Posters and Registration Set-Up
10.00 – 12.00	Arrival / Registration / Lunch
11.50 – 12.00	<b>Welcome to the Conference and introduction to the work of EHC</b> <i>Amanda Bok</i>
12.00 – 13.30	<b>Plenary 1: Bleeding disorders in girls and women (setting the scene)</b> <i>Session Chair: Minette van der Ven</i>
	12.00 – 12.30 Women and Bleeding Disorders in Europe: Results from EHC Survey <i>Naja Skouw-Rasmussen</i>
	12.30 – 13.00 An overview of rare bleeding disorders in women <i>Michelle Lavin</i>
	13.00 - 13.30 Q&A and discussions
13.30 – 14.00	<b>Coffee break</b>
14.00 – 16.00	<b>Plenary 2: Genetics 101 – Understanding transmission &amp; genetic testing</b> <i>Session Chair: Rezan Kadir</i>
	14.00 – 14.20 Haemophilia – inheritance, carrier detection <i>Eugenia Biguzzi</i>
	14.20 – 14.40 RBD – transmission – inheritance and carrier detection <i>Eugenia Biguzzi</i>
	14.40 – 15.00 Transmission, inheritance and detection in VWD <i>Karin van Galen</i>
	15.00 – 15.30 Prenatal testing and diagnosis <i>Rezan Kadir</i>
	15.30 – 16.00 Q&A and discussions
16.00 – 16.30	<b>Coffee break</b>
16.30 – 18.00	<b>World Federation of Hemophilia (WFH) - Symposium</b>
19.00 – 19.30	<b>Ice-breaker</b>
19.30 – 21.30	<b>Welcome Dinner</b>

Saturday 25 May 2019		
<b>08.00 – 09.30</b>	<b>Plenary 3 – Management of heavy menstrual bleeding</b> <i>Session Chair: Michelle Lavin</i>	
	08.00 – 09.00	Preparing for menarche and developing a management plan for heavy menstrual bleeding – Panel discussion  Panellists: <ul style="list-style-type: none"><li>- <i>Rezan Kadir</i></li><li>- <i>Roseline d’Oiron</i></li><li>- <i>Patient Representative TBC</i></li><li>- <i>Debra Pollard</i></li><li>- <i>Sylvia von Mackensen</i></li></ul>
	09.00 – 09.30	Q&A and discussions
<b>09.30 – 10.00 Coffee Break</b>		
<b>10.00 – 11.30 Symposium: Other gynaecological issues in WBD</b> <b>Session Chair:</b>		
	10.00 – 10.15	Surgery (incl. peri-operative plan and haemostatic assessment) <i>Cedric Hermans</i>
	10.15 – 10.30	Ovulation bleeding and ovarian cysts <i>Karin van Galen</i>
	10.30 – 10.45	Quality of life in relation to gynaecological bleeding <i>Sylvia von Mackensen</i>
	10.45 – 11.00	Pain management for women with rare bleeding disorders – focus on pelvic pain <i>Ioannis Tsimpanakos</i>
	11.00 – 11.15	Preparing for surgery – Patient Perspective <i>Evelyn Grimberg</i>
	11.15 – 11.30	Q&A
<i>This symposium was kindly donated to the EHC by CSL Behring</i>		
<b>11.30 – 12.00 Coffee Break</b>		
<b>12.00 – 13.30 Breakout sessions</b>		
<b>Stream 1</b>	<b>Family Planning</b>	<u>Fertility and Pregnancy in bleeding disorders</u> <i>Open discussion</i>  <i>Moderators: Roseline d’Oiron (TBC), Rezan Kadir &amp; Marie Lahn Roemcke</i>
<b>Stream 2</b>	<b>Everyday coping</b>	<u>Support from your NMO &amp; peer to peer</u>  <i>Moderators: representatives from the EHC French &amp; Dutch NMOs</i>
<b>13.30 – 14.30 Lunch</b>		

<b>14.30 – 16.00</b>	<b>Plenary 4 - Non-gynaecological issues in women with bleeding disorders</b> Session Chair: Olivia Romero-Lux	
	15.00 – 14.30	Detection & management of iron deficiency and anaemia in WBD's <i>Eugenia Biguzzi -</i>
	14.30 – 15.00	Oral care in WBD <i>Alison Dougall</i>
	15.00 – 15.30	Q&A and discussions
<b>16.00 – 16.30</b>	<b>Coffee break</b>	
<b>16.30 – 18.00</b>	<b>Movie Screening: 'Women and bleeding disorders in Europe'</b>	
	16.30 – 16.40	Movie introduction <i>Goran Kapetanovic, Naja Skouw-Rasmussen</i>
	16.40 – 17.40	Movie screening
	17.40 – 17.55	Q&A <i>Goran Kapetanovic, Ana Pastor &amp; Tajana Markovic</i>
	17.55 – 18.00	Closing and announcing of evening plan <i>Laura Savini</i>
<b>18.30 – 19.30</b>	<b>Bloody Mary's session (Apéro Talk shop)</b>	
<b>19.30 – 21.30</b>	<b>Dinner</b>	
<b>Sunday 26 May</b>		
<b>08.00 – 09.30</b>	<b>Plenary 5: Everyday issues</b> Roseline d'Oiron (TBC)	
	08.00 – 08.30	Impact of bleeding disorders on quality of life <i>Naja Skouw-Rasmussen</i>
	08.30 – 09.00	Psycho-social issues such as bullying, body image, isolation, sex, self-esteem <i>Debra Pollard</i>
	09.00 – 09.30	Q&A and discussions
<b>09.30 – 10.00</b>	<b>Coffee Break</b>	
<b>10.00 – 11.30</b>	<b>Breakout sessions</b>	
<b>Stream 1</b>	Family Planning	<u>Management of labour, delivery and neonatal care</u> Open discussion <i>Rezan Kadir + Angelika Batorova + patient reps (TBC)</i>
<b>Stream 2</b>	Everyday coping	<u>Support from HTC</u> Open discussions <i>Debra Pollard &amp; patient reps (TBC)</i>
<b>11.30 – 12.00</b>	<b>Coffee Break</b>	

<b>12.00 – 13.00</b>	<b>Closing session</b> <b>Session Chair: Amanda Bok</b>	
	12.00 – 12.40	<i>Closing panel: Rezan Kadir, Roseline d’Oiron (TBC), Debra Pollard and Naja Skouw-Rasmussen</i>
	12.40 – 13.00	Evaluations and feedback Laura Savini + Amanda Bok
<b>13.00 – 14.00</b>	<b>Lunch and departures</b>	