

EHC Women and RBD Conference 2019

24-26 May 2019

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	Welcome to the Conference and introduction to the work of EHC <i>Amanda Bok</i>
12.00 – 13.30	Plenary 1: Bleeding disorders in girls and women <i>Session chair: Minette van der Ven</i>
	12.00 – 12.30 Women and Bleeding Disorders (WBD) 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	Coffee break
14.00 – 16.00	Plenary 2: Genetics 101 – Understanding transmission & genetic testing <i>Session chair: Rezan Kadir</i>
	14.00 – 14.20 Haemophilia: Transmission, inheritance & carrier detection <i>Eugenia Biguzzi</i>
	14.20 – 14.40 Rare bleeding disorders: Transmission, inheritance and carrier detection <i>Eugenia Biguzzi</i>
	14.40 – 15.00 Von Willebrand Disease: Transmission, inheritance and detection <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	Coffee break
16.30 – 18.00	WFH Symposium
19.00 – 19.30	Ice-breaker – introduce the question box
19.30 – 21.30	Welcome Dinner

Saturday 25 May 2019		
08.00 – 09.30	Plenary 3 – Management of heavy menstrual bleeding <i>Session chair: Michelle Lavin</i>	
	08.00 – 09.00	Preparing for menarche: How to developing a management and treatment plan for heavy periods (incl. how to approach and prepare for adolescence). <i>Panel discussion between:</i> <ul style="list-style-type: none"> - Rezan Kadir - Roseline d’Oiron - Anna Tollwé - Debra Pollard - Sylvia von Mackensen
	09.00 – 09.30	Q&A and discussions
09.30 – 10.00	Coffee Break	
10.00 – 11.30	Symposium: Other gynaecological issues in WBD <i>This symposium was kindly donated to the EHC by CSL Behring</i> Session chairs: Evelyn Grimberg and Ana Pastor	
	10.00 – 10.15	Surgery (incl. peri-operative plan and haemostatic assessment) <i>Angelika Batorova</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
11.30 – 12.00	Coffee Break	
12.00 – 13.30	Breakout sessions	
Stream 1	Family Planning	<u>Fertility and Pregnancy in bleeding disorders</u> <i>Open discussion</i> <i>Session moderated by:</i> <i>Roseline d’Oiron, Rezan Kadir & Marie Lahn Roemcke</i>
Stream 2	Everyday coping	<u>Support from your NMO & peer-to-peer support</u> <i>Session moderated by:</i> <i>Representatives from the French & Dutch NMOs</i>

13.30 – 14.30	Lunch	
14.30 – 16.00	Plenary 4 - Non-gynaecological issues in women with bleeding disorders <i>Session chair: Olivia Romero-Lux</i>	
	15.00 – 14.30	Detection & management of iron deficiency and anaemia in WBD <i>Eugenia Biguzzi -</i>
	14.30 – 15.00	Oral care in WBD <i>Alison Dougall</i>
	15.00 – 15.30	Q&A and discussions
16.00 – 16.30	Coffee break	
16.30 – 18.00	Screening of the movie “Women and Bleeding Disorders” <i>Session chair: TBC</i>	
	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, Tajana Markovic & Naja Skouw-Rasmussen</i>
	17.55 – 18.00	Closing and announcing of evening plan <i>Laura Savini</i>
18.30 – 19.30	Bloody Mary’s session (Apéro Talk shop)	
19.30 – 21.30	Dinner	
Sunday 26 May		
08.00 – 09.30	Plenary 5: Everyday issues <i>Session chair: Roseline d’Oiron</i>	
	08.00 – 08.30	Impact of bleeding disorders on quality of life <i>Naja Skouw-Rasmussen</i>
	08.30 – 09.00	Psycho-social issues (incl. bullying, body image, isolation, sex, self-esteem) <i>Debra Pollard</i>
	09.00 – 09.30	Q&A and discussions
09.30 – 10.00	Coffee Break	
10.00 – 11.30	Breakout sessions	
Stream 1	Family Planning	<u>Management of labour, delivery and neonatal care</u> Open discussion <i>Session moderated by:</i> <i>Rezan Kadir & Angelika Batorova</i>

Stream 2	Everyday coping	<u>Support from haemophilia treatment centres</u> Open discussions <i>Session moderated by Debra Pollard & Liora Tevet</i>
11.30 – 12.00	Coffee Break	
12.00 – 13.00	Closing session <i>Session Chair: Amanda Bok</i>	
	12.00 – 12.40	Ask me anything + questions from question box <i>Closing panel:</i> <i>Rezan Kadir, Roseline d'Oiron, Debra Pollard and Naja Skouw-Rasmussen</i>
	12.40 – 13.00	Evaluations and feedback Laura Savini + Amanda Bok
13.00 – 14.00	Lunch and departures	