

The Big Get-Together

our conference for everyone with a bleeding disorder

The
Haemophilia
Society

Saturday 18 November, The Met Hotel Leeds, AGENDA

09.00 - 09.30am	Registration and refreshments - Met Suite		
09.30 - 09.45am	Welcome - Met Suite		
10.00 -11.30am Parallel sessions	Haemophilia track Chair: Clive Smith Met Suite	von Willebrand disorder track Chair: Jo Traunter Met 1	Rare and Bleeding Disorder Unknown Cause (BDUC) track Chair: Amy Owen-Wyard Met 15
	What treatment is right for me?	VWD and Me (includes genetics, diagnosis and treatment). Personal story. Update on VWD working group	Common themes amongst all rare and BDUC including mentalhealth and advocacy. Experience of becoming an advocate and the importance of educating yourself and others. Upcoming treatments
11.30 - 11.45am	Refreshment break		
11.45am -12.45pm Parallel sessions	Open discussion: How to get the most from sport and exercise if you have a bleeding disorder Chair: Clive Smith Met Suite	Infected Blood Inquiry - support going forward Chair: Susan Stretch Met 1	Supporting self-treatment Chair: Conan McIlwrath (Interactive session covering topics related to needle phobia and treatment infusions) Met 15
12.45 -1.30pm	Lunch		
1.30 -2.30pm	Ageing with a bleeding disorder / Pain Management Chair: Paul Sartain and Rayaz Chel Met Suite	The impact on daily life in people with bleeding disorders Chair: Anna Geffert and Gordon Dixon (How does it affect their education, work, social activities, and family life? Practical tips from nurses, social workers and/or psychologists, to help patients and their families adjust and learn to cope) Met 1	Moving from paediatric to adult care Chair: Natalie Lawson Met 15
2.30 - 2.40pm	Interval between workshops		
2.40 - 3.40pm Parallel sessions	Self-advocacy Chair: Clive Smith (Interactive discussion on how to become an expert patient to get the right treatment and care and film showing) Met Suite	SACRed project – focus groups - (for women and girls with bleeding disorders to share their experiences regarding the care they receive in the UK) Met 1	Navigating genetic testing and counselling - key things to consider Chair: Jo Traunter Met 15
3.40 -4.00pm	Refreshment break		
	SLAM sessions - Met Suite		
4.00 - 4.15pm	SACRed project update: women and girls with a bleeding disorder Speaker: Jeff Courtney		
4.15 - 4.40pm	Haemnet - SEEK Speakers: Sam Bristow and Luke Pembroke		
4.40 - 5.00pm	Youth Debates		
	Topic 1: Why are the youth not interested – youth morale. Speakers: Josh Crombie and Hannah Yarnall	Topic 2: Do rare bleeding disorders have an identity in the patient organisation? Speakers: Peta Dixon and Zaynab Ahsan	
5.00pm	Conference finishes - closing remarks and Q&A		