

The Big Get-Together

Saturday 16 November 2024, Leicester Marriott Hotel



AGENDA

09.00 - 09.30am	Registration and refreshments		
	Youth Workshop begins at 09:30 (Enderby Suite)		
09:30 - 09:45am	Welcome (Grove Suite) Kate Burt - Chief Executive		
10.00 - 11.00am Parallel sessions	Grove Suite	Ashby Suite	Quorn Suite
	Haemophilia track <i>Treatment updates: My treatment, my choice</i> Chair: Clive Smith and Jeff Courtney Panel: Ross Bennett and Paul Sartain	von Willebrand disorder track <i>Led by VWD working group</i> VWD treatment updates Chair: Jo Traunter and Hannah Yarnall	Rare and Bleeding Disorder Unknown Cause (BDUC) track <i>Led by Rare and BDUC working group</i> ERIN update - what is happening in Europe regarding Rare and BDUC. Followed by <i>group discussions</i> on common themes, wants and needs Chair: Amy Owen Wyard Speaker: Fiona Brennan
11.00 - 11.30am	Refreshment break		
11:30am - 12:30pm Parallel sessions	Ashby Suite	Grove Suite	
	Update on the Infected Blood Inquiry Chair: Debra Morgan Participants will have the opportunity to engage in an open forum with our public inquiry team	Dental Workshop Chair: Trustee Speakers: <i>Sarah Garside</i> , Lead Nurse at Leeds Comprehensive Care Centre and <i>Dr Lochana Nanayakkara</i> , Consultant in Restorative Dentistry, Royal London Hospital An informative session on oral health prevention for individuals with bleeding disorders, covering all ages from paediatrics to adults. Have the opportunity to join breakout groups with our expert speakers and ask them any burning questions you have about dental care and share your experiences with other members.	
12:30 - 1.30pm	Buffet Lunch in restaurant		
1.00 - 1.30 pm	Showing of a short film, 'What We Wished We Could Be': A couple affected by the contaminated blood scandal face a difficult decision when an offer of life-saving treatment threatens their dreams for the future (Grove Suite)		
1:30 - 2.30pm	Annual General Meeting		
2.30 - 3.30 pm	Mental Well-being for those with bleeding disorders (Grove Suite) Lead: Dr Hester Bancroft, Chartered Psychologist <ul style="list-style-type: none"> The impact our mental well-being has on our psychical health The importance of understanding your (or your child's) personal journey from diagnosis to now Understanding and managing stress and anxiety in ourselves and others When to seek support and what type may be helpful for you (or your child) Key steps to boost our own mental wellbeing 		
3.30 - 4.00pm	Refreshment break		
4:00 - 4:30pm	SACRed Project Report Update - women and girls with bleeding disorders (Grove Suite) Jeff Courtney - THS Policy and Public Affairs Manager		
4:30 - 5.30pm	Recognition Awards and closing remarks - (Grove Suite)		
5:30 - 7:00pm	Networking drinks reception including Mount Blanc Climb Film (Film in Grove Suite)		