

Ring 20 Family Conference 2017

Event Programme at a Glance

Friday 4th August

6pm – 8pm Reception with drinks and nibbles at the **Novotel Hotel, Hanover Street**

Saturday 5th August - Everton Football Club

8:00-8:15am Coach to Everton FC from Novotel Hotel arrives **8.00am (depart prompt 8.15am)**

If you've indicated you are travelling on the coach, but have any issues on the day or are running late, please notify **Allison on 07512 753544** to ensure the coach doesn't leave without you.

The Odyssey of the Ring Alex Young Suite		
Time	Topic	Speaker
8:30-9:00	Coffee and registration	
9:00-9:10	Welcome	Chris Garn – Trustee Treasurer
9:10-10:40	<p>Session 1: The Past What we know/don't know about r20? – summary of where we are from 3 different perspectives:</p> <ul style="list-style-type: none"> ❖ Clinical - Epilepsy in r(20) syndrome ❖ Genetic <ul style="list-style-type: none"> ○ Ring Chromosome Overview ○ Genetic Studies of r(20) ❖ Patients and families <ul style="list-style-type: none"> My life with r(20) r(20) Diagnosis to Prognosis – One family's journey <p>Panel Q&A on session 1 Chair – Dr Sophia Varadkar</p>	<p>Professor Maria Canevini - Associate Professor of Child Neuropsychiatry, Italy</p> <p>Professor Nancy Spinner - Professor of Paediatric Pathology, USA</p> <p>Laura Conlin - Assistant Professor in the Department of Pathology and Laboratory Medicine, USA</p> <p>Dale Ward - r(20) Volunteer</p> <p>Allison Watson - r(20) Co-founder - Secretary</p>
10:40-11:10	Tea/Coffee break	
11:10-12:30	<p>Session 2: The Present Practical information now...</p> <ul style="list-style-type: none"> ❖ Strategies for working with behavioural problems in children with epilepsy ❖ Management of epilepsy in Ring 20 - r(20) treatment options medications and beyond ❖ Update on VNS therapy ❖ EpiCARE: <ul style="list-style-type: none"> ERN for rare and complex epilepsies ePAG – Patient advocacy <p>Panel Q&A on session 2 Chair Don Gordon</p>	<p>Dr Sophie Bennett-Clinical Psychologist</p> <p>Dr Archana Desurkar - Consultant Paediatric Neurologist, UK</p> <p>Dr Sophia Varadkar - Consultant Paediatric Neurologist, UK</p> <p>Allison Watson - r(20) Co-founder - Secretary</p>
12:30-1:30	<p>LUNCH</p> <ul style="list-style-type: none"> ❖ Exhibition stands ❖ short guided tour of stadium (2x groups) 	<p>Group 1: 12:30pm-1:15pm</p> <p>Group 2: 1:15pm -2:00pm</p>

2:00-3:10	Session 3: The Future Update on current/future research projects for r(20): <ul style="list-style-type: none"> ❖ Learning & behaviour in epilepsy: can r(20) give us insights into causes and therapy? ❖ Current research on ring chromosomes Panel Q&A on session 2 Chair - Sophia Varadkar	Professor Sameer Zuberi - Consultant Paediatric Neurologist, UK Professor Nancy Spinner/ Assistant Professor Laura Conlin
3:10-3:30	Tea/Coffee break	
3:30-3:45	Young Ambassadors Our future in your hands... <ul style="list-style-type: none"> ❖ What do the youth want from those supporting them, what's important to the r20 youth? 	Emma Ninnis - Clinical Nurse Specialist, UK Janine Palm – Young Epilepsy, UK Presentation from young r(20) patients attending
3:45-4:15	Speakers panel Q&A	
4:15-4:25	Closing remarks: summary of the day	Don Gordon - r(20) Co-Founder - Chair
4:30-5:00	AGM	

5.00pm Coach arrives at Everton FC and will **depart 5.15pm** to get back to Novotel Hotel.

Young Ambassadors -Breakout session for Young People with r(20)		
Brian Labone Suite		
Time	Topic	Speaker
11:10-12:30	Session 2a: Living with r(20) Group session for our young people to speak to an Epilepsy Specialist Nurse (ESN) and Young Epilepsy transitions worker, without parents/doctors <i>Young people will work in 2 age appropriate groups: under 18's and 18-25 year olds</i> <ol style="list-style-type: none"> 1. Epilepsy Twister (To Be Wise in Safety Think Epilepsy Risks) 2. Transitional Support <ol style="list-style-type: none"> a. Going through the transitional stages b. Preparing for the appointment in the adult clinic 3. What's living with r(20) really like? Patient views... <ul style="list-style-type: none"> • What are the challenges faced living with epilepsy? 4. Prepare presentation for Young Ambassador's session (pm) 	Emma Ninnis - Clinical Nurse Specialist, UK Janine Palm – Transition Worker, Young Epilepsy UK

Saturday 5th August

7:00pm pre-dinner drinks at the **Jury's Inn, Liverpool (Keel Wharf)**

DRESS CODE: smart/casual

7:30pm -11pm Gala Dinner **Jury's Inn, Liverpool (Keel Wharf)** with surprise entertainer and Gala Prize Raffle

Sunday 6th August

10:00am- 12:30pm The Beatles Story (Guided Tour) at Albert Dock

12:30-1:00pm Time to say goodbye!

(Opportunities to visit the famous 'Cavern Club' at leisure)



www.ring20researchsupport.co.uk

[#Ring20familyconference](https://twitter.com/Ring20familyconference)

