Agenda

Please note that the timings for individual sessions have not yet been confirmed and remain subject to change. The final agenda will be issued nearer the event date following confirmation of all speakers and programme content.

Friday 30th October 2026

Session	Time	Presentation / Activity	Speaker	Affiliation	Talking points
Research	**10:00-16:00**	**Blood sample collection (throughout the day)**			
	12:00-13:00	**Lunch**			
Welcome	**13:00–13:10**	Welcome & Housekeeping	Lydia Hirst	Ring20 Chair of Trustees	Introduction, walk through of the agenda
Session 1: Research	**13:10-13:40**	UK Genomic study	Hannah Titheradge	Clinical Geneticist, UK	Introducing active research utilising advanced genomic sequencing techniques to see beyond the ring formation
	13:40-14:30	BEOND study	Rory O'Sullivan	Research Fellow, UK	A survey looking at behaviour, wellbeing, emotion, physical and mental health in **children and adults** with **rare genetic syndromes**
	14:30–14:45	**Refreshment Break**			

Session 2: Interactive workshops & discussion groups	**14:45–15:30**	Workshops: choose from: **1. AI: how it might help in epilepsy**	*Phil Tittensor* **Space 43**	Consultant Nurse, UK	How advances in AI might help with seizure forecasting, EEG/diagnostics, music therapy.
		2. Navigating r(20) as a female	*Sarah Tittensor* **Space 31**	Learning Disability Nurse, UK	Discuss issues that affect females living with r(20) epilepsy
	15:30–16:15	Introduction to Coaching, followed by Step Into The Ring	*Kallif Garlicki/ Dale Ward* **Space 43**	Ring20 volunteers	How can Coaching help you and a chance to sign-up to free sessions with Kallif
	16:15–16:30	**Comfort Break**			
	16:30–17:00	Meet the Ring20 Team	Lydia Hirst Allison Watson	Ring20 Trustees/ CEO	Meet the Ring20 Team, hear about Ring20's impact
		Introduction to Ring20 USA	Bill James	President, Ring20 USA	Find out about our colleagues across the pond
	17:00–18:30	**Free Time**			
Evening	**18:30-19:00**	**Drinks reception**			
	19:00-21:00	**Dinner/Networking**			

Saturday 31st October 2026

Session	Time	Presentation / Activity	Speaker	Affiliation	Talking points
Welcome		Registration			(for new attendees only)
	10:00–10:20	Welcome back, Introduction & video montage	Allison Watson	Ring20, CEO	Introduction, walk through of the agenda & video montage
Session 3: Ring20 study findings	**10:20-10:50**	**Patient Reported impact study**	Arun Soma		Findings from the study undertaken in 2023 and preview of the dashboard for families
	10:50-11:00	**Me & r(20) study**	Aavani Khalon	Ring20 intern	Findings from the follow-on Me & r(20) study from 2023
	11:00-11:20	**Audience Q&A**	Arun Soma/Aavani Khalon		A chance for families to ask questions about the study findings
	11:20-11:30	**Refreshment Break**			
Session 4: SUDEP and risk in r(20) syndrome	**11:30-11:40**	Ring20 family personal story (tbc)			
	11:40-12:10	SUDEP & r(20) - risk factors?	Philippe Ryvlin	Neurologist, Switzerland	What evidence do we have to quantify SUDEP risk in r(20) syndrome (pre-recorded 5 mins)
		Individualised risk workshop	Phil and Sarah Tittensor	Consultant Nurse, Learning Disability Nurse, UK	Interactive discussion around practical information on how to minimise risk at home.

Session 5:	**12:10-12:20**	**Epilepsy and Behaviour**	Lieselot Stijnen	Clinical Psychologist, Belgium	
	12:20-1230	**Understanding your EEG**	Amir G. Baroumand	epihunter Farow, Belgium	
	12:30-13:30	**Lunch**			
	13:30-13:35	Introduction to the afternoon	Allison Watson	Ring20 CEO, UK	
Session 5: Where are the opportunities in advancing knowledge in r(20) syndrome	**13:35-13:50**	Scientific Day summary	Allison Watson Tim Buckinx Clara Tang	Ring20 CEO Ring20 Trustee	A summary for families of key themes and messages from our Scientific Meeting with Professionals
	13:50-14:30	Panel Discussion	Chair: tbc		Professionals from the Scientific Day
	14:30-14:50	Audience Q&A			A chance for questions from families
	14:50–15:00	**Refreshment Break**			
Session 6: Ring20 Data Collection: Why, where, what, how?	**15:00-15:10**	Ring20 family personal story (tbc)			
	15:10-15:35	Overview of EpiNet: patient registry/Natural History database	Phil Tittensor	Consultant Nurse, UK	Why Ring20 need a database, what is the purpose, family involvement required
	15:35-15:50	What's next for r(20) research?	Lieselot Stijnen	Clinical Psychologist Ring20 Trustee	Introducing 2 new studies: - ARETAEUS

			Tim Buckinx		- PROSE
	15:50-16:00	Summary & Close	Allison Watson	Ring20 CEO	
	16:00-18:30	**Free Time**			
Evening	**18:30-19:00**	Drinks reception			Halloween themed fun!
	19:00-21:00	Dinner and games			

Sunday 1st November 2026

Session	Time	Presentation / Activity	Speaker	Affiliation	Talking points
Morning	**10:00–12:30**	Walk & Talk (other activities tbc)			A chance to get out in the fresh air and spend time with others
	12:30	**Time to say Goodbye!**			