

SATURDAY 18TH NOVEMBER 2023



PARENT & CARER CONFERENCE AGENDA

In-person at Leonardo Royal Hotel, London City Live-stream online

TIME	SPEAKER	TITLE
Registration and Arrivals		
08:30 - 09:00	-	Delegates arrive in-person at venue OR log in online
Introduction		
09:00 - 09:05	Galia Wilson	Welcome and introduction
09:05 - 09:30	Professor Ingrid Scheffer	Dravet Syndrome in 2023: where are we now and where are we going?
Research Updates: Advances in Treatment		
09:30 - 09:50	Professor Helen Cross & Professor Sameer Zuberi	The changing treatment landscape
09:50 - 10:20	Professor Sanjay Sisodiya & Professor Ingrid Scheffer	New and emerging treatments and what these mean for adult patients
10:20 - 10:30	Galia Wilson (Chair) & above speakers	Q&A on the above topics
10:30 - 10:50	Break	
Clinical Care Updates: Dravet Syndrome - Beyond Seizures		
10:50 - 11:10	Dr Elaine Hughes	Understanding non-seizure characteristics of Dravet Syndrome
11:10 - 11:30	Professor Ingrid Scheffer	What's new in vaccinations for people with Dravet Syndrome?
11:30 - 11:50	Professor Andreas Brunklaus	SCN1A Horizons: natural history of Dravet Syndrome
11:50 - 12:00	Galia Wilson (Chair) & above speakers	Q&A on the above topics
12:00 - 13:00	Lunch Break	
Daily Living and Care: DSUK Updates and Research Insights		
13:00 - 13:10	Galia Wilson & Claire Eldred	Updates from DSUK
13:10 - 13:25	Dr Lisa Clayton	Insights from DSUK research: feeding issues and gastrostomy
13:25 - 13:40	Professor Andreas Brunklaus	Insights from DSUK research: impact on caregivers
13:40 - 13:50	Galia Wilson (Chair) & above speakers	Q&A on the above topics
13:50 - 13:55	Galia Wilson	Introduction to breakout sessions
Daily Living and Care: Breakout Sessions (Please note that breakouts will not be available for those joining online)		
Each session will be run twice: 14:10 - 15:10 1st Session 15:10 - 15:20 Break 15:20 - 16:20 2nd Session		
Speakers per group		Break-out groups with presentation and Q&A
1. Fiona Scolding, QC		1. Accessing support: education health and care plans
2. Neil Williamson, Epilepsy Nurse Specialist		2. Puberty and managing sexual behaviours
3. Helen Taylor, Solicitor, and Emma Young, <i>Mencap</i>		3. Financial planning for the future: wills and trusts
4. Dr Michael Absoud, Dr Jennifer Baulcomb, Karen Pratt & Dr Elaine Hughes, <i>Evelina London Children's Hospital</i>		4. Managing challenging behaviour: perspectives from professionals
16:20 - 16:40	Galia Wilson (Chair) & all speakers	Final Q&A with all speakers
16:40 - 16:45	Galia Wilson	Close and thank you

The DSUK Conference Parent & Carer Day is kindly supported by:

