Dravet Syndrome UK 😘

Parent & Carer Day

Agenda 2021

Our Parent & Carer conference will take place on Saturday 20th November at the Macdonald Burlington Hotel in Birmingham. We will also be live-streaming the conference to enable parents/carers to attend virtually.

Time	Speaker	Title
08:00 - 09:00		Tea & coffee
09:00 - 09:05	Galia Wilson	Welcome
09:05 - 09:10	The MacDonald Family	What might the future hold? Living with Dravet Syndrome as an adult
09:10 - 09:50	Professor Helen Cross Professor Sanjay Sisodiya	What is Dravet Syndrome? An introduction for newly diagnosed families
09:50 - 10:00	Professor Helen Cross Professor Sanjay Sisodiya	Q&A on the above topic
10:00 - 10:40	Dr Elaine Hughes Professor Sanjay Sisodiya	Seizure management and how seizures change over time
10:40 - 11:00	Dr Andreas Brunklaus	Update on the Natural History Project co-funded by DSUK
11:00 - 11:20	Dr Elaine Hughes, Professor Sanjay Sisodiya, Dr Andreas Brunklaus, Professor Helen Cross	Q&A on the above topics
11:20 - 11:30		Break
11:30 - 11:55	Professor Helen Cross Professor Sanjay Sisodiya	Update on new optimised treatment options
11:55 - 12:20	Professor Sameer Zuberi Dr Rajvinder Karda	Update on next generation treatments
12:20 - 12:40	Professor Helen Cross, Professor Sanjay Sisodiya, Professor Sameer Zuberi, Dr Rajvinder Karda	Q&A on the above topics / close for virtual conference
12:40 - 13:40		Lunch
Each session w	ill be run twice: 13:40 - 14:40 1st Session, 14:40 - 15:	00 Break , 15:00 - 16:00 2nd Session
4. Asma Bennar 5. Anna Selby-W	e Kerr	Break-out groups with presentation and Q&A 1. Mental health and behaviours that challenge 2. Sleep problems 3. Statutory rights to access services (children session) 4. Statutory rights to access services (adult session) 5. Transition post-education for adults 6. Feeding issues
 16:00 - 16:10	Galia Wilson	Close & thank-yous



This independent meeting is supported by educational grants from GW Pharmaceuticals, Biocodex, Stoke Therapeutics, Encoded Therapeutics and Liva Nova

Book your ticket at: www.dravet.org.uk/events/



