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DRAVET Syndrome UK
Hope for families with life-limiting epilepsy

Dravet Syndrome UK Conference

Parents & Carers Day Programme

Saturday 15th November 2025

Location: Hotel Pullman, London St Pancras Live-stream online

www.dravet.org.uk | info@dravet.org.uk | 01246 912421

Registered Charity No: 1128289

PARENTS & CARERS DAY AGENDA

Saturday 15th November 2025 | 10.00-17.00

Timing	Session title	Presenter(s)
08.15-10.00	**Registration and arrivals**	
08.45-09.45	Introduction for conference 'first-timers'	Dr Elaine Hughes
09.45-10.00	**Main conference opens**	
10.00-10.05	Welcome and introductions	Galia Wilson (Chair)
10.05-10.15	1. Dravet Syndrome in 2025: are we at a tipping point?	Professor Helen Cross
10.15-10.30	2. Anti-seizure therapies in Dravet Syndrome: current and emerging treatments	Professor Sameer Zuberi
10.30-10.45	3. Disease modifying treatments: latest data and future expectations	Professor Andreas Brunklaus & Dr Archana Desurkar
10.45-11.10	**First Q&A**	**Panel chaired by Galia Wilson**
11.10-11.30	**Break**	
11.30-11.50	4. Adults living with Dravet Syndrome: what's new and what's next	Professor Sanjay Sisodiya
11.50-12.00	5. What has the SCN1A Horizons Natural History Study told us so far	Dr Amy McTague
12.00-12.20	6. Neurodevelopment and behaviours: what we've learnt from SCN1A Horizons	Dr Stewart Rust & Adriana Swindler
12.20-12.45	**Second Q&A**	**Panel chaired by Galia Wilson**
12.45-13.30	**Lunch**	
13.30-13.40	7. Overview of DSUK research activities	Ceri Hughes
13.40-13.50	8. Understanding autonomic dysfunction in adults with Dravet Syndrome	Dr Lisa Clayton
13.50-14.00	9. Advancing precision medicine – the future of gene therapy?	Dr Jenna Carpenter
14.00-14.20 (14.00-15.00 for live-stream participants)	**Q&A with DSUK's Medical Advisory Board and conference speakers**	**Panel chaired by Galia Wilson**
14:20-14:25	10. Little Moments Matter Awards ceremony	Galia Wilson
14.25-14.30	**11. Wrap up plenary session**	Galia Wilson
14.30-15.30	Breakout session 1	
	1. Wills and trusts: planning for the future	Philip Watford
	2. Living with intellectual disability: adjusting as a family	Dr Stewart Rust
	3. Navigating care assessments: getting the support you're entitled to	Fiona Scolding, KC
	4. Supporting young siblings: practical advice for families	Sibs UK
15.30-15.45	**Teas and coffees served**	
15.45-16.45	Breakout session 2 (As above)	
16.45-17.00	**Final wrap up and close**	Galia Wilson

PARENTS & CARERS DAY PLENARY SPEAKER BIOGRAPHIES

Professor Helen Cross, OBE

Professor Helen Cross is Chair of DSUK's Medical Advisory Board. She is the Prince of Wales's Chair of Childhood Epilepsy, Director of UCL Great Ormond Street Institute of Child Health, and Honorary Consultant in Paediatric Neurology Great Ormond Street Hospital for Children NHS Foundation Trust, London and Young Epilepsy. She is currently President of the International League Against Epilepsy.

Professor Sameer Zuberi

Professor Sameer Zuberi is a Consultant Paediatric Neurologist at the Royal Hospital for Children, Glasgow and Honorary Professor at the University of Glasgow. He is founder and Clinical Lead of the Scottish National Genetic Epilepsy Service and was President of the European Paediatric Neurology Society from 2018 until early 2022, and Editor-in-Chief of the European Journal of Paediatric Neurology from November 2014 until early 2021.

Professor Andreas Brunklaus

Professor Andreas Brunklaus, is a Consultant Paediatric Neurologist at the Royal Hospital for Children, Glasgow and Honorary Professor at University of Glasgow. He is an international expert in SCN1A related childhood epilepsies and Dravet Syndrome and he is the UK chief investigator for SCN1A Horizons natural history study. He is lead of the Scottish Paediatric Epilepsy Network and co-chair of the International League Against Epilepsy Task Force on Clinical Genetic Testing.

Professor Sanjay Sisodiya

Professor Sanjay Sisodiya is a professor of neurology at the UCL Institute of Neurology, honorary consultant neurologist at the National Hospital for Neurology and Neurosurgery and Transformation Director at the Epilepsy Society. He runs epilepsy and specialist epilepsy genomics clinics and is the chief investigator of several international projects.

PARENTS & CARERS DAY PLENARY SPEAKER BIOGRAPHIES

Dr Archana Desurkar

Dr Archana Desurkar is an NHS Consultant Paediatric Neurologist at Sheffield Children's Hospital. Her specialist area of interest and expertise is children's epilepsies, especially complex cases, ketogenic diet treatment for medication resistant epilepsies in children and evaluating children for potential epilepsy surgery.

Dr Amy McTague

Dr Amy McTague is a clinician scientist with a research group at the Zayed Centre for Rare Disease Research in Children. She is an honorary consultant paediatric neurologist at Great Ormond Street specialising in paediatric epilepsy, in particular early onset epilepsies. She is a co-investigator in trials of novel therapies for Dravet Syndrome and in a Dravet Syndrome natural history study.

Dr Stewart Rust

Dr Stewart Rust is the lead neuropsychologist at Royal Manchester Children's Hospital and has led the development of neuropsychological services at the hospital. The service is participating in international research collaborations in medicines research, including the SCN1A Horizons Natural History Study. He is a chartered psychologist and an Associate Fellow of the British Psychological Society as well as a Health Professions Council registrant.

Adriana Swindler

Adriana Swindler is currently pursuing a PhD on the Identification and Validation of Neuropsychological Biomarkers in SCN1A-Related Epilepsies at the University of Glasgow. She worked as Neuropsychology Research Assistant on the SCN1A Horizons study at the University of Glasgow, assessing children with Dravet Syndrome to better understand the neurocognitive profiles associated with SCN1A-related epilepsies. Their work focuses on describing developmental and cognitive outcomes, in order to improve clinical understanding and support.

PARENTS & CARERS DAY PLENARY SPEAKER BIOGRAPHIES

Dr Lisa Clayton

Dr Lisa Clayton is a consultant neurologist and senior clinical research fellow at the UCL Institute of Neurology and Chalfont Epilepsy Centre. She completed her PhD at the UCL Institute of Neurology in 2007 exploring vigabatrin-associated visual field loss. Her interest is in Dravet Syndrome and other developmental and epileptic encephalopathies in adults. She holds an Epilepsy Research Institute and Dravet Syndrome UK Emerging Leader Fellowship and is currently leading a project on understanding autonomic dysfunction in adults living with Dravet Syndrome.

Dr Jenna Carpenter

Dr Jenna Carpenter is a senior research fellow at UCL Queen Square Institute of Neurology, Department of Epilepsy. She received her PhD from UCL in 2020 investigating the mechanisms of Progressive Myoclonic Epilepsy and Ataxia. She holds an Epilepsy Research Institute and Dravet Syndrome UK Emerging Leader Fellowship and is currently leading a project on genome engineering for on-demand gene therapy in Dravet Syndrome.

Galia Wilson, Chair of Trustees

Galia Wilson has been Chair of Dravet Syndrome UK since 2015 and is mum to Arlo (aged 18) who is living with Dravet Syndrome. Before Arlo, Galia had a busy job working for a large public relations agency and had spent the previous 15 years working in healthcare communication. Galia now applies the skills she accumulated over those years, along with her experience and knowledge as a caregiver, to help improve the lives of those living with Dravet Syndrome.

Ceri Hughes, Chief Scientific Officer

Ceri joined Dravet Syndrome UK in May 2025 as Chief Scientific Officer. Ceri joins Dravet Syndrome UK from research publisher Frontiers in Neuroscience where she was a Publishing Specialist, working with international scientists. She has a degree in neuroscience and a master's degree in healthcare ethics and law, which have given her an understanding of the biology of Dravet Syndrome and the broader systemic interactions facing families. Ceri also has first-hand experience of the impact Dravet Syndrome has on families as her brother Iwan lives with the condition.

FOR FURTHER INFORMATION AND GUIDANCE

Please contact us on the details below or follow us on social media.

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DRAVET Syndrome UK

Hope for families with life-limiting epilepsy

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Registered Charity No. 1128289

Annual family weekend

SAVE THE DATE

Our annual family weekend away will take place on **Friday 12th June to Monday 15th June 2026** at Center Parcs, Sherwood Forest.

Scan the QR code for more information and updates

Regional family meet ups

DSUK is organising a new series of in-person get-togethers across different regions of the UK.

These informal gatherings are for parents and carers of children and adults living with Dravet Syndrome. They are an opportunity to spend time with others who truly understand the Dravet journey, including other families living in your region, as well as members of the DSUK team.

More information on dates and locations coming soon!