Biocodex, Encoded Therapeutics, Harmony Biosciences, Jazz Pharmaceuticals, Liva Nova, Stoke Therapeutics and UCB have all provided sponsorship funding to DSUK in support of the Biennial Professional Day Conference. These organisations have had no involvement in the development of the conference agenda, or any of its content.

DRAVET
Syndrome UK
Hope for families with life-limiting epilepsy

Dravet Syndrome UK Conference

Professionals Day Programme

Friday 14th 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

LEARNING OBJECTIVES

- Increased understanding of Dravet Syndrome, including its characteristics (seizures and comorbidities), how to diagnose and manage the condition, how to reduce associated risks of premature mortality (e.g. risks of SUDEP)
- Improved awareness and understanding of current and emerging treatments for Dravet Syndrome
- Increased understanding of new and ongoing research and clinical trials, including natural history and advances in genetic research

PROFESSIONALS DAY PROGRAMME

Friday 14th November 2025 | 09:00-16:00

Timing	Session title	Presenter(s)
09.00-09.05	**Welcome and introductions**	Professor Helen Cross
09.05-09.30	50 years of Dravet Syndrome research – key learnings and implications for other developmental and epileptic encephalopathies	Professor Helen Cross
09.30-09.50	Diagnosing Dravet Syndrome – how, why and when	Professor Andreas Brunklaus
09.50-10.10	Never too late: benefits of diagnosis and (re)testing in adults	Professor Sanjay Sisodiya
10.10-10.30	Comorbidities in adults: understanding the true burden	Dr Lisa Clayton
10.30-10.50	First Q&A	Panel chaired by Professor Helen Cross
10.50-11.00	**Break**	
11.00-11.20	SCN1A Horizons: what we've learnt so far	Dr. Amy McTague
11.20-11.40	Cognitive and behavioural insights from Horizons' neurodevelopmental assessments	Dr. Stewart Rust & Adriana Swindler
11.40-12.00	Supporting families after diagnosis	Neil Williamson
12.00-12.30	Second Q&A	Panel chaired by Professor Helen Cross
12.30-13.15	**Lunch**	
13.15-13.45	Dravet Syndrome UK research: current perspectives and future priorities	Ceri Hughes, Dr Lisa Clayton & Dr Jenna Carpenter
13.45-14.15	Anti-seizure therapies in Dravet Syndrome: current and emerging treatments	Professor Sameer Zuberi
14.15-14.30	**Break**	
14.30-15.15	Disease modifying treatments: latest data and future expectations	Professor Helen Cross, Professor Andreas Brunklaus & Archana Desurkar
15.15-15.45	Final Q&A	Panel chaired by Professor Helen Cross
15.45-15.55	Little Moments Matter Awards ceremony	Professor Helen Cross & Galia Wilson
15.55-16.00	**Wrap up and close**	Professor Helen Cross & Galia Wilson

PROFESSIONALS DAY 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 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.

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.

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 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.

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.

PROFESSIONALS DAY 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.

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.

Neil Williamson, Trustee and Epilepsy Nurse Specialist

Neil is a Children's Epilepsy Nurse Specialist. He runs an independent nursing and training service, and works at Lewisham and Greenwich NHS Trust. He was a member of DSUK's Medical Advisory Board before making the transition to join DSUK's Board of Trustees in September 2020. As a nurse with 20 years experience in epilepsy and neurology, Neil has a long-standing interest in Dravet Syndrome. He has worked with children and young people with Dravet Syndrome in the hospital setting, in hospices and within the community.

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

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Join the Dravet Syndrome UK **Health and Care Professionals Network**

Do you support families affected by Dravet Syndrome?

Dravet Syndrome UK is the only UK charity dedicated to improving the lives of those affected by Dravet Syndrome through support, education and medical research. We provide health and social care professionals with access to a range of free support including expert guides, events and insight articles by joining our Health and Care Professionals Network.

By joining you will receive:

- Educational literature, including our diagnosis guide, *Could it be Dravet?*
- Invites to exclusive events and conferences with the world's leading Dravet Syndrome experts
- A quarterly e-newsletter with the latest information and research
- Opportunities to apply for research grants and find out about the latest clinical trials

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