Parent & Carer Day

Galia Wilson

Galia Wilson has been Chair of Dravet Syndrome UK since 2015 and is mum to Arlo aged 12 who has Dravet Syndrome. When Arlo was only 10 weeks he had his first twenty minute long tonic clonic seizure. He continued to have regular complex partial seizures until at 5 months he had another tonic clonic seizure, which lasted more than 30 minutes. For the next year and a half, he went on to have many status seizures, often lasting well over an hour and a half. He was finally screened for SCN1a mutations at about a year, but it took nearly 18 months for the results to come back positive and a further six months before he got the diagnosis of Dravet Syndrome in April 2011. 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. She had even worked on several anti-epileptic drugs. Galia had planned to return to work after having Arlo but given the amount of time Arlo was spending in hospital this was not possible. Galia now applies the skills she accumulated over those years to help improve the lives of those living with Dravet Syndrome.

Professor Rima Nabbout

Professor Rima Nabbout gained her MD in 1990 from Saint Joseph University, Beirut, Lebanon and her Paediatric board from Descartes University, Paris, France. She has a PhD in Neuroscience from University Pierre and Marie Curie, Paris, France. She is currently Professor of Paediatric Neurology at Paris-Descartes University, Paris, France. Professor Nabbout is the director of the French National Centre for Rare Epilepsies at Necker Children's Hospital in Paris and is leading a research group at Inserm U1129 dedicated to "epilepsy in childhood and brain plasticity". Her main research topics are: electroclinical delineation of rare childhood epilepsies, genetic of epileptic encephalopathies and improving the methodology and indications of pharmacological and non-pharmacological antiepileptic therapies in childhood epilepsies.

Professor Helen Cross OBE

Professor Helen Cross was awarded an OBE in 2015 for her services to Children with Epilepsy. She is the Prince of Wales's Chair of Childhood Epilepsy at UCL-Institute of Child Health, Great Ormond Street Hospital for Children, London and the National Centre for Young People with Epilepsy, Lingfield, UK. She has been awarded two honorary doctorates, in Tartu and Gothenburg. She has research interests in early onset complex epilepsy, particularly outcomes and the role of intervention, surgery and the ketogenic diet, publishing more than 200 peer reviewed primary research articles and 50 review articles. She has edited four books, including a definitive childhood epilepsy text and a ketogenic diet cookery book, and written more than 40 chapters. She has been Chair of the ILAE Commission for Paediatrics 2005-2009, Co-Chair of the Task Force of the Global Campaign and a member of the ILAE Commission for European Affairs. She was Chair of the ILAE Task Force for Paediatric Epilepsy Surgery 2001-2013, Clinical Advisor to the 2012 NICE Guidelines for the Diagnosis and Management of the Epilepsies in Adults and Children, and Chair of the Trustees of Epilepsy Research UK 2005-2010. She is currently elected Secretary General of the ILAE 2013-2017, Clinical Advisor to the National Children's Epilepsy Surgery Service and Chair of the BPNA Research Committee. She was President of the BPNA 2008-10 and has been instrumental in the establishment of the BPNA Paediatric Epilepsy Training Courses.

Dr Elaine Hughes

Dr Elaine Hughes is Lead Consultant for Children's Epilepsy and for Regional Children's Epilepsy Services in South East London, Kent, and East Sussex. She established the South East Thames Paediatric Epilepsy Group and is co-founder of UK Paediatric Epilepsy Group (now BPEG), affiliated to BPNA. Elaine is a member of the Children's Epilepsy Surgery Service (CESS) National Steering Group and specialist advisor to Dravet Syndrome UK and to the TS Association. She is also part of the steering group for development of Paediatric Epilepsy Training (PET) courses, and participates in a variety of teaching courses for families and professionals. Her specialist interests are: early onset epilepsies, epilepsy surgery, metabolic and genetic epilepsies and the interaction between epilepsy, learning and behaviour. Her research interests are treatment interventions in complex epilepsy (vagus nerve stimulation, trigeminal nerve stimulation and deep brain stimulation), epilepsy surgery and effective assessment of co-morbidities in childhood epilepsy.

Jane Hanna OBE

Jane Hanna is Co-Founder and CEO of SUDEP Action, having previously been a barrister and Law Fellow of Oxford University. Jane led the NICE National Sentinel Clinical Audit of Epilepsy Deaths in 2002 and was representative on the NICE Guidelines on Epilepsies in 2004. Jane was presented with the Global Impact Award on Epilepsy by the International League Against Epilepsy and the International Bureau for Epilepsy in 2013 for achievement in tackling epilepsy mortality. Jane has authored and co-authored numerous papers on epilepsy mortality, SUDEP & epilepsy risks. She was awarded an OBE in 2010 in recognition of her work.

Fiona Scolding QC

Fiona Scolding QC is a Barrister at Landmark Chambers. Her practice focuses upon public law challenges in a wide variety of contexts concerning both local and central government and non governmental departmental bodies. She has particular expertise in areas concerning children and vulnerable adults, with a focus upon education, the Court of Protection, healthcare, community care, equality, human rights and discrimination. Fiona has been recommended by the Legal 500 for her work in education law since 2002, and is also recommended by them in administrative and public law, civil liberties and human rights. She is recommended by Chambers & Partners for her work in education law alongside the Court of Protection and local government. Fiona has a commitment to pro bono work. She also is on the EHRC panel counsel since 2010, and has a keen appreciation and understanding of equality and rights legislation. She was a member of the Attorney General's B panel from 2013 to 2017.

Professor Sameer M Zuberi

Professor Sameer Zuberi is Consultant Paediatric Neurologist at the Royal Hospital for Children and Honorary Professor in the University of Glasgow. His undergraduate training was in Edinburgh, with postgraduate training in paediatrics and paediatric neurology in Edinburgh, Sydney and Glasgow. His clinical and research interests include epilepsy, movement disorders, neurogenetics, channelopathies and neurological sleep disorders. In 2005 he established the Glasgow Epilepsy Genetics Service and has been its clinical lead since then. He is Chair of the International League Against Epilepsy Commission on Classification & Terminology, Editor-in-Chief of the European Journal of Paediatric Neurology and Board Member of the European Paediatric Neurology Society.

Professor Sanjay Sisodiya

Professor Sanjay Sisodiya is an academic Clinical Neurologist, whose research interests in refractory epilepsy are driven by clinical imperatives. He employs neuropathological, imaging and genomic analyses to study the causes, mechanisms and consequences of refractory epilepsy in man. MRI studies in genetically-selected individuals have revealed new causes of malformations; neuropathological studies in surgically-resected and post-mortem brain material have cast light on culpable processes and the fundamental tissue bases and responses in epilepsies. Most recently, pharmacogenomic, individual- and population-based genomic studies have begun to unravel the complexities of epilepsy biology, highlighting the need for multidisciplinary studies in well-characterised patients. Genomic and post-genomic studies, as windows to disease biology, now constitute his main research focus.

Dr Andreas Brunklaus

Dr Andreas Brunklaus, is a paediatric neurologist at the Royal Hospital for Children, Glasgow and honorary senior clinical lecturer at the University of Glasgow. He trained at the Charité Medical School, Humboldt University Berlin and completed his child neurology training at the Royal Hospital for Children in Glasgow and Great Ormond Street Hospital in London. He obtained his MD(Res) from the University of Glasgow and has an ongoing research interest in epilepsy genetics and ion channelopathies, in particular SCN1A and Dravet syndrome.

Neil Williamson

Neil Williamson is a Children's Epilepsy Nurse Specialist at Lewisham and Greenwich NHS trust, and South of England and Wales Clinical Coordinator for Over the Wall (part of the Serious Fun Camps founded by Paul Newman). Neil has been a nurse for over ten years with a special interest in Epilepsy. He has worked in Acquired Brain injury units, Acute Neurology, Cardiac and Metabolic services, and Palliative Care. Neil worked for 8 years at Richard House Hospice, meeting many children with Dravet Syndrome. Here he gained understanding into the complex needs of these young people. He focused a lot of attention on building a comprehensive transition service for young people within palliative care services to support and maximise

their potential as they emerge into adulthood. Now working in the community as a specialist Epilepsy Nurse, Neil has many young people under his care with Dravet Syndrome. He is fascinated by the complexity of Dravet Syndrome and passionate about ensuring these young people and their families are supported to live their lives as fully as possible and maximise their experiences. He is involved in shaping national pieces of work, such as the Marie Curie Transition Project. He is currently helping the Royal College of Paediatrics develop a national young people's epilepsy passport to make sharing information easier.

Dr Rajvinder Karda

Dr Rajvinder Karda is a Research Associate at the Institute for Women's Health, UCL. She completed her PhD in Gene Transfer and Neuroscience at Imperial College London in 2016. Her research team mainly focuses on developing gene therapy for childhood epilepsy, including Dravet Syndrome. Currently she is a co-investigator on a UK Medical Research Council Developmental Pathway Funding Scheme grant and a Dravet Syndrome UK charity grant in collaboration with Professor Stephanie Schorge and Simon Waddington to perform pre-clinical studies of gene therapy for Dravet Syndrome. She recently received funding as a principal investigator from Dravet Syndrome UK Charity and Great Ormond Street Hospital for an alternative approach for gene therapy for Dravet Syndrome. She is also working on developing a new gene therapy strategy for devastating childhood neurological diseases associated with mutations on a neuronal elongation factor.