

Epilepsies in children, young people and adults (NG217) – Working group to update valproate recommendations

Last updated: 23 January 2023

Name	Role with NICE	Type of interest	Description of interest	Interest arose	Interest declared	Interest ceased	Comments
Elizabeth Kay	Chair	Direct Financial	Non-executive director of acute Trust	April 2017	December 2022	Ongoing	Declare and participate Not specific to guideline
Elizabeth Kay	Chair	Direct Financial	Editor of Evidence-based Dentistry journal	March 2017	December 2022	Ongoing	Declare and participate Not specific to guideline
Elizabeth Kay	Chair	Direct Non-financial, professional and personal	President of the British Dental Association	September 2021	December 2022	Ongoing	Declare and participate Not specific to guideline
Helen Cross	Topic advisor	Direct Financial	The Prince of Wales's Chair of Childhood Epilepsy, UCL-Great Ormond Street Institute of Child Health, UCL Great Ormond Street Institute of Child Health		December 2022	Ongoing	Declare and participate Salaried employment in the NHS. Non specific interest.
Helen Cross	Topic advisor	Direct Non-financial, professional and personal	Chair, Medical Advisory Board, Matthews Friends	2008	December 2022	Ongoing	Declare and participate Providing advice to a charity is not a

							conflict with remit of the working group
Helen Cross	Topic advisor	Direct Non-financial, professional and personal	Chair, Medical Advisory Board, Dravet UK	2015	December 2022	Ongoing	Declare and participate Providing advice to a charity is not a conflict with remit of the working group
Helen Cross	Topic advisor	Direct Non-financial, professional and personal	Chair, Medical Advisory Board, Hope for Hypothalamic Hamartoma	2015	December 2022	Ongoing	Declare and participate Providing advice to a charity is not a conflict with remit of the working group
Helen Cross	Topic advisor	Direct Non-financial, professional and personal	Published first randomized controlled trial in use of ketogenic diet in children with epilepsy CI on RCT of use of ketogenic diet in infants, just completed	2008	December 2022	2008	Declare and participate Ketogenic diet not under consideration by working group
Helen Cross	Topic advisor	Direct Non-financial, professional and personal	CI on RCT of use of ketogenic diet in infants, just completed	2015	December 2022	2022	Declare and participate Ketogenic diet not under consideration by working group

Helen Cross	Topic advisor	Direct Non-financial, professional and personal	Director, Institute of Child Health	2022	December 2022	Ongoing	Declare and participate Not specific to guideline
Helen Cross	Topic advisor	Direct Non-financial, professional and personal	President, International League Against Epilepsy	2021	December 2022	Ongoing	Declare and participate Not specific to guideline
Helen Cross	Topic advisor	Indirect Financial	Investigator clinical trials GW Pharma, remuneration to department (cannabidiol)	2015	December 2022	2019	Declare and participate Cannabidiol not under consideration by working group
Helen Cross	Topic advisor	Indirect Financial	Investigator clinical trials Zogenix (recently become UCB), remuneration to department (fenfluramine)	2017	December 2022	2022	Declare and participate Fenfluramine not under consideration by working group
Helen Cross	Topic advisor	Indirect Financial	Investigator clinical trial Marinus remuneration to department (ganaxolone)	2018	December 2022	2022	Declare and participate Ganaxalone not under consideration by working group
Helen Cross	Topic advisor	Indirect Financial	Investigator clinical trial Stoke Therapeutics remuneration to department (ASO therapy in Dravet syndrome)	2021	December 2022	Ongoing	Declare and participate

							ASO therapy not under consideration by working group
Arjune Sen	Topic advisor	Direct Financial	Consultant Neurologist, Associate Professor, University of Oxford		December 2022	Ongoing	Declare and participate Salaried employment in the NHS. Non specific interest.
Arjune Sen	Topic advisor	Indirect Financial	Grant monies awarded by UCB Pharma for immune modulation study,		December 2022	Ongoing	Declare and participate Immune modulation not under consideration by working group
Arjune Sen	Topic advisor	Indirect Financial	Grant monies awarded by Bial for project investigating anti-epileptic medication in older people with epilepsy		December 2022	June 2022	Declare and participate Epilepsy in older people not under consideration by working group
Arjune Sen	Topic advisor	Indirect Financial	UK investigator for CORE VNS outcomes registry in people with epilepsy treated with VNS (Livanova): no monies to be personally received throughout.	June 2019	December 2022	Ongoing	Declare and participate VNS not under consideration by working group

Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	Member of the Medical Advisory Board for Ring Chromosome 20 foundation UK.	July 2019	December 2022	Ongoing	Declare and participate Ring chromosome 20 not under consideration by the working group
Arjune Sen	Topic advisor	Indirect Financial	Grant monies awarded by European Union for trial investigating EEG (SEIZE IT) To start in 2020.	July 2019	December 2022	Ongoing	Declare and participate EEG not under consideration by the working group
Arjune Sen	Topic advisor	Indirect Financial	We have initiated a global study on epilepsy during COVID-19. This is work being done in collaboration between University of Oxford and the charity SUDEP Action	June 2020	December 2022	Ongoing	Declare and participate Not specific to guideline
Arjune Sen	Topic advisor	Indirect Financial	Future partnership planned with UNPEG looking at ultra long monitoring of electroencephalograms (EEGs) using subcutaneous device. Work is currently on hold for this project. Though related to the topic, this procedure is not covered by NICE guidance, and is also not commissioned by the NHS.	25/8/20	December 2022	Ongoing	Declare and participate EEG not under consideration by the working group
Arjune Sen	Topic advisor	Indirect Financial	Epilepsy Monitoring Unit Study of Mortality focusing on SUDEP. This is a project in the U.S. We have been asked to be a lead UK site and I am PI. Analysis of data will be carried out in U.S. The Ethics Approval is in process so the study is not open yet. Funded		December 2022	Ongoing	Declare and participate SUDEP not under consideration by

			by the FACES Charity - non-commercial entity based in NY				the working group
Arjune Sen	Topic advisor	Indirect Financial	The VARIED study - this is looking at health utilisation behaviour related to VNS. This is at protocol stage. The project is supported by LivaNova, There is no reimbursement attached to the work. This will not report during the development of the guideline..		December 2022	Ongoing	Declare and participate VNS not under consideration by the working group
Arjune Sen	Topic advisor	Indirect Financial	Epilepsy Monitoring Unit Study of Mortality - this is the large-scale project from New York capturing retrospective data on people who have had telemetry. We are the lead UK site. Ethics Approval granted April 2021. TMA awaited. Funded by the FACES Charity - non-commercial entity based in NY. No personal monies will be received at any time related to this study		December 2022	Ongoing	Declare and participate Telemetry not under consideration by the working group
Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	Appointed to the World Health Organisation Topic Expert Group on Epilepsy (as part of the WHO intersectoral plan). No monies to be received.		December 2022	Ongoing	Declare and participate Not specific to guideline
Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	Eisai: Creating Capable Communities for PWE and Intellectual Disability in Oxford; 11th February 2022; no personal monies to be received	11/02/22	December 2022	11/02/22	Declare and participate Not specific to guideline
Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	UCB: Epilepsy focus meeting – 28.2.22; speaker; no personal monies to be received	28/2/22	December 2022	28/2/22	Declare and participate Not specific to guideline
Arjune Sen	Topic advisor	Direct	NHS-X: grant awarded to NeuroEvents Lab January 2022 to perform service evaluation video-based detection of nocturnal seizures;	January 2022	December 2022	Ongoing	Declare and participate

		Non-financial, professional and personal	sites at Oxford and Wolverhampton. No personal monies to be received				Nocturnal seizures monitoring not under consideration by working group
Arjune Sen	Topic advisor	Direct Financial	NHSE Transformation Project – Genseize – to explore genomic testing in people with epilepsy. Project initiated. Small contribution to salary, through NHS.	2021	December 2022	Ongoing	Declare and participate Genomic testing not under consideration by the working group
Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	Upcoming work: Plans in place for my organisation to be the centre for the UCB study investigating alprazolam which is a potential treatment for prolonged seizures. No monies to be personally received and the study is not open or locally approved as of yet.	2022	December 2022	Ongoing	Declare and participate Alprazolam not under consideration by the working group
Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	Publication on the intersection of tau with epilepsy. Supported by Eisai. No monies personally received	2022	December 2022	Ongoing	Declare and participate tau not under consideration by the working group
Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	Neurology in focus webinar; No monies personally received	24.5.22	December 2022	24.5.22	Declare and participate Not specific to guideline

Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	Appointed to ILAE Standards and Best Practice Council	5.7.22	December 2022	Ongoing	Declare and participate Not specific to guideline
Arjune Sen	Topic advisor	Indirect Financial	Investigator for the DANTE Study (Livanova). No monies personally received	27.7.22	December 2022	Ongoing	Declare and participate VNS not under consideration by the working group
Arjune Sen	Topic advisor	Indirect Financial	Investigator for the Equilibre Study. No monies personally received	27.7.22	December 2022	Ongoing	Declare and participate VNS not under consideration by the working group
Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	Talk for Eisai Symposium on NICE Guidelines at ILAE meeting. No monies personally received	16.8.22	December 2022	14.10.22	Declare and participate Talking about NICE guidelines is not a conflict
Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	Talk for Eisai on epilepsy and dementia. No monies personally received	June 2022	December 2022	June 2022	Declare and participate Not specific to guideline
Arjune Sen	Topic advisor	Indirect Financial	Appointed as investigator for novel treatment for focal epilepsy (Xenon). No monies to be personally received	October 2022	December 2022	Ongoing	Declare and participate Xenon not under consideration by

							the working group
Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	Appointed to ILAE Epilepsy in older people comission	October 2022	December 2022	Ongoing	Declare and participate Not specific to guideline
Arjune Sen	Topic advisor	Direct Non-financial, professional and personal	Appointed to lead on update to Essential Medicines List for WHO. No monies to be personally received	October 2022	December 2022	Ongoing	Declare and participate Not specific to guideline
Rachel Batchelor	Lay member		Nothing to declare				
Christine Cole	Working group member	Direct Financial	Clinical Nurse Specialist in Epilepsy (adults), Harrow Neurology Specialist Nursing Service		December 2022	Ongoing	Declare and participate Salaried employment in the NHS. Non specific interest
Christine Cole	Working group member	Direct Non-financial, professional and personal	Chair of London Epilepsy Nurse Specialist network (LENS)	2019	December 2022	Ongoing	Declare and participate Not specific to guideline
Christine Cole	Working group member	Direct Non-financial, professional and personal	Member of the Neurological Alliance expert advisory group, for development of the epilepasy service improvement navigation tool	May 2022	December 2022	Ongoing	Declare and participate Not specific to guideline
Anita Devlin	Working group member	Direct Financial	Paediatric neurologist, Great North Children's Hospital		December 2022	Ongoing	Declare and participate Salaried employment in

							the NHS. Non specific interest
Anita Devlin	Working group member	Direct Financial	Nutricia - Sponsorship to attend American Epilepsy Society meeting USA 2022	30/11/2022	December 2022	07/12/2022	Declare and participate Nutricia products not under consideration by the working group
Anita Devlin	Working group member	Direct Financial	Nnutricia - attendance core KDT International Consensus Meeting 21st Nov 2022 – Utrech	20/11/2022	December 2022	07/12/2022	Declare and participate Nutricia products not under consideration by the working group
Anita Devlin	Working group member	Direct Financial	NHSE Regional Clinical Adviser Epilepsy CYP North-East and Yorkshire	2022	December 2022	Ongoing	Declare and participate Not specific to guideline
Anita Devlin	Working group member	Direct Financial	Advisory Board - Takeda	25 th January 2022	December 2022	25 th January 2022	Declare and participate Takeda products not under consideration by the working group

Anita Devlin	Working group member	Direct Financial	Industry training Zogenix	3 rd March 2022	December 2022	3 rd March 2022	Declare and participate Zogenix products not under consideration by the working group
Anita Devlin	Working group member	Direct Financial	Invited chair of Nutricia symposium	23 rd June 2022	December 2022	23 rd June 2022	Declare and participate Nutricia products not under consideration by the working group
Anita Devlin	Working group member	Direct Non-financial, professional and personal	Chair of International League Against Epilepsy (ILAE) Global Task Force Dietary Therapies	2021	December 2022	Ongoing	Declare and participate Not specific to guideline
Anita Devlin	Working group member	Direct Non-financial, professional and personal	Member of the International League Against Epilepsy (ILAE) Global Commission Medical Therapies	2021	December 2022	Ongoing	Declare and participate Not specific to guideline
Anita Devlin	Working group member	Direct Non-financial, professional and personal	Chair of Board of Trustees and member of the Executive Board of International Neurological Ketogenic Society	2021	December 2022	Ongoing	Declare and participate Not specific to guideline
Anita Devlin	Working group member	Direct	Collaborator with other investigators and industry sponsors of a post-marketing survey on K.Vita: a blend of medium chain	2021	December 2022	Ongoing	Declare and participate

		Non-financial, professional and personal	triglycerides to manage drug-resistant epilepsy				K Vita not under consideration by the working group
Anita Devlin	Working group member	Direct Non-financial, professional and personal	Member of European Reference Network for rare and complex epilepsies (EpiCARE) Workstream 10 – dietary therapies	2017	December 2022	Ongoing	Declare and participate Not specific to guideline
Anita Devlin	Working group member	Direct Non-financial, professional and personal	Member of NHSE National Paediatric Epilepsy Oversight Group to design and advise on implementation of new bundle of care package as a priority	2021	December 2022	Ongoing	Declare and participate Not specific to guideline
Anita Devlin	Working group member	Direct Non-financial, professional and personal	Co-chair of the Tertiary care and Epilepsy Surgery Work Stream of the NHSE National Paediatric Oversight Group	2022	December 2022	Ongoing	Declare and participate Not specific to guideline
Anita Devlin	Working group member	Direct Non-financial, professional and personal	NHS England paediatric neurosciences clinical reference group	2019	December 2022	Ongoing	Declare and participate Not specific to guideline
Anita Devlin	Working group member	Direct Non-financial, professional and personal	Regional convenor of Epilepsy 12 national audit	2009	December 2022	Ongoing	Declare and participate Not specific to guideline
Anita Devlin	Working group member	Direct Non-financial, professional and personal	Member of the medical advisory board for MATTHEW'S FRIENDS (A national charity that supports families, education and research into ketogenic therapies)	2015	December 2022	Ongoing	Declare and participate Declare and participate

							Providing advice to a charity is not a conflict with remit of the working group
Mo Eyeoyibo	Working group member	Direct Financial	Learning Disabilities Psychiatrist, Kent & Medway NHS and Social Care Partnership Trust		December 2022	Ongoing	Declare and participate Salaried employment in the NHS. Non specific interest
Richard Grunewald	Working group member	Direct Financial	Adult neurologist, Sheffield Teaching Hospitals NHS Foundation Trust		December 2022	Ongoing	Declare and participate Salaried employment in the NHS. Non specific interest
Philip Smith	Working group member	Direct Financial	Consultant Neurologist and Honorary Professor, Cardiff University		December 2022	Ongoing	Declare and participate Salaried employment in the NHS. Non specific interest
Philip Smith	Working group member	Direct Financial	Co-editor of Practical Neurology	2011	December 2022	Ongoing	Declare and participate Not specific to guideline
Philip Smith	Working group member	Direct	Co-author of SANAD-II study Lancet 2021; 397: 1375–86.	2011	December 2022	2011	Withdraw from discussions relating to

		Non-financial, professional and personal					SANAD-II study, except to answer questions
Philip Smith	Working group member	Direct Non-financial, professional and personal	Author of paper 'Initial management of seizure' NEJM 2021; 385:251-263.	2021	December 2022	2021	Declare and participate. Appointed to the committee for expert knowledge on the initial management of seizure
Philip Smith	Working group member	Direct Non-financial, professional and personal	Author of editorial 'Management of established status epilepticus' NEJM 2019;381:2171-2172.	2019	December 2022	2019	Declare and participate. Appointed to the committee for expert knowledge on the management of seizures
Philip Smith	Working group member	Direct Non-financial, professional and personal	Chair of the NICE guideline committee for Heart Valve Disease	2019	December 2022	2022	Declare and participate Not specific to guideline
Philip Smith	Working group member	Direct Non-financial, professional and personal	Member of the NICE guideline committee for Vitamin B12	2022	December 2022	Ongoing	Declare and participate Not specific to guideline

Ashifa Triveda	Working group member	Direct Financial	Divisional Lead Pharmacist (Women & Children) Hillingdon Hospitals NHS Foundation Trust		December 2022	Ongoing	Declare and participate Salaried employment in the NHS. Non specific interest
Ashifa Triveda	Working group member	Direct Non-financial, professional and personal	Member of the NICE guideline committee for Women's Health	2018	December 2022	Ongoing	Declare and participate Not specific to guideline
Ashifa Triveda	Working group member	Direct Non-financial, professional and personal	NPPG – RCPCH Medicines Committee	2019	December 2022	Ongoing	Declare and participate Not specific to guideline
Ashifa Triveda	Working group member	Direct Non-financial, professional and personal	NPPG Committee	December 2022	December 2022	Ongoing	Declare and participate Not specific to guideline