

9 September 2019

Dear Government,

As senior leaders in epilepsy concerned with safeguarding patients, we are horrified at the defamatory statements made by the leader of the House of Commons this week, against a neurologist who gave his time as an expert to help the Government prepare for a No Deal Brexit. The Government requires doctors and nurses to whistleblow when they are concerned about patient safety, yet Dr Nicholl was attacked in the House of Commons where he had no opportunity to defend himself and assert the public interest and the interests of his patients. The Government cannot expect experts from any sector to work with them if they are at risk of such politically fuelled abuse.

After 10 months of research and campaigning on medicines shortages, we are deeply concerned about the lack of openness and dismissal of real concerns from real people about the significant risks to lives.

Epilepsy affects 600,000 people in the UK. There are **21 epilepsy-related deaths each week**, many in the young, many avoidable. Public Health England (**Public Health England neurological conditions report**, 2018) reported that deaths in people with neurological conditions have been rising, when deaths from all other conditions have fallen. People also facing deprivation are at significantly increased risk of early death. SUDEP Action - a charity which represents a community of bereaved families, supported by a network of health professionals, researchers and industry specialists - brought together a coalition of organisations and cross party MPs who have asked us to lead advocacy in tackling this devastating consequence.

It is deeply regrettable that we have not yet been able to access a meeting with a Government minister since 2018, despite repeated requests. As a result of this ongoing patient safety campaign, we have met recently with departmental officials aiming to provide assurance that appropriate plans were in place. We understand that the civil service is working hard to avoid any shortages and have established processes to attempt to mitigate these. Sadly, the epilepsy community has been facing significant levels of unmanaged risk for years. It continues to remain unclear who would be left accountable if deaths rise as a result of Government policy. The real potential for any failure in mitigation of risk due to medicines shortages, linked to Brexit or otherwise, is unacceptable to our community.

This is why we, with cross party support, are adding our voice to the **call for the publication of the Yellowhammer documents**, in particular the sections regarding medicines shortages and impact on the health sector, so that the public has an opportunity to be informed. The long term interest of doctors and other experts helping Government reach informed positions is at stake, and we support Dr Nicholl's request for a formal apology in the House of Commons so that the record can be put straight.

We have a duty of care to not let this issue lie, as we know on a daily basis the devastating and life-long impact of sudden avoidable epilepsy deaths on families and communities.

Jane Hanna OBE, CEO, SUDEP Action (linked charity Epilepsy Bereaved)

John Hirst CBE, Chair of SUDEP Action (linked charity Epilepsy Bereaved)

Paula Sherriff MP, Chair of the All-Party Parliamentary Group for Epilepsy

Dr Sarah Wollaston MP for Totnes
Norman Lamb MP for North Norfolk
Dr Philippa Whitford MP for Central Ayrshire
Carol Monaghan MP for Glasgow North West
Ben Bradshaw MP for Exeter
Professor Leone Ridsdale, Professor of Neurology and General Practice, Kings College, London
Professor Matthew Walker, Consultant Neurologist and President of the British Branch of the International League Against Epilepsy
Phil Tittensor, Epilepsy Specialist Nurse, Epilepsy Specialist Nurse Association
Maxine Smeaton, CEO, Epilepsy Research UK
Mark Devlin, CEO, Young Epilepsy
Simon Wigglesworth, Deputy CEO, Epilepsy Action
Lesslie Young, CEO, Epilepsy Scotland
Shirley Maxwell, Executive Director, Epilepsy Connections
Professor John Paul Leach, Consultant Neurologist and Head of Undergraduate Medicine, University of Glasgow
Dr Arjune Sen, Neurologist, The John Radcliffe Hospital, Oxford Professor
Esther Rodriguez-Villegas, Professor of Low-Power Electronics, Imperial College London
Professor Mike Kerr, SUDEP Action Trustee & Professor, Cardiff University
Dr Rohit Shankar MBE, Clinical Director Cornwall Partnership NHS Trust Hon. & Associate Cl. Professor Exeter Medical School
Dr Heather Angus-Leppan, Consultant Neurologist and Epilepsy Lead, Royal Free London NHS Foundation Trust
Dr Rhys Thomas, Honorary Consultant in Epilepsy & Intermediate Clinical Fellow, Newcastle University
Professor Hannah Cock, Professor of Epilepsy & Medical Education & Consultant Neurologist St George's, University of London
Dr Colin Dunkley, Consultant Paediatrician, Sherwood Forest Hospitals NHS Foundation Trust
Dr Craig Newman, Psychologist / Director, Uxclinician Ltd
Sammy Ashby, Deputy CEO, SUDEP Action (linked charity Epilepsy Bereaved)
Kim Morley, Epilepsy Specialist Nurse/Midwife Practitioner, Hampshire Hospitals NHS Foundation Trust
Dr Owen Pickrell, Clinical Lecturer (WCAT), Swansea University Medical School
Dr Manny Bagary, Consultant Neuropsychiatrist, Birmingham and Solihull Mental Health NHS Foundation Trust
Dr John Craig, Consultant Neurologist, Belfast Health and Social Care Trust and Chair UK and Ireland Epilepsy and Pregnancy Register
Dr Michael Kinney, Consultant Neurologist with sub-specialist interest in Epilepsy, Belfast, Northern Ireland
Dr Judy Shakespeare, Retired GP
Dr Thomas Peukert, Consultant Neurologist Belfast, Special interest: Acute Neurology