

31st January 2016

Sir,

As representatives of the millions of people in England living with a neurological condition and those who care for them, we would like to express our deep dismay at NHS England's decision to cut the role of National Clinical Director for neurology services, less than three years after it was instituted.

Once again, people with these complex and often severe conditions feel let down and neglected by the system. The NHS spends over £4 billion per year on neurology services, yet patients still face excessive waiting times and a postcode lottery in access to care. When 40% of patients wait for over a year to be diagnosed and 58% face difficulties accessing the specialist services they require, it is inexplicable that NHS England now intends to cut the only source of national clinical leadership for service improvement.

This short-sighted decision will harm the interests of patients and undermine the improvement initiatives that the National Clinical Director has led and coordinated. Furthermore, it reinforces the perception that people living with neurological conditions are a low priority constituency for the NHS. On behalf of patients, we urge NHS England to reverse this damaging decision.

Yours sincerely,

Arlene Wilkie Chief Executive, Neurological Alliance

Adrian Hale, Chair, Trigeminal Neuralgia Association UK

Alice Doyle, Chief Executive, Brain and Spine Foundation

Amy Bowen, Director of Service Development, Multiple Sclerosis Trust

Amy Couture, Chief Executive, Hemihelp

Andrea West, Chief Executive, Batten Disease Family Association

Angela Geer, Chief Executive, Epilepsy Society

Andrew Kemp, Acting Chair, South West Alliance of Neurological Organisations

Barbara Babcock, Chair, Tranverse Myelitis Society

Bernard Elwen, Secretary, Multiple Sclerosis National Therapy Centres

Caroline Morrice, Chief Executive, Guillain-Barre and Associated Inflammatory Neuropathies

Cath Stanley, Chief Executive, Huntington's Disease Association

Countess Mar, Chair, Forward M.E.

David White, Chair, Cavernoma Alliance UK

David Wray, Chair, Swindon and Wiltshire Neurological Alliance

Fergus Logan, Chief Executive, PSP Association

Glenys Marriot, Chair, Cumbria Neurological Alliance

Guy Parckar, Chief Executive, Dystonia Society

Heather Wallace, Chair, Pain Concern

Heidi Travis, Chief Executive, Sue Ryder

Heidi Wilson, Chair, I Have IIH Foundation

Jamie Miller, Chair, Oxfordshire Neurological Alliance

c/o Parkinson's UK, 215 Vauxhall Bridge Road, London, SW1V 1EJ | Tel: 020 7963 3996 | Web: neural.org.uk The Neurological Alliance is a charity registered by the Charity Commission for England and Wales (registration number 1039034) and a company limited by guarantee registered in England (registration number 2939840). Registered office is c/o Parkinson's UK, 215 Vauxhall Bridge Road, London, SW1V 1EJ



Jane Hanna, Chief Executive, SUDEP Action

Jayne Spink, Chief Executive, Tuberous Sclerosis Association

Jean Waters, Chair, Gloucestershire Neurological Alliance

John Livingston, President, British Paediatric Neurology Association

John Morgan, Chair, Staffordshire Neurological Alliance

Karen Butcher, Chief Executive, CMT United Kingdom

Karen Walker, Chief Executive, Multiple System Atrophy Trust

Katherine Carpenter, Chair of the Division of Neuropsychology, British Psychological Society

Linda McDonald, Regional Organiser, Yorkshire and Humberside Association of Neurological Organisations

Lindsay Easton, Chief Executive, Brain Research Trust

Margaret Stewart, Chair, Northern Neurological Alliance

Matt O'Neil, Chair, Narcolepsy UK

Michelle Mitchell, Chief Executive, Multiple Sclerosis Society

Michelle Williamson, Trustee, IIH UK

Mikes Barnes, Chair, UK Acquired Brain Injury Forum

Nanette Mellor, Chair, The Brain Charity

Paul Allen, Chief Executive, Royal Hospital for Neuro-disability

Paul Lenihan, Chief Executive, Action Duchenne

Peter Cornell, Chair, Black Country Neurological Alliance

Phil Lee, Chief Executive, Epilepsy Action

Philip Johnson, Assistant Chief Executive, Brain And Spinal Injury Centre

Philip Smith, President, Association of British Neurologists

Preston Keeling, Chair, Lincolnshire Neurological Alliance

Ruth Ingledew, Chief Executive, Myaware

Sally Light, Chief Executive, Motor Neurone Disease Association

Sarah Lindsell, Chief Executive, Brain Tumour Charity

Simon Parritt, Chair, Polio Survivors Network

Sonya Chowdhury, Chief Executive, Action for M.E.

Steve Ford, Chief Executive, Parkinsons UK

Sue Millman, Chief Executive, Ataxia UK

Suzanne Dobson, Chief Executive, Tourettes Action

Ted Hill, Chief Executive, British Polio Fellowship

Theresa Dauncey, Chief Executive, The National Brain Appeal

Tom Isaacs, President, Cure Parkinson's Trust

Wendy Thomas, Chief Executive, Migraine Trust