

Rt Hon Jeremy Hunt MP
Secretary of State for Health
Department of Health
Richmond House
London SW1A 2NS

25th January 2016

Dear Secretary of State,

We are writing to you to express the concern felt by people living with neurological conditions, their families and loved ones about NHS England's decision not to retain the post of National Clinical Director (NCD) for adult neurology beyond March of this year. This is a short-sighted move which will leave no strategic leadership for neurology within the NHS at the national level and will disrupt the improvement initiatives that Dr David Bateman, the current post-holder, has led and coordinated over the past two years.

You will be aware that neurology services already lag well behind other condition areas in terms of service access and quality, with 58% of people with neurological conditions having difficulty accessing the services they need, and 40% waiting over 12 months between first symptoms and being given a diagnosis (according to a survey of almost 7,000 patients). Local commissioners have disengaged from neurology services to the point where only 15% can state how much they spend on neurology locally. Access to specialist neurology services varies hugely by both region and CCG area, with 45 CCGs (22%) offering no local neurology services whatsoever.

In the short time since his appointment, the NCD has led a range of initiatives aimed at improving patients' experience of care. He has worked with NHS England's strategic clinical networks to modernise the referral processes for headache, and to develop measurable standards to audit local provision for acute neurological emergencies and scheduled care. His work with Public Health England's Neurology Intelligence Network has allowed patients to compare and scrutinise CCGs' performance and outcomes in neurology for the first time. He has taken the lead on strengthening and developing community neurology services, including developing plans with NHS England for a community care service for patients with long-term neurological conditions.

Cutting the NCD role so soon after its creation will undermine these efforts to improve the quality and value of neurology services. Neurology is not a minor issue for the NHS. There are an estimated 12 million cases of neurological conditions in England, and NHS spending on neurology services totalled over £4.1 billion in 2013/14, including funding for 827,242 emergency admissions. Consequently it is difficult to understand why NHS England does not value clinical leadership for neurology services. In addition, it is particularly concerning that there is still no commitment from NHS England and Public Health England to fund the Neurology Intelligence Network beyond March. In conjunction with the loss of the NCD role, this would leave neurology services with no national clinical leadership, and no access to comparative national data in order to scrutinise services and hold commissioners and providers to account.

As representatives of the millions of people living with neurological conditions, we believe that the decision not to maintain the role of neurology NCD is short-sighted and damaging to patients' interests. There is enormous scope to improve neurology services, but it will require effective clinical leadership at the national level. We urge you to use your influence as Secretary of State to raise this issue with NHS England and request that they commit to maintaining the

role beyond March 2016. The Neurological Alliance would be very pleased to meet with you to discuss this issue further if that would be helpful.

We have sent a copy of this letter to Simon Stevens.

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, Transverse 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 Marriott, 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

Jane Hanna, Chief Executive, SUDEP Action

Jayne Spink, Chief Executive, Tuberous Sclerosis Association

Jean Waters, Chair, Gloucestershire Neurological Alliance

John Morgan, Chair, Staffordshire Neurological Alliance

Karen Butcher, Chief Executive, CMT United Kingdom

Karen Walker, Chief Executive, Multiple System Atrophy Trust

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

Mike 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

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