

3rd June 2021

Dear Secretary of State

We are writing in response to Petition 565418: Fund research, treatment and awareness of Functional Neurological Disorder (FND) by the Department of Health and Social Care received on the 19th April 2021.

Your response (in summary) was as follows:

1. The National Neurology Advisory Group has currently in its work plan for 2021/2022 a priority to support development of a clinical pathway for FND.
2. Clinicians are supported in the diagnosis of FND by the guidance contained in “Suspected neurological conditions: recognition and referral” (2019).
3. People with FND are likely to be diagnosed within specialist neurological services which are distributed amongst 25 locations to provide equality of access.
4. The majority of services for people with FND are commissioned at a local level by Clinical Commissioning Groups, who are best placed to plan the provision of services, subject to local prioritisation and funding.
5. It is not normal practice for NIHR to ring-fence funding for particular conditions, but applications for research funding relating to FND would be welcomed.

We would like to respond to these points in turn.

1. Clinical Pathway

We are pleased that NNAG has selected FND as a priority for development of an optimal care pathway, and many of us have participated in the drafting and consultation process for this pathway. The working group agreed that people with FND face specific challenges in accessing appropriate care and support. These challenges include: stigma and misunderstanding regarding the diagnosis amongst healthcare professionals and society at large (suspicion of malingering/exaggeration of symptoms), poor quality or absent explanation of the diagnosis by neurologists, frequent discharge after diagnosis without treatment plan or follow-up, referral into treatment services (neurotherapy, mental health) that lack expertise, often resulting in early discharge without treatment, lack of coordination between mental and physical health services in assessment and treatment, lack of a clear pathway to access specialist services, lack of availability of specialist services.

The over-riding issue is that development of this pathway comes with *no guarantee or even route-map* for how it might be implemented in clinical practice. It therefore runs the risk of being a paper exercise only and appearing to those with FND and the healthcare professionals involved in their care as simply a way of demonstrating that “something is being done”, without there being any prospect of it producing change on the ground. This is in fact exactly what happened in a previous pathway development exercise in Scotland in 2012, sponsored by the Healthcare Improvement (Scotland), where the pathway was never implemented.

Our question is therefore: What is the route by which the optimal care pathway for FND developed by NNAG will be progressed into implementation in clinical practice?

2. Suspected Neurological Conditions Guidance

There is in fact very little in this document about FND. Where FND does appear, the main advice is that patients may *not* need referral into neurology services if the diagnosis has already been made and that they should be advised that symptoms may fluctuate at times of stress. This advice begs the question therefore of how a person with FND is meant to be able to access treatment and support.

3. Specialist Neurology Services

You advised us that there are currently 25 specialised neurological treatment centres geographically spread across England. However, below is a table of the specialised neurology centres and unfortunately 16 out of the 25 centres do NOT offer any form of specialist FND diagnosis or treatment. The following paper mentioned in the response [Neurosciences Specialised Neurology \(Adult\)](#), does not discuss FND, which we feel is a major oversight and provides an example of the way in which FND is marginalised, despite how common and disabling it is.

Even in those services where there is an FND clinic, it is clear that having a neurologist seeing some patients with FND within a specialist clinic is completely different from having a functioning care pathway with different treatment options for people with FND depending on their need. The latter doesn't really exist in a complete way anywhere within the UK.

Ref	Hospital	Comments
RF4	BARKING, HAVERING AND REDBRIDGE UNIVERSITY HOSPITALS NHS TRUST	No FND Service
RNJ	BARTS AND THE LONDON NHS TRUST	No FND Service
RXH	BRIGHTON AND SUSSEX UNIVERSITY HOSPITALS NHS TRUST	No FND Service
RGT	CAMBRIDGE UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	
RWA	HULL AND EAST YORKSHIRE HOSPITALS NHS TRUST	No FND Service
RYJ	IMPERIAL COLLEGE HEALTHCARE NHS TRUST	No FND Service
RJZ	KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST	
RXN	LANCASHIRE TEACHING HOSPITALS NHS FOUNDATION TRUST	No FND Service

RR8	LEEDS TEACHING HOSPITALS NHS TRUST	
RVJ	NORTH BRISTOL NHS TRUST	
RX1	NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST	No FND Service
RTH	OXFORD RADCLIFFE HOSPITALS NHS TRUST	Partial FND Service
RK9	PLYMOUTH HOSPITALS NHS TRUST	No FND Service
RAL	ROYAL FREE HAMPSTEAD NHS TRUST	No FND Service
RM3	SALFORD ROYAL NHS FOUNDATION TRUST	No FND Service
RHQ	SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST	
RTR	SOUTH TEES HOSPITALS NHS FOUNDATION TRUST	No FND Service
RHM	SOUTHAMPTON UNIVERSITY HOSPITALS NHS TRUST	No FND Service
RJ7	ST GEORGE'S HEALTHCARE NHS TRUST	
RTD	THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST	No FND Service
RET	THE WALTON CENTRE NHS FOUNDATION TRUST	
RRV	UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST	
RRK	UNIVERSITY HOSPITAL BIRMINGHAM NHS FOUNDATION TRUST	No FND Service
RJE	UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE NHS TRUST	No FND Service
RKB	UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS TRUST	No FND Service

Our question is: What are the plans to increase availability of specialist services within neuroscience centres for people with FND as are present for neurological conditions of a similar prevalence and severity such as Multiple Sclerosis and Parkinson's Disease?

4. Locally Commissioned Treatment Services

We would strongly disagree that there are adequate locally commissioned treatment services for people with FND. Feedback from patients and direct correspondence from services to health care referrers indicates that most areas have no specific treatment services at all, and generic mental health and neurotherapy services routinely reject referrals to treat people with FND on the grounds of funding/commissioning and lack of skills/expertise. This represents a fundamentally inequitable position for people with FND, as they are denied appropriate treatment from services who routinely treat people with other causes of similar symptoms. Given this current situation, we are not confident that Integrated Care Systems will offer any better standards of treatment for people with FND.

Our questions are: What is your evidence that treatment services for people with FND are actually commissioned at present? What are your plans to ensure equity of access to relevant treatment for people with FND?

5. Research

We are grateful for the support that NIHR has given to research work into FND. While we appreciate that it is unusual to ring-fence funds for a specific illness, this is not without precedent (e.g. Chronic Fatigue Syndrome), and we feel that FND has some specific issues that make it deserving of special recognition in this way. Historically it has been an area with very limited research despite how common it is, and therefore there is a need for some positive rebalancing of investment. This is particularly relevant given how costly the current management of the condition is due to, we would argue, the absence of a properly funded and structured care pathway. FND also sits at the border between neurology and psychiatry and suffers therefore of being neither properly within neurology or mental health. This is evidenced by its exclusion from important policy documents in neurology and psychiatry (for example the recent Suspected Neurological Conditions: recognition and referral Guideline). FND therefore does not completely benefit from research calls for mental health or neurology projects. We believe that there is a major opportunity for the UK to become a world leader in treatment and research into FND, with this research likely to have a direct, rapid positive impact on people with FND and the wider health economy.

Our questions are: What are your plans to ensure that the NIHR can ring-fence funds for Functional Neurological Disorder? What are your plans to ensure that FND is evidenced in important policy documents such as the Neurosciences Specialised Neurology (Adult) and in the Paediatric Neurosciences – Neurology?

We look forward to receiving your response to the above questions.

Yours sincerely



Dawn Golder
Executive Director
FND Hope UK England & Wales #1173607 & Scotland SC048333

Signed for and on behalf of:

Professor Mark Edwards,
Professor of Neurology, St
George's University Hospitals
NHS Foundation Trust

Dr Biba Stanton,
Neurologist, Kings College
Hospital

Dr Niels Detert,
Neuropsychologist, John
Radcliffe Hospital

Dr Michael Dilley,
Consultant Neuropsychiatrist in
Neurorehabilitation,
Wolfson Neurorehabilitation
Service, St George's University
Hospitals NHS Foundation Trust

Dr Leo Russell,
Professional Lead Community
Neuropsychology FNS, Devon
Partnership NHS Trust

Georgina Carr, CEO
Neurological Alliance

Clare Nicholson, Clinical Specialist Occupational Therapist, The National Hospital for Neurology and Neurosurgery

Dr Timothy Nicholson, Neuropsychiatrist, South London and Maudsley Hospital, London

Dr Christopher Symeon, Consultant Neuropsychiatrist, Wolfson Neurorehabilitation Service, St George's University Hospitals NHS Foundation Trust

Dr Abrar Hussain
Consultant Liaison Psychiatrist
Berkshire NHS Healthcare
Foundation Trust

Professor Markus Reuber,
Professor of Neurology, Royal
Hallamshire Hospital, Sheffield

Dr Glenn Nielsen,
Senior Lecturer in
Neurological Physiotherapy, St
George's, University of London

Dr Wendy Phillips, Neurologist,
Addenbrook's Hospital,
Cambridge

Professor Eileen Joyce
Professor of Neuropsychiatry
UCL Queen Square Institute of
Neurology

Dr Elizabeth Mallam,
Neurologist, Southmead
Hospital, Bristol

Dr Jason Price, Consultant
Clinical Neuropsychologist, The
James Cook University Hospital

Dr Richard J Brown,
Senior Clinical Lecturer and Hon
Consultant Clinical Psychologist,
University of Manchester
and Greater Manchester Mental
Health NHS Foundation Trust