Citizen Participation and Public Petitions Committee Wednesday 24 September 2025 14th Meeting, 2025 (Session 6)

PE2165: Raise awareness of and provide educational resources and training for Functional Neurological Disorder (FND)

Introduction

Petitioner Michelle Moir

Petition summary Calling on the Scottish Parliament to urge the Scottish

Government to help improve awareness of Functional

Neurological Disorder (FND) by providing funding for training and educational resources for medical professionals (including GPs, paramedics, call handlers), employers, and wider society

on the symptoms and impacts of FND.

Webpage https://petitions.parliament.scot/petitions/PE2165

1. This is a new petition that was lodged on 13 May 2025.

- 2. A full summary of this petition and its aims can be found at **Annexe A**.
- 3. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe B**.
- 4. Every petition collects signatures while it remains under consideration. At the time of writing, 241 signatures have been received on this petition.
- 5. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered.
- 6. The Committee has received submissions from the Scottish Government and the petitioner, which are set out in **Annexe C** of this paper.

Action

7. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee September 2025

Annexe A: Summary of petition

PE2165: Raise awareness of and provide educational resources and training for Functional Neurological Disorder (FND)

Petitioner

Michelle Moir

Date Lodged

13 May 2025

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to help improve awareness of Functional Neurological Disorder (FND) by providing funding for training and educational resources for medical professionals (including GPs, paramedics, call handlers), employers, and wider society on the symptoms and impacts of FND.

Background information

In March 2024, unable to walk or talk, I was diagnosed with Functional Neurological Disorder. We were handed a card with a website, https://neurosymptoms.org, and told I would receive a follow up appointment and "recover in the community". No treatments were offered, no support groups were recommended. My family and I were left to learn and accept a new way of life.

Since then, I've had to take long-term sick leave from work, attended several GP appointments and used ambulances where I have had to explain to them what FND was! My seizures and symptoms have been poorly and rudely handled. I am not alone in these experiences.

There are FND charities with helpful websites, however, nothing Scotland based. Most useful services are based in cities, however, this isn't always accessible for those who use walking aids or wheelchairs, most of which have been self-purchased due to lack of NHS Scotland support.

Annexe B: SPICe briefing on PE2165

Briefing for the Citizen Participation and Public Petitions Committee on petition <u>PE2165</u>: Raise awareness of and provide educational resources and training for Functional Neurological Disorder (FND) lodged by Michelle Moir

Brief overview of issues raised by the petition

The petitioner is seeking to raise awareness of and to improve training and resources on Functional Neurological Disorder (FND).

Following diagnosis, the petitioner was signposted to a website – neurosymptoms.org, established by Professor Jon Stone, a Consultant Neurologist with NHS Lothian. Professor Stone has, with colleagues, including Professor Alan Carson, carried out research into functional neurological disorders and their treatment since 1999 'driven by a desire to improve knowledge, understanding and attitudes towards functional disorders'.

The website provides a link to the <u>team's research pages on functional disorders – the Centre for Clinical Brain Sciences</u>, <u>University of Edinburgh</u>.

What are functional neurological disorders?

According to the Centre's website:

"Functional disorders are one of the commonest reasons for patients to see a neurologist. They include problems such as dissociative (non-epileptic) seizures, functional movement disorders (such as tremors, spasms or jerks) and functional limb weakness.

Functional Neurological Disorders (sometimes abbreviated to FND) are genuine and often disabling. They relate to a disorder of nervous system functioning, but not brain disease. Other terms used to describe these hidden and stigmatised disorders include conversion disorder and psychogenic disorders."

<u>Information about FND was updated on NHS Inform</u> in February 2025. There is information on the clinical features – distinctive ways that symptoms present that are unique to FND. It is these features that identify FND as distinct from other neurological conditions, with similar symptoms.

Treatments discussed are forms of rehabilitation therapy, to improve the ability to carry out everyday activities. NHS Inform states that many of the these are designed to 'retrain the brain'. Sometimes treatment is successful, sometimes not, and sometimes people go into remission, others do not.

One study carried out in Edinburgh found that 14 years after diagnosis, regardless of any interventions or treatment:

20% had completely recovered

- 31% had improved
- 23% were the same
- 14% were worse

FND National Pathway

In May 2024, the NHS Scotland Centre for Sustainability published a 'national pathway' document to provide:

"Benefits to People with FND:

- Recognition that FND is real, common, and disabling
- Better access to evidence-based treatment for FND

Benefits to Services:

- Recommendations to Health Boards and practitioners on the content of an FND service.
- More efficient, sustainable, and cost-effective use of existing services

The document states that FND 'is often suspected in primary care' and can be raised as a possibility by any health professional in any healthcare setting.

However, it is not clear what training is available to primary care medical and nursing staff to assist with diagnosis in primary care, so GPs would have to understand and link a variable set of clinical features. The Royal College of General Practitioners has produced a learning course, which includes a module on recognising and explaining FND.

Training and resources available to clinicians on FND

A short online course on FND for health practitioners

Allied Health FND Networking Group – <u>resources</u>, <u>recommendations</u>, <u>guidance and</u> articles for clinicians

Functional neurological disorders: effective teaching for health professionals

The objective of the study was, somewhat unusually, to create a course designed to develop the skills for diagnosis and management of FND. The experimental course was delivered biannually over 2 days, face to face to small groups of health professionals by experts in multidisciplinary management of patients suffering from FNDs (including a neurologist, psychiatrists, psychologists, physiotherapists and a clinical nurse. The study concluded:

"It is possible to make real change in the understanding and management of medical and allied health clinicians working with people with FND with a low-cost intervention. Also, the development of educational networks and multidisciplinary collaboration can lead to the creation of therapeutic platforms for the diagnosis, management and advocacy of this patient group.

Other guidance

The National Institute for Health and Care Excellence (NICE) has produced a 'clinical knowledge summary', (CKS) on FND. A CKS provides primary care practitioners with an 'accessible summary of the current evidence base and practical advice on best practice' in relation to certain conditions. This is not a full NICE guideline. There is a full guideline on 'Suspected neurological conditions: recognition and referral. NICE assesses all the evidence available about a disease or condition, and bases its recommendations on the strength of that evidence.

(see also <u>resources</u> indicated above, which contain links to **other guidance**, **from professional associations etc**)

Anne Jepson

Senior Researcher, SPICe

10 June 2025

The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However, if you have any comments on any petition briefing you can email us at spice@parliament.scot

Every effort is made to ensure that the information contained in petition briefings is correct at the time of publication. Readers should be aware however that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

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Annexe C: Written submissions

Scottish Government written submission, 2 June 2025

PE2165/A: Raise awareness of and provide educational resources and training for Functional Neurological Disorder (FND)

Does the Scottish Government consider the specific ask[s] of the petition to be practical or achievable? If not, please explain why.

No. Developing and disseminating new resources to provide training and education to medical professionals requires additional budget not currently available and it is considered that current work underway addresses the concerns raised in the petition. A number of funded projects support an improved awareness and understanding of FND described under section 4 of this form. Further work is required to implement more widely the approaches described and discussions will take place between Scottish Government, NHS boards and other providers on the best approach to improve awareness amongst GPs, the wider healthcare community and employers. There are, for example, Practice Based Small Group Learning Modules that can be developed for primary care practices and this would be an option that could be progressed if felt to be the most appropriate and cost effective approach.

What, if any, action the Scottish Government is currently taking to address the issues raised by this petition, and is any further action being considered that will achieve the ask[s] of this petition?

Through our 5 year strategy, Neurological Care and Support in Scotland: A Framework for Action 2020-2025 and the Centre for Sustainable Delivery the Scottish Government has funded the following resources:

- **FND Care pathway**: this was developed by the Centre for Sustainable Delivery in 2024: fnd-national-pathway.pdf. This provides recommendations to NHS Boards and practitioners on the content of an FND service and more efficient, sustainable, and cost-effective use of existing services.
- FND Clinical Network in NHS Lothian: The creation of an FND network facilitated by an FND specialist practitioner to improve clinical pathways, provide education and training to other healthcare professionals and a relapse service for people with FND. This project is still in progress and aligns with the FND Care Pathway. It is due to complete in the autumn of 2025. The specialist practitioner role includes delivering education about FND to those health professionals not in a primary neurological setting who come in to contact regularly with people with the condition. Although full data has still to be analysed, the early indications are that this approach will result in reduction in A&E attendance, and savings in hospital bed days. If we can make the case for wider adoption and spread of this model, it potentially provides a way of enabling people with FND to be supported and to be better able to manage their condition.
- NHS Grampian: GP Pathways for FND Education: pilot study investigating ways to enhance knowledge and diagnosis of FND within three GP surgeries.

Evaluation of training led to GP's feeling more confident in diagnosing and managing FND patients with their surgeries, improving confidence to initiate a joint learning model with patients and a shared understanding of supported self-management

- It should be noted that the project data at the time of reporting had not been fully analysed and we would need the final data to see what improvements in referral quality have resulted. Further consideration could be given to scale and spread of the GP education modules.
- <u>Functional Neurological Disorder (FND) A Patient's Guide to FND</u>: this
 internationally recognised website was developed by Professor Jon Stone of
 NHS Lothian and includes information on the causes, symptoms and
 treatment of FND. It is aimed at patients and professionals and contains
 accessible and in-depth information about the condition.

The petitioner references being signposted to this resource. It needs to be recognised as a source that, used appropriately, can enhance healthcare professional and patient literacy of the condition.

 Dissociative Seizures app: <u>Dissociative Seizures | Right Decisions</u>; dissociative seizure is a symptom experienced by people with FND. This module is available on the NHS Right Decisions Service and downloadable as an app.

We will continue to work with health and social care providers to integrate these approaches and resources with the goal of providing holistic care and support to all people with a diagnosis of FND.

Is there any further information the Scottish Government wish to bring to the Committee's attention, which would assist it in considering this petition?

We are working with all NHS boards on the delivery of improvement plans for neurological conditions. This includes services for people with FND. A Neurological Conditions Improvement Network has been established to support collaboration and sharing of good practice around improvement in neurology services. Boards are being asked to report on progress with these plans annually (commencing in May 2025).

Long Term Conditions Policy Unit, Quality and Planning Division

Petitioner written submission, 5 September 2025

PE2165/B: Raise awareness of and provide educational resources and training for Functional Neurological Disorder (FND)

I wish to raise some points regarding the response from the Scottish Government and the SPICe briefing dated in June 2025.

Regarding the government's response I would like to know if patients with FND will be consulted regarding the approaches to improving awareness to GPs. I also understand that Practice Based Small Learning modules is an online learning opportunity for various medical conditions. Will this become mandatory regarding

FND and be made available to GPs, A&E staff, paramedics and call handlers? As more and more people are diagnosed with FND and unaware of who to turn to when their own GP cannot support them, neither can NHS 24 or 999 call handlers understand and neither do paramedics. Therefore should the training modules not be mandatory rather than voluntary? These experiences are not just my own; these are experiences of thousands around the country.

Will the information collated via NHS Lothian be available for the public once it concludes in Autumn 2025? Also, any further data collected from NHS Grampian be shared publicly? What are the next steps once this ended?

In creating a social and face to face support group of over 200 members not one person has been made aware of the FND care pathway nor of the Dissociative Seizures app or site. Why is this information not more widely shared? Receiving a diagnosis and given a website to read is not enough support, and furthermore to get any further support or information patients are having to search through the internet to find these very valuable resources. Furthermore, out of the 200+ members none have heard of or been signposted to these sites by any medical practitioners and have not heard of NHS Right Decisions either. Why is none of this shared more publicly within GP practices, hospitals, etc?

Going forward, why are individuals such as myself, those in the support group we have created and those who are living daily with FND having to fight for information to be shared, when we have felt dismissed, medically gaslit and left to fend for ourselves? In regards to raising awareness in workspaces and in the wider community, what opportunities are there for this to be done other than ourselves raising awareness on social media and in our local communities?

NHS England are using the NHS app which is a free app where patients can see their medical appointments, test results and any diagnosis they have. Will this be available on NHS Scotland? This would be beneficial for those with FND and other health conditions for showing and sharing with paramedics, A&E staff etc if for example speech or cognition is impaired due to functional symptoms. It would also benefit the individual and employers as information regarding appointments and medications can also be shared. Due to the app showing historical appointments, referrals, medications and diagnosis it would also be beneficial for the individuals to understand their FND diagnosis and possibly pinpoint a potential risk or cause for FND.