



Pre Budget Submission 2025



FND Ireland, Ireland’s first registered not-for-profit organisation dedicated to advocating for and supporting those living with Functional Neurological Disorder (FND) has two key asks for Budget 2025.

SUMMARY OF KEY ASKS IN BUDGET 2025

1. Funding for the first specialist multidisciplinary FND clinic in Ireland
2. Develop a national FND pathway with multi-annual funding

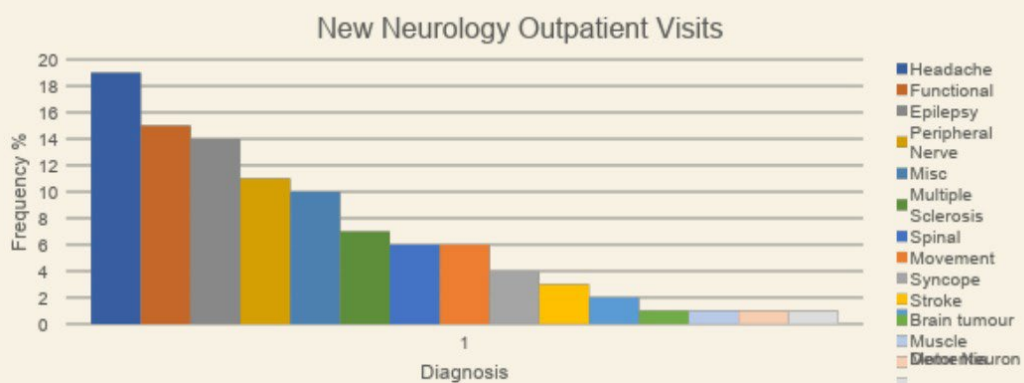
So what is Functional Neurological Disorder (FND) and how common is it?

FND is a condition that can present with a wide range of neurological symptoms, most commonly functional weakness, functional tremor, and functional seizures, but many other symptoms exist. FND occurs when there is a problem with the functioning of the nervous system, and this impacts how the brain and body send and receive signals. FND is a genuine condition which can occur alone or coexist with other illnesses and neurological conditions.

At present, Irish data on the prevalence of FND is lacking however extrapolating from international figures is reasonable; this means the presumptive community incidence rates are comparable to multiple sclerosis (MS). As a result, we estimate that approximately 9,000 people are living with FND in Ireland which compares favourably with recent estimates of 10,000 people in Scotland.

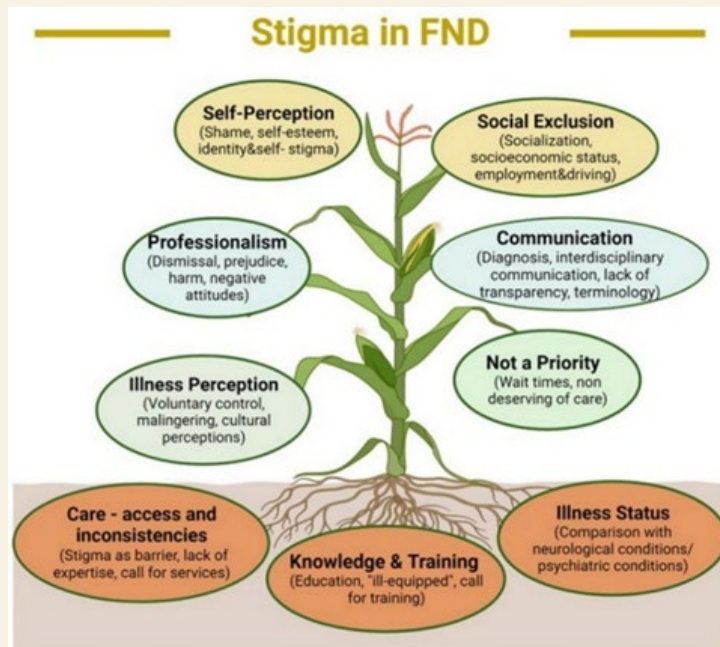
International research has shown that FND is the second most common reason to see a neurologist after all headache¹

It’s **common**, it’s disabling, and it can be chronic



(1) Stone. J et al. Clinical Neurology Neurosurgery 2010

Despite how commonly FND is seen, decades of neglect have resulted in an unseen problem with a higher stigma than that of other neurological conditions². This a major barrier to FND patients receiving the treatment and supports they deserve.



(2) Stigma in Functional Neurological Disorder (FND) – A systematic review

Anyone can be affected by FND, but it is more common in women than men. It can occur at any age, but in the main affects a young working-age population³. FND is increasingly diagnosed in teenagers but uncommon in children under 10 years.

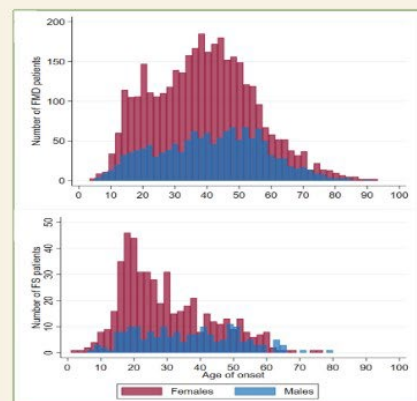
It affects a young, working-age population

Original research

OPEN ACCESS

Functional movement disorder gender, age and phenotype study: a systematic review and individual patient meta-analysis of 4905 cases

Sarah C. Lidstone^{1,2}, Michael Costa-Parke,¹ Emily J. Robinson,^{3,4} Tommaso Ercoli,⁵ Jon Stone,⁶ FMD GAP Study Group



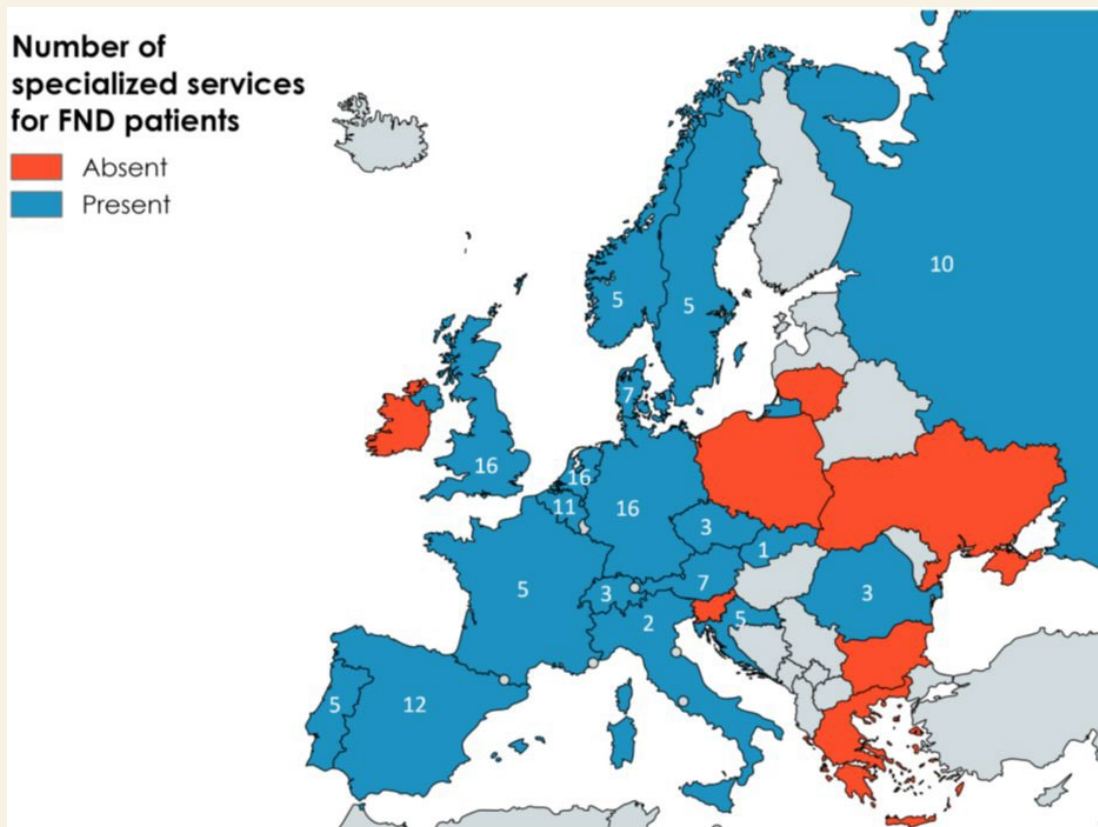
(3) Functional movement disorder gender, age and phenotype study 2022

ASK 1

Funding for the first specialist multidisciplinary FND clinic in Ireland

Why do we need this specialist multidisciplinary FND clinic?

Despite approximately 9,000 people living with FND in Ireland, Ireland is the only country in Western Europe without a specialised FND service according to a recent paper published this month - ‘Functional Neurological Disorder in Europe: regional differences in education and health policy’⁴. At present there are no dedicated services for FND patients in the country which results in patients receiving little or at best fragmented care within our health service. FND patients have no choice but to travel overseas to avail of specialist FND treatment which comes at a significant financial burden for private care, and those trying to access public services via the HSE Treatment Abroad Scheme encounter unacceptable wait times.



(4) Functional Neurological Disorder in Europe: regional differences in education and health policy 2024

It is the right thing to do:

FND Ireland launched in April this year but has already been contacted by hundreds of people with one common query; “where do we go for support and treatment?”

Here is what FND patients and their families are telling us:

“As you are aware there is **no support available in Ireland**”

“We have **nothing here in Ireland**”

“We have been **failed by the health system**”

“There are a **lack of specialists and long waiting times**”

“Trying to **source** anyone with **experience of FND is frustrating**”

“I have **not found a doctor** who could help me”

“I had **no follow up care** by anyone”

“Where do we go for support in terms of treatment”

“I am **not getting any access to neurological teams or services**”

“I’m **looking for names of consultants** that specialise in FND”

“Do you know of **anyone who could help me** as my daughter is under a paediatric doctor not a neurologist?”

It is not only FND patients and their families who are contacting FND Ireland. 10% of those contacting us to date are healthcare professionals, the majority of whom work within the HSE. These healthcare professional are doing their best to support FND patients but they are also looking for us to provide them with the names of healthcare professionals across different disciplines who have expertise in FND.

Here is what healthcare professionals are asking us:

‘I’m a physio supporting a person with FND. Would welcome talking to another physio with experience in FND’

‘I work as a Clinical Psychologist. I am eager to signpost a person to more specialist FND support in the country. I am now realising that this is very difficult to find!’

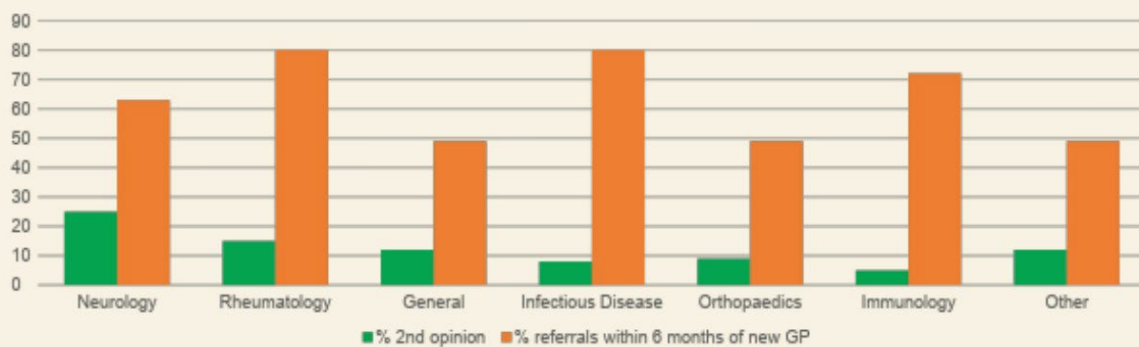
‘I am at OT, I have recently had a patient with FND in the hospital and am trying to source psychology follow up’

This specialist multidisciplinary FND clinic will not just benefit patients it will also benefit the HSE and Government.

International literature has shown that the development of a FND pathway:

- **Reduces repeat GP referrals to neurology and other clinics thus reducing waiting lists⁵.**

It can reduce repeat referrals which impacts waiting lists



(5) Crimlisk HL. J Psychosom Res 2000

- **Reduces repeat emergency department attendances⁶ and hospital admissions.**

It can reduce repeat ED attendances which impact overcrowding

To the emergency room and back again: Circular healthcare pathways for acute functional neurological disorders

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ABSTRACT

Background and objectives: Studies of Functional Neurological Disorders (FND) are usually outpatient based. To inform service development, we aimed to describe patient pathways through healthcare events, and factors affecting risk of emergency department (ED) reattendance, for people presenting acutely with FND.

Methods: Acute neurology/stroke teams at a UK city hospital were contacted regularly over 8 months to log FND referrals. Electronic documentation was then reviewed for hospital healthcare events over the preceding 8 years. Patient pathways through healthcare events over time were mapped, and mixed effects logistic regression was performed for risk of ED reattendance within 1 year.

Results: In 8 months, 212 patients presented acutely with an initial referral suggesting FND. 20% had subsequent alternative diagnoses, but 162 patients were classified from documentation review as possible (17%), probable (28%) or definite (55%) FND. In the preceding 8 years, these 162 patients had 563 ED attendances and 1693 inpatient nights with functional symptoms, but only 26% were referred for psychological therapy, only 66% had a documented diagnosis, and care pathways hinged around ED. These better practice pathway steps were each associated with lower risk of subsequent ED reattendance: documented FND diagnosis (OR = 0.32, *p* = 0.004), referral to clinical psychology (OR = 0.25, *p* = 0.004) and outpatient neurology follow-up (OR = 0.25, *p* < 0.001).

Conclusions: People that present acutely to a UK city hospital with FND tend to follow looping pathways through hospital healthcare events, attend ED, with low rates of documented diagnosis and referral for psychological therapy. When better practice occurs, it is associated with lower risk of ED reattendance.

162 FND patients presented to ED within Leeds NHS Trust; in the preceding 8 years, these 162 patients had 563 previous ED attendances & spent 1683 nights in hospital.

- Reattendance reduced by a
1. Documented diagnosis of FND
 2. Referral to psychology
 3. Attendance at a neurology outpatient clinic

(6) To the emergency room and back again: Circular healthcare pathways for acute functional neurological disorders 2022

- Reduces the inappropriate use of healthcare funding ⁷.

It will be more cost-effective than current resource spending

The cost of a delayed diagnosis of functional movement disorders

- Mean time to diagnosis 6.63 years
- The total direct cost for 40 patients €240,544

US estimates of resource use and spending for FND 2008-2017

- \$1.2 billion annually; repeat ED attendance, admissions, repeat investigations, and unnecessary medications. Low levels of rehabilitation services.

Undiagnosed functional seizures in the US

- \$100,000,000-\$900,000,000 per year in investigations, procedures and medications

Undiagnosed functional seizures vs. Diagnosis & psychological treatment in Ireland

- €20,995.30 vs. €8,728

(7) Tinazzi M et al. Front Neurology 2021 | Stephen CD et al. JAMA Neurology 2021
LaFrance WC et al. Neurology 2006 | Magee JA et al. Epilepsy Behav.

Funding the first specialist multidisciplinary FND clinic will be a valuable step forward in the development of optimal clinical pathways in our health service for those living with FND and will in fact save the health service money.

Where should this specialist multidisciplinary FND clinic be based and who does the team include?

We recommend that this specialist multidisciplinary FND clinic be based in St James's University Hospital in Dublin 8. Dr Aoife Laffan, Consultant Neurologist in St James's, has a specialist interest in FND and is the clinical lead for FND in the country. Dr Laffan has previously set up a monthly neurology FND clinic in St James's Hospital, however this clinic was suspended within months due to the high level of demand and the lack of multidisciplinary team support.

NHS Scotland published in May this year their Functional Neurological Disorder National Pathway. A key part of this pathway is the provision of a FND Multi-disciplinary Core Network ⁸. Here treatment is provided by a multidisciplinary FND team outlined in the figure below which provides a blueprint for the team required to serve the specialist multidisciplinary FND clinic in St James's.



(8) NHS Scotland Functional Neurological Disorder National Pathway 2024

We recommend that the multi-disciplinary FND clinic in St James's Hospital serve the hospital catchment area and provide expert input for more complex FND cases nationally.

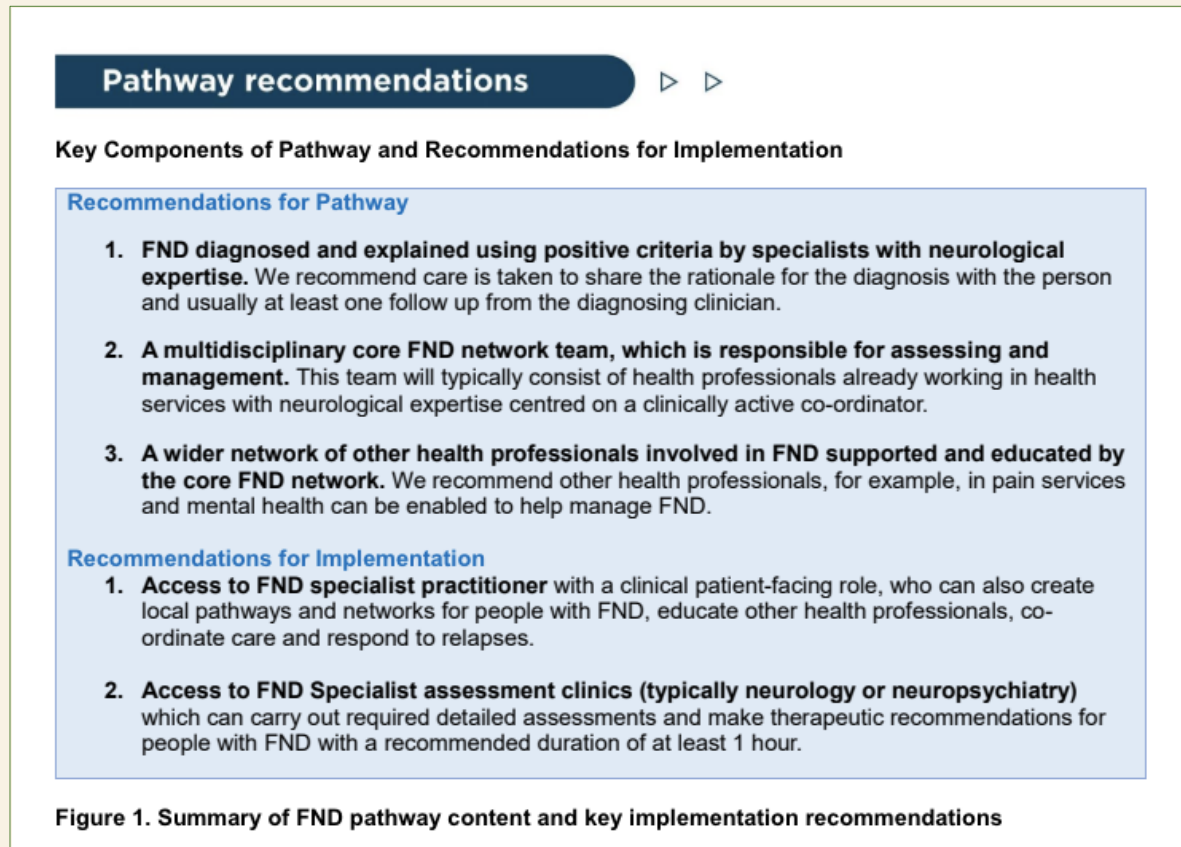
What would this specialist multidisciplinary FND clinic cost?

We estimate that the annual staffing cost for the multi-disciplinary FND clinic would be in the region of €1.5 to €1.8 million but would actually save the health service money. As noted earlier FND currently costs the health service significant funding in repeat referrals, repeat emergency department attendances and hospital admissions due to the lack of a dedicated FND service in this country. A study referenced earlier in Ireland carried out in 2014 showed the extra over cost of patients with undiagnosed functional seizures compared to those diagnosed and receiving treatment was €12,267 per annum, therefore just 100 of these patients if diagnosed and receiving appropriate treatment would have saved the Government over €1.2M. So why 10 years on despite this study noting "early diagnosis and intervention would result in a significant economic saving to the exchequer, a reduction in hospital waiting list times, and a better prognosis for patients" has nothing happened? It is now time for action!

ASK 2

Develop an FND pathway in our health service with multi-annual funding.

As mentioned earlier, NHS Scotland published in May this year their Functional Neurological Disorder National Pathway ⁸, much of which can be utilized to inform service development in Ireland.



(8) NHS Scotland Functional Neurological Disorder National Pathway 2024

For such a pathway to work in Ireland, we will need a total of four adult multi-disciplinary FND clinics, two in Dublin (one more in addition to the clinic in St James's Hospital), one clinic in the South and one clinic in the West. We also need a paediatric multi-disciplinary FND clinic in the new National Children's Hospital giving the increased diagnosis of FND in teenagers. It is very important that a patient-centred approach to the FND Pathway involves FND patients, their family members, and carers.

It is crucial that multi-annually funding is now ring fenced for these five clinics in the Neurology Programme, which we estimate to have a total staff cost of €7.5 to €9 million per annum.

We also require a wider network of healthcare professionals to be educated about FND in our hospitals, primary care, mental health, chronic pain services and first responders. The rollout of HSE community neurorehabilitation teams in all current CHO areas and regional healthcare areas will also be a crucial part of this wider network.



(8) NHS Scotland Functional Neurological Disorder National Pathway 2024

Summary:

Funding the first specialist multi-disciplinary FND clinic in the country will be life-changing for FND patients and their families. It will be the first step in the development of a national FND pathway which will transform how FND patients receive care. So we ask our Government to be as brave as the 9,000 people living with FND in Ireland, and address the decades of neglecting FND patients and fund the healthcare they deserve and support the healthcare professionals who want to make a difference.

FND Ireland also supports the Neurological Alliance of Ireland (NAI) pre-budget asks to fund the rollout of community neurorehabilitation teams in all HSE CHO areas and address the lack of neurology services in our regional hospitals.