

FND

Functional Neurological Disorder |



THE MOST
COMMON CONDITION
YOU HAVE NEVER
HEARD OF!



"NOTHING IS
WRONG, JUST DRINK
COFFEE" DR2012

VS

"TREATING FND IS A
SLOW PROCESS, BUT
IT WILL BE OK"
DR2023

ACTUAL ADVICE GIVEN TO ME BY NEUROLOGICAL CONSULTANTS

My FND diagnosis is
simply one part of me. it
does not wholly define me.

—Allison Dye



 **FND Aware**
Postcard Campaign

FND HOPE
FUNCTIONAL NEUROLOGICAL DISORDER UK



FND left me
disabled
overnight...
literally!

Clair

FND HOPE
FUNCTIONAL NEUROLOGICAL DISORDER UK



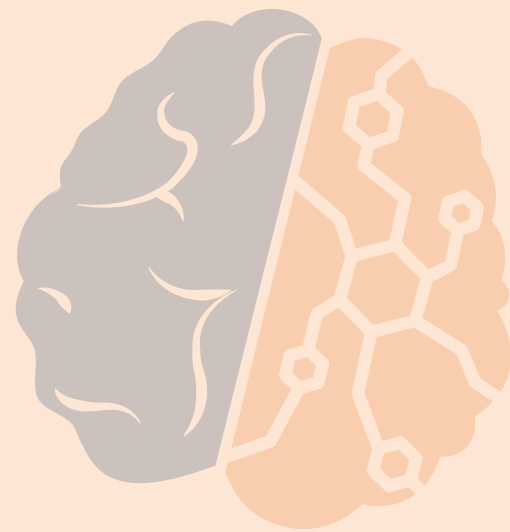
Living with FND has changed my life more
ways than I can fit in this box.
Some days I can stand, some days my legs
decide not to work.
I have lost independence and freedom,
but I have also gained a community of other
people living with FND so I don't feel as alone



FND HOPE
FUNCTIONAL NEUROLOGICAL DISORDER UK

FND HOPE
FUNCTIONAL NEUROLOGICAL DISORDER UK

2022 Impact report



Mission

To promote awareness, support affected individuals and advance research for the prevention, treatment and recovery of FND.

Vision

A world where FND patients can expect to be treated with dignity, care and respect, regardless of the cause of their symptoms.

✉ fndhopeuk@fndhope.org

✂ @FNDHopeUK

f www.facebook.com/FNDHopeuk

📷 www.instagram.com/fndhopeuk/

🌐 www.fndhope.org/about-fnd-hope/fnd-hope-uk/



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A Poem About FND

I may be looking well
But I was on the floor an hour
Before
Hiding all the pain I'm in
Forced myself out of the door

The outside world
Can consume me with fear
Constantly on edge
Of what symptoms will appear

It's hard to explain
When I'm suffering body shakes
When I'm talking with a stutter
And the energy that it takes

The reality of hard days
You feel you can't go on
You've lost the life you had
And just feel you don't belong

Nobody really understands
Why our symptoms vary
It can trigger out of the blue
From experience, it's scary

We don't require sympathy
We need support and care
To live with FND
An affliction we have to bear

K. Johnstone

Welcome from Our Chair of Trustees



This year we celebrated our first 5 years as a charity. Sadly, with half of the UK health boards and Clinical Commissioning Groups¹ having no specific agreement to treat FND or not treating FND at all, FND Hope UK's work to raise awareness and improve care for those diagnosed with the condition is more vital than ever.

The large majority of people suffering from the symptoms still encounter long waiting lists, lack of access to treatment and experience poor treatment due to stigma linked with FND.

As a charity, we are proud of our community and all the work that took place in the last 12 months. Innovative approaches, like myFND app or the virtual rehab v.FND, fill us with hope for a better future and provide further drive and ambition. We are excited about the direction we are going and grateful to all the people who are joining us on this journey. We stay passionate about the need for change.



Cindy Smulders

¹ Now replaced by Integrated Care Systems (ICSs)

? | What is FND

FUNCTIONAL NEUROLOGICAL DISORDER (FND)

Is a problem with the functioning of the nervous system and how the brain and body send and receive signals.


FND has multiple causes and can be triggered by physical injury, psychological or other trauma to the brain and/or body.


 More than **70% of FND patients** experience **continuing or deteriorating symptoms** after one year, and more than 70% are the same or worse after 10 years

 Over **80%** of patients felt they had been **treated poorly** due to **stigma** related to their FND diagnosis


 **FND** accounts for at least **5%-10%** of new **neurological consultations** [1]

 **Comorbid neurological conditions** occur in approximately 20% of cases

 FND disproportionately affects **women** (around 3:1) although, as age of onset increases, the proportion of men affected increases. [3]

 There is a high associated healthcare utilisation cost with FND, the estimated total **annual healthcare cost of FND**, narrowly defined, in a recent study from the US equated to **\$900 million**. [5]

 FND symptoms are associated with high levels of **physical disability**, equivalent to people with multiple sclerosis or epilepsy, and even higher frequencies of **psychological comorbidities** than these disorders [4]

 There is a **fear of misdiagnosis** of FND, however, studies have repeatedly demonstrated low rates of misdiagnosis (out of 1,030 patients with functional disorder diagnoses from a neurology clinic sample, only 4 patients had acquired a new neurological diagnosis that better explained their presentation after 18 months of follow up) [6]

50% of all clinical **commissioning groups and health boards** in the UK had **no specific agreement to treat FND** and 9% said that they did not accept referrals for treatment

Source Information

[1] Carson A, Lehn A. Epidemiology. In: Hallett M, Stone J, Carson A. (eds). Handbook of clinical neurology: Vol 139: Functional neurologic disorders. Elsevier, 2016:47-60.

[2] <https://neurosymbols.org/en/faq-2/how-common-is-fnd/>

[3] Bennet K, Diamond C, Hoeritzauer I, et al. A practical review of functional neurological disorder (FND) for the general physician. Clin Med 2021 Jan; 21(1):28-36.

[4] Carson A, Stone J, Hibberd C, et al. Disability, distress and unemployment in neurology outpatients with symptoms 'unexplained by organic disease'. J Neurol Neurosurg Psychiatry 2011;82:810-3.

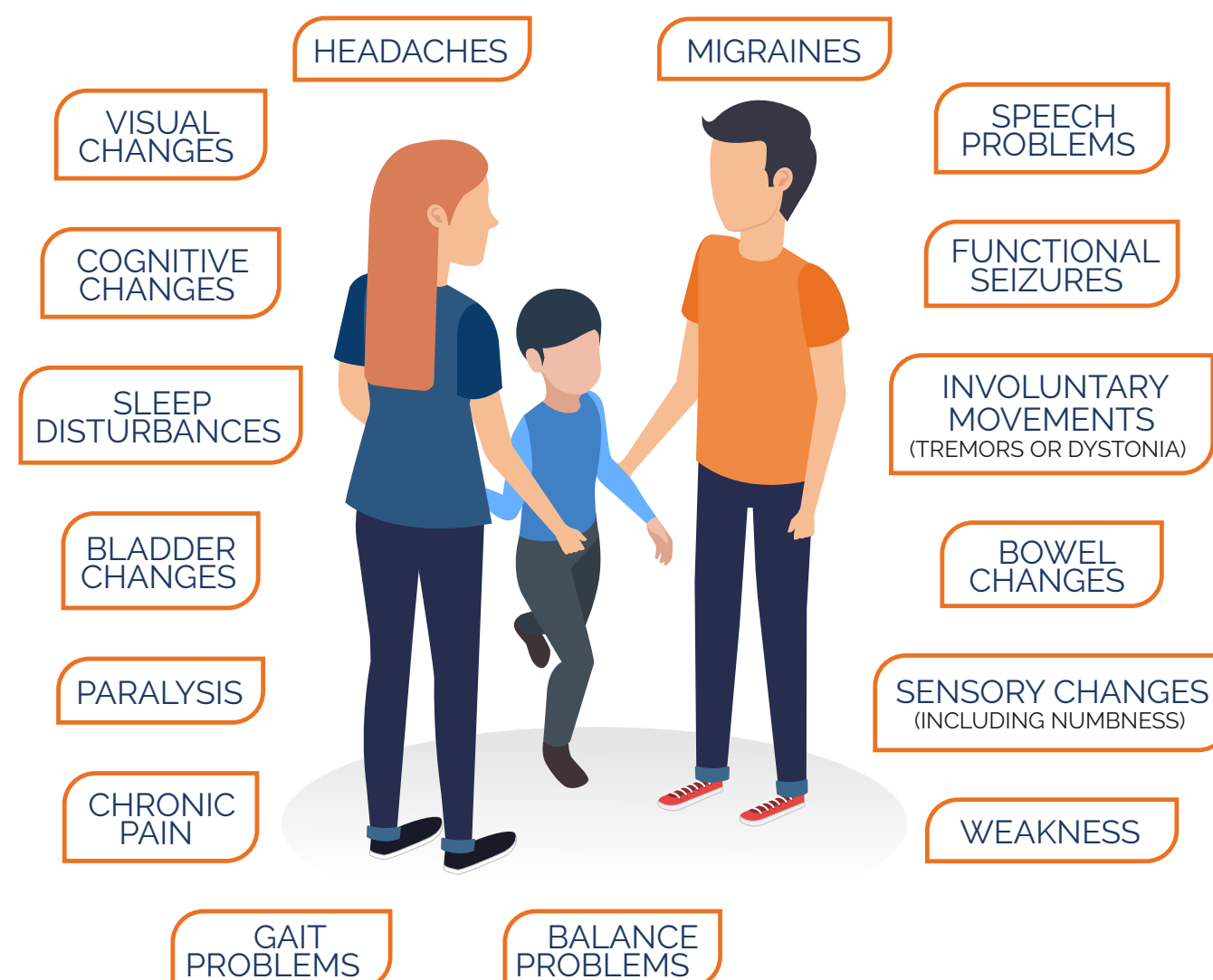
[5] Stephen C, Lungu C, Boston AE. Healthcare utilization and emergency department/inpatient costs in adult and pediatric functional neurological disorders. Movement Disorders International Congress 2019.

[6] Stone J, Carson A, Duncan R, et al. Symptoms 'unexplained by organic disease' in 1144 new neurology out-patients: how often does the diagnosis change at follow-up? Brain 2009;132:2878-88

| FND symptoms

FND is one of the commonest diagnoses made in neurology outpatient clinics. Symptoms experienced by people presenting with FND are varied and include seizure-like episodes, motor and sensory symptoms. Cognitive symptoms, pain and fatigue are also commonly present. In addition, mental health comorbidity is common.

“ Sometimes people fall back on the old ideas, thinking that patients are 'just making it up' or 'putting it on', because it's a threat to their idea of an illness. That's why FND is so interesting. There is the simplistic idea that an illness is when you have something physically wrong in your body, which then creates symptoms. We now know that this is incorrect. We know that with any illness there may be something that's wrong, but there are also layers of other things we do not fully understand, like meaning of symptoms, unconscious expectations, and people's previous experience of illness, which all interact. ” **Dr Sarah Cope, Clinical Psychologist**



Our community

We want to make sure that we support all members of our community and provide services that are relevant, helpful and of high quality. To ensure our ongoing understanding of the impact we have on our members, in May 2023 we carried out our annual member survey. Our findings were based on responses from 315 individuals who are linked with FND Hope UK.

84% of our respondents identify as female

93% of our respondents are of White descent

76% of respondents had not accessed any other services prior to engaging with FND Hope UK

Our most useful resources

81% social media content

78% FND patient booklets

76% newsletters & downloadable resources

74% Videos

Our most popular services

85% of respondents used the support provided through our social media sites

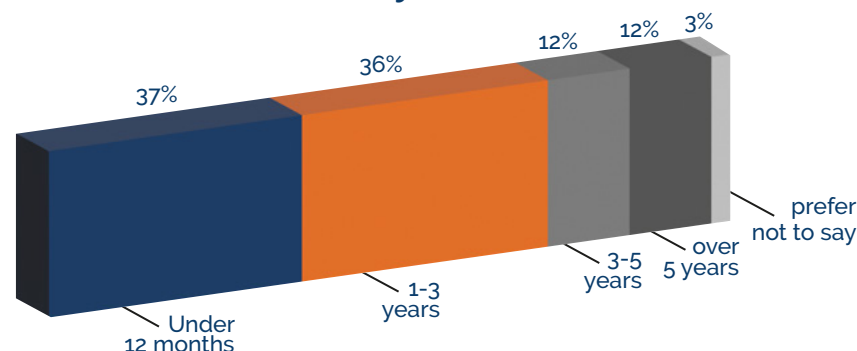
f 76% joined a closed Facebook group

74% attended a peer support group

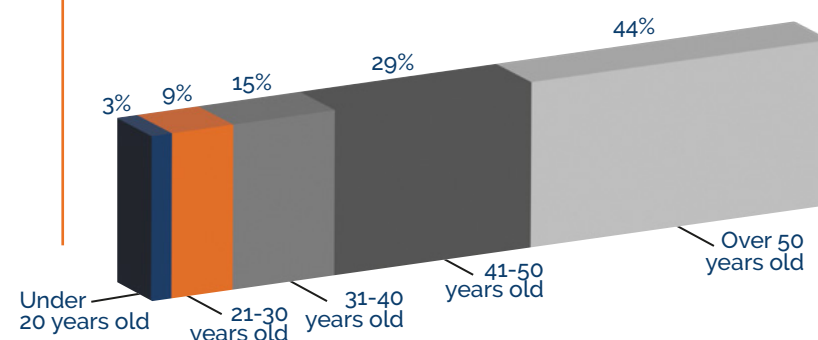
14% of our respondents carried out some form of fundraising for FND Hope UK

Our website is our most popular communication channel, closely followed by the newsletter and Facebook

How long have you been linked to the charity?



How old are you?






Supporting our community

For the last five years, our priority and main motivation for all of our activities has been our unwavering commitment and belief in a world where children, young people and adults who experience FND, have the right care, feel supported and empowered to live their best lives.

We supported our community through:		2021	2022	
	Active volunteers	15	39	↑
	People attending our Peer Support Groups	250	599	↑
	People attending our online movement and wellbeing groups (Yoga, Pilates, Dance, Mindfulness Meditation)	600	2,097	↑
	Online movement and wellbeing classes delivered	125	246	↑
	Emails responded to offering support	900	1143	↑
	People we connected with on social media	19,600	24,740	↑
	Visitors to our website	106,179	116,154	↑
	Patient booklets sent to our community and health professionals	3,300	10,700	↑
	Newsletters sent	9	10	↑
	People who read our newsletters	5,000	6,238	↑
	Online peer support groups	80	99	↑
	Research projects supported in the UK	12	15	↑
	People attending the Mindfulness for Positive Coaching Course	0	50	↑
	Leaflets distributed	0	10,000	↑
	People attending speaker sessions at Neuro Convention	0	116	↑

| You said, **we did**

What you asked	What we did	Further details
 Videos or recorded sessions for activities, which could be accessed at a time convenient to each person	We offered an online bundle of activities including: Seated Pilates for Adults, Yoga for Adults and Yoga and Meditation for Teens.	Unfortunately the completion rates of the courses were very low, with 165 people signing up and only 76 starting the course (with 1 person completing it). Therefore, we are not able to continue funding this service.
 More videos about people's journeys	As part of the FND Awareness 2023, we ran a Postcard Campaign, which provided us with a privilege to share the stories and experiences of our members.	You can find the campaign here: www.fndhope.org.uk/world-fnd-awareness-month-2023
 Help/advice/suggestions on how people can fundraise or get involved	<p>We changed our fundraising platform to make it simpler to use.</p> <p>We also offered the MOVEATHON challenge and Challenge 28 to celebrate our 5 years of being a UK charity.</p>	<p>You can find all of our fundraising events here: https://fndhopeuk.enthuse.com/profile</p>
 A more proactive approach to getting people involved (reaching out to help them get what they need)	As part of our future strategy, we are looking to create a community ambassador programme, which will engage our community in fundraising and raising awareness activities.	Keep an eye for future developments.
 More face to face groups (e.g. peer support groups) in more areas	We need to recruit more volunteers to enable us to run more groups. In the meantime, we have reviewed our offer of online peer groups. For more details, please see: https://www.fndhope.org.uk/about-fnd-hope/fnd-hope-uk/online-classes/	We are actively looking to engage with more volunteers. For more details, please see: www.fndhope.org.uk/get-involved/volunteer
 Easier access to and awareness of the latest research	We are adding all our latest research to our website and newsletter	For more details, please see: www.fndhope.org/fnd-research/advance-research

| Impact story: Scrambled signals

“I was told that I had FND. I was then discharged home with nothing, not even a website. Three months into my diagnosis I had no physio, no additional information. I felt suicidal.”

This is the beginning of Kirsty-Ann's journey with an FND diagnosis. Toni had a similar experience, where she found the information provided to her inaccessible.

“You are given a lot of medical jargon, which you do not understand. There's just so much, you can't process it all. Especially with younger people. When I look on social media, like Facebook groups and certainly on Twitter, it is evident that there's a lot of parents who are dealing with younger people and don't really know how to explain what is happening with their bodies. Because if you are not informed what's going on, how can you possibly get someone else to understand.”

The medium and format for conveying created additional barriers. “If I look at a screen for a long time, I will invariably end up having a seizure. I just can't concentrate when looking at a screen.”

“And I think sometimes people do not fully understand the difficulty in reading when all the text is crammed together. When I see a website full of information or a long essay of written text, I can't read it because I can't concentrate long enough on the words before it affects my vision.”

Living up to its name, FND Hope UK is a space where people, who are hopeful and unafraid to challenge the status quo, are able to come together and collaborate. That's how Scrambled

Signals was born.

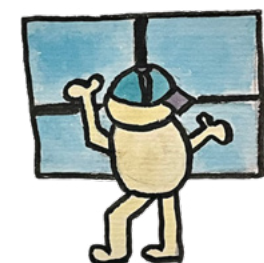
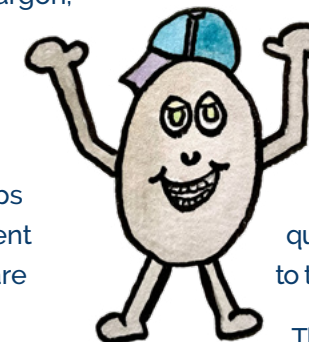
“We actually got chatting on the FND Hope UK Facebook support group” says Toni. “I had already written the words for Scrambled Signals and saw Kirsty-Ann's artwork, so I just asked if she'd be interested to see what I've written and create the illustrations to go with it, which she has done so beautifully.”

“We created a resource which adults can use when they have to explain FND to children. Not necessarily children who have it. It can also be children whose parents experience FND and sometimes act 'strange'. They can use it to say: 'Look, I'm this little character today.' So it's not quite so scary, as they can relate their experiences to the book.”

The format of the booklet makes it also more accessible and easier to use. “Why do I think the booklet is good? Well, it's written in short, easy to understand text. In my opinion, that makes it great.”

The impact has been great so far. “We saw it on photos of stands at exhibitions. We've also been told it's in hospitals and it's getting to medical professionals. I've given it to a couple of young people, for them to take to their friends and show what they are going through. We just wish it was more widely available, especially to people who need it most.”

We know that no one understands the needs of our community more than the community itself and we are proud to be able to support projects like Scrambled Signals to enable them to benefit wider groups of people. The online version of the booklet is available through our newsletter and physical copies can be obtained from FND Hope UK.



Diagnosis & access to treatment

In December 2021 and following discussions with the UK Medical Expert Committee, FND Hope UK agreed to send a Freedom of Information request to each Clinical Commissioning Group (CCG) and Health Board in England, Wales and Scotland. The initiative aimed to explore issues reported by NHS clinicians and the FND community regarding access to treatment for people with FND.

WE CONTACTED A TOTAL OF 126 CCGS/HEALTH BOARDS, INCLUDING:

The results of our survey highlighted the current patchy and inequitable provision of rehabilitative services for people with one of the commonest causes for neurological disability. Out of the surveyed UK Health Boards/CCGs:

50% had no specific agreement to treat FND or did not treat FND, with almost **10%** saying that they do not accept referrals for treatment

Between **14% & 43%** of services did not accept physiotherapy referrals or provide physio for people with FND

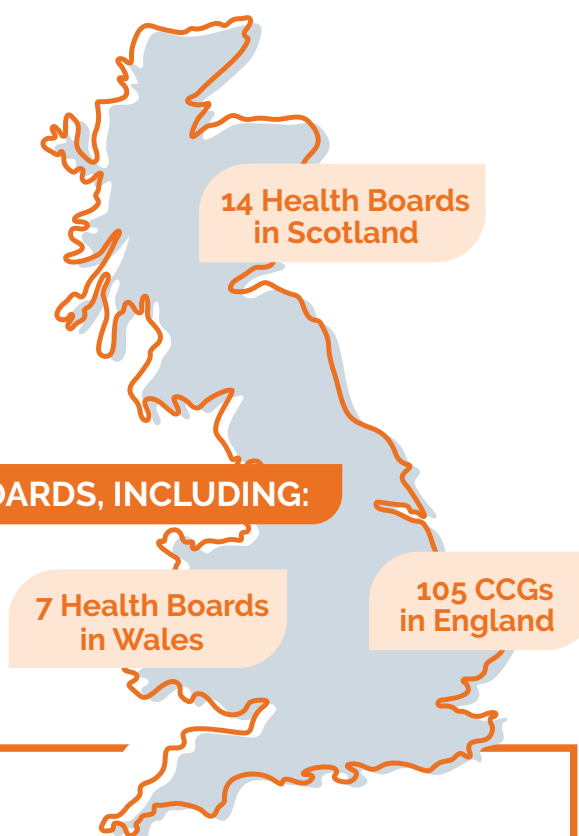
Between **22% & 43%** did not accept occupational therapy referrals or provide occupational health for FND, with just over a tenth saying they had neurology based occupational therapy services which would accept people with FND

Between **17% & 43%** did not accept speech and language therapy referrals or provide speech and language therapy for FND

Between **16% & 43%** did not accept psychology referrals or provide psychological therapy for FND

Only a **third** of services said they had plans to improve their provision for people with FND

Only **35%** were potentially interested in accessing further education or support to improve services.



“The Health Board does not provide treatment for FND. Consultants diagnose FND in our neurology clinics - there are no consultants in the area that are specialising or leading on this currently.”
Health Board

“The Planned and Specialist Team do not commission any services for FND patients. Despite “neurological” in the name, it is not considered a neurological condition, i.e. the patient’s neurology is functioning properly. For this reason, the units we commission for specialist inpatient rehabilitation do not accept FND patients.”
CCG

FND is likely to be more common than Multiple Sclerosis and have similar rates of long-term disability and impairment of the quality of life. In **February 2023**, the **National Neurosciences Advisory group** published the finalised version of the

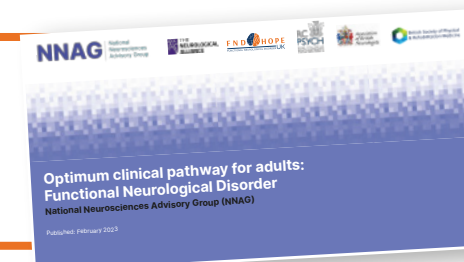
Optimum clinical pathway for adults: Functional Neurological Disorder

The pathway sets out what good treatment, care and support looks like for adults experiencing FND. It sets aspirations for good care, supports improvement of services and enables commissioning of quality services, both locally and nationally. It highlights the barriers experienced by patients and that achieving effective triage is a key outcome of an optimum clinical pathway for FND.

Barriers and enablers Patient flow

Barrier	Potential solution(s)
General neurology services to which patients most commonly present may fail to provide a well explained diagnosis, and often discharge patients rather than offering follow up or referral into treatment	<ul style="list-style-type: none"> Clear guidelines regarding expectations of general neurology services with regard to people with FND Education programmes on making and explaining the diagnosis of FND Clear pathway for accessing treatment or specialist assessment depending on symptoms and comorbidities
Community and Secondary care generic rehabilitation services often report lack of expertise and support for managing patients with FND	<ul style="list-style-type: none"> Education program for IAPT⁷, community neurotherapy and secondary care neurotherapy teams in FND Establishing direct links between specialist FND diagnostic and treatment services and community services for support and to facilitate patient flow
Lack of specialist diagnostic and treatment services	<ul style="list-style-type: none"> Support development of Specialist FND diagnostic and treatment services within each regional neuroscience centre underpinned by rigorous data collection on outcomes
Unclear which patients should be referred to which treatment	<ul style="list-style-type: none"> Clear referral guidelines agreed within each region

Full pathway can be found
<https://nnag.squarespace.com/optimal-clinical-pathway-adults-fnd-functional-neurological-disorder>



⁷ IAPT - Improving Access to Psychological Therapies

Supporting the research

At FND Hope UK, we recognise the importance of supporting researchers and clinicians in furthering the understanding of FND and improving treatment pathways available to our community. Through the efforts of FND experts, advocates, ambassadors and the FND community, over the last 10 years there has been more awareness, understanding and recognition of the disorder, more unified terminology to describe it and more funding from large funding bodies for research into FND. But there is still a long way to go.

Everyday we collaborate with researchers and clinicians to further the understanding of FND and improve treatment pathways available to our community. Over the last 12 months, we reviewed 15 UK research projects and advertised for our community to get involved.

We do this through:

- ✓ Becoming members of advisory panels
- ✓ Contributing to scientific papers
- ✓ Recruiting study participants
- ✓ Reviewing study proposals
- ✓ Providing feedback on study design and patient-facing documents, e.g. participant information sheets and consent forms
- ✓ Sharing adverts for studies
- ✓ Sharing study findings and papers
- ✓ Providing feedback on adverts for studies
- ✓ Reviewing drafts of results and papers
- ✓ Facilitating Patient Public Involvement (PPI) input
- ✓ Providing letters of support
- ✓ Supporting applications for grants

“For me as a clinician, FND Hope UK is sometimes the human face of the waiting lists. With long waiting lists, you may start to look at people as numbers. They remind you that you are dealing with people. As a researcher, collaboration with FND Hope UK has been fundamental to me being awarded research grants - they have been a big part of the application process. Research proposals are judged heavily on the quality of the PPI and organisations like FND Hope UK have an incredibly important role in getting that.”
Glenn Nielsen, Senior Lecturer in Neurological Physiotherapy and Specialist Neurophysiotherapist

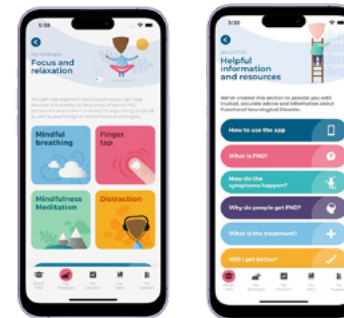
“The support from FND Hope UK is so integral and helpful to my research. They facilitate our recruitment of a broader range of patients, which is one of the most critical aspects of collaboration between us, researchers, and them, as a patient support organisation.”
Dr Susannah Pick, MRC Career Development Fellow & Honorary Lecturer, King's College London

“I think what's so helpful about having FND Hope UK's involvement is that you know that the person you are contacting to take part in your study genuinely wants to be involved and helpful. I think sometimes there might be a power imbalance between a researcher and a participant - being able to engage with patients through FND Hope UK removes that.”
Dr Sarah Cope, Clinical Psychologist

myFND



Innovation



myFND app was developed by a group of medical experts in FND treatment, who recognised that there wasn't much support in the community for people experiencing FND. A common occurrence for FND patients is being 'spoken to by professionals', which might feel overwhelming and often inaccessible, and being provided with a website 'to go and look at'.

“We wanted to develop an app, so that people can log on and read about FND in their own time, when they are in a positive mental space, they do not feel too fatigued.”

Dr Christopher Symeon, Neuropsychiatrist, St Georges University

myFND app includes

- Helpful information presented in an accessible way
- Advice and guidance on soothing - strategies for calming your nervous system, grounding and distracting yourself, when it's needed
- Space to diarise - allowing people to see patterns, leading to better understanding and management of their condition
- A directory of links to other useful resources & services

FND Hope UK invested £16.5k and funded the upgrade of the myFND app following feedback from the community. Improvements included: Multiple Symptom Tracking, downloadable PDF report of symptoms overtime, accessibility improvements such as dark mode; new grounding / mindfulness strategies; multiple languages, badge rewards and notifications.

The app can be downloaded free of charge through Google Play or App Store.



Virtual FND Service

“The waiting lists to access inpatient or outpatient therapy at the moment are between one and four years. That's a waste of time - people often get worse, deteriorate or have intractable symptoms. What we wanted to do was to develop a virtual service to outreach to patients so that, while on the waiting list for rehab, they can access rehab online.”

Dr Christopher Symeon, one of the creators of v.FND.

This innovative rehabilitation service is delivered by a full multidisciplinary team of FND experts, including a neuropsychologist, speech and language therapist, physiotherapist, occupational therapist and a psychiatrist. It works in the same way as an inpatient service, but both assessments and treatments are online.

“It really works. For some patients the outcomes are as good as if they accessed inpatient services. Patients can stay at home, they do not have to remove themselves from their family or work. And this is at 10% of the cost.”

v.FND is now an established pathway in St George's Hospital, London, where it doubled the service's capacity for patients throughout. The results are outstanding.

“All but one patient that we supported so far haven't had to come in for an inpatient admission afterwards. They accessed virtual rehab and then were able to carry on with their lives. This means better quality of life for our patients and huge savings for the NHS.”

The team is looking at how the model can be replicated in other areas so that the support offered to people with FND can be less reliant on geographical location.

“Rather than having to wait for people to get really unwell to bring them into the hospital for 12 weeks, we can start the treatment in the community. Instead of 12 weeks, we can do it in 6 weeks remotely - it's a no-brainer.”

Rehabilitation outcomes and healthcare costs were measured after a year of service delivery. The cost per patient to deliver the virtual service was £5,000 - a tenth of the cost of an inpatient rehabilitation. There was also a 90% reduction in referral to treatment time for the patients and the majority of patients rated their condition as 'much improved' or 'very much improved'. For their efforts, the v.FND Service Team has been awarded the 2022 HETT Unexpected Innovation Award for the Best Designed Virtual Service.



Raising awareness

Our vision of a world where FND patients can expect to be treated with dignity, care and respect, regardless of the cause of their symptoms feels more achievable with every positive development in diagnosis, treatment and holistic support for our community. FND Hope UK recognises the important role it plays in not only raising awareness but also supporting others to use their knowledge, expertise and lived experience to improve outcomes for everyone.

We are very proud of our **#FNDAware postcard campaign**, which allowed us to magnify the voices of our community.



In 2022 we have also....

- Attended Therapy Expo⁸, Neuro Convention⁹ and the Public Health and Primary Care convention¹⁰, delivering **talks in collaboration with medical experts**;
- Sent out over **20,000 patient booklets and information leaflets** to our community, those diagnosed with FND, medical and allied health professionals;
- Reviewed **15 UK research projects** and advertised for our community to get involved;
- Attended a number of **Study Days** to provide a patient perspective on FND and how FND Hope UK supports and advocates for the FND Community;
- Collaborated with Hidden Disabilities on creating a **Podcast**, alongside Dr Chris Symeon, on what FND is, personal FND journey and creating an FND Sunflower card for our community;
- Piloted a **telephone helpline** with the Brain & Spine Foundation¹¹;
- Facilitated and supported **focus groups** with Dr Sue McKenzie and Hugh Cunningham to better understand the current management of patients with FND within the NHS Fife catchment area, and if there is any understanding of a path through the healthcare system for the FND patient population within the NHS Fife, which was undertaken by Fife Health and Social Care Partnership;
- Supported, facilitated and arranged focus groups, with Dr Ania Crashaw, with the FND community to discuss the development of an online **FND Education Module for Healthcare Professionals**. The course is now available online;
- Reached almost **80,000 people** through 2 videos produced by Lorraine Kelly for FND Awareness Month (April 2022);
- Hosted our **FND Hope UK Community Choir** for FND awareness month with a reach of **14,700 people**;
- Reached over **half a million people** through our **FND & Us** videos, which share 4 patient journeys.

⁸ Therapy Expo is the largest leading educational event in the UK for physiotherapists, sports therapists, osteopaths, chiropractors, soft tissue therapists, massage therapists, neuro therapists, physical training instructors, exercise rehab instructors and MSK Healthcare professionals.

⁹ Neuro Convention showcases the latest technology and innovations in the neurological sector with the ultimate goal of improving patient outcomes. The show focuses on four key areas: rehabilitation, mental health, diagnostics and brain and spine injury.

¹⁰ The UK's leading event for GPs, trainee GPs, managers, podiatrists, physiotherapists, nurses, midwives, dietitians and other NGS and private clinicians working in primary and community care.

¹¹ 106 call-backs were completed, with an average call duration of 21.83 minutes. Due to low uptake, we agreed not to continue with this service.



Impact story: Rachael

“Like most people with FND, my journey to diagnosis, treatment and support was pretty awful, the current situation in healthcare just isn't good enough. When you have FND, if you get seen and diagnosed correctly by a medical professional as quickly as possible, it's more likely you will be able to either make a full recovery, or make a good recovery and live alongside it. But, if people are left not knowing what their condition is, how to help themselves or not even taken seriously, then they're less likely to get their lives back.



Going to the parliamentary event, I felt like I was useful again. To be dressed in work attire once again and to engage in discussions with people, made me feel empowered, it gave me an enormous sense of self-worth.

I brought the idea of setting up an all party parliamentary group (APPG) to FND Hope UK, to help raise awareness of

FND, and they were really on board with it. My local MP has agreed to chair it as well as sponsoring our next parliamentary event in 2024 at the request of FND Hope UK. Thanks to their experience with these kinds of events, my local MP has also offered loads of great ideas that could help make the next event more successful, based on what other charities have done.

Support for FND is gaining traction from the community. Now we really need the political support to get the funding for a care pathway to be properly established.

I was lucky enough to be a guest at the parliamentary event in February 2023, hosted by FND Hope UK. The team worked really hard to put together all of the documents and literature for the event and it was great to see the care pathway that has been designed that they are trying to get backing for.

It was nice to be able to talk to the MPs on a one-to-one basis, to find out what brought them to that room, as each one of them had some sort of trigger; sometimes just a tenuous link to FND. I was able to talk to them about my journey as well and they all seemed engaged - like they wanted to help and were empathetic.

I'm driven and confident to ask questions, but there are a lot of people that won't bother the system like I do, who won't have people advocating for them and so won't receive treatment as quickly as they should be able to. That's why these parliamentary events are imperative for everybody who has this condition; to get a nationwide understanding of FND. ”

We are immensely grateful to Rachael for the passion, drive and empowerment that she brings to FND Hope UK. FND Hope UK is proud to be able to represent our community and use our resources and knowledge to spread FND awareness.

| Impact story: Callum

“Unfortunately it is unavoidable that for some people with FND they have to stop working altogether, however, reasonable adjustments can be made in many cases to prevent this happening.”

FND Hope UK has been revolutionary for me, in terms of my knowledge and understanding of my condition. As a result of my involvement with the charity, I have been able to make informed decisions about my own care and have been empowered to take control of it.

Over 2 years ago, I was diagnosed with FND, which manifested as a chronic movement disorder with associated chronic fatigue, which completely altered my life. This included having to give up my previous charitable work. When I came across FND Hope UK, I was keen to become involved. Aside from having a vested interest, the voluntary roles were flexible to accommodate my needs, because I was still working on reduced hours.

I was particularly focused on helping to spread awareness in the general public, including the private sector. As a charity we had identified that through our volunteers and our wider FND community, we potentially had a considerable network in order to access a myriad of companies. With the current focus across industry on Corporate Social Responsibility (CSR), we felt this was an untapped opportunity to raise awareness of FND. What we needed was a template for hosting corporate awareness campaigns.

My employer, an industrial coding and marking multinational, with a global workforce of over 3,000, had been extremely supportive throughout my FND journey. Therefore, I thought we could potentially collaborate with them to pilot a corporate FND awareness campaign, aiding their CSR commitments. Fortunately they jumped at the chance to help support FND Hope UK. This was achieved through a social media campaign and an internal company educational webinar.

As part of the social media campaign, I featured in a company video explaining what FND is and why my employer was choosing to raise awareness. The message centred on the reasonable adjustments my employer had made to enable me to continue working and developing my career. The campaign emphasised various types of reasonable adjustments but crucially the resultant benefits of a having truly diverse workforces, by enabling more people to remain employed in spite of their conditions. The internal webinar echoed this messaging and included a short presentation from a leading FND Expert who is also a member FND Hope UK's Medical Expert Committee.

The social media campaign produced some fantastic results, with significant engagement across multiple platforms. The posts attracted many responses from people outside of my employers industry, who kindly shared their support and in some cases their own FND experience.

“I was incredibly grateful to receive such support from my colleagues and to work in an organisation where I felt able to share my personal story. We hope that others will feel empowered to do the same. When it comes to disability people are often unsure how to, and indeed if, they can ask questions about symptoms and conditions. By taking this approach, we hope that individuals will be more comfortable in having these conversations in the workplace, which in turn helps to develop these more open and diverse workforces.”

Work carried out by Callum to raise awareness in his place of employment has been invaluable. It has helped us understand how we can support our community to be able to have meaningful and positive conversations with their employers and colleagues.





Who are we

Our Reach

FND Hope UK is part of the first and only global patient-led charity for people with Functional Neurological Disorder. Originating as a grassroots campaign, it uncovers the hidden world of FND and empowers those affected to live their best possible life.

The hard work and dedication by a few UK advocates, patients and medical professionals working together has become fruitful and FND Hope UK started supporting our UK FND community in 2015 and later became a registered CIO in England and Wales 28th June 2017 and the first charity to be registered in Scotland 28th April 2018.

Our structure

In 2022, we had:

7 Trustees, 37 volunteers, no paid staff

Total volunteering hours: 2,800

(that equals to almost 8 hours every single day of the year)

Social media¹⁴

f Facebook reach
130,568 people

@ Instagram reach
34,000 people

X/Twitter impressions
134,000



Income

In 2022, we raised **£59,349** through fundraising activities, donations and legacies

In 2022, we secured **£16,673** in grants
Total income for 2022 - **£76,022**

Expenses

Our total expenses for 2022 were **£51,283**

¹⁴Based on the findings of a Social Media review carried out between 31/03/2023 and 30/04/2023



The future

In order to reach our mission of promoting awareness, supporting affected individuals and advancing research for the prevention, treatment and recovery of FND, we developed a 5-year plan for the charity to ensure that our choices are informed and that we allocate our resources in the most appropriate manner.

Over the next 5 years we will:

- ✓ Prioritise fundraising and Grants that are cost effective and offer attractive short term returns - this will include set up of Charity Lottery, utilising appropriate Government Grants and other new and ongoing initiatives, developing corporate sponsorships and applying for Grants to support new and ongoing projects and salaried roles within the charity.
- ✓ Reaching and building relationships with people newly and already diagnosed with FND - including promoting the charity through social media and PR, providing neurologists and paediatricians with a patient pack for those they diagnose, developing relationships with neurologists using UKMEC, attending conferences to raise awareness, build relationships with Pediatrics/CAMHS specialising in FND, attend the Annual Inaugural Parliamentary Event, create a Community Ambassador Program, develop an FND Hope UK membership package.
- ✓ Drive adoption of the FND care pathway by influencing key decision makers within ICS/ICB/Health boards and the Neurological Alliance - including creating an approach to influence implementation of the FND pathway and creating an FND All Party Parliamentary Group.
- ✓ Provide educational and support initiatives to those affected by FND, including family, friends and care partners. In the short term address the lack of a care pathway, and after it is implemented, compliment and address any gaps - including creating CPD Accredited Educational Modules for Schools, Employers, FND E-learning, Health Care Professionals, creating an FND Masterclass for people newly diagnosed with FND, continuing to support research projects and Patient & Public Involvement (PPI) when requested, creating literature such as Work Reasonable Adjustments, FND & Driving, Young Person's Leaflet, FND & Pregnancy, First Air for Functional Seizures, Carers and Siblings, FND and Schools.



! Taking action

Building a stronger community with fewer barriers and challenges is no small task. We certainly cannot do it alone. We want to use what we have learnt over the last five years to inform our work for the next five, equipping us to better engage with our community, support research and champion positive experiences for all people with FND.

How can you help

If you're a **member of the FND Hope UK Community**, you can take action by:

- Fundraising, donating or volunteering for FND Hope UK
- Encourage your employer or business to become a corporate partner
- Promote our work to your friends, family and colleagues
- Become FND Hope UK Ambassadors (launching soon)
- Provide information to your medical team about adoption of the FND care pathway
- Engage with your local MPs and lobby for better treatment of FND
- Download and use myFND app

If you are a **medical or allied health professional**, you can take action by:

- Referring your FND patients to us for additional support
- Referring your FND patients to our Master Classes (launching soon)
- Promoting and using training resources for medical and allied health students and trainees
- Encouraging your employer to adopt the FND care pathway (in England and Wales)
- Utilising FND Hope UK website for resources
- Ordering patient booklets and leaflets
- Promoting myFND app
- Encouraging your employer to replicate v.FND delivery model

If you are a **member of the public**, you can take action by:

- Learning more about FND
- Fundraising, donating or volunteering for FND Hope UK
- Encouraging your employer or your business to become a corporate partner
- Promoting FND Hope UK to your family, friends and colleagues

If you would like to get more information about any of the activities listed above, please get in touch through our website or Facebook.

Thank *you*

Our Trustees and Patron

Cindy Smulders, Abigail Bishop-Laggett, Stephen Betteridge-Sorby, Dr Chris Symeon, Bridget Mildon, Dr Penny Trayner and Lorraine Kelly CBE

Our incredible volunteers

Alison, Callum, Clair, Jayne, John, Kate, Kim, Lauren, Lindsay, Sarah, Sophie, Steve, Suzanne, Vanessa, Kim, Doreen, Chantelle, Anthony, Charlie, David, Emma, Franca, Helen, Henry, Jessica, Kim, Kirsty, Laura, Laura, Lesley, Linda, Nathan, Robert, Sarah-Jane, Suzanne, Vincent, Dawn

Our special thank you goes to **Dr Helen Bolter**, who provided us with invaluable support over the years in her role as a Trustee. Helen's expertise, knowledge and drive enabled us to become the charity we are today. Thank you for being there for us.

We would also like to thank

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