

To accompany accounts dated to 05/04/2022

Charity No.1176608

### Our Aims and Objectives

The aims and objectives of FND Friends is to provide support to anyone suffering from or affected by Functional Neurological Disorder (FND) in the Southwest of England by such means as the trustees deem appropriate, in particular but not limited to advancing the understanding and knowledge of FND among healthcare workers across the Southwest of England and providing a befriending service to help alleviate the isolation experienced by patients and their families.

The Trustees consider the above objectives to be for the public benefit and have due consideration to the Charity Commission's guidance on public health.

Summary of the activities within the 12 months between 6th April 2021 and 5th April 2022.

- 1. Our continuously growing online (Facebook) community of individuals affected by FND, be they patients, relatives or carers has become a valuable resource for all concerned. The number of members on our Facebook closed support group have grown tremendously. This community encourages peer support, demonstrating that individuals are not alone, regardless of where they are geographically or in their FND journey. Some people find us at the beginning of their journey, around time of diagnosis, others find us years down the line. Wherever an individual is, the knowledge that those with FND are part of a large family is important and can assist in acceptance, achieving remission or making the most of a bad day.
- 2. Provides a platform for the sharing of ideas, knowledge and experience. Many people gather valuable knowledge about how to live with symptoms, where to look for assistance and how to react to the ideas, thoughts and impressions of others.
- Provides a way in which people can socialise, reducing the social isolation felt by many but especially for those who are housebound by their symptoms.
- 4. Provides a pool of individuals whom may be willing to further FND research, either through participation or through the sharing of ideas.
- 5. Enables people to share both positive and negative experiences of the healthcare system within the Southwest of England. Greater knowledge helps people to understand what they can reasonably expect from a particular appointment type, who they can turn to when appointments go wrong and how to navigate the system to best find the assistance they need.
- 6. Provides us with a window so that we can see where we need to focus the efforts of FND FrieNDs.
- 7. Represents a small area of the UK. This allows us to discover other organisations within our area, work out how they might benefit our service users, and identify how we can work together to meet the needs of individuals. It also means that service users are more

- likely to find others in a similar situation, making it more likely that they can then benefit from meeting up and all that goes with that.
- 8. The Twitter account, for the dissemination of information about life with FND, is also proving to be a very useful way of finding those affected by the disorder in the SW of England, as well as a tool by which we can reach NHS communities (including CCG groups and NHS England), carers organisations, publicise events and run awareness days.
- 9. We are offering a new service, visiting isolated individuals who are desperately in need of advice, advocacy and signposting prior to joining some of our meet-ups or on-line communities. We can also accompany individuals to MDT meetings, discussing their needs and supporting them in any way necessary. These services have been strained this year due to Covid restrictions.
- 10. Upon request, we visit individuals while they are inpatients in the Rosa Burden Centre at Southmead Hospital, providing emotional and practical support as needed.
- 11. We are continuing discussions with a number of leading clinicians across the country, which has culminated in some networking that is shaping our current activities. We have been consulted in the writing of an article to appear in the BMJ about the diagnosis of FND, as well as policy making in Scotland (although this is out of area, we are still able to use our experience and share ideas for the benefit of all). In March 2022 we held a Southwest Conference.
- 12. We are compiling an FND friendly Consultant Neurologist database for the whole of the Southwest of England. This will not only help patients find the support that they so desperately want and need, it will also aid other healthcare workers (OTs, Physios etc) to find the most appropriate person to refer their patient to, we have also been receiving direct NHS referrals since March 2022.
- 13. We are continuing to work with other neurological patient support groups (such as the MS society, Parkinson's, Headway, MNA etc) based in the Bristol area and further afield to form neurological alliances. We also joined the FND Society and are networking with other professionals up and down the county.
- Organised patient support group meet-ups across the South West, with regular groups now meeting in Bristol, Swindon, Weston-super-Mare, Gloucester, Taunton, Yeovil. Exeter, Plymouth, Torbay, Bournemouth, Weymouth and St. Austell.
- 15. We expanded our second office and Drop-in centre in Devon which has been incredibly successful in reaching more local people and working with The local hospitals.
- Due to Covid we haven't been able to do any patient awareness in hospital but have online.
- 17. Designed and printed leaflets that describe what FND is, who we are and what we do. These leaflets have been distributed around our area, handed out at fetes and fayres, posted to those who have asked for them and offered at our local hospitals / Doctors' surgeries.
- 18. Raised sufficient funds through fundraising activities, grant writing etc to enable us to perform the above activities.
- 19. The Bristol office is still up and running but due to Covid we were following Government regulations.

## Optional objectives and activities

1. We are identifying projects that require grant funding and thinking about how and where to apply.

2. We are currently reliant on volunteers for any of the work done by the charity, not just that performed by the Trustees. This work includes fundraising, outreach, publicity, befriending etc.

### Achievements and performance

- 1. We are the first FND patient support group to work exclusively for people based in the Southwest of England, a population that is traditionally hard to reach and often neglected. We are also the first FND patient support group to offer face face consultations and discussion groups with invited external speakers.
- 2. The creation, promotion and hosting of two Facebook groups: one (closed) group purely for patients and their carers (currently reaching 1,380 members and growing daily) and another (open) group (@functionalsymptoms) available for anyone, including those working with FND patients. Whilst the actual numbers of people in the groups are still fairly low, the impact the organisation has through the Facebook groups is much wider.
- 3. The creation and continual development of a website (findfriends.com) which is receiving traffic most days. Through the website, it is not only a way to contact us but we can signpost individuals to different organisations in the South West of England and further afield that are intended to help those with disabilities, as well as share ideas, news, research ideas and more.
- 4. We have a Twitter account (@fndfriendsuk) and Instagram which we use to highlight the plight of patients diagnosed with FND, and to publicise ourselves, the disorder and events to the wider online community.
- 5. We joined 4 other FND patient support organisations to run a successful online awareness day on 25<sup>th</sup> March 2021 and again 2022. It attracted much attention (using platforms such as Twitter) from major organisations such as multiple NHS groups (such as commissioning groups) and news broadcasters (such as local BBC radio), as well as reaching out to individuals with the condition / blog authors / healthcare professionals who work with FND patients / researchers / and those purely with an interest in the condition. Our Facebook group grew rapidly as a direct result of the awareness day.
- 6. Encouraged the creation of short films describing life with FND, intended for distribution across social media with the #voices4fnd, as part of FND awareness day UK 2021 and again #WeCare4FND for 2022. These films are hosted on Youtube, and are an invaluable resource not just for patients, but for anyone affected by the condition.
- 7. The distribution of leaflets to doctor's surgeries, hospitals, chemists, as well as to individuals who have requested help through our Facebook groups.
- 8. The creation of links between FND FrieNDs and leading medics. This will help us to ensure that patients are being informed of the most up to date thinking, research and ideas, as well as providing us with credibility within the medical world.
- 9. The development of a feedback service between patients and NHS services provided for patients with FND in the Southwest of England. This enables us to provide a truthful and honest view of the service that is provided.
- 10. We held several social meet ups on Zoom due to covid restrictions we have been unable to put on awareness days in the Hospitals.
- 11. It is planned that FND Friends starts running training days for trainee and qualified healthcare workers, sharing experiences of what it is like to live with FND, how it can change lives (and not just that of the patient) and how to help people help themselves.
- 12. We have set up several meetups across the Southwest, but most notably in Bristol,

- Swindon, Gloucester, Salisbury, Taunton, Weymouth, Devon and Cornwall. We are hoping to increase are volunteers numbers to continue our work in these areas and to offer more activities and events in these areas.
- 13. We have supported other fundraising ideas, such as sponsored walks and coffee mornings and some on-line events.
- We have encouraged participation in research opportunities as and when they arise, by raising awareness of specific opportunities through our online communities.
- 15. Both our offices continues to run successfully as a drop-in centre, where those affected by FND can find help, a friendly ear or the opportunity to meet similarly affected individuals. Although the emergence of a Corona virus-Covid-19 may affect this over the coming months.
- 16. We ran a very successful Christmas online zoom party.
- 17. Other successful fundraising grants from a number of organisations. We have run several online events to raise funds, where the merchandise we have been selling is generally items made and donated by individuals supported by FND FrieNDs. We have also been investigating other funding streams (such as Easyfundraising.com, Amazon Smile, Torbay Lottery and PayPal Giving Fund) and have helped service users to raise money for the charity.
- 18. We have been working alongside Dr Mallam from Bristol Southmead hospital and Dr Leo Russel. To build on our services and the Hospital services throughout the Southwest and building better relationships with all the Hospitals throughout the southwest. This has come with a huge positive affect and has seen most of the Hospitals now referring patients to us after diagnosis and giving out our Website for information.

### Financial Review

- 1. The charity prepares its annual financial records using the Receipts and Payments accounting method, permitted to unincorporated charities with income of less than £250.000.
- 2. At the end of the reporting period, the charity held unrestricted cash reserves of £19,677 (2021 £22,826).
- 3. The charity will need to retain £10,000 in their account to cover the cost of the next 12 months for core cost such as both offices and activities and therapies sessions. Our Funding can vary as it can be hard applying for grants when more and more charities are applying for the same grants. We will continue to apply for grants for funding and continue with our fundraising events.
- 4. The charity Trustees believe the charity to still be a going concern and has a busy but productive 12 months ahead of us. We are looking at supporting new service users with all our activities and therapies that we provide.

## Structure, Governance and Management

- 1. The charity is governed by its CIO Foundation Document dated 10 January 2018 and amended on 11 February 2021 and is constitutes a CIO.
- 2. The Trustees will continue to recruit Volunteers for current positions available across the southwest. The Charity uses social media to advertise for new staff as well as on their website. The Charity appoints new trustees from our current volunteers at our AGM through a voting and nomination system.

# Reference and Administrative details

- 1. Charity registered name FND FrieNDs
- 2. Registered number 1176608
- 3. Principal address Bradbury House, Wheatfield Drive, Bradley Stoke, BRISTOL BS32 9D21B
- 4. Trustees
- 1. Amanda Hall
- 2. Caroline Martin (appointed October 2021)
- 3. Daniel Browne (appointed June 2021)
- 4. Jessica Edden-Thomson
- 5. Amy Reeves
- 6. Clara Edden-Thomson (appointed 2021)

In June 2021 Hannah stepped down from being Chairperson and trustee, Amanada become Chairperson, Jessica became Secretary and Daniel became Vice Chair.

Approved on behalf of the board of Trustees

Amanda Hall

Chair of the board of Trustees: FND FrieNDs

Date: 12/1/2023

CHARITY COMMISSION FIND FRIENDS 1176608

FOR ENGLAND AND WALFS THE TAILING	-NU FRIENDS		-		
	Receipts	and	payments acco	accounts	CC16a
	For the period from	06-Apr-21	То	05-Apr-22	
Section A Receipts and	payments				
	1	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest	to the nearest £			
A1 Receipts					44.083
DONATIONS	1,520			10.500	40.864
GRANTS RECEIVED	10,500			2 184	923
FUNDRAISING	2,184			2,104	
LEGACY INCOME					-
MERCHANDISE	6			*	50
PAYPAL	1,323			1,323	1 717
REFUNDS ON EXPENDITURE	8,359	, .		٠, ا	
Sub total (Gross income for AR)	23,886		•	23,886	57,641
A2 Asset and investment sales, (see table).					
	1				
Sub total					•
Total receipts	23,886			23,886	57,641
A3 Payments				7 703	4.731
RENT	325		,	325	325
OFFICE COSTS	531			531	7 773
PRINT, POST AND IT COSTS	6,246	.  .		0,110	17,292
CRAFT SUPPLIES	113			113	
PULICITY AND AWARENESS	553			553	0.11
TRAINING	10			0	9,741
BEFRIENDING COSTS				3 940	4.723
EXPENSES	3,940			-	730
FUNDRAISING COSTS	3.139		•	3,139	
SUBSCRIPTIONS	194				
STORAGE	795			3 224	5 158
OTHER MISC COSTS	3,234			0,204	20.00

Cash funds this year end	A6 Cash funds last year end	A5 Transfers between funds	Net of receipts/(payments) -	Total payments	Sub total			purchases, (see table)	A4 Asset and investment	Sub total		PAYPAL FEES
19,637	22,826	ı	3,189	27,075	•	1				27,075	1	292
		1				1	1				1	
19,637	22,826	-	- 3,189	27,075		-	-/			27,075	,	292
22,826	15,777	1	7,049	50,592						50,592		

#### **B1** Cash funds Section B Statement of assets and liabilities at the end of the period **B4** Assets retained for the **B2** Other monetary assets charity's own use **B3** Investment assets Categories None Paypal Bank account Details Savings account COMPUTERS Details Details (agree balances with receipts and payments account(s)) Total cash funds Fund to which asset belongs Fund to which asset belongs Unrestricted Unrestricted to nearest £ to nearest £ funds funds 19,637 18,283 1,355 Cost (optional) Cost (optional) Restricted Restricted to nearest £ to nearest £ funds funds 1,500 Endowment Endowment Current value Current value to nearest £ to nearest £ (optional funds (optional) funds 1,000

	Signed by one or two trustees on behalf of all the trustees				7	B5 Liabilities	ا م		
S. T.		,			NONE		Details		
0	Signature							28	,
	ture								
1									
DA							Fund to which liability relates		
C.A. MARTIN	Print						which		
RIV	Print Name						Ama (o)		
>						-	Amount due (optional)		
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23/2/23	Date of approval						When due (optional)		•