



Trustees Annual Report

For the period 1st January 2021 to 31st December 2021

Charity Name: FND Action

Charity Registered Number: 1169554

Administration Details:

Registered Charity Name: FND Action

Registered Charity Number: 1169554

Registered Address: 5a New Road Avenue
Chatham
Kent
ME4 6BB

Structure: Governing document: Constitution
Constituted as a CIO
Trustees selected and appointed by the Board

Trustees: Kim Hearne (Chair) - Appointed 10th October 2016
Eric Rosser – Appointed 17th January 2017
Tracey Shea – Appointed 16th April 2021
James Shipley – Appointed 3rd November 2021
David Rosser – Appointed 3rd November 2021
Timothy Nicholson – Appointed 16th November 2021

Governance, Structure and Management:

The Constitution was adopted on the 23rd September 2016.

FND Action is a Charitable Incorporated Organisation (CIO) and was registered with the Charity Commission on the 10th October 2016.

Trustee selection is undertaken through consensus amongst current trustees for roles which are required to further the charity's objectives. Trustee meetings are held periodically to discuss and agree the charity's objectives and activities. In planning the activities of the charity, trustees have considered the guidance on public benefit issued by the charity commission.

Objectives:

As per FND Action's Constitution, our objectives are:

The relief of sickness and preservation of health of persons suffering with Functional Neurological Disorder, in particular but not exclusively by:

- 1) Raising awareness of functional neurological symptoms through the provision of current information to the general public, health sector, caregivers, and those suffering from these symptoms.
- 2) Promoting awareness of functional neurological symptoms through charitable events, meetings, social media, online and offline resources, information packs, leaflets, and other educational materials as required for the public benefit.
- 3) Promoting ongoing research for functional neurological symptoms by encouraging participation through our website and social media, and publishing results.

Vision and Mission:

FND Action's vision is to shine a light on Functional Neurological Disorders so that people diagnosed feel heard, supported and empowered.

Our Mission includes:

Peer support: We aim to develop our website as a key resource for information, support and signposting through regular updates. We continue to provide online support groups for those diagnosed with functional neurological symptoms in the UK, their families and their caregivers. We recognise that having the chance to chat to other people diagnosed will eliminate isolation, and can have a positive impact on a condition that is still little known about. We also continue to provide a caring hand and experience to be able to offer one-to-one support and guidance.

Empowerment: We aim to encourage and help people to achieve a better quality of life and improved wellbeing. We believe that whilst there is no magic cure, there is a lot that can be done to help towards recovery and/or management of symptoms.

Awareness: We aim to do everything we can to raise awareness of functional neurological symptoms amongst the general public, healthcare sector, service providers and other related charities. We already have a strong social media presence, and aim to build on our advocacy work within areas such as education and social care.

Collaborations: We aim to continue to build on relationships with specialist health professionals, related charities and service providers. We understand that effective treatment and care of FND needs to have a holistic approach. We will also continue to assist researchers with project development and recruitment as we believe this is crucial for developing a better understanding of FND.

Activities:

FND Action's activities continue to be predominately undertaken remotely which allows us to provide support to people across the whole of the UK, and be able to engage in health-related advocacy and forums on a national scale.

We have fulfilled our objectives this financial year with the following activities:

- Providing support to those diagnosed through the provision of an informative website, online support groups, one-to-one support and signposting.
- Assisting with support aids by providing medical alert cards (for seizures), and sunflower lanyards following us joining the Hidden Disabilities Scheme in September.
- Raising awareness through the provision of online meetings, forums, steering groups, literature and merchandise to those diagnosed, the healthcare and social sectors, related organisation and charities, and the public.
- Ongoing development of our website as a leading resource for those diagnosed, caregivers and people with interest.
- Ongoing social media presence on Facebook and Twitter.
- Attendance of virtual conferences and events relating to FND and general health.
- Providing assistance to researchers and academics at submission and recruitment stage.
- Participation of the annual FND Awareness Day UK on the 25th March.
- Sitting on various steering groups/forums to be a voice for those diagnosed.
- Collaborations within the health and social care sector to raise awareness and educate.

Achievements and Performance:

From being the first registered charity for FND support in the UK in October 2016, FND Action has remained a leading charity supporting people diagnosed with FND in the UK. Our charity remains patient-led, and is therefore able to provide extensive knowledge of FND and recognition of people's needs. We also regularly converse with leading specialists to ensure information provided is current and accurate. Whilst it has been a difficult time through the pandemic for the charity sector, we have still been able to continue to support people remotely and fulfil our objectives.

At the start and near the end of our financial year, FND Action underwent some significant changes with the administration of the charity, so for short periods of time future planning was on hold. Day to day activities continued, and by the end of the year future planning was able to resume.

Our online support network has continued to grow, and our main group currently has the largest FND charity membership, standing at 6,899 by our year end. Member requests average around 250 a month, which has seen a gradual increase of around 6% over the year. The group continues to be a haven for those diagnosed and their caregivers in the UK, especially for those who have been newly diagnosed given there remains significant issues around accessing treatment and care. Our admin team on the group play a significant role in helping assist people where possible and to keep the group positive.

The impact of the pandemic has contributed to a further surge in people contacting us for direct support given the disruptions and backlogs it has caused within the NHS. However, this surge also reflects that FND Action is becoming better known as a charity who can support people diagnosed, and the main avenues for them reaching us is through social prescribing and easily finding our website online. We on average received around 100 enquiries each month, all of which we were able to help directly or signpost.

FND Action continue to be a member of the Neurological Alliance, which is a collaboration of 70+ neurological charities that unite to advocate directly to the NHS/Public Health for better care and awareness of neurological conditions in England and Wales. We also play an active role as a member of the Medway Neurological Network, which is again a collaboration with local neurological charities with focus on improving local services, ongoing wellbeing and holding events to raise awareness of neurological conditions.

FND Action continue to be a community partner organisation of the International Functional Neurological Disorder Society and the UKFNForum. This allows us the opportunity to help towards influencing changes in medical care, and also be kept up to date with latest developments such as with treatment.

The 25th March marked the 5th annual FND UK awareness day and was again very successful with raising much needed awareness. Activities included people sharing self-lived experiences of FND and we collaborated with other FND charities to host online activities people could get involved in. Social media once again played a key role in spreading awareness, especially given the current lockdown rules. With inclusion of fundraising events that took place for the day, £3,000 was donated to the AMH Neurosciences Research Foundation to support free education for AHO's working with people with FND.

In August FND Action joined the Hidden Disabilities Scheme as it was recognised that some people were being poorly treated out in public, and that many were isolated given their fear of being judged. The scheme entails us providing sunflower lanyards, free of charge, to people diagnosed with FND, and are recognised as being a discrete way of letting the public and businesses know that the wearer

may need some additional support. By year end (3 month period) we distributed in the region of 2,500 lanyards, and received many messages of gratitude.

In September FND Action was able to reach another milestone by establishing its first office in Chatham, Kent, which acts as the registered address for the charity. This will allow the administration of the charity to be run more efficiently, as well as acting a base for us to benchmark the development of FND Community Groups across the UK.

In October the FND Drop-in Café was re-opened in Rochester Kent, which is held every 4th Friday of the month in conjunction with Medway Neurological Network. The attendance thereon has increased each month. The café forms part of the FND community group being benchmarked in Kent.

FND Action played an active role throughout the year in assisting researchers and academics in delivering studies into FND, including helping with initial applications and recruitment of participants.

In Wales there is currently no care pathways for FND. We were extremely grateful to have the opportunity to work with Health Technology Wales in putting forward a call for change to NHS Wales.

In alignment with growth, the charity has continued to develop strong links across the UK with a variety of medical professionals, other related charities and service providers within the health and social care sector. There was a significant increase in contact within social care and education, which we plan to engage in further moving forward.

Financial Review:

Reserves: On the 31st December 2021 the sum of £45,680 was held in reserve to spend on charitable activities.

The charities policy is that the reserves will not fall below £1,000 without full agreement of the board of trustees.

In deficit: None.

Further Information:

Due to the generosity of fundraisers and donors, we raised £23,554 during the year.

Expenditure supporting and delivering the charity's objectives has increased this year to £23,377. The majority of this was accounted for in the following areas of activity:

1. £7,000 on lanyards distributed to those diagnosed after becoming a member of the Hidden Disability Scheme.
2. £3,000 donated to the AMH Neurosciences Research Foundation.
3. £5,144 on office expenditure.

We remain in a strong financial position which will enable the charity to continue in achieving its goals during the coming year.

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees:

A handwritten signature in black ink, appearing to be 'KH' with a horizontal line extending to the right.

Kim Hearne

Chair of Trustees of the Board: FND Action

Date: 14.06.2022



CHARITY COMMISSION
FOR ENGLAND AND WALES

FND ACTION

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Receipts and payments accounts

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For the period from	01-01-21	To	31-12-21
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Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
DONATIONS	23,554	-	-	23,554	16,566
AWARENESS MERCHANDISE	-	-	-	-	1,686
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	23,554	-	-	23,554	18,252
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	23,554	-	-	23,554	18,252
A3 Payments					
ACTIVITIES	10,121	-	-	10,121	1,175
EXPENSES/OFFICE	5,144	-	-	5,144	279
STATIONARY/POSTAGE	3,522	-	-	3,522	700
INSURANCE	100	-	-	100	100
MEMBERSHIP	296	-	-	296	523
WEBSITE	663	-	-	663	445
OTHER	3,531	-	-	3,531	174
	-	-	-	-	-
	-	-	-	-	-
Sub total	23,377	-	-	23,377	3,396
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	23,377	-	-	23,377	3,396
Net of receipts/(payments)	177	-	-	177	14,856
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	45,503	-	-	45,503	30,647
Cash funds this year end	45,680	-	-	45,680	45,503

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	BANK ACCOUNT	44,413	-	-
	PAYPAL	1,267	-	-
		-	-	-
	Total cash funds	45,680	-	-
	(agree balances with receipts and payments account(s))			

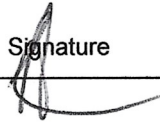

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	ERIC ROSSER	06/06/22
	KIM HEARNE	08/06/22