



Trustees' Annual Report for the period

Period start date
 From 01 01 2020 To 31 12 2020
 Period end date

Section A

Reference and administration details

Charity name FND Hope UK

Other names charity is known by FND Hope

Registered charity number (if any) 1173607 & SC048333

Charity's principal address 21 Chetwode

Banbury

Oxfordshire

Postcode OX16 1QN

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Matt Birtwistle	Chair		
2	Louyse McConnell-Trevillion	Trustee		
3	Bridget Danielle Mildon	Trustee		
4	Lucinda Sian Smulders	Trustee		
5	Robert Wilson Thomas	Trustee		
6	Richard Newland	Trustee	07.09.2020	
7	Joyce Davies	Trustee	07.09.2020	
8	Abigail Bishop-Laggett	Trustee	18.11.2020	
9	Christopher Symeon	Trustee	18.11.2020	
10				
11				
12				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
Independent Examiner	Warner Wilde Limited	4 Marigold Drive, Bisley. GU24 9SF

Name of chief executive or names of senior staff members (Optional information)

Dawn Golder

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Constitution of a Charitable Incorporated Organisation whose only voting members are its charity trustees dated 28 th June 2017
How the charity is constituted (eg. trust, association, company)	Charitable Incorporated Organisation (CIO)
Trustee selection methods (eg. appointed by, elected by)	<p>Trustees are recruited and appointed under clause 10 of the Constitution</p> <p>(1) Apart from the first trustees, every trustee must be appointed [for a term of [three] years] by a resolution passed at a properly convened meeting of the charity trustees.</p> <p>(2) In selecting individuals for appointment as charity trustees, the charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO</p>

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

Trustees have undertaken the following courses

- Online GDPR Awareness for Small Charities Course conducted by VSL Training
- Online Safeguarding Adults Awareness Course by Vital Skills
- Online Safeguarding Child Awareness Course by VSL Consulting

Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

FND Hope UK aim to change how functional symptoms are understood and defined within the UK.

We work in a concerted manner to advocate for the Men, Women and Children who have had their lives impacted by physical and often debilitating functional symptoms.

Our mission is to promote awareness, support affected individuals, and advance research for the prevention, treatment and recovery of FND.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

The relief of sickness and preservation of health of those affected by Functional Neurological Disorder (FND) and their families, carers and communities. In particular, but not exclusively by:

- 1) Raising awareness and understanding of the general public into the nature, causes, diagnosis, prevent, treatment and recovery of FND through social media, charitable events, medical conference and any other educational means such as leaflets and booklets
- 2) Coordinating a voluntary FND patients register to assist doctors in the advancement of new and ongoing research, prevent, treatment and recovery of FND in partnership with the Genetic Alliance.
- 3) Working with Medical and Allied Health Professionals to provide a better understanding of FND, improve medical protocols, and promote ethical standards for FND through personal contact, advocacy and training.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Peer Support Groups

- Due to the Global COVID Pandemic, we quickly had to change our strategy to bring our peer support groups online to still provide the support to our FND community. With the help and support of our 13 volunteers, together we organised 1 hour virtual peer groups using our Zoom platform each month.
 - London (1st Tuesday of every month)
 - Scotland (2nd Wednesday of each month)
 - Wales (3rd Monday of each month)
 - North East (1st Saturday of each month)
 - Norfolk (1st Wednesday of each month)
 - Surrey (3rd Friday of each month)
 - UK Wide (4th Wednesday of each month)
 - Berkshire (1st Thursday of each month)
 - BCP (Bournemouth, Christchurch, Poole) and Isle of Wight (2nd Monday of each month)
 - Parent Peer Groups (3rd Thursday of each month)
 - This is a vital source of support for our FND community, where they can reach out to peers going through a similar journey, ask questions, and provide support and advice to each other.
 - We have also seen medical professionals join our peer support groups to provide additional support and to answer questions : Dr Christopher Symeon from the Wolfson Rehab

Unit, London and Dr Jason Price, Middlesbrough.

- We have also put in place online training for our peer support workers to complete a Child Safeguarding course and an Adult Safeguarding Course supplied by VSL Consulting and Vital Services.

"FND Hope UK is so important for those of us with FND to get information and meet others with the same condition, so as not to feel so isolated" **Lesley Peer Support Worker for Scotland**

"The charity is important to me as living in a rural island, it's easy to feel alone but with FND Hope UK I feel part of a community". **Maureen - Service User**

"FND Hope UK is the first line of support for a condition of pandemic proportions, while sufferers wait for 6-12 months (minimum) for a first contact support/referral from a professional". **Leon – Service User**

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

UK Board

- We have strengthened our board by recruiting four new additional board members to increase the skill set and diversity.
 - Joyce Davies a master degree in clinical psychology and is also a Neurodiversity Education Officer with the SNP
 - Dr Christopher Symeon who is a Consultant Neuropsychiatrist from the Wolfson Rehab Unit as part of St Georges University Hospital
 - Richard Newland, a CEO & founder of AIMCommunity a Creative Arts Education and Mentoring charity, including a Masters Degree in Youth and Community Work.
 - Abigail Bishop-Laggett public relations and government affairs professional who is experienced in supporting healthcare organisations raise awareness of complex or lesser-known conditions.

Medical Expert Committee

- We have grown our UK Medical Expert Committee by inviting
 - Dr Ben Baig - Senior Lecturer in Child and Adolescent Psychiatry, St Thomas' Hospital, London
 - Dr Fiona Summers - Consultant Clinical Neuropsychologist, Aberdeen Royal Infirmary (NHS Grampian)
 - We now have a diverse range of medical and allied health professionals. We meet on a quarterly basis via Zoom, and discuss advancing research in both Adults and Young Children. Help to raise awareness of FND, support any public policy changes. We support research requests and survey studies and proactively engage our community to get involved.

"FND Hope UK has played a major role in changing the landscape for people with FND, their carers and families. They have been central to increased

awareness of FND and provide a lot of information and support with minimal resources. FND Hope UK also works really closely with health professionals such as myself in a wide variety of clinical and research projects. I have personally found this invaluable. The continued success of FND Hope UK is essential to patients with this common but hidden condition as well as the clinicians trying to improve services and research for them". – Professor Jon Stone – Professor of Neurology, Royal Infirmary Edinburgh and member of FND Hope UK Medical Expert Committee

"FND Hope UK plays a crucial role in raising awareness of FND as well as providing information and support to people with the condition. By representing those with lived experience of FND, they play a vital role in empowering patients and advocating for better FND services." Dr Biba Stanton, Neurologist, Kings College Hospital

"Stigma, negative attitudes and misunderstanding have historically and continue to surround the interactions of healthcare professionals with people with FND. FND Hope UK provides an essential bridge that allows patient voices to be really heard and the development of a shared understanding of this common and disabling condition. Through this process, research and clinical service developments are immeasurably strengthened, and the prospect of improved care and treatment for people with FND is brought significantly closer to reality". Professor Mark Edwards, Professor of Neurology, St Georges University Hospital

#FNDandUS Campaign



- FND Hope UK worked closely with Director Mike Rumsey from Rumsey Films where we were able to document the inspiring personal FND journeys of four of our service users. The campaign was launched by our Patron Lorraine Kelly, and became really successful with a total reach of **814,744** which is fantastic and shows just how much awareness we were able to raise on FND. On Twitter our reach was 99,869 and on Facebook and Instagram 714,875.
- On our You Tube Channel we had the following views (Total 7,445)
 - Lorraine launch – 1k
 - Jemma – 998 views
 - Anthony – 612 views
 - Georgia – 763 views
 - Robert – 572 views
 - Full Film – 3.5k views

Meet our inspiring individuals

- Robert – Trustee and Legal Advisor for FND Hope UK
- Jemma – FND Hope UK Peer Support Worker
- Anthony – FND Hope UK Peer Support Worker
- Georgia – FND Hope Warrior

- We were so overwhelmed by the response, that we have agreed to continue with this campaign in 2021

myFND app

- We supported the creation, provided feedback, and organised a webinar to launch the new myFND app created by Dr Christopher Symeon, Professor Mark Edwards, Dr Glenn Nielsen, Dr Mike Dilley, Dr Rahcel Dean from the Wolfson Rehabilitation Team.
- The app helps individuals to understand their symptoms, track how the symptoms change over time and learn different techniques to help manage their FND symptoms. The webinar has been watched over 700 times, and we have received some positive feedback on the App.

Neurological Alliance Partnership

- The Executive Director has been working very closely with The Neurological Alliance
 - Supported the Neurological Alliance survey, life with a neurological condition during COVID19 where we were asked to review the survey prior to promotion 7.61% responses were from the FND community. The report found that people with neurological conditions had been profoundly impacted by the pandemic, with many reporting disruptions to their treatment, care and support.
 - We signed a joint letter with many other neurological charities in collaboration with the Neuro Alliance to Sir Simon Stevens to look at restarting service for people with neurological conditions after the COVID19 pandemic.
 - Our Executive Director has also become a member of the Mental Health Sub Group which discusses Mental Health policies and how these can be changed, such as the Integrated Care Systems and Influence.
 - The Neurological Alliance formally asked our Executive Director to become the Vice Chair of the Policy Group where policy issues are raised and discussed to help support policy changes for all neurological conditions such as Long Covid, PIFU (Patient Initiated Follow Up).
 - The Executive Director has also been meeting with National Neuro Advisory Group (NNAG) part of the Neurological Alliance, on the Optimal FND pathway, which unfortunately was paused due to the COVID19 pandemic. Work will commence in 2021.

Wales Neurological Alliance

- We have started to work more closely with the Wales Neurological Alliance, specifically around the lack of FND Services. We have also connected with Dr Tanya Edmonds who will be organising a Task & Finish group for FND Services in Wales in 2021.

Neurological Alliance of Scotland

- We have started to work more closely with the Neurological Alliance of Scotland, specifically around the lack of FND Services and no

mention of FND on the NHS Inform platform. Our Trustee Robert Wilson Thomas has also joined the Wales Neurological Conditions Advisory Group

CoronaUnity

- CoronaUnity is a student led COVID19 organisation to help support charities on consultancy projects. The executive director worked with 6 students on the following projects
 - Social Media Audit of our Social Media Accounts
 - Creation of a Volunteer Handbook
 - Plan a PR Strategy for the roll out of our #FNDandUS campaign
 - It was great to work with some really enthusiastic students, and we were able to identify areas for improvement for our social media, the new Volunteer Handbook has now been created and the PR strategy helped us to plan and organise our #FNDandUS campaign

Charity of the Year

- Southampton RTC formally announced us as their charity of the year to help us raise awareness of FND and to help with fundraising. We'd like to thank them for their help and support.

World FND Month

- Encouraged participation from the general public and our FND community in our 7th Annual #FNDAware Awareness Campaign World FND Month
 - Our patron Lorraine Kelly also got involved in creating a positive message for our FND community, with over 2.7k views on our FND Hope You Tube Channel.

"April is World FND month and in these unprecedented times our aim is to continue to offer support throughout this pandemic, as we recognise that FND doesn't stop for anything. We all need to try to remain positive, and as active as possible.

Remember we are allowed to go out into the fresh air for exercise once a day, of course many of us are in isolation due to the lockdown, but remember physical social distancing does not mean emotional distancing. You can pick up the phone, write a letter, and join in with some of the activities during World FND Month.

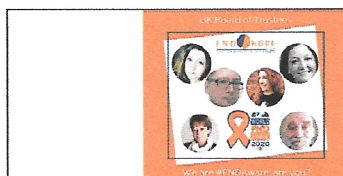
FND Hope UK are here for you. Any form of exercise for your mind and body is so positive to keep you motivated. So try and do what you can.

Let's try to look at what we do have this month rather than what we don't.

Positivity is the key when times are hard. So let's all keep motivated as best we can and help those around us, as together we've got this.

I'm FND Aware are you? Take care and stay well". Lorraine Kelly CBE Patron

- Many more also got involved



The board of Trustees getting involved to share with our community that we are #FNDAware

1014 people reached on our Open Facebook Page

	<p>Clinical Neuropsychologist at the John Radcliffe Hospital in Oxford, Dr Niels Detert, discusses Mindfulness during World FND Month</p> <p>524 views on You Tube</p>
	<p>The Brain Charity (Liverpool) getting involved in raising awareness of FND</p> <p>872 people reached on our Open Facebook Page</p>
	<p>Pembroke Castle lighting up Blue for World FND Month and to support the NHS, photo by Beverly Thomas</p> <p>1019 people reached on our Open Facebook Page</p>
	<p>Lauren share her story in the Barking and Dagenham Post</p> <p>1168 people reach on our Open Facebook Page</p>
	<p>Tom Plender writes about his FND journey for the Nihealthcare.com "A quest for clarity".</p> <p>669 people reached on our Open Facebook Page</p>
	<p>Alison Newland creates an inspiring video sharing her own FND journey for World FND Month.</p> <p>756 people reached on our Open Facebook Page</p>

Fundraising

- We have been very thankful for the fundraisers we have had in 2020, even with the Global Pandemic. Here are some of the fundraisers we'd like to mention, but we'd like to thank all our fundraisers in helping to support our charity and our FND community.

Just Giving (Total includes Gift Aid)

- Carl Knowles, Inverness ½ Marathon £1005.36
- Kate Bidwell, ½ mile walk for her 21st birthday £922.65
- Donna Stretton, 100 miles in August, £788.02
- Laura Cordell, Virtual Pub Quiz, £722.50

Virgin Money Giving

- Christina Golder, My Prudential BikeRide London, £616.25
- Sally Eason, 10 Flute-a-Thon, £588.36

Facebook

- Angelina Marren, £361.00
- Charlotte Alder, £320.00
- Val Stewart, £284.00
- Megan Elizabeth, £260.00

Webinars

- FND Hope UK organised a number of webinars for our FND community on the following topics
 - Dr Niels Detert, Mindfulness, with 553 views on our You Tube Channel
 - Professor Mark Edwards on FND and Relapses with 1.3k views on our You Tube Channel
 - Dr Chris Symeon, MyFND App with 770 views on our You Tube Channel
 - Dr Jason Price, Hypnosis and FND, with 684 views on our You Tube Channel

NICE Guidelines

- We provided feedback on the Suspected Neurological Conditions Quality Standards specifically for FND
- We held a meeting with Dr Paul Chrisp Director of FND Guidelines with Professor Mark Edwards on how to create an FND NICE Guideline. Due to the COVID Pandemic, most guidelines had been placed on hold due to a number of COVID related guidelines needing to take priority. Further discussions to be held in 2021.

Advocacy and Support

- We responded to over 500 emails from our community to support them with questions, identifying FND specialists, sign-posting them to resources we have on our website.
- We also supported 15 individuals with providing more detailed letters to help with requesting referrals to FND specialist units, providing letters to medical professionals to educate them on FND due to poor treatment, discussing reasonable adjustments in the workplace, and housing support.

Peer Support Groups

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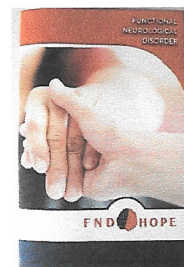
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FND Patient Booklets and Leaflets

- FND Hope UK collaborated with FND Hope International, Professor Jon Stone and Dr Tim Nicholson in the creation of an FND Patient Booklet are continuing to sent to Hospitals, medical professionals, to our Peer Support Workers, Healthcare professionals and community rehab centres to hand out to their FND community. We have sent over 8000 booklets so far with more to send on the horizon for 2021, and distributed over 10k leaflets to the General Public and our FND community to provide further information and raise awareness of FND.



Research

- Provided a platform to recruit participants for the following research projects exclusively to the UK:
 - Psychedelics in FND Treatment
 - Physiotherapist's experiences of communicating with people with FND
 - Interoception and executive functioning in relation to emotion perception
 - Priority Setting Partnership (PSPs) for Medically Not-Yet-Explained Symptoms (MNYES)
 - How long have people with FND had to wait for treatment
 - Shame, stigma and poorly understood medical conditions
- Provided advice and feedback on a feasibility study on EMDR Therapy for FND Treatment. Project to commence 2021

Collaboration Meetings

- Meeting held with South London and Maudsley regarding the new Inpatient Rehabilitation Unit to ensure that it meets the requirements of our FND community.

Section D

Achievements and performance

Social Media

- Our social media presence is increasing year on year

Social Media Account	2018	2019	2020	% Increase
FND Hope UK Facebook Page (followers)	656	2,691	4,769	+61%
FND Hope UK Facebook Group (followers)	3,200	4,412	5,237	+16%
FND Hope UK Instagram (followers)	219	444	1,350	+67%
FND Hope UK Twitter (followers)	600	1,421	2,274	+38%

Section E

Financial review

Brief statement of the charity's policy on reserves

The charity has agreed a reserve policy for the following:
£10,000.00 for the distribution and printing of Patient Packs
£5000.00 for the organisation of additional Peer Support Groups within the UK

Reserves are higher because we did not have the opportunity to spend due to COVID 19

Details of any funds materially in deficit

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

For this period the Charity can report

Revenue: £43,099
Net Surplus: £20,235

Total Funds: £70,200

Section F

Other optional information


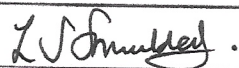
We are registered charity in England & Wales 1173607 and Scotland SC048333

Section G

Declaration

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

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Dawn Golder	Cindy Smulders
Position (eg Secretary, Chair, etc)	Executive Director	Chair

Date 26/08/2021

Independent examiner's report on the accounts

Section A

Independent Examiner's Report

**Report to the trustees/
members of**

Charity Name
FND Hope UK

**On accounts for the year
ended**

31 December 2020

**Charity no
(if any)**

1173607 &
SC048333

Set out on pages

1 and 2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 December 2020.

**Responsibilities and
basis of report**

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act (1)") and the Charities and Trustee Investment (Scotland) Act 2005 ("the Act (2)") and the Charities Accounts (Scotland) Regulations 2006 (as amended).

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act (1). The charity trustees consider that the audit requirement of Regulation 10(1) (d) of the Charities Accounts (Scotland) Regulation 2006 does not apply. It is my responsibility to examine the accounts as required under section 44(1) (c) of the Act (2) and to state whether particular matters have come to my attention.

**Independent
examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention (other than that disclosed below *) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act (1) or in accordance with Section 44(1) (a) of the 2005 Act (2) and Regulation 4 of the 2006 Accounts Regulations
- the accounts do not accord with the accounting records and comply with Regulation 9 of the 2006 Accounts Regulations

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Signed:



Date:

1 September 2021

Name:

F J Wilde

**Relevant professional
qualification(s) or body
(if any):**

FCCA DChA

Address:

4 Marigold Drive

Bisley
Surrey GU24 9SF

Section B**Disclosure**

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.



CHARITY COMMISSION
FOR ENGLAND AND WALES

FND Hope UK

1173607
SC048333

Receipts and payments accounts

CC16a

For the period from	Period start date 01/01/2020	To	Period end date 31/12/2020
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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 & Legacies	43,099	-	-	43,099	46,513
Charitable Activities	-	-	-	-	225
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	43,099	-	-	43,099	46,738
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	43,099	-	-	43,099	46,738
A3 Payments					
Raising Funds	-	-	-	-	1,656
Charitable Activities	1,660	-	-	1,660	2,041
Marketing and Brochures	11,735	-	-	11,735	11,144
Training Costs	791	-	-	791	-
Office costs	4,505	-	-	4,505	2,100
Legal and Professional fees	1,537	-	-	1,537	1,751
Accountancy	600	-	-	600	-
Conference Expenses	-	-	-	-	843
Subscriptions	678	-	-	678	864
Venue Hire, Hotel and Accommodation	372	-	-	372	-
Insurance	986	-	-	986	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	22,864	-	-	22,864	20,399
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	22,864	-	-	22,864	20,399
Net of receipts/(payments)	20,235	-	-	20,235	26,339
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	49,965	-	-	49,965	23,626
Cash funds this year end	70,200	-	-	70,200	49,965

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	HSBC	62,762	-	-
	Paypal	7,438	-	-
		-	-	-
		-	-	-
	Total cash funds	70,200	-	-
(agree balances with receipts and payments account(s))				


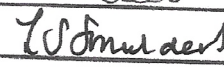
	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	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	FND Hope Int. (shared services charge 2019 and 2020)		4,527	
	IE Fee		612	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
	Dawn Golder	26/08/21
	Cindy Smulders	26/08/21