



# Trustees' Annual Report for the period

		Period start date					Period end date		
From		01	01	2022	To		31	12	2022

## 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	Lucinda Sian Smulders	Chair		
2	Bridget Danielle Mildon	Trustee		
3	Abigail Bishop-Laggett	Trustee		
4	Christopher Symeon	Trustee		
5	Vincent Smith	Trustee	Resigned: 04.04.2022	
6	Stephen Betteridge-Sorby	Trustee		
7	Helen Bolter	Trustee		
8	Robert Wilson Thomas	Trustee	Resigned: 22.06.2022	
9	Joyce Davies	Trustee	Resigned: 12.01.2022	
10	Penny Trayner	Trustee	Appointed: 01.03.2023	
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

**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 <sup>th</sup> June 2017
How the charity is constituted (eg. trust, association, company)	Charitable Incorporated Organisation (CIO)
Trustee selection methods (eg. appointed by, elected by)	Trustees are recruited and appointed under clause 10 of the Constitution  (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. (2) In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO

**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 online courses, created by VSL Consulting: An Introduction to Safeguarding Children - for Charities, The UK and EU GDPR's - Awareness Training for Charities, and An Introduction to Safeguarding Adults at Risk - for Charities

FND Hope UK had 39 active volunteers supporting our FND community with Peer Support, Marketing, Social Media, Finance and Grant Writing/Researching. We are extremely grateful to each and every volunteer who have given their time to help us support and advocate for our FND community. Our volunteers have also undertaken in completing the online courses: An Introduction to Safeguarding Children - for Charities, The UK and EU GDPR's - Awareness Training for Charities, and An Introduction to Safeguarding Adults at Risk - for Charities

## 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.

Summary of the main achievements of the charity during the year

Our mission is to promote awareness of FND, support those affected by the condition and advance knowledge and research for the prevention, treatment and recovery from FND. We are looking forward to a world where FND patients can expect to be treated with the dignity, care and respect they deserve, regardless of the cause of their symptoms.

### Supporting those affected by FND

#### myFND App



- FND Hope UK were grateful to have sponsored the upgraded development of the International myFND App following feedback from service users. The new app was launched on the 4<sup>th</sup> August 2022 following focus groups with the creators BM Inc and service users.
- Development updates included
  - The ability to create a report to share with healthcare providers
  - Rewards badges
  - Ability to select and track multiple symptoms overtime
  - Improved accessibility features such as dark mode
  - Lorraine Kelly, Patron for FND Hope UK helped to launch the new app via video, which was played 6,100 times
  - Since launch, there have been 11,975 downloads

#### Mindfulness for Positive Self Coaching



Collaborated with Irene Roura Garcia who has created a Mindfulness for Positive Coaching Course which last 3 weeks, 1.5 hours per session. We launched this in August 2022 and ran 5 courses, with 50 people attending.

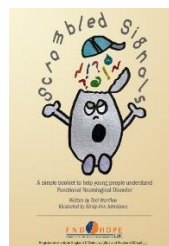
- During this course our attendees learned/refreshed on some basic concepts and techniques about mindfulness and Cognitive Behavioural Therapy, combining theory and practical exercises.
- The course was designed specifically for people experiencing FND, where they learned about mind and body, and techniques to help manage symptoms.

#### DVLA Terminology

We contacted the CEO of DVLA (Driving Vehicle Licensing Agency) to update the FEP1 form, specifically the change in terminology from Pseudoseizures and Non Epileptic Attack Disorder to Functional /

Dissociative Seizures. We received a response from the Senior Policy Team Leader on the 22nd September advising that the DVLA Senior Doctor agreed with our request, and the DVLA will now be updating the forms, policies and associated literature over the coming months

Scrambled Signals Booklet for our Younger Community



We collaborated with two members of our community to create Scrambled Signals. Toni Warrilow and Kirsty-ann Johnstone. The booklet was designed to help our younger community learn and understand FND. Booklets have been created in both Digital and Hard copies and have been distributed to both our community and health care professionals

FND Patient Booklet



Distributed 10,700 booklets in 2022 to our community and Healthcare professionals and 10,000 leaflets to raise awareness of FND.

Correspondance

Responded to 1143 emails in 2022, from our FND community, parents, carers, friends, and healthcare professionals, which has increased by 50% from 2021

Online Support Groups

We have a total of 9 Support Groups: England, Scotland, Wales, East of England, North East, London, Parents, Carers and South West. We held a total of 99 support groups via Zoom, with 599 attendees.

Online movement and Wellbeing Classes

In collaboration with Synergy Dance Outreach, and registered charity which provides innovative dance and yoga activities in schools, leisure centres, outreach centres and care homes. Inclusivity is vital to us. At Synergy, no one is left behind and we were determined lockdown would not stop us making a difference.

We offer our community Seated Dance, Seated Yoga and Seated Pilates. We have also collaborated with CREATE (Creative, Reflective, Emotive, Art Therapy for Everyone) to run Art classes and Mindfulness Energy to offer Mindfulness Meditation classes on a weekly basis.

In 2022, held 246 online movement and wellbeing with 2,097 people attending which is a 133% increase from 2021.

#### Website

We had 116,154 users to our website fndhope.org in 2022 from the United Kingdom

- 87,736 England
- 12,774 Scotland
- 4,120 Wales
- 2,208 Northern Ireland
- 905 Not Set
- 113 Isle of Man

#### Newsletters

We sent 10 newsletters in 2022 with 6,328 people reading our news. This enables us to communicate directly with our community, and healthcare professionals and provide invaluable updates on the work FND Hope UK are doing.

#### Webinars

Collaborated with Irwin Mitchell Solicitors, Kate Hayward – Occupational Therapist, Vocational Rehabilitation Service, The National Hospital for Neurology and Neurosurgery, London and Clare Nicholson – Occupational Therapist, FND Rehabilitation Service, The National Hospital for Neurology and Neurosurgery, London to present a webinar on Reasonable Adjustments in the workplace.

#### Telephone Helpline

Our pilot with the Brain & Spine Foundation finished in February 2022 after a 3 months study. 106 call-backs were completed, with an average call duration of 21.83 minutes.

- 69 call back were in relation to related to supporting people whose diagnosis has an impact on their mental health. 14 people were carers and 88 of the people supported were patients. We also spoke to 14 family members and 2 partners as well as 1 Health Professional. We captured the location of 99 people out of the 106 and South East was the area that most enquiries came from (20.2%).

We also identified in our own member survey, that whilst our community rated it a useful resource, over 50% had not used the service, we agreed not to continue with this service.

#### Advance Research

FND Hope UK have become Patient and Public Involvement where we evaluate and provide feedback on the research projects.

- Functional Sensory Symptoms - Glenn Nielsen, St Georges
- Physio4FMD Study – Glenn Nielsen, St Georges

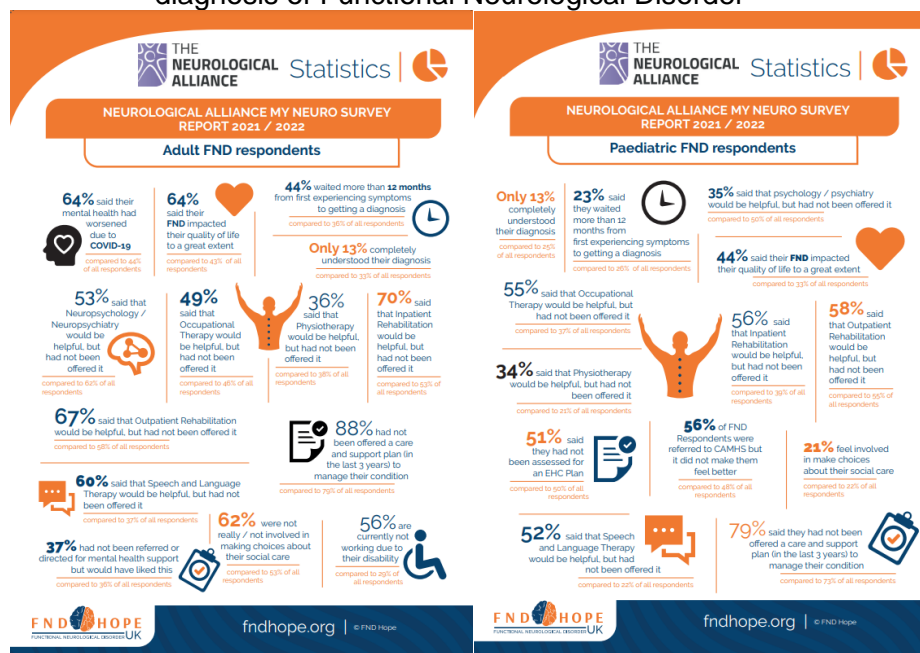
- NEUROADS - Understanding risk factors and symptom triggers in functional neurological disorder: a pilot investigation Study - Dr Susannah Pick, Kings College
- Randomised feasibility study of eye movement desensitisation and
- reprocessing therapy for functional neurological disorder: Dr Sarah Cope – St Georges
- UCLH Functional Seizures Project with Dr Mahinder Yogarajah and Rachel Dean, from University College Hospital and St Georges.

Facilitated and supported focus groups with Dr Sue McKenzie and High Cunningham on undertaken to better understand the current management of patients with Functional Neurological Disorder (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.

### Diagnosis & access to treatment

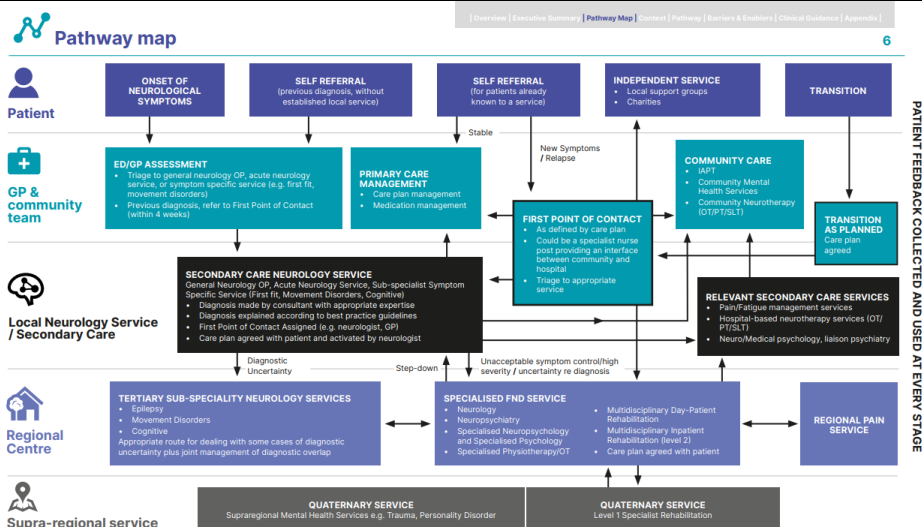
#### Neurological Alliance my Neuro survey

- Supported the creation and distribution of the My Neuro Survey to give a picture of the experience of care, treatment and support for people affected by neurological conditions. Over 8,500 people took part
  - 849 Adults and 64 Young Adults and Children took part with a diagnosis of Functional Neurological Disorder



#### Optimal FND Carepathway

We continued to collaborate on the Optimal FND Care pathway with the Neurological Alliance, National Neuro Advisory Group, Professor Mark Edwards and Dr Mike Dilley. We were actively engaged in the public consultation to gather input, view and experience from people with neurological conditions and wider stakeholders



### Neurological Alliance Policy Group

Our FND Hope UK Executive Director is the Vice chair to the Neurological Alliance Policy Group to support the Neurological Alliance's Policy Group in identifying opportunities to influence national public policy in the interests of the one in six people in England with a neurological condition.

### FND Education Module for Healthcare Professionals

Supported, facilitated and arranged focus groups, with Dr Ania Crawshaw from St Georges, with the FND community to discuss the development of an online FND educational module for Healthcare professionals to ensure patient priorities reflected in the course. The course is now on the FutureLearn website.

### Freedom of Information Project

In 2022, we surveyed, through a Freedom of Information request, all of the Clinical Commissioning Groups and Health Board in the UK as to their current provision of multidisciplinary rehabilitation for people with FND, as well as if they had active plans for developing or expanding services.

We found that:

- 50% of UK health boards / CCGs had no specific agreement to treat FND or did not treat FND, and almost 10% say that they do not accept referrals for treatment
- Between 14% (England), 21% (Scotland) and 43% (Wales) of services said that they did not accept physiotherapy referrals or provide physio for FND. Less than half (43%) said they had neurological physiotherapy services which would accept people with FND.
- Between 22% (England), 21% (Scotland) and 43% (Wales) of services said that they did not accept occupations therapy referrals or provide occupational health for FND and less than half (41%) said they had neurology based occupational therapy services which would accept people with FND.
- Between 17% (England), 14% (Scotland) and 43% (Wales) of services said that they did not accept speech and



language therapy referrals or provide speech and language for FND and only 39% said they had neurology-based speech and language therapy services which would accept people with FND.

- Between 16% (England), 29% (Scotland) and 43% (Wales) of services said that they did not accept psychology referrals or provide psychological therapy for FND, whilst 42% said they would accept people with FND.
- Only 35% said they had plans to improve their services for people with FND and only 35% said they were potentially interested in accessing further education or support to improve services.

This survey highlights the current patchy and inequitable provision of rehabilitative services for people with one of the commonest causes of neurological disability.

### Raising awareness in the general & medical communities

#### Conventions



To help raise awareness in our medical communities, we attended the Neuro Convention (our 3<sup>rd</sup> year running) which is an exhibition for healthcare professionals working in neuro rehabilitation.



We also attended Therapy Expo which is an educational event for physiotherapists, sports therapists, osteopaths, chiropractors, and neuro therapists. We also arranged for Glenn Nielsen to do a presentation on FND with 56 attendees learning more about FND

## Impact Report



We created our very first charity impact report which was distributed to our community, healthcare professionals, carers, friends and families and also shared with funders and supporters.

## World FND Month

Supported the annual World FND Month in April 2022 to continue to raise awareness of FND to our community, general public and healthcare professionals.



Our Patron, Lorraine Kelly created some short videos, explaining what FND is, and asking our community to get involved in our #FNDaware campaign by sharing the #FNDaware poster.

## Social Media Presence

Our social media presence is increasing year on year. In 2021 we had a total of 19,600 people follow us on our social media channels Facebook, Twitter, and Instagram. In 2022 this increased to 24,740 followers.

## BPS DoN Position Statement

FND Hope UK were asked to be part of the BPS DoN Position Statement on the role of clinical neuropsychology in the management of children and adults with functional neurological disorders as experts by experience and representing the FND community.

**Study Days**

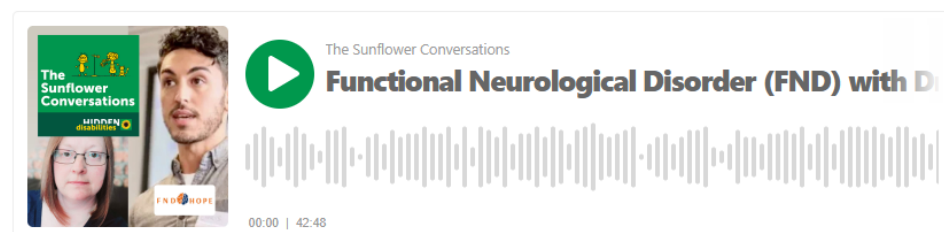
FND Hope UK were asked to attend a number of FND study days organised by different organisations, to provide a patient perspective on FND and how FND Hope UK supports and advocates for the FND Community

- Royal College of Emergency Medicine study day
- Speech and Language FND study day through the East Midlands Progressive Neurology Clinical Excellence Network
- Cygnet Health
- Royal National Orthopedic Hospital

**Hidden Disabilities****The Sunflower Conversations**

Functional Neurological Disorder (FND) with Dr Chris Symeon and Dawn Golder, FND Hope UK

JANUARY 08, 2023 HIDDEN DISABILITIES SUNFLOWER



We collaborated with Hidden Disabilities on creating a Podcast, alongside Dr Chris Symeon on what FND is and a personal FND journey, including creating an FND Sunflower card for our community.

**Finances**

We secured Grants of £16,144, including:

- The National Lottery Community Fund £8,169.00
- Versus Arthritis on behalf of Sports England £4,500.00
- D'Oyle Carte Charitable Trust £2475.00
- Girdlers Company £500.00

**Fundraising/Donations**

Thank you to our FND community, friends, family and healthcare professionals, we raised a total of £76,022.

**Section E****Financial review****Brief statement of the charity's policy on reserves**

The charity has agreed an unrestricted reserves policy of £14,700.00, which covers 6 months' worth of online movement and wellbeing classes, insurance, memberships and subscriptions. Reserves currently exceed this amount because the charity is waiting for FND Hope International to send the shared services invoices for 2022. Trustees are also looking to recruit full-time staff as the charity is growing and has been 100% volunteer led since its conception on the 28th June 2017. In addition, the charity is looking to create Educational Modules to support the education of Schools, Universities, Healthcare Professionals and Employers in the coming months.

**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: £76,022

Net Profit: £24,739

Total Funds: £103,459

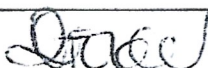
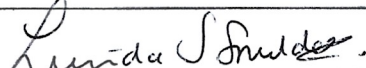
**Section F****Other optional information**

We are a 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	Lucinda Smulders
Position (eg Secretary, Chair, etc)	Executive Director	Chair

Date

30/08/2023





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 2022

Charity no  
(if any)

1173607 and  
SC048333

Set out on pages

1 - 2

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 December 2022.

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 and Trustee Investment (Scotland) Act 2005 (the 2005 Act), the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 44 (1) (c) of the 2005 Act and 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.

Independent  
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention 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 44 (1) (a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the Act or
- the accounts do not accord with the accounting records

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:

05/09/2023

Name:

Linda Dunford

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

FCCA CTA

Address:

4 Marigold Drive

Bisley

GU24 9SF



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name

FND Hope UK

No (if any)

1173607 & SC048333

## Receipts and payments accounts

CC16a

For the period  
from

Period start date  
01/01/2022

To

Period end date  
31/12/2022

### 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 and Legacies	59,878	-	-	59,878	66,783
Grants	9,169	6,975	-	16,144	4,680
		-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b> (Gross income for AR)	69,047	6,975	-	76,022	71,463

#### A2 Asset and investment sales, (see table).

	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	-	-	-	-	-

**Total receipts** 69,047 6,975 - 76,022 71,463

#### A3 Payments

Charitable activities	13,366	240	-	13,606	27,439
Marketing and brochures	21,191	-	-	21,191	8,448
Training costs	803	-	-	803	3,469
Office costs	3,322	-	-	3,322	3,466
Legal and professional fees	5,733	-	-	5,733	6,086
Accountancy	666	-	-	666	612
Subscriptions	1,196	-	-	1,196	869
Venue hire, hotel and accommodation	1,242	-	-	1,242	823
Insurance	837	-	-	837	844
Bank charges and interest	1,611	-	-	1,611	821
Travel	415			415	-
Grants returned	-	-	-	-	10,000
Sundry expenses	661	-	-	661	66
<b>Sub total</b>	51,043	240	-	51,283	62,943

#### A4 Asset and investment purchases, (see table)

	-	-	-	-	
	-	-	-	-	
<b>Sub total</b>	-	-	-	-	-

**Total payments** 51,043 240 - 51,283 62,943

**Net of receipts/(payments)** 18,004 6,735 - 24,739 8,520

**A5 Transfers between funds** - - - - -

**A6 Cash funds last year end** 78,480 240 - 78,720 70,200

**Cash funds this year end** 96,484 6,975 - 103,459 78,720

## 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 £
<b>B1 Cash funds</b>	HSBC	78,309	6,975	-
	Paypal	18,175	-	-
		-	-	-
	<b>Total cash funds</b>	<b>96,484</b>	<b>6,975</b>	<b>-</b>
	(agree balances with receipts and payments account(s))			


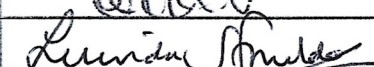
	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-

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

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

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
<b>B5 Liabilities</b>	Independent Examiner		708	
			-	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
	Dawn Golder	30/08/2023
	Lucinda Smulders	30/08/23