



# Trustees' Annual Report for the period

Period start date		Period end date	
<b>From</b>	01 01 2021	<b>To</b>	31 12 2021

## 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	Resigned 10.03.2021	
2	Louyse McConnell-Trevillion	Trustee	Resigned 18.02.2021	
3	Bridget Danielle Mildon	Trustee		
4	Lucinda Sian Smulders	Chair		
5	Robert Wilson Thomas	Trustee		
6	Richard Newland	Trustee	Resigned 19.05.2021	
7	Joyce Davies	Trustee		
8	Abigail Bishop-Laggett	Trustee		
9	Christopher Symeon	Trustee		
10	Vincent Smith	Trustee	Appointed 27.10.2021	
11	Stephen Betteridge-Sorby	Trustee	Appointed 27.10.2021	
12	Helen Bolter	Trustee	Appointed 27.10.2021	

### 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 <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, 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 and Volunteers have undertaken the following courses

- Online GDPR Awareness for Small Charities Course conducted by VSL Training
- 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)**

FND Hope UK had 22 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.

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**

**UK Board**

- We have strengthened our board by recruiting three new additional board members to increase the skill set and diversity.
  - **Vincent Smith** – CEO of Meningitis Research Foundation. Experience of being an international consultant, Chief Operating Officer and Head of Direct Marketing for organisations as diverse as Cancer Research UK and the African Centre for Economic Transformation (Ghana). Charity Strategy experience.
  - **Helen Bolter** - Studying for a Masters at Edinburgh University in: The Clinical Management of Pain. Completed short courses in Fundraising for Charity (University of Kent) and Business and Strategy for Charity (Directory of Social Change). Undergone NHS Level 2 training in Safeguarding of both children and adults. Previous experience in grant-writing and in teaching at undergraduate and postgraduate level.
  - **Stephen Betteridge-Sorby** - Carer for FND Partner. Nurse Consultant & Lecturer in Paediatrics. Held Executive positions in the NHS, Department of Health, Education and Charity Sectors. Appointed Medallist of the Order of the British Empire in the 2021 Queen's Birthday Honours list in recognition of his achievements.

**Medical Expert Committee**

The UK MEC currently comprises of 21 Medical and Allied Health Professionals across the UK

- The UK MEC have undertaken a number of projects during 2021
  - Commenced work on understanding the prevalence of FND which has been estimated to be between 50k and 100k adults in the UK
  - Discussions on how Long Covid patients are experiencing functional symptoms. Research is being done within this area
  - Commenced contacting all CCG's and Health Boards to identify if they are commissioned to treat FND patient, this will run into 2022.
  - UK MEC and FND Hope UK co-signed a letter addressed to the Health Minister in response to a petition which reach over 10k signatures.
  - Support in answering questions raised by our community
  - Discussions on NHS Choices and how we can separate FND from the Medically Unexplained Symptoms.

**myFND app**

- myFND is a mobile application which aims to enable users to understand and self-manage symptoms of Functional Neurological Disorder (FND). First released in May 2020, we now want to fund updates to the myFND app to make it easier to use, more engaging, and better positioned to help people affected by FND.
- The myFND app supports patients who need it most. It enables them to better understand their condition, recognise how their symptoms change, and learn how they can begin to self manage the disorder.
- The project to create the app was led by Dr Chris Symeon, Consultant Neuropsychiatrist, and the multidisciplinary team at The Wolfson Neurorehabilitation Service, St George's University Hospitals NHS Foundation Trust. Throughout the development, the team

consulted with clinicians and service users, along with getting input and evaluation from FND Hope UK and clinical and academic experts in the field. We also solicited support and guidance from DigitalHealth.London and NHS Digital.

- So far, the project has been funded by St George's Hospital Charity and Dr Chris Symeon was seeking further funding to expand the app's functionality and integration in line with direct user feedback.
- The next update of the myFND app will include accessibility improvements, such as additional font size control and dark mode, the ability to track multiple symptoms and push notifications. We will also incorporate additional strategies for self-management techniques and enhance the instructional and resource aspects of the app with an Info Hub website. The instructional/educational content will be searchable and users will be able to apply filters.
- FND Hope UK agreed to support and invest (Nov 2021) in updating the myFND App.

### Online Movement and Wellbeing Programs

We wanted to continue to support those affected by Functional Neurological Disorder (FND) through real-time online programming. FND Hope UK collaborates with Synergy Dance © Outreach to deliver accessible yoga, dance, and Pilates sessions, as well as Art Journaling for Wellbeing and Mindfulness / Meditation sessions. We offer five free interactive sessions every week, providing a low-barrier way to connect with others of all ages and improve physical, emotional, and mental health.

All classes are suitable for all ages and abilities, allowing everyone within our community to take part — even those who are bedbound or in a wheelchair. The sessions are held via Zoom, which is free for participants and platform-inclusive.

We continue to publicise our online programming through our existing channels, including Twitter, Facebook groups, our Peer Support network, and our monthly newsletter.

**125 Movement Classes held in 2021** via Zoom (Yoga, Dance, Pilates, Mindfulness Meditation and Art Journaling for Wellbeing ) providing activities for our community.

### Peer Support Groups

We offered **80 peer support groups** during 2021. With over **150 people** attending between September 2021 and December 2021 to keep our community safe during COVID. With the help and support of 13 volunteers, we organised 1 hour virtual peer groups using our Zoom platform each month in the following areas

- Wales
- England
- Parents
- Ireland / Northern Ireland
- Carers
- East of England
- London

*"Talking to people who understand what it is like will make a difference."*

**Service User**

*"I appreciate other people's experience and how to cope."* **Service User**

Between September 2021 and December 2021 close to **600 people** attended our Online Movement/Wellbeing Classes and Peer Groups.

### Collaboration with The Brain & Spine Foundation

FND Hope UK was delighted to be collaborating with the Brain and Spine Foundation to offer an appointment-based telephone helpline service for our FND community. The service would enable our FND community to speak directly with the Brain and Spine Foundation nurses bringing together two charity organisations specialising in FND who would provide support in a trusted environment.

We agreed to a 3 month pilot period starting on the 2<sup>nd</sup> December 2021 and finishing on 24<sup>th</sup> February 2022.

In collaboration with the Brain and Spine Foundation **52 call-backs** were completed between 2nd December and 23rd December with an average call length of 21.27 mins.

Pilot to continue until February 2022.

Videos released by FND Hope UK during 2021 via the FND Hope You Tube Channel for our #FNDandUS Campaign and FND Awareness Videos reached **94.7k views** with over **978 subscribers**

### #FNDandUS Campaign

- FND Hope UK continued to work closely with Director Mike Rumsey from Rumsey Films where we were able to document the inspiring personal FND journeys of six of our service users. The campaign was a continuation of our successful launch in 2020.
  - Our #FNDandUS Campaign saw over **800k video views** (Facebook, Twitter, Instagram and You Tube) to raise awareness of FND between July 2021 and December 2021 - Ellie, Andy, Summer, Alex, Leah and Brian

### World FND Month

- Encouraged participation from the general public and our FND community in our 9<sup>th</sup> Annual #FNDAware Awareness Campaign World FND Month
- **I'm Still Me** FND Awareness Video
  - Our FND Community, Patron, Medical and Allied Health Professionals, Friends, Families, and Carers have all come together in this video to help raise awareness of Functional Neurological Disorder. We would particularly like to thank Alison Newland our Peer Support Worker and Volunteer for writing and producing the song shown in the video called "I'm still me".
  - This had a reach of over **42,000** views on Facebook, **1,200** views on You Tube

### FND Awareness Videos by Professor Mark Edwards as part of World FND Month

Professor Mark Edwards, Professor of Neurology, St Georges University Hospital alongside Mike Rumsey from Rumsey Films, created 9 different videos to help raise awareness of FND for the general public, FND Community and Medical Community.

With over **6,500** video views on FND Hope You Tube channel, **228,199** impressions on Twitter, and **160,166** reach on Facebook and Instagram.

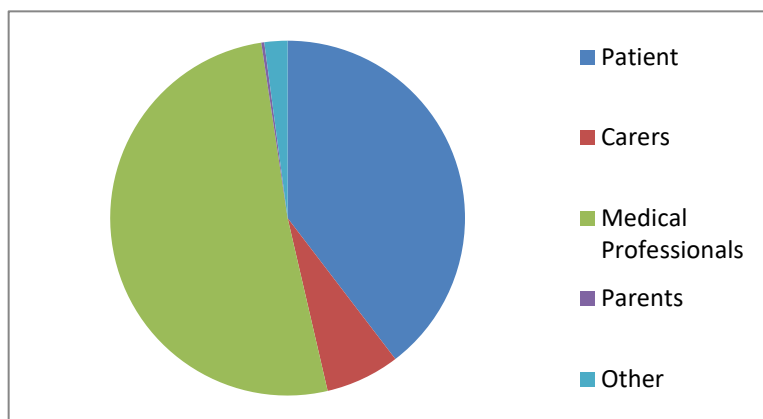
- What is FND
- FND Pathway
- Impact of FND
- Patient Organisations
- FND and Children
- FND Symptoms
- FND Diagnosis Part 1 and Part 2
- FND Treatment Services

### Advocacy and Support

- We responded to over **900 emails** from our community to support them with questions, identifying FND specialists, sign-posting them to resources we have on our website.

### FND Patient Booklets and Leaflets

- During 2021, we distributed **3,287** FND Patient Booklets to our FND community, Carers, Parents, Medical and Allied Health Professionals.



### Keeping our community informed

**9** Virtual Newsletters sent with over **5,000** people opening and reading our newsletters during 2021.

### Research

- Provided a platform via the Research Committee to review research projects and recruit accordingly. FND Hope UK supported **12** UK specific Research Projects.

### Neurological Alliance

- FND Hope UK has been working very closely with the Neurological Alliance and the National Neuro Advisory Group (NNAG) following

the Mental Health and Neuroscience Leaders away day in 2019. NNAG, along with Professor Mark Edwards, Dr Mike Dilley and our Executive Director and other stakeholders groups came together to discuss Functional Neurological Disorder. The outcome of the breakout session identified challenges in accessing appropriate care, support and treatment across the UK so together we developed an Optimal FND Care Pathway. FND Hope UK organised three focus groups with our service users to provide an overview of the pathway, and to obtain feedback. We were joined by members of the Neurological Alliance and Professor Mark Edwards.

- We supported the advertising of the new NeuroLifeNow app which was created by The Brain & Spine Foundation and the Neurological Alliance.
- The Executive Director was part of the working group for the My Neuro Survey which is run by the Neurological Alliance every two years. The aim of the survey is to understand the patient experience in all neurological conditions. The survey ran from October 2021 to Jan 2022 with FND being in the top 5 reported neurological conditions.
- The Executive Director remains co-chair of the policy group which is run every quarter.

#### 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.

#### Social Media

- Our social media presence is increasing year on year  
**19,600** people follow our news on Instagram, Facebook and Twitter.

#### Grants

FND Hope UK was successful in obtaining a Grant from Versus Arthritis for £4680.00 to enable us to continue to offer our online movements classes: Yoga, Dance and Pilates to our FND community free of charge for a 6 month period. The award was granted to start from 1st October 2021 to 31st March 2022.

#### Organising Focus Group for FND Education for Health Care Professionals

FND Hope UK in collaboration with Dr Ania Crawshaw a Neurology Registrar and Clinical Lecturer at St George's University London who is working together with Professor Mark Edwards to develop an online FND education module for healthcare professionals organised focus groups with the FND community to obtain their ideas on developing the project to ensure that patient priorities are included and reflected in the course content. The module is intended to include information about FND (including definition, current understanding about mechanisms, clinical features, positive diagnostic signs and management) and a section focusing on communication skills and language that can be helpful in consultations with patients who have FND.

#### Discussions with MPs



FND Hope UK wrote too many MP's to invite them along to discuss FND to help raise awareness and to inform them of the issues being experiencing by our FND community.

We were able to get the following Parliamentary Questions raised with responses

- **'To ask the Secretary of State for Health and Social Care, what plans he is putting in place to ensure consistent guidance and definition for the neurological condition 'Functional Neurological Disorder' across the NHS'. Dr Lisa Cameron, SNP and Chair of the APPG for Disability**

Answered 29.04.2021 - People with functional neurological disorder (FND) are likely to be diagnosed under a local clinical commissioning group care pathway and therefore any data would only be collected a local level. There are presently no specific plans to further ensure the collection of data on the number of patients with FND.

- **'To ask the Secretary of State for Health and Social Care, pursuant to the Answer of 29 April 2021 to Question 184486 on Functional Neurological Disorder, what plans are in place to ensure consistent coding and recording among CCGs and Health Boards of Functional Neurological Disorder through a nationally agreed data code and definition'? Dr Lisa Cameron – SNP and Chair of the APPG for Disability**

Answered 20 May 2021 - There are currently no specific plans to do so. The Department is currently funding research projects into functional neurological disorder through the National Institute for Health Research, which will improve understanding of the condition

- **'To ask the Secretary of State for Health and Social Care, what plans are in place to fund and deliver a national NHS care pathway for functional neurological disorder'? By Peter Dowd, Labour**

Answered 20 May 2021 - The National Neuro Advisory Group (NNAG), which includes NHS England and NHS Improvement, Public Health England, expert bodies, clinicians, academics, and patient voice organisations, develops and coordinates the national programme of neurology service improvement. The NNAG has a priority in their work plan for 2021/2022 to support development of a clinical pathway for functional neurological conditions, including functional neurological disorder.

- **'To ask the Secretary of State for Health and Social Care, what assessment he has made of the need for specific NICE guidance for the diagnosis and treatment of functional neurological disorder'? By Peter Dowd, Labour**

Answered 24 May 2021 - The National Institute for Health and Care Excellence (NICE) has guidance in place to support clinicians in the diagnosis of functional neurological disorder. The 'Suspected neurological conditions: recognition and referral' guideline published in 2019 covers the initial assessment of symptoms and signs that might indicate a neurological condition. It helps healthcare professionals to identify people more quickly who should be offered referral for specialist investigation and includes recommendations for people **who** have previously been diagnosed with functional neurological disorder. The guideline is available at the following link: [www.nice.org.uk/guidance/ng127](http://www.nice.org.uk/guidance/ng127)(opens in a new tab)

## Section D

## Achievements and performance

### Neuro Convention at the NEC

FND Hope UK attended the Neuro Convention on the 15th and 16th September 2021 to help raise awareness of Functional Neurological Disorder.

We held discussions with Occupational Therapists, Physiotherapists, Charities, members of our community and many other Allied Health Professionals highlighting the great work we are doing, how we support our community and much more.

### Partnership with Irwin Mitchell

FND Hope UK partnered with Irwin Mitchell Solicitors to organise a Financial Wellbeing Webinar on Monday 13th August 2021

The webinar consisted of discussing

- Cashflow planning
- Pensions
- Managing income and expenditure
- Dealing with debt
- Navigating these tools in exceptional circumstances.
- 

The webinar also explored how our community can ensure DWP understands how their condition affects them on a day-to-day basis, including:

- Understanding the DWP Criteria
- Knowing when to apply for benefits
- What medical evidence is relevant to support the application
- General tips on how to complete benefit application forms.

## 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: £71,463  
Net Surplus: £8,520

Total Funds: £78,720


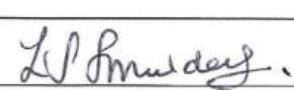
## Section F Other optional information

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	8/07/22	



# CHARITY COMMISSION FOR ENGLAND AND WALES

## 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 2021

**Charity no  
(if any)**

1173607 &  
SC048333

**Set out on pages**

1 to 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 31/12/2021.

**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").

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.

**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 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:**

21 July 2022

**Name:**

Frances Julie Wilde

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

FCCA, DChA

**Address:**

4 Marigold Drive

Bisley

GU24 9SF



CHARITY COMMISSION  
FOR ENGLAND AND WALES

FND Hope UK

1173607 &  
SC048333

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## Receipts and payments accounts

For the period from	01/01/2021	To	31/12/2021
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### Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
<b>A1 Receipts</b>					
Donations and Legacies	66,783		-	66,783	43,099
Grants		4,680	-	4,680	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	66,783	4,680	-	71,463	43,099
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	-	-	-	-	-
<b>Total receipts</b>	66,783	4,680	-	71,463	43,099
<b>A3 Payments</b>					
Charitable activities	24,499	2,940	-	27,439	1,660
Marketing and brochures	8,448	-	-	8,448	11,735
Training costs	1,969	1,500	-	3,469	791
Office costs	3,466	-	-	3,466	4,505
Legal and professional fees	6,086	-	-	6,086	1,537
Accountancy	612	-	-	612	600
Subscriptions	869	-	-	869	678
Venue hire, hotel and accommodation	823	-	-	823	372
Insurance	844	-	-	844	986
Bank charges and interest	821	-	-	821	-
Grants returned	10,000	-	-	10,000	-
Sundry expenses	66	-	-	66	-
<b>Sub total</b>	58,503	4,440	-	62,943	22,864
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	-	-	-	-	-
<b>Total payments</b>	58,503	4,440	-	62,943	22,864
<b>Net of receipts/(payments)</b>	8,280	240	-	8,520	20,235
<b>A5 Transfers between funds</b>	-	-	-	-	-
<b>A6 Cash funds last year end</b>	70,200	-	-	70,200	49,965
<b>Cash funds this year end</b>	78,480	240	-	78,720	70,200

## 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	71,462	240	-
	PayPal	7,018	-	-
		-	-	-
	<b>Total cash funds</b>	<b>78,480</b>	<b>240</b>	<b>-</b>
	(agree balances with receipts and payments account(s))			

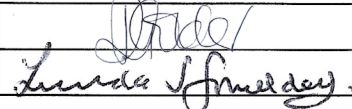
	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	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	IE Fee		666	
			-	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
	Dawn Golder	12/07/22
	Cindy Smulders	