



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 1.4.23 Period start date To 30.06.24 Period end date

Charity name: Forgotten Patients, Overlooked Diseases

Charity registration number: 1202442

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	<p>The Trustees of Forgotten Patients, Overlooked Diseases (FPOD) present their annual report and accounts for the first 15 months of the CIO's existence, and confirm that reporting complies with FPOD's governing document, Charities SORP (FRS 102), and relevant legislation.</p> <p>FPOD aims to develop resources for people with medically unexplained symptoms (MUS), overlooked health issues, or common unresolved health problems; provide support/signposting for patients & families not being helped elsewhere; facilitate or deliver research, and support the dissemination and/or application of the useful results of such, for the public benefit; promote knowledge in, and advance knowledge of medically unexplained symptoms, overlooked health issues, or common unresolved health problems. The term "overlooked diseases" refers to conditions for which there may be limited medical education or interest among healthcare professionals, providers, researchers, industry or government bodies.</p> <p>FPOD helps people with complex symptoms to find a diagnosis and access support. Modern healthcare can do so much, yet some people with undiagnosed complex symptoms may not receive potentially beneficial health interventions. Even people with common diseases can be overlooked. Organizations exist to support individuals with specific rare diseases, but those with unrecognised or incorrectly categorised diseases lack the support that disease-specific organizations can provide.</p> <p>FPOD's charitable activities aim to change that situation, by</p> <ul style="list-style-type: none">• developing practical, accessible resources for people trying to cope with the uncertainty of overlooked health issues• providing support/signposting for patients and families who are not being helped elsewhere• facilitating, sponsoring or delivering research• promoting education• encouraging the adoption of research findings.

Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	<p>FPOD's activities focussed on advancing knowledge of MUS, for those personally affected by MUS, and for their healthcare providers. As well as helping to raise general awareness of MUS and the often protracted search for diagnosis experienced by some patients, FPOD's activities increased the visibility of the charity, and generated significant feedback. Activities included -</p> <ul style="list-style-type: none"> • free educational webinar "Forgotten Patients, Overlooked Diseases and Lost Health Solutions". • "Medically Unexplained Symptoms" conference • publications in professional journals • production of a patient guide "How to make the most of your GP visit" • a survey relating to hyper-mobility • Engagement with EURORDIS (European Organisation for Rare Diseases) <p><i>Note: MUS is the term used in FPOD's Constitution. However there are other terms, such as persistent physical symptoms (PPS), used with reference to the long journey in search of diagnosis, which is experienced by some patients.</i></p>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	In setting objectives, trustees considered the Charity Commission's guidance on public benefit. FPOD's charitable activities benefit those affected by medically unexplained symptoms, overlooked health issues, or common unresolved health problems. As well as individuals who are personally affected, this includes their families and/or carers, and medical professionals involved in their treatment.

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	Grant-making is not part of FPOD's charitable aims/activities.
Policy on social investment including program related investment	Para 1.38	Social investment is not part of FPOD's charitable aims/activities
Contribution made by volunteers	Para 1.38	<p>FPOD values the contribution made by volunteers, who are essential to the charity's operation. 78 volunteers gave c.2000 hours to FPOD. A breakdown of the estimated hours is in the Annual Report. This does not give economic value to their contribution, but illustrates that FPOD could not provide projects or activities without the input of volunteers.</p> <p>FPOD volunteers include health and social care professionals, scientists, academics, ethicists, and people with medical conditions.</p>
Other		

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	<ul style="list-style-type: none"> • “Medically Unexplained Symptoms”: conference, addressing the impact of MUS on healthcare providers, and patients trying to navigate the healthcare system. • Patient Guide: make the most of your GP visit. • “Forgotten Patients, Overlooked Diseases and Lost Health Solutions”: educational webinar • Presentations at the Institute of Medical Ethics Annual Conference “Being Heard” • established contact with bodies such as the Community Engagement Task Force (CETF) initiated by EURORDIS (European Organization for Rare Diseases). CETF is a multi-stakeholder group of scientists and clinicians. • The Zebra Survey: issues around hyper-mobility <p>Publications:</p> <ul style="list-style-type: none"> • Noble B, Tookman A, Schmechel C, Stephens R, Oesterling C, Jani K, Speck P, Diehl-Wiesenecker E, Chrysostomou K, Walker S. The Challenge of Diseases and Forgotten Patients. RCGP Life, 12th August 2022. http://bit.ly/3A8ryua (accessed 1st November 2022) • Lifschitz, Carlos MD*; Walker, Steven MD†; Tookman, Adrian MD‡. Awareness of Tissue Disorders and Functional Gastrointestinal Diseases. Journal of Pediatric Gastroenterology and Nutrition 77(6):p e115, December 2023. DOI: 10.1097/MPG.0000000000003947 • Goa, Ivy; Jani, Kiran; Patel, Chantal; Oesterling, Christine; Tookman, Adrian; Walker, Steven. Update on rare diseases and genetic testing. RCGP Life (published 17th February 2024) http://tinyurl.com/3uzvzz6c • Forrest, Christianne; Speck, Peter; Rajput-Ray, Minha; Tookman, Adrian; Walker, Steven. Medically unexplained symptoms: Four perspectives. RCGP Life (published 4th March 2024) https://shorturl.at/zrXdh • Tookman, A; Verma, J; Forrest, C; Chrysostomou, K; Stephens, R; Walker, S. Rapid Response to Richards T. BMJ Opinion: Not “all in the mind”. BMJ 2024; 385:q1210. https://shorturl.at/6kcCk <p>Abstracts/posters</p> <p>Samira Nur, James Coultas, Louise Jones, Christine Oesterling, Adrian Tookman, Steven Walker, British Journal of General Practice 2024; 74(suppl 1): bjgp24X738093. DOI: 10.3399/bjgp24X738093</p> <p>Activities have elicited significant feedback, demonstrating the impact of these pieces of work, and expanded FPOD’s visibility to other groups who are working in this area. It is hoped that this will lead to FPOD being able to develop appropriate resources in the future, for forgotten patients and people with overlooked diseases.</p>

Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	<p>FPOD's main objectives for the first 2 years of operation are :</p> <ul style="list-style-type: none"> • to raise the visibility of FPOD among those whose lives are affected by overlooked health issues, so that they recognise FPOD as a reliable source of support and signposting; • to establish & maintain FPOD's reputation among healthcare professionals & providers, researchers, industry, government bodies. This may be achieved by delivering research encouraging the adoption of research findings. <p>The response to events and publications indicates that FPOD is meeting its objectives.</p>
Performance of fundraising activities against objectives set	Para 1.41	<p>No specific objectives were set, for fundraising activities. The one-day conference on 1.5.24 produced some income from ticket sales, but the primary intention was to ensure that as many people as possible had access to the wide-ranging discussion of topics on the programme.</p>
Investment performance against objectives	Para 1.41	Not applicable
Other		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	<p>FPOD's accounts have not been independently examined, as income has been less than £25,000.</p> <p>At the end of the reporting period, FPOD's financial situation was in deficit, due to expenditure on the one-day conference which took place on 1.5.24. An interest-free loan of £1500 was made to FPOD by St Gilesmedical Ltd, to pay the deposit relating to the conference. St Gilesmedical was subsequently appointed to act as an agent for FPOD, paying other costs relating to the conference directly: those costs totalled £3617. The total interest-free loan was £5117, of which £525 has been repaid. The remaining debt of £4592 will be repaid in instalments, over a period of 36 months. £420.69 was retained in FPOD's current account., to meet any minor expenditure.</p> <p>Trustees are aware of concerns about a loan from a trustee, and have taken steps to protect the charity:</p> <ul style="list-style-type: none"> • Confirmed FPOD's Constitution permitted the borrowing; • Concluded that the loan was necessary, as the conference would enable FPOD to carry out its charitable purposes more effectively; • Recognized the potential conflict of interest, implicit in accepting a loan from another trustee, and will abide by FPOD's Conflict of Interest policy and Risk Management policy; • The loan totalling £5117 is documented, and will be repaid in instalments. Repayment in full should be completed within 36 months of 1.5.24; • Trustee Dr Steven Walker, Scientific Director of St Gilesmedical, will absent himself from discussion relating to the debt, and has added the loan to his Declaration of Interests. All trustees ensure that their declaration is updated to reflect any changes in their situation, which may affect FPOD.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	FPOD's future reserves policy will reflect the intention to hold reserves sufficient to allow FPOD to continue operating for a minimum of 3 months, in the event of an unplanned closure, so that essential services are maintained for beneficiaries, until alternative support is located.
Amount of reserves held	Para 1.22	Nil
Reasons for holding zero reserves	Para 1.22	FPOD has not secured sufficient income, to be able to allocate any amount, for reserves. At present, FPOD has no regular overheads, as the charity has neither premises nor employees.
Details of fund materially in deficit	Para 1.24	As detailed above, FPOD's financial situation was in deficit at the end of the reporting period, with a debt of £4592 owed to St Gilesmedical.
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	Trustees do not believe that there is any uncertainty about FPOD's future as a going concern.

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	
Investment policy and objectives including any social investment policy adopted	Para 1.46	FPOD does not have an investment or social investment policy
A description of the principal risks facing the charity	Para 1.46	<p>The main risk facing FPOD is the difficulty of securing income. This does not threaten FPOD's existence as such, as FPOD currently has no regular overheads, but it could restrict possibilities for growth and development. We need to secure core funding, so that FPOD has some operating stability.</p> <p>Trustees are seeking someone to take a lead on fundraising, as a member of the board of trustees</p>
Other		

Structure, Governance and Management

Description of charity's trusts:		<p>FPOD is an independent charity without a parent body or subsidiary bodies, not part of any wider group structure. FPOD is a CIO with voting members other than its trustees. Membership is open to anyone who is interested in furthering FPOD's purposes.</p> <p>FPOD aims to develop resources for people with medically unexplained symptoms, overlooked health issues or common unresolved health problems, by</p> <ul style="list-style-type: none"> • developing practical, accessible resources for people trying to cope with the uncertainty of overlooked health issues • providing support/signposting for patients and families who are not being helped elsewhere • facilitating, sponsoring or delivering research • promoting education • encouraging the adoption of research findings.
Type of governing document (trust deed, royal charter)	Para 1.25	FPOD's governing document is a Constitution
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	FPOD is constituted as a CIO.
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	<p>FPOD welcomes expressions of interest, about becoming a trustee. After initial discussion with the Chair & trustees, 1) to ensure the applicant is eligible to be a trustee, and not disqualified from trusteeship, by any provisions in FPOD's Constitution, or the Charities Act 2011; 2) to ensure that the applicant understands the functions and duties of a charity trustee. To that end, the applicant would be provided with FPOD's Constitution, FPOD Trustees Code of Conduct, and the most recent Annual Report & Accounts. That would enable the applicant to make an informed decision, whether they want to proceed.</p> <p>At the AGM, members would be invited to vote on the appointment as a trustee, of the applicant.</p> <p>No external body or individual is entitled to appoint any FPOD trustees.</p>

Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	<ul style="list-style-type: none"> • Trustees' Code of Conduct • Trustees' Conflict of Interests Policy & Procedure • Finance Policy (including Trustee Expenses) • Risk Management Policy
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The charity's organisational structure and any wider network with which the charity works	Para 1.51	<p>With no employees yet, FPOD trustees are gradually assembling a structure that will allow the charity to develop in the future, when finances permit.</p> <p>FPOD works closely with the Forgotten Patients, Overlooked Diseases Advisory Forum, a multi-disciplinary group of health and social care professionals, public health experts, academics, scientists, ethicists, people with illness or medical conditions, spiritual care-givers, politicians, and campaigners with an international perspective. The Forum meets remotely, once a month.</p> <p>"Forgotten Patients, Ideas and Diseases Group" (as the FPOD Advisory Forum was initially known) was formed in early 2021, with 19 founding members: the Group developed into an innovative international network with 42 current members, whose strategy is to explore example diseases, using a holistic, multi-disciplinary approach, which could then be applied to other conditions. Among health problems of current interest to Forum members are Ehlers-Danlos syndrome//hyper mobility spectrum disorders, porphyria, fibromyalgia, and eosinophilic disease of the gastrointestinal tract.</p> <p>The FPOD Advisory Forum aims to make a measurable difference to the lives of forgotten patients, by drawing attention to overlooked diseases, ideas & initiatives benefitting affected individuals.</p>
Relationship with any related parties	Para 1.51	<p>St Gilesmedical Ltd - a science writing, health film, medical education & research company: Scientific Director Dr Steven Walker is a FPOD trustee. St Gilesmedical provides some administrative support for FPOD, on a voluntary basis.</p> <p>St Gilesmedical has made an interest-free loan to FPOD. The loan and its management is detailed in the Financial Review section of this form.</p>
Other		

Reference and Administrative details

Charity name	Forgotten Patients, Overlooked Diseases
Other name the charity uses	None
Registered charity number	1202442
Charity's principal address	c/o Suite 616 The Shepherds Building Charecroft Way London W14 0EE

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	Adrian Tookman	Chair	Not applicable	Not applicable
2	Steven Walker	Secretary	Not applicable	Not applicable
3	Fiona Strathern Lapraik		Not applicable	Not applicable
4	Richard Stevens		Not applicable	Not applicable
5	Jacques Tamin		Not applicable	Not applicable

Corporate trustees – names of the directors at the date the report was approved

Director name		
No corporate trustees		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	
None		

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	No funds held as custodian trustees on behalf of others
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	Not applicable
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	Not applicable

Additional information (optional)

Names and addresses of advisers (Optional information)

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

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Exemptions from disclosure

Reason for non-disclosure of key personnel details

Not applicable

Other optional information

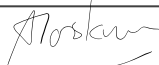
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Declarations

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

Signed on behalf of the charity's trustees

Signature(s)

	
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Full name(s)

Adrian Tookman	
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Position (eg
Secretary, Chair, etc)

Chair	
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Date

17.02.2025

Forgotten Patients, Overlooked Diseases (Registered Charity no. 1202442) : Accounts for 22.3.23 - 30.6.24									
INCOME			£			LIABILITIES		£	£
	Membership Fees		140			StGilesmedical Ltd	Loan	1500	
	Just Giving Donations		103				Conference expenditure *	3617	
	Other Donations		600						
	Conference Tickets		524				Partial repayment of loan		525
	Loan from StGilesmedical Ltd.		1500						
						Total still owed to StGilesmedical Ltd		4592	
		TOTAL	2867						
EXPENDITURE									
	Conference								
		Deposit (paid 11.10.23) ^^	1105						
		Artwork (paid 11.10.23) ^^	300						
		Accommodation (guest speakers) *	340						
		Balance of Delegate Package *	1575			Notes			
		Room Hire with Laptop *	260			* Payments made directly by St Gilesmedical Ltd.			
		CPD Approval *	78			acting as agent appointed by Forgotten Patients,			
		Sound Engineer *	535			Overlooked Diseases			
		Printing *	351			^^ Payments made by Forgotten Patients,			
		Name Badges *	15			Overlooked Diseases (from StGilesMedical loan)			
		Advertising *	300						
		Sundries *	27						
		Travel *	61						
		Banners *	75						
		Charity launch event	500						
	Test payment		3						
		TOTAL	5525						