



# Trustees' Annual Report

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YEAR ENDING 30 SEPTEMBER 2025

## **Forgotten Patients, Overlooked Diseases**

ADVANCING HEALTH FOR FORGOTTEN PATIENTS AND OVERLOOKED DISEASES, CHARITY  
NUMBER: 1202442 CHARITY ADDRESS: SUITE 616, THE SHEPHERDS BUILDING,  
CHARECROFT WAY, WEST KENSINGTON, LONDON |

## Introduction from the Chair

The past year has been one of significant development and growing recognition of the challenges faced by individuals with medically unexplained symptoms and overlooked diseases, specifically those navigating prolonged and uncertain diagnostic pathways.

Addressing these issues is a high-impact, cost-effective, and ethical imperative to reduce inequality and human suffering.

To help individuals navigate the healthcare system, achieve optimal outcomes, and reduce avoidable distress and delay, our focus remains on:

- Developing resources for people with overlooked health issues,
- Providing practical support and signposting for patients and families who are not being helped elsewhere,
- Facilitating, sponsoring, and delivering research,
- Promoting education, and
- Encouraging the adoption of research findings

During the year, the charity worked with patients, advocates, clinicians, researchers, and policymakers in the UK and internationally, ensuring that patient experience informs education, research, and advocacy.

At this early stage in the charity's development, it is naturally challenging to measure the full impact of the actions taken so far. However, we anticipate significant progress and growth in the coming period as our reach continues to expand.

## Our Achievements in 2024–2025

### 1. Presentations and Outreach

- I. FPOD Annual Conference (June 2025) – Held in partnership with the Guild of Health Writers, following high profile media attention on overlooked patient experiences. Several members presented their work, alongside patient representatives who shared their experiences, to raise awareness among healthcare writers and professionals.
- II. European Society of Emergency Medicine Podcast (July 2025) – FPOD delivered a presentation on fair treatment for patients with medically unexplained symptoms at a European forum in Vienna led by Dr. Bernard Foex, receiving excellent feedback and prompting further discussion on equitable emergency care.

- III. Representatives of FPOD were invited to speak at the Royal Society of Medicine's 44th Annual General Practice and Primary Care Update (September 2025), reflecting growing recognition of the charity's expertise in this area.



## 2. Collaboration with European and UK Agencies

- I. FPOD representatives were privileged to be invited to join EURODIS, a European organisation that empowers and advocates for people living with a rare disease in Europe. Joined to learn best practice and share patient-led insight relevant to overlooked and hard-to-diagnose conditions.
- II. We connected with KAL Research Initiatives to understand innovative diagnostic coding approaches, including the R69 initiative, to make diagnostic uncertainty visible in health records. The aim is that patients with hard to diagnose conditions can receive better tracking, support, and ultimately faster diagnoses.
- III. We connected with UK agencies including the NHS Rare Diseases Advisory Group, Mast Cell Action, and other charities, contributing patient experience and practical insight to collaborative discussions.
- IV. We contributed to parliamentary advocacy addressing the “fabricated illness” label which delays diagnosis in the paediatric population, highlighting the adverse impact on children and families.

### 3. Research and Publications

- I. Participated in multiple research projects, including studies on frequent hospital attenders, providing patient-centred perspectives and advisory input.
- II. Published and contributed to peer-reviewed articles (Tookman et al, 2025) on overlooked diseases, medically unexplained symptoms, and “forgotten patients”, supporting evidence-based discussion and improved understanding among professionals.
- III. Developed a PROSPERO-registered narrative review proposal on medical gaslighting. The proposal has since been accepted and the research is ongoing in conjunction with UCL and Imperial College, London.

### 4. Practical Resources and Website

- I. Further developed the charity’s website, which is freely accessible, now offering detailed patient guides and practical tools to help individuals manage healthcare visits and advocate for themselves effectively.
- II. Expanded signposting resources, empowering patients to access appropriate support, guidance, and relevant organisations at no cost.
- III. Early informal feedback indicates increased confidence among users when preparing for clinical appointments and discussions.

### Plans for 2025–2026

#### Key priorities include:

- Digital resources and storytelling – Continue to collect a series of patient stories, to share learning on the successful routes to diagnosis.
- Research and evidence – Develop a research programme to explore the use of patient stories in scientific research. The aim is to understand where diagnostic pathways fail, the potential value of symptom cluster identification, emerging management approaches and the potential role of artificial intelligence in successful diagnosis.
- Engagement and reach – Leverage social media to drive traffic to the website, share expertise, and connect patients with holistic support. Continue to enhance and develop useful online resources for patients via the website.

## Education, research, and innovation –

- Build and deliver a multidisciplinary hybrid conference, conference report and filmed summary.
- Complete a PROSPERO registered systematic review on patients and doctors' experiences of 'Medical Gaslighting' in underdiagnosed conditions for submission to a peer reviewed journal.
- Submit a response to the December 2025 editorial on Persistent Physical Symptoms, published in the Future Health Journal, outlining a call-to-action for the acknowledgement and legitimisation of, and official coding for, clinical diagnostic doubt for patients with PPS.

## Collaboration and learning –

Connect with other organisations to learn from patient experiences and international best practice, to improve signposting and guidance and to consolidate learning.

## Fundraising and sustainability –

Develop a focused fundraising strategy to secure sustainable funding to support the charity's work.

## Governance and capacity –

Strengthen governance structures to support the charity's growth and long-term sustainability.

## Public Benefit

All the charity's activities are undertaken to relieve sickness and suffering among people affected by overlooked diseases and medically unexplained symptoms by:

Providing free, practical support and signposting for individuals and families who may otherwise struggle to access appropriate guidance.

Developing openly available resources and guides that empower patients to navigate complex healthcare systems, communicate effectively with clinicians, and make informed decisions.

Promoting education, research, and knowledge-sharing among professionals and the wider public, contributing to improved understanding of diagnostic uncertainty and patient experience with the long-term aim of finding solutions.

As a small but growing charity, our focus in 2026 remains on strategic influence and partnership working rather than direct service delivery at scale.

## Financial Review

The charity operated a receipts and payments system of accounting during the year.

Summary of financial position for the year ended 30<sup>th</sup> September 2025:

Receipts: £1,242

Payments: £846

Assets: £836

Liabilities: £4,592

Receipts for the year include membership fees, donations, and sales proceeds of conference tickets. The expenditure in the period has been external conference expenses only. The charity's other running costs were nil as trustees voluntarily absorbed minor administrative costs during the year.

The liabilities include conference expenses initially funded by an interest-free loan from St Giles Medical Limited. The director of St Giles Medical Limited is also a trustee of the charity and, accordingly, this arrangement constitutes a related party transaction. The trustee concerned declared their interest and did not participate in the discussion or decision-making relating to this arrangement.

The loan is repayable on or before 02.04.2031. St Giles Medical Limited has formally confirmed that it will not demand repayment of the loan at any time when to do so would prejudice the charity's ability to continue its operations or meet its liabilities as they fall due.

Having considered this agreement, together with the charity's overall financial position, the trustees (excluding the conflicted trustee) are satisfied that the charity remains a going concern and is able to meet its liabilities as they fall due.

## Structure, Governance and Trustee Information

Forgotten Patients, Overlooked Diseases is a charity registered as a Charitable Incorporated Organisation on 22<sup>nd</sup> March 2023 and governed by written constitution.

There are currently 5 trustees and 15 members and a pool of some 80 attendees from a wide range of backgrounds. The trustees are:

Dr Adrian Tookman MB BS FRCP

Dr Steven Walker

Richard Stephens

Jennifer E. McCallum, PhD (appointed 29<sup>th</sup> October 2025)

Rosalind Caffyn (appointed 29<sup>th</sup> October 2025)

Fiona Lapraik (resigned in year)

Dr Jacques Tamin PhD (resigned in year)

Decisions are guided by the charity's trustees and strengthened by the support of its broad and engaged membership. The board brings together a diverse range of expertise, including distinguished healthcare professionals, dedicated patient advocates, experienced medical writers, and finance specialists, ensuring well-informed and balanced leadership.

The board identifies the need for new trustees by reference to skills gaps, activity expansion, trustee rotation and potential resignations. Candidates are sought principally via recruitment platforms and networking. The appointment and induction of new trustees is carried out in accordance with the governing document.

The current intention is to strengthen the board further with fundraising expertise and a suitable candidate is being actively sought.

## Declaration

The trustees have approved this report and confirm that it complies with UK charity law.

## Acknowledgements

We thank all members, volunteers, and supporters whose expertise and dedication have made this progress possible. Special recognition goes to Steven Walker and team, whose organisational skills have been key to managing this complex, international area of work successfully.

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Adrian Tookman MB BS FRCP

Chair, Forgotten Patients, Overlooked Diseases

Date: January 2026

## References to publications

**\*The challenge of medically unexplained symptoms, overlooked diseases and forgotten patients.** Published in BJGP Life. Bill Noble, Adrian Tookman, Carmen Schmechel, Richard Stephens, Christine Oesterling, Karim Jani, Revd Peter Speck, Eva Wiesenecker, Katia Chrysostomou, Steven Walker. Aug 2022

**\*The challenge of persistent physical symptoms.** BJGP Analysis Paper. Adrian Tookman, Jay Verma, Eva Diehl-Wiesenecker, Richard Stephens, Jennifer E McCallum, Ursula Unterberger and Steven Walker. December 2025



**Forgotten Patients, Overlooked Diseases****Registered Charity no: 1202442****Year ended 30.09.25**

Receipts and Payments	£	Assets and Liabilities	£
<b>Receipts</b>		<b>Cash at bank</b>	
Membership Fees	120	Brought forward	441
Just Giving Donations	745	Receipts	1,242
Other Donations	200	Payments	<u>(846)</u>
Conference Tickets	177	Carried forward	<u>836</u>
	<u>1,242</u>		
<b>Payments</b>		<b>Loan</b>	
Conference: Room	(300)	Brought forward	(4,592)
Audio Visual	(250)	Movements in year	<u>-</u>
Printing	(90)	Carried forward	<u>(4,592)</u>
Food	(128)		
CPD Approval	(78)		
	<u>(846)</u>		
<b>Net receipts / (payments)</b>	395		

**Basis of Accounting**

Accounts are prepared on a receipts and payments basis.

All funds are unrestricted.

**Related Party Transaction**

During the last accounting period ending 30.09.2024, the charity received a loan from St Giles Medical Limited of £5,117. One repayment instalment of £525 was made during the same period.

Dr Steven Walker, one of the trustees of the charity is also a director of the company that made the loan.

At the start of the year, the balance outstanding was £4,592. During the year, no sums were advanced or repaid. At the year end, the balance outstanding was £4,592.

The loan has been made interest-free, is unsecured and there is an agreement in place between the company and the non-related party trustees of the charity that the loan is not repayable before 02.04.2031

All loan decisions have been made by the charity's trustees in the absence of the related party trustee. The arrangement was authorised in accordance with the charity's governing document and relevant legal requirements