

Chairperson's Report

A message from our Chair

As I approach my 10th year as chairperson for PoTS UK, it is a pleasure to reflect on the changes, successes and challenges the charity has faced since it started in 2010.

Having developed our 3-year strategy in 2023-24, this year has been clearly focussed on forging ahead with our aims and goals. 2024-25 has been as busy as ever and we are proud of our achievements. As always, my primary thanks must go to our wonderful community who support us in so many ways. It has been another successful year for fundraising and we extend our heartfelt thanks to everyone who has fundraised or donated. We hosted our first PoTS UK celebration event in February 2025, and it was a joy to join together staff, fundraisers, medical advisors and volunteers to celebrate the positive impact they have on our charity.

There are many highlights from the past year, but I would like to pay particular attention to the following:

Parliamentary Campaign - Compared to this time last year, we feel the awareness of PoTS within UK governments and the NHS has increased significantly and ultimately, this will lead to positive change. In what must be our best team effort to date, the PoTS community came together in their support for our parliamentary campaign and managed to reach out via email to 575 of 650 MPs. In total, 2295 emails were sent, and we were delighted to be told by one MP that he has never received so many emails on one topic. This is something to be proud of and shows the strength in numbers! We must all play our part.

It was a pleasure to visit Portcullis House alongside a team of trustees, nurse specialists, consultants and staff to meet MPs to discuss inequitable access to healthcare for people with PoTS. MPs were given clear actions to take away and we are very grateful to those MPs who have shown interest and support.

Communications and responses from the Department of Health and Social Care are inaccurate, unhelpful and lacking in any guaranteed action. It mirrors the poor response to the January GOV.UK petition. Despite requesting a meeting, the DHSC has refused to meet with us due to time constraints. We will continue to respond and challenge them. I must say a special thank you to Sophie West who launched the petition and has shown such determination and strength in pushing it forward.

In July 2022, Jane Clarke initiated a petition to the Scottish Parliament requesting better services for people with dysautonomia. We have been working with Jane and Chest Heart Stroke Scotland to challenge the Scottish Government and NHS Scotland's false claims that there are high quality services and national guidelines available. This work is ongoing. All responses to date can be found here: <https://petitions.parliament.scot/petitions/PE1952> or <https://www.parliament.scot/get-involved/petitions/view-petitions/pe1952-specialist-services-for-patients-with-autonomic-dysfunction>

As health is a devolved matter in Scotland, Wales and Northern Ireland we need to ensure we are reaching out to the Members of the Scottish Parliament (MSPs), Members of the Senedd (MSs) and Members of the Legislative Assembly (MLAs). This will form part of our work in 2025/26.

We are forever reminded that our challenges are a marathon, not a sprint and this could not be truer than in the case of improving services. We know changes won't happen overnight but there has been a palpable shift in awareness and strides are being taken in the right direction.

Training Event for Healthcare Professionals – In March 2024, we were delighted to host a hybrid educational training event, attended by over 300 nurses and healthcare professionals to learn more about Autonomic Dysfunction including diagnosis, management and treatment. It is always fantastic to have the opportunity to raise awareness and knowledge amongst healthcare professionals and we continue to encourage trusts, ICBs and health boards to reach out to us to deliver this important education.

National PoTS guidelines would improve awareness, understanding of PoTS, and access to healthcare. It was a pleasure to meet with a team of PoTS experts in October 2024 to drive this forward and we hope that 2025/26 will show significant progress in this area.

I remain very proud of our **Peer Support Group** programme that have been running for almost 4 years now. Our team of volunteers has grown again throughout 2024/25, and they are committed, caring and compassionate. They dedicate time to not only run the groups but also to review and reflect on what changes could be made to improve them. We have been pleased to answer requests for topic groups on Neurodiversity, LGBTQIA+, and living with PoTS over the age of 50. The groups are diverse, inclusive and safe spaces. I encourage everyone to attend and see how our hosts can put you at ease and make the group work for your needs.

As always, I extend my thanks to our administrative team and my fellow trustees who all share the same passion, drive and determination. 2024/25 has welcomed lots of new volunteers and I am grateful for the role played by each individual.

I look forward to the year ahead. We are working towards holding an educational Masterclass in 2026, bringing together our community at a patient event and continuing to push our parliamentary campaign in order to improve services.

Raising awareness is at the heart of what we do and what we need to achieve. I urge everyone to reflect on what part they can play and not to underestimate the value in sharing social media posts, sharing your story and answering surveys to help us grow our pool of data that is an invaluable resource.

The annual report includes further information on the financials aspects, further achievements and a look ahead to the next year.



Dr Lesley Kavi

PoTS UK

Trustees Annual Report

2024 – 2025

Charity Overview

Name of the Charity: PoTS UK.

Registration number: 1159813, Charitable incorporated organisation (from 6 Jan 2015).

Address: Oakfield Cottage, Stratford Rd, Wootton Wawen, Henley-in-Arden B95 6DF.

Trustees:

Dr Lesley Kavi (Chair)

Lisa Bradford (Treasurer)

Dr Morwenna Opie-Moran

Michaela Nuttall RN

Chloe Smerklo

General Manger:

Joanne Bullingham

Charity Administrators:

Denise Chapman

Nikki Mills

Medical advisors:

Dr Nick Gall

Prof Julia Newton

Dr Arnold Deering

Dr Satish Raj

Dr Blair Grubb

Dr Ian Wilkinson

Dr Jane Simmonds

Melloney Ferrar

Helen Eftekhari

Prof Melvin D Lobo

Dr Sam Waterman

Dr Robert Sheldon

Medical patrons and supporters:

Dr Nick Gall

Prof Michael Gammage

Cat Smith MP

Dr Philip Hammond

Adam Jacobs

Peter Capaldi

Primary Bankers:

NatWest Bank

Royal Bank of Scotland (Reserves Account)

Independent examiner:

Beverly Walker

Tall Horse Consultancy

SBC House

Restmor Way

Wallington

SM6 7AH

Structure, Governance, and Management

PoTS UK is a Charitable Incorporated Organisation as of January 2015, constituted from that date and is governed by the Charity's constitution.

Organisational Structure:

The Charity is run by five trustees who are healthcare professionals, patients or carers of people affected by PoTS. Trustees are elected by mutual agreement by all other trustees and remain in post for a minimum of three years. The day-to-day operations are managed by the Chair and General Manager supported by a committed team of staff and volunteers. All members of the team work remotely and there are no office premises.

The charity employs three members of staff (making up just over 1FTE).

Charity Objectives

Our Mission, Vision and Values

PoTS UK supports and educates patients, family, friends and healthcare professionals within the United Kingdom about this under recognised and commonly misdiagnosed condition by sharing up to date evidence and resources.

- We work with healthcare professionals and other charities in the UK and abroad, and advocate for our members by seeking better NHS services, more research, and targeted treatments for people with PoTS.
- We aim to connect patients in a safe environment to empower them to self-manage their condition and reduce isolation.
- We produce evidence-based educational content for healthcare professionals which will improve awareness of PoTS, diagnosis and management, and improve health services for patients.

Mission: To provide accessible evidence informed support, education, and awareness for our growing community.

Vision: To optimise the health and quality of life of everyone impacted by PoTS.

Values:

We are committed to supporting the PoTS community by:

- Ensuring PoTS is universally known.
- Promoting fair and equitable access to healthcare.
- Facilitating ongoing advancement of our understanding of the condition and its management.
- Providing trusted and evidence informed resources.
- Challenging ourselves to be more inclusive, sustainable, and connected.
- Leading the change for a compassionate and open mindset.
- Collaborating with others who share our ambitions.

To achieve our mission, vision and values, our activities include:

- Educating individuals and groups of medical professionals.
- Providing evidenced based information in the form of a website which is accredited by the Patient Information Forum.
- Creating and distributing leaflets suitable for patient and medical professionals.

- Encouraging and engaging in journal publications and research.
- Producing newsletters for members.
- Encouraging accurate media coverage.
- Offering regular educational webinars (recorded and published on our YouTube channel).
- Providing online peer support groups.
- Using social media platforms to offer support, educate and raise awareness.
- Full details are available from our website www.potsuk.org

Strategy 2024-2026

The trustees developed a 9-point plan when developing the Charity's 3-year strategy at the AGM in January 2024 and have a detailed plan of work for each area.

These are:

1. Develop and grow our services to best suit the current and unmet needs of our beneficiaries.
2. Educate and empower the public to know and understand the signs and symptoms of PoTS and take action to improve their health.
3. Educate healthcare professionals to improve outcomes for people with PoTS.
4. Influence the health and social care system to identify and provide services to people with PoTS and report progress.
5. Build and improve engagement with those connected with us
6. Improve our inclusivity.
7. Increase our reach to raise awareness of the charity across the United Kingdom.
8. Continue to grow a sustainable organisation.
9. Measure and demonstrate our impact.

Public benefit statement

The trustees identify the need to have charitable aims and objectives to comply with the Charity commission's public benefit guidance.

Achievements and Performance

- Our 'What is PoTS?' video that launched on 1st October 2024 has had almost 50,000 views on YouTube and huge interaction on social media. This has been our most successful video to date.
- We have continued to run and develop online peer support groups, offering at least 10 each month. We have additional monthly topic groups including: neurodiversity, LGBTQIA+, periods and menopause.
- Awareness Day/Month 2024 – this included over 60 buildings across the UK lighting up purple, a daily yoga challenge and a surge in social media engagement through #31waystogetinvolved.

- GOV. UK petition published in January 2025 (with thanks to Sophie West). This has achieved over 17,000 signatures to date
- UK Parliamentary Campaign – use of campaigning software to reach large volumes of MPs, visit to Portcullis House and communications ongoing with the Department of Health and Social Care
- Since 2022 we have been pleased to support an ongoing petition to the Scottish Parliament for improved access to healthcare for people with dysautonomia, including PoTS and continue to work on this.
- Teaching/Education – ran a hybrid training event for over 300 healthcare professionals on Autonomic Dysfunction. Also ran independent training sessions across the country.
- Expanded our team of volunteers who help with a range of tasks including peer support, social media, and email enquiries.
- Held our first celebration event to recognise our team of medical advisors, volunteers and fundraisers.
- In association with the universities of Coventry and Warwick, we initiated a large-scale survey of adults with PoTS which we continue to analyse and process.
- Fundraising events – Yoga Challenge during Awareness Month and new annual fundraiser ‘Walk and Talk for PoTS’.
- Development of new web pages and comprehensive update of pages older than 3 years in line with PIF guidelines – this remains an ongoing project.
- Service provision project launched November 2023, and is ongoing. Freedom of Information Requests were circulated to all NHS commissioning organisations and acute trusts in England, Wales, Scotland and Northern Ireland. They reported that there are no established care pathways or formally commissioned services in place for people diagnosed with PoTS. There is limited specialist service provision available to patients with PoTS (21 trusts) across England, and no service provision generally available in Scotland, Wales and Northern Ireland, which is extraordinary for such a common, complex and disabling condition. Service provision for children is especially poor. We intend to use this information, alongside an Access to Services Survey to show the true picture that people with PoTS are facing when trying to access care. Reaching out to Integrated Care Boards/Trusts is likely to be our next step forward.
- The board made the decision made not to proceed further with the development of the PoTS App as it didn’t meet the needs of our target audience.
- Completed comprehensive Digital Strategy Review in order to help us grow our online presence.

Impact and Outcomes

- Significant increase in awareness within Government through campaigning and the petition.
 - Live education offered to hundreds of healthcare professionals with video content available online for catch up
 - We have a growing team of volunteers who offer a diverse range of skills and experience which enhances the support we can offer to our community.
 - Social media analysis shows increased presence
 - Greater support available to our community through peer support groups.
-

Looking ahead - Plans for 2025/26

In line with our strategy, our priorities over the next 2 years year will include:

- An educational masterclass for healthcare professionals
 - A patient retreat/ social get-together
 - Investment in our volunteers through training and team building
 - Development of National Guidelines for both adults and children
 - Continue with our current project to investigate NHS service provision for patients with Postural Tachycardia Syndrome throughout the UK with a view to improving understanding, access, and outcomes for patients.
 - Continue campaigning in parliament
 - Continue developing the peer support groups offering some social/craft sessions. Also explore a group for children (under 13s)
 - Maximising all opportunities to teach and educate
 - Celebration event to thank volunteers and fundraisers
 - Access to services survey to get a true understanding of the challenges our community are facing.
-

Financial review

Total income for 2024-25 was £67,460.

Total expenditure for the year was £72,428. This is a substantial increase in expenditure from 2023-24 (a low expenditure year) due to employing an additional member of staff and funding a number of projects including our Freedom of Information work, Parliamentary Campaign and Healthcare Professional Training Event. These expenses are recorded under 'Project Expenses' in the CC16a of our annual accounts.

The main areas of expenditure were:

- Training Event for Healthcare Professionals
- Development of National Guidelines
- Parliamentary Campaign/lobbying
- Freedom of Information project
- Staff wages
- Continuous management and maintenance of the online peer support groups.
- Training for staff and volunteers
- Software licences
- Travel/accommodation/meeting expenses for trustees, volunteers, and others who assist in pursuing the aims of the Charity.
- Website maintenance and mailing system

Reserves Policy

The trustees have established a reserves policy to maintain a level of unrestricted funds equivalent to 1-year of operational expenditure, approximately £45,000. This ensures that the charity can continue its activities in the event of unforeseen financial difficulties. This reserves policy will be reviewed annually at the AGM to ensure the amount remains suitable and

considers any changes within the charity. At the AGM in January 2024, trustees agreed to move a further £20,000 into the reserves account to take in to account rising costs and increase in staff.

The outlook for PoTS UK remains positive and careful management of funds will continue to be essential to ensure that the Charity remains in a healthy position.

Statement of Trustees' Responsibilities

The trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards.

Report Approval

The PoTS UK Trustee Report for 2024-2025 was approved by the board on 25th August 2025 meeting.

The report was signed on behalf of the trustees by:



Professor Lesley Kavi, Trustee and Chair, PoTS UK.

Date: 22nd October 2025



CHARITY COMMISSION
FOR ENGLAND AND WALES

PoTs UK

1159813

Receipts and payments accounts

CC16a

For the period
from

Period start date
06/04/2024

To

Period end date
05/04/2025

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 £
A1 Receipts					
Donations	66,128	-	-	66,128	76,744
Bank interest	1,332	-	-	1,332	420
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	67,460	-	-	67,460	77,164
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	67,460	-	-	67,460	77,164
A3 Payments					
Printing, postage and stationary	2,420	-	-	2,420	1,717
Advertising and promotional costs	-	-	-	-	-
Wages and salaries	36,484	-	-	36,484	26,564
Computer expenses and consumables	-	-	-	-	100
Fundraising costs	772	-	-	772	672
Accountancy fees	8,104	-	-	8,104	817
Training	1,060	-	-	1,060	1,463
Purchase of promotional items	3,590	-	-	3,590	4,387
Insurance	551	-	-	551	551
Legal & professional	-	-	-	-	600
Depreciation	-	-	-	-	1,138
Software and subscriptions	5,997	-	-	5,997	5,166
PayPal fees	604	-	-	604	237
Project expenses	8,062	-	-	8,062	1,749
Website development and maintenance	3,666	-	-	3,666	2,703
Other expenses	459	-	-	459	-
Speaker Fund	480	-	-	480	-
Membership fees	182	-	-	182	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	72,428	-	-	72,428	47,864
A4 Asset and investment purchases, (see table)					
Other assets	-	-	-	-	2,276
	-	-	-	-	-
Sub total	-	-	-	-	2,276
Total payments	72,428	-	-	72,428	50,140
Net of receipts/(payments)	- 4,968	-	-	- 4,968	27,024
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	121,412	-	-	121,412	94,388
Cash funds this year end	116,444	-	-	116,444	121,412

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	Bank accounts	116,444	-	
		-	-	-
		-	-	-
	Total cash funds	116,444	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Other assets	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
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 asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
PoTS UK

On accounts for the year
ended

5 April 2025

Charity no
(if any)

1159813

Set out on pages

1 and 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 **05/04/2025**.

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 (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 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.

** Please delete the words in the brackets if they do not apply.*

Signed:

Date: 21/10/2025

Name:

Beverley Walker

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

ACCA

Address:

Tall Horse Consultancy Services Ltd

Chartered Certified Accountants

SBC House
Restmor Way
Surrey
SM6 7AH

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.