

Chairperson's Report

A message from our Chair

I have been involved with PoTS UK since 2010 and chairperson since July 2016. I remain committed to reaching our vision of 'optimising the health and quality of life of everyone impacted by PoTS'. I know this will take time, but we are making significant strides forwards and we are very grateful to have a committed and passionate community at our side.

2023-24 was a busy and successful year for PoTS UK. The development of our 3-year strategy has allowed us to be clear in our goals and structured with the work we undertake.

On behalf of myself and fellow trustees, I would like to offer our heartfelt thanks to everyone who has fundraised or donated. 2023/24 is a record year for the charity in terms of income and we are always amazed by the generosity, determination, and support. Our charity would not exist without these incredible efforts.

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

Thanks to the support of our community with our **parliamentary campaign**, we managed to reach over 250 MPs throughout the UK and started to make some noise where it's needed. Alongside this, we also contacted every health board or equivalent in Scotland, England, Northern Ireland and Wales to explain what PoTS is and ask about the services they provide. The change of government following the General Election meant our plans needed to be put on hold but we are relaunching this campaign in January 2025.

I am extremely proud of our **Peer Support Groups** that have been running for almost 3 years now. Our team of volunteers has grown considerably throughout 2023/24 and they are committed, caring and compassionate. The success of these groups lies with them. The feedback we receive is wonderful and we will continue to invest in training and support to ensure these groups thrive.

Updating our website is a critical part of the work we do and we are accredited by the Patient Information Forum as being Trusted Information Creators. We have worked hard this year to keep the information up to date and this is an ongoing process. Thank you to everyone who volunteers their time to review the latest literature and update the pages accordingly. This takes considerable amounts of time, but we think it is essential that the information we are sharing is as evidence based, contemporary and as helpful as possible.

Teaching and education is an essential part of what PoTS UK do. It is always fantastic to have the opportunity to raise awareness with healthcare professionals and we encourage trusts and health boards to reach out to us to deliver this important education. Thank you to those who welcomed us this year and we hope you have been able to put this training in to practice.

Support for individuals. It has been a pleasure to welcome a team of specialist PoTS nurses who commit their time to answering queries that we receive via email. They are a huge asset to our team.

Awareness Day on 25th October is growing year on year and I took great pride in seeing over 80 buildings in the UK light up purple in 2023. Edinburgh Castle looked particularly magical. A lot of thought and work goes into Awareness Month and the day itself and I would like to thank everyone who is involved in its success.

I would like to thank our administrative team who are all passionate about this charity, and work well beyond the expectations of any employer. I would also like to thank my fellow trustees who are committed and wise and share in the challenges and successes of PoTS UK. All of our volunteers play an enormous role in the success of our charity, and I am constantly amazed and grateful for everything they do. PoTS UK is a team effort, and I am privileged to be part of it.

I look forward to the year ahead and feel confident it will be a positive year for the charity following our strategy and being ever mindful of our mission, vision, and values.

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

2023 - 2024

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:

Michael Brown - Chartered Accountant

Sobell Rhodes LLP

The Kinetic Centre

Theobald Street

Elstree

Hertfordshire

WD6 4PJ

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.

In November 2023, the charity employed its 3rd member of staff (making up just over 1FTE) increasing the capability and capacity within the busy administrative team.

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

- We have continued to run and develop online peer support groups, offering at least 10 each month.
- Awareness Day/Month 2023 - this included over 80 buildings across the UK lighting up purple, a daily yoga challenge and a surge in social media engagement through #31waystogetinvolved.
- UK Parliamentary Campaign - our community contacted over 250 MPs and began to change the response from the Government in terms of their understanding of current service provision.
- 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.
- Teaching/Education - we recorded a podcast for Capita who undertake some PIP Assessments for the DWP and want to develop tools to help their assessors when assessing people with PoTS. Additionally, training was delivered to Swansea University Wellbeing and Disability Service to enable them to better support their students.
- Expanded our team of volunteers who help with a range of tasks including peer support, social media, and email enquiries.
- 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 and plans for new annual fundraiser 'Walk and Talk for PoTS'.
- Attended British Association for Nursing in Cardiovascular Care (BANCC) conference to represent PoTS UK.
- 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 (ongoing) -In the initial phases of this project, we contacted every health service commissioning body in Scotland, England, Northern Ireland and Wales to investigate the clinical services that they provide for people with PoTS. We recruited a new member to the team, who has a wealth of experience in developing services to manage this project. This is on a self-employed basis.
- Preparation for our nurses training event in April 2024.
- Joined TikTok to reach new audiences.

Impact and Outcomes

- Increased attention on fundraising opportunities has led to a record year of income.
- We have a growing team of volunteers who offer a diverse range of skills and experience. This enhances what the charity is able to offer our community.

- Increased presence on social media – as a result, our medical membership and patient membership have increased considerably as well as followers on all social media channels showing an increased awareness and desire for knowledge.
- Greater support available to our community through peer support groups.

Looking ahead - Plans for 2024/25

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

- Host meeting with PoTS specialists and develop National PoTS guidelines
- Continue with our current project to investigate NHS service provision for patients with Postural Tachycardia Syndrome in the UK with a view to improving understanding, access, and outcomes for patients.
- Relaunch the parliamentary campaign with an aim to hosting a parliamentary event and securing a question/debate at Westminster.
- Development and launch of our new 'What is PoTS?' video to be placed on the homepage of the website.
- Launch and continuing the development of our PoTS App
- Continue developing the peer support groups and the training available to our volunteers with a focus on neurodiversity.
- Maximising all opportunities to teach and educate
- Celebration event to thank volunteers and fundraisers

Financial review

Total income for 2023-24 was £77,163.85 This is an 8% increase on 2022-23.

Total expenditure for the year was £47,868.58 a 16% decrease on 2022-23. No major events were held in this financial year which explains the reduced expenditure. There was an investment in IT of £3413.55 which is removed from the I&E account but replaced with annual depreciation.

Main areas of expenditure were:

- Staff wages
- Continuous management and maintenance of the online peer support groups.
- Training for staff and volunteers
- Software licences
- Travel 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.

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 2023-2024 was approved by the board on 02/12/2024 meeting.

The report was signed on behalf of the trustees by:

A handwritten signature in blue ink, appearing to be 'L. Kavi', written on a light blue background.

Professor Lesley Kavi, Trustee and Chair, PoTS UK.

Date: 19th December 2024



CHARITY COMMISSION
FOR ENGLAND AND WALES

POTS UK

1159813

Receipts and payments accounts

CC16a

For the period
from

Period start date
06/04/2023

To

Period end date
05/04/2024

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	76,744	-	-	76,744	50,725
Sales of merchandise	-	-	-	-	2,635
Bank interest	420	-	-	420	-
Grant to fund Masterclass	-	-	-	-	18,000
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	77,164	-	-	77,164	71,360
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	77,164	-	-	77,164	71,360
A3 Payments					
Printing, postage and stationary	1,717	-	-	1,717	1,004
Advertising and promotional costs	-	-	-	-	3,747
Wages and salaries	26,564	-	-	26,564	26,790
Computer expenses and consumables	100	-	-	100	2,448
Fundraising costs	672	-	-	672	-
Accountancy fees	817	-	-	817	2,220
Trustee travelling and other expenses	-	-	-	-	1,134
Office Supplies	-	-	-	-	308
Training	1,463	-	-	1,463	409
Purchase of promotional items	4,387	-	-	4,387	5,983
Insurance	551	-	-	551	611
Legal & professional	600	-	-	600	-
Depreciation	1,138	-	-	1,138	-
Research	-	-	-	-	1,588
Software and subscriptions	5,166	-	-	5,166	695
PayPal fees	237	-	-	237	216
Cost of providing masterclass	-	-	-	-	9,883
Meeting expenses	1,749	-	-	1,749	-
Website development and maintenance	2,703	-	-	2,703	-
Sub total	47,864	-	-	47,864	57,036
A4 Asset and investment purchases, (see table)					
Other assets	2,276	-	-	2,276	-
	-	-	-	-	-
Sub total	2,276	-	-	2,276	-
Total payments	50,140	-	-	50,140	57,036
Net of receipts/(payments)	27,024	-	-	27,024	14,325
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	94,388	-	-	94,388	102,801
Cash funds this year end	121,412	-	-	121,412	117,126

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	121,412	-	-
		-	-	-
		-	-	-
	Total cash funds	121,412	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	Other assets	2,276	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
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 2024

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 **05/04/2024**.

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:

20/12/2024

Name:

MICHAEL BROWN

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

ACCA

Address:

SOBELL RHODES LLP

CHARTERED ACCOUNTANTS

THE KINETIC CENTRE
THEOBALD STREET
ELSTREE
HERTFORDSHIRE
WD6 4PJ

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.