



PoTS UK Trustees Annual Report 2022 – 2023

5th February 2024

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PoTS UK Trustees Annual Report 2022 - 2023

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

Charity Secretary:

Joanne Bullingham

Charity Administrator:

Denise Chapman

Medical advisors:

Dr Nick Gall

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

Independent examiner:

Michael Brown
Sobell Rhodes LLP
The Kinetic Centre
Theobald Street
Elstree
Hertfordshire
WD6 4PJ

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.

PoTS UK began as a Facebook group in 2010, and until 2015 all the work was undertaken by three volunteer trustees. Since then, we have grown into an internationally recognised Charity. Our Charity supports all ages, genders, and ethnicities.

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 – accredited by 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

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.

The Charity is run by five trustees who are a mixture of healthcare professionals, patients and 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 trustees aim to have one or two face-to-face meetings a year and a monthly meeting via Zoom. The board also utilise email, WhatsApp and video calls as other forms of communication when required.

There are a range of skills within the board members from events management to risk assessment, governance, and financial management. These valuable skillsets are called upon throughout the year for varying requirements from governance measures development to planning awareness day events.

The Charity does not have an onsite office, however, utilises the Charity's secretary address for all correspondence due to the convenience of coordinating all communication and operations.

The Charity has two paid staff both working on a part time basis, these resources are to enable coverage of the Charity administrative and operational needs.

Public benefit statement

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

Significant Activities

The charity was delighted to secure funding of £18,000 from NHS England to run an educational training event for healthcare professionals on PoTS and Long-Covid (also called a Masterclass on PoTS and Long-Covid). This was the largest event the charity has ever held. Up to 100 people registered to attend in person and over 1000 people registered to attend virtually. The lectures were recorded and added to the Charity's YouTube channel and have since acquired over 1600 views. We are grateful to Mast Cell Action who also contributed £1000 to the event. This funding was sought through the charities contacts and work with the NHS, although this was a one off grant the charity has canvassed since the Masterclass to ascertain if continued funding was available, unfortunately this was not the case.

PoTS UK remain thankful to the fantastic community that supports the Charity and who continue to fundraise throughout the year. There were 20 fundraising pages set up on JustGiving during the year raising £27,866.12. A couple of fundraising events were held by supporters, in particular a PoTS Ball with over 200 guests and several sporting challenges like the Edinburgh Marathon saw some of the most significant donations.

Since the online Peer Support Groups started in January 2021, the charity has run 230 sessions and have had 3,169 people register in attendance. This shows the demand and enthusiasm for these groups with attendees returning month after month. At least ten separate support groups are held per month, predominantly split by region; but the charity also host a group for those who are newly diagnosed, a group for parents and carers, an afternoon session and more recently, a group for 13–17-year-olds. The volunteers meet Bi-monthly to review progress, feedback and discuss any changes needing to be implemented. This is an area the charity plan to continue to grow and invest time and resources in over the next year.

PoTS UK have commissioned a PoTS app that offers expert advice and also allows patients to track/monitor their symptoms along with comments so they can analyse trends and triggers. The potential benefits of this app will be to reduce the strength of self-criticism and associated negative emotions (including any anger, guilt or shame). Additionally, it may help to improve autonomic balance and function by activating soothing body systems and parasympathetic activity. The development has been considerably slower than anticipated since the project was initiated, however beta testing was completed in summer 2023. There is further work needed to be completed and tested to ensure the app is a useful product for patients on an ongoing basis. The app will remain a work in progress, and PoTS UK will continue to develop the functionalities of it post launch.

Financial review

Activity during 2022-2023, has seen a steady stream of donations and grants totalling £68,725, keeping the reserves at a sustainable level ensuring PoTS UK's core activity can continue during this period.

The year started with the Charity's bank account with NatWest having an opening balance of £79,423, and then closing off the 2022 – 2023 financial year balance with £86,897.

Reserves Policy

Although the Charity has no restricted reserves or respective policy in the 2022 - 2023 reporting period, this is being finalised and implemented in 2023-2024 on the best course of action for future strategic planning.

The Trustees have adopted a policy that the charity's reserves shall cover necessary costs and commitments during an unforeseen period of difficulty. The Trustees aim to maintain or hold the level of reserves equivalent to three months of expenditure with additional funds for legal costs, staff sickness and future activities.

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

Operating Review

PoTS UK continue to receive a monthly payment via PayPal Giving which comes from a range of sources including Facebook, GoFundMe and PayPal itself. The Charity also utilises JustGiving as its main fundraising platform and received £27,866 in 2022-2023. PoTS UK is signed up to AmazonSmile, Don'tSendMeACard and text donations.

Our merchandise is proving popular and is great for raising funds and awareness. In this reporting period, the charity have had gross sales of £5,744.

Additional funding is provided from the Charity merchandise via the Charity's website. New merchandise such as the FlipStick, a mobile device to assist with walking and converts into a portable seat, provides a steady income.

Other main expenditure has been on:

- Administration support.
- Continuous management and maintenance of the online peer support groups.
- Development of the PoTS App.
- Software licence for Zoom to allow the Charity to provide educational webinars for larger numbers of medical professionals and patients.
- Travel expenses for trustees, volunteers, and others who assist in pursuing the aims of the Charity.
- Website maintenance and mailing system.

PoTS UK continue to work tirelessly to ensure the Charity achieves its objectives, manage and governs the charity activities in line with the Charity's vision and values, these activities include but limited to: responding to email queries from patients, carers and healthcare professionals; provide training and awareness on the PoTS condition to requested parties, campaign for better services and care for patients; provide assistance to patients and carers through the Peer Support Groups; and advocate for PoTS.

Report Approval

The PoTS UK Trustee Report for 2022-2023 was approved by the board on 08/02/2024.

The report was signed on behalf of the trustees by:

A handwritten signature in black ink, appearing to be "LK" followed by a horizontal line.

Professor Lesley Kavi, Trustee and Chair, PoTS UK.

Date: 08 February, 2024.



CHARITY COMMISSION
FOR ENGLAND AND WALES

No (if any)

Receipts and payments accounts

CC16a

For the period
from

Period start date
06/04/2022


To

Period end date
05/04/2023

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	50,725	-	-	50,725	51,487
Sales of merchandise	2,635	-	-	2,635	9,463
Grant for wages	-	-	-	-	6,147
Bank interest	-	-	-	-	684
Retreat ticket sales	-	-	-	-	3,056
Grant to fund Masterclass	18,000	-	-	18,000	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	71,360	-	-	71,360	70,837
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	71,360	-	-	71,360	70,837
A3 Payments					
Printing, postage and stationary	1,004	-	-	1,004	763
Advertising and promotional expenditure	3,747	-	-	3,747	27,743
Wages and salaries	26,790	-	-	26,790	25,995
Computer expenses and consumables	2,448	-	-	2,448	2,485
Cost of providing Retreat	-	-	-	-	9,538
Accountancy fees	2,220	-	-	2,220	2,100
Trustee travelling and other expenses	1,134	-	-	1,134	1,290
Office Supplies	308	-	-	308	493
Training	409	-	-	409	120
Purchase of promotional items	5,983	-	-	5,983	19,325
Insurance	611	-	-	611	393
Legal & professional	-	-	-	-	720
Recruitment	-	-	-	-	150
Research	1,588	-	-	1,588	1,588
Subscriptions	695	-	-	695	764
Just Giving fees	216	-	-	216	108
Cost of providing masterclass	9,883	-	-	9,883	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	57,036	-	-	57,036	93,575
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	57,036	-	-	57,036	93,575
Net of receipts/(payments)	14,325	-	-	14,325	- 22,738
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	80,063	-	-	80,063	102,801
Cash funds this year end	94,388	-	-	94,388	80,063

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	94,388	-	-
		-	-	-
		-	-	-
		-	-	-
	Total cash funds		94,388	-
	(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 £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
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
			Lisa Bradford	08/02/2024



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
PoTS UK

On accounts for the year
ended

5 April 2023

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 **05/04/2023**.

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:

09/02/2024

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.