

PoTS UK Trustees Annual Report
6th April 2020 - 5th April 2021

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)

Dr Morwenna Opie-Moran

Mrs Michaela Nuttall RN

Mrs Naomi Stetson RN (resigned 1st November 2021)

Miss Vicky Nash (resigned 1st February 2021)

Miss Chloe Garner (appointed May 2021)

Miss Lisa Bradford (appointed August 2021)

Charity Secretary:

Joanne Bullingham

Medical advisors:

Prof Julia Newton

Dr Arnold Deering

Dr Satish Raj

Dr Blair Grubb

Dr Ian Wilkinson

Dr Jane Simmonds

Melloney Ferrar

Helen Eftekhari (joined July 2020)

Prof Melvin D Lobo (joined Feb 2021)

Medical patrons and supporters

Prof Michael Gammage

Dr Nick Gall

Cat Smith MP (joined January 2021)

Dr Philip Hammond

Adam Jacobs

Peter Capaldi

Primary Bankers:

NatWest Bank
HSBC Sheffield

Independent examiner

Martin I May Chartered Accountant
Sobell Rhodes LLP
The Kinetic Centre
Theobald Street
Elstree
Hertfordshire
WD6 4PJ

Objectives and Activities

- To raise awareness, educate and advise medical professionals of this disabling, under-recognised and misdiagnosed health condition, Postural Tachycardia Syndrome (PoTS)
- To offer support and information to patients, family and friends
- To provide up to date evidence-based resources.
- To promote research into PoTS to help gain a greater understanding of the condition so best treatment and management can be adopted.
- To collaborate with other organisations and charities with the same purpose

To meet these aims, our activities include:

- Speaking to individual and groups of medical professionals
- Providing evidenced based information in the form of a website
- 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 webinars (recorded and published on our YouTube channel)

Full details are available from our website www.potsuk.org

Due to Covid-19, our approach to managing these objectives has required greater use of technology to allow for more online meetings rather than face to face. Our Zoom account has been well utilised to allow us to meet with people safely and ensure raising awareness doesn't need to stop as a result of social distancing. The PoTS UK team are proud of the way they have managed the difficulties imposed by the pandemic and feel more resilient and better able to work remotely in all areas.

Structure, governance and management

PoTS UK is a charitable Incorporated Organisation as of January 2015, constituted from that date.

The charity is run by 5 trustees who are either 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 trustees aim to have one or two face-to-face meetings a year and a monthly meeting via Zoom. They also use email, WhatsApp and video calls when needed. Trustee, Vicky Nash resigned from her post in February 2021.

The charity has no office but appointed a paid, self-employed Charity Secretary in December 2018. The same person became the charity's first salaried employee on 1st January 2021.

Public benefit statement

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

Policy on reserves

Reserves are maintained at a level which ensures that PoTS UK's core activity can continue during a period of unforeseen difficulty.

When we reviewed our reserves at the start of the Covid-19 pandemic, we did not foresee any major concerns for the charity financially. We considered incoming funds were likely to reduce however staff costs remained low and outgoings manageable within current funds. It was necessary to reduce some activities due to government covid related guidance, and this postponed expenditure on these activities. The outlook for PoTS UK remains positive and careful management of funds will continue to be essential to

ensure the charity remain in a healthy position. Donations have gradually increased again more recently. PoTS UK will continue to promote different ways people can support the charity, including those that don't cost them any money such as donations through online shopping.

We have no restricted reserves.

Financial review

As expected, due to Covid-19, total income was almost £10,000 lower than 2019/20 but we continue to be extremely grateful for the hard work and effort people put into their fundraising efforts. We have highlighted these on social media when possible.

Monies have been received through fundraising activities carried out by members and include cake sales, sponsored dances, pottery auction, sporting events, and a sponsored head shave. The second PoTS National Awareness Day was held on 25th October 2020 and saw increased fundraising efforts with repeated initiatives such as 'Par-tea for PoTS' and the 30-day #PoTSUK Challenge. We were unable to hold an event in person like we did in 2019 due to Covid-19. Despite this, for a second year, there was a considerable increase in the funds received during October and November which supports the importance of the awareness day campaigns. PoTS UK continue to receive a monthly payment via PayPal Giving which comes from a range of sources including Facebook, GoFundMe and PayPal itself. VirginMoneyGiving continues to be used by lots of our members for online fundraising. PoTS UK is now signed up to AmazonSmile, Don'tSendMeACard and text donations and receives a small but increasing amount through these channels.

We have continued to receive a steady stream of small donations from members and their families. We are very grateful for every contribution. We had one large donation this year which will contribute greatly to the costs of the retreat in October 2021 and two large separate contributions that will be used to make the PoTS textbook more accessible for patients to purchase. Throughout 2020, sales of merchandise remained steady although we did stop selling between April and September due to Covid-19.

Other main expenditure has been on

- Development of the Compassionate Mind App
- Software licence for Zoom to allow us to provide educational webinars for larger numbers of medical professionals and patients
- The professional production of our 'What is PoTS?' video
- Travel expenses for trustees, volunteers, and others who assist in pursuing the aims of the charity
- Website maintenance and mailing system
- Administration support

Financial Planning

The charity's outgoings were noticeably less than 2019/20 as events that would usually use take place had to be rescheduled due to the pandemic.

The charity anticipates some large costs next year including re-branding, a new and improved website, patient retreat, education events for healthcare professionals and the roll out of virtual support groups. At the very end of the year, PoTS UK submitted an application for funding from the National Lottery to support these activities.

Risk assessment

Risks are assessed on an annual basis

Risks identified –

1. Legal support for ad hoc advice is necessary and a solicitor kindly volunteered to assist PoTS UK and continues to do so. As several issues requiring legal advice arose during 2020/21, the charity have instructed the services of Wright Hassall when necessary.
2. At the start of the Covid 19 pandemic in March 2020, the charity's financial status was reviewed and trustees considered that we are not at risk. No special measures were necessary to keep the charity viable. With only one paid member of staff, hours can be monitored closely to ensure staff costs remain manageable. A significant amount of the work is also undertaken on a voluntary basis by trustees. All expenditure will continue to be given great consideration to ensure funds are protected should this pandemic start to impact on the charity more significantly than predicted.
3. Merchandise can easily be copied which would impact upon our potential income from this revenue. Attempted to trademark PoTS UK but this failed and therefore the charity is re-branding in 2021/22 with a logo that is suitable to trademark.

4. Although the charity uses the standard Charity commission template for constitutions, it does not have a clause for the removal of trustees should this be necessary.

Achievements and performance

PoTS UK membership has grown to over 4387 registered members, 100 healthcare professional members and almost 15,000 Facebook followers (an increase of almost 2000 in the last year).

Raising awareness

As of 2019, PoTS UK registered its own PoTS National Awareness Day which is the 25th October. To celebrate the second year, the production and release of our 'What is PoTS? Video was made and shared widely. This has now had over 3200 views and we hope to continue expanding its reach via social media. A plane was also flown along the Blackpool/Fylde and Wyre Coast with a large banner saying PoTS UK on it. The wider PoTS UK team (including medical advisors) also contributed to a 'Meet the Team' video that was created and shared in October. This video celebrated the charity's 10th year. PoTS UK also created a Kudoboard and encouraged members to thank their healthcare professionals. This was a very low cost, new initiative that would be nice to repeat again and encourage greater engagement. Across the country, members hosted their own 'Par-tea for PoTS' and cake sales and one member arranged for Altrincham Town Hall to be lit purple on the day itself.

Despite the pandemic, throughout the year, Prof Kavi has presented and taught at many virtual events including the Heart Rhythm Congress and a session within a cardiology webinar, designed to increase awareness and knowledge of PoTS. This was later distributed to 100,000 cardiology specialists. She has also been developing an open access Syncope Toolkit and e-learning module for the Royal College of GPs, both of which contain information and training on PoTS.

Website

Regular expenditure includes website hosting and mass email system; these are 2 of our main platforms for providing information and we sent a combined total of 23 newsletters/updates in 2020/21 to our medical and patient members. PoTS UK signed up to The Patient Information Forum (PIF) in May 2020 and were awarded their kitemark following a successful review in June 2020. At the beginning of 2020, a process to review the entire

website content started and is now close to completion. It has been a considerable task and the team are proud of the work they have undertaken to complete this within the deadline. Thank you to Lorna Nicholson for leading this project in her role as Information Production Manager. As standard practice, our target audience is now consulted ahead of any new information production to ensure it is as useful as possible for the end user. In addition to reviewing the existing content, PoTS UK are proud to have added a new document, 'Employments and PoTS', the need for was highlighted in the PoTS Survey. The website now receives up to 50,000 visits per month. The feedback about the website, following the PoTS UK survey completed in January was extremely positive.

Social Media

The PoTS UK Facebook page continues to thrive and new initiatives have been added throughout the year to encourage engagement. These include a weekly Friday question. The charity is seeking support/advice in order to continue to grow and improve our social media presence and this will continue throughout 2021. Twitter (3500 followers) and Instagram (2040 followers) have been used less in 2020/21 but they have a good following and we see these platforms as a priority for 2021/22.

YouTube Channel

In February 2020, we launched our PoTS UK YouTube channel as a way of easily sharing both the London PoTS Masterclass videos and the monthly patient focussed webinars. This channel now has 884 subscribers.

National Lottery Grant Application

In April 2021, PoTS UK submitted their first, large scale grant application to the National Lottery Reaching Communities Fund. Sadly, we found out in November 2021 that we were unsuccessful with our application. We were told that it was one of several which were recommended for funding but ultimately not prioritised by the panel for the limited amount of funding available. The panel explained they could see PoTS UK has strong credibility in the voluntary and health sectors and that the project was well planned but sadly, their funding for 2021/22 was very limited compared to previous years. Whilst this is disappointing, we are pleased our proposal was recommended for funding and can use this application with confidence as a framework when applying for other grants in the future.

PoTS UK Charity Survey

In January 2021, patients/carers were invited to complete our survey. The survey aimed to discover what the charity does well, what we could improve upon and what else people would like us to do. It was completed by 1362 people. It was extremely useful in guiding our National Lottery Grant application and will continue to feed into the decisions that the charity makes – ensuring we are keeping patients' views at the heart of every strategic decision.

Merchandise

At the start of the pandemic, sales of merchandise had to cease. Sales commenced again at the end of October and items continue to be very popular with lots of sizes and colours now out of stock. As we are working on re-branding, we will not be purchasing any new merchandise until we have our new logo and branding in place in 2021/22.

Working with other Charities

We have been pleased to collaborate with EDS Support UK, Mast Cell Action, HMSA and the Arrhythmia Alliance.

Volunteers

The charity is very fortunate to have many volunteers who support it with a range of tasks. Thank you to everyone who has supported PoTS UK this year, especially Melloney Ferrar who answers the Support mailbox queries, Lorna Nicholson who supports the website review and Louise Thompson who amongst several other tasks, sends all of our thank you cards and emails to donors/fundraisers.

Health care professional education and patient events

Webinars - Monthly webinars commenced in April 2020 and have been very well received. Sessions so far include:

- Long-Covid & PoTS - Effect on life and work
- Astriid - Finding inclusive opportunities and supporting people on their journey back to work
- Q&A with Dr Nick Gall
- Managing Fatigue
- PoTS and Autonomic Disorders: Thinking outside the gastrointestinal box

- Breathing
- Advice for Parents of People with PoTS
- The role of exercise in managing PoTS
- Practical Tips - Visit to the clinic
- Nutrition and PoTS
- PoTS and Physical Activity
- Pilates for PoTS and Hypermobility
- Physical Activity and Emotional Well-being during lockdown

Retreat - The Cotswold retreat was due to be held on 4th April 2020 and was then rescheduled, due to Covid-19 until 24th October 2020. Restrictions at this time meant the event had to be postponed again and the charity agreed waiting for a full year would be the safest option. The date was changed to 24th October 2021 and offered as both an online and in person event to allow as many people as possible to attend. Those who had purchased tickets were offered the option of moving their tickets to the new date or a full refund. The retreat went ahead on the 24th October 2021 and was a huge success. We look forward to holding more of these events in the future.

UK PoTS Guidelines

The long-awaited textbook 'Postural Tachycardia Syndrome: a concise and practical guide to management and associated conditions' has been completed and was published by Springer in October 2020. PoTS UK trustee Prof Lesley Kavi, alongside PoTS UK medical advisors, Dr Nick Gall and Prof Melvin Lobo have contributed to and edited this book. We are very grateful for the contributions made by many PoTS specialists from the UK and North America who have given so freely of their time and expertise.

PoTS UK Publications

We have distributed hundreds of our PoTS booklets for patients to hospital clinics throughout the UK. We regularly receive requests for further booklets demonstrating that they have proved useful. These booklets will be updated in 2022.

Research and Academic Publications

Supporting Medical Research:

PoTS UK continue to support a number of research projects, especially by assisting with recruitment of patients.

PoTS Live (ongoing from 2019/20) – PoTS UK was delighted to support this research and helped recruit participants for the study. The project aims to explore what it is like living with PoTS on a day-to-day basis, for individuals who have PoTS and also for their families or partners. By sharing experience, the hope is that it will help other people with PoTS and healthcare professionals (doctors and nurses) to better understand the condition and the types of support that are needed. Origins Insights (<https://origins-insights.com/>), a health experience research company is organising and running the project in collaboration with PoTS UK. Participants were asked to film themselves for about five to ten minutes each day, for the duration of the project, using an app on their phone.

Analysis is now well underway, with the project team adopting Interpretative Phenomenological Analysis (IPA) which involves analysing all footage for one participant before moving on to the next. So far, the emerging themes are around misunderstanding of condition, the significant impact this can have in a variety of contexts, and also the difficulty in having a condition that mimics anxiety symptoms whilst patients don't necessarily feel cognitively anxious. PoTS Live has fed into the development of the Compassionate Mind App and is also leading to publications in peer-reviewed journals (provisionally accepted). Dr Samantha Waterman, lead researcher, is attending the retreat in October 2021 to give an update on how the project is progressing and to share early findings.

PULSE (ongoing from 2019/20) – A team of people from Coventry University, PoTS UK, UHCW, UCL and Warwick University have been awarded British Heart Foundation funding to Co-Create (develop with significant input from patients) to carry out a feasibility trial of a physical activity programme for people with PoTS. The grant application was developed with PoTS UK, people affected by PoTS, and healthcare professionals. The first stage of this funding is to work together to co-create with patients what the physical activity programme should look like, who it should include, and how it can be tailored to individuals.

<http://pulse-project.coventry.ac.uk/>

PoTS UK have supported a further 5 research projects and we look forward to seeing the results of these studies in 2021/22. We would like to thank all the patients and families who responded to these requests.

Supporting parents and patients

PoTS UK answers a large number of email enquiries from patients and family members/carers/friends and there has been a considerable increase in the number of enquiries since Covid-19. We also receive and answer enquiries from teachers, healthcare professionals and professionals from other disciplines who require advice and guidance in order to better support their clients with PoTS.

At the request of hospital clinicians, we were able to provide relevant covid related guidance on our website covering frequent enquiries to their service to reassure patients.

In response to the Covid-19 pandemic, we felt the need to offer more support to our members and our monthly webinars are becoming increasingly popular with every session reaching full capacity. We plan to further develop these in 2021/22.

The Parents of People with PoTS Facebook group set up many years ago by one of the PoTS UK trustees continues to be very active and well used and now has over 750 members.

PoTS UK have worked hard developing a compassionate mind coach app. The project is well underway and we hope it will be launched in 2021/22. 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. It might also help with the development of courage for self-care tasks which may help improve sleep and fatigue and engagement and quality of life.

Services for patients

- We continue to maintain an on-line register of NHS consultants with an interest in managing patients with PoTS. We regularly ask our members for updates on this via social media so we can keep it as up to date as possible.
- We continue to lobby for better patient services for affected people. We have contacted NHS England, government officials and various hospital trusts about the need to improve access the healthcare for affected patients. Our new patron, Cat Smith MP is also keen to

raise awareness and put PoTS in the spotlight at any suitable opportunities.

- We send monthly newsletters with up-to-date information

Goals for next year and the future

Patient/Parent support

- To pilot and release new Compassionate Mind App
- To hold the patient retreat in October 2021
- Continue to hold monthly webinars on a range of topics associated with PoTS
- Commence a pilot of geographical, virtual support groups
- To plan a family event suitable for all ages between Q4 2021/22 and Q2 2022/23
- To further develop remote and hybrid events if our grant application is successful

Medical professional awareness

- To raise awareness of PoTS amongst GPs
- To encourage contributions from overseas experts via the Visiting Speaker Fund and conference programming
- To begin planning the next Masterclass/regular podcasts – to take place in 2022. The scale of our offering will be dependent upon securing the National Lottery funding.

Research

- To support international and local research initiatives
- Continue to support PULSE Co-Creation physical activity programme
- To update our previous large patient survey - supported by researchers at Coventry University (incorporating Covid-19 impact)

Access to care

- To develop ideal patient pathways and patient-centred multi-disciplinary treatment approaches
- To set up a working party to service models, commissioning and access to NHS care

- Continue to work towards improved access to care for all patients throughout the UK

Charity Development

- Full re-branding
- To develop and implement Communications Strategy, particularly within our social media platforms.
- Ongoing review of charity structure and governance including recruitment of new trustees
- To provide further training to Trustees and charity secretary
- Develop new merchandise to sell – raising both funds and awareness
- Develop our volunteer framework
- Recruit a new member of the team for the 6-month placement via the DWP Kickstart scheme

Covid-19 has impacted the whole world and the impact on our small charity has been limited to date. As expected, fundraising reduced and the Patient Retreat has had to be rescheduled to October 2021. Experts are anticipating an explosion in the number of PoTS cases as a result of long-Covid, and media coverage about PoTS is increasing considerably as a result. The charity is hopeful that with the spotlight turning to PoTS, sufferers may achieve the long-awaited opportunity to be heard, understood and supported. PoTS UK intend to seize this opportunity and will be enlisting the services of a PR company to drive forward a targeted media campaign in 2021/22.

We will continue to refine how we will offer more patient and healthcare professional education and support virtually if the situation does not improve sufficiently. We have made positive steps towards this with the webinars which allow us to reach previously excluded individuals who live remotely or are unable to travel.

As the world adapts to a new way of working, as a small charity PoTS UK is able to adapt quickly to ensure we are still able to meet our goals and objectives.

Signed on behalf of the trustees by Prof Lesley Kavi, Trustee and Chair, PoTS UK

A handwritten signature in black ink, appearing to be 'Jm', on a light-colored rectangular background.

Date: 30/12/20



Receipts and payments accounts

CC16a

For the period
from

Period start date
06/04/2020


To

Period end date
05/04/2021

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	45,175	-	-	45,175	42,278
Sales of merchandise	1,607	-	-	1,607	9,807
Compensation receipts	-	-	-	-	132
Bank interest	-	-	-	-	11
Symposium ticket sales	-	-	-	-	3,075
Contribution to symposium cost	-	-	-	-	1,000
Contribution to retreat cost	-	-	-	-	300
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	46,782	-	-	46,782	56,603
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	46,782	-	-	46,782	56,603
A3 Payments					
Printing, postage and stationary	499	-	-	499	671
Advertising and promotional expenditure	5,798	-	-	5,798	1,080
Wages and salaries	9,701	-	-	9,701	7,720
Computer expenses and consumables	2,675	-	-	2,675	264
Cost of hosting Masterclass symposium	-	-	-	-	13,483
Cost of providing Retreat	1,383	-	-	1,383	3,465
Accountancy fees	2,100	-	-	2,100	1,836
Trustee travelling and other expenses	752	-	-	752	1,352
Office Supplies	276	-	-	276	320
Training	205	-	-	205	484
Purchase of promotional items	250	-	-	250	9,390
Insurance	393	-	-	393	348
Consultancy work	-	-	-	-	1,146
Selling fees	18	-	-	18	313
Other	-	-	-	-	68
Development of Compassionate Mind App	9,600	-	-	9,600	-
Trade mark application	320	-	-	320	-
Subscriptions	975	-	-	975	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	34,945	-	-	34,945	41,940
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	34,945	-	-	34,945	41,940
Net of receipts/(payments)	11,837	-	-	11,837	14,663
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	90,964	-	-	90,964	76,301
Cash funds this year end	102,801	-	-	102,801	90,964

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	Current account	102,759	-	-
	Savings account	42	-	-
		-	-	-
	Total cash funds	102,801	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
		Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
		Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Lesley Kavi	29/12/21	



CHARITY COMMISSION FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
PoTS UK

On accounts for the year
ended

5 April 2021

Charity no
(if any)

1159813

Set out on pages

102

(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 05/04/2021.

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:

31.2021

Name:

MARTIN MAY

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

ICAEW

Address:

SOBELL RHODES LLP

CHARTERED ACCOUNTANTS

THE KINETIC CENTRE
THEOBALD STREET
ELSTREE
HERTFORDSHIRE
WD6 4PJ