

PoTS UK Trustees Annual Report

6th April 2021- 5th April 2022

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 Ople-Moran

Mrs Michaela Nuttall RN

Mrs Naomi Stetson RN (Treasurer) (resigned 1st November 2021)

Miss Chloe Garner (appointed May 2021)

Ms Lisa Bradford (Treasurer) (appointed August 2021)

Charity Secretary:

Joanne Bullingham

Charity Administrator:

Azura Farrell-Mcleod (six-month placement from May-Nov 2021)

Denise Chapman (appointed May 2022)

Medical advisors:

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

Medical patrons and supporters:

Prof Michael Gammage

Dr Nick Gall

Cat Smith MP

Dr Phillip Hammond

Adam Jacobs

Peter Capaldi

Primary Bankers:

NatWest Bank

Independent examiner:

Martin I May Chartered Accountant
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

We have continued to use our newfound confidence in online/virtual offerings to manage these objectives. 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 – a problem that persisted throughout the year to varying degrees. 2021/22 has seen our first hybrid patient event and we strongly suspect this will become business as usual for future events as it opens the door for so many more people to attend. The PoTS UK team are proud of the way they have continued to manage 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 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. They also use email, WhatsApp and video calls when needed. Whilst we were sad to say goodbye to our treasurer Naomi Stetson, we have been delighted to welcome Chloe Garner and Lisa Bradford (Treasurer) as new trustees. They have a range of fantastic skills from events management to risk assessment, governance and financial management. 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 and remains in post. As part of a Department for Work and Pensions funded scheme, a fully funded part-time member of staff was appointed for six months from May-November 2021. This extra support was of great benefit to the charity and the charity provided training and work experience to the employee. The charity has recently appointed an additional member of staff on a self-employed basis due to the increasing workload and to cover maternity leave for nine months from August 2022.

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

Activity during 2021-22, has been a steady stream of incoming funds keeping the reserves at a sustainable level ensuring PoTS UK's core activity can continue during a period of unforeseen difficulty.

The reserves were reviewed at the end of 2021 as part of the handover process and a new strategy was developed, including regular reporting and updates to the board and the Chair. At the beginning of 2022, through the planning and management for the year ahead it was decided due to resourcing challenges, further resources would be acquired to support the running of the charity and therefore no large or major events will take place in 2022 (unless funded via grants). Existing budgeted projects will be supported.

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

Although the charity currently has no restricted reserves, this will be discussed with the accountant to formulate a plan on the best course of action for future strategic planning.

Financial review

After a difficult year, the lift in Covid restrictions (periodically) allowed fundraising to commence and we saw an increased appetite in organising large fundraising events. Thank you especially to Anne Smith and Francesca Foxcroft who raised substantial amounts for PoTS UK. Combined with a large one-off donation from a regular donor, we saw record income during 2021/22. We also received two large separate contributions that were used to make the PoTS textbook more accessible for patients to purchase. Other fundraising activities carried out by members included cake sales, sponsored dances and a variety of impressive sporting events.

The third PoTS National Awareness Day was held on 25th October 2021 and saw increased fundraising efforts with repeated initiatives such as 'Par-tea for PoTS' and the '30 ways to get involved' in a challenge. We were finally able to run our twice postponed PoTS retreat for patients on 24th October and this coincided nicely with the Awareness Day. The cost to patients of attending the Retreat was heavily subsidised by PoTS UK to make it more affordable for all.

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 closed in November 2021 and the charity registered with JustGiving as our new main fundraising platform. PoTS UK is signed up to AmazonSmile, Don'tSendMeACard and text donations and receives a small, but increasing amount through these channels, particularly AmazonSmile.

In May 2021, the PoTS UK team decided to lead by example and took on their own fundraising challenge. In conjunction with the CaptainTom100 challenge, our team cycled, swam, ran and walked 100km over the 4-day challenge period and raised over £1000. We continue to receive a steady stream of small donations from members and their families. Our 'Donate' button on the new website has encouraged further donations, especially as people can easily add a donation when purchasing merchandise. We are very grateful for every contribution.

In line with our new branding and website, revealed on 25th October, new merchandise was purchased and this provides a steady income.

Other main expenditure has been on:

- Development and roll out of our new website
- Development of our new logo/branding
- Setting up online peer support groups
- Engaging the services of a PR company, Chamberlain Dunn
- Development of the PoTS App
- Software licence for Zoom to allow us 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
- Administration support

Financial Planning

The charity's expenditure reached its highest ever in 2020/21. Firstly, the pandemic prevented lots of plans in 2019/20 so we anticipated it being a more costly year as we rolled out the delayed projects. In addition, as the charity was showing exponential growth, the trustees felt it was the right time to re-brand, commission a new website and invest in PR support - all of which were costly. The patient retreat was another main area of expense but was very well received and for the first time ever, we offered this as a hybrid event to ensure everyone was able to participate.

Risk assessment

Risks are assessed on an annual basis

Risks identified –

Covid-19 continues to cause disruption to all and the charity remains mindful of the impact this could have on the health of our members (and the need for extra support/additional enquiries), fundraising and events.

Legal support for ad hoc advice is necessary. As several issues requiring legal advice arose during 2020/21, the charity have instructed the services of Wright Hassall when required.

At the beginning of 2022 a review of the charity's financial status was reviewed through the planning and management for the year ahead. It was decided due to resourcing challenges, further resources would be acquired to support the running of the charity and therefore no large or major events will take place in 2022 (unless funded via grants). However, existing budgeted projects will be supported.

Merchandise can easily be copied which would impact upon our potential income from this revenue. As a result, it was agreed to produce a more distinctive logo and re-brand and this was launched in October 2021.

Achievements and performance

PoTS UK membership has grown to over 5250 registered members, 300 healthcare professional members and over 16,000 Facebook followers. This is an incredible increase and highlights the increase in the number of people with PoTS as a result of long-covid and raised awareness.

Raising awareness

For our third awareness day, we were delighted to see a huge number of buildings light up purple in support of PoTS UK and to raise awareness of PoTS. We reached out to our community in order to achieve this and they did not disappoint. It was wonderful to see so many photos on Awareness Day and we hope to make this an even bigger part of Awareness Day 2022.

Across the country, members hosted their own 'Par-tea for PoTS' and cake sales along with a plethora of other creative fundraising events including a ticketed Halloween party.

Chair of PoTS UK, Prof Kavi and a patient were asked to present via Zoom for Octopus energy's disability awareness week. As a thank you, they kindly donated £1000. This was an excellent opportunity to share information with people who have never heard of PoTS and was wonderful to see an employer take strides in showing their support for their employees with disabilities.

PR Company – From May to September, we worked closely with PR company Chamberlain Dunn. The increased spotlight on PoTS as a result of Covid seemed like the perfect opportunity to invest financial resource in acquiring some expert skills in reaching a wider audience.

A large number of resources were developed with their support and generated record levels of engagement on social media. The biggest success in terms of reach was an article in the Mail on Sunday that was then duplicated by many other national newspapers. Whilst the headline was disappointing and somewhat trivialising, the content was good and their readership figures are vast:

<https://www.dailymail.co.uk/health/article-10075495/Could-Long-Covid-little-known-nervous-problem.html>

We have also been contacted by other papers and would like to thank our community for being brave enough to speak out to the media. Some examples are below:

<https://www.yorkpress.co.uk/news/19866514.student-reveals-struck-illness-similar-long-covid/>

<https://www.bbc.co.uk/news/uk-wales-60287344>

Online Peer Support Groups

In October 2021, five pilot peer support groups were held. These were a fantastic success and as a result, a plan was put in place to launch these from January 2022. Each month, ten separate groups are held. These are predominantly split by region, but we 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 monthly to review progress, feedback and discuss any changes we may wish to make.

In the future, with further volunteers, we hope to run adhoc sessions on specific topics (e.g. – Employment and PoTS, Pregnancy and PoTS and a Men only group).

All volunteers are required to complete our application form, provide two references, undergo DBS checks and complete safeguarding and other training.

We continue to develop the training on offer and have plans for training on transgender health and terminology later this year.

Website

Our website and mailing system are two of our main platforms for providing information and we continued to send newsletters and updates in 2021/22 to our medical and patient members.

In October 2021, in line with our new website, we moved our mailing system over to Mail Chimp.

The feedback about the new website has been extremely positive and we continue to strive to add more useful information. We can see from analytics that our website is accessed from all over the world and consequently added google translate as a functionality to ensure as many people as possible can benefit from our information. We have also added a 'Rate this page' function and hope to spend some time in 2022/23 doing more detailed analysis of what information is being utilised the most. This will help pave the way for further development.

The Patient Information Forum (PIF)

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. The charity is assessed annually and met the required standards with ease at the 2021 assessment. There are just two outstanding documents requiring updating as of July 2022. We are proud to have updated our 16-page information booklet. Thank you to Lorna Nicholson for her continued support and work in her role as Information Production Manager. As standard practice, our target audience is 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 several new pages this year, including 'Bladder and PoTS' and an enhanced version of our diagnosis and living with low blood pressure pages.

Social Media

The PoTS UK Facebook page continues to thrive and engagement is increasing all of the time. We have introduced 'Questions in confidence' to allow members to ask questions confidentially and seek input from their peers. Comments are monitored by PoTS UK to

ensure they are evidence based, appropriate and accurate. The charity would like to improve on consistency and visual appeal of the posts and hope the appointment of the new member of staff will provide this based on their experience and skills. Twitter has seen an increase of over 2000 followers in the last year (now 5802) and Instagram has seen a further 1500 followers in the last years (now at 3672). Increased volunteer support with these platforms has been a great asset and we are reaching a wider community now. We also use LinkedIn and currently have 410 followers. We aim to adapt our posts to suit the different audiences that these platforms have and continue to work on improving the way in which we disseminate information.

YouTube Channel

In February 2020, we launched our PoTS UK YouTube channel as a way of easily sharing both the 2019 London PoTS Masterclass videos and the monthly patient focussed webinars. This channel has now doubled in the number of subscribers in the last year and now has 1770. We regularly add to our channel and share videos intermittently throughout the year on our different social media platforms. Our 'What is PoTS?' video has nearly had 10,000 views and continues to be shared widely within our community.

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.

Merchandise

Our merchandise is proving popular and is great for raising funds and awareness. To date, we have had gross sales of £9,087.07.

Working with other Charities

We have been pleased to collaborate with EDS Support UK, Mast Cell Action, HMSA and the Arrhythmia Alliance. EDS Support UK provided invaluable help and advice when we were in the process of setting up our online peer support groups for which we are extremely grateful.

Volunteers

Our volunteer network has thrived over the last 12 months and in addition to our long-standing volunteers, we now have an additional 20 peer support volunteers who have worked collaboratively with us from the outset of setting the groups up. They are committed and passionate and we feel privileged to welcome them to our team.

Quarterly review meetings are also held with our other volunteers to keep them updated on latest charity news and invite their feedback and suggestions. Working parties are now regularly set up for different projects and the input from volunteers has proved invaluable.

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 and Rachel Carlisle who have played a huge part in the setting up of the online peer support groups. A special thank you also to Michelle Orris and Sarah Fender for their work with our social media platforms.

Stories

We are always very happy to share patients' stories and know that this is a well utilised area of our website. A new Initiative for sharing stories was launched in March 2022. Over the coming months, we will ask patients to share their stories via video and we hope to be able to convert these as podcasts also. The pilot was filmed in March with one volunteer 'interviewing' a patient. It is due to be shared soon and providing it is well received and deemed useful, we will continue with this new format in addition to the written stories on our website.

Campaigning to keep clinic open

The clinic at Derriford Hospital in Plymouth helps about 200 patients with Postural Tachycardia Syndrome (PoTS), who rely on specialist services. With the impending retirement of the consultant the hospital planned to close the clinic. As a result of successful campaigning from patients and support from PoTS UK, the clinic has been able to remain open for the time being.

<https://www.bbc.co.uk/news/uk-england-devon-56742712>

Health care professional education and patient events

Teaching

Professor Kavi has continued to present and teach at a range of 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 developed an open access Syncope Toolkit and e-learning module for the Royal College of GPs, both of which contain information and training on PoTS.

NICE

Professor Kavi was invited to join the NICE expert panel on long-term effects of Covid-19.

Webinars

Monthly webinars (aimed at patients) have continued to be popular since they commenced in April 2020. In the last year, we have added the following to the existing 13 sessions.

PoTS – The basics for those newly diagnosed

Long Covid and the autonomic nervous system – a top down and bottom-up approach

Breathing Pattern Disorders
Pregnancy and PoTS
PoTS UK – Plans for 2022 and how to get involved
Orthostatic Intolerance in young people
How psychology support can be involved in PoTS care

Retreat

The retreat was scheduled 18 months later than originally planned and with persistent challenges as a result of Covid 19, we were thrilled to be able to host the PoTS Retreat for patients in the Cotswolds in October 2021. This was attended by 100 people in person and 100 virtually. The sessions were recorded so people have been able to purchase these after the event which has been popular. It was a wonderful day and a great opportunity for patients to be able to meet one another, share experiences and offer peer support. We are very grateful to the companies who donated products that made up the goodie bags for those attending in person. The cost to patients of attending the Retreat was heavily subsidised by PoTS UK to make it more affordable for all. The feedback from the day was excellent and we were proud to ensure our online attendees felt included throughout the day. This was our first hybrid event and we learnt a lot about live streaming and sound quality that will be very useful for future events. Thank you to Rupal Thakarshi who kindly donated her time to manage the IT on the day and edit the recordings. Thank you also to our fantastic volunteers who helped to ensure this day was a success.

UK PoTS Guidelines

The medical textbook 'Postural Tachycardia Syndrome: a concise and practical guide to management and associated conditions' was published by Springer in October 2020. Due to the considerable generosity of two donors, we were able to purchase 250 copies of this book for a reduced price and sell them (for no profit) to our members. A ballot was held to make it as fair as possible and the demand was considerably higher than anticipated. We have received lots of positive feedback.

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 have recently been updated.

Educating GPs

Trafford CCG invited the charity to present to over 80 GPs in Trafford - educating them on PoTS and other associated conditions. PoTS UK were joined by Dr Amy Small and Anita Kiernan who kindly agreed to share their stories of what it is like living with PoTS. Both provided such powerful stories that we are sure will stay with the GPs who attended and help improve the services offered. The feedback from this presentation was excellent and has since had a further 650 views on YouTube.

In addition, Professor Kavi has had several opportunities to teach GPs and trainees about PoTS and syncope through a variety of platforms.

Educating Paramedics

Professor Lesley Kavi was invited by Birmingham and Solihull NHS Training Hub to deliver a talk and answer questions on PoTS and Syncope.

Medical News Today's 'In Conversation' podcast

Professor Lesley Kavi was very happy to be asked to join cardiovascular medicine specialist Dr. Artur Fedorowski, Dr. Tae Chung, director of the Johns Hopkins PoTS Program, and Angela Meriquez Vázquez, COVID-19 long hauler and Body Politic president to talk about Covid and non-covid PoTS.

University Courses

In addition to the above, Professor Kavi has taught students about PoTS at various universities on a range of courses.

Journal Library

A nurse volunteer kindly keeps the journal library up to date.

Primary Care – Issues and Answers

We have partnered with Primary Care Issues and Answers, a unique new digital learning platform for the community of healthcare professionals who deal with millions of patients in primary care.

Research and Academic Publications

NICE Guidelines

As a stakeholder in the long covid and ME/CFS NICE guidelines PoTS UK had opportunities to represent patients and provide feedback.

The British Journal of Cardiology

Drs Gall and Kavi published a paper describing a series of patients who developed PoTS following long covid in January 2022. It was the largest case series from the UK at the time, and among the largest in the world, detailing the clinical characteristics of patients affected with PoTS developing after a COVID-19 infection.

In March 2022, the charity was invited to write an editorial for The British Journal of Cardiology. Trustees, Dr Morwenna Ople-Moran and Mrs Michaela Nuttall wrote a powerful article that was very well received. It was titled 'Pipedreams, the pandemic and PoTS: is the post-COVID-19 era a turning point for PoTS services?' and can be viewed here:

<https://bjcardio.co.uk/2022/03/pipedreams-the-pandemic-and-pots-is-the-post-covid-19-era-a-turning-point-for-pots-services/>

British Journal of General Practice

Prof Kavi was invited to write an editorial on PoTS by the British Journal of General Practice – the leading journal read by GPs in the UK and one of the most popular in the world. The paper was tweeted over 2000 times by Twitter users. Altmetric Attention Score is an academic tool that monitors the attention received by academic journal publications and this BJGP paper was among the top 5%.

Supporting Medical Research

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

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.

This research was published in November:

<https://journals.sagepub.com/doi/10.1177/17423953211054032>

PoTS UK are delighted to have welcomed lead researcher, Dr Samantha Waterman to our team of medical advisors.

PULSE study (ongoing from 2019/20)

A team of people from Coventry University PoTS UK, UHCW, UCL and Warwick University were awarded British Heart Foundation funding to co-create (develop with significant input from patients) 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 project is now well underway. Some aspects had to be adapted to be delivered remotely due to covid.

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

Other research projects

PoTS UK have supported a further five research projects and we look forward to seeing the results of these studies in 2022/23. We would like to thank all the patients and families who responded to these requests.

Supporting parents and patients

PoTS UK continues to answer 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.

We continue to offer regular educational webinars as described above. We regularly seek feedback on topics of interest and try to tailor the webinars to meet the needs of our community.

The roll out of our online peer support groups has become a valuable resource to many and we hope this will continue to grow over time.

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 development has been considerably slower than anticipated when this project first started, but we are now confident it will be fully rolled out by Autumn 2022. 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. The app will remain a work in progress, and we hope to continue to develop the functionalities of it post launch.

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 to 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. We encourage patients to write to their local GPs, CCGs and MPs etc to raise awareness and have provided template letters to make this task easier.

Goals for next year and the future

Patient/Parent support

- To pilot, release and develop the new PoTS App
- Continue to hold monthly webinars on a range of topics associated with PoTS
- Continue to run virtual support groups and increase the number of attendees and volunteers
- To plan a family event suitable for all ages
- To further develop remote and hybrid events

- To provide a range of activities that people can get involved with over Dysautonomia Awareness Month/Awareness Day
- To begin planning the next Patient Retreat – to take place late 2023
- To repeat the Jan 2021 charity survey to ensure we are meeting the needs of our patients and seek areas for Improvement

Medical professional awareness

- To further raise awareness of PoTS amongst GPs
- To host the Long Covid and PoTS Masterclass on 1st July 2022
- To encourage contributions from overseas experts via the Visiting Speaker Fund and conference programming

Research

- To support international and local research initiatives
- Continue to support PULSE Co-Creation physical activity programme
- To roll out the Power to PoTS Survey and encourage record participation
 - 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

- To continue to develop and implement Communications Strategy, particularly within our social media platforms
- Ongoing review of charity structure and governance
- To provide further training to Trustees and charity secretary and administrator
- To continue to develop our volunteer framework
- Organise training for PoTS UK staff, trustees and volunteers on Equality and Diversity
- To continue to review PoTS UK's strategic development at our AGM in November

2021/22 year has been an exceptionally busy but rewarding year for the charity with considerable steps forward taken in terms of developing the charity and raising awareness about PoTS.

Looking ahead to 2022/23, we hope to capitalise on all of the opportunities the last year has presented us with and sincerely hope to see an improvement in services offered to people with PoTS.

We will continue to work tirelessly to ensure we achieve our objectives.

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

Date: 12th DECEMBER 2022.



CHARITY COMMISSION
FOR ENGLAND AND WALES

POTS UK

1159813

Receipts and payments accounts

CC16a

For the period
from

Period start date
08/04/2021

To

Period end date
05/04/2022

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	61,487	-	-	61,487	48,176
Sales of merchandise	9,463	-	-	9,463	1,807
Grant for wages	6,147	-	-	6,147	-
Bank interest	684	-	-	684	-
Retreat ticket sales	3,068	-	-	3,068	-
	-	-	-	-	-
Sub total (Gross income for AR)	79,837			79,837	48,782
A2 Asset and investment sales, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total					
Total receipts	79,837			79,837	48,782
A3 Payments					
Printing, postage and stationary	763	-	-	763	499
Advertising and promotional expenditure	27,743	-	-	27,743	8,798
Wages and salaries	25,988	-	-	25,988	9,701
Computer expenses and consumables	2,485	-	-	2,485	2,876
Cost of providing Retreat	9,638	-	-	9,638	1,383
Accountancy fees	2,100	-	-	2,100	2,100
Trustee travelling and other expenses	1,280	-	-	1,280	782
Office Supplies	493	-	-	493	276
Training	129	-	-	129	286
Purchase of promotional items	18,328	-	-	18,328	250
Insurance	393	-	-	393	383
Legal & professional	720	-	-	720	-
Setting fees	-	-	-	-	18
Recruitment	160	-	-	160	-
Research	1,688	-	-	1,688	-
Development of Compassionate Mind App	-	-	-	-	9,600
Trade mark application	-	-	-	-	320
Subscriptions	784	-	-	784	876
Just Giving fees	108	-	-	108	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	83,576			83,576	34,946
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total					
Total payments	83,576			83,576	34,946
Net of receipts/(payments)	22,738			22,738	11,837
A5 Transfers between funds					
A6 Cash funds last year end	102,801			102,801	80,864
Cash funds this year end	80,863			80,863	102,801

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	80,063	-	-
		-	-	-
		-	-	-
		-	-	-
	Total cash funds (agree balances with receipts and payments account(s))	80,063	-	-


	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
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 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 L. SPADFORD	Date of approval 16/01/2025
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**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 2022

**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 05/04/2021.

**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:

17.1.2023

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

Section B Disclosure

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.