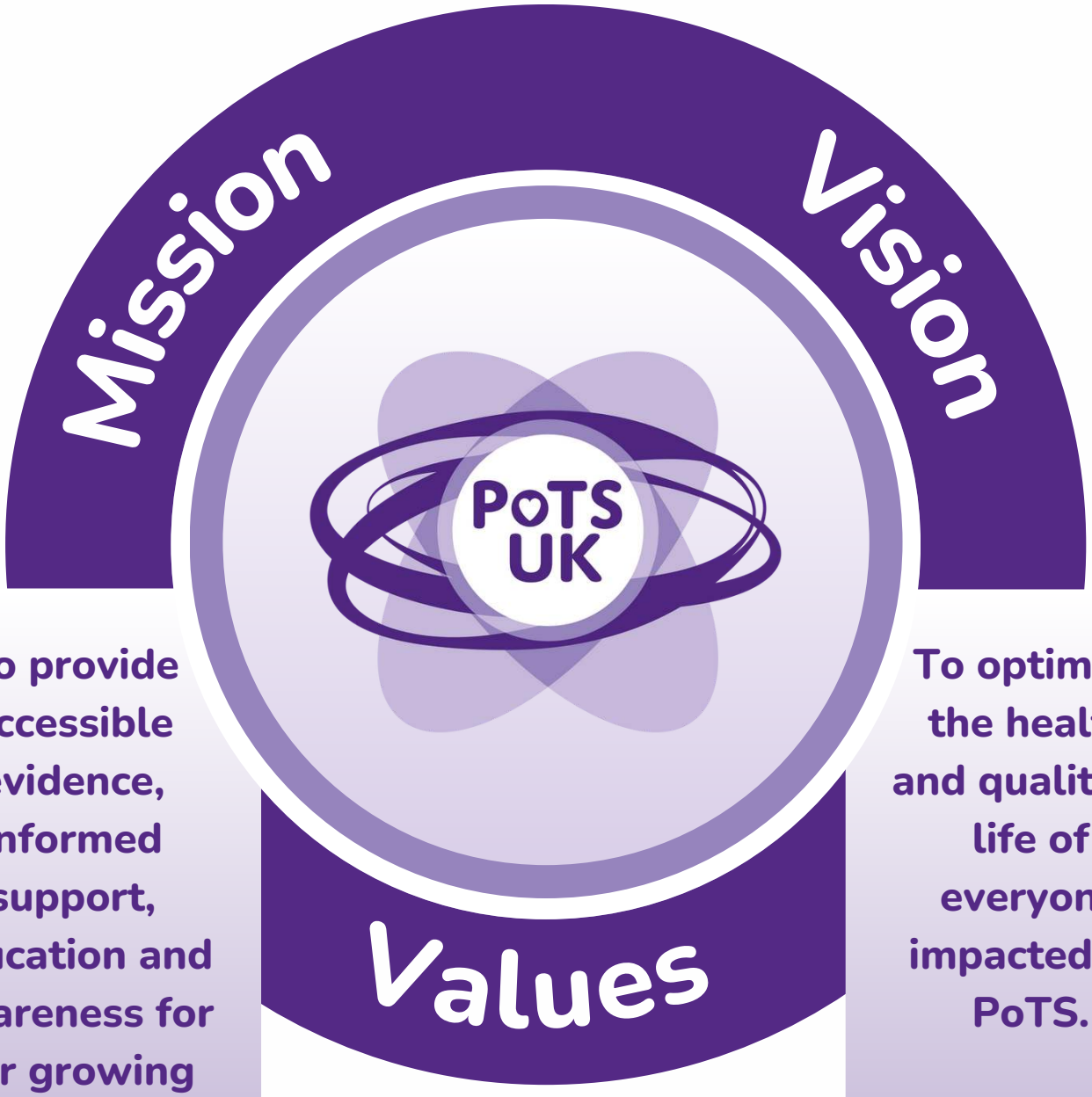
Postural Tachycardia Syndrome

2024 Impact Report



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

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

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 of PoTS.**
- **Providing trusted and evidenced-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.**

Welcome from our Chair Dr Lesley Kavi

As a small charity with big goals, every year is busy. Despite our size, we don't shy away from a challenge and 2024 was no exception.

As Chair of PoTS UK, I am passionate and 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 such a dedicated and loyal community at our side.

2024 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 financial year was 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 have relaunched now and hope we can count on your input once again.

I am extremely proud of our Peer Support Groups that have been running for over 3 years now. Our team of volunteers has grown considerably throughout 2024 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. We were delighted to host a hybrid educational training event, attended by over 300 nurses and healthcare professionals to learn more about Autonomic Dysfunction including diagnosis, management and treatment. It is always fantastic to have the opportunity to raise awareness 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 last 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 60 buildings in the UK light up purple in 2024. 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 seeing what 2025 has in store 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.

I hope you will enjoy reading some of our fantastic facts and figures about 2024 within this Impact Report.

Dr Lesley Kavi

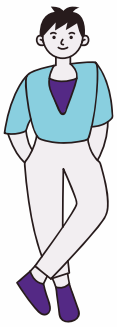
Postural Tachycardia Syndrome (PoTS) can be a life altering and debilitating health condition.

Symptoms include:

- Dizziness or pre-syncope (almost fainting)
- Palpitations
- Fatigue
- Headaches/migraine
- Brain fog
- Sense of anxiety
- Syncope (fainting)
- Shakiness
- Visual problems
- Gut problems (including nausea, diarrhoea, pain)
- Sweating
- Chest pain
- Poor sleep
- Purplish discolouration of skin due to blood pooling in hands and feet
- Bladder problems

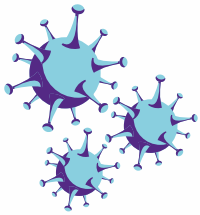
Disability caused by PoTS is severe.

PoTS can occur at any age but the most common age for PoTS to develop is in young adulthood.



PoTS is often misdiagnosed.

PoTS can be caused by other associated conditions.



Up to 85% of POTS patients are told that their symptoms are 'all in their head'.

Many healthcare professionals are not aware of PoTS.

Many patients are denied access to NHS specialists and treatments.

Our year in numbers....

We held
140
Online Peer Support Groups and over
1640
registered to attend.

We recruited new Peer Support Volunteers bringing our total number of volunteers to
36

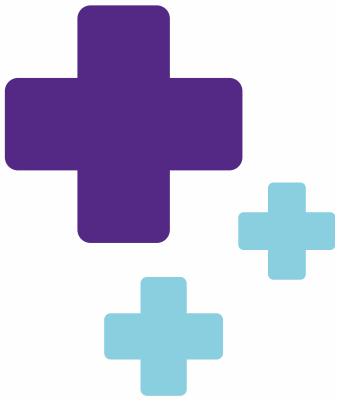
65+ buildings 'Lit Up In Purple" on 25th October for our PoTS Awareness Day, thanks to our amazing volunteers and your support for making this happen.

Between them and our other amazing volunteers, they volunteered
1200
hours for PoTS UK, supporting you in many ways.

Our team of specialist nurses responded to nearly
300
emails throughout the year, providing you with invaluable support and advice.

Our Chair and Trustees volunteered over
2000
hours of their own time delivering training to GPs, universities, community and hospital staff, attending meetings and events, assisting with research....the list goes on!

We list **35** NHS doctors and nurses with an interest in PoTS and who are supportive of PoTS UK on our website.



Our YouTube channel had

43,822

views last year and **386** new subscribers.

We launched our Tik Tok channel and have nearly

1700

followers.

Our website had

445,000

active users, from countries all over the world.

682

new people signed up for our newsletter, bringing the total subscribers to

7066

Our social media

Our social media channels help us raise awareness of PoTS. You can help by following us, liking and sharing our posts.

Facebook	Instagram	X (Twitter)	LinkedIn	Tik Tok
20,889 followers	9,167 followers	7,331 followers	991 followers	1693 followers

Your donations and fundraising....

Throughout 2024 your amazing and generous support raised almost

£63,000

You took part in

63

fundraising events which raised nearly

£36,000

This included our first ever Walk and Talk for PoTS. Thank you to all who took part, raising awareness of PoTS and almost

£4,000

which is amazing!

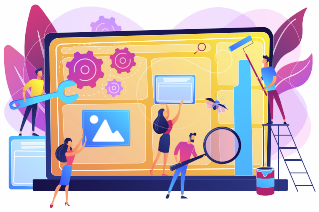
Your overwhelming generosity meant that we received donations amounting to over

£20,000

You bought PoTS merchandise to the value of nearly

£6,500

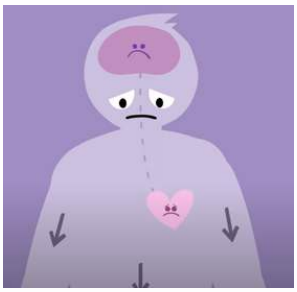
The funds you raise for PoTS UK enable us to continue the work that we do for PoTS patients.....



Website development and maintenance.

Training for our Peer Support Volunteers to ensure we offer up to date information and support in our Online Peer Support Groups.

Ongoing research projects.



Production of our What Is PoTS? video

Producing our PoTS booklet for hospital clinics and our range of PoTS leaflets.

Developing UK PoTS guidelines.

Lobbying to improve patient services.

Educational events for healthcare professionals.

This year your fundraising and donations have enabled us to.....

Host a hybrid educational training event, attended by over 300 nurses and healthcare professionals to learn more about Autonomic Dysfunction including diagnosis, management and treatment.

We 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. This information will support our Parliamentary Campaign greatly.

Provide additional training to our volunteers and staff, including training on Neurodiversity to ensure that our Peer Support Groups are the best they can be.

Feedback following our Online Peer Support Groups.

This is just a small proportion of the amazing feedback received following our Online Peer Support Groups.

A big thank you to the volunteers as without your help tonight would not have been possible. This group tonight has given me hope and a better understanding of my condition. Thank you so much.

WONDERFUL! Thank you to the volunteers for their time. It was lovely to meet others in the same 'boat' and share tips and experiences.

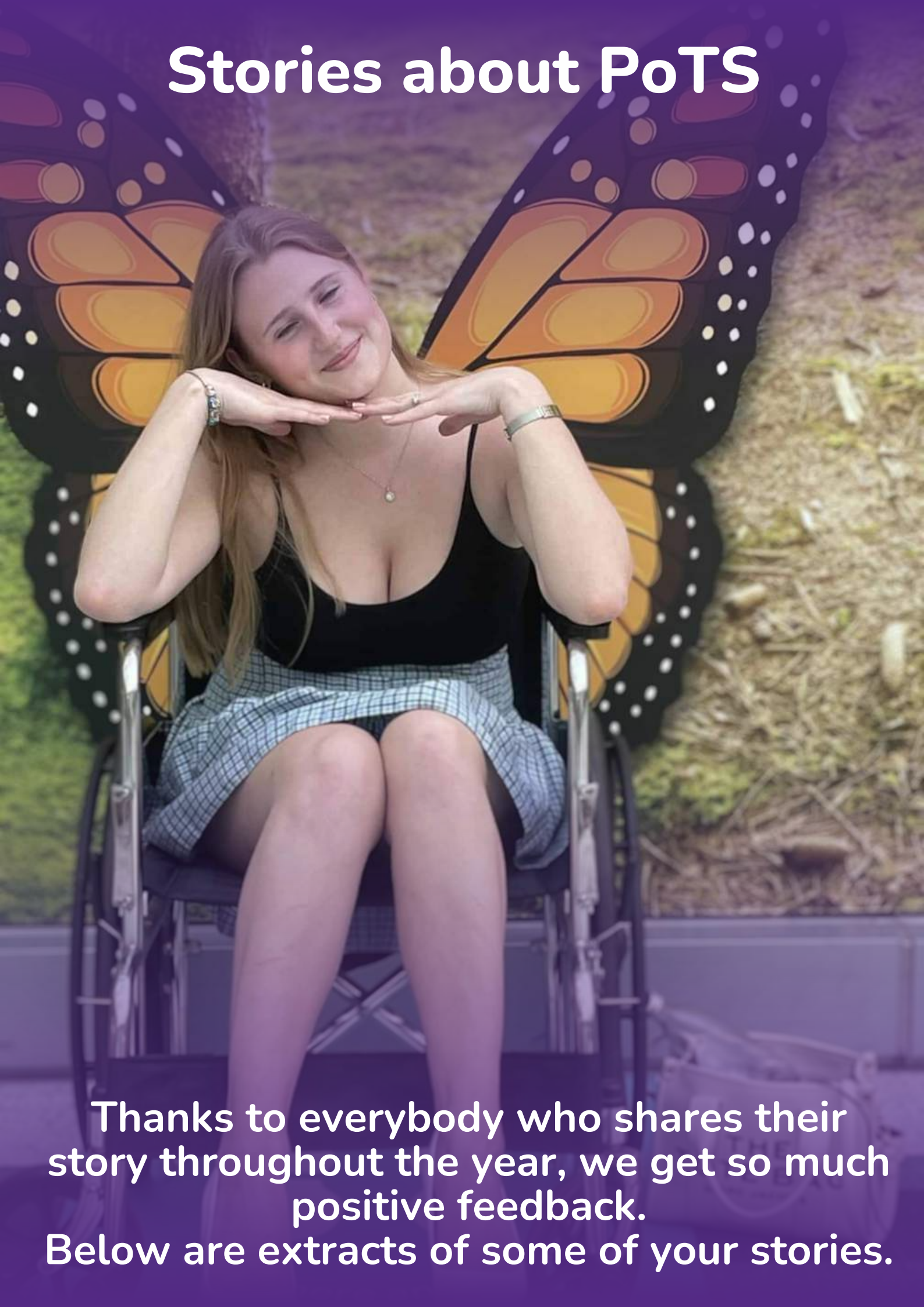
Really lovely to spend time with people who genuinely know how it feels to live with PoTS.

Thank you so much - it's made me feel quite emotional to speak to people who actually understand and relate to what I go through and suffer with daily.

Talking with this group has made me feel like a person today. Thank you ladies so much!

I've been attending for about 2.5 years now and it has been absolutely incredible. Having such an amazing PoTS community to basically grow up with and help me learn to cope and manage with my symptoms has been amazing. I am so thankful to both Tash and Laura for running this every month and providing such a fun session to both laugh and be serious in, I've enjoyed every minute and it has helped me so much. Just an absolutely massive thank you!

Stories about PoTS



Thanks to everybody who shares their story throughout the year, we get so much positive feedback.
Below are extracts of some of your stories.

Kelly

It feels strange now to think back on what my life was like before, as PoTS has now become such a huge part of my identity.

Sophia

It all started one random Sunday afternoon just after my 17th birthday.

I was sitting there one minute and next minute waking up on the floor confused, pain all over my body, scared. No one had any idea what had just happened.

James

I developed what I now know to be PoTS at the beginning of 2018 after coming down with Glandular Fever, it was brutal!

I suddenly entered the world of chronic health problems and the NHS. It was a shock to the system and a radical change to my life as I had rarely even had a cold before.

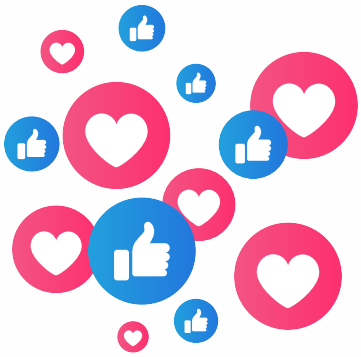
Sarah

I hope by sharing my story it brings a small amount of positivity and the notion to hold on, that hope never ends!

Receiving a diagnosis came with mixed feelings of relief, sadness and a fear over what the future may hold.

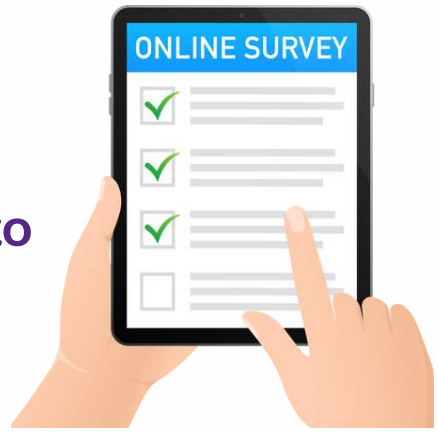
Please visit https://www.potsuk.org/about-pots/stories/ to read these and other stories about PoTS.

Finally, you have supported us (and one another) in many other ways.....



You have commented on, liked and shared our social media posts and supported others in need of advice and support.

You have completed our PoTS Charity Survey that enables us to adapt and develop the services we are offering to support you.



You have provided invaluable feedback about our Peer Support Groups, ensuring that our volunteers meet your needs.

You actively took part during Awareness Month, contacting buildings to ‘Light Up’, posting daily for our Make A Pledge For PoTS , taking part in our yoga challenge and raising awareness whenever you could.

Without your amazing fundraising, donations and ongoing support we would simply not be able to continue the work that we do for PoTS patients.

We look forward to continuing our journey with you throughout 2025 and beyond.

Thank you!