

The PSP Association

(A Company limited by guarantee)

Report and Financial Statements

Year ending 31 December 2024

Charity number 1037087

Company number: 2920581

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The PSP Association (PSPA) Report of the Trustees for the Year Ending 31 December 2024

The Trustees are pleased to present their annual directors' report together with the financial statements of the charity for the year ending 31 December 2024 which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association, and Accounting and Reporting by Charities; Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2015)

Trustees Report

Objectives and Activities

PSPA's purpose is to create a better future for everyone affected by Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD).

Our goals are to:

- Enable people with PSP and CBD and their families to live their best lives possible with high quality support and information.
- Improve the quality of life of people living with PSP and CBD through research and influencing.
- Put people living with PSP and CBD at the heart of what we do.

PSPA was first registered as a company limited by guarantee and as a charity in 1994. It is one of only three charities of any significant size in the world focussing on PSP & CBD. The others are the USA based charity, CurePSP, and the Swedish not-for-profit foundation, CBD Solutions.

PSP & CBD

PSP is a complex neurological condition caused by the death of nerve cells in the brain. It progressively affects movement, balance, vision, speech and swallowing. It belongs to a category of disorders called Atypical Parkinsons Disorders. It often gets misdiagnosed as Parkinson's disease (60% of respondents to our 2022 survey said they had been misdiagnosed). The average time from onset of symptoms to death is seven years.

PSP is associated with an over-production of the tau protein in some areas of the brain. The protein forms into clumps (neurofibrillary tangles) that lead to the death of nerve cells, especially in the motor areas of the brain, although the intellect often remains intact. Symptoms include:

- Falling backwards
- Postural instability
- Slowness of movement
- Motor recklessness

- Eye problems due to the rigidity of the eye muscles
- Speech slurring and softness
- Swallowing problems
- Cognitive changes
- Mood swings, apathy, and irritability

CBD has a similar pathology and progression to PSP. It usually presents similar symptoms to PSP, but one side of the body may be more affected, as well as affecting cognition. Symptoms may include 'alien' movements and tremor in the affected side.

Research by the PROSPECT study has concluded that prevalence of PSP|CBD is potentially twice what we previously thought with up to 10,000 people in the UK directly affected by the conditions. The diseases are not inherited, although research indicates that some people may have a genetic disposition that makes them more susceptible.

Review of the Year's Achievements and Performance

2024 marked the 30th anniversary of the creation of PSPA which was founded by Michael Koe in 1994. To mark the occasion, we celebrated the work of the association at a 30th Birthday party, at the offices of a corporate partner in central London. For our 30th anniversary we also launched our 30th anniversary awards, these awards recognised all people within our community, including those diagnosed with the conditions, carers, volunteers, fundraisers and family members.

Our 30th year marked a renewed effort to make the advances that people affected by PSP and CBD so desperately need. To do this we made three commitments in 2024:

- **To introduce new services** to improve the quality of life of people living with the condition now. We did this through support from the National Lottery Community Fund for our Mind, Body and Soul service which included counselling and on-line exercise classes.
- **Investing in policy and influencing work** with a new post of Director of Policy and Influencing. The postholder started in March 2024 and we have been able to increase our capacity to engage in consultations, build stronger relationships within the healthcare system and with professional bodies. And to start to build a programme of collecting rich data on the lives of people with PSP and CBD to strengthen our influencing strategy.
- **Increase our annual income through our 30 for 30 campaign and our research appeal, so that we can do more.** Our supporters rallied to the challenge, no more so than our annual Walk for Hope, where income increased from £15,000 in 2023 to £58,000 in 2024. We are grateful to a generous funder who offered to match fund Walk for Hope income of up to £30,000 to help provide an incentive to our walkers. 2024 saw record-breaking income of over £1.9m, an increase of 18% on our previous highest income in 2018. The additional income is allowing us to invest in 2025 with reserves released to increase resources in the Helpline, to launch research grant calls totaling £350,000 and in digital marketing to help raise awareness.

In 2024

- 4,106 individuals were registered to receive support from PSPA, including people living with a PSP or CBD diagnosis, carers and family members (3,538 in 2023).

- 1,943 Health and Social Care Professionals were registered to receive support and information (1,888 in 2023).
- 129 people were supported to access statutory funding (214 in 2023).
- 246 support group meetings took place (141 in 2023).
- 214 people were registered as PSPA volunteers (196 in 2023), providing 1428 hours of volunteering.

The charity remains in good financial health which will enable us to be more ambitious with our strategy. At the end of the 2024 financial year income was £1,963,095 (**2023**: £1,535,118). The surplus for the year 2024 was £462,160 (**2023**: surplus £143,050). The Board of Trustees has released reserves for 2025 to invest in delivery of services, expansion of our research programme and in digital marketing. Our reserves policy requires us to hold 9 months reserves.

By the end of 2024 we had eleven research grants in operation up from six in 2023.

Involvement

People living with PSP, CBD their carers and family members are involved in the development of our services and communications through our Services Committee, focus groups and our Patient and Public Involvement group in research (PRIM).

In 2024 we set up a Youth Advisory Group who designed new resources for our website targeted at young people who have a family member with a PSP or CBD diagnosis, helping them to understand two complex conditions. The young people aged 8 to 18 who worked on the website all have lived experience of PSP or CBD.

Volunteers

Volunteers are crucial to our ability to support people in their community and to help raise awareness. They provide vital support in running support groups, leading education sessions for Health and Social Care Professionals, in a care/nursing home setting and our Link Volunteer service. Nearly all our volunteers have personal experience of PSP or CBD and use that experience to support people currently affected by the conditions. At the end of 2024 we have 214 registered volunteers (2023 196), who provided 1428 hours of volunteering during the year. Volunteers all receive training in safeguarding and other legal requirements such as GDPR.

Improving Care and Support

"It was lovely to hear from everyone. It can be a lonely place looking after a loved one with this awful condition and I feel less alone after this meeting. I look forward to our next meeting."

A key part of the PSPA strategy is the support we provide to people living in the community with a diagnosis of PSP or CBD and to their families and carers. This is currently provided through:

- A Helpline, which is open Mon to Fri from 9am to 9pm
- Literature on PSP & CBD
- On-line exercise classes in partnership with Neuro Hero's
- Counselling services in partnership with Rare Minds
- A quarterly magazine called PSPA Matters
- A Link Volunteer service
- Support groups both in person and on-line
- Support grants and voice banking
- Carers support groups

- Podcasts

New Services in 2024

PSPA is committed to finding new ways to improve the quality of life of people affected by PSP and CBD. In 2024 three new services were introduced:

- A counselling service.
- On-line Exercise classes.
- A carers support group for male carers

Counselling with Rare Minds

The Counselling Service was launched at the end of April 2024 in partnership with Rare Minds who provide counsellors who are experienced therapists trained in both the psychological and emotional aspects of rare disease. There was a high level of uptake from the outset. This was accommodated by releasing additional money from reserves to deal with the waiting list. The top three issues for those using the service are: Exhaustion and fatigue, disease or condition progression and loss & grief (non-bereavement).

In the first year of this service 164 counselling sessions have been provided to 22 people, ranging from people living with the condition, their carers and children.

"How wonderful it is that the counsellors know about neurological conditions, and can make supportive, informed suggestions re coping etc. We are finding it very beneficial to have space to communicate our thoughts and feelings, from someone who isn't directly involved with our loved one's care."

On-line exercise classes in partnership with Neuro Heroes

Neuro Heroes is an online Neuro gym, providing live exercise sessions over Zoom run by Specialist Neuro Physiotherapists. The sessions aim to educate and demonstrate the importance of exercise and being active to help manage common symptoms people experience with PSP & CBD. Sixty one people have benefited from the classes in 2024.

'I feel I must give you direct feedback and my eternal thanks to the Association. The Neuro Heroes classes are having such an impact on my wife June. The physical gains are great but in addition the mental stimulation is fantastic. It gives her determination each day to repeat some of the moves and we do them together. June volunteered for the classes from the start they are doing a great job.'

Helpline

I wanted to thank you so much for all the support and information you have given me to help my Dad so he could be as comfortable as possible.

*I spoke to members of the team so much, they knew who I was in the end every time I called up!
I found you all to be so lovely and kind and we all truly appreciate what you do.*

The confidential free Helpline is open between 9am-9pm and is staffed by Helpline Care Navigators who respond to enquiries and make proactive outreach calls, which are designed to reduce isolation and loneliness, particularly amongst carers. Help can be provided on all aspects of living with PSP or CBD from symptom management, benefits, entitlements, and everyday living. You can get emotional support and signposting to other services. Helpline trained volunteers kindly give their time to cover the evening slot from 7pm to 9pm. 2024 saw the 10th anniversary of the evening

Helpline, we held an online event to thank our volunteers some of whom have been volunteering on the Helpline for the whole 10 years.

In 2024 there were 9578 contacts (10,334 in 2023) with the helpline (phone and email) a slight decrease from 2023. As we have introduced a wider range of services, including carers groups, counselling and a link service we are finding that the people we support can get advice and information from a wider range of services and are not as dependent on the helpline. However, the Helpline remains an important resource for people affected by the condition, and we are expanding services in Scotland and Wales to build tailored support to those nations.

Link Volunteer Service

Thanks to a grant from 'Global Make Some Noise' we launched a Link Volunteer Service in 2023. Link Volunteers provide short-term support to people affected by PSP & CBD to improve well-being and help navigate difficult times. Those accessing the service will receive up to twelve weekly or fortnightly in-person visits or phone calls from a Link Volunteer. Link Volunteers provide a listening ear to give you the opportunity to talk through your feelings. In this second year of the service, we have recruited a further 11 volunteers (12 in 2023) and 20 people living with PSP or CBD have received support from a Link Volunteer (11 in 2023).

Support Groups

Support groups continue to provide an opportunity for people to get together and make links with others who are living with PSP and CBD. Some groups are in person with others deciding that having gone on-line during the pandemic, mobility issues and transport problems meant that staying on-line provided the best opportunity to continue to meet. There were 36 groups in operation by the end of 2024 (33 in 2023). With new groups starting in Shropshire, South Yorkshire, Bradford and Devon and Cornwall. Apart from the specialist groups (outlined below) the groups are run by volunteers who are a vital resource for PSPA. There were 246 support group meetings in 2024.

Support for Carers

Virtual carers groups continued to provide support to carers throughout 2024. There were 673 attendances at carers support group meetings in 2024 (557 in 2023). Part of the increase was a result of introducing a new group for male carers. This group is facilitated by a volunteer and provides men with a chance to connect with other men caring for a loved one with PSP and CBD.

The carers guide, co-produced with carers in 2023, has gone from strength to strength with 1,413 guides being mailed or downloaded from the website in 2024, (486 in 2023). The guide has become a critical resource for carers.

Newly Diagnosed Support Groups

The online Newly Diagnosed group meetings are aimed at people who have received a diagnosis in the last six months. We know from feedback how important it is for people to meet others who are experiencing the same feelings and emotions following diagnosis. Each meeting includes a Health and Social Care professional as a guest speaker to support people to manage their symptoms and care. The guest speakers give people the opportunity to ask questions and learn more about their diagnosis and how to obtain support.

CBD Group

The online CBD group, set up in 2021, has continued to grow and provides a vital opportunity for people living with the condition to make links with others in the same position. 97 people living with CBD are signed up to the group (74 in 2023).

Events

We held two Friends and Family days in 2024. The first took place in Leeds with over 40 people attending to hear from experts in PSP & CBD care and research. In the afternoon we were joined by the English National Ballet who let the group through a 'Dance for Parkinson's workshop'. The second was held in Stirling, with a morning session attended by 40 people affected by the condition

Support Grants and Voice Banking

Introduced in 2020, PSPA support grants provide a one-off payment of up to £250 and aim to help improve the quality of life for people who are living with or are affected by PSP or CBD.

Support grants contribute to items and services in 2024 grants included:

- Specialised art easel for use in a wheelchair
- Personal training sessions
- Transport and carer support to attend a local day centre
- Part payment towards a holiday in an adapted cottage

Voice banking has also been on offer provided in partnership with 'SpeakUnique'. Voice banking is a process of recording your voice and using the recording to generate a personalised synthetic voice. This synthetic voice can then be used on a device, where it converts text to speech, allowing you to communicate with a voice which is identifiably your own when you lose the ability to speak because of the condition.

118 people were awarded support grants or accessed voice banking in 2024 (128 in 2023), a decrease of 8% from 2023.

PSPA Matters

PSPA Matters is the in-house quarterly magazine providing information and support to the PSPA Community. Each edition was sent to approximately 10,300 people, either by email or post (9,700 in 2023). PSPA Matters keeps readers up to date with PSPA support services, research, news, fundraising, how to get involved in raising awareness and much more.

Devolved Nations

We continue to work to increase the number of people we support across all the four nations of the UK. The numbers of people we support in the devolved nations increased by the following % in 2024:

- Scotland 31%
- Northern Ireland 27%
- Wales 23%

Due to the success of building partnerships in Scotland and a positive fundraising year in 2024, we will be recruiting a Helpline Care Navigator to be based in Scotland and one for Wales to build similar partnerships.

Funding and Promoting Research

Research Strategy

In 2020 we published a research strategy outlining how we will develop our research activities over the five years from 2020 to 2025. As well as prevention and treatment the strategy highlights the

importance of research that will help people living with PSP & CBD to receive better care and an enhanced quality of life. The strategy was based on a structured consultation with patients, carers, health professionals, scientists, and researchers. It identifies five themes as being priority areas for people living with PSP & CBD:

1. Raising awareness
2. Improving diagnosis
3. Supporting people
4. Preventing and identifying the causes
5. Developing treatments

Public and Patient Involvement in Research

As part of our commitment to strengthen the voice of people affected by PSP and CBD, we continued to build the PSPA Research Involvement Members group (PRIM). The group aims to increase the quality and impact of our research to ensure the views of those it affects are considered and that research is relevant to the public. They assist, support, and advise researchers and drug development companies. The group acts as a 'critical friend' on how best we can improve the design of research projects we support or include PSP & CBD affected people. The group has grown to 10 members (8 in 2023) and has met on 9 occasions during 2024 (9 in 2023). They have taken on a range of tasks, from advising a pharmaceutical company on a clinical trial participant and carer information sheet to assisting an academic on how to make their project more inclusive. Overall, they have taken part in 16 engagement activities (21 in 2023).

International Research Symposium

The Research Coordinator attended two international conferences in Washington DC and Toronto to hear updates on the global efforts in PSP and CBD research.

Research Information Sessions

To make our Research Information days more accessible for attendees, we altered the format to create multiple shorter sessions throughout the year. We held two Research Information Sessions which were both well attended, with over 100 attendees signing up to each. We also held a standalone session on the QOLAPS study for people interested in participating.

Research Participants

We continued to signpost PSPA members to active research studies. People have access to a virtual 'interest in research' form and can receive a paper copy. The research coordinator then shares monthly consenting members' encrypted details with five study coordinators working on different studies across the UK, including PROSPECT-M-UK and QOLAPS.

Research Committee

Our research investments are overseen by the PSPA Research Committee and in August 2024 we were delighted to welcome Professor Karen Morrison as the new committee chair. We also welcomed several new committee members, Professor Huw Morris, Professor Peter Garard, Professor Wendy Noble, Dr Maura Malpetti and Dr Victoria Marshall. We would like to thank Professor Nigel Leigh, our previous committee chair as well as departing committee members Professor James Rowe, Dr Alistair Church, Prof Dianne Hanger, Prof Michelle Hu and Professor Amriptal Mudher.

Ongoing Research Projects

PROSPECT

The PROSPECT - M - UK study is a research programme, funded by PSPA up to December 2024, which uses MRI scanning, genetic and biochemistry analysis of blood, cerebrospinal fluid samples, skin biopsies and clinical assessments to find ways of tracking disease progression, and improving diagnosis of patients with PSP and CBD. The full study title is Progressive Supranuclear Palsy Cortico-Basal Syndrome Multiple System Atrophy Longitudinal Study UK.

The programme is a multicentre project led by Professor Huw Morris based at University College of London (UCL) and the National Hospital for Neurology and Neuroscience. By the end of 2024, it had recruited nearly 1,600 participants across 29 study sites in the UK, making it one of the largest studies of PSP in the world. The study is ongoing and carries out in-depth tests on the existing cohort of patients, to monitor how the disease is progressing, as well as recruiting further participants who are at an earlier stage of the condition. The PSPA grant completed at the end of 2024, however UCL will continue to recruit participants.

With the data collected by this study, researchers have been able to explore a variety of avenues to better understand underlying disease biology, potential therapeutic targets, genetic determinants, and clinical heterogeneity of atypical parkinsonian disorders. It also paved the way for the formation of a UK wide research network known as PROSPECT. The project's infrastructure has been invaluable to recruit participants to clinical trials involving treatment options.

Outputs of this collaboration have been more than 20 publications in highly respected, peer-reviewed journals including 'JAMA Neurology', 'The Lancet Neurology' and 'Brain'. Another outstanding achievement of PROSPECT has been the creation of a bio-bank of samples. Data and samples have been requested and released to multiple investigators around the world and led to further research collaborations.

Prof. Morris was awarded a grant by the Medical Research Council for a new study called the ExPRESS study (Early assessment, diagnosis, and treatment of Parkinson's Plus Related Syndromes). This will be complimentary to the PROSPECT study in that the team will be trying to identify patients with PSP, CBS and MSA at the earliest stages in the referral process (the average time to diagnosis in PSP is over 3 years after the onset of clinical symptoms). ExPRESS will build on the success of the PROSPECT-M-UK study and the support received from the PSPA. It demonstrates how government investment in rare diseases research can be unlocked by early investment from charity's. The PSPA will continue to support the study with Patient and Public Involvement and Engagement (PPIE).

PSPA Clinical Research Fellowship

PSPA follows Association of Medical Research Charities (AMRC) processes to identify candidates to receive research fellowship grants, and Dr Robert Durcan started his PhD doctoral fellowship in 2023. The project focuses on the "Noradrenergic deficits in Progressive Supranuclear Palsy and Parkinson's disease: a precision medicine approach". Dr Durcan is based at the Cambridge University Department of Clinical Neuroscience and supervised by Prof. James Rowe. PSPA funding covers the salary of the post providing £265,130 over three years. In 2024 the Research and Communications Managers visited the University of Cambridge to meet with Dr Durcan to hear about his research and he also presented at one of the Research Information Sessions to aid in recruitment to the NORAPS study he is working on, a trial of an ADHD medication that aims to reduce apathy and impulsivity in people with PSP.

Small Grant Call

In 2024, we launched small grants of £30,000 to fund research projects. By the end of 2024 we had received 6 proposals and the grant awards will be made early in 2025.

Projects completed in 2024

- Dr Boyd Ghosh (Southampton) received a small grant for a 3-month project which began in June 2024 to investigate if feeding tubes are beneficial and improve quality of life for people with PSP & CBD. The costs covered the salary for a medical student placement for 3 months to work on this project. A write up of this project is under review for journal publication.
- Dr Maura Malpetti (University of Cambridge) completed her project Inflammation blood tests in progressive supranuclear palsy funded by a small grant. Data was presented in the form of two Posters submitted by research assistants assisting with this project as well as talks at multiple conferences by Dr Maura Malpetti including at Neuro2024 in Toronto. Dr Malpetti secured further funding from CurePSP as a result off the back of this research.
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- Dr Annelies Quaegebeur's small grant supported the project titled 'Characterising neuroinflammation in Progressive Supranuclear Palsy brains with high-plex spatial protein profiling.' A manuscript is under preparation and the project was presented orally at the Neuroimmunology Symposium in Cambridge in April 2024.

Future Commitments: Proposed Research Fellowship

Following the year-end, the trustees approved a proposal to commit up to £350,000 towards funding a new three-year research fellowship, scheduled to commence in September 2026. This proposal aligns with the charity's strategic objective to invest in long-term research capacity focused on PSP and CBD. The funding remains subject to final approval and contractual agreement, and will be delivered through a structured fellowship programme in partnership with the Association of British Neurologists (ABN).

Policy and Influencing work

This is an area in which we want to have more impact and 2024 has been used to develop a long-term strategy to raise awareness to bring about systems change for people affected by PSP and CBD. We invested in a dedicated post to focus on this work, and the post holder has used the year to develop the foundations for success in the future.

Our awareness week in June focussed on writing to general election candidates to raise awareness of PSP & CBD and saw more than 250 of our supporters joining in the activity. Alongside this we put time into getting people to respond to the Neurological Alliance's 'My Neuro Survey', to improve the data we have about living with PSP and CBD and in building our relationships in key alliances.

We secured 35 national and local press articles during the year (17 in 2023). In the first part of the year, we launched a film 'Inside Neurology: My Unique Brain', in partnership with the ITN News Channel. There were over 34,000 views of the film helping to raise awareness of the conditions with a wide range of people. The film is a long-term resource for promotion and awareness raising.

To maximise our impact, PSPA continues to collaborate with national and international organisations including the National Neurological Alliance and the Neurological Alliances in Scotland and Wales, as well as CurePSP in the US.

Health and Social Care Professionals

PSP & CBD are relatively rare diseases, and many health and social care professionals may have very little, if any, experience of supporting those living with the conditions. Through our information and education, we support local health and social care providers to gain a greater understanding of the care needs of people with PSP or CBD. We publish a range of free resources to support health and social care professionals who are caring for those with the conditions. We had 396 new health and social care professionals join our network in 2024, bringing the total to 1,943. Expanding our network is key to raising awareness.

In 2024, 436 Health and Social Care professionals received PSPA training from PSPA. 93% of HSCP's taking part in PSPA training report improved knowledge about PSP and CBD because of the training and 77% report feeling more confident to support people with PSP or CBD. The training included an afternoon study workshop for Health and Social Care professionals in Sterling, which was attended by over 50 people. Talks were welcomed from specialist physiotherapists and a Speech and Language lead.

Environmental Commitments

In 2024 we continued our commitment to reduce our carbon footprint. We continued to encourage people to download publications and receive our quarterly magazine PSPA Matters electronically. We have seen a considerable increase in downloads from our website across all our publications.

We rent office space in serviced offices so are not able to control emissions from heating and lighting. However, we are pleased that those offices have introduced movement sensitive lighting reducing the energy used.

Many Thanks

PSPA is extremely grateful to all the donors, trusts and foundations who continue to support our work. There have been so many who have taken on challenges and committed their time to helping raise funds.

We would like to thank the National Lottery Community Fund, The Masonic Charitable Foundation and Global Make Some Noise for their multi-year grants.

And we would like to thank all those who have left a gift through a Legacy.

Finally, we are extremely grateful to all the volunteers who have contributed their time and commitment to the charity in 2024.

Plans and Priorities – 2025 onwards

Our top five priorities for 2025 are:

1. Increased Helpline Capacity

Having built our work in Scotland over the last three years to increase the number of people we support (currently 378) we will be investing in a new Helpline Care Navigator role for Scotland to continue the work supporting the clinics and families impacted by PSP and CBD. In an effort to replicate that expansion in Wales there will also be a new Helpline Care Navigator post for Wales. This will free up capacity in the rest of the team to provide services across England and Northern Ireland.

2. New research funds

Our research appeal has now raised £650,000 of the £2m target we set. As a result, we will launch a new research grant call in the spring when we will be releasing £350,000 for research into PSP and CBD. These grants will be on top of the eleven research projects we are already supporting.

3. Expanding support for Carers

For Carers we will have two new on-line Carers Groups in 2025: one for carers who are caring for a loved one living in long term care and one for carers who have recently been bereaved. The carers groups introduced in 2023 have gone from strength to strength and as a result we have identified there are some specialist groups that are needed. We will also be introducing a 'Rare Resilience' training course for carers, this will be led by the team from Rare Minds

4. Improving knowledge of PSP & CBD amongst Health and Social Care Professionals (HSCP's)

To build the knowledge of PSP and CBD amongst HSCP's we will be introducing targeted masterclasses, the first in March will be for Orthoptists. Alongside the masterclasses we will be producing a specialist guide for Speech and Language therapists and an animation about CBD to match our existing animation about PSP.

5. Improving awareness

Raising awareness will focus on:

- Maximising the opportunities created by the release of The Salt Path Film.
- Running a campaign focused on the state of Continuing Health Care Funding.
- Producing a state of awareness report to highlight the low levels of knowledge of PSP and CBD amongst healthcare professionals.
- Improving our data insights through running a patient survey.

Fundraising Approach

We maintain our commitment to the Code of Fundraising Practice in all our fundraising, including when we work with third parties. We adhere to the principles of our Fundraising Promise, aligned with the Fundraising Regulator and Code of Fundraising Practice.

We are committed to upholding our Fundraising Promise to our supporters, and will always:

- Commit to high standards.
- Be clear, honest, and open.
- Be respectful.
- Be fair and reasonable.
- Be accountable and responsible.

Our approach, along with how we manage and use supporters' data, is set out in our supporter promise and privacy statement on our website. When we identify people who may be in vulnerable circumstances, we take appropriate steps to protect them from fundraising requests.

We work with a small number of commercial partnerships to raise money. We monitor these third parties to ensure they meet the same high standards as our own fundraisers and have agreements in place to ensure this happens.

We capture and monitor communications across various channels. It's vital to our work that supporters can easily send us their comments or complaints. We aim to answer the phone in five rings and respond to letters, emails, and queries through our website within five working days of receiving them. If we can't, we aim to keep supporters informed of progress.

We take all complaints seriously. Simple complaints are generally dealt with immediately by the Fundraising team, and we aim to resolve the complaint or acknowledge receipt within five working days. More serious complaints are escalated to the Chief Executive Officer and Trustees so they can consider the lessons learned. Our feedback and complaints procedure are available on our website. There was one fundraising complaint in 2024 (one in 2023).

Financial Review

Thanks to the generosity of its supporters PSPA recorded a surplus of £462,160 in 2024 (**2023**: £143,050) against total income of £1,963,095 (**2023**: £1,535,118)

The charity experienced an increase in income during 2024, particularly in donations and legacy contributions, which totalled £1,861,573 (2023: £1,259,525). Legacy income rose to £321,175 (2023: £243,873), while In Memoriam donations amounted to £208,986 (2023: £184,534). Personal donations decreased to £209,530 (2023: £246,314), but Voluntary Fundraising saw significant growth, reaching £561,930 (2023: £411,311). Thanks to our generous supporters, direct mail appeals raised £15,754 (2023: £9,871).

Support for our 2024 Research Appeal has been generous with £159,894 raised in 2024.

2024 saw us producing a strong surplus which will support our planned increase in our cost based for increased awareness raising and research spend in 2025 and beyond.

Our sincere thanks to all the Major donors, Charitable Trusts and Foundations which have supported our work, not just in the past year, but in many cases for several years. Their continued interest and support are a huge encouragement to us.

Investment Powers and Policy

The Trustees continue to maintain a conservative approach to the management of financial resources considering research funding commitments, the operating cash needs of PSPA and uncertainty over the timing and extent of future income generation in the current economic and geopolitical environment. We continue to use the investment options provided by the Charities Aid Foundation Platform to ensure we generate income from our cash balance. This platform provides access to a range of deposit accounts providing attractive interest rates investing in financial institutions covered by the UK Government Financial Services Compensation Scheme.

Reserves Policy and Going Concern

Charities maintain reserves to bridge the gap between spending and income received from donations and fundraising activities. Based on a 2021 benchmark against the policies of other charities of a similar size, the PSPA reserves policy requires 9 months budgeted fixed costs to be held as reserves. We are currently in excess of this level and as a result have increased spending plans across support, influencing and research.

The Trustees have remained alert to the continuing impact of the cost-of-living crisis on the finances of the charity. However, given the prudence of the reserves policy, the high level of cash liquidity

and continuing action taken to manage costs, they are confident that the charity has sufficient funds to continue to operate and meet liabilities as they fall due.

Principal Risks and Uncertainties

Risk Management

The trustees acknowledge their responsibility for the charity's systems of internal control and risk management. There is a risk management strategy in place which comprises:

- an annual review of the principal risks and uncertainties that the charity faces
- the establishment of policies, systems and procedures to mitigate those risks identified in the annual review; and
- the implementation of procedures designed to minimise or manage any potential impact on the charity should those risks materialise

The main risk categories relevant to PSPA are financial risk; reputational risk; fundraising risk; external environment risk; and legal and regulatory risk, including GDPR, health and safety, cyber security and new fundraising standards.

Structure, Governance and Management

Reference and Administrative Details

Committees of the Board

Finance, Audit and Risk Committee

This is a committee of the board with ongoing responsibilities for monitoring and review of financial performance, and the identification and management of financial and operational risk. The committee performs a detailed review of the annual budget, oversees the financial audit and undertakes detailed reviews of the quarterly management accounts.

The committee includes a minimum of 3 members of the board, including the chair of the board. The committee is chaired by one of the members (not being the chair of the board) who must have recent and relevant financial experience. It is attended by the CEO and Head of Finance (both *ex officio*).

Nomination and Remuneration Committee

Tasks include the scrutiny of prospective directors, the appointment of the CEO and senior staff, and the review of available skills within the board. The committee is also responsible for ensuring that staff are appraised by the CEO and, in this regard, acts as a committee of appeal for disputes arising between the staff and the CEO. The committee's other responsibilities include:

- advising the board and the executive on succession planning
- advising the board on non-financial operational risks and relevant procedural, disciplinary and administrative issues.

The committee includes a minimum of 3 members of the board. It is encouraged to take outside advice, where appropriate.

Research Committee

The Research Committee takes delegated responsibility on behalf of the Board of Trustees for the research strategy. This Committee ensures there is a framework for accountability, and that the

charity is working within appropriate legal and ethical boundaries, to fund research of the highest quality, and of greatest benefit to people with PSP & CBD.

The Research Committee will adhere to the recommendations of the Association of Medical Research Charities (AMRC) for the management of research.

Primarily composed of outside members, the committee must include at least one member of the board and is attended by the Chair, CEO and Research Coordinator (all *ex officio*).

Services Committee

The Services Committee has been formed to ensure continuous improvement of quality and standards across the charity's services provision. The committee will be the main forum for patients, carers and professionals to have direct impact on the design and delivery of services and the strategy of PSPA. The aims of the committee are to ensure that the charity maximises its performance on behalf of people affected by PSP & CBD and to increase the use of coproduction to develop and design services. This Committee is coordinated by the Director of Engagement.

Appointment of Trustees

The board may select new trustees by any means it deems appropriate, which may include the introduction of personal contacts, by advertising, or by direct approach to individuals. All applicants to become trustees are interviewed by a selection panel of at least 3 trustees including the Chair. New trustees are appointed for a 3-year term, which may be extended by mutual agreement for a second period of 3 years. The chair is appointed for a non-renewable term of 5 years.

Trustee Induction and Training

The Chair provides oversight of new trustee orientation, which includes their legal and fiduciary obligations under charity and company law, the Charity Commission guidance on public benefit, the charity's Memorandum and Articles of Association and governance processes, the business plan and recent financial performance of the charity.

Related Parties and Co-operation with Other Organisations

None of our trustees receive remuneration or other benefit from their work with the charity. Any connection between a trustee or senior manager of the charity and a related party must be disclosed to the full board of trustees. Details of research awards connected to Trustees are disclosed in note 10.

Remuneration Policy and Senior Staff

The directors consider that the board of directors who are the Association's trustees, and the senior management team comprise the key management personnel of the charity in charge of directing and controlling, running and operating the Association on a day-to-day basis. All directors give their time freely and no director received remuneration in the year. Details of directors' expenses and related party transactions are disclosed in notes 7 and 10 to the accounts.

The pay of the senior staff is reviewed annually and normally increased in accordance with average earnings.

Statement of Trustees' Responsibilities and Corporate Governance

The charity trustees (who are also the directors of The PSP Association for the purposes of company law) are responsible for preparing a trustees' annual report and financial statements in accordance

with the applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the charity trustees to prepare financial statements for each year which give a true and fair view of the situation of the charitable company and of the incoming resources and application of resources, including income and expenditure, of the charity for that period. In preparing the financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities SORP
- make judgements and estimates that are reasonable and prudent
- state whether applicable UK accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements
- prepare the financial statements on a going concern basis unless it is inappropriate to presume that the charity will continue in business

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the corporate and financial governance. The preparation and dissemination of financial statement may differ from legislation in other jurisdictions.

Statement as to the disclosure to our auditors

In so far as the trustees are aware at the time of approving our trustees' annual report:

- There is no relevant information, being information needed by the auditor in connection with preparing their report, of which the charity's auditor is unaware, and
- The trustees, having made enquiries of fellow directors and the charity's auditor that they ought to have individually taken, have each taken all steps that he/she is obliged to take as a director to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

By order of the Board of Trustees

.....
Ms R Ironside Chair

Date : 16 June 2025

Organisational Information

Charity number: 1037087

Company number: 2920581

Registered Office: Margaret Powell House, Midsummer Boulevard, Milton Keynes, Buckinghamshire, England, MK9 3BN

Our Advisers

Auditors: Field Sullivan 9 Hare & Billet Road, Blackheath, SE3 0RB

Bankers: Lloyds Bank 1-5 The Broadway, Crawley, West Sussex, RH10 1DU

Board of Trustees

Chair: Rowena Ironside

Paul Inness (Resigned December 2024)

James Noble

Jon Garrard

Dr Boyd Ghosh

Alison Goold

Greg Richardson (Appointed 1 January 2024)

Dr Maria Tenant (Appointed 1 January 2024)

Andrew Harrington (Appointed 1 January 2024, resigned August 2024)

John Redfern (Appointed 1 January 2025)

Thomas Whittle (Appointed 1 January 2025)

Company Secretary: Rebecca Packwood

Key Management Personnel:

Chief Executive Officer: Rebecca Packwood

Director of Service Improvement & Development (Deputy CEO): Carol Amirghiasvand

Research Committee

Chair: Prof Nigel Leigh (resigned August 2024)

Chair: Prof Karen Morrison (Appointed August 2024)

Prof Johannes Attems

Prof Siddharthan Chandran (resigned 2024)

Prof James Rowe (resigned July 2024)

Dr Alistair Church (resigned 2024)

Dr Boyd Ghosh

Prof Diane Hanger (resigned Feb 2024)

Prof Michele Hu (resigned Feb 2024)

Prof Amritpal Mudher (resigned Nov 2024)

Prof Peter Garrard (Appointed Feb 2024)

Dr Maura Malpetti (Appointed Feb 2024)

Dr Vicky Marshall (Appointed Feb 2024)

Prof Wendy Noble (Appointed Feb 2024)

Prof Huw Morris (Appointed Feb 2024)

Navin Sewak (lay member)

Independent Auditors Report to the Trustees of The PSP Association

Opinion

We have audited the financial statements of The PSP Association (the 'charitable company') for the year ended 31 December 2024 which comprise the balance sheet as at 31 December 2024, the statement of financial activities, statement of cashflows, and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2024, and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the charities Accounts (Scotland) Regulations 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the entity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the Trustees' annual report, other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the financial statements. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with

the financial statements, or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' report (incorporating the directors' report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of our knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of directors' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of Trustees

As explained more fully in the Trustees' responsibilities statement set out on page 16, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee

that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The specific procedures for this engagement and the extent to which these are capable of detecting irregularities, including fraud is detailed below:

Identifying and assessing potential risks related to irregularities

In identifying and assessing the risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, we considered the following:

- The nature of the charity's activities and sector, control environment and financial performance;
- Enquiring of management and the Trustees, including obtaining and reviewing supporting documentation, concerning the charitable company's policies and procedures relating to:
 - Identifying, evaluating and complying with laws and regulations and whether they were aware of any instances of non-compliance;
 - Detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected or alleged fraud;
 - The internal controls established to mitigate risks related to fraud or non-compliance with laws and regulations.
- Discussing among the engagement team and involving relevant internal specialists, including tax, and charity specialists (where relevant) regarding how and where fraud might occur in the financial statements and any potential indicators of fraud; and
- Obtaining an understanding of the legal and regulatory frameworks that the charitable company operates in, focusing on those laws and regulations that had a direct effect on the financial statements, such as provisions of the UK Companies Act, charity legislation and tax legislation or that had a fundamental effect on the operations of the charitable company; including General Data Protection requirements, anti-bribery and corruption policy.

Audit response to risks identified

As a result of performing the above, we identified various provisions of the Charities Act and the Charity Commission guidance as key audit matters related to non-compliance with laws and regulations and the receipt of donations and the making of grants as key audit matters related to the potential risk of fraud. In common with all audits under ISAs (UK), we are also required to perform specific procedures to respond to the risk of management override.

In addition to the above, our procedures to respond to risks identified include the following:

- Review of the financial statement disclosures and testing to support documentation to assess compliance with provisions of relevant laws and regulations described as having a direct effect on the financial statements;
- Enquiring of management, the Trustees and in-house and external legal counsel where relevant concerning actual and potential litigation and claims;
- Performing analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud; and
- Reading minutes of meetings of those charged with governance, reviewing internal reports where relevant and correspondence.
- Reviewing compliance with relevant charity legislation.

- Reviewing and testing the receipt of donations.
- Reviewing and testing the making of grants.
- In addressing the risk of fraud through management override of controls, testing the appropriateness of journal entries and other adjustments; assessing whether the judgements made in making accounting estimates are indicative of a potential bias; and evaluating the rationale of the charity for any significant transactions that are unusual or outside the normal course of business.

We also communicated relevant identified laws and regulations and potential fraud risks to all engagement team members and remained alert to an indications of fraud or non-compliance with laws and regulations throughout the audit.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

As part of an audit in accordance with ISAs (UK), we exercise professional judgment and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal controls.
- Obtain an understanding of internal controls relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the charitable company's internal controls.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Trustees.
- Conclude on the appropriateness of the Trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charitable company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charitable company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Use of our report

This report is made solely to the charitable company's Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's Trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Tim Sullivan (Senior Statutory Auditor)
for and on behalf of Field Sullivan (Chartered Accountants) Ltd, Statutory Auditor
9 Hare & Billet Road
London
SE3 0RB

Date:

Field Sullivan Chartered Accountants is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

The PSP Association Statement of Financial Activities for the Year Ending 31 December 2024

		Unrestricted Funds	Restricted Funds	Total Funds 2024	Total Funds 2023
	Note	£	£	£	£
Income And Endowments					
From:					
Donations and Legacies	3	1,480,115	381,458	1,861,573	1,259,525
Charitable Activities		-	-	-	179,707
Other Trading Activities		22,743	-	22,743	49,572
Investments		78,779	-	78,779	45,766
Other		-	-	-	548
Total Income		1,581,637	381,458	1,963,095	1,535,118
Expenditure On:					
Raising Funds		345,107	-	345,107	290,412
Other Trading Activities		15,668	-	15,668	7,194
Charitable Activities	4	566,878	350,979	917,857	823,948
Investments		29	-	29	2,828
Other		222,274	-	222,274	267,687
Total Expenditure		1,149,956	350,979	1,500,935	1,392,068
Net Income/(Expenditure)		431,681	30,479	462,160	143,050
Net Movement in Funds		431,681	30,479	462,160	143,050
Reconciliation of Funds:					
Total Funds Brought Forward		1,696,518	414,654	2,111,172	1,968,122
Total Funds Carried Forward		2,128,199	445,133	2,573,332	2,111,172

The statement of financial activities includes all gains and losses recognised in the year.
All income and expenditure derive from continuing activities. The comparative Statement of Financial Activities for 2023 is shown in note 22.

The notes on pages 25-41 form part of these financial statements.

The PSP Association Balance Sheet as at 31 December 2024

	Note	2024 £	2023 £
Fixed Assets:			
Tangible Assets	12	11,539	12,145
Investments	13	100	100
Total Fixed Assets		11,639	12,245
Current Assets:			
Debtors	14	-	60
Stock		22,431	23,476
Accrued Investment Interest		7,948	14,160
Prepayments and accrued income		73,591	34,566
Cash at Bank and in Hand.		2,702,250	2,247,310
Total Current Assets		2,806,220	2,319,572
Liabilities:			
Creditors: Amounts Falling Due Within One Year	15	(244,527)	(220,645)
Net Current Assets		2,561,693	2,098,927
Total Net Assets or Liabilities		2,573,332	2,111,172
The Funds of the Charity:			
Restricted Income Funds	16	445,133	414,654
Unrestricted Funds	16	2,128,199	1,696,518
Total Charity Funds		2,573,332	2,111,172

The Trustees have prepared these accounts in accordance with section 398 of the Companies Act 2006 and section 138 of the Charities Act 2011. These accounts are prepared in accordance with the special provision of Part 15 of the Companies Act relating to small companies and constitute the annual accounts required by the Companies Act 2006 and are for circulation to members of the company.

These financial statements were approved by the members of the committee on the

16 June 2025 and are signed on their behalf by:

.....

Rowena Ironside

.....

Alison Goold

The PSP Association Statement of Cash Flows for the Year Ending 31 December 2024

		2024	2023
	Note	Total £	Total £
Cashflows from Operating Activities:			
Net Cash Provided By (In Use) Operating Activities		462,160	143,050
Adjustments to cash flows from non-cash items			
Investment income		(78,779)	(45,766)
Depreciation	12	6,272	5,796
Net Cash Provided By (In Use) Investing Activities		389,653	103,081
Working capital adjustments			
(Increase)/decrease in stock		1,046	(11,056)
(Increase)/decrease in debtors		(32,754)	(26,799)
Increase/(decrease) in creditors		23,882	95,622
		381,827	160,848
Cashflows From Investing Activities:			
Dividends, Interest and Rents from investments		78,779	45,766
Purchases of Property, Plant and Equipment	12	(5,666)	(9,895)
		73,113	(35,871)
Change in Cash and Cash Equivalents in the Reporting Period		454,940	196,717
Cash at Bank and in Hand Less Overdrafts at the Beginning of the Year	18	2,247,310	2,050,593
Cash at Bank and in Hand Less Overdrafts at Year End	18	2,702,250	2,247,310

The notes on pages 25-41 form part of these financial statements.

Notes to the Accounts

1. ACCOUNTING POLICIES

The principal accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

Basis of Preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP (FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

The PSP Association meets the definition of a public benefit entity under FRS 102. Assets and Liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Preparation of the Accounts on a Going Concern Basis

The Association reported a cash inflow of £454,940 for the year. (2023 £196,717). The Trustees are of the view that based on the budgeted cash flow forecast, the charity will have available liquid funds to settle debts as they fall due beyond the next accounting period.

Income Recognition

Income is recognised when the charity has entitlement to the funds, it is probable that the income will be received, and the amount can be measured reliably. Income from government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received, and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably, and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Donated Services and Facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity of the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), general volunteer time is not recognised; for more information about their contribution refer to the Trustees' annual report.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

Interest Receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

Fund Accounting

Unrestricted funds are available to spend on activities that further any of the purposes of charity. Designated funds are unrestricted funds of the charity which the Trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the Charity's work or for specific projects being undertaken by the Charity.

Judgements in applying accounting policies and key sources of estimation uncertainty

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the periods in which the estimate is revised where revisions affects only that period, or in the period of the revision and future periods where the revisions affects both current and future periods.

The following judgement had a significant effect on the amounts recognised in the financial statements:

The charity holds stock, primarily consisting of awareness materials and fundraising merchandise. A significant judgement has been made in assessing the net realisable value of this stock, particularly in determining whether any adjustments for obsolescence or slow-moving items are necessary. Given the nature of the stock, its usability and demand can fluctuate based on campaign activity and external factors. The trustees have considered historical sales trends, future demand projections, and any potential write-offs when assessing the appropriate carrying value. This judgement directly impacts the valuation of stock in the financial statements and, consequently, the reported financial position of the charity.

Additionally, judgement has been applied in the recognition of deferred income, particularly in relation to grant funding and event income. The charity receives income that may be subject to performance conditions or restrictions on use. Where income is received in advance of the related activities taking place or conditions being met, it is deferred and recognised in future periods. The trustees have assessed each funding stream to determine whether conditions exist that would require income to be deferred, ensuring compliance with applicable accounting standards. This judgement affects the timing of income recognition and, consequently, the reported surplus or deficit for the financial year.

Expenditure and Irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required, and the amount of the obligation can be measured reliably.

Expenditure is classified under the following activity headings:

- Costs of raising funds comprise all costs attributed to the fundraising activities undertaken, including support costs.
- Expenditure on charitable activities includes the costs of information and support events and other educational activities undertaken to further the purposes of the charity and their associated support costs.
- Other expenditure represents those items not falling into any other heading.
- Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

Tangible Fixed Assets

Tangible fixed assets are recorded at cost, including incidental costs of acquiring the asset.

Depreciation is provided so as to write off the cost of the fixed asset, less its estimated residual value, over their expected useful lives using the following basis:

Leasehold Improvements	20% straight line
Fixtures and Fittings (electrical equipment)	20% straight line
Computer Software & Equipment	33% straight line

Stock

Stocks are held on the balance sheet at the lower of cost or net realisable value

Cash at Bank and in Hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a maturity of three months or more from the date of acquisition or opening of the deposit or similar account.

Creditors and Provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

Financial Instruments

The Association only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

Operating Leases

Rentals applicable to operating leases where substantially all the benefits and risks of ownership remain with the lessor are charged to the SOFA on a straight-line basis as they arise.

Grants

Grants are split between current, non-current liabilities and commitments. The provision for a multi-year grant is recognised at its actual value where settlement is due over more than one year from the date of the award, there are no unfulfilled performance conditions that would permit the

charity to avoid making the future payment(s) and settlement is probable. The effect of discounting has been reviewed and is considered immaterial in both current and prior year ends.

2. Legal status of the association

The Association is a company limited by guarantee and has no share capital.

3. Income from Donations and Legacies

Income from donations and legacies was £1,861,573 (**2023**: £1,259,525).

	2024			2023
	Unrestricted	Restricted	Total	Total
	£	£	£	£
Voluntary Fundraising	556,391	5,539	561,930	411,311
Legacies	321,175	-	321,175	243,873
Trusts and Foundations	59,925	210,306	270,231	79,400
In Memoriam	204,154	4,832	208,986	184,534
Personal Donations	208,693	837	209,530	246,314
Direct Mail	15,754	-	15,754	9,871
Unsolicited Donations	105,008	50	105,058	65,728
Major Donors	2,000	-	2,000	2,250
Corporate	7,015	-	7,015	16,245
Research Appeal 2024	-	159,894	159,894	-
Other	-	-	-	-
	1,480,115	381,458	1,861,573	1,259,525

The Association benefits greatly from the involvement and enthusiastic support of its many volunteers, details of which are given in our annual report. In accordance with FRS 102 and the Charities SORP (FRS 102), the economic contribution of general volunteers is not recognised in the accounts.

4. Analysis of Expenditure on Charitable Activities

The following three tables show the total expenditure on charitable funds, then the split between expenditure on unrestricted and restricted funds.

	Research Activities	Info & Support Costs	Volunteer Costs	2024 Total	2023 Total
	£	£	£	£	£
Total Charitable Activities					
Salaries & Wages	40,619	387,062	-	427,681	303,854
Awareness	-	78,952	-	78,952	58,304
Purchases	6,278	143,211	7,690	157,179	196,856
Other Grants	-	10,245	-	10,245	10,731
Research Grants	205,382	-	-	205,382	205,442
Facilities & Infrastructure	1,475	15,250	-	16,725	15,842
Insurances	191	1,977	-	2,168	2,023
IT & Communications	1,577	17,948	-	19,525	31,296
	255,522	654,645	7,690	917,857	823,948

	Research Activities	Info & Support Costs	Volunteer Costs	2024 Total	2023 Total
	£	£	£	£	£
Unrestricted funds					
Salaries & Wages	-	326,252	-	326,252	310,819
Awareness	-	77,194	-	77,194	44,909
Purchases	5,447	108,856	6,397	120,700	109,456
Other Grants	-	4,314	-	4,314	10,481
Research Grants	-	-	-	-	-
Facilities & Infrastructure	1,475	15,250	-	16,725	15,842
Insurances	191	1,977	-	2,168	2,023
IT & Communications	1,577	17,948	-	19,525	31,296
	8,690	551,791	6,397	566,878	524,826

	Research Activities	Info & Support Costs	Volunteer Costs	2024 Total	2023 Total
	£	£	£	£	£
Restricted Funds					
Salaries & Wages	40,619	60,810	-	101,429	(6,965)
Awareness	-	1,758	-	1,758	13,394
Purchases	831	34,355	1,293	36,479	87,001
Other Grants	-	5,931	-	5,931	250
Research Grants	205,382	-	-	205,382	205,442
Facilities & Infrastructure	-	-	-	-	-
Insurances	-	-	-	-	-
IT & Communications	-	-	-	-	-
	246,832	102,854	1,293	350,979	299,122

5. Grant Making Activities

Research grants were awarded by the research committee to fund research projects that have been approved by peer review.

	2024 £	2023 £
Analysis of Grants Paid		
Research Grants	205,382	205,442
Support Grants	10,245	10,231
	215,627	215,672
Grants to Institutions		
University College London	138,177	91,014
University Hospital Southampton	17,480	1,924
University Hospitals Plymouth	-	882
University of Cambridge	41,312	94,075
Various Other Small Grants	8,413	17,547
	205,382	205,442
Support Grants to Individuals	10,245	10,481

Research grants are generally paid quarterly in arrears. Grants can be awarded for a period of up to five years, each grant is different. For administrative reasons it can take some time for the grantee to gain ethical approval and to appoint suitable staff. Consequently, some grants may remain partly unpaid at year end; this may require an adjustment in a subsequent period in this respect. It is generally accepted that the grant is taken up within twelve months of the award date; allowances can be made on approval by the Research Committee and Trustees.

In addition to the expenditure recognised in the accounts, the charity has outstanding commitments to fund PROSPECT full payment of which is contingent on the outcome of annual reviews.

	2024 £	2023 £
Research Commitments		
Payable within one year	248,003	72,916
Payable in years two to five	179,911	245,783
	427,914	318,699

6. Net Income/(Expenditure) For the Year

		2024 £	2023 £
This is after charging:			
Depreciation	Note 12	6,272	5,796
Operating Lease Rental		12,000	11,774
Audit		7,602	7,380
Audit of the financial statements			

7. Analysis of Staff Costs, Trustee Remuneration and Expenses, and the Cost of Key Management Personnel

One employee had remuneration (excluding employer pension costs) in excess of £60,000 (**2023**: 1 employee). The charity Trustees and key management received no personal remuneration benefits during the year (**2023**: £nil). No charity Trustees received payment for professional or other services supplied to the charity (**2023**: £nil).

	2024 £	2023 £
Total staff costs were as follows:		
Salaries & Wages	704,316	599,114
Holiday Pay Accrual	3,362	2,591
Social Security	65,157	57,751
Pension Contributions	12,610	11,051
	785,445	670,507

Trustee expenses of £90 were reimbursed during the year (**2023**: £199). There was no Directors' remuneration during the year.

8. Staff Numbers

	2024 No.	2023 No.
No. of Operational & Admin Staff	16	16
No. of Management Staff	5	4
	<u>21</u>	<u>20</u>

9. Pension Costs

The charity makes contributions for employees to a group personal pension plan. This is a defined contribution scheme administered by Royal London.

10. Related party transactions

Due to the nature of the charity's operations and the composition of the board of Trustees, it is possible that transactions may take place with organisations in which a trustee may have an interest, including the awarding of research grants (see note 5). All grant transactions involving organisations in which a trustee may have an interest follow a strict grant approval process which includes external peer review of applications and the exclusion of any related party trustee from any decision making. Professor Rowe (who resigned from the Board of Trustees in July 2023) is a named Principal investigator on one such grant held by the University of Cambridge. Dr Boyd Ghosh has been awarded small research grants of £2,754 which began in June 2024, £2,915 (approved by the Research Committee on 21st June 2022) and a two-year grant of £58,799 comparing utilisation of health services and quality of life between centres which began in August 2024.

Donations totalling £5,006 were received from Trustees during the year (**2023**: £409)

There were no other related party transactions during the year.

11. Corporation taxation

The charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

12. Tangible Fixed Assets

	Leasehold Improvements £	Computer Equipment £	Fixtures & Fittings £	Total £
COST				
At 1 January 2024	2,958	32,696	19,234	54,888
Additions	-	5,173	493	5,666
Disposals	-	(16,566)	(16,636)	(33,202)
At 31 December 2024	2,958	21,303	3,091	27,352

Depreciation

At 1 January 2024	2,958	22,398	17,387	42,743
Charge for the year	-	5,714	558	6,272
Eliminated on disposals	-	(16,566)	(16,636)	(33,202)
At 31 December 2024	2,958	11,546	1,309	15,813

NET BOOK VALUE

At 31 December 2024	-	9,757	1,782	11,539
At 31 December 2023	-	10,299	1,846	12,145

13. Investments

	Subsidiary Undertaking Shares £
Cost	
At 1 January 2024	100
Additions	-
At 31 December 2024	100
Provision for Diminution in Value	
At 1 January 2024	-
Charge for the Year	-
At 31 December 2024	-
Net Book Value	
At 31 December 2024	100
At 31 December 2023	100

13.1 Holdings of 20% More

The company holds 20% or more of the following companies:

	Country of Incorporation	Nature of Business	Shares Held - Class	Proportion of Voting Rights & Shares Held
Subsidiary Undertaking				
The PSPA Trading Company Ltd (Co Reg No 09030995)	England	Dormant	Ordinary	100%

The aggregate amount of capital and reserves and the results of that undertaking for the last relevant financial year were as follows:

	Capital & Reserves	Profit/Loss on Ordinary Activities before Taxation for the Year
The PSPA Trading Company Ltd	£100	£nil

14. Debtors

	2024 £	2023 £
Other Debtors	-	60
Accrued Investment Income	7,948	14,160
Prepayments and Accrued Income	73,591	34,565
	81,539	48,785

15. Creditors: Amounts Falling Due Within One Year

	2024 £	2023 £
Taxation & Social Security	18,422	14,272
Payroll Creditor	-	(471)
Pension Creditor	-	2,747
Trade Creditors	14,295	34,266
Deferred Income	70,534	-
Accruals	23,167	30,771
Research Accrual	118,109	139,060
	244,527	220,645

16. Analysis of Charitable Funds

Analysis of Charitable Funds	Balance 1 January 2024 £	Incoming Resources £	Resources Expended £	Transfer £	Funds 31 December 2024 £
General Fund	1,696,518	1,581,637	(1,149,956)	(435,957)	1,692,242
Research Fund	-	-	-	435,957	435,957
	1,696,518	1,581,637	(1,149,956)	-	2,128,199

Analysis of Movement in Restricted Funds					
Research	303,467	282,343	(246,832)	-	338,978
Information & Support	111,187	99,115	(104,147)	-	106,155
	414,654	381,458	(350,979)	-	445,133

Research restricted funds include all monies donated to PSPA for research activities which include research grants, information and events such as the International Symposium.

Information and support restricted funds support the delivery of counselling services, on-line exercise classes, the link volunteering programme and PSPA support to carers.

During the year, a transfer of £435,957 was made from the General Fund to the Research Fund to advance our mission of funding innovative research into PSP & CBD. This investment supports ongoing and future research initiatives, driving progress forward. At PSPA, we are committed to empowering our community and giving hope a voice through vital research.

Analysis of net assets between funds 2024:

	General Fund £	Restricted Funds £	Total £
Tangible and Investments Fixed Assets	11,639	-	11,639
Cash at Bank and in Hand	2,319,353	445,133	2,764,486
Other Net Current Assets	(202,793)	-	(202,793)
Total	2,128,199	445,133	2,573,332

Comparative for Analysis of Charitable Funds

	Balance 1 January 2023 £	Incoming Resources £	Resources Expended £	Funds 31 December 2023 £
Analysis of Charitable Funds				
General Fund	1,441,262	1,348,202	(1,092,946)	1,696,518

Analysis of Movement in Restricted Funds

Research	463,569	132,516	(292,618)	303,467
Information & Support	63,291	54,400	(6,504)	111,187
	526,860	186,916	(299,122)	414,654

Analysis of net assets between funds 2023:

	General Fund £	Restricted Funds £	Total £
Tangible and Investments Fixed Assets	12,245	-	12,245
Cash at Bank and in Hand	1,832,656	414,654	2,247,310
Other Net Current Assets	(148,383)	-	(148,383)
Total	1,696,518	414,654	2,111,172

17. Contingent assets

Legacy Income

As of 31 December 2024, the charity had received eight notifications of legacies (**2023**: two)

18. Analysis of Cash and Cash Equivalents

	2024 £	2023 £
Cash at Bank and In Hand	2,702,250	2,247,310
Total Cash and Cash Equivalents	2,702,250	2,247,310

19. Operating Leases

Total rentals payable under operating leases:

	2024 Total	2023 Total
	£	£
Land and buildings		
	12,000	11,774
Current year		
Future Minimum Lease		
Payments Due		
Not Later Than 1 Year	3,000	226
Later Than 1 Year and Not Later Than 5 Years	-	-
Total Payments	15,000	12,000

20. Indemnity insurance

The Charity paid for the insurance premiums to indemnify Trustees, Directors and senior staff from any loss arising from neglect or defaults of Trustees, Directors or staff and any consequent loss. The cost to the Charity was £419 (2023: £534). Premiums are based on the annual income.

21. Non adjusting events after the financial period

Following the year-end, the trustees have proposed the release of funding of up to £350,000 for a three-year research fellowship, scheduled to commence in September 2026. The funding commitment remains subject to final approval and contractual arrangements. As this event occurred after the balance sheet date and no obligation existed at year-end, it is treated as a non-adjusting post balance sheet event.

22. Prior year Statement of Financial Activities

		Unrestricted Funds	Restricted Funds	Total Funds 2023	Total Funds 2022
	Note	£	£	£	£
Income And Endowments					
From:					
Donations and Legacies	3	1,238,684	20,841	1,259,525	1,593,829
Charitable Activities	4	13,632	166,075	179,707	13,007
Other Trading Activities		49,572	-	49,572	5,700
Investments		45,766	-	45,766	2,392
Other		548	-	548	-
Total Income		1,348,203	186,916	1,535,118	1,614,928
Expenditure On:					
Raising Funds		290,412	-	290,412	260,047
Other Trading Activities		7,194	-	7,194	(4,706)
Charitable Activities	5	524,826	299,122	823,948	566,625
Investments		2,828	-	2,828	-
Other		267,687	-	267,687	220,245
Total Expenditure		1,092,946	299,122	1,392,068	1,042,210
Net Income/(Expenditure)		255,256	(112,206)	143,050	572,718
Net Movement in Funds		255,256	(112,206)	143,050	572,718
Reconciliation of Funds:					
Total Funds Brought Forward		1,441,262	526,860	1,968,122	1,395,404
Total Funds Carried Forward		1,696,518	414,654	2,111,172	1,968,122