

**The PSP Association**  
**(A Company limited by guarantee)**  
**Report and Financial Statements**  
**Year ending 31 December 2025**  
**Charity number 1037087**  
**Company number: 2920581**

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## The PSP Association (PSPA) Report of the Trustees for the Year Ending 31 December 2025

The Trustees are pleased to present their annual directors' report together with the financial statements of the charity for the year ending 31 December 2025 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 & CBD and their families to live their best lives possible with high quality support & information.
- Improve the quality of life of people living with PSP & CBD through research and influence.
- Put people living with PSP & 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 two charities of any significant size in the world focussing on PSP & CBD. The other is the USA based charity, CurePSP.

#### PSP & CBD

PSP is a complex neurological condition caused by the death of nerve cells in the brain. It progressively affects movement, balance, cognition, vision, speech and swallowing. It belongs to a category of disorders called Atypical Parkinsons Disorders. It often gets misdiagnosed as Parkinson's disease. 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 (known as 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. Symptoms may include 'alien' movements and tremor in the affected side.

Research by the PROSPECT study, funded by PSPA 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 pre-disposition that makes them more susceptible.

## Review of the Year's Achievements and Performance

### In 2025

- 6,131 individuals were registered to receive support from PSPA, including people living with a PSP or CBD diagnosis, carers, and family members (4,106 in 2024).
- 2,518 Health and Social Care Professionals were registered to receive support and information
- 314 support group meetings took place (246 in 2024).
- 152 people were registered as PSPA volunteers, providing 1,829 hours of volunteering (1,428 in 2024).

The charity continues to be in a strong financial position, and in 2026 we will agree a new 5-year strategy that leverages this financial strength to increase our impact across support, research, and awareness.

Income for the 2025 financial year was £2,074,902 (2024: £1,963,095). The surplus for the year was £380,014 (2024: surplus £462,160).

At the end of 2025 we had 10 research grants in operation (11 in 2024) with a total grant commitment of £450,134.

In December 2025 we were sad to say goodbye after 4 years to our CEO Rebecca Packwood, whilst at the same time being delighted to welcome our incoming CEO, Dr James Cusack.

### Involvement

Our **Service Committee**, made up of people living with PSP & CBD, their carers, family members, and health professionals continued to play a vital role in shaping and reviewing our service provision throughout the year. Their contributions extended beyond core services, offering valuable guidance across a range of charity projects. In 2025 the committee supported the review of the PSPA Voice Banking Service and the Link Volunteer Service, also providing insightful feedback in the review of PSPA podcasts, e-newsletters, the 2025 Patient Survey, and our new Research Strategy.

As part of our commitment to strengthen the voice of people affected by PSP & CBD, in 2025 we continued to build our **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 to improve the design of research projects we support or to include PSP & CBD affected people. The group grew to 12 members and met on 10 occasions during 2025 (9 in 2024). Tasks included advising a researcher on the lay summary of their project, evaluating the new PSPA Research Strategy, and reviewing a total of 15 grant applications.

## Volunteers

Across the UK, our network of volunteers continues to make an invaluable contribution. They lead support groups that enable people affected by PSP and CBD to come together to share tips, form friendships and feel a sense of community. They provide personalised one-to-one support through home visits or phone calls. They also deliver education sessions for Health and Social Care Professionals within care and nursing home settings, and play key roles at fundraising and awareness events.

By the end of 2025, we had 152 registered volunteers who collectively contributed 1,829 hours of service (1,428 in 2024). All volunteers complete induction training, including safeguarding and GDPR, and receive ongoing support and development.

## Improving Care and Support

A key goal within our strategy is to enable people living with PSP & CBD and their families to live their best lives possible, with high quality support and information.

To help achieve this we provide a range of support and information services. These include:

### Helpline

Our confidential helpline operates from 9am to 9pm Monday to Friday. Our Helpline Care Navigators each cover a specific region. They respond to phone and email enquiries, providing emotional support and specialist information and guidance on all aspects of living with PSP or CBD such as symptom management, benefits and entitlements, and overcoming day-to-day challenges. They also make proactive outreach calls people in their region, helping to reduce isolation and loneliness, particularly among carers. Our trained helpline volunteers generously give their time to cover the evening service from 7pm to 9pm.

In 2025 we recruited two additional Helpline Care Navigators to cover Scotland and Wales, enabling us to raise our profile, develop relationships with health and social care professionals, and deliver more tailored support to people affected by PSP and CBD within these nations. This has resulted in a rise in referrals to us from healthcare professionals, enabling people in Scotland and Wales to access our support earlier and at a more appropriate stage in their journey. In Scotland we supported 378 people in 2025 (271 in 2024) and in Wales we supported 228 people (156 in 2024).

In 2025, there were a total of 9,984 phone or email contacts with our helpline (9,578 in 2024).

*"It was good to talk to you; it is comforting knowing that I can call the helpline and talk through my concerns in an understanding and informed way. The information you have sent is very useful, and is clear and well written, without being overwhelming".*

## Support Groups

Our in-person and online support groups provide an opportunity for people affected by PSP & CBD to come together to make connections with others and share information. They include local support groups, regional carers' support groups, a men's carers' support group, and a group for the newly diagnosed.

In 2025 we launched two new online support groups – one for bereaved carers, and one for carers of a loved one living in a care home. We also launched a new local support group in Portsmouth. There were 34 groups in operation by the end of 2025, with 3,161 attendances across 314 support group meetings.

## Support Grants and Voice Banking

Support grants of up to £250 can be used towards items or services which improve the wellbeing and quality of life for people who are living with or affected by PSP or CBD. In 2025 support grants included:

- Spa Day and Afternoon Tea for a carer
- Part payment towards a wheelchair
- Transport to regional support group meetings
- Voice Amplifier to assist with communication

Voice banking, which facilitates the generation of a personalised, synthetic voice when someone loses the ability to speak is also on offer, provided in partnership with 'SpeakUnique'.

143 people were awarded a support grant or accessed voice banking in 2025 (118 in 2024).

## Befriending service

In 2025, following consultation with our existing volunteers and Trustees, we amended the role of Link Volunteer to Befriending Volunteer.

Our Befrienders offer personalised one-to-one support through in-person home visits, regular phone calls or online conversations, ensuring that families affected by PSP & CBD receive companionship, understanding and a listening ear when they need it most.

13 Link Volunteers transitioned into the Befriending Volunteer role, with a further 6 new Befriending Volunteers being recruited and undertaking training at the end of 2025 and into 2026. 25 individuals/families were supported by a Befriending Volunteer in 2025.

## Counselling

Our counselling service is delivered in partnership with Rare Minds and forms part of our Mind, Body and Soul project, which was launched in 2024 following the award of a four year grant from The National Lottery Community Fund.

Specialist support is provided to help people navigate the emotional challenges associated with PSP & CBD and build their resilience. In 2025, 266 counselling sessions were provided for 37 people (22 in 2024) living with PSP or CBD, their carers or family members.

*"I feel that having counselling helped me to accept my condition and gave me a good opportunity to talk about how I feel and how it affects me and my family. I found my counsellor very nice to talk to, they were understanding and kind. I am extremely grateful to have had the opportunity to have counselling."*

## Online exercise classes

Delivered in partnership with Neuro Heroes as part of our Mind, Body and Soul project, these online exercise classes enable people living with PSP & CBD to take part in safe, accessible physical activity from their own homes. Sessions are tailored to individual ability levels and focus on maintaining mobility, improving confidence, and supporting overall wellbeing. For many participants, the classes have become a valued weekly routine that fosters both motivation and connection. 78 people benefited from the classes in 2025 (61 in 2024).

*"Would like to say I have really enjoyed the online exercise classes. It can feel very isolating living with PSP"*

*"These sessions have been of value to me because they have enabled me to overcome some of the demotivation about exercise"*

## Events

We held a Family Day in Milton Keynes, welcoming 58 attendees. The morning programme featured presentations from a leading neurologist, a dietitian, and the CEO of Rare Minds, offering valuable clinical and psychological insights. The afternoon was more interactive, with an engaging exercise session delivered by Neuro Heroes. Throughout the day, attendees also participated in Art Therapy, creating three impressive canvases that are now displayed in the PSPA office.

## PSPA Matters

PSPA Matters is our quarterly magazine keeping the PSPA community up to date with news and information about support, research, awareness raising and fundraising activities. Each edition was sent to approximately 11,400 people, either by email or post (10,300 in 2024).

## Funding and Promoting Research

### Research Strategy

2025 saw the end of our 2020-2025 Research Strategy and the creation of the 2026-2030 strategy. Titled '*Research for Impact*', the new strategy covers the three domains of Diagnosis, Treatment and Care.

Projects funded under the new strategy should either lead to or be working towards research to improve 1) earlier, accurate diagnosis; 2) effective symptomatic or disease modifying treatments or, 3) establishing and enhancing care standards for everyone living with PSP & CBD.

Our new strategy can be found here:

<https://www.pspassociation.org.uk/research/research-information/research-strategy/>

### Research Committee

Our research investments are overseen by the PSPA Research Committee with Professor Karen Morrison completing her first full year as the committee chair. We also welcomed several new committee members, Professor Maria Grazia Spillantini and Dr Kathryn Bowles as experts in the field, as well as Professor Heather Angus-Leppan and Fiona Lindop MBE as trustees on the committee. We would like to thank Professor Wendy Noble who stepped down in 2025 for her time and expertise on the committee.

## Communication of Research

In 2025 we held three well-attended online research information sessions for people living with PSP & CBD as well as their carers, family members and friends (two in 2024). Fifteen academics, clinicians and students shared their research projects and answered questions from the audience. These sessions are available to watch on our website.

We also released a podcast on brain donation, as well as featuring research participants experience of what it's like to take part in a clinical trial in PSPA Matters.

## Research Participation

We continue to signpost PSPA members to active research studies, facilitated via an online 'expression of interest in research' form (also available by post). Each month the research coordinator shares encrypted details from consenting members with study coordinators working on different studies across the UK. We also share new opportunities for research participation on our social media channels, through our website, and in PSPA Matters.

- In 2025 we were involved in signposting interested members to a clinical trial called The PROSPER Study, a Phase 2 clinical trial run by Ferrer to evaluate how safe and effective a medicine called FNP-223 may be in treating PSP.
- A highlight has been working alongside Durham University academic Professor Daniel Smith on a project examining the effectiveness of PRISM glasses. We sent questionnaires to those who have received PRISM glasses from PSPA to evaluate how easy they are to use and identify improvements.

## Projects Completed in 2025

Research completed in 2025 has delivered significant scientific and translational impact:

- Dr Edwin Jabbari: Using a novel 4-repeat tau seed amplification assay (SAA) to enhance the diagnosis and predict the progression of PSP. Dr Jabbari's project has led to further £2.3 million MRC Clinician Scientist Fellowship which will begin in August 2026 to continue this work. He also received the highly prestigious junior award at the International Movement Disorders Society conference and gave a platform talk on this work as well as publishing two papers (<https://movementdisorders.onlinelibrary.wiley.com/doi/full/10.1002/mds.30019>, [https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(25\)00157-7/fulltext](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(25)00157-7/fulltext)). The SAA shows high specificity in post-mortem tissue and work is ongoing to replicate this in ante-mortem spinal fluid samples.
- Dr Mansoureh Hnazaee: Non-invasive neurophysiological assessment of the human brain stem in vivo. Dr Hnazaee's project concluded early in 2025, with a publication in production. A poster was also presented at the MEGUKI conference in Birmingham.
- Dr Pat Cullinane: Nanopore sensing of tau post-translational modifications.

These projects have laid important foundations for future clinical and biomarker development.

Our PSPA Fellow, Dr Rob Durcan, resigned in August 2025 two years into his fellowship, after being offered a prestigious role close to his family in Ireland. Whilst this means we are no longer paying for the third year of the fellowship, Dr Durcan is committed to completing

the research (with the support of his supervisor at Cambridge University) and will continue to be involved with PSPA in his new role as a consultant neurologist in Ireland.

## Research Grants

In 2025 we invested £100,000 in four Small Grants of ~£25,000. The projects funded include research into understanding astrocyte cells; investigating protein imbalance in PSP; using a smartphone application and artificial intelligence to improve PSP diagnosis; and understanding the role of the TRIM11 gene in PSP. The four grants were selected from ten applications and in November, the awardees had the opportunity to present their projects in person to donors, trustees and staff at an event in London.

We also awarded two Large Grants (totalling £433,357), selected from five full grant applications. The volume of grant applications in 2025 is evidence that we are increasing our visibility as a research funder in the academic community.

## Future Research Activities

2026 will be a big year for PSPA research. As well as presenting a poster at a prestigious neurological conference in Copenhagen using data from the 2025 PSPA Member Survey, we will also be co-hosting Neuro26, an international symposium focused on PSP & CBD to be held in London in November 2026.

There are also plans to award further Small Grants with the remainder of the funds raised by the Understood Appeal.

## Awareness Raising, Policy and Influencing

In 2025 we continued to build our Policy and Influencing capacity as part of our long-term strategy to improve awareness of PSP & CBD and bring systems change for people affected by the conditions.

### Raising Awareness among Health and Social Care Professionals

PSP & CBD are relatively rare conditions, and many health and social care professionals have limited experience in supporting those affected. Through our information resources and education programmes, we help professionals develop a deeper understanding of the care needs of people living with PSP or CBD.

In 2025, we introduced a series of shorter, targeted online education sessions through our new PSPA Masterclasses. These sessions were designed to equip frontline professionals with the knowledge needed to reduce delays in diagnosis and to support effective symptom management. The Masterclass topics included Neuro Orthoptics in PSP & CBD, Diagnosing PSP & CBD, and Falls & Mobility Management in PSP & CBD. A total of 1,032 professionals registered for these sessions (436 received training in 2024).

*“Many thanks for a very practical and informative session. The videos brought to life the complexities that people with these conditions suffer, and I have recommended this masterclass to several of my colleagues.”*

We also continue to publish a wide range of free resources to support health and social care professionals in their work with individuals living with PSP or CBD. In 2025, 1,085 new professionals joined our network (396 in 2024), bringing the total to 3,028. Expanding this network remains central to raising awareness and improving the quality of care available across the UK.

## Policy and influencing

Early in the year, we published our first policy report on the State of NHS Continuing Healthcare. Drawing on the lived experiences of the PSP & CBD community alongside national NHS data, the report highlighted nationwide challenges within NHS Continuing Healthcare (CHC). These included a fall in the number of people receiving CHC to fewer than one in five of those assessed, significant delays, and wide postcode variation across the country.

The report's recommendations formed the basis of our campaign for PSP & CBD Awareness Week in June, #FixCHC. Supporters were encouraged to write to their Member of Parliament sharing their own experiences of CHC and calling for a change. As a result, 260 PSPA supporters wrote to their MP and the campaign led to written parliamentary questions being raised with the Department for Health & Social Care.

During the year, we also launched the PSPA Survey 2025, which significantly expands on our previous surveys conducted in 2016 and 2022. More than 750 people living with PSP or CBD and their carers completed the survey. It explores experiences of diagnosis, living with the conditions, interactions with health and care services, and wider quality of life. The findings will provide PSPA with robust, up-to-date evidence to inform our future policy and influencing priorities.

In addition, we made submissions to several key government consultations and parliamentary inquiries, including the Department for Work & Pensions Pathways to Work Green Paper and the House of Commons Health & Social Care Committee's inquiry into adult social care, as well as sending a briefing to Members of Parliament on the passage of the Terminally Ill Adults (End of Life) Bill.

To maximise our impact, PSPA continued to collaborate with national and international organisations including the Neurological Alliances of England, Scotland, Wales and Northern Ireland; and the Care & Support Alliance, Disability Benefit Alliance and CurePSP in the United States.

## Plans and Priorities

Building on this work, our policy and influencing priorities for 2026 and beyond will focus on strengthening our evidence base and raising awareness of PSP & CBD among decision-makers and healthcare professionals:

1. Improving and communicating our evidence base, including:
  - Publishing a report on the findings and insights from the PSPA Survey 2025.
  - Producing a state of awareness report to highlight the low levels of knowledge of PSP & CBD amongst healthcare professionals.
  - Publishing a further in-depth policy report in the second half of the year.
2. Raising awareness of PSP & CBD among decision-makers & healthcare professionals:
  - Hosting a parliamentary event to raise awareness of PSP & CBD and how MPs can support affected constituents.
  - Having a presence at the major party-political conferences and key professional body conferences and congresses throughout 2026.

## Environmental Commitments

In 2025 we maintained our commitment to reducing our carbon footprint. We continued to encourage people to download publications and receive our quarterly magazine PSPA Matters electronically and we have seen a considerable increase in downloads from our website across all our publications.

We rent office space in serviced offices so cannot 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 grateful to all donors, trusts, and foundations whose support makes our work possible.

We thank those who have taken on challenges or dedicated their time to fundraising, the National Lottery Community Fund for their multi-year grants, and everyone who has remembered the charity through a legacy.

We are also deeply appreciative of our volunteers for their commitment and contribution throughout 2025.

## Plans and Priorities– 2026 onwards

After an exciting five years, we will be developing a new organisation strategy in 2026. This will be an opportunity for PSPA to strengthen existing activities and reflect on new areas of opportunity for the charity.

**We have already established the following activities as priorities for 2026:**

### 1. Establishing a Community of Practice

A peer-led group of health and social care professionals with a shared passion for improving care and symptom management in PSP & CBD. We plan to do this by bringing together experts to share their knowledge with other health professionals wishing to advance their skills and practice.

### 2. Expanding our reach

To strengthen awareness and engagement in areas of the UK where PSPA has historically had lower visibility, our Helpline Care Navigators will deliver a series of regional in-person events. Each Helpline Care Navigator will host an event within their region, ensuring that communities with lower engagement receive focused attention. These regional events will play a key role in **raising awareness of PSP & CBD**, strengthening professional understanding, and helping families connect with PSPA earlier in their journey.

### 3. Accreditation for our volunteering service and our patient facing resources

We will be working towards achieving two important quality standards - the Investing in Volunteers (IiV) kitemark and the Patient Information Forum PiF Tick for our patient-facing information.

- ✓ Gaining the IiV kitemark will demonstrate our commitment to providing high quality, well-supported volunteering experience and will help ensure that our volunteers feel valued, equipped, and confident in their roles.

- ✓ Securing the PiF Tick will provide external assurance that our information for people affected by PSP & CBD meets recognised standards of accuracy, clarity, accessibility, and relevance. This accreditation will strengthen trust in our resources and reinforce our commitment to delivering reliable, evidence-based information that empowers individuals and families.

## 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 2025 (one in 2024).

We are committed to a wide range of income streams in order to increase our sustainability and long-term future. We do not receive any routine statutory funding. Our fundraising strategy focuses on building long-term support across our fundraising streams.

## Financial Review

2025 was a successful year for fundraising, with total income exceeding £2million for the first time.

Donations and legacy contributions totalled £1,983,136 (£1,861,573 in 2024) although legacy income fell to £178,817 (£321,175 in 2024), demonstrating the unpredictability of this income stream.

Voluntary fundraising experienced significant growth, reaching £633,262 (£561,930 in 2024), influenced by our partnership with Run for Charity which enabled us to increase the range of running events available for fundraisers to participate in, and the successful Pathway to Progress campaign (our re-branded Walk for Hope).

Support for our Understood Research Appeal was generous with £337,184 raised in 2025 (£159,894 in 2024).

Thanks to the generosity of our supporters, we produced a strong surplus of £380,014 (£462,160 in 2024) despite the planned increase in the cost base in the year to support additional funding of awareness raising and research spending in 2026 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

PSPA maintains reserves to ensure it can continue operating effectively during periods of fluctuating income. Our policy, benchmarked against similar-sized charities, requires general reserves equivalent to nine months of budgeted fixed costs. We currently hold general reserves above this level (equivalent to 10.6 months budgeted fixed costs) due to successive years of higher than budgeted income, and lower than anticipated expenditure (a result of staff vacancies and delayed payments of research grants).

Trustees have agreed a planned and controlled approach to reducing our general reserves. This will be achieved through increased investment in support, influencing and research activities. Trustees will continue to monitor reserves levels closely to ensure reserves are brought back in line with the policy over an appropriate timeframe.

PSPA's funds are allocated to three specific reserves:

- Restricted Reserve: unspent funds held for research and service delivery programs, which can only be used for the intended purposes outlined by the funders.
- Designated Reserve: funds set aside for the charity's research strategy.
- General Reserves: unrestricted funds that safeguard operations and cover at least nine months of fixed costs.

The Trustees have considered the impact of economic pressures on our finances and, given the strength of our reserves and cash liquidity, are confident the charity can continue to meet its obligations.

Reserve levels are reviewed regularly by the Finance, Audit, and Risk Committee, and the policy is formally reviewed each year to ensure it continues to support PSPA's strategic and operational needs.

The Charity's reserves levels as of 31 December 2025 were as follows:

- Restricted Reserve: £682,644 (2024: £445,133).
- Designated Reserve: £435,597 (2024: £435,957).
- General Reserve £1,834,745 (2024: £1,692,242)

## 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 three 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*).

##### Nominations 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 includes a minimum of three members of the board and is chaired by the chair of the board (except for the recruitment of a new board chair). 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 was created to ensure continuous improvement of quality and standards across the charity's services provision. The committee is 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 Service Development and Improvement.

#### 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 the Nominations Committee.

New trustees are appointed for a 3-year term, which may be extended by mutual agreement for a second period of three years. The chair is appointed for a non-renewable term of five years. Where the board of trustees agree it is appropriate the term may be extended for a further period of one year.

#### 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, along with the strategy, 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 from 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 : 20 May 2026

## 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

Unity Bank Four Brindleyplace, Birmingham, B1 2JB.

### Trustees

who are also directors under company law, who served during the year were as follows:

Rowena Ironside (Chair)

James Noble (Resigned June 2025)

Jon Garrard

Dr Boyd Ghosh

Alison Goold (Treasurer)

Maria Tennant

Greg Richardson

John Redfern (Appointed 1 January 2025)

Thomas Whittle (Appointed 1 January 2025)

Fiona Lindop (Appointed 1 April 2025)

Prof Heather Angus-Leppan (Appointed 1 April 2025)

**Company Secretary:** James Cusack (Appointed 1 December 2025)

Rebecca Packwood (Resigned 30 November 2025)

### Key Management Personnel:

Chief Executive Officer: James Cusack (Appointed 1 December 2025)

Rebecca Packwood (Resigned 30 November 2025)

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

### Research Committee

Prof Karen Morrison (Chair)

Prof Johannes Attems

Dr Boyd Ghosh

Prof Peter Garrard

**Dr Maura Malpetti**

**Dr Vicky Marshall**

**Prof Wendy Noble**

**Prof Huw Morris**

**Dr Kathryn Bowles (Appointed January 2025)**

**Prof Maria Grazia Spillantini (Appointed 1 January 2025)**

**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 2025 which comprise the balance sheet, 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 2025 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.

### 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 annual report other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. 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, which includes the directors' report prepared for company law purposes, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report included within the trustees' report has been prepared in accordance with applicable legal requirements.

#### **Matters on which we are required to report by exception**

In the light of the 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 trustees' 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 requires 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 trustees' 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 it 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.

The extent to which our procedures 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 and 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 indication 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 control.
- Obtain an understanding of internal control 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 control.
- 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.

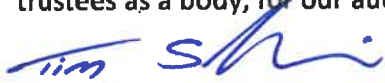
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

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.

A further description of our responsibilities is located on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

### Use of our report

This report is made solely to the charitable company's directors, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, and 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: 21/5/21

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 2025

		Unrestricted Funds	Restricted Funds	Total Funds 2025	Total Funds 2024
	Note	£	£	£	£
<b>Income And Endowments</b>					
<b>From:</b>					
Donations and Legacies	3	1,410,143	572,993	1,983,136	1,861,573
Charitable Activities		-	-	-	-
Other Trading Activities		14,486	-	14,486	22,743
Investments		77,280	-	77,280	78,779
Other		-	-	-	-
<b>Total Income</b>		<b>1,501,909</b>	<b>572,993</b>	<b>2,074,902</b>	<b>1,963,095</b>
<b>Expenditure On:</b>					
Raising Funds	4	487,651	-	487,651	345,107
Other Trading Activities		12,266	-	12,266	15,668
Charitable Activities	4	859,489	335,482	1,194,971	917,857
Investments		-	-	-	29
Other		-	-	-	222,274
<b>Total Expenditure</b>		<b>1,359,406</b>	<b>335,482</b>	<b>1,694,888</b>	<b>1,500,935</b>
<b>Net Income/(Expenditure)</b>		<b>142,503</b>	<b>237,511</b>	<b>380,014</b>	<b>462,160</b>
<b>Net Movement in Funds</b>		<b>142,503</b>	<b>237,511</b>	<b>380,014</b>	<b>462,160</b>
<b>Reconciliation of Funds:</b>					
Total Funds Brought Forward		2,128,199	445,133	2,573,332	2,111,172
<b>Total Funds Carried Forward</b>		<b>2,270,702</b>	<b>682,644</b>	<b>2,953,346</b>	<b>2,573,332</b>

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 2024 is shown in note 21.

The notes on pages 27-40 form part of these financial statements.

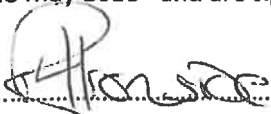
## The PSP Association Balance Sheet as at 31 December 2025

	Note	2025 £	2024 £
<b>Fixed Assets:</b>			
Tangible Assets	12	8,476	11,539
Investments	13	100	100
<b>Total Fixed Assets</b>		<b>8,576</b>	<b>11,639</b>
<b>Current Assets:</b>			
Stock		17,990	22,431
Debtors	14	-	-
Accrued Investment Interest	14	22,827	7,948
Prepayments and accrued income	14	155,782	73,591
Cash at Bank and in Hand.		2,820,599	2,702,250
<b>Total Current Assets</b>		<b>3,017,198</b>	<b>2,806,220</b>
<b>Liabilities:</b>			
Creditors: Amounts Falling Due Within One Year	15	(72,428)	(244,527)
<b>Net Current Assets</b>		<b>2,944,770</b>	<b>2,561,693</b>
<b>Total Net Assets or Liabilities</b>		<b>2,953,346</b>	<b>2,573,332</b>
<b>The Funds of the Charity:</b>			
Restricted Income Reserves	16	682,644	445,133
Designated Reserves	16	435,957	435,957
General Unrestricted Reserves	16	1,834,745	1,692,242
<b>Total Charity Funds</b>		<b>2,953,346</b>	<b>2,573,332</b>

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

20 May 2026 and are signed on their behalf by:

  
.....

**Rowena Ironside**

  
.....

**Thomas Whittle**

## The PSP Association Statement of Cash Flows for the Year Ending 31 December 2025

	2025	2024
	Total	Total
Note	£	£
<b>Cashflows from Operating Activities:</b>		
<b>Net Cash Provided By (In Use) Operating Activities</b>	<b>380,014</b>	<b>462,160</b>
<b>Adjustments to cash flows from non-cash items</b>		
Investment income	(77,280)	(78,779)
Depreciation	7,878	6,272
<b>12</b>	<b>310,612</b>	<b>389,653</b>
<b>Working capital adjustments</b>		
(Increase)/decrease in stock	4,441	1,046
(Increase)/decrease in debtors	(97,070)	(32,754)
Increase/(decrease) in creditors	(172,099)	23,882
	<b>45,884</b>	<b>381,827</b>
<b>Cashflows From Investing Activities:</b>		
Dividends, Interest and Rents from investments	77,280	78,779
Purchases of Property, Plant and Equipment	(4,815)	(5,666)
<b>12</b>	<b>72,465</b>	<b>73,113</b>
Change in Cash and Cash Equivalents in the Reporting Period	118,349	454,940
<b>Cash at Bank and in Hand Less Overdrafts at the Beginning of the Year</b>	<b>2,702,250</b>	<b>2,247,310</b>
<b>18</b>	<b>2,820,599</b>	<b>2,702,250</b>
<b>Cash at Bank and in Hand Less Overdrafts at Year End</b>	<b>2,820,599</b>	<b>2,702,250</b>
<b>18</b>		

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 £118,349 for the year. (2024 £454,940). 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 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 affect only that period, or in the period of the revision and future periods where the revisions affect 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.
- Support costs include the costs of general management (including finance, IT and HR).
- Governance costs include the costs of compliance with constitutional and statutory requirements, external audit and the cost of legal advice for the Trustees, as well as staff time spent on governance matters.
- Governance and support costs are allocated to the Charity's activities based on staff per capita per department.
- Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.
- Other expenditure represents those items not falling into any other heading.

### **Tangible Fixed Assets**

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

Depreciation is provided 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 estimated selling price less costs to complete and sell.

### **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 except for 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 typically awarded for research projects extending over more than one financial year and are paid in instalments subject to agreed milestones and continuing eligibility.

Grant expenditure is recognised when the charity has a present legal or constructive obligation to make a payment, settlement is probable, and the amount can be measured reliably.

Where grant awards are subject to performance-related or other conditions, no liability is recognised for amounts relating to conditions that have not been met.

Grant liabilities are recognised at the best estimate of the amount payable and are included within creditors. Amounts falling due within one year and after more than one year are disclosed separately where material. 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 £1,983,136 (2024: £1,861,573).

	Unrestricted	2025 Restricted	Total	2024 Total
	£	£	£	£
Voluntary Fundraising	624,614	8,648	<b>633,262</b>	561,930
Legacies	157,817	21,000	<b>178,817</b>	321,175
Trusts and Foundations	44,342	176,783	<b>221,125</b>	270,231
In Memoriam	225,374	12,310	<b>237,684</b>	208,986
Personal Donations	234,017	1,484	<b>235,501</b>	209,530
Direct Mail	12,231	130	<b>12,361</b>	15,754
Unsolicited Donations	95,425	3,954	<b>99,379</b>	105,058
Major Donors	5,000	2,000	<b>7,000</b>	2,000
Corporate	11,323	9,500	<b>20,823</b>	7,015
Research Appeal 2024	-	337,184	<b>337,184</b>	159,894
	<b>1,410,143</b>	<b>572,993</b>	<b>1,983,136</b>	<b>1,861,573</b>

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	2025 Total	2024 Total
	£	£	£	£	£
<b>Total Charitable Activities</b>					
Salaries & Wages	43,041	488,922	-	531,963	427,681
Awareness	-	126,884	-	126,884	78,952
Purchases	26,526	154,274	16,762	197,562	157,179
Other Grants	-	14,933	-	14,933	10,245
Research Grants	74,758	-	-	74,758	205,382
Share of Support Costs	15,655	227,004	-	242,659	38,418
Share of Governance	401	5,811	-	6,212	-
	<b>160,381</b>	<b>1,017,828</b>	<b>16,762</b>	<b>1,194,971</b>	<b>917,857</b>

	Research Activities	Info & Support Costs	Volunteer Costs	2025 Total	2024 Total
	£	£	£	£	£
<b>Charitable Activities Unrestricted funds</b>					
Salaries & Wages	-	446,200	-	446,200	326,252
Awareness	-	126,884	-	126,884	77,194
Purchases	1,191	28,242	7,799	37,232	120,700
Other Grants	-	302	-	302	4,314
Research Grants	-	-	-	-	-
Share of Support costs	15,655	227,004	-	242,659	38,418
Share of Governance	401	5,811	-	6,212	-
	<b>17,247</b>	<b>834,443</b>	<b>7,799</b>	<b>859,489</b>	<b>566,878</b>

	Research Activities	Info & Support Costs	Volunteer Costs	2025 Total	2024 Total
	£	£	£	£	£
<b>Charitable Activities</b>					
<b>Restricted Funds</b>					
Salaries & Wages	43,041	42,722	-	85,763	101,429
Awareness	-	-	-	-	1,758
Purchases	25,335	126,032	8,963	160,330	36,479
Other Grants	-	14,631	-	14,631	5,931
Research Grants	74,758	-	-	74,758	205,382
Share of Support Costs	-	-	-	-	-
Share of Governance	-	-	-	-	-
	<b>143,134</b>	<b>183,385</b>	<b>8,963</b>	<b>335,482</b>	<b>350,979</b>

## Raising Funds

### Unrestricted Funds

	2025	2024
Salaries	237,842	195,466
Purchases	153,471	130,002
Share of Support Costs	93,933	19,639
Share of Governance Costs	2,405	-
	<b>487,651</b>	<b>345,107</b>

## 5. Grant Making Activities

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

	2025	2024
	£	£
<b>Analysis of Grants Paid</b>		
Research Grants	74,758	205,382
Support Grants	14,933	10,245
	<b>89,691</b>	<b>215,627</b>
<b>Grants to Institutions</b>		
University College London	(19,657)	138,177
University Hospital Southampton	19,404	17,480
University of Cambridge	66,018	41,312
Various Other Small Grants	8,993	8,413
	<b>74,758</b>	<b>205,382</b>
<b>Support Grants to Individuals</b>	<b>14,933</b>	<b>10,245</b>

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.

	2025 £	2024 £
<b>Research Commitments</b>		
Payable within one year	197,592	248,003
Payable in years two to five	569,878	179,911
	<u>767,470</u>	<u>427,914</u>

## 6. Net Income/(Expenditure) For the Year

	2025 £	2024 £
<b>This is after charging:</b>		
Depreciation	Note 12 7,878	6,272
Operating Lease Rental	12,000	12,000
Audit of the financial statements	7,908	7,602

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

One employee had remuneration (excluding employer pension and NI costs) between £70,000-£79,999 (2024: one employee). The total employee benefits (including pension contributions and employer's NI) of the Senior Management Team was £333,363 (2024 £329,894).

The charity Trustees and key management received no personal remuneration benefits during the year (2024: £nil). No charity Trustees received payment for professional or other services supplied to the charity (2024: £nil).

	2025 £	2024 £
<b>Total staff costs were as follows:</b>		
Salaries & Wages	828,904	704,316
Holiday Pay Accrual	1,371	3,362
Social Security	89,565	65,157
Pension Contributions	16,045	12,610
	<u>935,885</u>	<u>785,445</u>

Trustee expenses of £183 were reimbursed during the year (2024: £90). There was no Directors' remuneration during the year.

## 8. Staff Numbers

	2025 No.	2024 No.
No. of Operational & Admin Staff	20	16
No. of Management Staff	5	5
	25	21

## 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) was a named Principal investigator on one such fellowship grant held by the University of Cambridge, which ended in August 2025. 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 21<sup>st</sup> 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 £1,719 were received from Trustees during the year (2024: £5,006)

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 £
<b>COST</b>				
At 1 January 2025	2,958	21,303	3,091	27,352
Additions	-	4,815	-	4,815
Disposals	-	-	(310)	(310)
<b>At 31 December 2025</b>	<b>2,958</b>	<b>26,118</b>	<b>2,781</b>	<b>31,857</b>
<b>Depreciation</b>				
At 1 January 2025	2,958	11,546	1,309	15,813
Charge for the year	-	7,322	556	7,878
Eliminated on disposals	-	-	(310)	(310)
<b>At 31 December 2025</b>	<b>2,958</b>	<b>18,868</b>	<b>1,555</b>	<b>23,381</b>
<b>NET BOOK VALUE</b>				
At 31 December 2025	-	7,250	1,226	8,476
At 31 December 2024	-	9,757	1,782	11,539

## 13. Investments

	Subsidiary Undertaking Shares £
<b>Cost</b>	
At 1 January 2025	100
Additions	-
<b>At 31 December 2025</b>	<b>100</b>
<b>Provision for Diminution in Value</b>	
At 1 January 2025	-
Charge for the Year	-
<b>At 31 December 2025</b>	<b>-</b>
<b>Net Book Value</b>	
At 31 December 2025	100
At 31 December 2024	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
<b>Subsidiary Undertaking</b>				
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
	£100	£nil
The PSPA Trading Company Ltd		

## 14. Debtors

	2025	2024
	£	£
Other Debtors	-	-
Accrued Investment Income	22,827	7,948
Prepayments and Accrued Income	155,782	73,591
	<b>178,609</b>	<b>81,539</b>

## 15. Creditors: Amounts Falling Due Within One Year

	2025	2024
	£	£
Taxation & Social Security	22,951	18,422
Payroll Creditor	-	-
Pension Creditor	-	-
Trade Creditors	6,938	14,295
Deferred Income	-	70,534
Accruals	13,882	23,167
Research Accrual	26,116	118,109
Other Creditors	2,541	-
	<b>72,428</b>	<b>244,527</b>

## 16. Analysis of Charitable Funds

Analysis of Charitable Funds	Balance 1 January 2025 £	Incoming Resources £	Resources Expended £	Transfer £	Funds 31 December 2025 £
General Fund	1,692,242	1,501,909	(1,359,406)		1,834,745
Research Fund	435,957	-	-	-	435,957
	<b>2,128,199</b>	<b>1,501,909</b>	<b>(1,359,406)</b>	<b>-</b>	<b>2,270,702</b>
<b>Analysis of Movement in Restricted Funds</b>					
Research	338,978	467,641	(143,134)	-	663,485
Information & Support	106,155	105,352	(192,348)	-	19,159
	<b>445,133</b>	<b>572,993</b>	<b>(335,482)</b>	<b>-</b>	<b>682,644</b>

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 are used to deliver the charity's information and support activities. These include the provision of advice, information and guidance, helpline and support services, education and awareness-raising, policy and influencing activity, and support for beneficiaries and those who care for them.

The Designated Research fund forms part of the Research Appeal and will be used to fund future research activities and initiatives.

### Analysis of net assets between funds 2025:

	General Fund £	Restricted Funds £	Total £
Tangible and Investments Fixed Assets	8,576	-	8,576
Cash at Bank and in Hand	2,137,955	682,644	2,820,599
Other Net Current Assets	124,171	-	124,171
<b>Total</b>	<b>2,270,702</b>	<b>682,644</b>	<b>2,953,346</b>

## Comparative for 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	435,597
	<b>1,696,518</b>	<b>1,581,637</b>	<b>(1,149,956)</b>	-	<b>2,128,199</b>
<b>Analysis of Movement in Restricted Funds</b>					
Research	303,467	282,343	(246,832)	-	338,978
Information & Support	111,187	99,115	(104,147)	-	106,155
	<b>414,654</b>	<b>381,458</b>	<b>(350,979)</b>	-	<b>445,133</b>

## 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)
<b>Total</b>	<b>2,128,199</b>	<b>445,133</b>	<b>2,573,332</b>

## 17. Contingent assets

### Legacy Income

As of 31 December 2025, the charity had received 10 notifications of legacies (2024: 8)

## 18. Analysis of Cash and Cash Equivalents

	2025 £	2024 £
Cash at Bank and In Hand	2,820,599	2,702,250
<b>Total Cash and Cash Equivalents</b>	<b>2,820,599</b>	<b>2,702,250</b>

## 19. Operating Leases

Total rentals payable under operating leases:

	2025	2024
	£	£
<b>Land and buildings</b>		
Current year	12,000	12,000
<b>Future Minimum Lease Payments Due</b>		
Not Later Than 1 Year	16,741	3,000
Later Than 1 Year and Not Later Than 5 Years	4,537	-
<b>Total Payments</b>	<b>33,278</b>	<b>15,000</b>

## 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 £654 (2024: £419). Premiums are based on the annual income.

## 21. Prior year Statement of Financial Activities

		Unrestricted Funds	Restricted Funds	Total Funds 2024	Total Funds 2023
	Note	£	£	£	£
<b>Income And Endowments</b>					
<b>From:</b>					
Donations and Legacies	3	1,480,115	381,458	1,861,573	1,259,525
Charitable Activities	4	-	-	-	179,707
Other Trading Activities		22,743	-	22,743	49,572
Investments		78,779	-	78,779	45,766
Other		-	-	-	548
<b>Total Income</b>		<b>1,581,637</b>	<b>381,458</b>	<b>1,963,095</b>	<b>1,535,118</b>
<b>Expenditure On:</b>					
Raising Funds		345,107	-	345,107	290,412
Other Trading Activities		15,668	-	15,668	7,194
Charitable Activities	5	566,878	350,979	917,857	823,948
Investments		29	-	29	2,828
Other		222,274	-	222,274	267,687
<b>Total Expenditure</b>		<b>1,149,956</b>	<b>350,979</b>	<b>1,500,935</b>	<b>1,392,068</b>
<b>Net Income/(Expenditure)</b>		<b>431,681</b>	<b>30,479</b>	<b>462,160</b>	<b>143,050</b>
<b>Net Movement in Funds</b>		<b>431,681</b>	<b>30,479</b>	<b>462,160</b>	<b>143,050</b>
<b>Reconciliation of Funds:</b>					
Total Funds Brought Forward		1,696,518	414,654	2,111,172	1,968,122
<b>Total Funds Carried Forward</b>		<b>2,128,199</b>	<b>445,133</b>	<b>2,573,332</b>	<b>2,111,172</b>