



**The PSP Association**

**(A Company limited by guarantee)**

**Report and Financial Statements**

**Year ending 31 December 2023**

**Charity number 1037087**

**Company number: 2920581**

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## The PSP Association (PSPA) Report of the Trustees for the Year Ending 31 December 2023

The Trustees are pleased to present their annual directors' report together with the financial statements of the charity for the year ending 31 December 2023 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 neurological condition caused by the progressive death of nerve cells in the brain. There is no treatment to reduce the progression of the disease. The average life expectancy from the onset of symptoms is seven years and current treatments are therefore limited to the management of symptoms. It is often misdiagnosed (60% of respondents to our 2022 survey said they had been misdiagnosed), most commonly as Parkinson's Disease.

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, and symptoms may also 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

In 2023

- 3,538 individuals were supported by PSPA, including carers and family members.
- 1,888 Health and Social Care Professionals registered to receive support and information.
- 214 people were supported to access statutory funding.
- 141 regional group meetings took place (116 in 2022).
- 196 people were registered as PSPA volunteers (145 in 2022).

The charity remains in good financial health which will enable us to be more ambitious with our strategy. At the end of the 2023 financial year income was £1,535,119 (**2022**: £1,614,928). The surplus for the year was £143,051 (**2022**: surplus £572,718). The Board of Trustees is committed to increasing investment in research and returning to pre-pandemic plans for expansion of the research programme. Our reserves policy requires us to hold 9 months reserves.

By the end of 2023 we had six research grants in operation including a new Fellowship. We had also appointed a Director of Policy and Influencing as part of our plan to invest in improving our awareness raising and having a greater input into policy developments that could improve quality of life or support research.

## Improving Care and Support

*Many thanks to PSPA for funding the voice repair and for all the support through the monthly online zoom meetings for carers, it's very helpful to hear from others in a similar position.*

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
- Our new Link Volunteer service
- Support groups both in person and on-line
- Support grants and voice banking
- Carers support groups
- Podcasts
- PSPA Matters magazine.

Results from our survey in 2022 showed that 72% of people rated PSPA services as good or excellent. 46% of responders use between three and six PSPA services. The most used services are PSPA

Matters and the Helpline. Satisfaction was highest with the Helpline and lowest with the Website. In 2023 we made changes to the website, including a mega menu to improve navigation as a result of the feedback. Improvements to the website will continue in 2024.

## Involvement

This year saw the launch of our Services Committee, providing people living with PSP or CBD, their carers and Health and Social Care professionals the opportunity to input into the design, evaluation and development of services. The committee currently has eight members and met twice in 2023 supporting the development of the carers survey.

## Volunteers

Volunteers are crucial to our ability to support people in their community and to help raise awareness. They provide vital support in running regional groups, leading education sessions for Health and Social Care Professionals in a care/nursing home setting and in our new 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 2023 we have 196 registered volunteers.

## Helpline

*"I have contacted you quite a few times for help and advice for my dad who had PSP, however sadly died. I just wanted to thank you so much for all the support and advice you have given me to help my dad so he could be as comfortable as possible"*

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.

In 2023 there were 10,334 contacts with the helpline (phone and email) an increase of 11% from 2022.

## Link Volunteer Service

Thanks to a grant from 'Global Make Some Noise' we launched a new 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 first year of the service, we have recruited 12 volunteers and 11 people living with PSP or CBD have received support from a Link Volunteer.

## 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 activity 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 33 groups in operation by the end of 2023, up from 28 at the end of 2022. Apart from the specialist groups (outlined below) the groups are run by volunteers who are a vital resource for PSPA. There were 141 local group meetings in 2023.

## Support for Carers

Virtual carers groups continued to provide support to carers throughout 2023. We introduced a new group specifically for male carers this year in recognition of some of the challenges they face sharing their experiences. We are grateful to the volunteer who has taken on leading the men's carers groups. The groups share experiences as well as tackling subjects such as managing your own health and wellbeing. There were 557 attendances at carers support group meetings in 2023.

During Carers Week at the beginning of June we launched our new A Carers Guide to PSP & CBD. The guide is a coproduction between PSPA and a small group of carers who helped share their ideas and experiences. Since its launch 486 copies of the guide have been distributed. The guide was the focus of our June carers meeting which all took place during carers week.

## 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.

During 2023, 108 people signed up for one of the two six-month blocks of meetings.

## 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. 74 people living with CBD are signed up to the group.

## 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 such as:

- A three wheeled walker
- Part payment towards a motorized wheelchair
- Complementary therapies
- Physio sessions
- Taxis to support groups

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.

128 people were awarded support grants or accessed voice banking in 2023, an increase of 33% from 2022.

## Podcasts

Following consultation with a focus group our podcasts branched out from being just for carers to a wider audience, engaging with people living with PSP & CBD and our wider supporters. We produced two podcasts in 2023 with 271 listens and 534 visits to the website podcast page.

## PSPA Matters

PSPA Matters is our magazine providing information and support to the PSPA Community. In 2023 we moved to producing four editions a year (up from three). Each edition was sent to approximately 9,700 people, either by email or post. PSPA Matters keeps readers up to date with PSPA support services, research, news, fundraising, how to get involved in raising awareness and much more.

## Friends and Family Days

Our in-person Friends and Family Day took place for the first time since the pandemic. We were delighted to welcome 62 members of our community to the event, which included talks from a Speech and Language Therapist and a Parkinson's dance for movement workshop run by the Royal Ballet. We held a second event in Belfast to engage with families and Health and Social Care Professionals to work towards building a PSP & CBD community in Northern Ireland.

## 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 2023:

- Scotland 25%
- Northern Ireland 38%
- Wales 17%

The CEO attended the Rare Disease Day event at Stormont to strengthen links with organisations in Northern Ireland. In February the Director of Engagement and Helpline Manager met with Health and Social Care professionals in N. Ireland to discuss ways we can work more closely, including a visit to the Atypical Parkinson's clinic at the Royal Victoria Hospital in Belfast and we ran a Friends and Family day in Belfast. This was followed up with a Family and Friends Day in April with 18 people attending.

In Scotland the Care Navigator for Scotland attends the quarterly Atypical Parkinson's clinic in the Queen Elizabeth Hospital in Glasgow. This is a multi-disciplinary team (MDT) clinic where patients are seen by a neurologist, physio, and a movement disorders clinical nurse specialist. We contributed to a series of webinars in partnership with the QE Hospital Glasgow answering questions submitted by people living with PSP & CBD, carers, and family members. PSPA contributed to the Neurological Alliance of Scotland (NAoS) resources to raise awareness of self-directed support (SDS) amongst Health and Social Care Professionals.

In December the Care Navigator for Wales attended the Parkinsons Disease Network event in Cardiff to present to 12 Parkinsons Nurses.

## 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

Following delays in projects during the pandemic our research commitments are now back on track. New grants awarded in 2023 totalled £152,164, all these projects will start in 2024. A new fellowship grant started 2023 at a cost of £265,130 over three years.

### 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 8 members (up from 6 in 2022) and has met on 9 occasions during 2023. They have taken on a range of tasks, from advising a pharmaceutical company on a drug protocol to assisting with the International Symposium. Overall, they have taken part in 21 engagement activities.

### International Research Symposium

In partnership with our US counterparts, CurePSP, we held an International Research Symposium in London in October 2023. Over 250 scientists and clinicians from around the world gathered to share the latest discoveries into PSP and CBD, and to pave the way for the next breakthroughs in research. We had scientists from afar as Singapore, India, Germany, Spain, and Canada. We had over 30 poster submissions, many from junior researchers who we hope will develop a career in researching PSP & CBD. We were delighted that our Patron the Duchess of Gloucester was able to join us on the second day.

### Research Information Day

In February 138 members of the PSPA Community met on-line to hear from 17 researchers and health and social care professionals. The aim was to update people living with PSP, CBD, carers, and family members on the current research landscape. Talks ranged from causes and cures to updates on clinical trials and navigating and improving the health and social care system.

*"My wife and I wanted you to know we found today's sessions very worthwhile. The programme stimulated us and gave us a lot to think about. Presenters were competent and their presentation clear"*

### 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 via admin and the helpline. 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.



## Ongoing Research Projects

### PROSPECT

The PROSPECT - M - UK study is a research programme, funded by PSPA, 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 2022, it had recruited over 1,200 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 longitudinal study is now set to complete by December 2024, with the cross-sectional arm being funded going forward by Prof Morris' new grant for the ExPRESS study.

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 has recently been 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 the willingness of the government to invest in rare diseases research.

### PSPA Clinical Research Fellowship

PSPA followed AMRC processes to identify a candidate to receive a fellowship grant, 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 will be based at the Cambridge University Department of Clinical Neuroscience and supervised by Prof. James Rowe. PSPA funding will cover the salary of the post providing £265,130 over three years.

### Small grant awards

In 2023, we launched a small grants call and three awards were offered:

- Dr Boyd Ghosh (Southampton) will receive £2755 for a 3 month project beginning in June 2024 to investigate if feeding tubes are beneficial and improve quality of life for people with PSP & CBD. This will allow for better guidance for Neurologists and AHP's. If found to be beneficial,

- more patients could benefit from this intervention. The costs will cover the salary for a medical or summer student placement for 3 months to work on this project.
- Dr Mansoureh Hnazaee (UCL) was awarded £9983 for her 10-month project starting in January 2024. The project is investigating the potential of a new non-invasive piece of technology called optically pumped magnetoencephalography (OP-MEG)'s to study the brain stem – firstly done in 2 healthy individuals. This will allow them to build a framework to use this new tech to study in PSP, MSA and PD, to investigate if OP-MEG complements current methods for improved early diagnosis. The costs for this project will be used to purchase an OPM head cast optimised for the brainstem and pay for the access charges for using the OPM and other equipment.
- Dr Patrick Cullinane (UCL) will receive £5000 to look at how tau is modified before folding by using new nanopore technology. The data will help improve understanding of why tau may misfold and become toxic to cells but will also inform the development of biological markers that can be detected in the early stages, improving diagnosis. This project will begin in August 2024 and will last 12 months. The grant will go toward buying different equipment for the project.

We also awarded funding to 2 larger projects:

- Dr Edwin Jabbari (UCL) will receive £75,626 for a 12-month project beginning in February 2024. Dr Jabbari will use a novel tau seed amplification assay (SAA) to detect tau seeding in PSP patient samples. To assess their diagnostic ability both the tau and alpha-synuclein assays will be used on stored samples from PSP patients, PD patients and controls to look for differentiation between the groups. He will also investigate if certain secondary measures (called kinetic parameters) that can be calculated from the seeding reaction as potential predictors of how quickly or slowly the disease may progress. The grant will fund 50% of the salary for the lead applicant and basic travel costs so Dr Jabbari can be trained in the use of SAA's.
- Dr Boyd Ghosh (Southampton) will receive £58,799 for a 24-month project beginning in August 2024. Currently there is little research on how patients should be cared for and how this should be assessed. To assess the impact on quality of life they will use questionnaires to compare patients seeing a specialist MDT service in Wessex and a general neurology service in Surrey. They aim to indicate the benefit of a clinical coordinator and a specialist coordinating clinic. These initial data will guide the design and increase the competitiveness of further research. Their goal is to provide data to help patient charities, the NHS and the National Institute for Health and Clinical Excellence (NICE), to set up services that give patients and their families the support that achieves (i) the best quality of life (ii) better prognosis and (iii) reduced health and social care costs. The grant will fund a band 6 NHS salary part time for the 24-month project alongside some travel costs to assess patients.

## Campaigning and Raising Awareness

PSP/CBD Awareness week in June aimed to improve diagnosis of PSP & CBD by educating healthcare professionals and the public about early symptoms. We specifically targeted opticians and ophthalmologists by creating an 'Eye red flag' poster to be distributed to high street opticians. The eye signs of PSP may not be noticed in everyday life or cause any symptoms but eye movements can change very early on in PSP so they could be a way into early diagnosis. Supporters did an amazing job getting out and about resulting in over 800 posters being distributed to high street opticians.

There was seven 'Walks of Hope' in 2023, helping to raise awareness in local communities and raising £15,000.

The PSPA Research Coordinator presented a research poster at the Royal College of Physicians and Surgeons of Glasgow. The poster 'Awareness and delayed diagnosis of rare neurodegenerative conditions. A charity Improvement.' Showed the results comparison between data from our 2016 and 2022 survey helping to raise awareness in the clinical community.

We secured 17 national and local press articles during the year, including a case study in the Daily Mail. In the last quarter we worked with the ITN Business Channel to produce a short film about PSP & CBD to be released early in 2024.

We launched our first awareness raising grants to empower our supporters and stakeholders to play a part in raising awareness. Two grants were awarded:

1. Plymouth Ocular Motility Unit (Dominic Burden) for a 'Progressive Supranuclear Palsy case series: a proposed eye movement assessment procedure.' This will continue to help raise awareness amongst ophthalmologists and orthoptists.
2. Dr Boyd Ghosh for a 'Wessex Atypical Parkinsons network' which is focussed on raising awareness amongst Health and Social Care Professionals across the Wessex area. Aiming to improve the quality of care that people with PSP & CBD receive.

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 503 new health and social care professionals join our network in 2023, bringing the total to 1,888. Expanding our network is key to raising awareness.

To add to our series of specialist guides, this year we coproduced a guide for Physiotherapists. The guide aims to provide physiotherapists with information about PSP & CBD and to guide and support their intervention and practice. 424 copies of the guide were distributed in 2023. The guide was also shared by the Association of Chartered Physiotherapists In Neurology (ACPIN) in their weekly e-news. Thanks goes to the team of physiotherapists who contributed to the production of the guide.

In 2023 848 Health and Social Care professionals received PSPA training or attended our on-line study day. 100% of attendees at the annual study day rated the day as good or excellent with 70% saying they felt more confident in supporting people with PSP and CBD.

## Environmental Commitments

In 2023 we launched several initiatives to improve the environmental performance of PSPA. In collaboration with staff, we identified actions that we could implement within the year we were successful in: removing the poly wrapping from our magazine PSPA Matters and moving to paper envelopes, printing the magazine on recycled papers, double siding all printing in the office and

getting all the desk phones repurposed and recycled when we moved to a virtual phone system this year. Our commitments to net zero will be part of our annual planning process so we can continue to improve how we work for the good of the planet.

## 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 particularly like to highlight the work of Andrew Coney and his 'Walk for Lindsay' which raised over £51,00, a remarkable achievement for one individual.

We would also like to thank the Peacock Charitable Trust, Robert Luff Foundation and Houghton Dunn Charitable Trust for their continued support, and thanks to PF Charitable Trust and Reso Charitable Foundation for their generosity.

And we would like to thank all with 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 2023.

## Future Plans and Priorities

2024 marks 30 years since the creation of PSPA and we plan to use this year as a springboard for growth. We have set ourselves an ambitious target of raising an additional £2million over the next two years to significantly expand our investments in research

## Support to People with PSP & CBD and Their Families

Thanks to a grant from the National Lottery Community Fund, we will be introducing two new services in 2024 as part of our Mind, Body and Soul service. They are:

- A counselling service in partnership with Rare Minds
- An on-line exercise programme with Neuro Hero's.

We are committed to growing support groups in the coming year with the target of setting up an additional seven groups in 2024. Other targets for 2024 include:

- 5% annual growth in the numbers of people we support with PSP & CBD.
- 10% growth in the number of contacts with the Helpline.
- 84% of carers saying that attending a PSPA carers group improves their wellbeing.

## Support to Health and Social Care Professionals (HSCP's)

We will continue to raise awareness amongst health and social care professionals so that all those diagnosed with PSP & CBD are able to access the right care at the right time and are offered the best support from health professionals.

Our targets for 2024 include for 88% (83% in 2023) of HSCP's attending training report improved knowledge or feel more confident to support people with PSP & CBD.

## Awareness Raising

2024 sees the start of a new investment in awareness raising, with the ultimate goal of improving diagnosis and standards of care. We will be producing an awareness-raising strategy to identify where we can have the biggest impact and start to build stronger relationships within the healthcare system and with professional bodies.

## Research

Historically, PSPA's investments in research have often acted as a catalyst for researchers to obtain significant follow-on grants from large funders such as the MRC (Medical Research Council), Wellcome Trust and NIHR (National Institute for Health Research). Using our research investment in this way, along with our ability to respond quickly to new opportunities, has ensured that the charity can create significant impact with limited funds. We will continue to provide 'seed funding' for research in this way, under the guidance of our Research Committee.

We are committed to increasing the annual spend on research to between 25% and 30% of our budget. In 2023 it made up 15%, with an increased number of grants planned expenditure for 2024 is 21% of the budget.

At the start of 2024 PSPA will have outstanding research commitments of £318,699

We are launching our research appeal aiming to raise £2million over the next three years.

## 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 2023.

## Financial Review

Thanks to the generosity of its supporters PSPA recorded a surplus of £143,051 in 2023 (**2022:** £572,718) against total income of £1,535,119 (**2022:** £1,614,928)

The charity experienced a slight decrease in income during 2023 particularly across its donation and legacy income of £1,259,525 (**2022:** £1,593,829). In particular, there was a fall in the contributions from Legacies of £243,873 (**2022:** £748,967), In Memorium of £184,534 (**2022:** £204,467) However, income from personal donations increased £246,314 (**2022:** £91,894) as well as Voluntary Fundraising £411,311 (**2022:** 313,669).

Thanks to our generous supporters, direct mail appeals raised a total of £9,871

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 is a huge encouragement to us.

## Investment Powers and Policy

The Trustees continue to maintain a conservative approach to the management of financial resources taking into account research funding commitments, the operating cash needs of PSPA and uncertainty over the timing and extent of future income generation as a consequence of the cost of living crisis. Given the significant increase in interest rates and the impact of inflation, the Trustees have undertaken a more proactive approach to cash management and have deployed Funds on the Charities Aid Foundation Platform. 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

Reserves are needed to bridge the gap between spending and income received from donations and fundraising activities. In December 2021, the Trustees reviewed the level of reserves which were benchmarked against other charities of a similar size, and it was agreed to change the reserves policy to 9 months' budgeted fixed costs. Whilst we have reduced the minimum level of reserves which are required to be maintained in line with our revised reserves policy, we are currently in excess of this level whilst plans to invest in resources and research are put in place.

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 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 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 11.

## Remuneration Policy and Senior Staff

The directors consider 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 8 and 11 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 state of affairs 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 information included on the charitable company's website. Legislation in the United Kingdom governing 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 in order 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

*Rowena Ironside*

.....  
Ms R Ironside Chair

19/10/2024  
.....Date

## 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 1-3 London Rd, East Grinstead, RH19 1AH

CAF 25 Kings Hill Avenue, Kings Hill, West Malling, Kent, ME19 4JQ

### Board of Trustees

Chair: Rowena Ironside

Paul Inness

Professor James Rowe (Resigned 31 July 2023)

James Noble

Jon Garrard

Dr Boyd Ghosh

Alison Goold

Andrew Harrington (Appointed 1 January 2024)

Greg Richardson (Appointed 1 January 2024)

Maria Tenant (Appointed 1 January 2024)

**Company Secretary:** Rebecca Packwood

### Key Management Personnel:

Chief Executive Officer: Rebecca Packwood

Director of Engagement: Carol Amirghiasvand

### Research Committee

Chair: Prof Nigel Leigh

Prof Johannes Attems

Prof Siddharthan Chandran

Dr Alistair Church

Dr Boyd Ghosh

Prof Diane Hanger

Prof Michele Hu

Prof Amritpal Mudher

Prof James Rowe (trustee representative)

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 2023 which comprise the balance sheet as at 31 December 2023, 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 2023, 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 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 any 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 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.

### **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: 21/10/24

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 2023

		Unrestricted Funds	Restricted Funds	Total Funds 2023	Total Funds 2022
	Note	£	£	£	£
<b>Income And Endowments</b>					
<b>From:</b>					
Donations and Legacies	3	1,238,684	20,841	1,259,525	1,593,829
Charitable Activities		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	-
<b>Total Income</b>		<b>1,348,203</b>	<b>186,916</b>	<b>1,535,119</b>	<b>1,614,928</b>
<b>Expenditure On:</b>					
Raising Funds		290,412	-	290,412	260,047
Other Trading Activities		7,194	-	7,194	(4,706)
Charitable Activities	4	524,826	299,122	823,948	566,624
Investments		2,828	-	2,828	-
Other		267,687	-	267,687	220,245
<b>Total Expenditure</b>		<b>1,092,946</b>	<b>299,122</b>	<b>1,392,068</b>	<b>1,042,210</b>
<b>Net Income/(Expenditure)</b>		<b>255,256</b>	<b>(112,206)</b>	<b>143,051</b>	<b>572,718</b>
<b>Net Movement in Funds</b>		<b>255,256</b>	<b>(112,206)</b>	<b>143,051</b>	<b>572,718</b>
<b>Reconciliation of Funds:</b>					
Total Funds Brought Forward		1,441,262	526,860	1,968,122	1,395,404
<b>Total Funds Carried Forward</b>		<b>1,696,518</b>	<b>414,654</b>	<b>2,111,173</b>	<b>1,968,122</b>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure amounts above relate to continuing activities.

The notes on pages 24-37 form part of these financial statements.



## The PSP Association Balance Sheet as at 31 December 2023

	Note	2023 £	2022 £
<b>Fixed Assets:</b>			
Tangible Assets	12	12,145	8,046
Investments	13	100	100
<b>Total Fixed Assets</b>		<b>12,245</b>	<b>8,146</b>
<b>Current Assets:</b>			
Debtors	14	60	-
Stock		23,477	12,421
Accrued Investment Interest		14,160	-
Prepayments and accrued income		34,566	21,986
Cash at Bank and in Hand		2,247,310	2,050,593
<b>Total Current Assets</b>		<b>2,319,572</b>	<b>2,084,999</b>
<b>Liabilities:</b>			
Creditors: Amounts Falling Due Within One Year	15	(220,645)	(125,023)
<b>Net Current Assets</b>		<b>2,098,927</b>	<b>1,959,976</b>
<b>Total Net Assets or Liabilities</b>		<b>2,111,173</b>	<b>1,968,122</b>
<b>The Funds of the Charity:</b>			
Restricted Income Funds	16	414,654	526,860
Unrestricted Funds	16	1,696,518	1,441,262
<b>Total Charity Funds</b>		<b>2,111,173</b>	<b>1,968,122</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.

The notes on pages 24-37 form part of these financial statements.

*Rowena Ironside*

Rowena Ironside

*Alison Goold*

Alison Goold

Trustees on behalf of the Trustees

Approved by the Trustees on...18 October 2024



The PSP Association Statement of Cash Flows for the Year Ending 31 December 2023

		2023 Total £	2022 Total £
<b>Cashflows from Operating Activities:</b>			
<b>Net Cash Provided By (In Use) Operating Activities</b>		<b>143,051</b>	<b>572,718</b>
<b>Adjustments to cash flows from non-cash items</b>			
Investment income		(45,766)	(2,392)
Depreciation	12	5,796	5,017
<b>Net Cash Provided By (In Use) Investing Activities</b>		<b>103,081</b>	<b>575,343</b>
<b>Working capital adjustments</b>			
(Increase)/decrease in stock		(11,056)	(12,421)
(Increase)/decrease in debtors		(26,799)	4,995
Increase/(decrease) in creditors		95,622	5,451
		<b>160,848</b>	<b>573,368</b>
<b>Cashflows From Investing Activities:</b>			
Dividends, Interest and Rents from investments		45,766	2,392
Purchases of Property, Plant and Equipment		(9,895)	(5,271)
		<b>35,871</b>	<b>(2,879)</b>
Change in Cash and Cash Equivalents in the Reporting Period		196,717	570,489
<b>Cash at Bank and in Hand Less Overdrafts at the Beginning of the Year</b>	18	<b>2,050,593</b>	<b>1,480,104</b>
<b>Cash at Bank and in Hand Less Overdrafts at Year End</b>	18	<b>2,247,310</b>	<b>2,050,593</b>

The notes on pages 25-37 form part of these financial statements.

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

18 October 2024

and are signed on their behalf by:

*Rowena Ironside*

Rowena Ironside

*Alison Goold*

Alison Goold

## 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 £196,717 for the year. 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.

### **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 £1,259,525 (2022: £1,593,829) of which £20,841 (2022: £489,015) was restricted.

	Unrestricted	2023 Restricted	Total	2022 Total
	£	£	£	£
Voluntary Fundraising	411,311	-	411,311	313,669
Legacies	243,873	-	243,873	748,967
Trusts and Foundations	58,900	20,500	79,400	62,739
In Memoriam	184,534	-	184,534	204,467
Personal Donations	246,063	251	246,314	91,894
Direct Mail	9,781	90	9,871	7,395
Unsolicited Donations	65,728	-	65,728	104,275
Major Donors	2,250	-	2,250	250
Corporate	16,245	-	16,245	60,173
	<b>1,238,684</b>	<b>20,841</b>	<b>1,259,525</b>	<b>1,593,829</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 £	Volunteering Costs £	2023 Total £	2022 Total £
<b>Total Charitable Activities</b>					
Salaries & Wages	21,569	282,285	-	303,854	307,242
Awareness	1,032	46,725	10,546	58,304	51,756
Purchases	91,969	100,624	3,864	196,856	21,632
Other Grants	-	10,731	-	10,731	4,029
Research Grants	205,442	-	-	205,442	139,526
Facilities & Infrastructure	1,500	14,342	-	15,842	13,709
Insurances	191	1,832	-	2,023	-
IT & Communications	1,207	30,089	-	31,296	28,730
	<b>322,910</b>	<b>486,629</b>	<b>14,410</b>	<b>823,948</b>	<b>566,624</b>

For 2023 some costs that were previously categorised as overheads were identified as being costs to run the charity and have, therefore, been recategorised as a direct cost and fall into Charitable Activities under Purchases. Some of these costs include the production of PSPA matters, Research expenditure, such as training and development and event costs and the cost of staff to provide charitable activities.

	Research Activities £	Info & Support Costs £	Volunteering Costs £	2023 Total £	2022 Total £
<b>Unrestricted Funds</b>					
Salaries & Wages	21,569	289,250	-	310,819	292,242
Awareness	-	42,338	2,571	44,909	51,756
Purchases	5,824	99,768	3,864	109,456	11,932
Other Grant	-	10,481	-	10,481	-
Research Grant	-	-	-	-	139,526
Facilities & Infrastructure	1,500	14,342	-	15,842	13,709
Insurances	191	1,832	-	2,023	-
IT & Communications	1,207	30,089	-	31,296	28,730
	<b>30,292</b>	<b>488,100</b>	<b>6,435</b>	<b>524,826</b>	<b>537,895</b>

	Research Activities £	Info & Support Costs £	Volunteering Costs £	2023 Total £	2022 Total £
<b>Restricted Funds</b>					
Salaries & Wages	-	(6,965)	-	(6,965)	15,000
Awareness	1,032	4,388	7,975	13,394	-
Purchases	86,144	857	-	87,001	9,700
Other Grant	-	250	-	250	4,029
Research Grant	205,442	-	-	205,442	-
Facilities & Infrastructure	-	-	-	-	-
Insurances	-	-	-	-	-
IT & Communications	-	-	-	-	-
	<b>292,618</b>	<b>(1,471)</b>	<b>7,975</b>	<b>299,122</b>	<b>28,729</b>

Salaries and wages are a negative figure due to an over-accrual of project costs in 2022.

## 5. Grant Making Activities

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

	2023 £	2022 £
<b>Analysis of Grants Paid</b>		
Research Grants	205,442	139,446
Support Grants	10,231	4,029
	<b>215,672</b>	<b>143,475</b>
<b>Grants to Institutions</b>		
University College London	91,014	139,446
University Hospital Southampton	1,924	-
University Hospitals Plymouth	882	-
University of Cambridge	94,075	-
Various Other Small Grants	17,547	-
	<b>205,442</b>	<b>139,446</b>
<b>Support Grants to Individuals</b>	<b>10,481</b>	<b>4,029</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.

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.

	2023 £	2022 £
<b>Research Commitments</b>		
Payable within one year	72,916	176,109
Payable in years two to five	245,783	39,741
	<b>318,699</b>	<b>215,850</b>

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

	2023 £	2022 £
<b>This is after charging:</b>		
Depreciation	5,796	5,016
Operating Lease Rental	11,774	3,000
<b>Audit</b>		
- Audit of the financial statements	7,380	4,188

## 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 (2022: 1 employee). The charity Trustees and key management received no personal remuneration benefits during the year (2022: £nil). No charity Trustees received payment for professional or other services supplied to the charity (2022: £nil).

	2023 £	2022 £
<b>Total staff costs were as follows:</b>		
Salaries & Wages	599,114	536,878
Holiday Pay Accrual	2,591	1,567
Social Security	57,751	50,190
Pension Contributions	11,051	12,301
	<b>670,507</b>	<b>600,936</b>



Trustee expenses of £199 were reimbursed during the year (2022: nil). There was no Directors' remuneration during the year.

## 8. Staff Numbers

	2023 No.	2022 No.
No. of Operational & Admin Staff	16	16
No. of Management Staff	4	4
	<u>20</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 6). All grant transactions involving organisations in which a trustee may have an interest are conducted following 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 is a named Principal investigator on one such grant held by the University of Cambridge and Dr Boyd Ghosh has been awarded a small research grant of £2,915 (approved by the Research Committee on 21<sup>st</sup> June 2022).

Donations totalling £409 were received from Trustees during the year (2022: £145)

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 2023	2,958	23,986	18,049	44,993
Additions	-	8,710	1,184	9,895
Disposals	-	-	-	-
<b>At 31 December 2023</b>	<b>2,958</b>	<b>32,696</b>	<b>19,234</b>	<b>54,888</b>
<b>Depreciation</b>				
At 1 January 2023	2,951	17,342	16,655	36,948
Charge for the year	7	5,056	732	5,796
Eliminated on disposals	-	-	-	-
<b>At 31 December 2023</b>	<b>2,958</b>	<b>22,398</b>	<b>17,387</b>	<b>42,744</b>
<b>NET BOOK VALUE</b>				
At 31 December 2023	-	10,298	1,846	12,145
At 31 December 2022	7	6,644	1,394	8,045

## 13. Investments

	Subsidiary Undertaking Shares £
<b>Cost</b>	
At 1 January 2022	100
Additions	-
<b>At 31 December 2023</b>	<b>100</b>
<b>Provision for Diminution in Value</b>	
At 1 January 2022	-
Charge for the Year	-
<b>At 31 December 2023</b>	<b>-</b>
<b>Net Book Value</b>	
At 31 December 2023	100
At 31 December 2022	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 (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	£100	£nil

## 14. Debtors

	2023 £	2022 £
Other Debtors	60	-
Accrued Investment Income	14,160	-
Prepayments and Accrued Income	34,566	21,986
	<b>48,785</b>	<b>21,986</b>

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

	2023 £	2022 £
Taxation & Social Security	14,272	13,651
Payroll Creditor	(471)	41
Pension Creditor	2,747	2,045
Trade Creditors	34,266	21,567
Deferred Income	-	15,000
Accruals	30,771	24,123
Research Accrual	139,060	48,597
	<b>220,645</b>	<b>125,024</b>

## 16. Analysis of Charitable Funds

Analysis of Charitable Funds	Balance 1 January 2023 £	Incoming Resources £	Resources Expended £	Funds 31 December 2023 £
General Fund	1,441,262	1,348,203	(1,092,946)	1,696,518
<b>Analysis of Movement in Restricted Funds</b>				
Research	463,569	132,516	(292,618)	303,467
Information & Support	63,291	54,400	(6,504)	111,187
	<b>526,860</b>	<b>186,916</b>	<b>(299,122)</b>	<b>414,654</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 support the delivery of counselling services, on-line exercise classes, the link volunteering programme and PSPA support to carers.

### Analysis of net assets between funds:

	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)
<b>Total</b>	<b>1,696,519</b>	<b>414,654</b>	<b>2,111,173</b>

### Comparative for Analysis of Charitable Funds

Analysis of Charitable Funds	Balance 1 January 2022 £	Incoming Resources £	Resources Expended £	Funds 31 December 2022 £
General Fund	1,328,830	1,125,913	(1,013,481)	1,441,262
<b>Analysis of Movement in Restricted Funds</b>				
Research	17,596	445,973	-	463,569
Information & Support	48,978	43,042	(28,729)	63,291
	<b>66,574</b>	<b>489,015</b>	<b>(28,729)</b>	<b>526,860</b>

	General Fund £	Restricted Funds £	Total £
Tangible and Investments Fixed Assets	8,146	-	8,146
Cash at Bank and in Hand	1,523,732	526,860	2,050,593
Other Net Current Assets	(90,617)	-	(182,630)
<b>Total</b>	<b>1,441,262</b>	<b>526,860</b>	<b>1,968,122</b>

## 17. Contingent assets

### Legacy Income

As at 31 December 2023 the charity had received two notifications of legacies (2022: two)

## 18. Analysis of Cash and Cash Equivalents

	2023 £	2022 £
Cash at Bank and In Hand	2,247,310	2,050,593
<b>Total Cash and Cash Equivalents</b>	<b>2,247,310</b>	<b>2,050,593</b>

## 19. Operating Leases

Total rentals payable under operating leases:

	Land and Buildings £	2023 Total £	2022 Total £
Payable During the Year	11,774	11,774	9,000
<b>Future Minimum Lease Payments Due</b>			
Not Later Than 1 Year	226	226	3,000
Later Than 1 Year and Not Later Than 5 Years			
<b>Total Payments</b>	<b>12,000</b>	<b>12,000</b>	<b>12,000</b>

## 20. Indemnity insurance

The Charity paid for the insurance premiums to indemnify Directors and senior staff from any loss arising from neglect or defaults of Directors or staff and any consequent loss. The cost to the Charity was £534 (2022: £570).