

**The PSP Association**

**(A Company limited by guarantee)**

**Report and Financial Statements**

**Year ending 31 December 2022**

**Charity number 1037087**

**Company number: 2920581**

## Contents

The PSP Association (PSPA) Report of the Trustees for the Year Ending 31 December 2022 ..3	
Trustees Report.....3	
Objectives and Activities.....3	
Review of the Year’s Achievements and Performance.....4	
Future Plans and Priorities.....10	
Support to People with PSP & CBD and Their Families .....10	
Support to Health and Social Care Professionals (HSCP’s) .....10	
Research.....11	
Fundraising Approach .....11	
Financial Review.....12	
Investment Powers and Policy.....12	
Reserves Policy and Going Concern.....12	
Principal Risks and Uncertainties.....13	
Risk Management .....13	
Structure, Governance and Management .....13	
Reference and Administrative Details .....13	
Committees of the Board.....13	
Appointment of Trustees.....14	
Remuneration Policy and Senior Staff .....14	
Statement of Trustees Responsibilities and Corporate Governance .....14	
Organisational Information.....16	
Our Advisers.....16	
Board of Trustees.....16	
Key Management Personnel:.....16	
Research Committee.....16	
Independent Auditors Report to the Trustees of The PSP Association .....17	
The PSP Association Statement of Financial Activities for the Year Ending 31 December 2022 ..22	
The PSP Association Balance Sheet as at 31 December 2022 .....23	
The PSP Association Statement of Cash Flows for the Year Ending 31 December 2022 .....24	
Notes to the Accounts .....25	

## The PSP Association (PSPA) Report of the Trustees for the Year Ending 31 December 2022

The Trustees are pleased to present their annual directors' report together with the financial statements of the charity for the year ending 31 December 2022 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 2019)

### 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, 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 2022 we conducted a patient survey (previously conducted in 2016) enabling us to hear directly about people's experiences of diagnosis, care and PSPA services. The results of the survey have informed our new strategy, ensuring we focus on what is important to people living with PSP and CBD. Over 400 people living with the conditions responded to our survey providing a wealth of information to inform our plans. The headlines from the survey show that whilst times for referral to a neurologist have slightly improved, and GP fewer visits to the GP are required before getting a referral, the challenges of obtaining a diagnosis remain the same as in 2016. Nearly 60% of people are initially misdiagnosed, most commonly with Parkinson's.

*'After a year I had to prompt the consultant to get a scan as the Parkinson's medication wasn't working. He referred me to a neurologist, and I had MRI and PET scans and the Neurologist confirmed that I had PSP. However, three weeks later my consultant told me I had a severe form of Parkinson's. I asked for a phone call with my GP, who confirmed the PSP diagnosis.'*

The results around ongoing care were disappointing, although not surprising given the resourcing challenges in the NHS and the impact of Covid. The survey showed fewer people had a named person to coordinate their care – down to 60% from 68% in 2016. There was a marked decline in how well people thought that the relationship worked, down by 14% on 2016 figures. Satisfaction with GP's had also declined from 87% to 63%.

The results show how important the work of PSPA remains. Raising awareness remains key to improving diagnosis alongside continued investment in research to understand the diseases better and to develop treatments and a cure.

It was the first full year with our new CEO Rebecca Packwood in post. The team returned to full strength having carried some vacancies over the pandemic. Trustees have agreed a new strategy and measurement framework, set to launch in early 2023 which outlines the vision for the next four years.

In 2022 there were:

- 5,355 individuals supported by PSPA, including carers and family members.
- 3,713 new joiners within the PSPA community.
- 116 local group meetings took place.
- 141 registered volunteers.

The charity remains in good financial health which will enable us to be more ambitious with the new strategy. At the end of the 2022 financial year income was £1,614,928 (2021: £1,242,804) thanks to



some very generous legacies (£748,967). The surplus for the year was £572,718 (2021: surplus £334,254). The Board of Trustees is committed to increasing investment in research and returning to pre-pandemic plans for expansion of the research programme. We have adopted a new reserves policy moving from 12 to 9 months reserves which will allow for increased investment in research and awareness raising. As a result, plans are being developed to invest more in awareness raising and policy development with the aim of improving diagnosis rates. The plans will be in place by the end of 2023.

Trustees are mindful of the potential impact of the Cost-of-Living crisis both on expenditure and income and are managing the situation through the risk register and monitoring of financial performance. The fundraising team has expanded to take account of the need to diversify income streams to mitigate risk of some income streams declining.

## Improving Care and Support

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:

- The Helpline
- Support groups both in person and on-line
- Support grants and voice banking
- Podcasts for carers
- PSPA Matters magazine.

### Helpline

The 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. Helpline trained volunteers kindly give their time to cover the evening slot from 7pm to 9pm.

In 2022 there were 9,293 contacts with the helpline (phone and email) an increase of 20% on 2021.

### Support Groups

*"Thank you so much for organising the face-to-face meeting on Wednesday. The tea and cakes were delicious, and I feel I have made new friends who understand the path ahead of us and yet live a full life. Thank you one and all."*

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 returned to in person activity with others deciding that mobility issues and transport problems meant that staying on-line provided the best opportunity to continue to meet. There were 28 groups in operation by the end of 2022 spreading from the Isle of Wight to Scotland. Apart from the specialist groups (outlined below) the groups are run by volunteers who are a vital resource for PSPA. There were 116 local group meetings in 2022.

### New Virtual Carers Groups

In 2022 we introduced new virtual carers groups, specifically to provide support and combat the isolation of being a carer. Five groups meet monthly on-line facilitated by an external facilitator. The groups share experiences as well as tackling subjects such as managing your own health and wellbeing. 50 carers support group meetings were held in 2022 with 425 carers signed up to receive monthly invites.

*"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".*

## Newly Diagnosed Support Groups

The 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 living with PSP/CBD 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 2022, 75 people signed up for one of the two six-month blocks of meetings.

## CBD Group

The CBD group, set up in 2021, has continued to grow and provides a vital opportunity for people living with the condition. 72 people living with CBD are signed up to the group.

## Youth Support Group

With support from one of our volunteers, we launched the Youth Support Group in September 2020. This group brings together people aged between 18 and 30 years old across the world who have a loved one who is living with PSP or CBD. The group supports 11 younger people who meet monthly.

## 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.

In 2022, 26 support grants were approved contributing to items and services such as:

- A communication aid, e.g. a tablet
- A mobility aid, such as a wheelchair or scooter
- Respite care
- Counselling sessions

*'Many thanks to you and the team at the PSPA association for awarding us this grant. Both Mike and myself are very grateful not only for the financial help itself but for the speed and efficiency with which our application has been dealt. The wheelchair will, without doubt, make a big difference to our everyday lives!'*

Voice banking has also been on offer, 43 people have been able to make use of this service which is 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.

## Podcasts for Carers

Our podcasts for carers entered their second year with 7 podcasts produced in 2022 covering subjects such as Support for Young People, Advance Care Planning and how the PSPA Helpline can help carers.

The podcasts had over 1,000 listens, the most popular podcast was on 'How the Helpline can help'. There were nearly 800 visits to the website podcast page.



## 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

Delays in the delivery of research projects resulting from the pandemic have led to a decline in research commitments payable in the next two to five years as the delays had a knock-on impact on the starting of new research projects. New grant calls are planned in 2023 totalling £120,000 and a new fellowship award will also come on track in 2023 returning our research commitments in line with our historic level.

### Updated Research Leaflet

Extensive work, in collaboration with the head of engagement, the communication manager, the helpline, a research volunteer, and the Patient Involvement in Research Group, has been undertaken to update the PSPA research leaflet. It is a 20 pages leaflet titled "Understanding the Causes to Find Treatment for People Living with PSP & CBD". The leaflet has been made available in digital and paper format for the people we support living with PSP and CBD.

### Patient Involvement in Research

In 2022, PSPA set up a patient involvement in research group, the PSPA Research Involvement Members (PRIM), which is a key part of our commitment to put people living with PSP and CBD at the heart of what we do. 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 currently 6 members and has met on 8 occasions during 2022. They have taken on a range of tasks, from advising a pharmaceutical company on a drug protocol to assisting with the redesign of our new research leaflet and advising on the agenda for a Research Day Conference.

### 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

The PROSPECT - M - UK study is a research programme, funded by PSPA, which uses MRI scanning, genetic and biochemistry analysis of blood and cerebrospinal fluid samples, and clinical assessments to find ways of tracking disease progression, and improving diagnosis of patients with PSP and CBD. The 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. PSPA has granted a no-cost extension to Prof. Morris in 2022 so the study is now set to complete by December 2024.

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 this PROSPECT collaborative study 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.

The PROSPECT-MR arm of the study was completed in December 2022. Researchers looked for ways to measure what is happening inside the brain when disease modifying drugs for PSP are being tested, and how this relates to any changes in the patient's condition by combining MRI scanning with a variety of other methods. The project brings together researchers from four major research centres in Oxford, Cambridge, Manchester and London (UCL), who worked with PSP patients and their carers over a three-year period.

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 has followed AMRC processes to identify a candidate to receive a fellowship grant. Dr Robert Durcan will start 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 2022, we launched a £20,000 small grants fund and two awards were offered:

- Dr Annelies Quaegebeur (Cambridge) will receive £4,760 to assist her study, characterising neuroinflammation in PSP brains with high-plex spatial protein profiling. Dr Quaegebeur will use the fund to cover equipment and conference costs.
- Dr Maura Malpetti (Cambridge) will receive £9,279 to support her study, looking into the application of neuroimaging techniques (PET and MRI scans) to investigate the pathophysiology of neurodegenerative diseases (how they develop). And to also identify early diagnostic and prognostic markers, signals that can tell clinicians which disease is at which stage. Dr Malpetti will use the funds to cover the cost of a research assistant.

The small grant award offered to Dr Ghosh in 2021 was activated and recruitment is ongoing.

## Campaigning and Raising Awareness

Ed's Lace is a community led awareness campaign, where people were encouraged to wear Ed's Lace with one plastic end of the lace cut off so it can fray naturally. The fraying end represents the progressive nature of PSP & CBD and aims to open conversations about the rare conditions. Ed's Lace was the main feature of PSP/CBD Awareness week in 2022, during that week we distributed 980 laces, had a reach of 45,000 on social media. Awareness week was covered by Heart FM, Rare Revolution magazine and Warrington Guardian.

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. We promoted the Neurological Alliances 1 in 6 campaigns throughout the year.

## 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 and in 2020 we added our Red Flags for General Practitioners – one for PSP and one for CBD.

In 2022 we held an on-line study day for Health and Social Care professionals with 159 people attending. It was an informative event with knowledge and experience shared to improve awareness of how to provide care and support for people living with PSP and CBD.



## Many Thanks

PSPA is extremely grateful to all the donors, trusts and foundations who continue to support our work.

We would particularly like to thank Talbots Underwriting Ltd for supporting PSPA, and particularly Kelly Hooper who co-ordinated efforts at Talbots to raise an amazing £134,886.

We would also like to thank the Houghton Dunn and Robert Luff families for their ongoing support of PSPA through their family trusts and Global Make Some Noise, who's donation has enabled PSPA to develop a new Volunteer service.

And we would like to thank all with those who have left a gift through a Legacy, particularly Dr Elizabeth Cott, Owen Donovan, and Elizabeth Fiddler. These will have a lasting impact on our services.

Finally, we would like to put on record our thanks to the late Anne Silk who has been a long-standing supporter of PSPA through the funding of Prism glasses. Anne passed away this year and we are hugely grateful for all the support she gave us over the years.

## Future Plans and Priorities

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

We are committed to putting people living with PSP, CBD and their families at the heart of what we do. Building on our Patient involvement in research group which started in 2022 and recruitment this year we will hold our first Services Committee made up of patients, family carers and health and social care professionals in 2023. This will ensure continuous improvement in quality and standards across PSPA services increasing the role of coproduction in the development and design of services.

Following a generous grant from Global Make Some Noise, we are launching a link volunteer service. The service extends our support services and focuses on supporting individuals and families who can often feel confused, scared and alone as they face rapidly changing challenges that advancing symptoms bring. The service will provide short term emotional support and friendship as well as providing information about other support available at PSPA.

On the Helpline we are investing in an additional Helpline Care Navigator to increase the amount of proactive outbound calls and attendances at clinics. We aim to:

- Increase the number of contacts with the helpline by 10%.
- Increase the number of new joiners to the helpline by 5%.

We are committed to growing support groups in the coming year with the target of an additional six groups to set up in 2023. We will see the return of an in-person friends and family day in July, and we hope we will be joined by families from across the country.

In carers week in June, we will be launching our specialist guide for Carers.

### 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. In 2023 we plan to launch our new 'Guide to PSP and CBD for physiotherapists' and we will be holding a study day in September.



Our target is to increase the number of new Health and Social Care Professionals sign ups by 25% in 2023.

## 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.

At the start of 2023 PSPA will have outstanding research commitments of £251,850 (note 6). In 2023 we plan to launch a small and medium sized grants call to the value of £120,000 along with a new three year fellowship.

In partnership with CurePSP we will be holding an International Symposium in the autumn of 2023 to bring together researchers and neurologists from across the world to share the latest breakthroughs in PSP & CBD research.

## 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 which is available to view 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 were no fundraising complaints in 2022.

## Financial Review

Thanks to the generosity of its supporters PSPA recorded a surplus of £572,718 in 2022 (**2021**: £334,254) against total income of £1,614.9 million (**2021**: £1,242.8 million)

The charity experienced a significant increase in income during 2022 particularly across its donation and legacy income of £1,593,829 (**2021**: £1,197,239). In particular, there were significant contributions from Legacies of £748,967 (**2021**: £306,948), In Memorium of £204,467 (**2021**: £226,210) and from Trusts £62,739 (**2021**: £67,042). Despite the ongoing impact of the Covid pandemic and ongoing cost of living crisis, income from voluntary fundraising and events, including the London Marathon, increased by 11% to £313,669 (**2021**: £282,234). Talbots Underwriting Ltd deemed PSPA as their charity of the year, helping to grow income from Corporate Sponsorship to £60,173 (**2021**: £74,713).

Thanks to our generous supporters, direct mail appeals raised a total of £7,395. Donations also held up strongly at £196,169, again courtesy of the amazing generosity of the charity's supporters and friends.

The strong surplus for the year was also partly driven by a continuing focus on the cost base with total expenditure of £1,042,210 (**2021**: £908,550) increasing more slowly than the increase in revenue. Research funding increased slightly to £189,915 (2020: £187,875), and is expected to increase further as new research initiatives are implemented.

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 decided to deploy Funds on the Charities Aid Foundation Platform from 2023 onwards. 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, its delivery and funding streams. 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 (due to start in 2023)

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



**Ms R Ironside Chair**

18 September 2023

**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:** Harris & Co 2 Pavilion Court, 600 Pavilion Drive, Northampton, NN4 7SL

**Bankers:** Lloyds Bank 1-3 London Rd, East Grinstead, RH19 1AH

### Board of Trustees

Chair: Rowena Ironside

Paul Inness

Professor James Rowe

James Noble

Jon Garrard

Dr Boyd Ghosh

Alison Goold

**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 2022 which comprise the balance sheet as at 31 December 2022, the statement of financial activities, balance sheet, 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 2022, 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. Our evaluation of the Trustees' assessment of the charitable company's ability to continue to adopt the going concern basis of accounting included:

- Enquiring of management regarding the assumptions used in the going concern models;
- Evaluating the charitable company's current and projected cash position.
- Reading sector reports and data and other external information to determine if it provided corroborative or contradictory evidence in relation to management's assumptions;
- Comparing forecasted income to recent historical financial information;
- Testing the underlying data generated to prepare the forecast scenarios and determined whether there was adequate support for the assumptions underlying the forecast; and
- Evaluating the charitable company's disclosures on going concern against the requirements of United Kingdom Generally Accepted Accounting Practice and the Companies Act 2006.

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 charitable company'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 an indications of fraud or non-compliance with laws and regulations throughout the audit.

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

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

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal 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.

Phillip Harris BA FCA (Senior Statutory Auditor)

for and on behalf of Harris & Co (Accountants) Ltd, Statutory Auditor

2 Pavilion Court

600 Pavilion Drive

Northampton

NN4 7SL

Date: 18 September 2023

Harris and Co 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 2022

		Unrestricted Funds	Restricted Funds	Total Funds 2022	Total Funds 2021
	Note	£	£	£	£
<b>Income And Endowments</b>					
<b>From:</b>					
Donations and Legacies	3	1,104,814	489,015	1,593,829	1,197,239
Charitable Activities	4	13,007	-	13,007	25,250
Other Trading Activities		5,700	-	5,700	20,069
Investments		2,392	-	2,392	246
Other		-	-	-	-
<b>Total Income</b>		<b>1,125,913</b>	<b>489,015</b>	<b>1,614,928</b>	<b>1,242,804</b>
<b>Expenditure On:</b>					
Raising Funds		260,047	-	260,047	247,685
Other Trading Activities		(4,706)	-	(4,706)	-
Charitable Activities	5	537,895	28,729	566,624	558,246
Other		220,245	-	220,245	102,619
<b>Total Expenditure</b>		<b>1,013,481</b>	<b>28,729</b>	<b>1,042,210</b>	<b>908,550</b>
<b>Net Income/(Expenditure)</b>		<b>112,432</b>	<b>460,286</b>	<b>572,718</b>	<b>334,254</b>
<b>Net Movement in Funds</b>		<b>112,432</b>	<b>460,286</b>	<b>572,718</b>	<b>334,254</b>
<b>Reconciliation of Funds:</b>					
Total Funds Brought Forward		1,328,830	66,574	1,395,404	1,061,150
<b>Total Funds Carried Forward</b>		<b>1,441,262</b>	<b>526,860</b>	<b>1,968,122</b>	<b>1,395,404</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 24-36 form part of these financial statements.



## The PSP Association Balance Sheet as at 31 December 2022

	Note	2022 £	2021 £
<b>Fixed Assets:</b>			
Tangible Assets	13	8,046	7,791
Investments	14	100	100
<b>Total Fixed Assets</b>		<b>8,146</b>	<b>7,891</b>
<b>Current Assets:</b>			
Debtors	15	21,986	26,981
Stock		12,421	-
Cash at Bank and in Hand		2,050,593	1,480,104
<b>Total Current Assets</b>		<b>2,084,999</b>	<b>1,507,085</b>
<b>Liabilities:</b>			
Creditors: Amounts Falling Due Within One Year	16	(125,023)	(119,572)
<b>Net Current Assets</b>		<b>1,959,976</b>	<b>1,387,513</b>
<b>Total Net Assets or Liabilities</b>		<b>1,968,122</b>	<b>1,395,404</b>
<b>The Funds of the Charity:</b>			
Restricted Income Funds	17	526,860	66,574
Unrestricted Funds	17	1,441,262	1,328,830
<b>Total Charity Funds</b>		<b>1,968,122</b>	<b>1,395,404</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 24-36 form part of these financial statements.



Rowena Ironside



Alison Goold

Trustees on behalf of the Trustees

Approved by the Trustees on 7<sup>th</sup> August 2023

## The PSP Association Statement of Cash Flows for the Year Ending 31 December 2022

	Note	2022 £	2021 £
<b>Cashflows from Operating Activities:</b>			
<b>Net Cash Provided By (In Use) Operating Activities</b>	<b>19</b>	<b>573,368</b>	<b>267,038</b>
<b>Application of Cash:</b>			
Dividends, Interest and Rents from Investments		2,390	246
Purchases of Property, Plant and Equipment	<b>13</b>	(5,271)	(3,252)
<b>Net Cash Provided By (In Use) Investing Activities</b>		<b>(2,881)</b>	<b>(3,006)</b>
<b>Cashflows From Financing Activities:</b>		<b>-</b>	<b>-</b>
Change in Cash and Cash Equivalents in the Reporting Period		570,487	264,032
<b>Cash at Bank and in Hand Less Overdrafts at the Beginning of the Year</b>	<b>20</b>	<b>1,480,104</b>	<b>1,216,074</b>
<b>Cash at Bank and in Hand Less Overdrafts at Year End</b>	<b>20</b>	<b>2,050,593</b>	<b>1,480,104</b>

The notes on pages 25-35 form part of these financial statements.

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

7<sup>th</sup> August 2023 and are signed on their behalf by:



**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 2019) - (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 £573,368 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 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

**Cash at Bank and in Hand**

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less 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 £1,593,829 (**2021: £1,197,239**) of which £489,015 (**2021: £70,489**) was restricted.

	Unrestricted	Restricted	2022	2021
	£	£	£	£
Voluntary Fundraising	312,133	1,536	<b>313,669</b>	<b>282,234</b>
Legacies	312,994	435,973	<b>748,967</b>	<b>306,948</b>
Trusts and Foundations	33,179	29,560	<b>62,739</b>	<b>67,042</b>
In Memoriam	197,897	6,570	<b>204,467</b>	<b>226,210</b>
Personal Donations	91,493	401	<b>91,894</b>	<b>75,604</b>
Direct Mail	3,840	3,555	<b>7,395</b>	<b>27,713</b>
Unsolicited Donations	103,105	1,170	<b>104,275</b>	<b>94,775</b>
Major Donors	-	250	<b>250</b>	<b>42,000</b>
Corporate	50,173	10,000	<b>60,173</b>	<b>74,713</b>
<b>Total</b>	<b>1,104,814</b>	<b>489,015</b>	<b>1,593,829</b>	<b>1,197,239</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. Income from Charitable Activities

	Unrestricted	Restricted	2022	2021
	£	£	£	£
Raffle	13,007	-	<b>13,007</b>	<b>13,860</b>
Service Provision	-	-	-	<b>4,690</b>
Government Grant - Scotland	-	-	-	<b>6,700</b>
<b>Total</b>	<b>13,007</b>	-	<b>13,007</b>	<b>25,250</b>



## 5. 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	2022	2021
Total Funds	£	£	£	£	£
Salaries and Wages	44,960	262,282	-	307,242	359,108
Awareness	935	41,318	9,503	51,756	39,876
Purchases	1,719	19,893	20	21,632	9,905
Other Grant	-	4,029	-	4,029	4,564
Research Grant Activities	139,526	-	-	139,526	101,097
Facilities & Infrastructure	1,246	12,463	-	13,709	33,426
IT & Communications	1,529	27,201	-	28,730	8,888
Bank Charges and Interest	-	-	-	-	232
Insurance	-	-	-	-	1,150
<b>Total</b>	<b>189,915</b>	<b>367,186</b>	<b>9,523</b>	<b>566,625</b>	<b>558,246</b>

	Research Activities	Info & Support Costs	Volunteering Costs	2022	2021
Unrestricted Funds	£	£	£	£	£
Salaries and Wages	44,960	247,282	-	292,242	352,254
Awareness	935	41,318	9,503	51,756	36,862
Purchases	1,719	10,193	20	11,932	3,410
Research Grant Activities	139,526	-	-	139,526	68,118
Facilities & Infrastructure	1,246	12,463	-	13,709	33,426
IT & Communications	1,529	27,201	-	28,730	8,888
Bank Charges and Interest	-	-	-	-	232
Insurance	-	-	-	-	1,150
<b>Total</b>	<b>189,915</b>	<b>338,457</b>	<b>9,523</b>	<b>537,895</b>	<b>504,340</b>

	Research Activities	Info & Support Costs	Volunteering Costs	2022	2021
Restricted Funds	£	£	£	£	£
Salaries and Wages	-	15,000	-	15,000	6,854
Awareness	-	-	-	-	3,014
Purchases	-	9,700	-	9,700	6,495
Other Grant Activities	-	4,029	-	4,029	4,564
Research Grant Activities	-	-	-	-	32,979
<b>Total</b>	<b>-</b>	<b>28,729</b>	<b>-</b>	<b>28,729</b>	<b>53,906</b>

## 6. Grant Making Activities

Research grants were awarded by the research committee to fund research projects that have been approved by peer review. No new research awards were made in the year to 31 December 2022.

	2022	2021
	£	£
<b>Analysis of Grants Paid:</b>		
Research Grants	139,446	101,097
Support Grants	4,029	4,564
	<b>143,475</b>	<b>105,661</b>
<b>Grants to Institutions:</b>		
University College London	139,446	101,097
<b>Research Grants</b>	<b>139,446</b>	<b>101,097</b>
<b>Support Grants to Individuals</b>	<b>4,029</b>	<b>4,564</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 appoint suitable staff and consequently some grants may remain partly unpaid at year end; consequently, there may be 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 and the Sarah Koe Clinical Research fellowship; full payment of which is contingent on the outcome of annual reviews.

	2022	2021
	£	£
<b>Research Commitments</b>		
Payable within One Year	176,109	177,781
Payable in Years Two to Five	39,741	97,305
	<b>215,850</b>	<b>275,086</b>

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

	2022	2021
	£	£
<b>This is After Charging:</b>		
Depreciation	5,016	5,698
Operating Lease Rental	3,000	3,000
Auditors' Remuneration		
- Audit of the Financial Statements	4,188	3,856



## 8. 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 (2021: £nil). The charity Trustees and key management received no personal remuneration benefits during the year (2021: £nil). No charity Trustees received payment for professional or other services supplied to the charity (2021: £nil).

	2022	2021
	£	£
Total staff costs were as follows:		
Salaries and Wages	536,878	474,940
Holiday Pay Accrual	1,567	8,425
Social Security	50,190	42,312
Pension Contributions	12,301	11,378
	<b>600,935</b>	<b>537,055</b>

No Trustees were reimbursed expenses during the 2022 or 2021. There was no Directors' remuneration during the year.

## 9. Staff Numbers

	Dec 2022	Dec 2021
Number of Operational & Admin Staff	16	11
Number of Management Staff	4	3
	<b>20</b>	<b>14</b>

## 10. Pension Costs

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

## 11. 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 £145 were received from Trustees during the year (2021: £205) and sales valued at £0 (2021: £30) of Christmas cards were made to members of the Board.

There were no other related party transactions during the year.

## 12. 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.

## 13. Tangible Fixed Assets

	Leasehold Improvements	Computer Equipment	Fixtures & Fittings	Total
Cost	£	£	£	£
At 1 January 2022	2,958	19,819	16,945	39,722
Additions	-	4,167	1,104	5,271
Disposals	-	-	-	-
<b>At 31 December 2022</b>	<b>2,958</b>	<b>23,986</b>	<b>18,049</b>	<b>44,993</b>
<b>Depreciation</b>				
At 1 January 2022	2,359	16,268	13,304	31,931
Charge for the Year	592	1,074	3,351	5,016
Eliminated on Disposals	-	-	-	-
<b>At 31 December 2022</b>	<b>2,951</b>	<b>17,342</b>	<b>16,655</b>	<b>36,947</b>
<b>Net Book Value</b>				
At 31 December 2022	7	6,644	1,395	8,046
At 31 December 2021	599	3,551	3,641	7,791

## 14. Investments

	Subsidiary Undertaking Shares
Cost	£
At 1 January 2022	100
Additions	-
<b>At 31 December 2022</b>	<b>100</b>
<b>Provision for Diminution in Value</b>	
At 1 January 2022	0
Charge for the Year	-
<b>At 31 December 2022</b>	<b>0</b>
<b>Net Book Value</b>	
At 31 December 2022	100
At 31 December 2021	100



#### 14.1 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)	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

#### 15. Debtors

	2022 £	2021 £
Other Debtors	-	546
Prepayments and Accrued Income	21,986	26,435
	<b>21,986</b>	<b>26,981</b>

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

	2022 £	2021 £
Taxation and Social Security	13,651	12,369
Payroll Creditor	41	7,404
Pension Creditor	2,045	-
Trade Creditors	21,567	61,614
Deferred Income	15,000	-
Accruals	24,123	3,635
Research Accrual	48,597	34,500
	<b>125,023</b>	<b>119,572</b>

Income received from Global Make Some Noise has been deferred as the project start is in 2023. Equally, the costs due to be incurred have been accrued.

## 17. Analysis of Charitable Funds

	Balance 1 January 2021	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>Sub Total Restricted Funds</b>	<b>66,574</b>	<b>489,015</b>	<b>(28,729)</b>	<b>526,860</b>

### Analysis of net assets between funds:

	General Fund	Restricted Funds	Total
	£	£	£
Tangible and Investment 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))	-	(90,617)
<b>Total</b>	<b>1,441,262</b>	<b>526,860</b>	<b>1,968,122</b>

## 18. Contingent assets

### Legacy Income

As at 31 December 2022 the charity had received two notifications of legacies (2021: two)

## 19. Reconciliation of Net Movement in Funds to Net Cash Flow from Operating Activities

	2022 £	2021 £
<b>Net Income/(Expenditure) for the Reporting Period (as per the statement of financial activities)</b>	572,718	334,254
Adjustments For:		
Depreciation Charges	5,016	5,698
Dividends, Interest & Rents from Investments	(2,392)	(245)
(Increase)/Decrease in Debtors	(7,426)	(21,494)
Increase/(Decrease) in Creditors	5,451	(51,175)
<b>Net Cash Provided By and Used in Operating Activities</b>	<b>573,368</b>	<b>267,038</b>

## 20. Analysis of Cash and Cash Equivalents

	2022	2021
	£	£
Cash at Bank and In Hand	2,050,593	1,480,104
<b>Total Cash and Cash Equivalents</b>	<b>2,050,593</b>	<b>1,480,104</b>

## 21. Operating Leases

Total rentals payable under operating leases:

	Land and Buildings	2022 Total	2021 Total
	£	£	£
Payable During the Year	9,000	9,000	9,000
<b>Future Minimum Lease Payments Due</b>			
Not Later Than 1 Year	3,000	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>9,000</b>

## 22. 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 £570 (2021: £867).