

**The PSP Association**

**(A Company limited by guarantee)**

**Report and Financial Statements**

**Year ending 31 December 2021**

**Charity number 1037087**

**Company number: 2920581**

## Contents

The PSP Association (PSPA) report of the trustees for the year ending 31 December 2021	4
Trustees Report	4
Objectives and activities	4
PSP & CBD	4
Review of the year's achievements and performance	5
Improving care and support	6
Funding and promoting research	8
Campaigning and raising awareness	10
Many thanks	11
Future plans and priorities	11
Research	12
Fundraising approach	13
Financial review	13
Investment powers and policy	14
Reserves policy and going concern	14
Principal risks and uncertainties	14
Risk Management	14
Structure, Governance and Management	15
Reference and administrative details	15
Committees of the board	15
Appointment of trustees	16
Trustee induction and training	16
Related parties and co-operation with other organisations	16
Remuneration policy and senior staff	16
Statement of trustees responsibilities and corporate governance	16
Organisational information	18
Our advisers	18
Board of trustees	18
Key management personnel	18
Research Committee	18
Independent auditors report to the Trustees of The PSP Association	19

The PSP Association Statement Financial Activities for the year ending 31 December 2021	24
The PSP Association Balance Sheet as at 31 December 2021 .....	25
The PSP Association Statement of Cash Flows for the year ending 31 December 2021 .....	26
Notes to the accounts.....	27

## The PSP Association (PSPA) report of the trustees for the year ending 31 December 2021

The trustees are pleased to present their annual directors' report together with the financial statements of the charity for the year ending 31 December 2021 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

The objectives of PSPA are to:

- Promote and sponsor research to improve diagnosis, to fully understand the causes and to discover a cure or at least disease-modifying treatments for Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD).
- Support families coping with PSP & CBD by providing support, information and assisting their access to NHS and other public or voluntary sector assistance.
- Develop an awareness, particularly amongst relevant medical professionals and social services of PSP, CBD and PSPA in order to develop and promote best practice when meeting the needs of people and their carers living with these conditions.

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. We cooperate with both charities, especially in the field of research.

### 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

*"Since mum's diagnosis the PSPA has amazed me with the support and information they provide, you really have been a godsend for us."*

Whilst 2021 continued to present many challenges for charities across the UK with continuing Covid-19 restrictions, the impact of the restrictions reduced throughout the year and we were able to implement learning from 2020 to build up services and to look ahead with more certainty than the previous year. We have been privileged to continue to work alongside a team of volunteers who give their time, experience, passion, and support to make PSPA what it is.

On the personnel front we said goodbye to our Chair Simon Koe in 2020 and the CEO Andrew Symons in early 2021, we would like to thank them for their work and contribution to PSPA. The Koe family have led this charity since its inception, and we hope to honour their legacy as we move ahead.

We were delighted to appoint Rowena Ironside as our new Chair of Trustees in April 2021, who has brought a renewed energy and enthusiasm to the Board and direction of the Charity. Rowena was joined by a new Chief Executive, Rebecca Packwood, in November and a new Head of Fundraising, Helen Holman, in December.

An increase in the opening hours of the Helpline alongside awareness raising with professionals and new on-line groups have led to a significant increase in the number of people we support and to the amount of support we provide to them. Calls and emails, both to and from the Helpline, have increased by 79% from 2020.

In 2021 there were:

- 6,551 individuals supported by PSPA, including carers and family members
- 1,177 new joiners within the PSPA community
- 149 local group meetings held
- 183 registered volunteers

We have not let the pandemic stop us from innovating; for the first time we have created a series of 'Podcasts' for carers helping to inform and connect carers across the UK. Although we remained unable to return to in person groups and conferences, we have continued to support people on-line and through the Helpline. The new groups introduced in 2020 have continued to grow and provide essential support. These include the 'Newly diagnosed group', the youth support group and a group specifically for people living with CBD. For some of the groups on-line communication provides much needed flexibility, but we recognise the importance of face-to-face interaction and we are pleased to have been able to start back some groups face to face in 2022.

Despite the many challenges, our cautious approach to building reserves in previous years ensured that the charity started the year with sufficient financial resilience to navigate the changing environment. At the end of the 2021 financial year income was £1,242.8 million (2020: £924,209) thanks to some very generous legacies (£306,948), the surplus for the year was £334,254 (2020: deficit £22,790). The Board of Trustees is committed to increasing investment in research and returning to pre-pandemic plans for expansion of the research programme.

Despite the continuing Covid restrictions, especially in the early part of 2021, we were able to return to more traditional fundraising events, such as, the London Marathon towards the end of the year. As always, our supporters have been extraordinarily generous both with their time and their money and we are grateful for their continued support. Their commitment along with that of volunteers is what makes PSPA the organisation it is.

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.

## 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
- Local groups (currently on-line)
- Support grants and voice banking
- Podcasts for carers
- PSPA Matters magazine

### *Helpline*

- In 2021, we increased the capacity on the helpline by extending the opening hours to 9am-9pm where previously we had closed at 5pm. Helpline trained volunteers have kindly given their time to cover the evening slot from 7pm to 9pm. Alongside increasing our availability to handle incoming calls, this enabled the team to provide more proactive outreach calls, which are designed to reduce isolation and loneliness, particularly amongst carers. This is reflected in this year's statistics in which the outbound calls increased by 434%.

- Helpline statistics for 2021
  - incoming calls/emails handled: 3,900 (up from 3,589 in 2020)
  - proactive outbound calls made: 3,848 (up from 720 in 2020)

### *Local groups online*

*'My husband & I took part in the Kent area Zoom meeting on Wednesday. It was great, as we met a lovely couple on there who live not far away from us. It was great to interact with people that are going through exactly the same experience as us. We look forward to our next meeting in November.'*

Local groups continued on-line in 2021 with the support of volunteers who have harnessed the use of technology to help people maintain connections and benefit from peer support. With the addition of some new specialist groups, we have held a total of 149 meetings in 2021 an increase of 18% on 2020. Details of the new specialised support groups are outlined below.

### *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 different guest speaker from a multidisciplinary team who 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 2021, 97 people signed up for one of the two six-month blocks of meetings. 40 people from these two cohorts went on to form a 'Not so newly diagnosed group' when the six-month block ended and met six times during the latter part of 2021. As Helpline Care Navigators return to attending clinics, we hope that we can reach even more people close to their point of diagnosis in 2022.

### *CBD Group*

Following feedback from people living with a diagnosis of CBD a new group for people living with CBD started in 2021. Over 80 people registered for the group which met eight times in 2021 with an average of 20 people attending each meeting.

As one participant said

*'Thank you so much for hosting the meeting this morning. I felt very emotional as it was the first time, I had met other people with CBD. I'm glad you are going to do this meeting regularly, thank you.'*

### *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 15 younger people who met nine times on-line over the year.

### *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 affected by PSP or CBD.

In 2021, 35 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

*'You have recently supported my mum with the cost of buying predictive software for her tablet. As a family we will always be eternally grateful as it's mums main form of communication now. Thank you x.'*

Voice banking has also been on offer for the first time and 19 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.

### *Podcasts for Carers*

We launched our first podcast for carers in Carers week in June 2021 and produced 7 editions during the year. The podcasts feature the voice of carers relating subjects direct from personal experience. We would like to thank Corporate supporter Pavers Ltd for the grant to produce the podcasts which have enabled us to reach out to people in a new way. The podcasts have 40 followers on the Anchor app, on which they were launched and have additionally been accessed over 1,300 times on our website. To extend their reach, they are now available via Spotify, Apple and other podcast providers.

### Funding and promoting research

#### *New 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 and identified 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



The strategy was officially launched on 23 January 2021 at an online Research Information Day. This was a hugely informative and useful session, a recording of which is available on our website.

## *Ongoing Research projects*

### **1. PROSPECT programme**

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 2021, it had recruited over 1,115 participants across 28 active study sites in the UK, making it one of the largest studies of PSP in the world. 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.

The first stage of the project has been completed and recruited 222 participants. 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 treatments options. Outputs of this collaborative have been publications in highly respected, peer-reviewed journals including 'JAMA Neurology' and 'The Lancet Neurology'.

The second stage of the PSPA funded programme, known as PROSPECT-2, is ongoing and carries out further 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. Recruitment so far is almost at 560 patients. 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 second stage is looking 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 UCL, who are working with PSP patients and their carers over a three-year period.

## **2) Sara Koe Clinical Research Fellowship**

PSPA has provided funding for Dr Danielle Lux for a clinical research fellowship at the University College of London under the supervision of Dr Huw Morris. The fellowship was completed in Dec 2021. Dr Lux worked on the PROSPECT 2 study, establishing a longitudinal clinical cohort of PSP/CBD, Multiple System Atrophy, and Atypical Parkinsonism patients and controls UK wide. The chief aim is to understand the many different manifestation of these conditions, tracking their progression and identifying biomarkers to help improve diagnosis.

The study has contributed to eight articles in publications ranging from Lancet Neurology to Nature Medicine and seven presentations at conferences. The study has also fostered collaborations with institutions both in Europe and the US.

## **3) Improving diagnosis and care in PSP & CBD, Dr Diane Swallow, University of Aberdeen**

PSPA co-funded a research fellowship awarded to Dr Diane Swallow based at the University of Aberdeen (2016-2019, study ongoing). Her study focused on improving diagnosis and care in PSP & CBD. As well as determining a prevalence rate for PSP & CBD in Scotland. Nearly 100 people in Scotland with PSP or CBD were recruited and followed as they progressed with their condition.

Outputs include 2 publications and several presentations at national and international events.

## **4) Small grant awarded**

PSPA awarded a small grant fund to Dr Boyd Ghosh (on the Board of Trustees) for his study comparing quality of life and health utilisation in patients in different parts of catchment areas with availability of services in different regions of Dorset. Researchers will ask the patients and their carers to fill out questionnaires and will obtain clinical and visit data from Trusts clinical electronic patient records. The study, set to start last year, has been delayed due to COVID restrictions. It is now at approvals stage.

## **Campaigning and raising awareness**

In 2021 our '10,000 voices' campaign was a big success. Launching on Rare Disease Day, the campaign asked supporters to reach out to their Local Member of Parliament to raise awareness of PSP & CBD. This resulted in a number of meetings with MP's and follow up letters as well as some social media content. The campaign flowed throughout our activities during the year, with the spring raffle renamed the 10,000 Voices Raffle, giving players motivation for selling tickets and aiding our awareness raising efforts.

In May, the campaign launched the 10,000 voices awards with categories for campaigners, carers, fundraisers, corporate supporters, researchers, volunteers and the always amazing awards for people living with PSP & CBD. Celebrating achievements has been a great way to reward and highlight some of the amazing work that goes on to support families and people living with PSP & CBD. In addition, fundraisers were tasked with taking on ten themed challenges in support of the campaign, this included several people walking 10,000 steps a day for a month, taking part in a 10km run and a weight loss challenge too.

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

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

Many thanks

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

We would also particularly like to thank.

Dr Anne Silk, for her funding of prism glasses for people with PSP.

Talbots Underwriting Ltd for choosing PSPA to be their charity partner during 2021 and 2022 and Kelly Hooper for nominating us.

The Peacock and Houghton Dunn families for their ongoing support of PSPA through their family trusts.

Christine Harrison for her tenacity and creative approach to fundraising, and Michael Aquilina, Elizabeth Burrell, and Matthew Hammond for their huge generosity and effort.

## Future plans and priorities

### Support to people with PSP & CBD and their families

The big change in 2022 will be a return to in person groups and events. We are planning for a return to our Friends and Family days, Volunteer Development Day and our annual study for professionals. Local groups will have the option to meet on-line or in person and will decide locally what works best for them. At this time, it looks like many will choose a hybrid approach to be inclusive to all.

We plan to develop new on-line support groups for carers. We recognise the pressure on carers is immense and the evidence shows a negative impact on both physical and mental health. In response to the Carers UK state of Caring Survey in 2018:

- 72% of carers said they had suffered mental ill health because of caring
- 61% said they had suffered physical ill health
- 8 in 10 people caring for loved ones say they have felt lonely or socially isolated

We know that the pandemic and lock downs further increased the pressure on carers and we want to respond to that. Monthly on-line regional groups focussed on the health and wellbeing of carers will be piloted in the first half 2022.

Thanks to a grant from 'Global Make Some Noise' we will also be introducing a new Link Volunteer service which will provide one to one support for families at a local level who have recently received a diagnosis, as well as provide support to navigate the complex and changing needs of living with PSP & CBD with the aim of reducing the sense of isolation that people can feel living with these conditions.

We are committed to putting people living with PSP, CBD and their families at the heart of what we do. This year we will be introducing a Services Committee made up of patients, family carers and health and social care professionals to ensure continuous improvement in quality and standards across PSPA services increasing the role of coproduction in the development and design of services.

This will be accompanied by conducting a patient survey which we last completed in 2016. The results of the survey will provide PSPA with much needed data to shape the strategy and service design in the coming year.

## 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 providing that care. This year we will return to offering tailored training and education through our Helpline Care Navigators and our Education Volunteers either online or face to face. Our Annual Study Day will take place in September where we will welcome health professionals from across the UK. Later in the year we will see a new addition to our health professional's resources 'A Guide to PSP & CBD for Physiotherapists'.

## 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.

In 2022 we plan to launch our small grants programme focusing on improving quality of life.

At the start of 2022, PSPA had outstanding research commitments of £275,086 (note 6), the majority of which is linked to the PROSPECT study project. However, due to the impact on research as a result of the pandemic there may be further requests to extend the existing grants beyond the 31 July 2023 current latest end dates. Trustees are committed to

increasing investment in research and in 2022 have appointed a new research co-ordinator and approved investment in a new fellowship.

## 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. This information can be seen on our website.

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 is available on our website.

## Financial review

Thanks to the generosity of its supporters PSPA recorded a surplus of £334,254 in 2021 (2020: deficit £22,790) against total income of £1,242.8 million (2020:£ 924,209).

The charity experienced a significant increase in income during 2021 particularly across its donation and legacy income of £1,197,239 (2020 £855,383). In particular, there were significant contributions from Legacies of £306,4948 (2020 £154,963), In Memorium of £226,210 (2020 £176,602) and from Trusts £67,042 (2020 £48,940). Despite the ongoing impact of the Covid pandemic, income from voluntary fundraising and events, including the London Marathon, increased by 62% to £282,234 (2020 £169,152). Talbots Underwriting Ltd deemed PSPA as their charity of the year, helping to grow income from Corporate Sponsorship to £74,713 (2020 £36,405).

Thanks to our generous supporters, direct mail appeals raised a total of £27,713. Donations also held up strongly at £170,379, again courtesy of the amazing generosity of the charity's supporters and friends.

The strong surplus for the year was also driven by a reduction in expenditure to £908,550 (2020 £946,999) which was partly due to careful management of the cost base given the financial uncertainties arising from the Covid pandemic. In addition, research funding reduced to £187,875 (2020: £237,136) as research activities took time to recover as vulnerable people were shielding or remaining cautious throughout 2021.

As a result of the strong Surplus generated in the year, Cash inflow from operating activities increased to £267,038 (2020: outflow £58,552). This resulted in an increase in the year end cash balance to £1,480,104 (2020 £1,216,074).

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, having considered research funding commitments, the operating cash needs of PSPA, the prevailing low deposit interest rates available in the market, and the current uncertainty over the timing and extent of future income generation as a consequence of the pandemic, decided to retain liquid funds in the main bank account supported by fixed term deposits. This approach will be reviewed again in 2022.

## Reserves policy and going concern

Reserves are needed to bridge the gap between spending and income received from donations and fundraising activities. During 2021, the Trustees sought to maintain the level of reserves at the equivalent of 12 months' budgeted fixed costs. Whilst managing expenditure to keep reserves in line with this policy, reserves were marginally below expenditure at a few points throughout the year although cash liquidity remained strong throughout the period. 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 pandemic on the finances of the charity. However, given the prudence of the reserves policy, the high level of cash liquidity and the 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 2022)*

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.

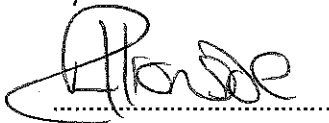
The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statement may differ from legislation in other jurisdictions.

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

13/9/2022 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 (appointed 1 April 2021)

Paul Inness

Barbara Johnston (Resigned 31 March 2021)

Steven Le Hellidu (Resigned 31 March 2021)

Professor James Rowe

James Noble

Jon Garrard

Dr Boyd Ghosh (appointed 1 July 2021)

Alison Goold (appointed 1 October 2021)

**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 2021 which comprise the balance sheet as at 31 December 2021, 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 2021, 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: 13 September 2022

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 Financial Activities for the year ending 31 December 2021

		Unrestricted	Restricted	Total funds	Total funds
	Note	Funds	Funds	2021	2020
		£	£	£	£
<b>Income and endowments from:</b>					
Donations and legacies	3	1,126,750	70,489	1,197,239	855,383
Charitable activities	4	18,550	6,700	25,250	13,732
Other trading activities		20,069	-	20,069	13,416
Investments		246	-	246	2,269
Other		-	-	0	39,409
<b>Total</b>		<b>1,165,615</b>	<b>77,189</b>	<b>1,242,804</b>	<b>924,209</b>
<b>Expenditure on:</b>					
Raising Funds		247,685	-	247,685	243,471
Charitable activities	5	504,340	53,906	558,246	629,831
Other		102,619	-	102,619	73,697
<b>Total</b>		<b>854,644</b>	<b>53,906</b>	<b>908,550</b>	<b>946,999</b>
<b>Net income/(expenditure)</b>		<b>310,971</b>	<b>23,283</b>	<b>334,254</b>	<b>(22,790)</b>
<b>Net movement in funds</b>		<b>310,971</b>	<b>23,283</b>	<b>334,254</b>	<b>(22,790)</b>
<b>Reconciliation of funds:</b>					
Total funds brought forward		1,017,859	43,291	1,061,150	1,083,940
<b>Total funds carried forward</b>		<b>1,328,830</b>	<b>66,574</b>	<b>1,395,404</b>	<b>1,061,150</b>

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

All income and expenditure above amounts relate to continuing activities.

The notes on pages 24-36 form part of these financial statements.

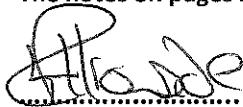


## The PSP Association Balance Sheet as at 31 December 2021

	Note	2021 £	2020 £
<b>Fixed assets:</b>			
Tangible assets	13	7,791	10,236
Investments	14	100	100
		<b>7,891</b>	<b>10,336</b>
<b>Current assets:</b>			
Debtors	15	26,981	5,487
Cash at bank and in hand		1,480,104	1,216,074
		<b>1,507,085</b>	<b>1,221,561</b>
<b>Liabilities:</b>			
Creditors: Amounts falling due within one year	16	(119,572)	(170,747)
		<b>1,387,513</b>	<b>1,050,814</b>
<b>Total net assets or liabilities</b>		<b>1,395,404</b>	<b>1,061,150</b>
<b>The funds of the charity:</b>			
Restricted income funds	17	66,574	43,291
Unrestricted funds	17	1,328,830	1,017,859
		<b>1,395,404</b>	<b>1,061,150</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... 30/08/2022

## The PSP Association Statement of Cash Flows for the year ending 31 December 2021

	Note	2021 £	2020 £
<b>Cash flows from operating activities:</b>			
<i>Net cash provided by (in use) operating activities</i>	19	<u>267,038</u>	<u>(58,552)</u>
<b>Application of cash:</b>			
Dividends, interest and rents from investments		246	2,269
Purchases of property, plant and equipment	13	<u>(3,252)</u>	<u>(560)</u>
<i>Net cash provided by (in use) investing activities</i>		<u>(3,006)</u>	<u>1,709</u>
<b>Cash flows from financing activities:</b>			
		<u>-</u>	<u>-</u>
<b>Change in cash and cash equivalents in the reporting period</b>		264,032	(56,843)
<b>Cash at bank and in hand less overdrafts at the beginning of the year</b>	20	<u>1,216,074</u>	<u>1,272,917</u>
<b>Cash at bank and in hand less overdrafts at year end</b>	20	<u>1,480,104</u>	<u>1,216,074</u>

The notes on pages 24-36 form part of these financial statements.

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

30<sup>th</sup> August 2022 and are signed on their behalf by:



Rowena Ironside



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:

#### a) 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).

#### b) Preparation of the accounts on a going concern basis

The Association reported a cash inflow of £267,038 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.

#### c) Income

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.

#### d) 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.

e) 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.

f) 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.

g) 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.

h) 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

i) 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.

j) 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.

k) 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.

l) 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.

m) 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 £1,197,239 (2020: £855,383) of which £70,489 (2020: £90,095) was restricted.

	Unrestricted	Restricted		
	2021	2021	2021	2020
	£	£	£	£
Voluntary fundraising	277,947	4,287	282,234	169,152
Legacies	306,948	-	306,948	154,963
Trust and Foundation	33,042	34,000	67,042	48,940
In Memorium	213,127	13,083	226,210	176,602
Personal donations	74,801	803	75,604	74,297
Direct mail	15,187	12,526	27,713	37,421
Unsolicited donations	90,985	3,790	94,775	76,489
Major donors	42,000	0	42,000	81,114
Corporate	72,713	2,000	74,713	36,405
	<u>1,126,750</u>	<u>70,489</u>	<u>1,197,239</u>	<u>855,383</u>

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	Total	Total
	2021	2021	2021	2020
	£	£	£	£
Service Provision	4,690	-	4,690	2,550
Government Grant - Scotland	-	6,700	6,700	6,990
Raffle	13,860	-	13,860	4,192
	<u>18,550</u>	<u>6,700</u>	<u>25,250</u>	<u>13,732</u>

### 5. Analysis of expenditure on charitable activities

Unrestricted Funds	Research activities	Info & Support costs	Volunteering costs	Total 2021	Total 2020
	£	£	£	£	£
Wages & salaries	83,360	268,894	-	352,254	368,029
Awareness	0	35,310	1,552	36,862	43,211
Purchases	1,449	948	1,013	3,410	4,721
Other grant making activities	-	-	-	-	173
Research grant making activities	68,118	-	-	68,118	12,706
Consultancy Fees	-	-	-	-	-
Facilities & Infrastructure	703	32,216	507	33,426	23,169
IT & communications	920	7,704	264	8,888	7,509
Bank charges & interest	116	116	-	232	90
Insurance	230	690	230	1,150	1,926
	<u>154,896</u>	<u>345,878</u>	<u>3,566</u>	<u>504,340</u>	<u>461,534</u>

Restricted Funds	Research activities £	Info & Support costs £	Volunteering costs £	Total 2021 £	Total 2020 £
Wages & salaries	-	6,854	-	6,854	30,795
Awareness	-	3,014	-	3,014	1,287
Purchases	-	6,495	-	6,495	2,621
Other grant making activities	-	4,564	-	4,564	850
Research grant making activities	<u>32,979</u>	<u>-</u>	<u>-</u>	<u>32,979</u>	<u>132,744</u>
	<u>32,979</u>	<u>20,927</u>	<u>-</u>	<u>53,906</u>	<u>168,297</u>

## 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 2021.

Analysis of grants paid :

	Dec-21 £	Dec-20 £
Research Grants	101,097	145,450
Support Grants	4,564	1,023
	<u>105,661</u>	<u>146,473</u>
<b>Grants to institutions</b>		
University College London	101,097	141,581
University of Cambridge	-	1,992
University of Aberdeen (Chief Scientific Office Scotland joint award)	-	1,877
<b>Research Grants</b>	<u>101,097</u>	<u>145,450</u>
<b>Support Grants to individuals</b>	<u>4,564</u>	<u>1,023</u>

Research grants are generally paid quarterly in arrears. Grants can be awarded for a period of up to five years, each grant is different. As a consequence of the impact of the pandemic on research and patient facing activity there has been a delay in expenditure against grants and there may be a further request for a no-cost extension which would impact on the allocation of the research commitment payable within one year in the note below. 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.

## Commitments Research

	Dec-21	Dec-20
	£	£
Payable within one year	177,781	193,918
Payable in years two to five	97,305	230,681
	<u>275,086</u>	<u>424,599</u>

## 7. Net income/(expenditure) for the year

This is after charging

	Dec-21	Dec-20
	£	£
Depreciation	5,698	6,340
Operating lease rental	3,000	12,000
Auditors' remuneration:		
- audit of the financial statements	3,856	2,600
	<u>12,554</u>	<u>20,940</u>

## 8. Analysis of staff costs, trustee remuneration and expenses, and the cost of key management personnel

No employee had remuneration (excluding employer pension costs) in excess of £60,000 (2019: 1). The charity trustees and key management received no personal remuneration benefits during the year (2019: £nil). No charity trustees received payment for professional or other services supplied to the charity (2019: £nil).

Total staff costs were as follows:

	Dec-21	Dec-20
	£	£
Salaries and wages	474,940	505,849
Holiday pay accrual	8,425	22,190
Social security costs	42,312	46,749
Pension contributions	11,378	13,563
	<u>537,055</u>	<u>588,351</u>

Termination payments of £83,342 were paid in 2021 (2020: £nil).

No Trustees were reimbursed expenses during the 2021 or 2020. There was no Directors' remuneration during the year.

## 9. Staff numbers



	Dec-21	Dec-20
Number of administrative staff	<b>11</b>	<b>11</b>
Number of management staff	<b>3</b>	<b>3</b>
	<b><u>14</u></b>	<b><u>14</u></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 2021).

Donations totalling £205 were received from Trustees during the year (2020: £1,335) and sales valued at £30 (2020: £31) 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 £
<b>COST</b>				
At 1 January 2021	2,958	18,895	16,945	38,798
Additions	-	3,252	-	3,252
Disposals	-	(2,328)	-	(2,328)
At 31 December 2021	<u>2,958</u>	<u>19,819</u>	<u>16,945</u>	<u>39,722</u>
<b>DEPRECIATION</b>				
At 1 January 2021	1,771	16,870	9,920	28,561
Charge for the year	588	1,726	3,384	5,698
Eliminated on disposals	-	(2,328)	-	(2,328)
At 31 December 2021	<u>2,359</u>	<u>16,268</u>	<u>13,304</u>	<u>31,931</u>
<b>NET BOOK VALUE</b>				
At 31 December 2021	<u>599</u>	<u>3,551</u>	<u>3,641</u>	<u>7,791</u>
At 31 December 2020	<u>1,187</u>	<u>2,025</u>	<u>7,026</u>	<u>10,236</u>

## 14. Investments

	Subsidiary undertakings shares £
<b>COST</b>	
At 1 January 2021	100
Additions	-
At 31 December 2021	<u>100</u>
<b>Provision for Diminution in value</b>	
At 1 January 2021	0
Charge for the year	-
At 31 December 2021	<u>0</u>
<b>NET BOOK VALUE</b>	
At 31 December 2021	<u>100</u>
At 31 December 2020	<u>100</u>

### 14.1 Holdings of 20% or more

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

Subsidiary undertaking	Country of incorporation	Nature of Business	Shares held class	Proportion of voting rights and shares held
The PSPA Trading Company Ltd (Co. Reg. No. 09030995)	England	Dormant	Ordinary	100%

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

The PSPA Trading Company	Capital and Reserves £100	Profit/Loss on Ordinary activities before taxation for the year £nil

## 15. Debtors

	Dec-21 £	Dec-20 £
Other Debtors	546	-
Prepayments and accrued income	<u>26,435</u>	<u>5,487</u>
	<u>26,981</u>	<u>5,487</u>

## 16. Creditors: amounts falling due within one year

	Dec-21	Dec-20
	£	£
Taxation and social security	12,369	13,181
Payroll creditor	7,404	22,190
Pension creditor	-	2,275
Trade creditors	61,614	91,125
Accruals	3,635	4,236
Deferred Income	-	6,700
Research accrual	34,550	31,040
	<u>119,572</u>	<u>170,747</u>

## 17. Analysis of charitable funds

	Balance 1 January 2020	Incoming resources	Resources expended	Funds 31 December 2021
General fund	<u>1,017,859</u>	<u>1,165,615</u>	<u>(854,644)</u>	<u>1,328,830</u>
<b>Analysis of movement in restricted funds</b>				
Research	-	50,575	(32,979)	17,596
Information & Support	42,275	19,914	(13,211)	48,978
Scotland	1,016	6,700	(7,716)	-
Sub total restricted funds	<u>43,291</u>	<u>77,189</u>	<u>(53,906)</u>	<u>66,574</u>

## Analysis of net assets between funds:

	General Fund £	Restricted Funds £	Total £
Tangible and Investments fixed assets	7,891	-	7,891
Cash at bank and in hand	1,413,530	66,574	1,480,104
Other net current assets	(92,591)	-	(92,591)
<b>Total</b>	<u>1,328,830</u>	<u>66,574</u>	<u>1,395,404</u>

## 18. Contingent assets

### Legacy income

As at 31 December 2021 the charity had received two notifications of legacies (2020: two)

## 19.Reconciliation of net movement in funds to net cash flow from operating activities

	2021 £	2020 £
<b>Net income/(expenditure) for the reporting period (as per the statement of financial activities)</b>	<b>334,254</b>	<b>(22,790)</b>
Adjustments for:		
Depreciation charges	5,698	6,340
Dividends, interest and rents from investments	(245)	(2,269)
Loss on Disposal of property	-	0
(Increase)/decrease in debtors	(21,494)	8,579
Increase/(decrease) in creditors	(51,175)	(48,412)
<b>Net cash provided by (used in) operating activities</b>	<b><u>267,038</u></b>	<b><u>(58,552)</u></b>

## 20.Analysis of cash and cash equivalents

	2021 £	2020 £
Cash at bank and in hand	1,480,104	1,216,074
<b>Total cash and cash equivalents</b>	<b><u>1,480,104</u></b>	<b><u>1,216,074</u></b>

## 21.Operating Leases

Total Rentals payable under operating leases:

	Land and Buildings £	2021 Total £	2020 £
Payable during the year	9,000	9,000	12,000
Future minimum lease payments due			
Not later than 1 year	-	-	3,000
Later than 1 year and not later than 5 years	-	-	-
<b>Total Payments</b>	<b><u>-</u></b>	<b><u>-</u></b>	<b><u>3,000</u></b>

As at 31 December 2021 the charity was renewing its lease and the contract was not yet signed at that date.

## 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 £867 (2020: £963).