

**The PSP Association**  
**(A Company limited by guarantee)**  
**Report and Financial Statements**  
**Year ending 31 December 2019**  
**Charity number 1037087**  
**Company number: 2920581**

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## **The PSP Association (PSPA) report of the trustees for the year ending 31 December 2019**

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

### **Chair's report**

#### **Our purpose and activities**

The purposes 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.

A research study PROSPECT 1 funded by PSPA concluded at the end of 2019 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. This assumption was based on the outcome of this research which identified that there is an almost 50% misdiagnosis rate.

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**

If 2018 was a year of dramatic change at PSPA, 2019 was the year when two years of restructure and renewal were finally concluded. In January we introduced a new structure to the organisation. Our most substantial change was to merge the Volunteering and Information & Support teams into a new 'Engagement' directorate. The Engagement team was boosted by the arrival of a full time Communications Manager later in the year, who would support not only her internal team, but would also work cross-team to ensure consistency and quality of messaging. A long-standing member of staff with experience of running both volunteering and information & support was promoted to Director of Engagement to ensure continuity.

At the end of 2018 PSPA benefited from a third party review of the performance of the fundraising team, which resulted in structural change in the team and the need to recruit additional staff. Trustees backed this assessment and approved the additional headcount. An historic post (Director of Development) was made redundant in the new structure and a dedicated Head of Fundraising was recruited for the first time in our history. It was recognised during the year that further investment in the team would be required and Trustees are supportive of this.

In 2019 we sold PSP House generating £441,000 additional reserve allocation to ensure that, should income dip over the next 12-18 months, the charity would be prepared for the resultant financial shock.

As the end of year figures demonstrate, whilst income was lower than in 2018, our reduced expenditure during 2019 – a combination of costs savings identified in earlier years, and deferred spend on our research due to administrative invoice delays at our research centres – we managed to generate a surplus to increase reserves further. Because of the prudence demonstrated in this planned approach, we are better placed to continue to invest in the charity in future years. Particularly in the area of fundraising where we need to start to demonstrate the consistent income growth that has eluded us in the last decade.

The Board of Trustees welcomed one new Trustee during the year. James Noble will help the executive team and Trustees with his extensive experience developing third sector strategy as a



consultant with New Philanthropic Capital. We have all already benefited from his experience and staff and Trustees alike look forward to working with him during his tenure.

Despite all this change, in 2019 PSPA continued to deliver high quality services to our members and support a wide network of fundraisers and volunteers.

- The number of people living with PSP & CBD, their families and carers that we support grew by 4% to 5,269.
- Our Helpline handled over 5,500 calls for the second consecutive year.
- PSPA's health forum continues to grow, increasing active members by 7% in 2019 to 969.
- Social media engagement across a range of metrics and platforms increased by between 10 and 11%
- Volunteer numbers increased by 48%, and the number of health & social care professionals who were educated rose by 450% compared to 2018
- The number of local groups reached a year end high at 39, and the total number of meetings attended by 8-30 people rose to 327 in the year. A record for the charity.

PSPA's total income for the year of £1.265 million resulted in a £252,726 surplus, largely through deferred spend on research. There was a near historic record amount of income generated by the London Marathon at £163,774, and most income streams held up well despite an extended period during the year when the fundraising team staffing levels were very low. Major donor income rose by over 20% to £87,665 for the year.

Overall, the Board of Trustees is satisfied with the financial standing of the organisation, and is pleased to see an increase in the charity's net assets as funded by cash balances of nearly £600,000 for the year.

### **Support to Families**

2019 was another year of growth for PSPA in relation to the people we support. The number of people known to us, people living with PSP|CBD, carers and family members, increased by 4% over the year to 5,269. Our Helpline continues to provide support by phone and email and handled over 5,500 enquires. Our new Helpline Care Navigators established relationships with health and social care professionals in their allocated regions, as well as proactively contacting families to ensure people are accessing the services and care available to them.

Our online forum, HealthUnlocked ended the year with 969 members an increase of 7% on 2018.

We continue to work closely with the Department of Work and Pension Visiting Service and referred 21 people to the service in 2019. Each one resulting in a successful application.

Just over 80 delegates attended our Family & Friends Day in Newport, South Wales where a leading neurologist spoke about PSP|CBD and current research. We were also joined by a specialist Occupational Therapist (OT) who spoke about her role and the importance of being linked to an OT who understood PSP|CBD. One of the outcomes of the day was a new group setting up in South Wales in 2020, our first ever in this region.

Our library of resources continued to grow, both for people living with the conditions as well as health and social care professionals. 2019 saw the launch of our online interactive resource for health and social care. A world first for PSP & CBD. This resource provides evidence-based

information on symptom management and best practice. We know that lack of knowledge and awareness of PSP & CBD can hamper health professionals' ability to provide good care. This resource will provide health and social care professionals directly caring for people with PSP & CBD with all the information they need to provide the best possible standard of care. Health professionals can download information and build a care plan for people they are supporting.

The interactive resource was accessed 798 times in its first month with 38% of those visits being undertaken internationally. We must thank our lead consultant, Karen Pearce, the many professional volunteers who provided the information on the app, and CBD Solutions (Sweden) who partnered us in this undertaking and very kindly sponsored its development.

Our new 'What to expect from your care' guides, for both PSP & CBD were launched in December 2019 and have been very well received.

### **Raising Awareness in the Health and Social Services**

Our Helpline Care Navigators continue to build relationships with health and social care professionals in their region. They attended five events as part of their education work and in total over 500 professionals received information on symptom management, the work of the charity and the importance of multidisciplinary team working.

A major success this year was the launch of our interactive resource for healthcare professionals. This innovative web application allows a user to build a personalised guide for PSP or CBD based upon severity of symptoms.

The number of health professionals (including care/nursing home staff) requesting copies of our professional information pack increased from 204 in 2018 to 370 in 2019.

### **Advocacy and Lobbying**

We continue to work with the following organisations to lobby Government to improve NHS, Social Care and Benefits services for those living with neurological conditions:

- Neurological Alliance
- Disability Benefits Consortium
- Continuing Healthcare Alliance

We were also interested stakeholders in the development of NICE guidelines for 'Suspected neurological conditions – recognition and referral' – and undertake our own advocacy and lobbying.

At the end of 2019 we received part-funding from the Scottish government to recruit a Country Manager, Scotland. Her role is to lobby, and raise awareness of PSP|CBD at the strategic level in Scotland, focussed on NHS Scotland, the Scottish Parliament, and others involved in generating health policy and care provision. The Country Manager has attended cross party parliamentary groups including one focussed on rare diseases and another on palliative care since joining PSPA.



## Our Volunteers

2019 saw a 50% increase on our volunteer cohort. We welcomed 35 volunteers to our new 'Micro Volunteer' role to help us with events, tin collections and reviewing information. We had four new groups form in Frome, the Black Country, Milton Keynes and Macclesfield, adding to the existing network and resulting in us holding 327 meetings (+7.6% over 2018), with the number of attendees ranging from 8 to 30 per meeting.

Our number of education volunteers increased by three, to 14. This team of volunteers reached 4.5 times as many healthcare professionals as in 2018, with 1,414 people educated at 40 events (itself an 85% increase in 12 months) across the UK. They provided information on PSP|CBD, and the work of the charity, with many able to share their own experiences of caring for someone with PSP|CBD.

We were very fortunate to receive a £10,000 grant from QBE Insurance Group which funded a development weekend for 40 of our volunteers, who were able to learn more about research, fundraising as local groups, and best practice, as well as a variety of other topics. These events are extremely important to PSPA volunteers as they provide the opportunity to meet other volunteers and engage with PSPA staff.

We very much appreciate the work of our volunteers and the tremendous contribution they make to raising awareness of PSP|CBD.

## Research

### Launch of the Research Strategy Consultation

In October 2019, the charity launched a consultation to develop a new research strategy. The consultation involved an in-depth study of the impact of the research funded by PSPA over the last 25 years, a review of the current funding strategies, and a look into the future at what the charity should be funding through stakeholder consultation. It is clear that through the funding of innovative research, PSPA's aims are to improve diagnosis, discover effective treatments, to understand the conditions and look to identify better ways to improve the health, quality of life and care for those living with these diseases to ultimately find a cure.

To achieve these objectives, and to ensure that the future strategy encompasses the research needs of people affected by PSP|CBD, a research survey was circulated to members with the conditions, and also to carers, researchers, and health & social care professionals via an online survey which asked respondents to identify the research questions that mattered most to them. We received 132 completed questionnaires which generated over 2,000 questions, many of which overlapped or followed a similar theme. These themes, which will directly influence our future research strategy, are summarised as follows:

1. **Awareness of PSP|CBD** - how can we better inform GP's, Neurologists, primary care practitioners and the general public about these conditions?
2. **Diagnosis of PSP|CBD** - how can we improve development of diagnostic tests and speed up diagnosis rates for people and reduce the incidence of misdiagnosis?
3. **Living with PSP|CBD** - how can we ensure the best care is available in the community for both patients and carers?



4. **Prevention and causes of PSP|CBD** - how can we help identify the causes of the disease by studying the influence of genetic, dietary, or other environmental factors - and through this discover how can it be prevented?
5. **Treatments for PSP|CBD** -in the absence of treatments for PSP|CBD what can be done to improve the quality of daily life of people with the conditions, and how can we better involve patients in clinical trials?

A further study was also undertaken to look at the impact PSPA funded research has made over the last 25 years. The analysis of this data from respondents involved in the 22 research studies that PSPA has funded during this period is ongoing and is due to be published in 2020.

The new Research Strategy based on the findings of the consultation will be launched in 2020.

#### **We report on the current research projects funded by PSPA:**

##### **PROSPECT**

The PROSPECT study is a multi-centre study led by Professor Huw Morris based at the National Hospital for Neurology and Neuroscience, with recruitment into one arm of the study from 7 different centres across the UK and collating data on symptoms, undertaking MR scans and collecting spinal fluid samples for analysis. To date, 151 people have been scanned, with results demonstrating how different symptoms are related to changes in different parts of the brain.

A further 'natural history' arm of the study recruits people with PSP|CBD from across the UK, collecting blood samples and detailed medical history. This part of the study aims to improve diagnosis and understand these diseases better. For example, we want to know how it is that patients' symptoms vary so much even with the same diagnosis; how best to track the disease over time; and, how to show that a new treatment is working to protect the brain. 88 PSPA members are involved in the natural history arm of the study and we continue to recruit new patients to this study from our members.

A ground-breaking research paper, highlighting the findings from the PROSPECT study, went to print on 20th December 2019 in the prestigious journal JAMA Neurology. It evidenced the discovery of two new sub-types of PSP, and highlighted the fact that 50% of the patients in the study had been misdiagnosed initially. It also highlighted how crucial this research is in finding a more definitive diagnosis mechanism for PSP|CBD, which is one of the key aims of the PROSPECT study.

##### **Dr Diane Swallow, PSPA/Chief Scientist Office Scotland Joint Clinical Research Fellowship, University of Aberdeen**

This research is looking at the prevalence of PSP|CBD in Scotland, how patients are referred and diagnosed, and what care they receive. Recruitment to the diagnosis and care arm of this study using prospective patient data has exceeded expected numbers (originally forecast at 50 PSP|CBD patients). We managed to recruit 92 patients with PSP|CBD, 86 carers and 79 age-sex matched controls. The findings from this study are due to be published in 2020, and it is hoped that by having clear data on the prevalence of PSP|CBD we can lobby the Scottish parliament and NHS Scotland to improve care and diagnosis for people living with these conditions.

##### **Dr Ed Jabbari – Sara Koe Clinical Research and MRC Fellowship, University of London**

This research has involved the assessment of cerebrospinal fluid (CSF) and plasma neurofilament light chain (NF-L) as predictors of disease progression in PSP, the identification of novel diagnostic

and prognostic biomarkers of atypical parkinsonian syndromes, and a genome-wide association study (GWAS) of phenotypes in PSP. It has led to the publication of two research papers. As a result of his PSPA funded work, Ed has successfully secured an additional **£1.5 million** of funding from the Medical Research Council to continue his work in this area. PSPA has redirected Ed's remaining funding in partnership with CBD Solutions (Sweden) to a new research fellow, Dr Danielle Lux who will continue research into CBD at UCL under Professor Huw Morris.

#### **Dr Danielle Lux - Sara Koe Clinical Research Fellowship, University of London**

This research, which is in its early stages, is analysing biomarkers for CBD and following a similar approach to that of Ed Jabbari's research on PSP. An interim report is due in 2020.

### **Communications**

We continue to support all types of media to supply our membership with support materials, awareness raising literature and other information so that they receive their requests in their preferred format. Social media continues to grow, as does the number of documents and information distributed by emails, whilst the amount of mailed hardcopies remains stable.

We closed the year with 8,900 Facebook likes, which represents an 11% increase on 2018, with the number of followers of this platform increasing by a similar percentage to 8,790. Our Twitter following in the year also increased by just over 10%. On all platforms, posts about research and clinical trials continued to arouse the high levels of engagement.

Our Awareness Week campaign, #Unmute, reached 11,720 people on Facebook, and led to peaks in videos played (+112%), page follows (+42%) and overall post reach up 66%. This was reflected in Twitter statistics with 4,503 impressions of the campaign launch post.

We also extended our reach through our involvement 'over the air.' Three Counties Radio invited Director of Development, Carol Amirghiasvand and supporter, Lisa Rodriguez, to talk about Lisa's experiences of CBD and the work of PSPA. Similarly, volunteers Charlotte Harman and Janet Hewitt were invited onto Radio Lincs.

Following the Three Counties Radio interview Lisa Rodriguez was contacted by BBC Inside Out to take part in their programme about Advance Care Planning. Filming for this programme will take place in 2020.

The Helpline's role also fundamentally changed during the year, switching from just receiving calls from those seeking assistance, to making proactive calls to those living with, and affected by, the conditions. This new approach is designed to help PSPA build stronger relationships with its members and supporters.

Our printed literature continued to be updated throughout the year. PSPA Matters magazine received positive feedback from its readership. We mail out 6,500 copies of the magazine to supporters, whilst around 6,100 emails are sent with a link to an electronic copy of the magazine. We are extremely proud of PSPA Matters which now comes in winter, spring and autumn editions.



## **Fundraising**

We entered 2019 with optimism, on the back of record-breaking levels of income in 2018. Whilst we did not hit the income heights of 2018, it was a good year for introducing our restructure, welcoming new staff and setting out our direction for the future.

From a fundraising performance perspective, running, walking and cycling events continued to be popular activities with our fundraisers. We had 72 participants in the Virgin London Marathon and nine cyclists taking part in the Ride London. In other challenge events, our oldest fundraiser in this category undertook an abseil at the age of 76. Overall we saw high participation levels, with some new additions to our event calendar, meaning that this continued to be our single largest source of income at over £280,000.

Legacy income was more modest this year, contributing 9% of our total income. This was a reduction on the previous year's 18%. However, as part of the holistic renewal of our approach to fundraising, we reintroduced our legacy leaflet and actively promoted it for the first time in our history, ending the year with six legacy pledges – the most we have ever had. We are extremely grateful that six of our supporters feel able to provide for the charity in the future in this way.

We continued to find ways to motivate our supporters and help them raise funds. Our supporters undertook 305 fundraising activities over the course of the year, not only raising £170,000, but also raising vital awareness for PSP|CBD.

Support from individual donors continued to underpin our income. We received over 11,293 gifts totalling £406,428 through our appeals programme, regular giving products, general donations and in-memoriam giving.

We are extremely grateful to all who took part in events to fundraise and who made donations for their contribution to the work of PSPA. Their generosity enables us to continue to support people living with, and affected by, PSP|CBD and fund vital research.

### **Fundraising Approach**

We have maintained 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 don't always get it right. In 2019, we received 2 complaints from supporters not receiving acknowledgements for donations.

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**

PSPA recorded a surplus of £252,726 in 2019 (2018: surplus £172,004) against a total income of £1.265 million

The main sources of income to the Association were: voluntary fundraising & events £303,136, with the London Marathon adding a further £163,774 to the events total; income from trusts was lower than 2018 at £142,821; and, in memoriam income fell by 7% to £183,059. Legacy income of £111,622 was received.

Our sincere thanks to all the Charitable Trusts and Foundations that 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.

Thanks to our generous supporters, direct mail appeals raised a total of £50,794, which whilst lower than 2018 is very good result in a year when the charity did not run a research appeal. Donations also held up strongly at £154,860, again courtesy of the amazing generosity of the charity's supporters and friends.

### **Investment powers and policy**

The Trustees, having considered the research funding requirements, combined with the operating cash needs of PSPA and the prevailing low deposit interest rates available in the market, decided to retain liquid funds in the main bank account. This approach will be reviewed in early 2020.

### **Reserves policy and going concern**

Reserves are needed to bridge the gap between spending and income received from donations and fundraising activities. During the year, Trustees raised the level of reserves from the equivalent of

four months future fixed costs to 12 months. At the end of the accounting period the level of cash and cash equivalent was just greater than 12 months of budgeted fixed costs.

Cash inflow from operating activities of £153,499 reflects a substantial surplus of £252,726 for the year brought about by lower than forecast expenditure on research which has been deferred to 2020.

Cash balances were further supplemented by receipt of the net sales proceeds of PSP House (£441,072).

At the date of the accounts the trustees are continuing to assess the potential impact of COVID 19 on the charity and review plans, monitoring our finances closely. The immediate priority had been to support the senior management teams decision to ensure our people's safety through home working and the safety of our fundraisers and supporters through the cancellation or postponement of events planned for the coming months. As with many other charities we therefore expect COVID 19 will significantly reduce our voluntary income whilst the effects of the pandemic crisis last. The cash balances held at 31 December 2019 have provided a strong foundation to support the charity through the initial financial effects of the pandemic in 2020. The trustees will continue to consider these issues and how to manage them as the pandemic develops.

#### **Plans for future periods**

2020 will be a period of consolidation as the organisation absorbs the substantial change that has taken place over the previous two years. We have put in place all the building blocks for a successful organisation.

PSPA will invest in its staff, training and developing them to achieve higher levels of performance. Similarly, we will maintain our infrastructure, refreshing our website and IT systems to ensure we are able to leverage them to increase supporter engagement - and build stronger relationships with those supporters.

This year saw the departure of the Chair of Trustees. Simon Koe served as Chair for five years and oversaw important and much needed change. He leaves the charity on a secure foundation and with his profound thanks for the hard work and dedication of all the charity's supporters, volunteers, donors, his fellow Trustees and our staff. As I end my own term, I echo those thanks. Looking forward, the charity has the good fortune to have Trustees who are well-placed to appoint a new Chair and to guide PSPA in these challenging times.



**Shauna Mackenzie**

**Trustee**

13 OCTOBER 2020

## References and administrative details

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

### ***Directors and trustees***

The directors of the charitable company (the charity) are its trustees for the purpose of charity law. The trustees and officers serving during the year and since the year end were as follows:

#### **Key management personnel The PSP Association: Trustees and Directors**

Chair:	SRB Koe (resigned 7 September 2020)
Co-opted Trustees	Professor Sir Colin Blakemore (resigned 18 June 2019) C Perry (resigned 18 June 2019) S Mackenzie (interim chair 7 September 2020) P Inness B Johnston (interim chair 7 September 2020) S Le Hellidu Professor J Rowe J Noble (appointed 18 June 2019) J Garrard (appointed 25 February 2020)
Secretary	A Symons

#### **Key management personnel:**

##### **Senior managers of The PSP Association:**

Chief Executive Officer	A Symons
Director of Engagement	C Amirsghiavand



### The Medical Advisory Panel:

**Chair:** Vacant

**Members:** Prof Y Agid (France)  
Prof L Golbe (USA)  
Prof I Litvan (USA)  
Prof Dr W Poewe (Germany/Austria)  
Prof N Quinn (UK)  
Prof S Reich (USA)  
Prof M Rosser (UK)  
Prof E Tolosa (Spain)  
Prof N Wood (UK)  
Prof D Burn (UK)  
Dr P Damier (France)

Honorary member: Prof J Steele (Canada/Guam)

Associate member: Dr D Machado (Portugal)

Medical co-ordinator (Europe): Dr P Pramstaller (Italy)

### Research Committee

**Chair:** Prof Hugh Perry (Southampton) resigned 19 August 2020

**Members:** To be appointed, committee is in process of being reformed.

## Structure, Governance and Management

### ***Governing Document***

The PSP Association is a company limited by guarantee governed by its Memorandum and Articles of Association dated 19 April 1994. It is registered as a charity with the Charity Commission.

### ***Appointment of trustees***

As set out in the Articles of Association the chair of the trustees is nominated by ordinary resolution presented to The Executive Committee for a period of five years. The other trustees are appointed by ordinary resolution to The Executive Committee for a term of three years.

### ***Trustee induction and training***

New trustees undergo an orientation day to brief them on their legal obligations under the charity and company law, the Charity Commission guidance on public benefit, and inform them of the content of the Memorandum and Articles of Association, the committee and decision-making processes, the business plan and recent financial performance of the charity. During the induction day they meet key employees and other trustees. Trustees are encouraged to attend appropriate external training events where these will facilitate the undertaking of their role.

### ***Organisation***

The board of trustees, which can have up to 10 members and not less than 5, administers the charity. The board normally meets quarterly and there are sub-committees covering nomination and remuneration, plus finance, audit and risk, which normally meet quarterly. A Chief Executive is appointed by the trustees to manage the day-to-day operations of the charity. To facilitate effective operations, the Chief Executive has delegated authority, within terms of delegation approved by the trustees, for operational matters including finance and employment.

### ***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. In the current year no such related party transactions were reported.

### ***Pay 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 note 6 to the accounts.

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

### ***Risk management***

The trustees have a risk management strategy 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 procedure designed to minimise or manage any potential impact on the charity should those risks materialise.

This work has identified that financial sustainability is the major risk to the charity. A key element of the management of financial risk is a regular review of available liquid funds to settle debts as they fall due.

### **Trustees' responsibilities in relation to the financial statements**

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



Shauna Mackenzie (Trustee)

13<sup>th</sup> October 2020



## Independent Auditor's 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 2019 which comprise Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement 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.

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 2019, and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

### Basis for opinion

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

### Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least

twelve months from the date when the financial statements are authorised for issue.

### **Other information**

The trustees are responsible for the 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. 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.

In connection with our audit of the financial statements, 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 audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. 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.

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

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the financial statements is inconsistent in any material respect with the trustees' report; or
- the charitable company has not kept adequate accounting records; or
- the financial statements are not in agreement with the accounting records and returns; 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 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**

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with regulations made under section 154 of that Act.

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.

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. 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.



Philip Harris BA FCA  
Senior Statutory Auditor  
For and behalf of Harris and Co  
Chartered Accountants

13 October 2020

2 Pavilion Court  
600 Pavilion Drive  
Northampton  
NN4 7SL

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 2019

		Unrestricted	Restricted	Total funds	Total funds
	Note	Funds £	Funds £	2019 £	2018 £
<b>Income and endowments from:</b>					
Donations and legacies	3	985,747	226,681	1,212,428	1,598,992
Other trading activities		19,247	0	19,247	15,345
Other		33,265	0	33,265	49,020
<b>Total</b>		<b>1,038,259</b>	<b>226,681</b>	<b>1,264,940</b>	<b>1,663,357</b>
<b>Expenditure on:</b>					
Raising Funds		337,331	0	337,331	307,222
Charitable activities	4	424,442	131,888	556,330	1,062,354
Other		118,553	0	118,553	121,777
<b>Total</b>		<b>880,326</b>	<b>131,888</b>	<b>1,012,214</b>	<b>1,491,353</b>
Net gains/(losses) on investments		0	0	0	0
<b>Net income/(expenditure)</b>		<b>157,933</b>	<b>94,793</b>	<b>252,726</b>	<b>172,004</b>
<b>Net movement in funds</b>		<b>157,933</b>	<b>94,793</b>	<b>252,726</b>	<b>172,004</b>
<b>Reconciliation of funds:</b>					
Total funds brought forward		811,504	19,710	831,214	659,210
<b>Total funds carried forward</b>		<b>969,437</b>	<b>114,503</b>	<b>1,083,940</b>	<b>831,214</b>

The statement of financial activities includes all gain and losses recognised in the year.  
All of the above amounts relate to continuing activities.

The notes on pages 24-33 form part of these financial statements.

## The PSP Association Balance Sheet as at 31 December 2019


	Note	2019 £	2018 £
<b>Fixed assets:</b>			
Tangible assets	12	16,016	499,387
Investments	13	100	100
<i>Total fixed assets</i>		<u>16,116</u>	<u>499,487</u>
<b>Current assets:</b>			
Debtors	14	14,066	54,087
Cash at bank and in hand		1,272,917	684,093
<i>Total current assets</i>		<u>1,286,983</u>	<u>738,180</u>
<b>Liabilities:</b>			
Creditors: Amounts falling due within one year	15	(219,159)	(406,453)
<i>Net current assets or liabilities</i>		<u>1,067,824</u>	<u>331,727</u>
<i>Total assets less current liabilities</i>		<u>1,083,940</u>	<u>831,214</u>
<i>Net asset or liabilities excluding pension asset or liability</i>		<u>1,083,940</u>	<u>831,214</u>
<b>Total net assets or liabilities</b>		<u>1,083,940</u>	<u>831,214</u>
<b>The funds of the charity:</b>			
Restricted income funds	16	114,503	19,710
Unrestricted funds	16	969,437	811,504
<i>Total unrestricted funds</i>		<u>969,437</u>	<u>811,504</u>
<b>Total charity funds</b>		<u>1,083,940</u>	<u>831,214</u>

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 24-33 form part of these financial statements.



Shauna Mackenzie



Barbara Johnston

Trustees on behalf of the trustees


Approved by the trustees on 13th October 2020

# The PSP Association Statement of Cash Flows for the year ending 31 December 2019

	Note	2019 £	2018 £
Cash flows from operating activities:			
<i>Net cash provided by (in use) operating activities</i>	20	153,499	304,908
Application of cash:			
Proceeds from sale of property, plant and equipment		441,071	
Purchases of property, plant and equipment	12	(5,746)	(21,023)
<i>Net cash provided by (in use) operating activities</i>		435,325	(21,023)
Cash flows from financing activities:			
		435,325	(21,023)
Net increase/(decrease) in cash		588,824	283,885
Cash at bank and in hand less overdrafts at the beginning of the year	20	759,093	475,208
Change in cash and cash equivalents due to exchange rate movements		0	0
Cash at bank and in hand less overdrafts at year end	20	1,347,917	759,093

The notes on pages 24-33 form part of these financial statements.

These financial statements were approved by the members of the committee on the ~~13 OCTOBER~~ 2020 and are signed on their behalf by:



Trustee Director

13th October 2020



## 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 £153,499 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), the general volunteer time of the Friends is not recognised and refer to the trustees' annual report for more information about their contribution.

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 fund raising 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 (with the exception of freehold land), less its estimated residual value, over their expected useful lives using the following basis:

Freehold buildings	50 years straight line
Leasehold improvements	20% straight line
Fixture and fittings (furniture)	12.5% straight line
Fixtures and fittings (electrical equipment)	20% straight line
Computer software & equipment	33% straight line

Freehold land is not depreciated. No depreciation is provided on freehold buildings in the year of purchase.



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 £1,212,428 (2018: £1,598,992) of which £226,681 (2018: £215,546) was restricted.

#### INCOME FROM DONATIONS AND LEGACIES

	Unrestricted	Restricted		
	2019	2019	2019	2018
	£	£	£	£
Voluntary fundraising	465,856	1,067	466,923	587,894
Legacies	111,622		111,622	290,891
Donor Trust	18,750	124,071	142,821	208,750
In Memorium	168,288	14,771	183,059	196,121
Personal donations	62,391	61	62,452	56,017
Direct mail	50,794		50,794	69,200
Unsolicited donations	90,697	1,711	92,408	82,757
Major donors	2,665	85,000	87,665	72,765
Corporate	14,683	0	14,683	34,597
	<b>985,747</b>	<b>226,681</b>	<b>1,212,428</b>	<b>1,598,992</b>

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

### 4. Analysis of expenditure on charitable activities

Unrestricted Funds	Research activities £	Info & Support costs £	Volunteering costs £	Total 2019 £	Total 2018 £
Wages & salaries	58,340	135,042	34,182	227,564	147,525
Research grant making activities	0	0	0	0	329,118
Purchases	2,280	39,564	380	42,224	62,882
Awareness	3,654	64,004	711	68,369	185,732
Consultancy Fees	13,840	16,765	36	30,641	52,828
Facilities & Infrastructure	6,566	16,909	3,650	27,125	18,660
IT & communications	5,857	17,668	0	23,525	31,259
Bank charges & interest	697	1,014	280	1,991	1,594
Insurance	1,502	1,501		3,003	2,380
	<b>92,736</b>	<b>292,467</b>	<b>39,239</b>	<b>424,442</b>	<b>831,978</b>
Restricted Funds	Research activities £	Info & Support costs £	Volunteering costs £	Total 2019 £	Total 2018 £
Wages & salaries	-	67,660	-	67,660	136,130
Awareness		807	3,981	4,788	-
Purchases		15,088	12,800	27,888	-
Research grant making activities	31,552	-	-	31,552	94,246
	<b>31,552</b>	<b>83,555</b>	<b>16,781</b>	<b>131,888</b>	<b>230,376</b>

### 5. Grant making activities

Research grants were awarded by the research committee to fund research projects that have been approved by peer review. No new awards were made in the year to 31 December 2019.

Analysis of grants paid :

	Dec-19 £	Dec-18 £
Research	<u>31,552</u>	<u>423,364</u>
Grants to institutions		
University College London	(37,450)	316,846
University of Cambridge	49,482	73,100
University of Aberdeen (Chief Scientific Office Scotland joint award)	<u>19,490</u>	<u>33,418</u>
	<u>31,522</u>	<u>423,364</u>

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 and therefore only 12 months of liability has been recognised at the year end.

Commitments

	Dec-19 £	Dec-18 £
Payable within one year	194,236	338,415
Payable in years two to five	<u>376,343</u>	<u>242,890</u>
	<u>570,579</u>	<u>581,305</u>

6. Net income/(expenditure) for the year

This is after charging

	Dec-19 £	Dec-18 £
Depreciation	6,345	13,364
Loss on disposal of property	41,701	
Operating lease rental	12,000	12,000
Auditors' remuneration:		
- audit of the financial statements	<u>2,400</u>	<u>2,400</u>

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

One employee had remuneration (excluding employer pension costs) in excess of £60,000 (2018: 1). The charity trustees and key management received no personal remuneration benefits during the year (2018: £nil). No charity trustees received payment for professional or other services supplied to the charity (2018: £nil).



Total staff costs were as follows:

	Dec-19 £	Dec-18 £
Salaries and wages	442,612	432,648
Social security costs	44,717	41,430
Pension contributions	9,142	5,691
	<u>496,471</u>	<u>479,768</u>

Termination payments totalling £11,000 were paid to two employees in the year whose contracts were terminated by the charity; and paid in full in the year when the staff left (2018: £0).

Trustees were reimbursed expenses during the year £0 (2018: £323).

	Dec-19 £	Dec-18 £
<b>Trustees expense payments</b>		
Travel - paid to 1 trustee	0	173
Accommodation - paid to 1 trustee	0	150
	<u>0</u>	<u>323</u>

#### 8. Staff numbers

	Dec-19 No.	Dec-18 No.
Number of administrative staff	12	11
Number of management staff	2	2
	<u>14</u>	<u>13</u>

#### 9. Pension Costs

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

#### 10. Related party transactions

Due to the nature of the charity's operations and the composition of the board of trustees, it is possible that transactions may take place with organisations in which a trustee may have an interest, including the awarding of research grants (see note 6). All grant transactions involving organisations in which a trustee may have an interest are conducted following a strict grant approval process which includes external peer review of applications and the exclusion of any related party trustee from any decision making. Professor Rowe is a named Principal investigator on one such grant held by the University of Cambridge.

Donations totalling £540 were received from Trustees during the year (2018: £495) and sales valued at £72 (2018: £18) of Christmas cards were made to members of the Board.

There were no other related party transactions during the year.

## 11. Corporation taxation

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

## 12. Tangible fixed assets

	Freehold Property £	Leasehold Improvements £	Computer Equipment £	Fixtures & Fittings £	Total £
<b>COST</b>					
At 31 December 2018	574,773	2,958	56,080	70,125	703,936
Additions	0	0	4,538	1,208	5,746
Disposals	(574,773)	0	(26,662)	(53,896)	(655,331)
At 31 December 2019	<u>0</u>	<u>2,958</u>	<u>33,956</u>	<u>17,437</u>	<u>54,351</u>
<b>DEPRECIATION</b>					
At 31 December 2018	92,000	592	54,520	57,437	204,549
Charge for the year	0	592	2,266	3,487	6,345
Eliminated on disposals	(92,000)	0	(26,662)	(53,896)	(172,558)
At 31 December 2019	<u>0</u>	<u>1,184</u>	<u>30,124</u>	<u>7,028</u>	<u>38,336</u>
<b>NET BOOK VALUE</b>					
At 31 December 2019	<u>0</u>	<u>1,774</u>	<u>3,832</u>	<u>10,409</u>	<u>16,015</u>
At 31 December 2018	<u>482,773</u>	<u>2,366</u>	<u>1,560</u>	<u>12,688</u>	<u>499,387</u>

## 13. Investments

	Subsidiary undertakings shares £
<b>COST</b>	
At 1 January 2019	100
Additions	<u>0</u>
At 31 December 2019	<u>100</u>
<b>Provision for Diminution in value</b>	
At 1 January 2019	0
Charge for the year	<u>0</u>
At 31 December 2019	<u>0</u>
<b>NET BOOK VALUE</b>	
At 31 December 2019	<u>100</u>
At 31 December 2018	<u>100</u>

### 13.1 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:

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

#### 14. Debtors

	Dec-19 £	Dec-18 £
Gift aid receivable	0	9,800
Prepayments and accrued income	14,067	44,287
	<u>14,067</u>	<u>54,087</u>

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

	Dec-19 £	Dec-18 £
Taxation and social security	13,886	11,724
Payroll creditor	0	26,644
Pension creditor	2,216	1,285
Trade creditors	63,563	69,022
Accruals	3,749	5,721
Research accrual	135,745	292,057
	<u>219,159</u>	<u>406,453</u>

#### 16. Analysis of charitable funds

##### Analysis of movement in unrestricted funds

	Balance 1 January 2019 £	Incoming resources £	Resources expended £	Transfers £	Funds 31 December 2019 £
General fund	811,504	1,038,259	(880,326)	0	969,437

##### Analysis of movement in restricted funds

	Balance 1 January 2019 £	Incoming resources £	Resources expended £	Transfers £	Funds 31 December 2019 £
Research	7,660	97,618	(31,552)	0	73,726
Information & Support	12,050	110,563	(83,555)	0	39,058
Volunteering	0	18,500	(16,781)	0	1,719
	<u>19,710</u>	<u>226,681</u>	<u>(131,888)</u>	<u>0</u>	<u>114,503</u>

## 17. Analysis of net assets between funds

	General Fund	Restricted Funds	Total
	£	£	£
Tangible fixed assets	16,116		16,116
Cash at bank and in hand	1,158,414	114,503	1,272,917
Other net current assets	(205,093)		(205,093)
<b>Total</b>	<b>969,437</b>	<b>114,503</b>	<b>1,083,940</b>

## 18. Contingent assets

Legacy income

As at 31 December 2019 the charity had received two notifications of legacies (2018: nil)

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

	2019 £	2018 £
Net income/(expenditure) for the reporting period (as per the statement of financial activities)	252,726	172,004
Adjustments for:		
Depreciation charges	6,345	13,364
Loss on Disposal of property	41,701	
(Increase)/decrease in debtors	40,021	(18,093)
Increase/(decrease) in creditors	(187,294)	137,633
<b>Net cash provided by (used in) operating activities</b>	<b>153,499</b>	<b>304,908</b>

## 20. Analysis of cash and cash equivalents

	2019 £	2018 £
Cash in hand	1,272,917	684,093
Overdraft facility repayable on demand	75,000	75,000
<b>Total cash and cash equivalents</b>	<b>1,347,917</b>	<b>759,093</b>

## 21. Operating Leases

Total Rentals payable under operating leases:

	Land and Buildings £	2019 Total £	2018 £
Payable during the year	12,000	12,000	12,000
Future minimum lease payments due			
Not later than 1 year	12,000	12,000	12,000
Later than 1 year and not later than 5 years	3,000	3,000	15,000
<b>Total Payments</b>	<b>15,000</b>	<b>15,000</b>	<b>27,000</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 £802 (2018: £1,119).

## 23. Non-adjusting events

The Trustees have carefully considering the impact of Covid-19 on whether the charity remains a going concern. While some of our fundraising income is expected to reduce as a result of Covid-19, in particular challenge events (including the London Marathon) given the prudence of our reserves policy, the Trustees are confident that the charity has sufficient funds to continue to operate and meet our liabilities as they fall due, over the next 12 months (from the date of this report). Therefore, the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.



