

PSP/

2018 IN REVIEW

***STARTS
HERE***



IT'S BEEN A

JANUARY

PSPA and the office of the Scottish Chief Scientist jointly funded research study begins recruiting people with PSP & CBD from across Scotland

FEBRUARY

Team planning away-day



MAY

Raffle raises over **£20,000**



JUNE

Work starts on the world's first Professionals' Guide to CBD



SEPTEMBER

Launch of new brand and website



OCTOBER

PSP & CBD International Symposium with world leading neurologists and researchers



BUSY YEAR

MARCH

Launched our new virtual 5K



APRIL

#TeamPSPA raises **£157,000** by completing the London Marathon



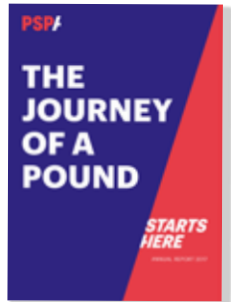
JULY



Moved to new offices in Milton Keynes

AUGUST

85% of readers surveyed said our annual review made them feel proud to be part of PSPA's community



NOVEMBER

Research appeal raises **£69,000** for PROSPECT 2



DECEMBER

Hummingbirds literally fly out of PSPA office and onto Christmas trees throughout the world!



2018 – THE YEAR OF MORE

The year 2018 marked a huge shift for PSPA. It was the year we organised the largest ever international gathering of leading neurologists and researchers for a conference on PSP & CBD. It was the year we unveiled a new brand – one focused on action and achieving more for people living with both devastating conditions. And it was the year we launched the first ever Professionals' Guide to CBD.

For PSPA, 2018 was the year of more. We raised £1.66 million in 2018 compared to £1.18 million in 2017. We supported more people living with PSP & CBD, families and carers than ever before. We achieved the largest number of health and social care professionals at our annual Study Day. And, finally, we made our largest ever investment in research.

THESE ACHIEVEMENTS PROVIDE A SOLID FOUNDATION FOR OUR 2019 GOALS.

OUR YEAR IN NUMBERS

Supported

5,100

people of which **2,000**
were directly affected by
PSP & CBD

Helpline handled over

5,500

calls and emails

£516,000

invested in research
including **£333,000** in
direct research grants

900

active members of
our online forum,
HealthUnlocked, which
is an 11% increase

300

health & social care
professionals attended
our Study Day

200

neurologists and
researchers from 18
countries attended our
International Symposium



INTERNATIONAL SYMPOSIUM ON PSP & CBD

Over two days, 220 leading scientists and researchers travelled from 18 countries for our International Symposium on PSP & CBD, jointly held with CurePSP. The event covered the latest research, from the basic biology of tau to immunotherapy trials, from PSP & CBD brain banks to patient registries, from imaging and fluid markers to genetics.

Clinicians and researchers attending the event were united by a common aim; to better understand the complexities of PSP & CBD and to provide better clinical care to people living with both conditions.

ATTRACTING YOUNG MINDS

Young researchers who will be tomorrow's leading research figures were also in attendance, with 40 early career investigators presenting their work at the poster presentation sessions.

DR JOHN STEELE



Opening the event was John Steele, who along with Dr Richardson first described and recognised PSP as a condition 55 years ago. John told the room full of PSP & CBD researchers: "I believe we can now find the cure. That is my optimism and your challenge. Solve this mystery of the last 50 years."

PROSPECT 2

Our PROSPECT study is a world first for PSP & CBD, and has created a network of specialist centres of excellence across the UK. So far over 400 people living with PSP & CBD have participated in the study. Many have been involved in the study for three years, providing us with a huge amount of clinical information that is contributing to our understanding of how both diseases develop, and how we can use that knowledge to inform future clinical trials.

In 2018, we agreed to continue to help fund this ground-breaking work for the next five years to enable researchers to:

- Expand recruitment to create the world's largest PSP & CBD cohort.
- Improve diagnosis by discovering diagnostic markers of PSP & CBD.
- Better understand the progression of PSP & CBD to help to define new treatments.
- Support upcoming clinical trials and ultimately accelerate the discovery of future treatments.

CLINICAL TRIALS

We continued to support the current Biogen tau-antibody clinical trial in the recruitment of people with PSP. We have also held discussions with pharmaceutical companies including UCB and AbbVie on potential future studies.

SARA KOE CLINICAL FELLOWSHIPS

Our Sara Koe Clinical Research Fellow, Dr Ed Jabbari, published the results of his work in the journal *Annals of Neurology*. He set out to understand why some people with PSP experience faster progression than others. His work offers a significant contribution towards neurologists being able to give families a more accurate prognosis.



One of our greatest challenges is raising awareness, with around half of people misdiagnosed initially, and many health professionals unaware of PSP & CBD. To face these challenges, we set a target to build a strong brand that unites and brings together everyone affected by PSP & CBD.

We secured the free services of leading branding consultancy, Brandpie, and, following a year of preparation and consultation, in September we launched our new identity.

Our new brand will help us bring more attention to PSP & CBD, secure better care and invest more in research. Alongside the new brand, we updated our website, dramatically improving the site's functionality and content.

BUILDING OUR SOCIAL PRESENCE

👍 8,010 Facebook likes

🐦 3,350 Twitter followers

Our engagement and follower numbers increased across both social platforms. During 2018, we increasingly used the platforms to raise awareness and educate, with week-long social campaigns for Carer's Week, Volunteer's Week, and a focus on research and CBD.

PSP MATTERS

We relaunched *PSP Matters*, with a new format. The content of the magazine has been redeveloped and now every edition features an interview with a prominent researcher or neurologist, and an informational article from a health and social care professional. The magazine continues to receive positive reviews from readers.

EXPANSION OF LOCAL GROUPS

During 2018, our local group network expanded, with the creation of three new groups in Lincolnshire, West Sussex and the Isle of Wight.

EXPANSION OF EDUCATION VOLUNTEERS

Education Volunteers more than doubled in 2018 to 11. These volunteers provide an education service to health and social care professionals, and over the next few years will form a significant part of our battle to raise awareness of PSP & CBD.

The volunteers ran 27 events in the year, attended by 308 healthcare professionals. We want to increase their numbers in the coming year as we become more ambitious in our plans to spread awareness of these conditions.

£25,000 FUNDING TO MAKE AN IMPACT

We secured £25,000 of funding from The Masonic Charitable Foundation to 'make an impact' in Northumbria. We recruited an Engagement Officer on a twelve month contract in September. The purpose of the role is to act as a hub for the PSP & CBD community in the region. The role is a pilot that if successful, we will roll out in other areas, subject to securing funding.



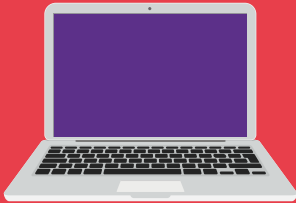
5,100

people affected by
PSP & CBD supported



5,500

enquires to our Helpline



900

active members of our online
forum, HealthUnlocked



Over **100**

people attended our
Family & Friends Day



22

people referred to the Department
of Work and Pension, resulting in
benefits worth over **£100,000**.



495

copies of our 'Your Personal
Guide to PSP' requested

DOING MORE FOR PEOPLE WITH CBD

Thanks to generous sponsorship from CBD Solutions we launched the first ever *A Professionals' Guide to Corticobasal Degeneration* at our Study Day event last October.

This new care pathway provides an overview of the standards of care people with CBD, their carers and family members should expect. It will be complemented by an on-line interactive resource and up-to-date framework that will be able to launched in 2019.

MORE THAN 300 OF THE GUIDES HAVE SO FAR BEEN REQUESTED.

EDUCATING HEALTHCARE PROFESSIONALS

Our annual Study Day attracted over 300 health professionals including consultants, GPs, physiotherapists, PD Nurses, speech and language therapists, social workers and commissioners.

1,800 health & social care professionals were educated by PSPA staff and education volunteers at other events throughout the year. Over 200 healthcare professionals, including nursing home staff, requested copies of our Professional Information Packs.





£1.66 million

total income



£408,000

raised by #TeamPSPA



£157,000

raised by London
Marathon runners



£209,000

from Trusts




£15,000

raised from 5K for PSPA



£291,000

from gifts in wills



As a direct result of increased engagement in 2018 we achieved our best fundraising results since the charity was founded in 1994, ending the year with a total income of £1,66m.

Our PSP & CBD community gets stronger every year, and, in turn enables us to be stronger in the fight against both devastating conditions. In 2018, record levels of fundraisers challenged themselves by running, walking, riding, skipping or jumping.

From babies to pensioners, our amazing supporters generously gave up their time to organise fundraising events, concerts, plays, tea-parties, cake bakes and golf competitions.



OUR FIRST VIRTUAL EVENT

In 2018, we introduced a new virtual fundraiser, 5K for PSPA. Our new event proved to be the perfect opportunity for family and friends to get together. Across the country thousands walked, ran or were pushed through parks, roads and towns, raising £15,000 for PSPA.

SUPPORTERS CAME OUT IN FORCE TO SUPPORT PROSPECT 2

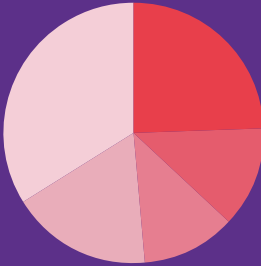
Our direct mail appeal aimed to raise funds to invest in the second stage of PROSPECT. The appeal exceeded expectations and raised £69,000. Thank you.

We are extremely grateful to all who took part in events to fundraise, donate or volunteer in support of PSPA. It is thanks to them we are able to continue to support people living with and affected by PSP & CBD and fund vital research.

“I DON’T KNOW WHEN A CURE FOR PSP WILL BE FOUND. WHAT I DO KNOW IS, IF THIS HORRIBLE ILLNESS IS GOING TO BE BEATEN, IT WILL ONLY BE THROUGH PEOPLE RAISING MONEY AND VOLUNTEERING.” MICHAEL SHEPHERD

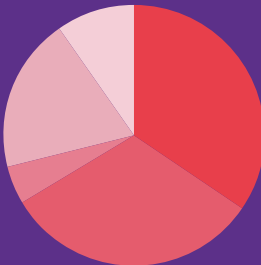
FINANCIAL REVIEW

£1.66M TOTAL INCOME



- Voluntary fundraising and events **£408,000**
- Trusts **£209,000**
- In memoriam **£196,000**
- Legacy income **£291,000**
- Donations and gifts **£560,000**

HOW WE SPENT THE POUNDS YOU RAISED



- Research **£516,000**
- Information and support **£478,000**
- Volunteering **£69,000**
- Fundraising **£286,000**
- Administration and Governance **£143,000**

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