

2023 IMPACT REPORT



WELCOME TO PSPA'S IMPACT REPORT FOR 2023



2023 was a year of growth and investment for the charity across all areas of our work; and one where we set new goals to underpin our determination to create a better future for everyone affected by PSP & CBD.

It was a busy year for research, with our new research fellow Dr Robert Durcan starting a three-year PhD at the University of Cambridge, working towards a symptomatic treatment for people living with PSP. Fellowships like Dr Durcan's support and encourage the next generation of clinical and research talent committed to improving the lives of individuals touched by PSP & CBD. October saw the successful two-day Neuro 2023 Symposium in London, where we partnered with the US charity CurePSP to bring together over 250 scientists, researchers and clinicians to share and explore the latest developments in PSP & CBD research.

Following on from PSPA's investment in PROSPECT, in 2023 we were excited to learn that the UK government has committed to funding this important longitudinal project as part of the new Early Assessment, Diagnosis and Treatment of Parkinson's Plus related syndromes (ExPRESS study). This investment by the government reflects the significance and value of PROSPECT and it has enabled us to start investing in new research and awareness grant ideas.

Awareness, or the lack thereof, is one of the biggest challenges faced by people affected by PSP & CBD. Whether this is evidenced by delays in diagnosis, the difficulty explaining the conditions to healthcare professionals, or by the challenges accessing appropriate health and social care, improving awareness of the conditions is a key priority.

So, in 2023 we took the decision to invest more in awareness-building, in the form of a new post of Director of Policy and Influencing, who starts in March 2024. We also launched our Eye Red Flags campaign with opticians across the UK.

Providing information and support is a central part of our work and our Helpline team handled an increasing number of contacts in 2023 as the number of people we support continued to grow. We further expanded the support we provide in both in-person and online group meetings across the country and secured funding from the National Lottery Community Fund to begin in 2024, reflecting the significant impacts on both mental and physical health that accompany a diagnosis of PSP & CBD - both for those with a diagnosis and their carers.

An important area for improvement in 2023 has been our ability to measure and report on the charity's impact. The 2022 survey of people living with PSP & CBD provided confirmation of what is most important to our beneficiaries, and we are improving the way we capture data to understand the impact we have on the three main goals of our current strategy.

Everything we do is made possible by the ongoing support and involvement of you, our fundraisers, volunteers, donors and supporters. Thank you for all your contributions in 2023.

Rowena Ironside
Chair, PSPA Board of Trustees

GOALS YOU ARE HELPING US TO ACHIEVE

To help create a better future for everyone affected by PSP & CBD, in 2023 PSPA set out three core goals within our new three-year strategy.



These goals help to drive us forward with a renewed focus to create a better future for the 10,000 people living with PSP & CBD in the UK.

Throughout 2023, your help has enabled us to develop our support and information, invest in research and awareness raising and ensure the experiences of people living with PSP & CBD inform our decision making.

GOAL 1 SUPPORT AND INFORMATION

Enable people to live the best life possible



PSPA is the UK's leading centre of knowledge, experiences and support for people living with PSP & CBD and their families.

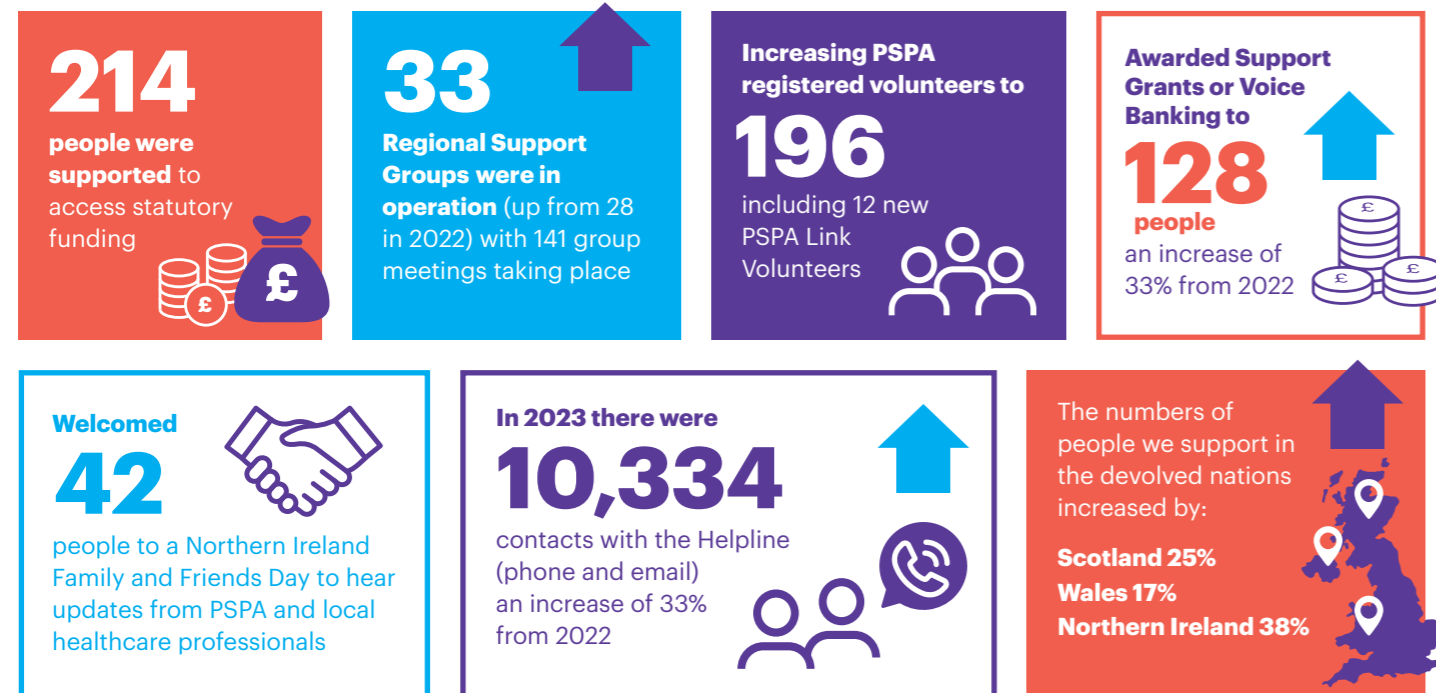
We have the experience and knowledge to help individuals understand the conditions and support available to them.

The support and information we provide to families is important and we are constantly looking to expand our provision to complement our existing services.

Thanks to the support from the Masonic Charitable Foundation, in 2023 we introduced A Carer's Guide to PSP & CBD, as well as established an online support group for male carers, in addition to our existing carers support groups.

In addition, a generous grant from Global's Make Some Noise meant we could begin offering one-to-one support via our new Link Volunteer Service.

OUR ACHIEVEMENTS IN 2023 INCLUDE:



GROWTH FOR THE FUTURE

2024 marks 30 years since the creation of PSPA, and we will use this year as a springboard to growth.

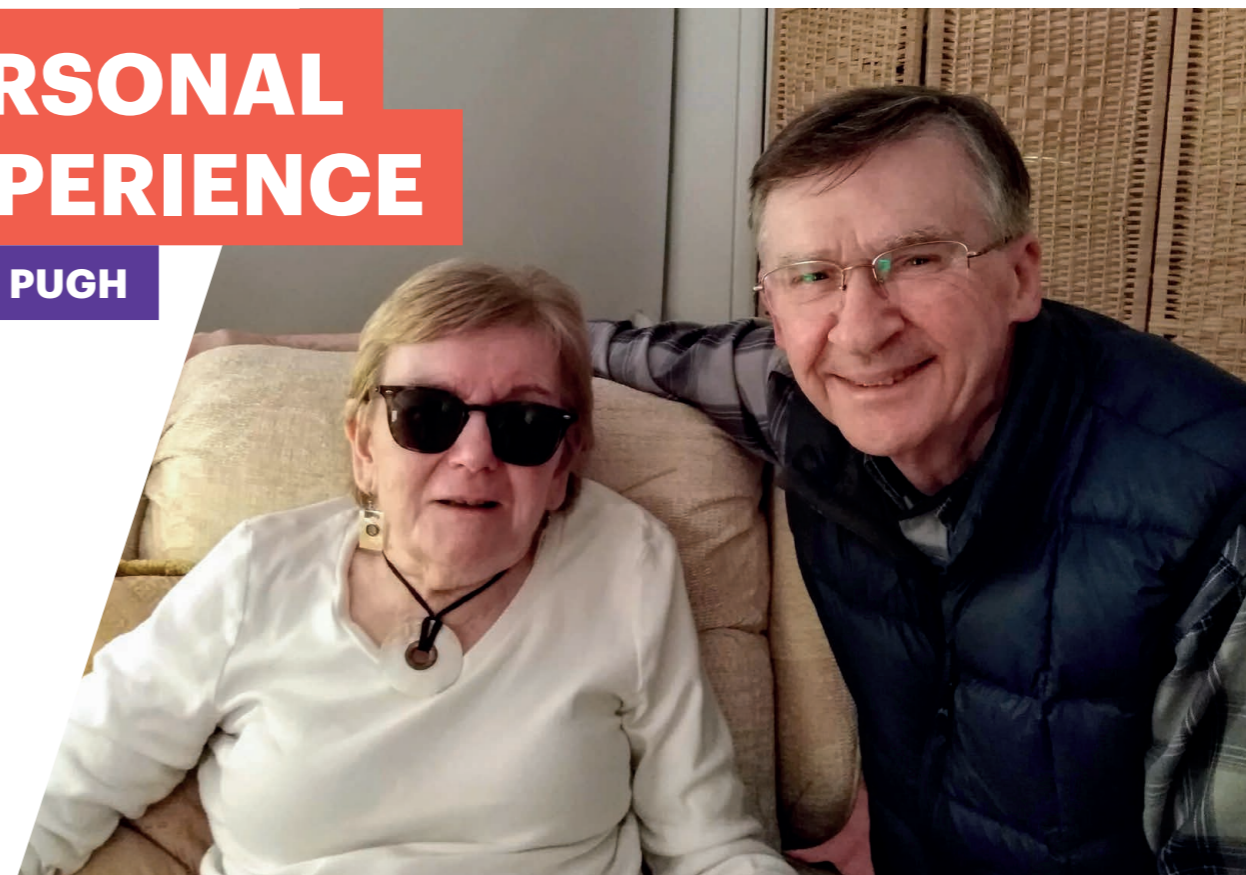
Continued growth to our information and support service in 2024 will include setting up seven additional support groups, adding to our library of publications and aiming to increase the number of people we support by 5%.

A grant from the National Lottery Community Fund means we will be introducing two new services in 2024 as part of our Mind, Body and Soul project;

- An online and telephone counselling service in partnership with Rare Minds for individuals and couples
- Tailored online exercise sessions with Neuro Heroes for people living with PSP or CBD.

PERSONAL EXPERIENCE

DAVID PUGH



David has been volunteering for the charity since February 2023, when he signed up to become a PSPA Link Volunteer providing one-to-one support to people affected by PSP & CBD, using his experience of caring for his wife.

David said: "After Rosalind was diagnosed with PSP in 2017, she was very keen to talk to everyone she could about the conditions. She read all there was to read and was very keen to educate everyone. Following her death, and upon seeing PSPA's call for Link Volunteers, I felt signing up would be a great way to continue Rosalind's legacy and do my bit too."

David continues: "I remember speaking to the PSPA Helpline whilst Rosalind was still alive, and what I really appreciated was an unspoken understanding. No need to explain what PSP is and how it was impacting my life, before I got onto the real reason I reached out, which was really refreshing."

"As a PSPA Link Volunteer, I feel I get to give this same sense of understanding back to the people I support. I know people have appreciated this and the fact my support to them is very much tailored to their current needs, whether it is better understanding their diagnosis, planning for the future, or pointing them to local support and care."

David had been volunteering for several months, when he was approached in July 2023 to help lead online support group meetings for male carers.

"I was having a catch up with PSPA about how my volunteering was going, when they mentioned they needed someone to lead the new Men's Carers Support Group. In the same vein that I signed up as a Link Volunteer, I agreed to take on the role, to ensure we can reach as many men as possible."

"The Men's Carers Support Group meetings help to provide a real sense of camaraderie and peer support. The meetings are online, which makes them very accessible for busy carers, and people can dip in and out as they need. It is a great source of friendship and sharing of local information and tips."

"AS A PSPA LINK VOLUNTEER, I FEEL I GET TO GIVE THIS SAME SENSE OF UNDERSTANDING BACK TO THE PEOPLE I SUPPORT."

GOAL 2 RESEARCH AND AWARENESS RAISING

Improve quality of life

As a charity, our work is important because people living with PSP & CBD do not receive a timely diagnosis or adequate support and care.

From our 2022 survey of people living with PSP & CBD we learned approximately 60% of people living with

PSP or CBD initially receive a misdiagnosis, and many are dissatisfied with the level of local care they receive following their diagnosis.

This is why in 2023, we extended our investment into research and awareness raising.



IN 2023 OUR RESEARCH AND AWARENESS RAISING ACTIVITIES HAVE INCLUDED:

<p>Increased the number of healthcare professionals we support to</p> <p>1,888</p>	<p>Distributed</p> <p>424</p> <p>copies of A Guide to PSP & CBD for Physiotherapists</p>	<p>Educated</p> <p>848</p> <p>healthcare professionals via training or our online Study Day</p>
<p>Created</p> <p>6 education videos</p> <p>to raise awareness and educate healthcare professionals in Scotland</p>	<p>Presented at the South Wales Parkinson's Disease Nurse Specialist</p> <p>Annual Conference</p>	<p>Welcomed</p> <p>more than 250</p> <p>of the world's leading researchers to our PSP & CBD International Symposium in partnership with CurePSP</p>
<p>Funded five new research studies totalling</p> <p>£152,799</p> <p>and invested</p> <p>£285,000</p> <p>in a three-year research fellowship for Dr Robert Durcan</p>	<p>Distributed</p> <p>more than</p> <p>800</p> <p>'Eye Red Flags for PSP' for opticians aimed at improving diagnosis</p>	<p>Delivered an education session at the Neurology Unit, Musgrove Park Hospital, Belfast</p>

GROWTH FOR THE FUTURE

We have set ourselves an ambitious target of raising £2 million over the next two years, for research above and beyond our usual income.

We will set up a working group of healthcare professionals to help provide a forum for sharing best practice and raising awareness within a medical setting.

We recruited a Director of Policy and Influencing to drive our work building relationships with partner organisations and healthcare decision makers.

To provide objective and unbiased support to the Board of Trustees, membership to our Research Committee will change; with five new professionals joining.

Our Research Information Day will return as multiple smaller sessions across the year to improve accessibility.

We also aim to increase our annual research spend by 6%.

PERSONAL EXPERIENCE

DR EDWIN JABBARI

MBBS, MRCP, PHD



After completing his general medical training, Dr Edwin Jabbari was appointed as a PSPA Research Fellow in 2016.

As a result of this fellowship, Dr Jabbari published research papers detailing key findings from the PSPA funded PROSPECT study. This included in 2019, the discovery of different phenotypes of PSP, increasing the number of people affected by the condition, and then in 2020 the identification of the genetic variant LRRK2, which can help determine the speed PSP progresses.

In 2023, Dr Jabbari applied for further funding from PSPA, to continue his important work in developing biomarkers for PSP.

"I began my PhD via PSPA's Sara Koe fellowship between 2016 and 2019. This allowed me to go on to obtain a Clinical Research Training Fellowship from the Medical Research Council to focus on discovering genetic determinants of disease progression in PSP.

"PSPA HAS BEEN CENTRAL TO DEVELOPING MY CAREER AS A CLINICAL ACADEMIC SINCE 2016."



"More recently, as a post-doctoral researcher, PSPA has again supported me via a research grant to start work on developing novel diagnostic biomarkers for PSP.

This will provide a platform for me to apply for fellowships later this year as I transition towards becoming an independent clinician scientist who is dedicated to improving the diagnosis and treatment of PSP."

GOAL 3 INVOLVEMENT

Put people living with PSP & CBD at the heart of what we do.



More than 90% of people have never heard of PSP or CBD before their diagnosis.

A lack of awareness of the conditions can mean families coming to terms with a diagnosis experience feelings of isolation, fear and being overwhelmed.

That's why in 2023 we established multiple forums for our supporters to share their experiences, to feel heard and listened to, and for their views to help shape future services and research.

IN 2023, OUR INVOLVEMENT WORK INCLUDED:

Recruited
143 people to our research register

We ran
20 engagement activities informing changes to the website, development of our 30th Anniversary Awards, and the evaluation for our online carers groups

The services committee was established with eight members feeding back quarterly

Helped to recruit participants for
5 research studies

We recruited PSPA Research Involvement Members **to ensure lived experience of people with PSP & CBD and their carers are acknowledged and appreciated**

Our PSPA Research Involvement Members volunteers took part in
21 engagement activities including assessing grant applications and reviewing protocols for drug trials with pharmaceutical companies

GROWTH FOR THE FUTURE

In 2024, we look forward to seeing the outcomes from research and support service-based projects, and the impact this will have on the PSP & CBD community. This includes input into research studies such as ExPRESS, further development of

PSPA's website and production of our publication for young people.

We are committed to growing our involvement programme to ensure people living with PSP & CBD are kept at the heart of what we do.

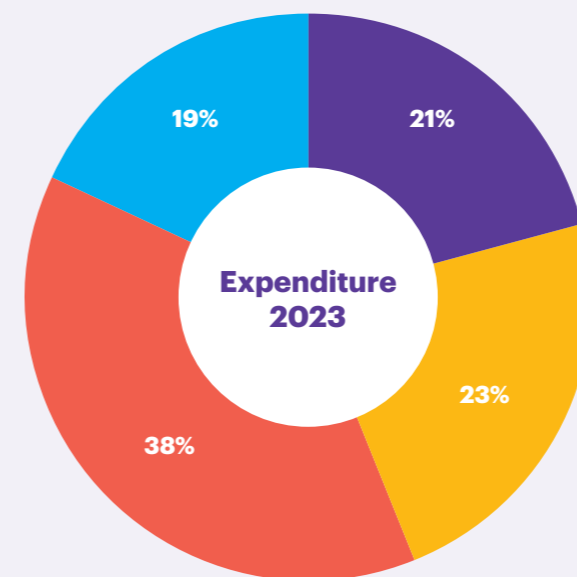
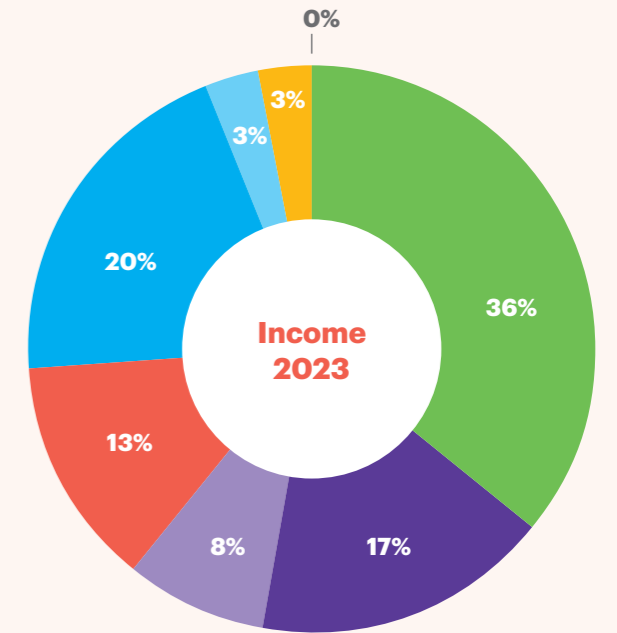


2023 FINANCIALS

Income

	2023 Total £
Voluntary Fundraising and Events	533,913
Legacies	246,373
Trusts and Grants	121,830
In Memoriam	198,479
Donations	291,614
Investments	45,766
Retail	50,606
Other	2,048

TOTAL INCOME
1,490,629



Expenditure

	2023 Total £
Raising Funds	290,412
Research	312,955
Service, Information and Support	517,937
Admin, Management and Governance	257,846

TOTAL EXPENDITURE
1,379,150

THANK YOU



At the end of my second year as CEO at PSPA I continue to be amazed by the support and commitment we receive from our network of supporters and volunteers; without this we could not achieve all that we do. From fundraising to awareness raising and volunteering, our supporters are the bedrock of PSPA. Most of our supporters have been moved to be involved through a close family connection, showing the lasting impact that PSP & CBD can have on families and friends.

Volunteers provide places for people to meet and share experiences at regional Support Groups and our new team of Link Volunteers are providing one-to-one support for people who have received a diagnosis or face a current challenge. Fundraisers run marathons, jump out of planes, host bake sales and quizzes, and help us to find corporate supporters and Trusts, ensuring we can fund new services and research.

As a charity, we need to be courageous in our fight to bring about change for the thousands of people living with a PSP & CBD diagnosis across the UK. Diagnosis is slow and inaccurate, there are no treatments, no cure, and no national standards of care. We need to do more and better to change the landscape for everyone affected by PSP & CBD. Improved diagnosis, consistent care and treatments are our goals.

As we reach our 30th Anniversary in 2024 we are investing more in research, awareness raising and influencing to build networks and improve the standards of care.



WE NEED TO DO MORE AND BETTER TO CHANGE THE LANDSCAPE FOR EVERYONE AFFECTED BY PSP & CBD

We have set ourselves the ambitious goal of raising £2 million to fund the next generation of research and will be introducing new counselling and specialist online exercise classes for people with PSP & CBD.

Finally, I would like to acknowledge the dedication and hard work of the staff and Trustees, all who go the extra mile to make sure that services meet the highest standards and that we continue to be ambitious in creating a better future for everyone affected by PSP & CBD.

Rebecca

Rebecca Packwood
PSPA CEO

SUPPORTING THE PSP & CBD COMMUNITY

IN 2023, PSPA SUPPORTED 3,538 INDIVIDUALS, INCLUDING CARERS AND FAMILY MEMBERS.

84% of Carers Support Group attendees say the meetings improve their wellbeing.



"Get in touch with PSPA. The help and information you receive from them will prepare you much better for the future ahead."

JASON



"The Helpline is so supportive. They not only helped in terms of practicalities – pushing me to get support at home. But also, emotionally – there were days I'd just call up and cry down the phone to them. They were so reassuring, and they sent all the useful information and publications out, which I have shared with our GP, John's physio and more recently his care home too."

SUZANNE

"For me, the PSPA Support Group meant I knew there are other people out there who are going through this experience too. Both people living with the condition and carers."

LIZ



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



"The Family and Friends Day in Windsor was so well organised, interesting, and fun! The food was delicious, the speakers were excellent, and we were very well looked after by the PSPA staff and volunteers. We are so grateful to have the support of PSPA, it makes such a massive difference whilst dealing with a condition that is so rare and quite frankly horrible."

88% (83% in 2022) of healthcare professionals attending training report improved knowledge or feeling more confident to support people with PSP & CBD.

"I am new to the role of Parkinson's disease nurse therefore all the information was invaluable to me."



"I learnt a lot from hearing the patient/relative perspective. How a son supports his mum with PSP, and the ways that quality of life can be enhanced. The optical input was very useful."

"Understanding the potential progression of the conditions will help me obtain realistic goals for my patients living with PSP & CBD."

GET IN TOUCH

If you would like to support PSPA, please get in touch

Visit: www.pspassociation.org.uk

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