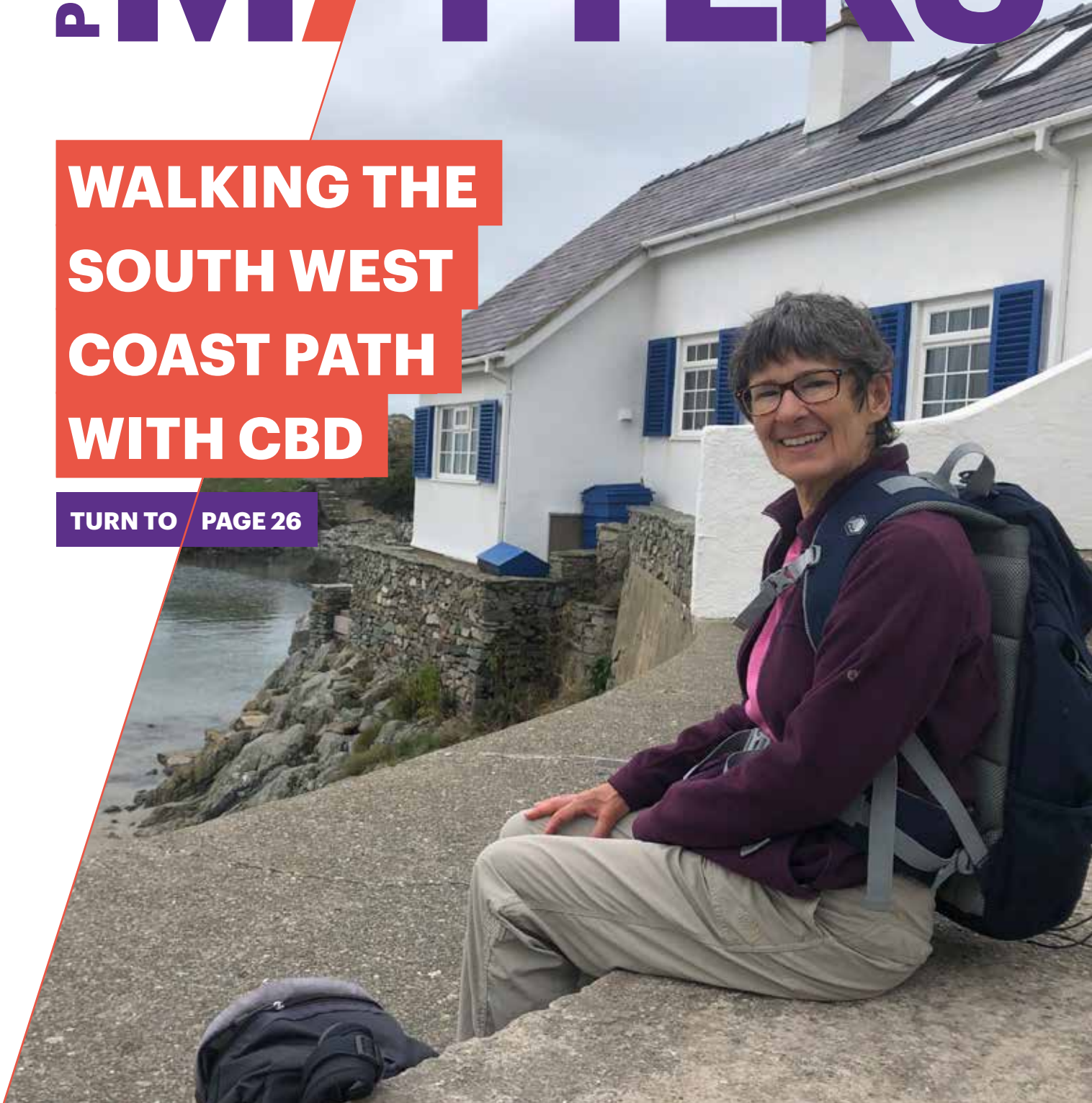


EDITION 1 / 2023

PSPA MATTERS

**WALKING THE
SOUTH WEST
COAST PATH
WITH CBD**

TURN TO PAGE 26



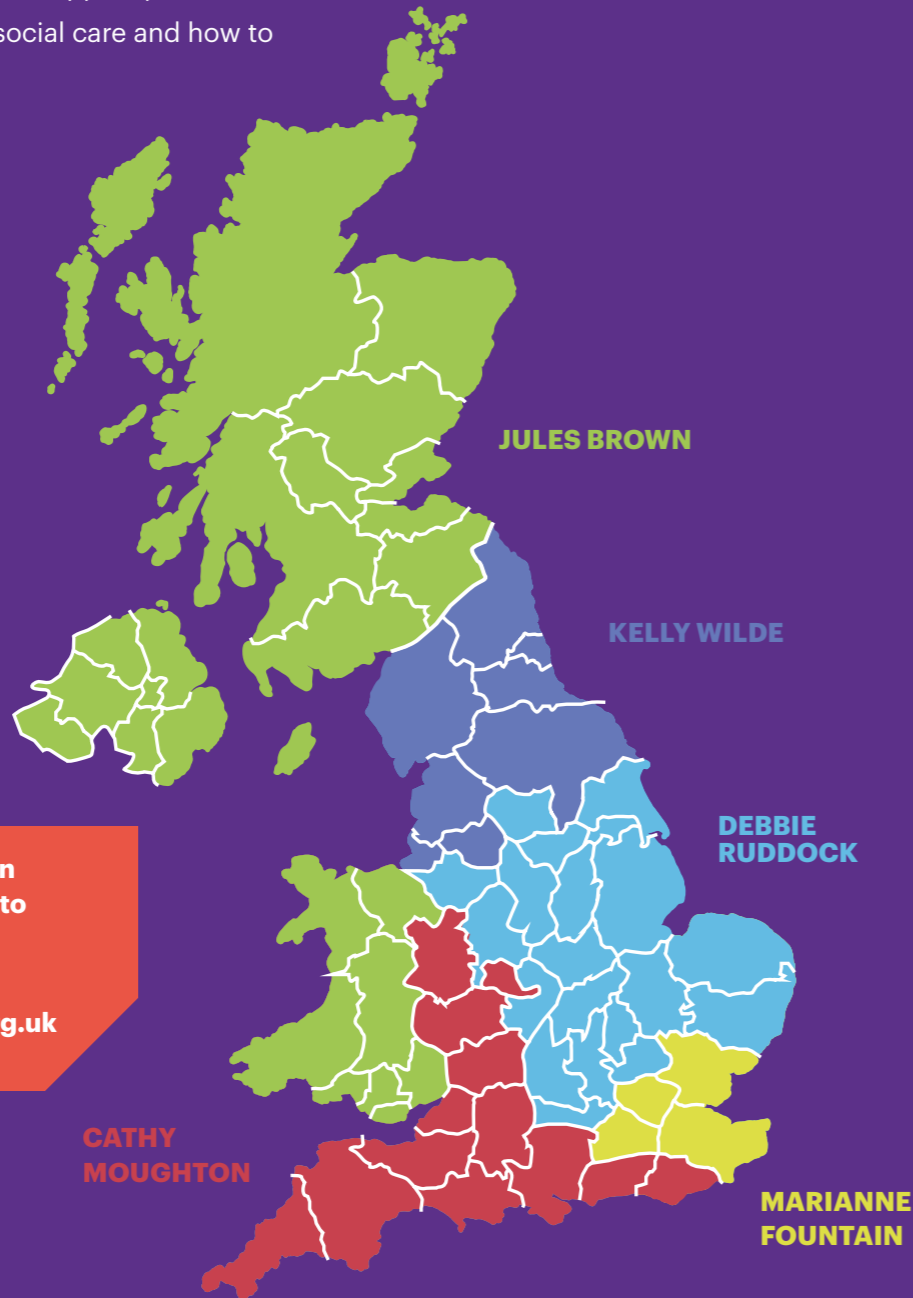
IN THIS ISSUE

- News • Awareness • Personal Experience • Research
- Information and Support • Fundraising • Volunteering

HERE FOR YOU

Our Helpline Care Navigators are here to support everyone affected by PSP & CBD. Each Helpline Care Navigator has a designated area (see map) where they provide proactive support, including:

- Information on all aspects of living with PSP & CBD, such as symptom management, benefits and entitlements and everyday living
- Emotional and practical support
- Contact details for local support, which may include Support Groups
- Information about how PSPA can support you
- Information about health and social care and how to access these services
- Signposting to other sources of information
- Referral for non-means tested benefits applications via Department of Work and Pensions (DWP) home visiting service
- Supporting evidence about PSP & CBD for Blue Badge applications and Continuing Healthcare applications
- Provide specific information written for health and social care professionals and access to Education Volunteers.



Our Helpline and information service is available Monday to Friday 9am to 9pm.

Tel: 0300 0110 122 or email helpline@pspassociation.org.uk

WELCOME

A New Year, a new strategy, and new plans!

After a year at PSPA I'm excited we are launching our new strategy and Trustees have decided to invest more resources in expanding services and raising awareness. In 2023 we are increasing the resources we have on the Helpline, enabling us to make more outbound calls and crucially to provide more time to attend clinics and run education events for health and social care professionals. Results from the survey for people living with PSP & CBD show raising awareness amongst this group is your number one priority so it must be ours too. Thank you to the 400 plus of you who completed the survey, it is helping to influence what we do and how we do it. Visiting local Support Groups has put personal stories to the data gained in our survey. Your willingness to share your stories of diagnosis and your ongoing health journeys are a huge help in identifying what we can do. I will continue my visits this year and look forward to meeting more of you.

We are blessed at PSPA with many dedicated and enthusiastic supporters, often who have come to us having been impacted by PSP or CBD and who turn their efforts to trying to change the future for others. But not everyone falls into that category. I wanted to take this opportunity to pay tribute to Dr Anne Silk who passed away in December 2022. Dr Silk was a dedicated and generous donor to PSPA having paid for the prism glasses PSPA distributes for free for many years. She was a former clinician who developed an international contact lens consultancy. In her retirement she had a second career in neuroscience and the environment, producing a wide range of research outputs and supporting innovative scientific research. We are grateful to have had Anne's support for many years.

Rebecca

Rebecca Packwood
PSPA CEO



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PSPA NEWS

CHRISTMAS BAUBLE APPEAL 2022

Thank you to everyone who kindly donated to our Christmas Bauble Appeal during November and December 2022.

Our head office Christmas tree was bursting with special messages for loved ones by the beginning of January 2023.

The funds raised from the Bauble Appeal will help us continue vital support services including our Helpline.

Thank you for your continued support.



VOLUNTEER FOR PSPA!

We're currently recruiting for more Volunteer Support Group Coordinators to help extend the reach of our support in local communities.

If you are interested in becoming a Volunteer Support Group Coordinator, please email volunteering@pspassociation.org.uk

FAMILY AND FRIENDS DAY COMING THIS SUMMER!

Keep a check on our website for more information.



PSPA'S SUMMER RAFFLE IS COMING!

Our popular annual summer raffle is fast approaching! Tickets will be hitting your doormat in June, and if you would like to be in with a chance of winning a cash prize of up to £500, you will need to return your tickets stubs by 31 August.

The aim of our raffle is to help spread the word about PSP & CBD as well as support our annual awareness campaign. As always, a hamper prize will be available to the person or group who sells the most tickets!

If you are not signed up to receive PSPA raffles, you can be added to our mailing list by emailing fundraising@pspassociation.org.uk



PSPA WEBSITE DEVELOPMENTS

You may have spotted our website is now looking a bit different! During the latter half of 2022, we were busy responding to your website experiences, to make some important changes. The aim is to make the website easier to use, and for you to be able to find the information you need, faster.

We hope you like the changes we have made to the home page, menu and search facility!

Our website work, hasn't finished! We will be continuing to improve content during 2023. We hope the upcoming developments will provide you with more information, relevant to you and your location, and make it easier for people newly diagnosed to find us via search engines such as Google.

Thank you to members of the Website Focus Group for their time and insight into what your needs and challenges with our website have been.



WELCOME TO VIVIENNE MURRAY!

"I joined PSPA on 15 December 2022. I used to work locally for a motorcycle speed way company but was unfortunately made redundant. Before this I worked as a legal secretary in London for 22 years. My father had Parkinson's which people with PSP are often misdiagnosed with and this is why the role resonated with me. I am looking forward to my year here covering maternity leave and learning more about PSP & CBD and spreading awareness of this rare disease."

Meet our new Volunteer Project Coordinator, Anna Joynson, and learn about our Link Service on page 11.



SAVE THE DATE - PSPA STUDY DAY

We are pleased to announce our 2023 healthcare professionals' Study Day will be held both in person and online. **The event will take place on Wednesday 27 September in Birmingham.**

We will be covering a wide range of topics and it will be a great chance for professionals to further their knowledge of PSP & CBD as well as network with colleagues. This is a free event and places will be limited so please keep checking your PSPA newsletters for when registration opens. Programme to follow.



DONATE TO PSPA

If you would like to support our work, there are many ways you can donate to PSPA.



By phone - call 01327 322414

By text - text TEAMPSPA to 70085

Online - please visit www.pspassociation.org.uk/fundraising/donate to make a one-off donation or set up a regular gift.

Every penny you give will help PSPA create a better future for everyone affected by PSP & CBD. Your donation will help fund high quality information and support, allow us to fundraise as well as to fund and promote life-changing research.



WHAT YOU TELL US ABOUT YOUR EXPERIENCES OF DIAGNOSIS, CARE AND SUPPORT AND OUR SERVICES WILL SHAPE WHAT WE DO OVER THE NEXT FEW YEARS.



2022 SURVEY FOR PEOPLE LIVING WITH PSP & CBD

The survey data is a crucial part of PSPA being able to provide support and to campaign for change based on the views and priorities of people who live with PSP or CBD.

More than 400 people completed the 2022 survey. This is a similar number to those who completed the last survey in 2016 and we are busy analysing the huge amount of data we now have.

In this issue we can tell you about some of the headline messages.

DIAGNOSIS

The good news is that it is getting quicker to get a referral from a GP to a neurologist. 29% of people said they only had to visit the GP once before getting a referral which is a 6% increase from 2016. The number of people who had to visit a GP five times or more was down from 23% to 17%.

Equally the time from referral to diagnosis had also got quicker with 43% getting a diagnosis within three months of referral compared to 35% in 2016. Whilst there is a long way to go these numbers are going in the right direction, but some people are still having to seek alternative routes to diagnosis.

“With the NHS, I was just being fobbed off. They were saying I had anxiety, depression, and insomnia caused by the depression, an arthritic knee causing a limp and left foot dragging. Hence the only option was to go private to find out exactly what was the problem as I knew what the GP was saying, was not correct.”

However, the story on the challenges of getting a correct diagnosis remains the same. 41% of people said they got a correct diagnosis of PSP or CBD compared to 40% in 2016. Significant numbers of people are still getting a Parkinson’s diagnosis first (38% of respondents). Without further research, diagnosis remains problematic but there is more we can do to raise awareness of the symptoms of PSP & CBD amongst health and social care professionals to improve diagnosis and that is a priority over the next three years.

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

ONGOING CARE

In this section the results were not so positive.

Fewer people had a named person to coordinate their care: down to 60% from 68% in 2016 and there was a marked decline in how well people thought that relationship worked down 14% between 2016 and 2022. Satisfaction with GP’s had also declined from 87% to 63%.

We suspect a large part of this could be due to the pandemic and the impact on the NHS. People have been seen less on a face-to-face basis and there are chronic staffing issues. To explore if this hypothesis is true, we will be talking to partner charities to see if they have the same outcomes from surveys for other neurological conditions.

PSPA SERVICES

The three most frequently used PSPA services were PSPA Matters, the Helpline and the website. As a result of this information we are doing three things:

1. Creating an extra Helpline Care Navigator post to make sure the Helpline has enough resources
2. For the next two years we are planning to up the number of editions of PSPA Matters from three to four times a year
3. Upgrading the website. We realise some of the facilities on the website have not been up to scratch and we have been working on both a new design and improving the search facility. Changes will be coming online in early 2023 with more developments planned through the year. The results of the survey are reassuring us that it is right to invest in improving the website and its accessibility as a core way for people to access support.

60%

OF PEOPLE WERE INITIALLY MISDIAGNOSED WITH OTHER CONDITIONS, SUCH AS PARKINSON’S.



FUTURE PSPA SERVICES

The three things you told us that were most important for PSPA to do in the future were:

- Increasing knowledge of PSP & CBD amongst health and social care professionals – 53%
- Providing support to people with PSP & CBD in terms of information and support – 48%
- Funding and promoting research into the causes and treatments of PSP & CBD – 42%

We have tried to reflect these priorities in the new strategy (see page 18) and the focus on our awareness week this year will be on health and social care professionals.

There is lots more analysis to do and we will be coming back time and time again over the next three to four years to check the data and ensure that what we do fits with what you have told us.

GET INFORMATION AND SUPPORT

Contact our Helpline, Monday to Friday
9am to 9pm Tel: 0300 0110 122
Email: helpline@pspassociation.org.uk



SIX MARATHONS FOR MUM



"I WILL RUN MY SIXTH LONDON MARATHON FOR PSPA THIS YEAR TO FINISH WHAT I SAID I WOULD DO. SIX MARATHONS FOR THE SIX YEARS MUM LIVED WITH PSP."

"My fundraising page is filling up with messages of support for me and for PSPA. And I can't thank you enough for that."



Scan the QR code to help support Steve's six marathons challenge.



This April, PSPA supporter Steve Watson will be running in his sixth London Marathon for the charity. Here Steve talks about why he chose to run six marathons for his mum.

"If someone told me they were running six London Marathons, I'd go right ahead and assume it was for some kind of personal challenge or bucket list type of thing.

Sadly, for me, that isn't what this is.

I ran the London Marathon three times before my Mum died. She'd lived bravely with PSP for six years by the time she passed away on Christmas Day, 2015.

I ran the London Marathon for a fourth time in April 2016 to commemorate my Mum, having hoped when I'd signed up that she'd still be here. But ultimately, I ended up running it as an outlet for my grief.

The reason I had signed up to run those London Marathon events was to raise money for PSPA, a small but hands-on charity that supported my Mum and our family from the start. Raising money for the charity allows them to keep offering practical and emotional support, but also allows them to fund research into a disease that is so rare and so cruel that there is no specific treatment or cure.

The effect of the disease since Mum's diagnosis in 2009 was always a strange one for me. It was rapid in the sense that every single day did in fact show us that something had gotten progressively worse. Yet at the same time, everything was so drawn-out that it must have been a very slow and isolating experience for my Mum.

I'd always been a keen runner, and so I thought that if I could attempt something like the London Marathon, I knew I had a shot of using the event to raise some funds and awareness to show people affected by the disease, they weren't alone.

A lot has happened since Mum passed away, including the arrival of her first grandchild, Lily, in 2017. Having spent her life caring for other people's children (as well as her own) as a registered childminder, it hurts me so much every day that my Mum never got to hold Lily, to spoil her, or to watch her grow into the wonderful little girl she is today.

For six years my Mum was progressively taken from us. Six times I have trained for those London Marathon events, and though it has felt tough at times, it's not lost on me how what my Mum went through all day, every day, was so much worse.

I will run my sixth London Marathon for PSPA this year to finish what I said I would do. Six marathons for the six years Mum lived with PSP. It's the least I can do to honour my Mum, and the most powerful thing I can do to raise money to show all people living with the condition, and their families, who battle knowing exactly what this disease has in store for them, that they are most certainly not alone.

My fundraising page is filling up with messages of support for me and for PSPA. And I can't thank you enough for that."

SUPPORT STEVE'S CHALLENGE

You can support Steve's six marathons challenge, here: <https://tclondonmarathon.enthuse.com/pf/steven-watson>



“CAN'T YOU COME AND SEE ME? RATHER THAN ME HAVE TO TALK OVER THE PHONE? I'VE GOT NO ONE TO TALK TO, I CAN'T GET OUT AND I FEEL SO ALONE.”



PSPA LINK VOLUNTEER SERVICE

We are pleased to welcome and introduce Anna Joynson to the PSPA Team as our Volunteer Project Coordinator, focusing on setting up the new Link Volunteer Service. We aim to have the Link Volunteer Service up and running as soon as possible so families affected by PSP & CBD will be able to access support in their local area.

INTRODUCING ANNA

Hello! I'm Anna, the Volunteer Project Coordinator at PSPA. I joined the team in January, and it's been very exciting to get started on the new Link Volunteer Service.

For the past four years I have worked within the charity and voluntary sector; most recently as a Volunteering Project Coordinator within higher education. I have experience setting up and managing multiple projects that support a wide range of groups including children and young people, adults with learning disabilities, refugees and asylum seekers, and older people.

I am passionate about making meaningful change to the lives of people who need it the most and I hope my work on the Link Volunteer Service, will do just that!



BECOME A PSPA LINK VOLUNTEER

Following a generous grant from Global's Make Some Noise we are ready to start recruiting volunteers to our brand new Link Volunteer Service. This service extends our support services and will make a real difference to families affected by PSP & CBD.

PSPA recognises the impact PSP & CBD has on individuals and how families can feel confused, scared and alone as they face the rapidly changing challenges increasing symptoms bring. We hope this new service will reduce isolation and all those feelings, by providing ongoing one to one support to families either face to face, by telephone, email or online.

We see our Link Volunteers performing a vital role in supporting people in their local community by offering short term emotional support and friendship as well as providing information about the support PSPA provides and services in their area, that will help people make informed choices.

The Link Volunteer will also provide time to offer people the opportunity to talk about their feelings and let people know what help is available to them. They can explain in detail the support and services PSPA can offer and also they will be on hand to identify problems as they arise and signpost people to the right support.

Our Link Volunteers will work closely with our Helpline and Support Groups and will get to see first hand the impact they have on a family's life.

Having someone, in the local community, offering time and a listening ear will make such a difference to families affected by PSP & CBD. But we cannot provide this invaluable service without you. If you are a good listener and communicator and would like to offer direct support to people affected by PSP & CBD in your local area then join PSPA as a Link Volunteer and help create a better future for everyone affected by PSP & CBD.

For more details visit our website
www.pspassociation.org.uk/get-involved/volunteering/ways-to-volunteer/pspa-link-volunteer/

Alternatively, contact us directly on
01327 368597 or email us at
volunteering@pspassociation.org.uk



A HUGE THANK YOU TO ALL THE SPEAKERS WHO HAVE SHARED THEIR FINDINGS SO FAR.



PSPA RESEARCH INFORMATION DAY 2023

On Friday, 3 February, 138 people met on Zoom to share information regarding PSPA funded and ongoing research around PSP & CBD.

The informative event boasted contributions from 17 speakers, sessions chaired by four healthcare and research professionals and the PSPA Chair of the Board of Trustees.

Professor James Rowe and our research coordinator Dr Annalisa Casarin scheduled the event and invited speakers to provide short, layman language updates to offer people living with PSP & CBD, carers, family members and professionals the opportunity to hear about the current research landscape.

Our speakers told the 138 attendees about their research findings and future projects.

HERE IS A SUMMARY OF THE SPEAKERS' UPDATES.

OBSERVATIONAL STUDIES – WHAT ARE THEY FOR AND WHAT HAVE WE LEARNED?

- 1. PROSPECT-M-UK, PROgressive Supranuclear Palsy CorTico-Basal Syndrome Multiple System Atrophy Longitudinal Study UK:** Professor Huw Morris gave an update about the information collected from 1,312 participants (among them 810 people with PSP, CBD and Atypical Parkinsonian Syndrome). They collected fluid samples and brain tissue. Research on this data and samples resulted in more than 20 manuscripts and provided information on the diseases progression. PROSPECT-M-UK is funded by PSPA and MSA Trust.
- 2. OxQUIp, Oxford QUantification In Parkinsonism:** Professor Chrystalina Antoniadou updated participants about her study into people living with Parkinson's Disease and PSP. The study is taking place over a three-years period, with the aim of identifying measures to detect disease progression over much shorter time periods than is possible at present. Participants in the study perform a range of tasks while wearing sensors that accurately measure their performance.
- 3. Pick's disease and Progressive supranuclear palsy Prevalence and Incidence study (PiPPIN):** this is an epidemiological research study, a "head count" of everyone with PSP & CBD and frontotemporal dementia in Cambridgeshire and Norfolk. The team is led by Professor James Rowe and the interesting talk was delivered by Dr Katherine Stockton. They combine the blood, brain and behavioural markers to build a better picture of the diseases and how people affected can be treated.



"IN THE UK, WE ARE LUCKY TO HAVE A CADRE OF OUTSTANDING SCIENTISTS AND CLINICIANS AND A GROWING COMMUNITY OF EARLY CAREER RESEARCHERS DEDICATED TO FINDING ANSWERS TO THE KEY CHALLENGES FACED BY PEOPLE LIVING WITH PSP & CBD."

PROFESSOR NIGEL LEIGH



PSPA RESEARCH INFORMATION DAY 2023

CAUSES AND CURES: HOW TECHNOLOGIES CAN HELP

- 4. Neuroimaging (brain imaging) with Positron Emission Tomography (PET):** Dr Maura Malpetti, from Cambridge University Hospital, talked about the difference between PET and magnetic resonance to see the early changes in the brain in people living with PSP.
- 5. Neuropathology:** Dr Annelies Quaegebeur, also from Cambridge, told us about the study of brain tissue under the microscope. The main feature of brains affected by PSP & CBD is an abnormal build up of the protein Tau. Neuropathology help the diagnosis of these conditions.
- 6. Genetics:** Is PSP genetic? Dr Ed Jabbari, from University College of London, gave us a crash course in genetics. Studying samples from the PROSPECT-M-UK, he discovered that people with a normal genetic variation at the Tau gene, represents a significant genetic risk factor for developing PSP. Dr Jabbari research project was sponsored by PSPA.
- 7. Stem cells:** Professor Siddharthan Chandran, from Edinburgh, taught us that human stem cell platforms can be used to discover drugs that might be useful for testing in human clinical trials. The brain is the most complicated organ in the human body, and we are unable to study it directly. With stem cells, we could create artificial brains to study during drug trials.
- 8. Artificial Intelligence:** Dr Tim Rittman is based in Cambridge, he told us that with the help of artificial intelligence (AI) researchers can better interpret brain scans in terms of diagnosis and detecting brain changes.
- 9. Brain-banks:** Professor Tammaryn Lashley, is based at the Queen's Square Institute of Neurology in London. She explained the importance of brain donations and the links between the study of brain tissue and clinical and imaging data to confirm diagnosis and learn about neurodegenerative conditions.



"I DID ENJOY THE DAY AND FELT I LEARNT A LOT ABOUT THE RESEARCH THAT IS GOING ON FROM YOUR TREMENDOUSLY EXPERIENCED RESEARCHERS."

CLINICAL TRIALS UPDATE

- 10. NORAPS, Noradrenaline treatment of apathy and impulsivity in participants with PSP syndromes:** this is a Cambridge based study on the use of the hormone noradrenaline for treatment of apathy and impulsivity in participants living with PSP. Professor James Rowe explained what apathy and impulsivity are and how he hopes this drug can help people.
- 11. Novartis:** Safety, Tolerability and Pharmacokinetics of Multiple Ascending Doses of Intrathecally Administered NIO752 in Participants with PSP. Dr Boyd Ghosh, based at Southampton University Hospitals, told us about the drug study happening in collaboration with the drug company Novartis. Intrathecal (in the fluid filled space around the brain and spinal cord) injections of NIO752 or placebo will be given four times over three months to see if it is a safe drug and can improve symptoms.
- 12. International overview:** Emeritus Professor Larry Golbe joined us from New York City (USA) to give us an overview of past, present and future studies on PSP & CBD survival and symptoms.

CARE – NAVIGATING AND IMPROVING THE HEALTH AND SOCIAL CARE SYSTEM

- 13. Lesson learnt from the MND community to accelerate PSP & CBD care:** Nurse consultant and care centre coordinator Rachael Marsden joined us explaining the set up and effect of centre of care for people with Motor Neurone Disease (MND). Since 1990, MND centres improve the support and coordination of services for people living with MND as well as promoting effective, integrated working between health, social, research and voluntary sectors.
- 14. NICE guidelines:** building up the argument. For the second time, Dr Boyd Ghosh shared his view and experience on creating a better life for people with PSP & CBD. This time, he talked about the influence charities and researchers can exert on government to provide care and support.

"AFTER ALL THE HARD WORK AND TIME NEEDED TO PRODUCE SUCH A SUCCESSFUL EVENT LAST FRIDAY, CONGRATULATIONS!! THE SPEAKERS WERE EXCELLENT AND CLEARLY KNOWLEDGEABLE IN THEIR OWN FIELD OF RESEARCH."



SCAN THE QR CODE TO FIND OUT MORE

COULDN'T TAKE PART?

If you missed taking part in the day, you will be pleased to hear that we recorded the event. You can view the sessions of the event, as well as download the programme for the day at: www.pspassociation.org.uk/research-information-day-2023/

PATIENTS' VOICES USING SURVEYS AND FOCUS GROUPS

- 15. THIS Institute survey on end-of-life:** Professor Graham Martin joined us from the THIS Institute in Cambridge to show the results of a survey on end-of-life, our members were involved in responding to sensitive questions and shine a light on people's view on this important topic.
- 16. Results of the 2022 survey of people living with PSP & CBD:** our own Head of Engagement, Carol Amirghiasvand, shared the results of the 2022 survey. The replies received from more than 400 members will help us shape our services to support you and your caregivers (see page 6 for more information).
- 17. PSPA public involvement group:** our research coordinator, Dr Annalisa Casarin, explained that PRIM is (PSPA Research Involvement Members), a group of volunteers involved in research who meet monthly to discuss research priorities and support researchers. We are very grateful to Liz who joined Annalisa and shared her experience of being part of PRIM.



SCAN THE QR CODE TO SIGN UP

REGISTER TO BE PART OF THE PRIM GROUP

Read more about how you can take part in any of the research studies which are currently recruiting new patients or to be part of the PRIM group visit: www.pspassociation.org.uk/research/patient-carer-voices-in-research/register-your-interest-with-us/



“I WANTED TO FIGHT BACK AND PROVE WE CAN STILL DO THE THINGS WE LOVE TO DO TOGETHER.”

PSP DOESN'T STOP OUR LOVE OF TRAVEL

As travel buddies, Caroline Oliver and her dad Keith have seen the world together. It was on one of their travels Keith's PSP symptoms began to surface. Here Caroline shares details of their PSP journey and their recent dream trip to Canada.

“PSP. We all know what it stands for now. When it was taking our loved ones, but we still didn't know what was going on, with no diagnosis, we all had no idea.

My Dad is my best friend. We are travel buddies and have travelled the world together in my 40 years. In 2016, whilst on those travels Dad had a serious fall in France splitting his head open. At the time, we had to put it down to clumsiness but over the next four years to July 2020, when dad received his PSP diagnosis, there were hundreds of incidents, causing stress and anxiety for our whole family.

Since 2020 and the diagnosis, Dad has gone from being wobbly to now using a wheelchair and sleeping in a hospital bed. We also completed works in the house to accommodate a downstairs bathroom and bedroom in order to ease the pressure. In addition, we now have hospice care and carers 30 hours a week so I can continue to work. How life has changed and in a short space of time. Sleep is four hours at best and the arguing and impulsive behaviour is exhausting. That's just from a carer's point of view. How Dad must feel is incomprehensible.

Dad is a retired professional cricketer. He loved to walk, play golf, watch ice hockey and go to sporting events on his own. He also would take mum shopping and go out for meals. I feel it is so sad to see everything taken from a man who was so independent and active.

I wanted to fight back against PSP though and prove we can still do the things we love to do together, even if it does take a little more effort and organisation. As part of this, I was keen to go to Niagara Falls with Dad, a place we both really wanted to visit.

So, on Monday 5 September 2022 we started a journey to add to our travels, to make our memories together and to show PSP and everyone living with the condition, you can travel, and you can make dreams come true. Was it scary? Yes, definitely. But it was worth it to see Dad's face when we got to Niagara Falls.

During our week in Canada, we not only saw the falls, we went to Toronto again and we also went to Buffalo for a baseball game. It was amazing to make memories like that. There was a lot of planning and we were helped by so many people, PSPA in the UK and the corresponding charity in Canada were a huge support. But I am proud we did it, and just the two of us.

We applied for a PSPA Support Grant to pay for taxis to and from the airports. This took some pressure off me and ensured Dad travelled door to door, reducing travel times and enabled us to both relax.”



My tips for anyone wanting to travel would be:

- Book with a well-known company. We used British Airways and they ensured the accommodation was suitable for our needs, and we had help throughout the airport and the flight. The flight crew were amazing and presented Dad and I with a gift and a card each as they were so honoured to be a part of a PSP journey
- Take plenty of day-to-day aids with you, for example Dad uses a Starbucks cup for all drinks as he struggles to hold cups. BA were happy to pop his drinks in that and clean it out in between too
- Take a small case onto your flight with a few essential items (urinal bottle for night) that way should your case go for a wander to another country you have those items with you
- Pull together a folder with all documents in it to ensure they are in one place
- Book private transfers to and from the airports to relieve stress and then hire a car once you arrive
- Carry everything you need each day in a ruck sack so you can attach it to your loved one's wheelchair to save you carrying bags
- Tell people about PSP. Don't be afraid to say this is the disease, this is what it is doing and this is how they can help
- Finally – take plenty of pictures. Make memories and enjoy every moment.



OUR NEW THREE-YEAR STRATEGY

**OUR PURPOSE IS TO
CREATE A BETTER
FUTURE FOR
EVERYONE AFFECTED
BY PSP & CBD.**

In 2023 our commitment and vision for a better life for people living with PSP & CBD remains as strong as ever. We want to increase the support we provide, to raise awareness and ramp up investment in research. In addition, to ensure that the priorities of the people we support are at the heart of what we do; we will involve them in developments from shaping the design of research through to driving improvements in the quality of PSPA services.

During 2022 we set about looking at our priorities, finding out what had changed in the last five years through a survey for people living with PSP & CBD and asking what you thought we should be doing. As a result, we have set out our goals through to 2026. Each year we will use these goals to plan our activities and to evaluate how well we are doing, keeping an eye on what is important and reporting to you the progress we make.



SUPPORT & INFORMATION

Enabling people to live the best life possible



RESEARCH & AWARENESS RAISING

Improving quality of life



INVOLVEMENT

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

Our three goals are to:

1 **ENABLE PEOPLE WITH PSP & CBD AND THEIR FAMILIES TO LIVE THEIR BEST LIVES POSSIBLE WITH HIGH QUALITY SUPPORT AND INFORMATION.**

Living with a diagnosis of PSP or CBD is challenging for everyone involved. Knowing that PSPA will be with you at all stages of your journey can be a huge help; our support and information can enable both patient and carer to live their best lives possible. But we can't do this alone, families need to receive high quality care from health and social care professionals (HSCP's) and the NHS more broadly and therefore we remain committed to providing high quality information to support the improvement in care across all sectors.

2 **IMPROVE THE QUALITY OF LIFE OF PEOPLE LIVING WITH PSP & CBD THROUGH RESEARCH, EDUCATION AND AWARENESS RAISING.**

A better quality of life is underpinned by developing a greater understanding of the causes and development of PSP & CBD. Building a network of interest in research, amongst health and social care professionals (HSCP's) and creating communities that are inspired to raise awareness is part of the roadmap to improving lives of people with a diagnosis.

3 **PUTTING PEOPLE LIVING WITH PSP & CBD AT THE HEART OF WHAT WE DO.**

We will only achieve our purpose if we listen and empower people affected by PSP & CBD to help shape the support they receive. Their voices will influence our priorities, what we do and how we do it. Their voices will also underpin our ability to influence public policy and public services that impact on their quality of life.

To read the strategy in full, please visit our website www.pspassociation.org.uk/about-us



COMMUNITY FUNDRAISING CHAMPIONS

Every year, PSPA supporters head out into their communities to raise awareness and fundraise to support our vital work.

Here, we share, two fun community fundraising activities from last year to help inspire anyone who might be thinking of holding a fundraiser in 2023.

GASTONBURY MUSIC EVENT

Linda Moore, Volunteer Support Group Coordinator, shares details of the fundraising event the Norwich Support Group held for PSPA in July 2022.

“It was a beautiful July summer’s day, in quiet sleepy Norfolk. But the quiet was soon to change, not with rain, which is what we would expect, but by music.

The Norwich PSPA Support Group, were invited to the garden of a member of the group to enjoy local bands playing their music, to raise money for their mutual interest and involvement with PSPA.

The Norwich Support Group set up tables, umbrellas, bunting, balloons and an array of delicious homemade cakes and scones.

A separate table displayed a large selection of generously donated raffle prizes.

The scene is set, music wafted around the garden and the PSPA volunteers went about their mission, selling beautiful cakes and raffle tickets.

It was a lovely afternoon and evening and the wonderful amount of £622.74 was raised in aid of PSPA too! A special thanks to JD Tree Services who donated £100.

Many thanks to all those involved in the day.”

“IT WAS A LOVELY AFTERNOON AND EVENING AND THE WONDERFUL AMOUNT OF £622.74 WAS RAISED IN AID OF PSPA.”



BOAC 500 CHARITY SLOT CAR RACING EVENT

Slot car racing enthusiast, Mike Thomas, who is living with PSP, details how he and his friends from his local model racing car club organised a charity event for PSPA.

“In December 2021, I drove a lap of Brands Hatch on my electric scooter as a fundraiser and to raise awareness of PSP. Several friends I have through our shared passion for Slot Car Racing came along to support me on that day and later inspired them to do a bit of fundraising too.

Shortly after, my friends decided to run a charity model racing car event to raise funds for PSPA and it was to be called the BOAC 500 (partly because the aim was to raise £500), with entry fees on the day set at £20 per competitor.

On the morning of 3 July, I was greeted by a large number of competitors, many I had heard of, but never actually met, and amounted to 36 entries!

This meant funds raised had already reached £720. Also invited, were many of the friends I had made over many years of racing at clubs throughout the south east of England and that I found very cheering.

The cars used for the event were all owned by the club, which meant very even racing (normally competitors would bring their own “special cars” tuned by themselves”) and using club owned cars it meant they are well used. For this event, all of the cars were serviced to a very high standard by my good friend, Mike Read. The racing included qualifying, heats, and many finals to decide the event’s overall victor.

The total raised on the day was an excellent £1,635. It went so well I am pleased to confirm there is to be an annual Charity Slot Car Race called “The BOAC 500” (or maybe the next race will be called “The BOAC 1000” or even “The BOAC 1500”!).”



2023 CARERS SUPPORT GROUP MEETINGS

Launched in 2022, read how our regional Carers Support Group meetings can help you.

Many of you may not see yourself as a carer. You see yourself as a wife, a husband, a sibling. Or a mother, father, friend. Of course you are and will always remain so, however if you have someone in the family living with PSP or CBD and you are supporting them, you are a carer too!

The National Institute for Health and Care Excellence (NICE) defines carers as follows: 'Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and undertake vital work and emotion management'.

Being a carer can be challenging and can lead to poor quality of life and affect people emotionally and physically. At PSPA we recognise that carers need support, and this is why last year we set up our virtual monthly Carers Support Groups for carers across the UK.

The groups have been well received and we know from feedback that attending the support groups have improved peoples' well being, and that social support provided by the group is both stimulating and supportive. People value the opportunity to share their experiences of being a carer with other carers and find out about resources that are available to them. Some attend and just listen to the conversation which is also beneficial as it helps people realise they are not alone and there is support if they need it.

We hold four evening meetings and one daytime meeting each month. There is a different topic of conversation each month and ample opportunity during the meeting for carers to share their experiences and their feelings should they want to. The groups are lively and supportive but most of all welcoming.

Many of you have already attended the groups however there are still lots of carers out there yet to give it a try. Why not make 2023 the time to look after yourself and join us once a month to chat with others who understand what it's like to care from someone with a progressive condition like PSP or CBD.



JOIN THE MEETINGS

If you are interested in attending a Carers Support Group meeting, please contact volunteering@pspassociation.org.uk and we will make sure you receive an invite to join.

NEXT MEETING DATES

7 March - 11am and 7pm

9 March - 7pm

14 March - 7pm

"I'D LIKE TO THANK PSPA SO MUCH FOR YOUR SUPPORT, HELP AND INFORMATION WHICH HAS BEEN SUCH A COMFORT TO ME. THROUGH THE CARERS GROUPS I MET A LOCAL LADY WHO I NOW MEET ONCE A MONTH FOR COFFEE, LAUGHTER AND WE CAN SHARE EXPERIENCES WHICH NO-ONE ELSE WOULD UNDERSTAND. SO, A BIG THANK YOU."



“I CAME TO PHYSIOTHERAPY LATER IN LIFE GRADUATING FROM THE UNIVERSITY OF SOUTHAMPTON IN 2006.”



REBECCA BRAY

A DAY IN THE LIFE OF A PHYSIOTHERAPIST

As part of our ‘Day in the life’ features Rebecca Bray, Neurology Specialist Physiotherapist at NHS Wiltshire Health and Care, shares details of her role.

“I came to physiotherapy later in life graduating from the University of Southampton in 2006. I knew early on neurology was the area I wanted to focus on having been inspired by an experienced and dedicated Neuro Physiotherapist during a work experience placement. However, at that time I had little concept of what that might entail and no awareness of conditions such as PSP or CBD.

In early 2007, I secured a permanent post close to home in Wiltshire. At this time national health policy was driving investment in community services to support people at home with the aims of improving accessibility to services and avoiding unnecessary hospital admissions. Aside from a short period working on a Stroke Unit in Oxfordshire, I have worked for the NHS community health service in Wiltshire (now called Wiltshire Health and Care) ever since. I can honestly say I wouldn’t want to work anywhere else apart from the community setting, and truly believe that delivering healthcare services in the home is better for individuals and is an absolute privilege to me as a therapist.

Whilst in training I had imagined I would be providing therapeutic intervention that would rehabilitate people back to their previous level of function. However, through professional development and personal experience of my late father living with CBD, I recognise supporting people to manage progressive conditions is incredibly valuable and equally rewarding. It is also an area that is under resourced.”

SUPPORTING PEOPLE LIVING WITH PSP & CBD

“In my permanent role as Neurology Specialist Physiotherapist in the community neuro service, I support people with CBD & PSP and their families in several ways. Some individuals are referred to us on diagnosis, but others may already be known to us due to an earlier diagnosis of Parkinsonism and symptoms relating to mobility and falls. Initial assessment always involves a home visit with a partner/family member/carer present if that is preferred. I try to arrange this as a joint visit with my occupational therapy (OT) colleagues. A home visit immediately provides a wealth of information regarding the individual’s living environment, their support network and what is important to them – such as family life, pets and evident hobbies/interests. We introduce ourselves, our service and take a detailed medical and psychosocial history.

On physical assessment I look at joint range of motion, muscle strength and tone, balance, mobility and function e.g. rolling over in bed, lie to sit, sit to stand, mobility on stairs. I may also look at vision

dependent on the diagnosis and difficulties raised. If my OT colleague is present, they will be looking at similar issues but from a slightly different perspective. Whilst we are both aiming to support optimal function, wellbeing and quality of life, what we can offer to contribute towards this differs.

The intervention I offer is determined by numerous factors including diagnosis and stage of disease progression, the priorities for the individual and their partner/family/carer, the level of information they are ready to take on and ability to engage. This may include advice about equipment such as walking aids, safety advice, transfer practice, exercise provision, advice on stretches and splinting or activities to incorporate exercise advice into day to day function and activity. I am always mindful of anticipated disease progression and my intervention will be preparing for this as far as is possible.

Specific interventions can be found in the new PSPA Physiotherapy Guidelines (see pages 30 and 31) which I was privileged to contribute towards, alongside other highly skilled and knowledgeable physiotherapists. Whilst there is negligible research evidence to underpin physiotherapy practice in PSP & CBD, we know from experience we can make a difference to the quality of life of people living with the conditions and their families. There is also valuable research evidence in other neurological conditions that can be drawn on and as awareness of PSP & CBD improves, I am sure that future research will start to produce evidence to support and inform physiotherapy practice further.

Finally, I am currently seconded to the role of Neurology Specialist Practitioner. In this role I carry out reviews with patients with progressive neurological diseases including PSP & CBD. This can be in a clinic environment or in the person’s home depending on their circumstances and the aim is to identify any problems they are experiencing, provide support and advice and signpost or refer to other disciplines or services as appropriate. This in turn is enabling me to gain a greater understanding of the conditions and also how the non-motor symptoms can be managed.

I am incredibly proud to be a physiotherapist working to support people with progressive neurological diseases. I have met some amazing and inspiring people both colleagues, patients and their families. These are incredibly cruel diseases and I personally know the impact they have on the individual and their families. This will always motivate me professionally to contribute to improve services and outcomes for people with PSP & CBD.”



"WE FINISHED THE SOUTH WEST COAST PATH IN AUTUMN 2021. THE LAST LEG WAS QUITE CHALLENGING BUT IT WAS A GREAT AND EMOTIONAL EXPERIENCE OVERALL."

WALKING THE SOUTH WEST COAST PATH WITH CBD

Beth Shephard-Walwyn was diagnosed with CBD in 2020 after experiencing symptoms for around three years. With a love of walking, Beth shares how she keeps active and what has inspired her ongoing walking challenges.



BETH AND HER HUSBAND WALKING THE WELSH COAST PATH

"Walking the South West Coast Path had been an ambition of mine for many years. A good friend, Sandra and I said we'd do it when we retired. However, shortly after I met my husband, we completed a small part of the path and enjoyed it so much we decided not to wait for retirement, but to do it now!

So, in 2013 we made a start. Largely we used our annual leave or long weekends to tackle sections. We often stayed in a B&B or even camped at times, with our belongings in a rucksack and doing a stage of the route each day.

Around the halfway mark in 2017, I started to notice my walking pace was slowing. I had always been the faster walker of the two of us, then all of a sudden, my husband started to stride out ahead of me. Then I took a fall whilst crossing a river. Crossing rivers is a regular feat when you walk, so it shouldn't have been an issue, but I just lost concentration (something that happens increasingly now) and fell flat on my bottom. Alongside this, at home, I started to find playing the piano more difficult. I was only 60 years old at the time, but when these little abnormalities occurred, I thought it was just part of the process of ageing. As well as this, I was caring for my father who had dementia, so I was a bit distracted with that too.

I did head to my GP though, just to check it out. Initially I was diagnosed with a form of ataxia. I was left to google what that meant and was overwhelmed and frightened by the list of symptoms and possible progression that I was greeted with. The diagnosis didn't quite sit right with me though, so with Covid in the offing we arranged an appointment with a private

neurologist for a second opinion. Unfortunately, due to Covid I was then given a number of telephone consultations with various neurologists during which Parkinson's was mentioned. However, when things finally opened again I was able to see my current neurologist in person and he cautiously diagnosed CBD.

My daughter bought me a copy of "The Salt Path" prior to my diagnosis, mainly because it documents Raynor and Moth Winn's walk along the South West Coast Path. During our walk, I revisited the book and in the first few pages there is a description of how Moth had struggled to get his coat on. This resonated with me and also, knowing how walking the Coast path had helped him improve his symptoms, this spurred me on to continue walking.

We finished the South West Coast Path in autumn 2021. The last leg was quite challenging but it was a great and emotional experience overall.

Our walking challenges didn't stop there. Knowing how well I was feeling from all the walking and exercise, I was determined to keep going. We are now walking the Welsh Coast Path and last summer we went on a church camp to Barmouth and one day we were able to walk the section from Harlech back to our campsite at Taly Bont. Before going on holiday, the local Rehab Centre had made a Lycra splint for my alien arm and thanks to this aid, I was able to clip up the buckle on my rucksack, something I hadn't previously been able to do!"



PSP & CBD AWARENESS WEEK 2023

This year our awareness week is taking place 17 to 23 June.

To make an impact during PSP & CBD Awareness Week we will be reaching out to healthcare professionals, to educate them about the symptoms of the two conditions.

We hope this will improve diagnosis and also ensure people have access to support and care that is co-ordinated, consistent and compassionate.

This June we will:

1 RED FLAG SYMPTOMS TO OPTICIANS

Reflecting on common early symptoms of PSP, we will be targeting opticians and ophthalmologists with a new vision specific Red Flag campaign.



We will also educate how opticians and ophthalmologists can aid the process of diagnosis, hopefully reducing delays so people can get specialist support from a neurologist sooner.

> **You can help by distributing the posters to opticians in your community and logging where you have taken them on our interactive website map.**

2 DELIVER MORE EDUCATION SESSIONS TO HEALTHCARE PROFESSIONALS

Garnering support from our amazing Education Volunteers, we will reach out to healthcare professionals, within the NHS and care sector, to ensure more have heard of PSP & CBD. As well as how PSPA can help them to support their patients.

> **You can help by flagging up NHS teams, care homes or GP surgeries who may benefit from receiving education sessions about PSP & CBD.**

3 LAUNCH AWARENESS GRANTS

To help broaden the reach of our awareness raising, we will be launching new Awareness Grants this June.

The grants will be open to anyone who would like to deliver an initiative in their place of work or community. The aim is to help more people spot the signs and symptoms of PSP & CBD, and how best to care for people living with the condition, at the different stages of their progression.

4 TAKE A WALK OF HOPE FOR PEOPLE LIVING WITH PSP & CBD

During the summer, we will also be encouraging our supporters to take part in a 5km Walk of Hope to help raise awareness in local communities.

> **You can help by signing up to take part in a Walk of Hope in your area. Read more about the Walk of Hope on page 29.**

5 START CONVERSATIONS WITH ED'S LACE

Our popular community awareness initiative continues in 2023. Ed's Lace is a great tool for starting conversations about PSP & CBD as well as explaining the degeneration which occurs when people are living with the conditions.



> **You can help by wearing Ed's Lace with pride during PSP & CBD Awareness Week.**



Visit our website for more updates about our awareness plans.
www.pspassociation.org.uk

GET ACTIVE THIS SUMMER WITH PSPA!

The PSPA Walk of Hope is returning... join us this summer to walk or wheel 5km in your area to raise awareness of PSP & CBD.

#TEAMPSPA



THE BRESLIN FAMILY ON THEIR WALK OF HOPE IN 2022

Complete your Walk of Hope at any time during June, July and August and raise a minimum of £100 for PSPA, to receive an exclusive medal.

GET INVOLVED!

Registration opens on 1 February 2023. It is just £10 to enter and there is no minimum sponsorship requirement, although if you have a chance to fundraise we will support you to do so.

For teams of four or more, PSPA t-shirts will be included.

To set this as a target for 2023, you can come and join #teamPSPA by contacting fundraising@pspassociation.org.uk or call 01327 322417.

Walking is simple, free and one of the easiest ways to get more active, lose weight and become healthier, so if you'd like to get fitter in 2023, come and join the team.

The aim of the PSPA Walk of Hope is to walk 5km in your area, raising money to help fund the vital support PSPA provides for individuals and families living with PSP & CBD.

Your walk could be indoors or outdoors! With your pets or without. As part of a relay team or racing against others. Bring your community together to raise awareness of PSPA.

BE PART OF THE #TEAMPSPA MOVEMENT

If you decide to take up the challenge, we will support you all the way. Upon sign up you will receive your own Ed's Lace, plus a fundraising pack complete with plenty of ideas to help you gain sponsorship or fundraise.

Share the fun by forming a 5km team with friends or colleagues or keep the kids entertained during the summer holiday, by signing up the whole family and completing the walk together. Whether all at once, or over a number of days.



Top walking tips to help get you started!

If you're signing up to take part in the Walk of Hope 2023, here are a few tips to help get you started!

- Wear comfortable shoes or trainers that provide adequate support and do not cause blisters
- Drink plenty of water to stay hydrated during your walk
- Depending on how long you will be out, healthy snacks, a spare top, sunscreen and a sun hat may also be useful
- Also, pack a waterproof jacket... just in case!



“FOR ME, IT’S A DESIRE TO MAKE A DIFFERENCE AND IMPROVE THE PATIENT EXPERIENCE AND RAISE AWARENESS OF THE CONDITIONS.”

A GUIDE TO PSP & CBD FOR PHYSIOTHERAPISTS

This year, we are pleased to publish a brand-new guide to PSP & CBD for healthcare professionals, this time providing support and information for physiotherapist. Here, Jade Donnelly, Specialist Physiotherapist and APS Coordinator at Southampton General Hospital, shares details of the guide and how it was developed.

“For the past six years I have been coordinating a specialist clinic for people living with atypical parkinsonian syndromes (APS), also referred to as Parkinson’s plus. As a physiotherapist I was keen to ensure patients receive the right intervention and advice at the right time throughout the course of their condition. PSPA has excellent information for professionals including guides to PSP & CBD for OTs, GPs and the Primary Healthcare Team. As a physiotherapist I felt it was important that there were also physiotherapy guidelines. PSP & CBD are rare movement disorders, they are not taught or discussed at an undergraduate level and many therapists will not come across the conditions until they appear on a ward or referral list. There is also a lack of evidence base to what therapy intervention is most appropriate.

With this in mind I was delighted when PSPA agreed to developing the new physiotherapy guidelines. They have been developed using available evidence and professional opinion. To write these guidelines required the support of several physiotherapists from across the UK who volunteered to share their knowledge and expertise. The therapists came from a range of backgrounds, including falls specialists, community rehabilitation and palliative care. Our aim was to share knowledge, best practice and evidence base for this client group. We hope we will be able to build on these guidelines in the future to create pathways of care and aspire to having NICE guidelines for PSP & CBD. We all agreed on the professional reasons for having the guidelines but for many of us it was more personal.

For me, it’s a desire to make a difference and improve the patient experience and raise awareness of the conditions. Weekly I speak to patients with PSP & CBD, as well as their carers. I see first-hand their challenges and frustrations. They value having someone who has heard of their condition and someone who has an insight into their problems. I remember advising a therapist in the Midlands who was seeking advice for a patient she was treating and she asked “Why is there no physio guide? I’ve read the OT guide and professional guide, both were helpful but why no physio guide?” So, I was delighted when we were given the green light to go ahead with this project. Often simple changes can make a huge difference to people living with the conditions and their families. We hope the guide has illustrated some of these strategies.

Thank you to the team, who helped produce the guide. Here are their reasons for being involved in the project.

Ciara Baker – Clinical Specialist Neurological Practitioner, Community Neurology Service, Dorset.

Ciara has day to day, hands on experience of the conditions in the community. Through her work she has seen how patients present differently and how we need to adapt our approach accordingly and treat everyone as an individual.

Emma Secker – Specialist Palliative Care Therapist in the community in Northumbria. Emma was keen to bring together her knowledge and experience of the condition from diagnosis to end of life care.

Louise McGregor – Therapy Consultant at St Georges’, London. Louise was keen to increase knowledge on what best physiotherapy practice looks like throughout the course of the condition.

Rebecca Bray – Specialist Neurological Physiotherapist from Wiltshire. Rebecca was thrilled to be given the opportunity to improve experiences for individuals with progressive neurological disease and for more personal reasons. In 2015, her Dad was diagnosed with CBD. On attending his initial physiotherapy appointment, he was advised that there was nothing that could be done to help him. She very much hopes that these guidelines will ensure that neither a physiotherapist nor a person with PSP or CBD will have that same experience in the future. Read more about Rebecca on pages 24 and 25.

We hope that the guidelines will be a helpful, one stop shop for physiotherapists. There are top tips sections for easy reference and we have also included a couple of case studies. Evidence and research is constantly developing, so the guidelines will be reviewed and updated regularly.

If you are a physiotherapist and would like a copy of the guidelines, you can download them on the PSPA website. Or you can request a copy by contacting the PSPA Helpline.

If you are living with PSP or CBD and have a physiotherapy appointment coming up please request a copy from the Helpline and share with your physiotherapist.”

Scan the QR code using your phone’s camera to visit our publications web page.





PSPA SMALL RESEARCH GRANTS UPDATE

Thanks to the kind donations from our supporters, who raised more than £10,000 in our 2021 Research Appeal, we are pleased to confirm PSPA awarded three Small Research Grants at the end of 2022.

The three grants we have awarded are detailed below:



DR BOYD GHOSH (SOUTHAMPTON AND SALISBURY), CONSULTANT NEUROLOGIST, WILL RECEIVE £2,915.

Dr Ghosh was awarded a Small Research Grant to employ a medical student to help on a project to assess the benefits of specialist multidisciplinary teams within a specialist clinic for patients with PSP & CBD.

Boyd is working towards creating evidence for the National Institute of Care Excellence (NICE) to establish clinical guidelines for people with PSP & CBD. This will enable all patients to receive appropriate and timely care. NICE is the public body funded by the Department of Health and Social Care that looks at evidence and decide to recommend therapies, services, devices to the Government for implementation in the NHS and public/social care systems. It is not an easy task for Boyd and his colleagues, so PSPA decided to support them in this journey as much as we can.



DR ANNELIES QUAEGEBEUR (CAMBRIDGE), CONSULTANT NEUROPATHOLOGIST, WILL RECEIVE £4,760.

Dr Quaegebeur received a Small Research Grant to assist her study, characterising neuroinflammation in PSP brains with high-plex spatial protein profiling. This is a technique that looks at the architecture of altered brain tissue. For a scientific description of the technique please look at www.nature.com/articles/s41576-022-00515-3.

This strategy will enable the identification of molecular phenotypes (how molecules take different shapes) that are most relevant in the early stages of PSP, and hence, will guide the design of novel neuroimmune therapies and new disease biomarkers. Annelies will use the fund to cover equipment and conference costs.



DR MAURA MALPETTI (CAMBRIDGE), RESEARCH FELLOW, WILL RECEIVE £9,279.

Dr Malpetti was awarded a Small Research Grant to support her study, looking into the application of neuroimaging techniques (PET and MRI scans) to investigate the pathophysiology of neurodegenerative diseases (how they develop). And to also identify early diagnostic and prognostic markers, signals that can tell clinicians which disease is and at which stage. The grant will help Maura look into inflammation blood tests in PSP, CBD and frontotemporal dementia. The study will clarify how inflammation in brains of affected individuals spreads, enabling a more accurate staging of the disease, and improve clinical trials (clinicians can follow the changes in the brain when patients are given new drugs). Maura will use the fund to cover the cost of a research assistant.



UPDATES FROM THE DEVOLVED NATIONS

As a charity, PSPA provides support across England, Scotland, Wales and Northern Ireland. Jules Brown, our Helpline Manager, covers the devolved nations as part of her role, which includes supporting families living with the condition and raising awareness amongst health and social care professionals.

NORTHERN IRELAND

In early February, myself and Carol Amirghiasvand, Head of Engagement, travelled to Northern Ireland to meet with health and social care professionals (HSCPs) supporting families affected by PSP & CBD. The focus of the visit was to promote PSPA support services and discuss ways of working more closely with HSCPs to ensure people living with the conditions are offered the best possible care and can access all the support available to them.

During the visit we met the Atypical Parkinson's team at The Royal Victoria Hospital, Belfast, to hear about the support the team offer to people receiving or living with a diagnosis, through their quarterly clinic. To strengthen relationship with both HSCPs and people living with PSP & CBD, I plan to attend the clinic regularly. Time was also spent providing education sessions for a team of speech and language therapists and neuro-

physiotherapists at the Neurology Unit, Musgrave Park Hospital.

The visit offered the opportunity for us to meet with Sandra Campbell from the Northern Ireland Rare Disease Partnership. This enabled us to talk about exciting developments taking place within their organisation. Also, how we can work together to improve the quality of life, treatment and care for people living with rare diseases in Northern Ireland.

Carol and I also managed to meet with Caroline Dooley-Martyn, Chairperson and Director of PSP Ireland. At this meeting we heard about their plans for 2023 in the Republic of Ireland with regards support for people living with the conditions.

We will be returning to Northern Ireland in April to meet families affected by PSP & CBD, with the hope of setting up a Northern Ireland Support Group.

SCOTLAND

WORKING WITH THE NEUROLOGICAL ALLIANCE OF SCOTLAND

I have been working with the Neurological Alliance of Scotland (NoAS) to support the creation of new guidance resources, alongside other neurological charities represented in Scotland.

The resources have been created to raise awareness of Self-Directed Support (SDS) amongst health and social care professionals and charities supporting those living with neurological conditions.

Alongside updated SDS Statutory Guidance published in November 2022, the resources highlight what should be considered when health and social care professionals are supporting people living with PSP & CBD, and other neurological conditions, and signposting them to accessing SDS.

SDS aims to give people control of the support they receive and the life they lead. It is often referred to as 'personalisation' or a 'personal budget' and it is a scheme intended to empower and enable individuals. The scheme is an option for people who want to manage their assessed care and pay for that care, using money allocated to them by the local authority. Not everyone will want to access this system and social services can still be fully involved in planning and delivering care and support if this is the preferred choice.



The new resources developed by the NAoS are available for download from their website. Scan the QR code on the left to access them.

SDS AIMS TO GIVE PEOPLE CONTROL OF THE SUPPORT THEY RECEIVE AND THE LIFE THEY LEAD.

PSPA 'MEET THE EXPERT' WEBINAR SERIES

On top of this collaborative work, I have also been working with health and social care professionals to increase awareness of PSP & CBD and how the PSPA Helpline can help.

Working with the multidisciplinary team from the Atypical Parkinson's clinic at the Queen Elizabeth University Hospital in Glasgow, I recently recorded a series of short question and answer sessions. Questions were sent into the Helpline from people living with PSP & CBD, carers, family members and health and social care professionals.

This series of six webinars features:

Dr Dave Anderson, Consultant Neurologist – What is PSP & CBD and how are they diagnosed?

Dr Vicki Marshall, Consultant Neurologist – Treatment and symptom management

Fiona Turnbull, Movement Disorder Neuro Physiotherapist

Dr Susan O'Connell, Consultant Clinical Psychologist

Joanna Wallace, Specialist Speech and Language Therapist

Elaine Thompson, Specialist Movement Disorder Nurse



The webinars are available to watch on our website, just scan this QR code.

WALES

We're excited to be planning visits to Wales in March and May. We will report back about what was achieved during the visits, in the next edition of PSPA Matters





“WE HAVE BEEN EXTREMELY PROUD TO BE TALBOT UNDERWRITING’S CHARITY PARTNER FOR TWO YEARS.”

CELEBRATING OUR CHARITY PARTNERSHIP WITH TALBOT UNDERWRITING

PSPA’s charity partnership with Talbot Underwriting came to a close on 31 December 2022. To celebrate what the partnership achieved, James Holden, PSPA’s Corporate and Community Fundraising Manager, looks back at the support the company provided during 2021 and 2022.



Talbot, an underwriting company based in London, have completed an astounding array of varied fundraising for us and are on course to raise over **£150,000** for PSPA in this period!

The partnership began as a result of a personal connection with PSPA, as Talbot employee Kelly Hooper sadly lost her mum to PSP in 2015. Kelly who had previously fundraised for us, applied for PSPA to become the Talbot Charity Partner for 2021 and 2022. A successful bidding process at the end of 2020 followed, which was rather tricky due to lockdown restrictions and all took place virtually, and then, after winning more than 50% of the employee votes, the partnership began.

Exceptionally led by Kelly, the partnership took off in January 2021. A range of internal and virtual events were rolled out while the country slowly came out of lockdown, before in person events came back into their own.

Over the last two years the amount of varied fundraising has been incredible. In fact, it’s hard to keep track of all the activities which took place across Talbot. There had been a constant stream of inventive ideas coming from within the office. There were fun activities such as sweepstakes, bake sales, quizzes, raffles and even a sunflower growing competition. Another great idea which helped to raise money, came from emptying the drawers, lockers or pedestals of any employee who either moved desk or left the organisation. All the loose change found during this process was collected and added to the fundraising pot. In December 2022, some of the PSPA team, visited the offices and counted up all these loose coins, which went into the hundreds of pounds!

Other than these wonderful internal activities, Talbot helped spread the awareness of PSPA considerably throughout our partnership. From email footers reaching thousands of people, to banners, t-shirts and flags at all events, PSPA and Talbot have been side by side.

Outside of the office the vast array of events has been phenomenal! The Talbot team have thrown themselves into numerous challenges, many doing something for the very first time. The list includes:

- **A team of eight at the 2022 London Marathon**
- **Ride London**
- **Tandem Skydive**
- **Yorkshire Three Peaks Challenge**
- **Royal Parks Half Marathon**
- **ASICS London 10k**

Employees even took on their own challenges, with a special mention to Jon, who ran 300km throughout the month of March in 2022!

Behind these incredible acts are personal stories. Time, effort, sweat, stress and a face of the unknown, and the Talbot team were unwavering in this aspect. Individuals from all parts of the company keen to test themselves and try something new, different, or unique. From their first ever 10km run, to overcoming a fear of heights whilst jumping out of a plane, they really tried it all!

One of the many wonderful ways that Talbot supported PSPA is the way that they embrace charity partnerships. They match funded every donation raised by their employees. This is both a hugely generous way to support the partnership and shows a support and level of respect to all of their fundraisers.

As the partnership closes, both PSPA and Talbots have reflected on the incredible support they have given, and look forward to what future partnerships may bring. While our partnership with Talbot will always remain unique, and incredibly special, we hope going forward it is just one of many relationships we make.

BECOME A PSPA PARTNER

If you would like to support PSPA with help from your workplace, please do contact james.holden@pspassociation.org.uk



A TRIBUTE TO LYNNE LOXLEY

After living with symptoms for almost ten years, Lynne Loxley sadly passed away from PSP in August 2021. Here, Lynne's daughter Claire, shares a tribute to her mum and an insight into her family's PSP journey.

"My mum was a very friendly and chatty person who loved spending time with her friends and family; often socialising at monthly lunches with friends and fortnightly pub quizzes.

She was pretty good at the quizzes and with an enquiring mind, she also enjoyed some quiet time at home, reading the newspapers or keeping in touch with all of the regular soaps. Coronation Street was her favourite and she loved Strictly too.

She was always there for her family. Whether it was for teenage dramas, work problems or teaching me to cook a roast dinner in my mid-20's (my Yorkshire puddings are never as good as hers were though). She was there with hugs and wisdom to help make everything better.

It was sad, that at a time when my parents were just retiring, in 2010 and 2011, mum began to get ill. And even tougher to lose mum, less than three years after she received her PSP diagnosis in 2018.

My dad was the first to notice the changes in mum. Just small differences to her personality to start with, such as becoming angry all of a sudden, and then calming down as quickly as it came on, and increasing anxiety.

Mum admitted she had noticed some changes herself. She hadn't cried when my grandad passed away, and she thought that was strange as she can be quite an emotional person.

Initial chats with mum's GP lead to discussions about her needing a holiday and eventually some counselling support, which she was quickly discharged from.

And then, when she began to move a bit robotically, the falls team prescribed physio to help refocus her centre of gravity after losing some weight.

In 2018, we paid to see a private neurologist, to try and get to the bottom of mum's symptoms, and within a week of that appointment mum received her PSP diagnosis.

We felt lucky to be quickly referred to PSPA by Dr Lindahl, once back in NHS services. We gladly began attending the Coventry and Warwickshire Support Group, who were fantastic at signposting what support we should be seeking.

Caring for mum at home, we managed to uphold many of her interests throughout her PSP experience. She still attended her quizzes and lunches, until her mobility declined. And latterly, to help her maintain her communication with us, I fashioned a tool using a children's toy, since there was a long wait for a loan of a Light Writer device from the hospital.

Mum and dad moved to a bungalow to help making getting about in the home easier, and they adapted things like the bathroom and installed grab rails about the place, to help mum maintain her independence for as long as possible.

Towards the end, once mum started to have problems with swallowing, we receive great palliative care support at home, meaning mum remained in a familiar environment, surrounded by her friends and family throughout. This is something that even now, still brings so much comfort to us all."



PAY TRIBUTE

If you would like to pay tribute to a loved one who lived with PSP or CBD in PSPA Matters, please email communications@pspassociation.org.uk.

Please include 400 to 800 words about your loved one and a selection of photos.

FREE WILL SCHEME

PSPA
CREATING A BETTER FUTURE FOR
PEOPLE LIVING WITH PSP & CBD

Leaving a gift in your Will can help create a better future for people living with PSP & CBD.

Once you have planned for the needs of your family, a gift in your Will can create a huge and lasting impact for PSPA, enabling us to invest in research and support families living with PSP & CBD.



SCAN THE QR
CODE TO FIND
OUT MORE



To help you make or update your Will, we have teamed up with Farewill to offer a free Will scheme.

By using this service, you are under no obligation to leave a gift to PSPA, but we would be delighted if you would consider it.

**TO FIND OUT MORE, PLEASE CONTACT
FAREWILL ON 020 8050 2686 OR VISIT
WWW.FAREWILL.COM/PSPA-WINTER23**

 Farewill