

EDITION 2 / 2023

PSPA MATTERS

HOW YOU CAN HELP
MORE PEOPLE
#BEAWARE OF
PSP & CBD

TURN TO PAGE 19



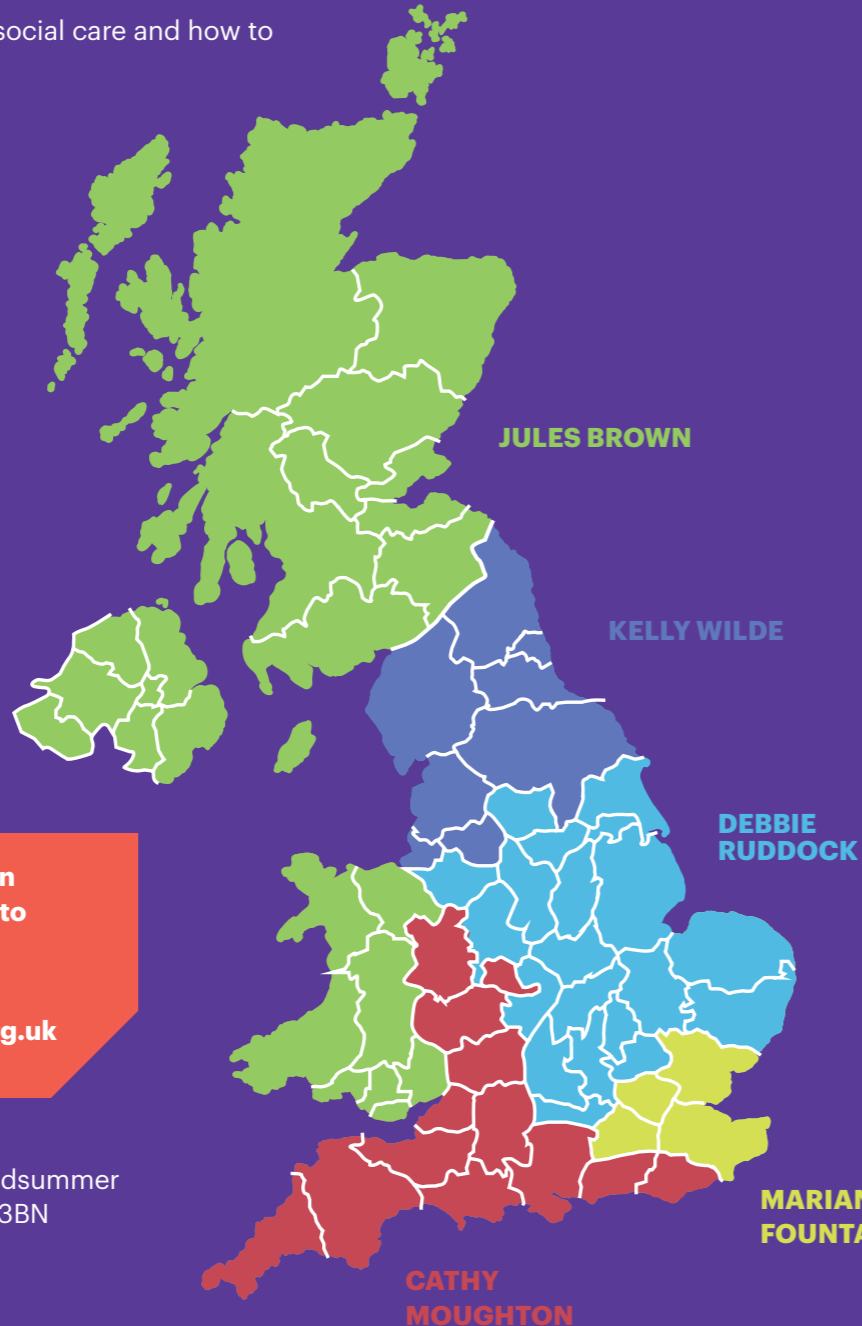
IN THIS ISSUE

- 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

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Registered charity number England and Wales 1037087 and Scotland SCO41199.

WELCOME

PSP & CBD Awareness week begins on 17 June and the team are all ready to go with our new #BeAware campaign. This year, we aim to raise awareness with opticians and ophthalmologists as part of our commitment to improve the speed of diagnosis. I have found three opticians in walking distance from my home in South London and I shall be heading out on 17 June with my Eye Red Flag poster to spread the word. I will then pop my visits onto our awareness map (page 22) to help track where the posters are being placed.

It's going to be a busy week, we also have our 'Walk for Hope', tickets to sell for the annual raffle and the wearing of Ed's Laces to promote discussion about what CBD & PSP are.

To make inroads in improving awareness and promoting partnership working we are also launching 'Awareness Raising Grants'. If you have a good idea about raising awareness and need financial support to make that happen then please read more on page 23.

On the research front, I am delighted in this issue that we have an update on the PROSPECT research from Professor Huw Morris. PROSPECT has been a huge success and the outcomes will help to make future investments and partnerships in testing treatments possible. We also have an article from our new fellowship award winner Robert Durcan, about his research study on page 26.

So, another packed issue of PSPA Matters, my thanks to Editor Helen Chapman and all who contribute to the magazine. As always, we welcome feedback about PSPA Matters and are open to suggestions about future articles.

Rebecca

Rebecca Packwood
PSPA CEO



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PSPA NEWS

A BIG 'THANK YOU' TO ALL PSPA VOLUNTEERS

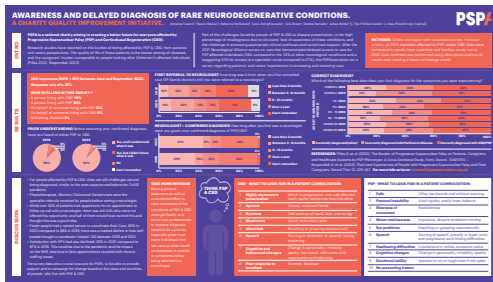
National Volunteers' Week, 1 to 7 June, gives us an opportunity to say a great BIG 'thank you' to all of our amazing volunteers.

We currently have 173 volunteers registered with us, all of whom regularly donate their time and efforts

to help us to provide information and support to everyone affected by PSP & CBD across the UK.

We know without our volunteers' support, we couldn't achieve what we do as a charity. So, thank you, to all our volunteers for everything you do.

RAISING AWARENESS AT THE RCP GLASGOW CONFERENCE



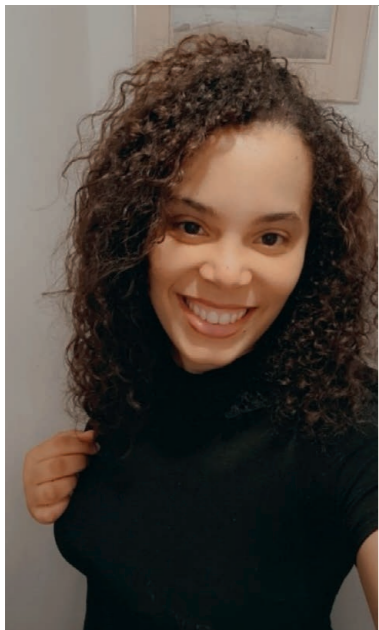
On 31 March we were excited to present a research poster to The Royal College of Physicians and Surgeons of Glasgow at their Glasgow conference.

The poster shared results received from our 2022 survey of people living with PSP & CBD and it was accepted as one of the top three submissions for their neurology conference. We displayed a digital poster that was viewed by delegates throughout the duration of the event. Our Research Coordinator, Annalisa Casarin, was invited to

present the findings to the audience via a pre-recorded video and answered questions live via a virtual platform.

The poster 'Awareness and delayed diagnosis of rare neurodegenerative conditions. A charity improvement.' showed the results comparison between data from the 2016 survey and 2022 survey.

We hope presenting the results of our survey, gave us the opportunity to create evidence around delayed diagnosis, difficult access to care, and decrease in service satisfaction across the UK, will help raise awareness among clinicians. We will continue to find opportunities to share this knowledge and show the poster at academic conferences.



WELCOMING LYDIA TO PSPA!

"I joined PSPA on 22 February 2023 as the Communications Assistant. I studied Business Enterprise at the University of Buckingham on a scholarship. From there I started working as Volunteer Coordinator at another charity as well as becoming a Social Media Influencer- which led me here. I am looking forward to this new role within PSPA and to see where my journey leads. I have a passion for helping others and want to contribute to PSPA's mission by creating a better future for everyone affected by PSP & CBD."

NEW! CARERS GUIDE TO LAUNCH DURING CARERS WEEK

We've developed a new guide to help support all the family and friends who are caring for a loved one living with PSP & CBD.

The carers guide is full of information and activities to help you in your role as a carer.

You can download the guide from our website from 5 June 2023. Alternatively, you can request a guide to be posted out to you by contacting our Helpline.

PSP & CBD INTERNATIONAL SYMPOSIUM

We are thrilled to announce we will be holding the second International PSP & CBD Research Symposium.

PSPA and CurePSP will again join forces in bringing the Tau research community together in London on 19 and 20 October 2023. The symposium will provide scientists, researchers, clinicians and pharmaceutical companies insights on how research in PSP & CBD has grown and produced some very encouraging results.

We are looking forward to two days of learning about cutting-edge research in the fields of PSP, CBD, and beyond. Topics range from basic to clinical research, including biomarker development, care research, and pathological mechanisms in tauopathies. We will hear about the genetics of PSP & CBD, current clinical trials, international neuropathological studies, and patient registries.

We will also host a competition for research posters, and expect many of the presenters will be early-career researchers who will present very exciting results from their studies.

The event will be targeted at a scientific audience; and members of our PRIM group (PSPA Research Involvement Members) will be invited to attend.



BE AWARE! THE PSPA SUMMER RAFFLE IS HERE!

Help raise awareness of PSP & CBD whilst being in with a chance of winning up to £500 by taking part in our Be Aware Raffle.

We are asking for PSPA supporters to buy or sell 40 raffle tickets this summer to help more people spot the signs and symptoms of PSP & CBD.

If you haven't signed up to receive raffle tickets, and you would like to receive some, please email fundraising@pspassociation.org.uk or call 01327 322414

Raffle tickets are £10 for a book of ten.



PSPA SUPPORTER PUBLISHES A BOOK CALLED PUMPKINS

Pumpkins is a little book about big stuff. Sue Wilsea tells her husband Mike's story from his diagnosis of PSP until his death last year. Why Pumpkins? Mike was Mr Mammoth Pumpkin 1978 and at his funeral pumpkin seeds were distributed to those present. To learn the full story, you'll need to buy the book!

Pumpkins is not a miserable read. Yes, it's sad in places – how could it not be? But it is also full of laughter and hope, some poetry and quirky illustrations. Where else could you find pumpkin riddles, learn fascinating facts about pumpkins or read a fairy story about the NHS. There's plenty of information too: about the not widely known condition of PSP and the work of PSPA to which all Pumpkins profits will be donated.

The cost of the book is £5 and you just need to complete the online order form: Visit: <https://forms.gle/xafwFYbd3P9eb7Kk6>





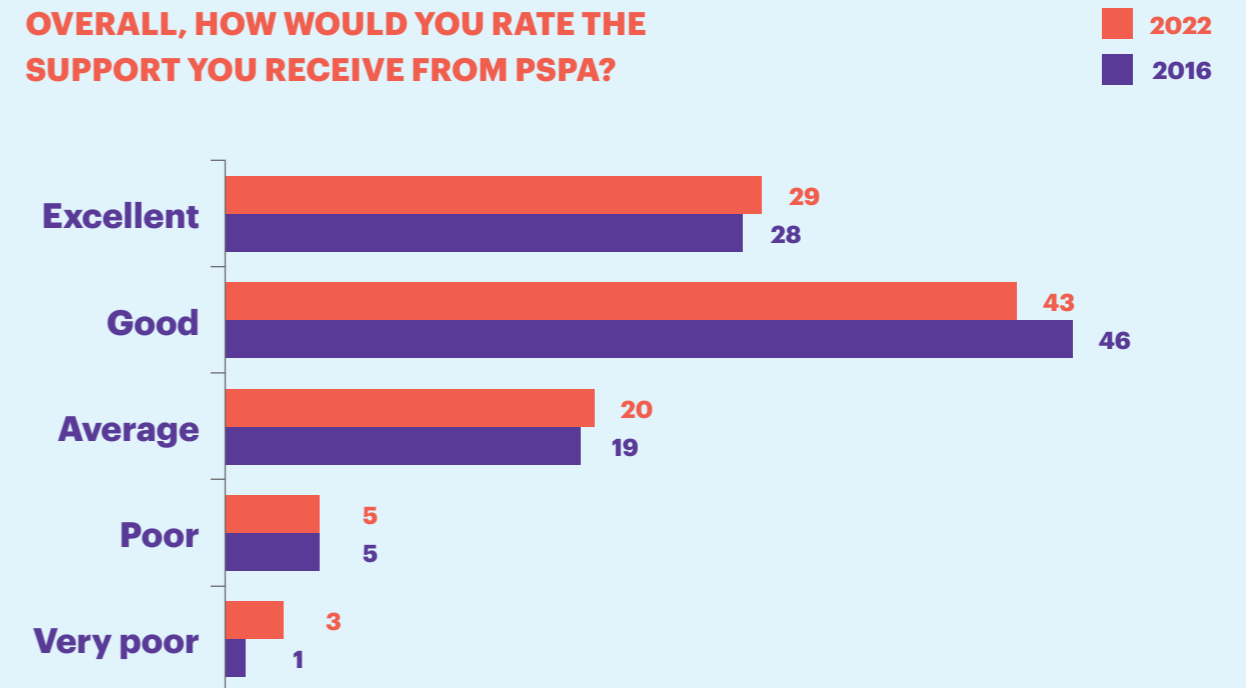
WE KNOW THAT THE WEBSITE IS A CRUCIAL TOOL FOR YOU, WITH 53% OF RESPONDENTS SAYING THEY USE THE WEBSITE WHICH IS UP 8% ON THE 2016 SURVEY.



WHAT YOU SAID ABOUT PSPA SERVICES

In the last issue of PSPA Matters we profiled the headlines from our survey of people living with PSP & CBD, carried out last year. In this edition we are covering some of the feedback we received in the survey, about PSPA services.

OVERALL, HOW WOULD YOU RATE THE SUPPORT YOU RECEIVE FROM PSPA?



Overall, it is a positive result with ratings of PSPA services holding up (72% of people rating the support excellent or good) whilst elsewhere i.e. satisfaction with care, things seem to have got worse for people. However, there are also signs that people are using our services a bit less and are rating them slightly less well than before. We are going to investigate why this is and if some people are more likely to say this.

We know the most used services are PSPA Matters, the Helpline, and the website. 46% of respondents use between three and six PSPA services, showing how important it is that we provide a range of services to cater for people’s differing situations and requirements.

Satisfaction is highest with the Helpline and lowest with the website. We hope the recent changes to the look of the website and a new search facility have improved this. We have more changes planned to the content over the coming months. We know that the website is a crucial tool for you, with 53% of respondents saying they use the website which is up 8% on the 2016 survey.

“Very kind and compassionate - the lady we spoke to gave us information about applying for CHC. She was really encouraging and supportive when we felt like giving up.”

Around one in three (28%) say they attend Support Group meetings, with 17% saying they attend regularly. Transport and proximity to a group continues to be the main barrier to attendance. There were lots of changes with groups during the pandemic and we are trying to rebuild them with a target of six new groups this year. If you are interested in volunteering to run a group, please get in touch by emailing volunteering@pspassociation.org.uk.

“As long as it continues, the support group is a lifeline”.

There were lots of suggestions for what we could do better. They range from support groups in specific locations (we are trying to recruit more volunteers), campaigns to raise awareness (keep an eye out for this year’s awareness week plans on page 19) and a greater emphasis on CBD (we have introduced a strapline to the logo to highlight we cover both PSP & CBD, our recent headline story in the last edition of the magazine and newspaper articles we secured in the Daily Mirror and Daily Express featured a PSPA supporter who is living with CBD).



HELLOS AND GOODBYES



A SAD FAREWELL

As new volunteers join us sadly some of our amazing volunteers step down. We would like to take this opportunity to say a fond farewell and a really big thank you to Kirsty Gemmell. Kirsty joined PSPA as a Support Group Coordinator nearly 10 years ago to set up the East Kilbride Group. She has in that time supported many families through really difficult times as well as raising awareness of PSP & CBD at any opportunity. During the pandemic Kirsty continued the support group via Zoom and it became known as West of Scotland Support Group.

Thank you, Kirsty, for everything you have done, not only for the families you have supported but also for the time and commitment you have given to PSPA.

A WARM WELCOME

We would like to welcome Support Group Volunteer Sunil Sood, who will be facilitating the PSPA London Support Group. The group held their first meeting on 24 April, which was a great success. Lots of information sharing and getting to know each other. They are currently meeting via Zoom monthly but hope to host some face-to-face meetings as the group grows.



Sunil shares why he decided to volunteer for PSPA and set up a group in his area. "My mother was first diagnosed with PSP in late 2019. Unlike some, I knew a little about PSP and in a cruel twist of fate I had a close friend who had not long ago lost his mother to this cruel illness.

Over the next few years, I wanted to ensure that mum had the best possible care and support and some of this came from the London PSPA group.

Mum passed away in May 2022.

I wanted to restart the PSPA Support Group in London to help get people of all stages a way to support each other ranging from the newly diagnosed to people further along in their journey. If I can make a difference I know that it would make my mum proud."

If you are interested in joining the London Support Group please contact volunteering@pspassociation.org.uk or call 01327 368597.

"IF I CAN MAKE A DIFFERENCE I KNOW THAT IT WOULD MAKE MY MUM PROUD."

"AS WE ARE ALL NOW FORMER CARERS, WE FEEL WE WANT TO OFFER SUPPORT TO OTHERS GOING THROUGH THE EXPERIENCE OF A LOVED ONE WITH PSP OR CBD."

WELCOME TO THE LEICESTERSHIRE GROUP

We would like to take this opportunity to welcome Roger Penford, Di Newton, Sue Holford and Edna Ross as the new volunteer group coordinators for PSPA Leicestershire Support Group. Sue provided us with a little insight into why they wanted to restart the group and their future plans.

"The four of us met by Zoom during the pandemic period. Two of us were former carers and two of us were caring for our partners. As someone dealing with a newly diagnosed husband, the friendship and comfort from these meetings was invaluable. We all later subsequently enjoyed regularly meeting up in person over coffee and lunch and from these meetings it was decided that re-forming a local support group for our area was what we would like to do.

Geographically we cover quite a large area, and our meetings are held at the LOROS hospice in Leicester, where we are able to use the large community meeting room. The venue gives space, level access and suitable toilet facilities as well as a superbly appointed kitchen perfect for serving up Edna's delicious cakes!

As we are all now former carers, we feel we want to offer support to others going through the experience of a loved one with PSP or CBD. We don't profess to have all the answers but can give a listening ear, advice borne from experience, and the chance to just be amongst people with shared circumstances and lives.

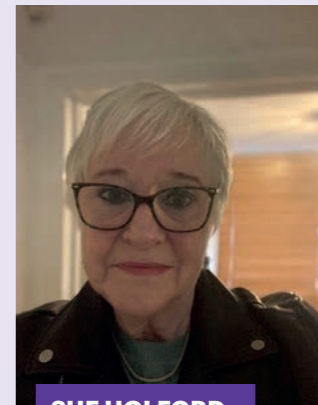
Our first meeting was a 'getting to know you' time and over the next few meetings we plan to gauge what people want to do, whether it be some activities or 'chill and chat' time. It was great to meet so many people. Do join us if you can, whether on your own as a carer or supporter or with your loved one. This year we are meeting Saturdays between 2pm to 4pm every six weeks.



ROGER PENFORD



DI NEWTON



SUE HOLFORD



EDNA ROSS

MEETING DATES

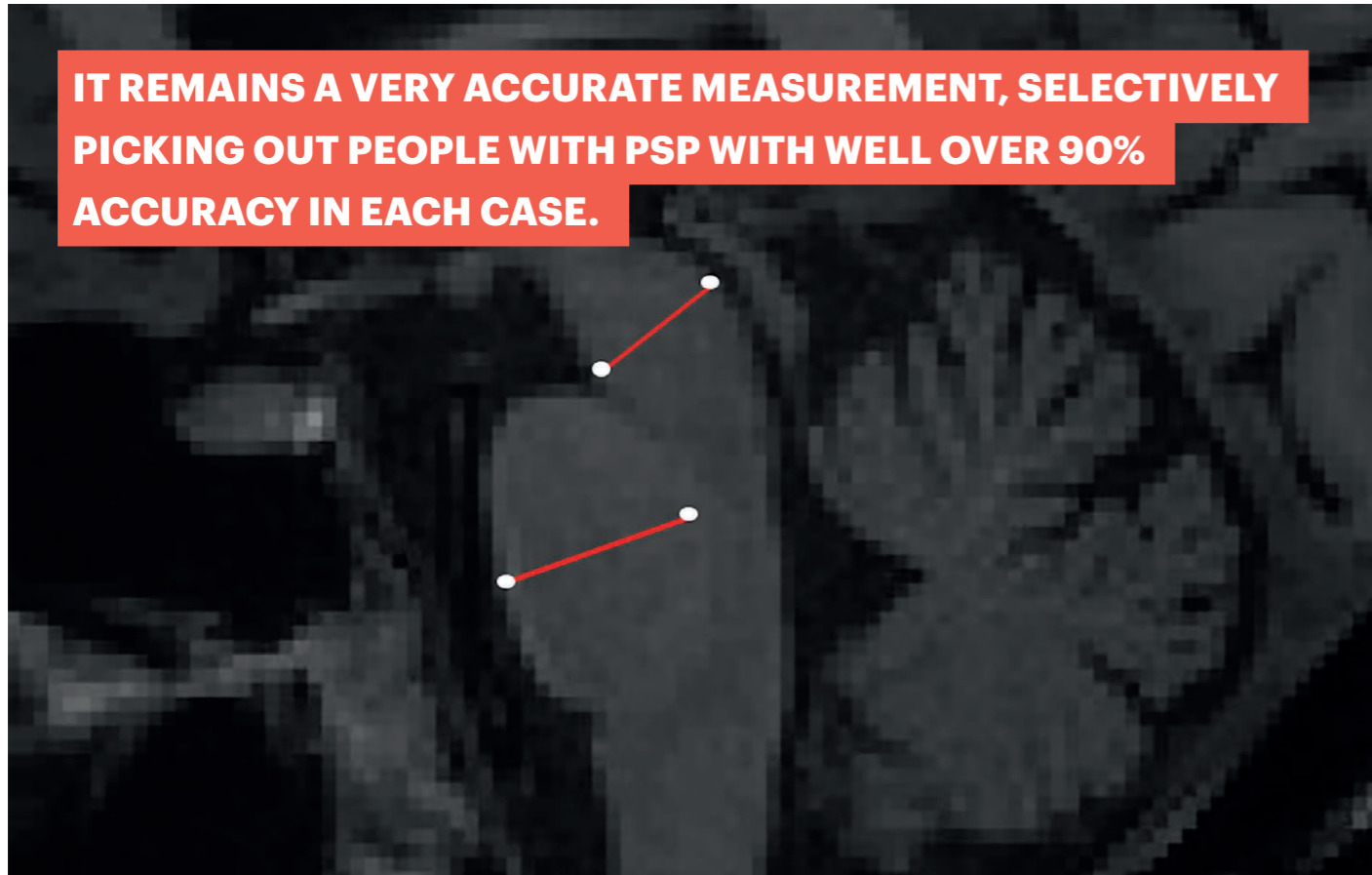
- 15 July
- 9 September
- 18 November



If you are interested in attending the Leicestershire Support Group, please contact volunteering@pspassociation.org.uk or call 01327 368597.



IT REMAINS A VERY ACCURATE MEASUREMENT, SELECTIVELY PICKING OUT PEOPLE WITH PSP WITH WELL OVER 90% ACCURACY IN EACH CASE.



HOW ARTIFICIAL INTELLIGENCE CAN AID RESEARCH INTO PSP & CBD

Following the popular session delivered during our Research Information Day in February, Dr Timothy Rittman shares how AI is helping research into PSP & CBD.

"If you could pick a buzz-word for the past few years, then it would be hard to beat "Artificial Intelligence". Often shortened to AI, it has rarely been out of the headlines. There has been much hype around Chat-GPT, an online AI 'bot' that can answer questions in a way a human expert might. In fact, when I mentioned that I had to write this article in clinic earlier today, one of my patient's daughters suggested I use Chat-GPT to do it for me (I can promise I didn't!). I did at least ask Chat-GPT how to distinguish between PSP and

Parkinson's disease, and it gave a reasonable answer, with the conclusion "a careful neurological evaluation can help differentiate the two conditions." So, it looks like, as a Neurologist, I'm not out of a job just yet.

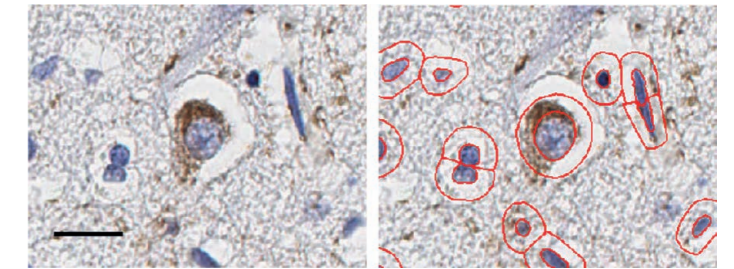
But, going beyond the hype, are there ways in which AI might help me to make the diagnosis of PSP & CBD more accurately, and help us to understand these diseases better? I'm going to take you through a few ways that we're working on in Cambridge trying to do exactly that.

The first use of AI is to help make an accurate diagnosis using brain scans. Brain scans are perfectly suited to AI – they are complicated, and have lots of patterns to find. As a human trying to decide on a diagnosis of PSP, I often look at a part of the brain called the midbrain that joins the brain to the brainstem and spinal cord. The midbrain shrinks in PSP, and gives an appearance often said to look like a hummingbird. Marion, a PhD student working with me, realised that a key measurement of the brainstem (called the midbrain-pons ratio) could be calculated using AI. To do this, she used a flavour of AI called reinforcement learning. To calculate the midbrain-pons ratio, you need to find four bits of the brain and compare their sizes. So, in Marion's AI, she sets off four 'agents', that I like to think of as little men running around the brain trying to find the right place. Once they've found their places, then we can use them to measure the midbrain-pons ratio. It turns out this is incredibly accurate (98%) in differentiating PSP from Parkinson's disease.

Why bother doing this with AI when the same measurement could be made by hand? The reason is speed. Without breaks, it might take a human 15 hours to get through 300 scans. A set of machines will manage it in less than two minutes. Not bad, eh? This means that, as well as comparing PSP with Parkinson's disease, we've been able to use AI to compare PSP with other Parkinson's-like disorders, such as CBD and Multiple System Atrophy which has not been done before. And it remains a very accurate measurement, selectively picking out people with PSP with well over 90% accuracy in each case. Our next project will be to look into sets of scans with thousands of patients – the AI will be done processing all of these in the blink of an eye – and to seeing whether AI can predict what happens to people in the future (i.e. prognosis).

Another PhD student working with me, Mariana, is doing something similar applying AI to a different type of brain scan that looks at brain connections, called Diffusion Tensor Imaging, that should help with both PSP & CBD. We're also looking at other types of neurodegenerative disease, including Alzheimer's disease. I hope that in a few years we'll have built up a suite of AI tools that can really make a difference in clinics to get the most information possible out of brain scans, and help us to make an accurate diagnosis much earlier.

AI doesn't just help with diagnosis. It is also helping us to understand what is going on 'under the bonnet' in these diseases. Many of our patients are generous enough to donate their brains to the brain bank. Pathologists are doctors who look at these brains under the microscope. We're lucky in Cambridge to have Dr Annelies Quaegebeur. Annelies who spends hours looking at brain cells, painstakingly counting each cell and assessing whether it has evidence of the troublesome tau protein. Could we use AI to help speed up this process?



Tanrada is a PhD student working with me who has done just this. Tanrada's AI algorithm is as good as Annelies at identifying the different types of tau that build up in PSP brain cells. Although AI is no substitute for Annelies' knowledge and experience, it can be much quicker to help identify patterns. Similar to the brain scans, we can look at far more brain regions than we could in the past. Usually a pathologist such as Annelies will look at five or six brain regions to look for the changes of PSP or CBD, which might take an hour. In a fraction of the time, the AI will have looked at 20 different regions. Not only that, but Annelies only has the time (and patience!) to look at a small part of each brain slide, which might contain a few thousand brain cells. The AI can look at a whole slide, which contains hundreds of thousands of brain cells. We still need Annelies' expertise to help train up the AI algorithm, and to interpret the results. But, the AI is enabling us to do research on brains at a speed and scale we could only dream of a couple of years ago. This is helping us to examine the patterns in which tau appears in the brain, and the consequences on brain scans and day-to-day function.

So, beyond the hype, we are beginning to use AI to make a difference to the diagnosis of diseases like PSP & CBD, and to the speed and scale of research we're able to do in brain scans and neuropathology. AI might be a buzz-word, but it's one that is here to stay."



RUNNING THE BRIGHTON MARATHON FOR MY DAD

"I TOLD MY DAD WHAT I WAS DOING, HE MANAGED TO SAY THE WORD 'BONKERS' WHICH MADE ME LAUGH."

Susannah Rose's dad was diagnosed with CBD in 2018, after experiencing problems with balance and falls. Since the family experienced a lack of awareness around CBD, Susannah decided to run the Brighton Marathon.

"My dad has always been full of energy. Just when most would be enjoying retirement, at the age of 70, my dad opened a local gallery in Brighton, selling antique artefacts and paintings by local artists.

Dad's gallery was only open two or three years, when he started to experience problems with his balance and falling regularly. Dad had a doctor friend who recognised some of these symptoms and encouraged him to seek medical support.

Dad chose to go private with his medical investigations. Initially, there was talk about him possibly having Parkinson's. But after a few more tests and scans, dad was diagnosed with CBD; a condition we had never heard of before.

Unfortunately, not long after, due to becoming even more unsteady on his feet, dad had to give up his new venture, the art gallery. He still kept very upbeat and busy though. He saw and went out with his friends regularly, and although no longer married, my mum has been a great support and friend to him.

Taking control of his decreasing mobility, dad decided it was best to move into a care home, just before the pandemic hit. It was a difficult decision to make but he knew he wasn't safe living at home by himself. Although going private for his diagnosis meant dad had answers quite quickly, his pathway into receiving care support, was tricky.

Mum and dad did all the research and visits to care homes themselves, meaning dad was very much in charge of his own decisions. This included seeking financial advice around affordability.

We definitely saw an immediate decline in dad following the start of the pandemic. Having limited contact, with me sometimes only being able to see dad over the care home's garden fence, meant his speech and mobility got far worse over this period.

He did, however, use the time to work with a friend on an autobiography. Another friend then printed the book for dad, which provides lovely memories for us as a family and also a great talking piece, particularly for new carers who are getting to know dad.

It was a nice touch that dad's current care home (he has moved several times and is now up in Warwickshire to be close to myself and my mum) read from dad's autobiography as part of their story time afternoons, which dad enjoyed very much.

Literature from PSPA has been really useful in helping to assist the care home staff, better understand CBD and my dad's needs.

But throughout this journey we have noticed awareness of CBD seems to be low.

As a runner, I decided to sign up and run the Brighton Marathon in April 2023. I thought this would be a great opportunity to raise awareness of CBD and I wanted to do it now, so dad could be part of the experience. Choosing Brighton, seemed a natural thing to do, since it holds lots of special family memories for me.

Training was tough, particularly during the winter period. But I have lots of local runner friends who have helped to keep me motivated and even at times inspired me to run faster.

I couldn't wait to share the experience with dad, once I'd completed the marathon. I told him what I am doing and although he now can't say much at all, he still managed to say the word 'bonkers' to me. Which made me laugh."

"INITIALLY, THERE WAS TALK ABOUT HIM POSSIBLY HAVING PARKINSON'S. BUT AFTER A FEW MORE TESTS AND SCANS, DAD WAS DIAGNOSED WITH CBD; A CONDITION WE HAD NEVER HEARD OF BEFORE."



**“I FEEL GETTING TO KNOW
SOMEONE IN THEIR OWN
HOME AND SURROUNDINGS
IS THE BEST WAY TO
BUILD TRUST
AND RAPPORT.”**



MIA MAXWELL

A DAY IN THE LIFE OF A SPECIALIST PALLIATIVE CARE NURSE

As part of our ‘Day in the Life’ feature, Mia Maxwell from LOROS Hospice in Leicestershire shares details of her role as a Specialist Palliative Care Nurse.

“I knew pretty early on in my nursing training that I was keen to work outside of a hospital setting. By experiencing a variety of different placements, I knew people in hospital were always keen to get home and back to their life, as fast as is possible. So, working in the community was always a goal of mine.

I got drawn into the area of end-of-life-care because I saw the benefits of providing continuity of support in the community, and also giving someone a sense of having their power back, at a really important time.

Initially I worked as an End of Life Nurse in the community for 18 months. This role then led to my position at LOROS Hospice where I am a Specialist Palliative Care Nurse. Again, I could see all the amazing services LOROS provides, but I was keen to be out in the community, rather than ward based. I feel getting to know someone in their own home and surroundings is the best way to build trust and rapport. In people’s homes, there are so many different talking points, even if they are overwhelmed or are losing their speech, there are always photos, furniture or ornaments that can help me get to know a person and what is important to them.

I’ve been working for LOROS for two years now and in this role, I really want to make a difference to people’s end of life care. I feel giving people the ability to have a good death is really important. By this I mean, symptoms are managed well, there’s a good quality of life at different stages of illness and plans are made so peoples’ wishes are upheld.

The usual route to receive support from a nurse like myself is via a GP. However, I often find that referrals for support for people living with PSP or CBD come through local Speech and Language Therapists (SLT). This tends to be at the point when speech or swallowing begins to be an issue.

After receiving a referral, I will make contact to arrange an initial home visit. Sometimes people want the first meeting to be just me and them, for one-to-one support, or they will want their whole family there.

At the first meeting, I will conduct a full integrated, holistic assessment. Largely this looks at activities of daily living, and what they need support with. I also look at complex symptom management including what medication they take and whether a review of their medication is needed, what their diet is like, any impact on bowel and bladder, and family dynamics/ what support system they have in place.

Whilst I am there I will also assess the person using the Integrated Palliative Care Outcome Scale. This looks at a person’s physical and psychological symptoms, social and spiritual issues, communication, information needs and practical concerns.

This scale helps, along with discussions, to plan what support is needed and how frequently. On the whole, if people have symptoms which are well managed I will visit them once a week or fortnight. If symptoms are at a more complex point, I may visit more often and will phone people in between visits too, just to keep on top of any changes that may be occurring.

The support offered very much depends on the individual’s needs or preferences. Largely, we are there to help improve quality of life, but sometimes that can just mean providing a listening ear. On other occasions it can be just a medication review or calling in support from adult social care, who can provide technologies to help someone to remain independent, whilst living in their own home. Examples could be providing items such as chair risers, steps, or talking clocks that can provide reminders for medication.

Referrals might also be made onto other LOROS services such as day therapy or counselling.

In my role, I feel I am very much part of a person’s journey, from diagnosis to death. I do feel talking about death is important and can assist with Advance Care Planning. This does help to take the pressure off family members.

Ideally, talks around Advance Care Planning would happen early on following a referral to me. However, it does vary from person to person and how ready they are to make such plans. Discussions will usually centre around care provision, preferred place of care at end of life, and any details of wishes they would like to be followed.

If discussions around Advance Care Planning are regularly blocked, I will suggest to the person that we gain support from a Consultant, who can come along to a visit and lead the conversation.

I very much enjoy my role as a Specialist Palliative Care Nurse. I enjoy the one-to-one aspect of providing community support, and I like to think I am empowering individuals and families, and give them back the control around their end-of-life-care.”




WHAT WE DID IN 2022


Thanks to the support of our amazing and loyal supporters and volunteers, in 2022 we were able to continue to provide lifeline support services such as our Helpline, as well as develop our support to include: regional Support Groups for Carers of people living with PSP & CBD, holding our first PSP & CBD Study day since the pandemic, and collecting your feedback in our 2022 survey of people living with PSP & CBD.

HERE ARE JUST A FEW MORE ACHIEVEMENTS YOU HELPED US TO DELIVER DURING 2022.


5
new monthly **Carers Support Groups** were introduced from March




20%
A **20% increase** on contact to our **Helpline**.




28
local Support Groups ran regular sessions either in person or via Zoom



36
PSP & CBD education session were delivered to **235 healthcare professionals**




69
people received **financial support** through Voice Banking or PSPA Support Grant. This is a 27% increase on 2021.




1,288
people living with PSP or CBD, carers and family members **registered to receive support** from PSPA. This is a 9% increase from 2021.


2,245
HSCP's registered to receive PSP & CBD **education or information**



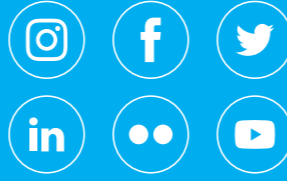
4,454
PSPA **publications** were circulated by post or email




11,451
PSPA Matters **subscribers**



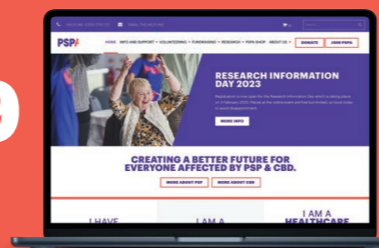
Engage with **15,960** people across social media



Host **8,440** people in our online forum – **HealthUnlocked**



Provide information to **55,559** website users



BUSINESS NETWORKING WITH PSPA

At PSPA, we have many ways to get supporters involved in the charity's work. One of the avenues we have been developing over the past year is that of Corporate Fundraising.

We already have many ways to get involved with Corporate fundraising at PSPA such as Charity of the Year Partnerships, sponsoring our in-house magazine, hosting an event or having a collection tin in your office.

A new and ever-growing opportunity we are developing is our Business Networking Group.

The PSPA Business Networking Group is a community for supporters with an interest in business, and focuses on making connections and idea sharing. The group is open to anyone who is self-employed, a business owner, partner or contributor, or involved with an organisation who is keen to understand or learn more from other likeminded people.

Our Networking Group is an opportunity to share information, knowledge and stories. While these are predominantly professional, with the primary aim in sharing your area of expertise, you can also touch on any personal link to PSPA if you would like to. This is a place where we discuss skillsets, offer advice and support other members in their work, building and developing relationships as we go.

This is all tied into hearing about what PSPA is working on as a charity, as well as ways to get involved, and contribute towards our priorities and aims. Each meeting also has a guest speaker. This is either someone from within the charity, or an individual with links to the charity from the business world, who provides a specialist update at each meeting.

The meetings are hosted by PSPA supporter and time management trainer and coach Steve Watson, alongside our Corporate Fundraising Manager, James Holden.

If this sounds like something you might be interested in coming along to, and getting involved with, and you have a link to business or an interest in networking, then please email james.holden@pspassociation.org.uk to find out more.

“Many people support charities close to their hearts. What I love about PSPA is that being a micro volunteer means I can support in areas that I can add value to. I was invited to join the monthly Business Network Group, where people associated with PSPA can collaborate and share business ideas and help each other out or support others who are dealing with the condition. This has bought me closer to the cause, the PSPA team and others who have been affected by PSP. This is another great connection point with the charity.”

Eram Osman, Digital Marketing Consultant



“The primary objective of the group is to see what we can do to help each other from a business perspective, along with collectively discussing how we can raise the profile and fundraising opportunities for PSPA as a charity.

I've been genuinely impressed by how much I've gained from attending the meetings... James and Steven both do a cracking job of chairing the meetings.

As a result of attending this group, I've also had the opportunity to understand much more about PSP and I would recommend attending if you have any experience / interest of PSP and would like to network accordingly.”

David Carter, BNI Support Director Consultant



MEET THE HELPLINE TEAM

To help you get to know our knowledgeable Helpline team, each edition we will be introducing a member of the team. This edition, we say hello to Cathy.



CATHY
MOUGHTON



"Hello, I am Cathy Moughton, Helpline Care Navigator for the West and South West of England.

I started working at PSPA three years ago after previously working in the local authority and social care sector. I enjoy the role as it is so varied, no two days are the same.

My day always includes responding to calls and emails coming in to the Helpline. I enjoy being able to listen and support people with questions about symptoms or issues surrounding their diagnosis, ongoing care support or to give carers the time and space to discuss their caring role.

As a wider part of the Helpline Care Navigator role, I also spend time raising awareness and knowledge of PSP & CBD amongst health and social care professionals. This includes forging partnerships and close working relationships with key health and social care professionals in my region, who support people living with a diagnosis of PSP or CBD, such as neurologists, parkinsons nurses, speech and language therapy teams, occupational therapists and physios.

I proactively contact professionals in my area, either by phone or email and arrange a convenient time to discuss the services we and they provide in more detail and the best ways of working in partnership to ensure that we are able support as many people with PSP & CBD and their carers. This may include delivering an awareness and education session to a wider team. We often provide these sessions via Zoom as this enables us to join team learning sessions to give them an overview of both PSP & CBD and also importantly about the information and support PSPA provides.

By linking in and talking with health and social care professionals, it gives me the opportunity to work collaboratively. This means I can gain an understanding of support and services available in an area, how referral processes might work, enabling us to ensure that people who contact the Helpline are receiving the right support at the right time.

Another element of my role is attending hospital clinics. I currently attend two movement disorder clinics, one in Southampton and more recently one in Devon. I am coordinating attendance with other clinics in my region with the hope that these links will increase.

Being at clinic enables us to meet people with PSP & CBD and their carers in person, the added bonus of attending clinic is it helps to increase our understanding and knowledge of PSP & CBD. Knowing how diagnosis is made and what happens on a visit gives us the ability to explain this to people when they call and helps to dispel fears they may have about an appointment. Of course, often people have just been diagnosed when I am in clinic and have a lot to take in, I always encourage them to contact the helpline, where they will find a safe and open place to discuss their experiences with someone who has an understanding of them.

HOW YOU CAN HELP OTHERS #BEAWARE OF PSP & CBD

This June, we are launching a new awareness campaign with the aim of improving diagnosis of PSP & CBD by educating healthcare professionals and the general public about early symptoms. During PSP & CBD Awareness Week, 17 to 23 June 2023, we encourage you to get involved in a variety of activities to help us ensure more people can Be Aware of the two conditions.



SHARE OUR NEW EYE RED FLAG POSTER

Since you fed back in our 2022 survey of people living with PSP & CBD that educating healthcare professionals is one of your top priorities, this year we will be specifically targeting opticians and ophthalmologists.

To do this we have created a new poster highlighting Eye Red Flags so opticians and ophthalmologists can #BeAware of these key signs people living with PSP may experience. The aim of the poster is to encourage opticians and ophthalmologists to advise any patients showcasing the symptoms, to get advice from their GP or even a referral to a neurologist.

Professor James Rowe, PSPA Trustee and Cambridge University Professor of Cognitive Neurology and Consultant Neurologist, confirms raising awareness of eye symptoms could help improve diagnosis rates:

"It's time to look up to PSP! The eye signs of PSP may not be noticed in everyday life, or cause any symptoms. But, our eye movements can change very early on in PSP. So, they could be a way in to early diagnosis."

Many of us have our eyes checked regularly at high street opticians, for glasses/contact lenses, glaucoma or other eye conditions. Wouldn't it be great to have a quick check at the same time for possible PSP? Many people could be spared from long delays to get assessed."



HOW YOU CAN HELP

You can help spread awareness of the Eye Red Flags, by sharing our new poster (please use the tear off poster at the back of the magazine) with your local opticians. You can then log where you have taken the poster on our website awareness map.

If you would like more Eye Red Flag posters, you can:

Download a copy from our website:
www.pspassociation.org.uk/information-and-support/awareness-tools/

Contact us to receive copies in the post on 01327 322410 or email info@pspassociation.org.uk



HOW OPTICIANS HAVE HELPED

Katy Butterill knows all too well the importance of spotting those all-important eye changes.

Katy's mum was diagnosed with PSP in 2020. After multiple visits to the GP, and whilst waiting for a neurology appointment, Katy's mum's eye issues were picked up during an optician appointment.

"My mum had been to the GP several times over balance issues but nothing conclusive had been found. Eventually they did refer her to neurology but there was quite a wait. During this wait, the GP suggested going for an eye test.

The optician picked up on limited eye movement (this of course, meant nothing to us at the time) and said she would do a report for the GP. As a result of this mum was referred to a neuro- ophthalmologist and the appointment came through quite quickly. In the ophthalmology report, PSP was mentioned for the first time. This diagnosis was confirmed later when mum finally had her neurology appointment."



KATY'S MUM'S EYE ISSUES WERE PICKED UP DURING AN OPTICIAN APPOINTMENT

PSPA volunteer, Maria. C.Rodrigues-Hancock's dad was diagnosed with PSP in 2016 and an optician also aided his diagnosis of PSP:

"My dad's first awareness of PSP came in the summer of 2016 during his annual eye test.

My dad received expert eye care from Zag who had detected issues with dad's vision and referred him to an ophthalmologist in our local hospital eye department.

At this time, dad had also been experiencing problems with balance and mobility so had visited his GP several times. The GP said the symptoms he was experiencing was to do with his age.

Thanks to the result of dad's eye test, paired with some other symptoms, it was determined dad needed to have further investigations, including a brain scan. It took a few months of tests to get a definitive diagnosis of PSP in December 2016. Sadly, dad passed away in 2020. It is because of dad's experience I volunteer for PSPA and support all plans to raise awareness of PSP & CBD."



STEPPING UP AWARENESS IN YOUR COMMUNITY

As well as helping us to distribute our new Eye Red Flag posters, there are a number of ways you can help make sure people in your community can #BeAware of PSP & CBD too.

TAKE PART IN A WALK OF HOPE

Throughout the summer, we are encouraging you to get out in your local community and take part in a Walk of Hope.

Our Walk of Hope is an awareness raising 5km walk or wheelchair push. You can take part in a local event (see events listed on our awareness map) or host your own walk with your friends, family and colleagues. The beauty of this awareness raising event, is you can organise it to suit your needs. Walk or push 5km in one go, or break the distance up into smaller chunks across a number of days. You can even organise a relay so you only need to complete a portion of the walk yourself.

You can look the part during your Walk of Hope, by wearing a PSPA t-shirt and Ed's Lace (see all the awareness raising items our website shop has to offer at the back of the magazine). Not only will the striking colours raise awareness of our charity, the lace will help create conversation points so more people can #BeAware of PSP & CBD in your area.

LACING UP YOUR PERSONAL EXPERIENCES

Whether you are organising or attending a Walk of Hope event, delivering an important PSP & CBD education session or organising for an optician to attend a Support Group meeting, there is always a place for wearing Ed's Lace.

Following the successful relaunch of Ed's Lace last year, we are keen to keep the conversation starter part of our ongoing awareness plans.

Wearing an Ed's Lace is something everyone can do, during PSP & CBD Awareness Week and beyond. Keep an eye on our Facebook and Instagram profiles for great ideas for utilising Ed's Lace to create conversations about PSP & CBD and an opportunity for you to share your personal experience too.

THE BRESLIN FAMILY ON THEIR WALK OF HOPE IN 2022



HOW PSPA VOLUNTEERS ARE RAISING AWARENESS

EDUCATING HEALTH AND SOCIAL CARE PROFESSIONALS

As part of our commitment to educating health and social care professionals across the UK about PSP & CBD, we are rallying our fantastic Education Volunteers to get out in their community.

This June, PSPA Education Volunteers will be organising informative education sessions with their local GP surgeries, care homes and community groups to ensure more people can #BeAware of PSP & CBD.

As well as raising awareness of the two conditions, the education sessions also inform how symptoms progress, meaning they are able to better support everyone affected.

OPTICIANS WELCOME AT SUPPORT GROUP MEETINGS

In addition, to our Education Volunteers helping with our awareness plans, we are also encouraging Support Groups to invite an optician to join one of their meetings during the month of June.

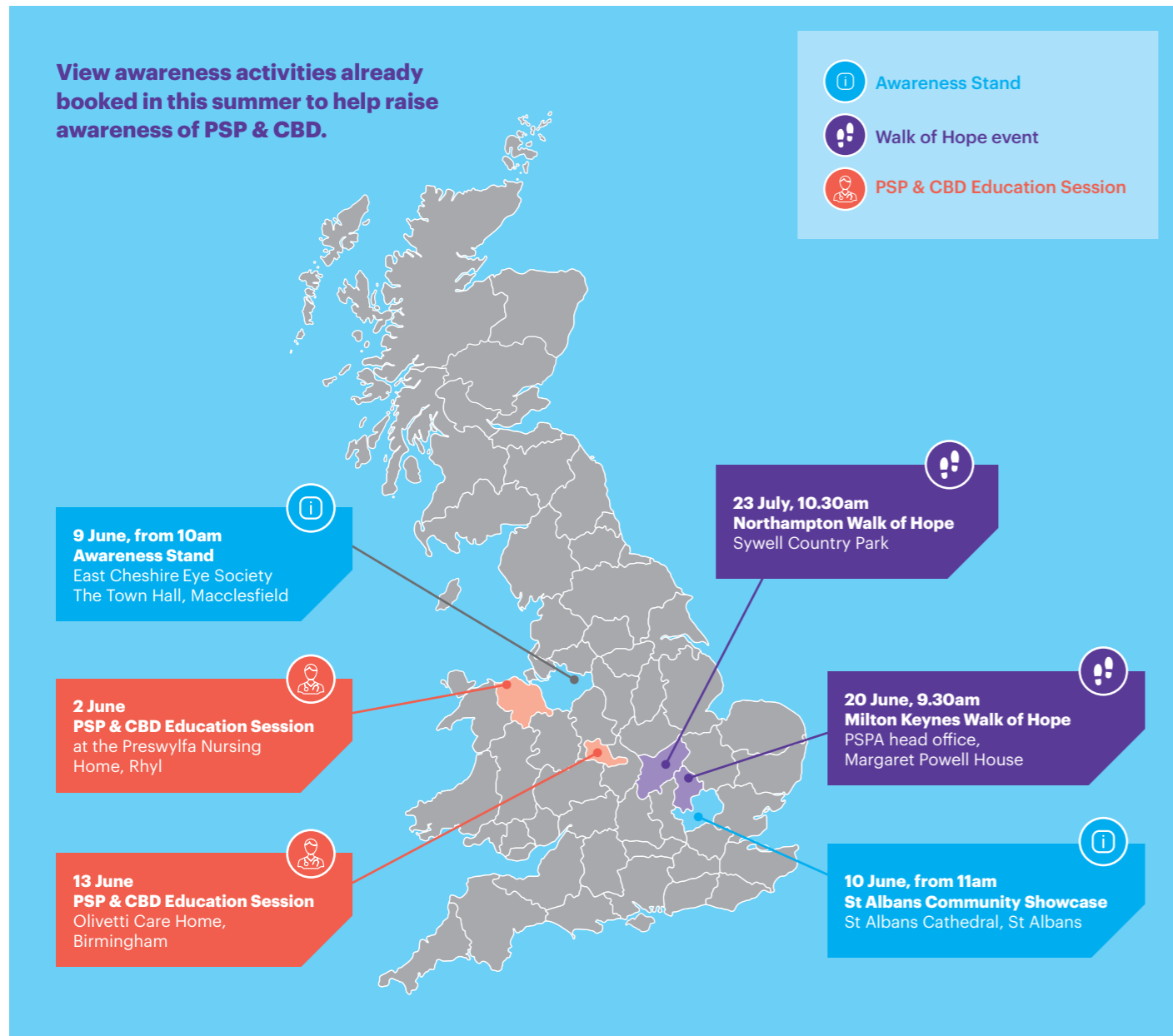
As well as building relationships with key health and social care professionals, opticians attending meetings will help them learn more about PSP & CBD and how it impacts daily life. In turn, this will help opticians better understand how they can assist diagnosis and contribute to the ongoing care people living with PSP receive. They can also offer tips on eye health for people living with CBD.

FOLLOW US ON SOCIAL MEDIA

Facebook: @PSPAassociation
Instagram: @teampspa



PSP & CBD AWARENESS MAP



PSP & CBD AWARENESS PACK

We've created a fun and informative PSP & CBD Awareness pack to keep you updated with our plans. The pack also contains lots of ideas to help inspire you to get out in your community to help more people #BeAware of the conditions.

Inside the pack you will also find useful documents such as:

- Our new Red Flag poster to share with an optician
- A template press release to help you share your experience with your local newspaper or radio station
- A sponsorship form to help you raise funds towards our fight to improve diagnosis and care
- Details of items we sell in our shop so you can look the part whilst you raise awareness.

To download this useful pack, please visit www.pspassociation.org.uk/information-and-support/awareness-tools/

PSPA AWARENESS RAISING GRANTS 2023



In the PSP & CBD community we all know awareness of the conditions is a real problem, impacting on diagnosis, care and support, access to resources and research.

In our latest patient survey 94% of people said they had not heard of PSP or CBD before they were diagnosed, and we know there are similar problems within the health and social care community.

We are committed to raising awareness of PSP & CBD alongside putting people at the heart of what we do. We know we can't do everything on our own and need to work in partnership to achieve our goals, we need you to help us. This year we have earmarked £10,000 to put power in the hands of our supporters and stakeholders to raise awareness.

Our new 'Awareness Raising Grants' are there to harness the ideas, skills and experience of people living with PSP or CBD, health and social care professionals, volunteers, and supporters to help raise awareness in their communities.

Grants will fall into four categories:

- Raising awareness to improve diagnosis
- Raising awareness to improve the quality of care and support
- Raising awareness of the services and support people living with PSP or CBD are entitled to and how to access those services
- Raising awareness to improve the resources allocated to supporting people with PSP or CBD in the health and social care system.

HOW MUCH CAN YOU APPLY FOR?

There are two levels of awards:

1. Under £1,000 – there is no lower limit.
2. £1,000 to £2,500

WHAT CAN YOU APPLY FOR?

We don't have an exhaustive list of what you can apply for, but to give you an indication it could include:

- Staff time to develop a learning network for health and social care professionals
- Publicity materials
- Travel to be part of a network/organisation like HealthWatch
- Making a short film or funding for a film screening
- Writing a book about PSP or CBD
- Developing learning materials
- An information session for a specific community
- Travel and accommodation to speak at a conference or workshop.

HOW DO YOU APPLY?

If you have an idea about how you can help raise awareness and need some funding to make it happen, then go to the website to find out how to apply.

The deadline for applications is midnight Thursday 31 August 2023.

www.pspassociation.org.uk/information-and-support/awareness-tools/



CRUISING THE MEDITERRANEAN

Eileen and Michael Chin have always loved travelling. After Michael was diagnosed with PSP last year, the couple was keen to continue their passion with a cruise. Here Eileen shares their experience of cruising the Mediterranean last September.

“Michael received a working diagnosis of PSP last summer after experiencing frequent falls, and changes to his speech. The diagnosis was confirmed in December 2022 although we suspect there were signs of PSP for up to three years prior to this.

Before Michael started experiencing PSP symptoms he was always very active and had lots of hobbies. We enjoyed travelling the world, taking in countries including Japan, Malaysia and Australia. And we regularly visit our son, who lives in America too.

We had been on cruises before, and enjoyed them very much, but it didn't cross our minds when we first thought about taking a trip following Michael's diagnosis.

I did speak to the PSPA Helpline about holidays. Michael was beginning to feel a little frustrated, since he was used being out and about and experiencing different locations and cultures on a regular basis up until he became ill. But now his balance and mobility are affected I felt like our options were limited. It was the Helpline who suggested a cruise and I am so glad they did.

“I JUST NEEDED TO COMPLETE A FORM DETAILING MICHAEL'S PSP AND MOBILITY NEEDS. I FOUND NOTIFYING CUNARD IN ADVANCE OF OUR NEEDS REASSURING.”

We cruised previously with Cunard so I contacted them to look into their accessible options.

Once we had chosen what type of cruise we wanted, we went with a Mediterranean cruise, taking in Spain, France and Italy as part of its itinerary, I just needed to complete a form detailing Michael's PSP and mobility needs. I found notifying Cunard in advance of our needs reassuring, knowing people would be on hand to help and staff would be aware of Michael's mobility issues before we even boarded. We decided to holiday with my son and his girlfriend this time, to have some extra support in case I needed it.



We were very excited when September came around. The cruise departed from Barcelona, so the first leg of the journey was to fly from the UK a day ahead of departure.

Once in Barcelona, it was really easy to board the ship. We chose a smaller ship for the trip to make it easier for getting around once on board, and we had a really lovely cabin with plenty of room and a balcony to enjoy too.

We took in some beautiful sights whilst on the cruise. We didn't always leave the ship when it docked in the different ports. We saw plenty from onboard the ship and there was always so much to do anyway, we were happy to sometimes stay behind and relax instead of exploring.

We did get off at some ports, including Sicily and Naples. We would disembark for a few hours to have a quick look around, enjoy a local café and get something to eat. Naples was slightly harder to get around as it was quite hilly, and Michael used a wheelchair when off the ship.

Whilst on the ship we kept ourselves busy with the different entertainment available every day. Michael was particularly interested in the range of talks and lectures on offer. And whilst he enjoyed those, I got artistic at a watercolour class. We regularly enjoyed taking in afternoon tea and each evening there was a different show.

A range of restaurants were available, from buffets right through to high class dining. We preferred the seated meals so didn't try the buffets but there seemed to be something to appeal to every taste.

The break away did us all no end of good. A cruise is such a great option for us. Everything you need is all in one place plus there is lots of help on board should you need it, which I found very safe and reassuring. There is also a medical wing on board should you or your loved one become ill or take a fall.

Michael enjoyed travelling again and taking in new sights, and I enjoyed a chance to relax and break away from the daily routine. We are already thinking about our next trip and have booked a cruise in November to see the Northern Lights, something we have always wanted to experience.”

Top tips for cruising holidays

- Pick a smaller ship such as the Queen Elizabeth. Cruise ships can be vast so picking a smaller ship means that it is easier to get around to the different areas and activities
- If you need it, cruise ships do have accessible rooms available. Cunard offer accessible states room with wheel in wet rooms. These get booked quite quickly so booking early is important
- Flying to and from Barcelona was very tiring for Michael. In future, we will pick cruises which sail from Southampton, so we just need to concentrate on one journey there and back
- Make sure you make the cruise company aware of any mobility or dietary requirements ahead of your trip
- If you are still waiting for a diagnosis, ask your neurologist to provide a 'working diagnosis'. This will allow you to get insurance for your trip, whilst you wait for your diagnosis to be confirmed
- Chose insurance which includes cruise specific cover. It is more expensive but it covers unlimited medical expenses including repatriation if necessary
- Do a bit of prior research into locations to see which areas most accessible, this should help you plan your trips, should you choose to disembark at any port.





“I AM EXTREMELY GRATEFUL TO THE PSPA FOR SUPPORTING MY RESEARCH OVER THE NEXT THREE YEARS.”



DR ROB DURCAN

INTRODUCING THE NEW PSPA FELLOW

As part of our commitment to supporting the rising stars of PSP & CBD research, we recently awarded our third Sara Koe Fellowship. Dr Rob Durcan shares details of his three-year study which is funded by PSPA.

“Hello, I’m Rob. I’m an Irish neurologist, and I’ve recently received funding from PSPA to undertake a PhD at the University of Cambridge, working towards new treatments for people living with PSP as the charity’s Sara Koe Research Fellow.

To help research into effective treatments for PSP & CBD, I recently moved to the Cambridge Centre for Parkinson-plus. PSP & CBD can be very challenging conditions, for patients and caregivers. Better diagnosis and treatment are urgently required – and are in sight, with recent advances.

I am extremely grateful to PSPA for supporting my research over the next three years. My research will focus on a chemical called noradrenaline. It is the brain’s natural form of adrenaline, our “fight or flight” hormone. Noradrenaline is necessary for many aspects of thinking and behaviour including motivation, attention, decision-making, multi-tasking, and sleep amongst other things. It is produced in a small area in the base of the brain called the locus coeruleus. This bit of the brain is badly damaged by PSP.

The PSP junk protein we call “Tau” builds up early on in the locus coeruleus. By the end of the illness, as much as 90% of this critical brain area has been lost. The damage is quite severe even at the time of first symptoms. We think this damage to noradrenaline production in the brain causes the behavioural and personality changes that families often notice. Apathy, for example, is strongly linked to the loss of noradrenaline. Apathy and impulsivity are bothersome symptoms for people living with the conditions, and their families. They can cause conflict and stress, and are associated with poorer outcomes. So treatment could help in many ways.

A person living with PSP may be less aware of these changes, but they are still important. For example, they affect care needs, and predict how fast or slow the illness moves. By boosting noradrenaline, we might improve cognition and wellbeing in people with PSP. This is the aim of the Noradrenaline Treatment of Apathy and Impulsivity in participants with PSP syndromes (NORAPS) trial, that is currently running at several sites across the UK.

One of the challenges for this research is that people vary so much from each other. This has an impact on whether someone is likely to respond to a noradrenaline type treatment. Part of my research is to understand this variation, and get ways to predict who will respond to medication.

To do this, we need to measure how much noradrenaline capacity remains in people living with PSP. The noradrenaline centre in the brain, called the locus coeruleus, is hard to measure. It is tiny, not much bigger than a couple of grains of rice. Using specialist MRI scans developed in Cambridge, we can now accurately measure it. We can also measure the chemical capacity of the brain, using another type of scanner called PET.

My research funded by PSPA has three aims. First of all, to use novel PET scanning and powerful ultrahigh-field MRI scanning to measure the locus coeruleus noradrenaline capacity in people with PSP. Second, I will relate individual differences in the noradrenaline capacity to people’s own symptoms. Third, I will look at how this variation from person to person affects the benefit of a noradrenaline-boosting drug called Atomoxetine, which is being used in the NORAPS clinical trial to treat apathy and impulsivity.

The NORAPS trial is up and running in the UK, with two sites open and at least three more due to go live in the summer. I am thrilled to be part of such an exciting study. We are hopeful the study will be successful, based on laboratory studies with people affected by PSP and Parkinson’s disease; and the beneficial effect of noradrenergic medicines in other diseases like Alzheimer’s disease and childhood attention deficit disorder. To know if it helps in PSP, each person gets two months on Atomoxetine and two months on a dummy pill. The participant and the research team are “blinded” to the order of treatment, so people are not biased in the reporting of effects of the medication. If it works, the medication could be a valuable addition to current treatment options.

FIND OUT MORE

If you would like to know more about NORAPS across the UK, or the PET and MRI brain scanning studies in Cambridge, please do get in touch. My email is rd693@medschl.cam.ac.uk



Image courtesy of LOROS Hospice

Image courtesy of LOROS Hospice

Image courtesy of LOROS Hospice

IMPROVING QUALITY OF LIFE WITH HOSPICE CARE

Local hospices can provide a wealth of support to people living with PSP & CBD to help improve your quality of life. To highlight the different types of services hospices can offer, we spoke to the nurses at LOROS Hospice about how they can support an individual as well as the whole family.

Hospice care aims to improve the quality of life and wellbeing of people who have a terminal illness or a long-term condition that cannot be cured such as PSP & CBD. It is free for patients, their carers and family members.

Hospice care can be provided at any stage of a person's condition, not just at the end of their lives. It can include symptom management, and social, practical, emotional and spiritual support. It helps people live as fully and as well as they can to the end of their lives, however long that may be.

This type of care is also known as palliative care, and can also be provided in other places, such as in a hospital, at home, or in a community setting.

IN-PATIENT SUPPORT

Depending on the available facilities, some hospices offer inpatient support. This is free nursing and medical care which is offered for both symptom management and/or end of life care.

You may be able to stay a few days or weeks, whilst you need specialist care and then return home again. Some people choose to stay in a hospice for the last few days or week of their life.

HOSPICE AT HOME

Some hospices may offer support in your own home – this is called hospice at home. Availability of such services will depend on individual needs.

DAY THERAPY

Many hospices, in addition to in-patient support, also offer Day Therapy services. The aim of Day Therapy is to reduce isolation and provide holistic care and support to people living with PSP & CBD or other illnesses.

You can be referred to hospice Day Therapy by your GP or any other health professional involved in your care. It may also be possible to refer yourself. The services range from seated exercise, arts and crafts, socialising, chaplaincy support, and managing fatigue.

Day Therapy tends to consist of eight to ten sessions, fortnightly. Often, transport to and from the activities can be provided also.

You can be referred back into Day Therapy, as your circumstances and needs change, or you can be referred on to benefit from other types of support.

COMPLEMENTARY THERAPY

Some hospices may also offer a wide range of complementary therapies to help reduce stress, ease aches and pains, improve sleep and relieve anxiety. Examples of treatments which might be available

for people living with PSP & CBD as well as their carers and family members include reiki, massage, aromatherapy, relaxation, hypnotherapy, Indian head massage and reflexology.

COUNSELLING SUPPORT

Confidential counselling support is also a service hospice will offer. Being diagnosed with a complex condition like PSP & CBD can leave you with lots of questions and different feelings.

A counselling service at a hospice, provides both people living with the condition, and their family members an opportunity to talk through their experience with trained counsellors who enable people to make more sense of their feelings.

BEFRIENDING SERVICES

Many hospices will offer a befriending service to help reduce isolation and improve wellbeing, for the person affected as well as their carer.

In addition to providing emotional support and friendship, sometimes a befriending service can help a carer get out and about for a few hours too.

Befriending services can be offered by telephone, or alternatively they may be in person, with the volunteer coming and visiting you in your home. Home visits can be handy, as it can mean carers have an hour or two to pop out, whilst the befriender keeps the person living with PSP or CBD company.

Please note, services provided by hospices may vary in each area.

GET SUPPORT

If you are unsure if there is a hospice close to you, speak to your Parkinson's nurse or GP who will be able to advise you about your local services. Alternatively, you can search for hospices close to you at www.hospiceuk.org

Unfortunately, not every area will have a local hospice. If you do not have a hospice in your area, your GP will be able to advise about the palliative and support services your community can provide instead.

You can also get support from the PSPA Helpline, Monday to Friday, 9am to 9pm on **0300 0110 122** or by emailing helpline@pspassociation.org.uk

FIND OUT MORE

Read more about how hospice staff can help improve the quality of your life, in our latest 'Day in the life' feature on page 14.



DRIVING AWARENESS FROM JOHN O'GROATS TO LANDS END

This April, Rob Hutchings climbed aboard his vintage Land Rover to drive from John O'Groats to Lands End to raise awareness of PSP which his mum lived with until recently. Here Rob shares the inspiration behind his epic trip.

"Whilst I completed my A Levels and went to Uni, mum decided to go back to school herself, completing her A Levels at the same time and then following onto University herself reading History and then gaining her teaching qualifications to enable her to follow her dream of becoming a primary school teacher. It was the perfect role for her since she is so bubbly and chatty.

She had just started to wind down to retirement, still keeping her hand in doing supply teaching and running Victorian Day classes when her PSP symptoms began. She was in her mid-sixties at the time.

The initial symptoms included repeating conversations and saying the odd strange thing followed by starting to become withdrawn, less chatty and not her normal self. Alongside this she started to fall backwards without any reason causing herself injuries and then lost coordination further so we had to advise her to stop driving.

My dad was back and forth to the GP with mum, trying to find out what was wrong. Like many people, mum initially was diagnosed with Parkinson's. The neurologist started new investigations when it was clear the Parkinson's medications weren't having any effect. That is when PSP was diagnosed.

At this time there was little information provided about what to expect or how it would impact mum's (and dad's) lives. We only found out about PSPA by chance in the later stages of my mum's illness in a conversation my Dad had with a friend. Two years ago, my mum's condition deteriorated to the point that as a family we decided it was safer for her to move into a care home to make sure her changing needs were met. The care home were fantastic and although mum would have preferred to stay at home she seemed fairly happy there and they were able to provide the constant care she required.

As the disease progressed, particularly when my mum lost her ability to communicate and the Covid measure's were in full swing, the situation was exceptionally upsetting for all my family.

By the time the restrictions lifted, my vintage Land Rover was nearing completion of its nut and bolt restoration, much to the disappointment of my wife and daughter. So on New Years Day 23, feeling quite down at the realisation of my Mums disease nearing an end, the idea of the John O'Groats to Land End drive came to me in a desire to do something positive to help and raise awareness.

I'm part of a big Land Rover community online and the business I work for is very supportive of charitable giving therefore as I advertised my challenge I quickly gained some exceptional support and offers of help. A classic Land Rover magazine covered the challenge, I gained sponsorship from local businesses and my work place and members of the community offered to join me for different aspects of the drive.

It was really exciting to see an idea grow and become reality and very humbling to see the levels of donations being made.

The final part of the restoration of 'Lenny' my vintage Land Rover, was to have it branded with PSPA logos, details of how people can volunteer and where they could find more information about PSP and the charity. Myself and my family (my son joined me on the whole drive in a support vehicle, and my daughter and wife joined me around half way through the challenge) all had branded jackets to wear too.

Unfortunately, my mum lost her battle with PSP just a few weeks before the challenge began, so she didn't get to see what I was doing for her however my dad, brother, sister and her friends joined me in a stage through Chatsworth which we completed in my mum's memory which was emotional for us all.

I was excited but also a little daunted when the start of the challenge came around on 6 April realising that my plans had become reality. I shouldn't have worried, 'Lenny' didn't miss a beat and the experience has been fantastic despite the 1,000 miles plus travelled at a maximum of 55mph in sun, wind and gale force wind and rain.

Now the challenge is complete I am very proud of what we have achieved and hope being able to lift the profile of PSP via the challenge and the funds raised will assist other people diagnosed and their families before the disease progresses."

**ROB RAISED AN AMAZING
£15,000 FOR PSPA WITH HIS
CHALLENGE AS WELL AS
GAINING MEDIA COVERAGE,
TO HELP WITH HIS AWARENESS
RAISING. THANK YOU SO MUCH
ROB AND HIS SUPPORTERS!**



SUPPORTING PEOPLE IN NORWICH

Linda Iaccarino and Linda Moore have been coordinating the Norwich Support Group for 11 years. Here they share how they set the group up and what support it offers to people living in and around Norwich.

Linda I said: "My husband was diagnosed with CBD in 2009. At the time, PSPA was running quarterly support groups regionally and although I was happy to travel I felt more was needed locally. PSPA put me in touch with Linda M, who was experiencing something similar."

Linda M added: "My aunt was diagnosed with PSP in 2005. I had been talking to PSPA, saying I would be happy to help run a group but we were unable to find a suitable venue and that is where Linda came in."

Linda I: "At the time, I was running a restaurant called 'The Old Mill' with my husband. The restaurant had a side room which was big enough to welcome around 26 people, so the ideal space really. I joined forces with Linda and we launched our first meeting in March 2012, with 15 attendees coming to visit and support each other."

Linda M: "Attendance at the group has been pretty consistent ever since. We still attract between 15 and 26 attendees. This is a mixture of people living with PSP & CBD, family members, and past carers, who like us, are passionate about supporting people with the conditions."

Linda I: "The pandemic didn't detract from attendance. With PSPA's support, we moved our meetings onto Zoom so we could stay in touch regularly. But the group were very keen to meet in-person again, so as soon as we safely could meet face-to-face again, we did."

Linda M: "The group meets every five to six weeks. The meetings do focus on connecting with each other. In the first half of the meeting, we always have introductions, so new people can get to know the members. It is also an opportunity for them to voice how symptoms are affecting them and any support they need. We then have a different discussion topic each time, this generally comes from the group. For example, recently a few people have been asking about brain donation, so we collected some literature and discussed that at our last meeting."

Linda I: "We try and keep the meetings as informal as possible. We are a lively bunch so there is plenty of time for humour, as well as tea and cake."

Linda M: "We are also quite sociable, so we organise social outings and fundraisers separately to the group meetings, so the support aspect is always there."

Linda I: "We've hosted a range of social events, these can be anything from a meal out, to a trip to the beach or a boat ride along the broads. Our next social this summer is a Fair Haven Trust Walk. An entrance fee is applicable at this social but it is a very nice and

accessible walk. In general, we either try and get group discounts or keep things as cheap as possible as we know people might not be able to get out and about much."

Linda M: "In addition, we've run fundraisers such as quizzes, summer fairs, crafts and cake baking. We all pitch in to help. Our next fundraiser is on 15 April. This is a craft fair and raffle. We always offer out options to the group and then they choose what it is they would like to do – for example for our next meeting we have offered to run a quiz or have a bingo session. The group chose bingo, so that is what we will do."

Linda I: "We do attract group members from 20 miles or more away because we've built a great community. Recently we asked for some feedback about what our members enjoy about the group most, and it was exactly that – the community feel. Knowing you're not alone and that you can come along, no questions asked, as people just understand what it is you're experiencing."

Linda M: "I am really proud of the group we have built between us, the support we are able to provide. By volunteering just a few hours of my time each month, it is such a small yet rewarding gift to help people living with PSP & CBD. And hopefully, it helps make their journey a little easier, having us here."

Linda I: "I agree. Not everyone has a large support network in their family, so it is nice to be able to help. We know things aren't easy, getting the diagnosis and then the support you need at different points during the illness, so giving up our time is just a small thing we can do to help things along."



JOIN THE NORWICH SUPPORT GROUP

The Norwich Support Group meet at the Stoke Holy Cross Church Hall, Norwich, NR14 8NX.

THEIR NEXT MEETINGS ARE:

24 June at 11am

29 July at 11am

2 September at 11am

If you would like to receive invites to the Norwich Support Group meetings, please email volunteering@pspassociation.org.uk



AN UPDATE ON THE PROSPECT STUDY

The PROSPECT study is a UK-wide observational study which aims to improve our understanding of Parkinson Plus syndromes such as PSP & CBD. The study has now been running for eight years and we have recruited over 1,350 participants, making PROSPECT one of the largest studies of atypical parkinsonism in the world.



The study is led at UCL with a network of specialist neurologists and researchers across 29 different UK sites. Thanks to the funding and support from PSPA, and from patients and families with PSP & CBD, the study continues to grow.

WHAT DOES THE STUDY INVOLVE?

We study PROSPECT participants with neurological assessment by a doctor, self-completed questionnaires, cognitive assessments, blood collection and optionally a lumbar puncture, skin biopsy and/or an MRI scan. Over the years, this has helped to build a rich anonymised dataset

which allows us to look at patterns in symptoms in atypical parkinsonism, genetic markers, protein and imaging biomarkers. We ask people to repeat these tests after one year, and then to complete some questionnaires on a yearly basis.

Should participants wish to participate remotely, as opposed to visiting their local study site, they can donate blood at their local GP and complete some questionnaires from their own home. The option for participants to take part remotely was crucial to keeping the study going throughout the COVID-19 pandemic from 2020 onwards.

WHAT HAVE WE FOUND SO FAR?

- PSP affects people in different ways and some forms of PSP are similar in the early stages to Parkinson's (PSP-parkinsonism)
- We estimate that PSP is twice as common as was previously thought and may affect around 10,000 people in the UK
- Variation in genetic factors (TRIM11 and LRRK2) may determine the different PSP clinical presentations and the progression of PSP; we hope that this will be used to define new treatments
- Early onset PSP is defined by motor symptom onset from 55 years old, and we have shown that early onset PSP is often clinically similar to Parkinson's and that genetic analysis (genetic risk score) can help differentiate between the two disorders
- There is ancestral variation in the frequency of variants/mutations of genes known to be associated with PSP, such as MAPT, H1, TRIM11 and LRRK2 in PSP, as shown by some preliminary analysis of PSP in patients from different ancestry backgrounds, for example South Asian and African-Caribbean
- The accuracy of diagnosis in atypical parkinsonism is high in PSP and less high in CBD, as shown by analysis of participants who have died and had a post-mortem examination. Diagnostic accuracy may be improved by paying close analysis of key factors in sub-domains of clinical rating scales
- We have identified some rare families in which multiple people have been affected by PSP who carry rare variation in genes such as the Tau gene and this provides major insights into the biology of PSP & CBD.

FUTURE RESEARCH

We are currently carrying out a comprehensive analysis of around 400 cases of CBD from multiple cohorts, including PROSPECT. We will look at age of onset, frequency of specific symptoms, biomarkers and MRI imaging. This will help us learn more about the disease, its early phases and how it progresses. Ultimately, this will help with the development of treatments and recruitment of early-stage patients with biomarker-confirmed CBD to drug trials.

We are also carrying out analysis of all PROSPECT-M participants who have passed away and who donated their brain tissue to a UK Brain Bank. We are comparing the clinical diagnosis they received in life to their diagnosis deciphered at post-mortem (the gold-standard diagnosis), to find out how often we correctly diagnose atypical parkinsonism.

We are also looking to identify clinical features which could help improve accurate early diagnosis in the future.

We are in the process of testing DNA samples from PROSPECT-M samples for pathological expansions in a gene called C9orf72. There has been a lot of research interest in this gene in the last decade since it was discovered as one of the most common causes of familial frontotemporal dementia and amyotrophic lateral sclerosis (motor neuron disease). However, there is growing evidence that it may be involved in other neurological diseases. If we can show that it occurs in patients with atypical parkinsonism, then future treatments developed for this genetic variation could be adapted for these patients.

Thanks to Professor Huw Morris and Riona Fumi for the update.

HOW CAN I GET INVOLVED?

If you would like to get involved in the PROSPECT-M study, please email the coordinating team at prospect@ucl.ac.uk or call us on **07825 076 394**. We welcome anybody living with PSP or CBD to take part.



A TRIBUTE TO DIANE FROST

Diane Frost experienced symptoms from around 2015, but unfortunately wasn't diagnosed with PSP until early 2022. Here, Diane's daughter Kerri shares a tribute to her mum and how she inspired an 80-mile awareness walk.

"Mum was born on 23 March 1943, the only daughter of Harry and Nora Winifred (Joan) Lightfoot. The family lived in Wilford and mum attended school at West Bridgford Grammar. She was a keen tennis player and had a love for horse riding.

After leaving school and following further education, at age 18 mum joined the East Midlands Electricity Board (EMEB). Mum was the fastest typist ever known, that's probably why she went on to be secretary to the Managing Director of Shell Oil during the late 70s. Shopping lists in the most incredible shorthand would baffle our family – it was like some sort of secret code...

Mum met my dad (Brian) in 1962 and after a couple of years dating, they married at Wilford Church on 3 October 1964. They set up their first home and eventually after some persuasion mum joined my dad in his love for golf and they both became long standing members of Stanton on the Wolds Golf Club.

Mum was so caring and loving and her commitment to my schooling and hobbies was clear. She always attended my dance shows and wouldn't think twice about having to sew by hand leotard sequins one-by-one.

I was just as committed to my parents as they were to me. I remember being their caddy for many years strolling around the course on a Sunday evening, enjoying family time. Their attempts to upskill me however failed and lessons with the local golf professional didn't help me to get the ball off the ground in the same way as mum and dad!

Mum relished her involvement with the social scene at the golf club – particularly the ladies Christmas shows (where she helped to organise and took part too). For a lady of utmost morals and values she was still always able to let her hair down and knew when to have fun.

Mum loved getting away with family and friends – big group family holidays to Tenby, Budleigh Salterton, Holimarine, had such memories. The purchase of a caravan in Sutton on Sea meant that the Lincolnshire coast became a second home and such an important and great part of life.

There were also lots of group holidays abroad, including Portinaxt in Ibiza, and Paleokastritsa in Corfu. And mum even managed to holiday alone to see her friend Laurie and family in Canada.

In 1979, mum joined dad in a business partnership taking over JW Alvey and Son, the motor engineering company my dad had worked at since he was a young lad. Mum and dad turned this into a thriving business with a fantastic team behind them and mum continued to run the business on her own when my dad passed away in 1999.

In 2015, mum experienced her first fall and an arm break meant that she was out of action for some time. During this time, mum's behaviours changed and socially she became a little withdrawn. There followed a good few years of changes in habits, more falls, eyesight changes, and a long period of time being alone during Covid that didn't help mum's situation, which was unknown to us at this time.

After some family discussions it was decided that mum's home White Walls would be renovated to allow my family to move in and live with her - to keep her company and ensure her safety.

In January 2022, we all moved into the house together and it was here that changes were a lot more obvious. Despite regular visits to the GP, her symptoms were put down to 'getting older' and thinking it was Parkinson's I pushed for more investigations. In February I persuaded mum to visit a neurologist who was the person who made the diagnosis of PSP.

In the months that followed, mum's health deteriorated so quickly, and she died peacefully, at home with us all around her in September. She was aged 79 years old.

Mum never deserted friends who needed her help. She would never forget someone's birthday and you could always guarantee her Christmas card would be the first to arrive in December!

In return and during her last weeks – friends came and spent time, looked at photos, made her laugh, did her hair, gave her beauty treatments, or just sat and sang with her.

As a family, we used mum's last weeks. We spent time in the garden (mum helped me create her dedicated area in the garden which is now her memory garden), we visited Dunelm (a lot!), Ashleigh (granddaughter) did her hair and nails, we enjoyed ice cream by the river and watched Rubie (granddaughter) play football. Even though it was a struggle and mum's horrendous symptoms often got in the way - we conquered it all. After mum's diagnosis, I spent much of my time explaining what PSP was to different healthcare professionals involved in her care. It was frustrating no one had heard of the condition.

As a result, I decided to challenge myself, in memory of my mum, to help raise awareness of PSP & CBD, and funds for vital research to improve the lives of people affected and to help people recognise those early signs.

I decided to take on an 80-mile walk for mum, to help mark what would have been her 80th birthday. It is also 80-miles from my house to my mum's favourite place, Sutton on Sea. I was going to physically walk from my house to Sutton on Sea, but logistically I was finding it difficult. So, in the end, I walked the mileage on a treadmill.

I started my walk on 2 March, supported by friend and Biomechanics Coach Rachel Frances Thomson, and fitness coach Hannah Warren, carrying my mum's ashes in a rucksack on my back. And I managed to walk the full distance by 22 March.

On 23 March, which was mum's 80th birthday, me and my family travelled to Sutton on Sea. On the beach, we held a lovely memorial for mum and scattered her ashes.

In total, I raised £1,500 for PSPA via sponsorship for my challenge.

For me the challenge was great, although I got loads of blisters, knowing I had mum with me and that I was taking her to her final resting place really helped me to focus."



EDUCATING TRAINEE GPs IN THE NORTH WEST



Val Wallace has been a valued PSPA volunteer for many years after establishing the Macclesfield Support Group in 2018. After the pandemic the group found a new venue which allowed them to extend their reach and are now known as Stockport and Cheshire Support Group. As well as supporting people through the group Val is passionate about educating healthcare professionals and has now also become a PSPA Education Volunteer.

"I signed up to become a PSPA Education volunteer during 2020, completing the training during the lockdown.

Having chatted with the families attending the Support Group meetings, they were clearly concerned about the lack of knowledge and understanding of PSP & CBD amongst the health professionals. Just as I had felt when caring for my husband, Neil.

Through talking to the GPs and the Postgraduate GP trainee at my own surgery about PSP & CBD, I asked about how I could do more to help with training people about the conditions. I was given a telephone number for Health Education England (HEE) North West Teams office. The business manager was very keen to help and emailed me the contact details for each training group in the Greater Manchester and Cheshire area. I subsequently emailed each group and received four replies.

So far, I have delivered two PSP & CBD education sessions to trainee GPs in the area.

Although sessions can be offered via Zoom I do prefer to deliver them face to face because I feel that personal contact, discussion and Q&A creates a better understanding and knowledge of the topic.

As part of my presentation, I always give a personal introduction before moving onto an explanation of symptoms and causes of PSP & CBD and routes to diagnosis. I then make attendees aware of the support PSPA offers, from publications to research. I also talk about other issues which may affect a family during their PSP & CBD journey, such as practical, financial and legal support and planning for the future. To finish up I try and end with a personal perspective of PSP

or CBD, whether that is my own experience of my husband living with PSP or including a visit from a local family affected by one of the conditions.

The content of the education session may depend on the time I am allocated. For example, I was only given 30 minutes in a session for trainee GPs in Tameside, however the session with trainees in Mid-Cheshire was one and a half hours, so I was able to cover the whole spectrum of topics.

The education sessions were both received well, with the trainees mostly asking questions around what symptoms appeared first. Of course, this may vary from person to person, but it is a great way of being able to demonstrate that no two people living with the conditions will be the same.

Some of the trainees mentioned targeting medical schools to get awareness out among healthcare professionals early in their career. My plan is to talk to PSPA about this so they can add it to their programme of activity.

I plan to book in another education session booked with Mid-Cheshire trainees later this year, which I am really looking forward to."

"AS PART OF MY PRESENTATION, I ALWAYS GIVE A PERSONAL INTRODUCTION BEFORE MOVING ONTO AN EXPLANATION OF SYMPTOMS AND CAUSES OF PSP & CBD AND ROUTES TO DIAGNOSIS."

GET READY

FOR PSP & CBD AWARENESS WEEK

**PSP & CBD
AWARENESS
WEEK**

17 to 23 June
2023

Stock up on all your PSPA essential awareness tools, ready to make a big impact this PSP & CBD Awareness Week

All proceeds will help PSPA work towards improving diagnosis for the 10,000 people living with PSP & CBD.

**LOOK THE PART
THIS AWARENESS
WEEK**

**AMAZING
AWARENESS
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ORDER ONLINE
All items can be purchased from the PSPA website shop
www.pspassociation.org.uk/fundraising/shop/

EYE RED FLAGS OF PROGRESSIVE SUPRANUCLEAR PALSY (PSP)

Progressive Supranuclear Palsy (PSP) is a severe neurological condition which changes many ocular and oculomotor functions. These easy-to-check eye red flags could speed up detection and treatment.

On average it takes three years to get a diagnosis of PSP. To improve diagnosis and access to relevant care and support, we have developed a list of red flags for opticians and ophthalmologists that may raise clinical suspicion of PSP.

If you see these red flag signs, you may want to suggest a visit to the GP. The GP can look into possible causes, and consider a specialist referral.

1. EYE MOVEMENTS

- **Limited up or down range of eye movements**
- **Trouble voluntarily shifting gaze up or down**
- **Slow or curved vertical saccades**

2. EYE LIDS

- **Difficulty in opening the eyes.**
- **Tendency to not blink ('stare' look)**

3. FIXATION

- **Square wave jerks (involuntary, horizontal, saccadic intrusions that interrupt fixation).**

To learn more, you can read the article on the link, left which includes a film to illustrate what the eye red flags look like.



PSPA is the UK's leading centre of knowledge, experiences and support for people living with PSP or CBD, their families and health and social care professionals.

PSPA Helpline and Information Service
Telephone: 0300 0110 122
Email: helpline@pspassociation.org.uk