

EDITION 3 / 2023

# PSPA MATTERS

**CONNECTING  
PEOPLE AT OUR  
2023 FAMILY AND  
FRIENDS DAY**

**TURN TO PAGE 22**



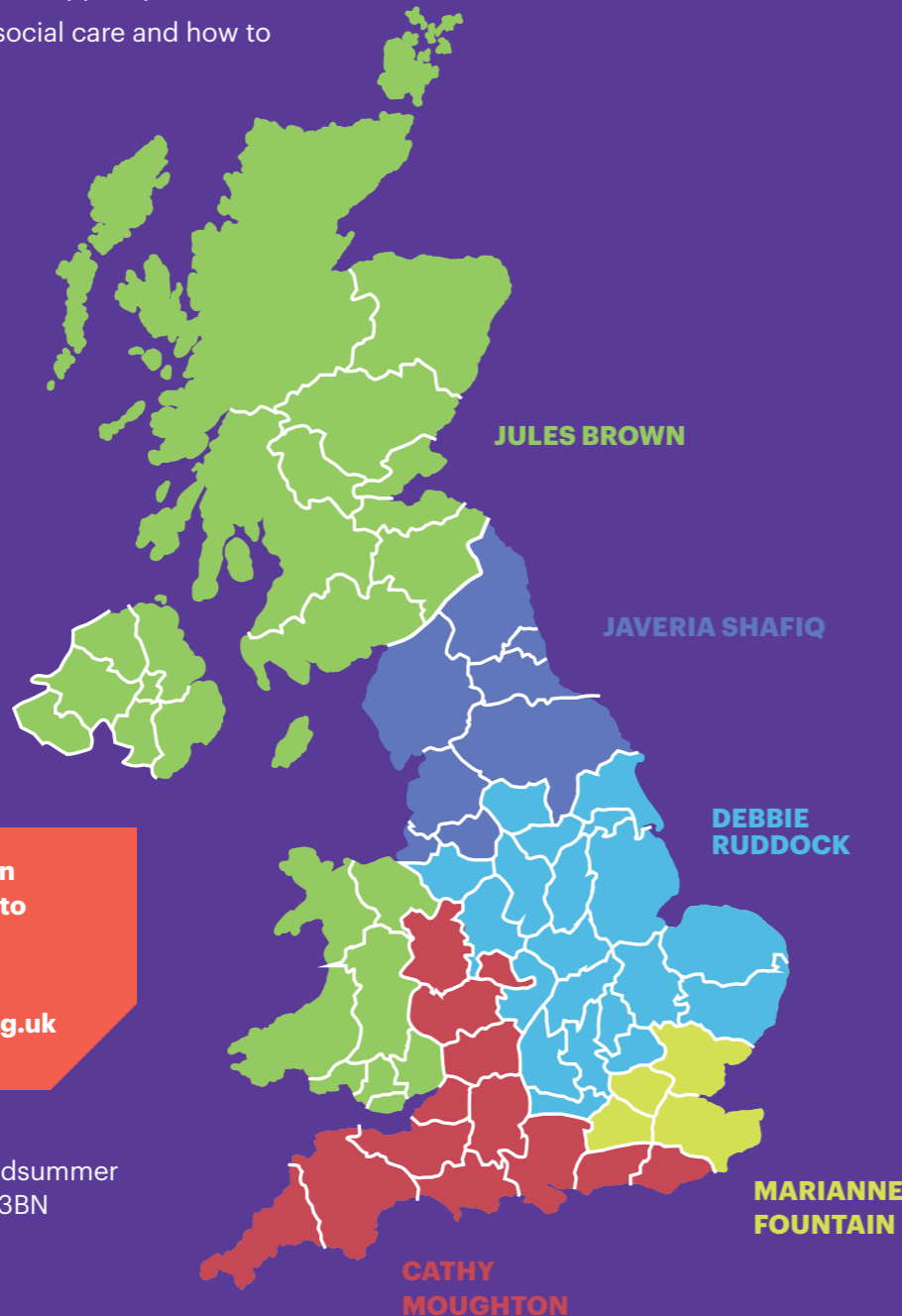
**IN THIS ISSUE**

- 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](mailto:helpline@pspassociation.org.uk)**

**PSPA**  
Margaret Powell House, 415a Midsummer Boulevard, Milton Keynes, MK9 3BN

Registered charity number England and Wales 1037087 and Scotland SCO41199.

# WELCOME

It was a privilege to attend my first Family and Friends Day in July. Getting people together after the pandemic is extra special, and I learnt a lot from chatting to families and hearing from the speakers. Coupled with my visit to the Kenilworth group in May and cheering on our runners in the London Marathon in April, it's been a good time to connect with the wider PSPA family. Conversations with people affected by PSP & CBD, volunteers and our supporters help to shape what we do and provide the impetus and motivation to do our best.

It seems like only a couple of weeks ago that I was cheering on 40 plus PSPA runners through the streets of London on their way to completing the marathon. The 2024 event planning is under way and our Challenge Events Manager, has been busy filling the places we have for the London Marathon in 2024. Amazingly 90 of you have signed up! There are always places on the waiting list (injuries and dropouts are inevitable) and non-runners can join our cheerleaders on the sidelines. Opportunities in other events and activities are available, please get in touch if you feel motivated to get active and help raise awareness and funds for our work.

The autumn will see the return of our International Research Symposium in partnership with our American counterparts CurePSP. The event will showcase research conducted by distinguished neuroscientists and is open to all researchers who are interested in preclinical and clinical neuroscience. Events such as this are important to connect researchers across the world to advance our understanding of PSP & CBD and to provide a gateway to treatments in the future.

This is also our first edition of PSPA Matters printed on recycled paper. This is one of several initiatives we have taken at PSPA to improve our contribution to environmental sustainability. If you receive the magazine by post, you may also have noticed that it now arrives in an envelope rather than poly-wrapped as we are trying to reduce our use of plastic.

**Rebecca Packwood**  
PSPA CEO



# CONTENTS

- 04** PSPA NEWS
- 06** AWARENESS WEEK UPDATE
- 08** ANDREW CONEY WALK FOR LINDSAY
- 10** CARE SUPPORT AT HOME
- 12** PSPA FUNDED RESEARCH
- 14** BAUBLE APPEAL
- 16** A DAY IN THE LIFE DR O'CONNELL
- 18** NEURODEGENERATION
- 20** LEAVING A GIFT IN MY WILL
- 22** FAMILY AND FRIENDS DAY
- 24** SUPPORT FOR CARERS
- 25** CORPORATE SUPPORTERS
- 26** HELPLINE CARE NAVIGATOR
- 27** STRATEGY UPDATE
- 28** EXPRESS GRANT ANNOUNCEMENT
- 30** LINK VOLUNTEER SERVICE
- 32** SMALL RESEARCH GRANTS
- 34** A TRIBUTE TO BOB STRAKER-COOK
- 36** PSPA CHRISTMAS SHOP

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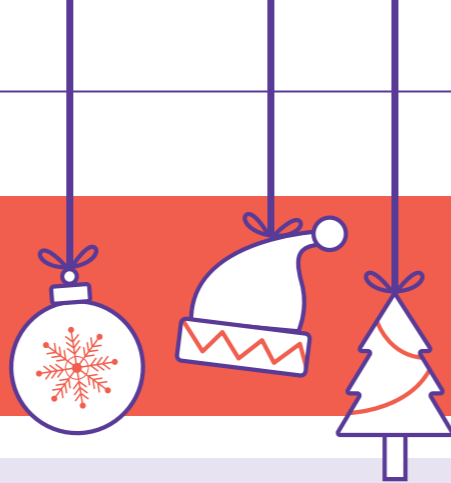
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# PSPA NEWS

## PSPA'S CHRISTMAS RANGE NOW AVAILABLE

You can stock up on all your Christmas essentials and stocking fillers in the PSPA website shop.

We have numerous fun and traditional Christmas card designs to choose from, each coming in a pack of 10 for just £5.

In addition, we have three colours now available for our popular 'hummingbird' ornament, a beautiful

addition to any Christmas tree. You can add items such as pens, notelets and Teddy Bears as thoughtful stocking fillers which also help to fund our essential work.

**Turn to the back page to view some of our Christmas range or head to [www.pspassociation.org.uk/fundraising/shop](http://www.pspassociation.org.uk/fundraising/shop)**

## RUN LONDON LANDMARKS HALF MARATHON



Join us once again, for London's MOST FUN Half Marathon.

The 2024 London Landmarks Half Marathon will take place Sunday 7 April. This is a closed road, central London event, and the only half marathon to take in the city's cultural landmarks, heritage, and quirky hidden secrets. Runners will get to explore the capital on a route like no other!

Pictured is our supporter Lily Bliss who ran the 2023 race and had this to say "It was such a good day! I will definitely be doing more events in the future and I can't believe the amount of support donated!"

The London Landmarks Half Marathon is not your average half marathon – you'll be treated to several themed mile markers and cheer points, music along with a party atmosphere will fill the streets, delight your senses, and make those 13.1 miles feel fun! We hear such positive feedback about this event, and it somehow manages to get better and better each year!

**We are currently recruiting for our final five places on the team. If you'd like to join us, please send an email to [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk)**

**If you have your own place in this event and would like to run as part of #TeamPSPA please let us know. All our runners receive a PSPA running top.**

## NEURO 2023 RESEARCH SYMPOSIUM

The Neuro 2023 Research Symposium, jointly organised by PSPA and CurePSP is fast approaching on 19 to 20 October.

The event, which is taking place at the Pan Pacific Hotel, London, will bring together experts from all over the world to share the latest scientific breakthroughs.

The symposium will showcase PSP & CBD research conducted by distinguished neuroscientists and

is open to all researchers who are interested in preclinical and clinical neuroscience. This hybrid symposium will offer both online and in-person learning opportunities!

**Learn more about the event at: [www.pspassociation.org.uk/research/information-for-researchers/neuro-2023/](http://www.pspassociation.org.uk/research/information-for-researchers/neuro-2023/)**



The PSP and CBD International Research Symposium

## BECOME A MEDIA CASE STUDY

As we ramp up our awareness raising efforts this year, we are seeing requests for media case studies increase.

A media case study is someone who is willing to share their experience of PSP or CBD with media outlets such as newspapers, radio stations and magazines.

Topics for stories vary, however largely the case study request we are being approached for include:

- People being diagnosed with PSP or CBD at working age
- Caring for a family member whilst still working or supporting others in the community
- Volunteers who support others in memory of a loved one
- Fundraisers who do amazing things in honour of a family member
- Supporters who campaign and raise awareness in their communities and beyond

We would love to say yes to more of these media requests. If you would be interested in signing up to become a media case study to help us create a greater impact with our awareness raising, please email [communications@pspassociation.org.uk](mailto:communications@pspassociation.org.uk)



## THANKING PROFESSOR JAMES ROWE

We would like to extend a BIG thank you to Professor James Rowe, who stepped down from his position as PSPA Trustee in July 2023.

Professor Rowe joined the Board of Trustees in 2018 and has supported the charity through many challenges and achievements, using his experience as a leading neurology consultant and researcher, and his passion for PSP & CBD.

Professor Rowe will continue to work closely with PSPA, remaining an active member of the PSPA Research Committee.

**Thank you for your support and commitment to PSPA.**



## PRISM GLASSES WANTED!

We are currently running low on both upward and downward prism glasses.

If you have any at home, which are not being used, please consider returning them to PSPA. You can return any unwanted prism glasses by popping them into the post to **PSPA FREEPOST**.

Thank you for your support.

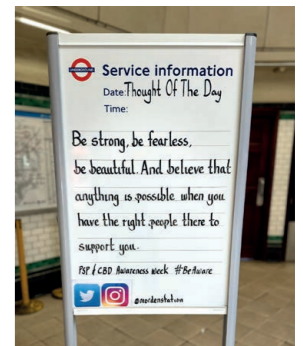






## RAISING AWARENESS ACROSS THE UK

Thank you to everyone who helped to support our #BeAware campaign, which officially launched during PSP & CBD Awareness Week, 17 to 23 June.



It was great to see and hear about people supporting the campaign by hosting a Walk of Hope event, sharing an Eye Red Flag poster with opticians, or inviting an optician to a Regional Support Group Meeting.

We also loved the many inspiring ways people have chosen to raise awareness in their own way, such as hosting an awareness stand at a community event, sharing PSP & CBD Awareness newsletters across their company (thank you Paragon) or walking 100-miles (see Our Walk for Lindsay article on page 8-9).



### HERE IS A SUMMARY OF JUST SOME OF THE ACTIVITIES...

<p><b>969</b></p> <p><b>Eye Red Flags</b> have been shared with our supporters to distribute to opticians.</p> 	<p><b>8</b></p> <p><b>Walk of Hope events</b> took place raising more than <b>£14,000</b>.</p> 	<p><b>4</b></p> <p><b>PSP &amp; CBD Education sessions</b> were held virtually and in person.</p> 
<p><b>4</b></p> <p><b>Articles published</b> on websites or in local newspapers.</p> 	<p><b>2</b></p> <p><b>Awareness stands</b> were held in local communities.</p> 	<p><b>40</b></p> <p>PSPA awareness items purchased, raising <b>£223</b>.</p> 

### GET INVOLVED

PSP & CBD Awareness Week helped to create a great impact across the summer. And we want to keep the momentum going! If you would still like to get involved to help more people #BeAware of PSP & CBD, visit our website to learn how: [www.pspassociation.org.uk/information-and-support/awareness-tools/](http://www.pspassociation.org.uk/information-and-support/awareness-tools/)





**THE JUSTGIVING PAGE WE SET UP FOR THE WALK RAISING A STAGGERING TOTAL JUST SHY OF £52,000**

## OUR WALK FOR LINDSAY

Lindsay Coney was diagnosed with PSP in November 2021. After ensuring Lindsay’s health needs were met, her husband Andrew, set about raising awareness of the condition. Andrew talks to us about the 100 miles-walk he undertook in June for his wife.

“Lindsay is my wife of 35 years and the mother of our three sons. At the age of 60 years old, and after at least two and a half years of experiencing symptoms, Lindsay was diagnosed with PSP. Early symptoms included a loss of balance and cognitive skills; impaired speech and vision along with sensitivity to light and general depression.

Having established Lindsay’s diagnosis and prioritised Lindsay’s care, I wanted to devise a way to find something positive out of Lindsay’s situation. My answer was to plan a charity walk to firstly raise awareness of PSP and the work of PSPA, and secondly to raise funds for the latter.

After researching local walks that would be a challenge, I decided to walk the Two Roses Way. This is a recognised long distance walk of 100 miles which is circular and starts and finishes in Lindsay’s local village of Whalley, in the Ribble Valley in Lancashire. The walk takes a route from Whalley to Gisburn to Skipton to Malham to Slaidburn and Chipping and then back to Whalley through some of the most picturesque parts of Lancashire and Yorkshire and was devised to be walked in six days so that is what we did.

I obtained five sponsors for the walk to help raise funds but also crucially to give me access to networks of staff, clients and friends. I then devised a three-month social media campaign on Facebook, Instagram, TikTok and Twitter with dedicated “Walk for Lindsay” pages and posted multiple times a week. Content included posts about Lindsay, PSP, the walk, and our family and friends. This, along with local and other publicity including interviews on local radio and in the local printed media meant I could reach far beyond my own extensive network of family, friends and clients.

I found the use of social media to post frank and open videos and written blogs about Lindsay’s condition, the views of the family thereon, PSPA and PSP itself, and news of the preparation and undertaking of the walk produced a real connection between our family

and the outside world – in the words of a social media expert – “we created a brand and told a story which people really connected to personally”.

In telling a strong personal story about Lindsay, I raised awareness of PSP to literally thousands of people and nearly 600 of those people and organisations donated to the JustGiving page we set up for the walk raising a staggering total just shy of £52,000 (including Gift Aid) for PSPA.

With my careful planning, and by involving as many people as wanted to participate in the event, be they walkers, supporters, carers or others and also involving a good number of local businesses in addition to sponsors, helped ensure the success of the event.

On the last day of the walk, I was pleased to invite members of the PSPA team and fellow supporters of PSPA to join our walk. Rebecca Packwood and James Holden from PSPA, amongst others, walked the sixth day of the walk and indeed Lindsay joined the walkers in her wheelchair for the last three miles.

In reflecting on the “Walk for Lindsay campaign”, I am pleased our hard work and planning and the support of so many people has meant our activity also created the most wonderful shared experience for all those that took part and the most wonderful positive memories out of a very sad situation.

**We are all very proud of what we have achieved and once again would like to thank all involved”.**

Andrew Coney and his family would like to thank the sponsors of his challenge, who include:

- P Wilson & Company
- Gilbert Meher
- Litton
- NFU Mutual (Preston)
- Naphens LLP







## GETTING CARE SUPPORT AT HOME

There may come a time in your family's PSP or CBD journey, when care assistance may be needed. If you and your family wish for the care support to be provided at home, knowing where to start can feel overwhelming. To help, a PSPA supporter has shared their family's experience of sourcing self-funded carers to come and help at their home.

"After a lengthy stay in hospital due to a fall and needing a hip operation my dad needed assistance with his personal care and required at least four care calls a day.

We always wanted to look after dad at home, it was his wish and that of the family. We wanted to do whatever we could to keep him at home and make him as comfortable as possible. Dad was always quite independent but with PSP came many challenges - issues with eyesight, falls and with coordination and balance. Dad needed to start using a walking stick and this progressed to needing to use a walking frame, the need for personal care and then moving to using a wheelchair.

After dad's hip operation, he spent a long period of time in hospital. Before he could be discharged, we needed to have carers in place to assist with his personal care. Luckily our home already had been adapted with a downstairs bedroom and large ensuite wet room.

Initially carers were arranged through the local authority, and we were self-funding. The first carers we had were not a good match and being new to the

care journey we learnt a lot. Following this we had a private carer who was originally working with the agency. She was kind and supportive of the family's wish to help dad stay mobile. She would help him walk and assist with exercises set by a physio that the family had engaged. Through word of mouth we found a man who worked as a carer and who used to provide care for an hour in the afternoons. However, both carers needed to have lengthy periods of time off and so the challenge of finding good support was ever present.

When searching for carers, we looked online for agencies who covered our area and looked at Care Quality Commission (CQC) ratings, where they were available, and reviews on the websites. Some issues we experienced when looking for personal care, included that many agencies may not be able to fill your desired time slots or may have a minimum call out times of at least one hour. Costs of agencies are also high, and many want you to sign contracts on engagement which can be tricky especially if they are not a good match. It is hard to know how good the match will be until at least a few care calls have been completed.

Finding good carers is hard and we wanted dad to have carers who could work with him so that they knew his routine and his habits, and he would feel comfortable and secure with them. Only a few carers will have heard about PSP, and because the condition can be unpredictable and fluctuate with good days and some not so good, it can be hard for others including carers to understand why an individual may be okay with doing something one day and not the next day. Finding carers who have empathy is important more so than someone who just knows about the condition. It is important that a carer understands and is experienced in providing complex

care for someone. Likewise, it is helpful if they have worked with individuals with limited mobility, and have experience in caring for people who are unable to communicate so easily.

Care agencies may want to come and do an assessment of a future client, and there should be no charge for this. However, the information they take may not filter to the carers that they allocate the job to. They may also not fully understand some of the intricacies in providing care from an assessment. Often a care plan may be written and put into a client folder. It is worth reviewing the notes as we often found some errors".



### Some tips we found that helped us:

- Ask if the care coordinator or assessor can accompany the carers to the first call so that nothing gets lost in translation. The care assessor can see exactly what is needed. This will help to identify if the carers selected can manage or need more training or assistance
- Ask if it is possible to trial the carers for a week before having to sign any contract as there can be lengthy cancellation clauses
- Check if they are flexible if care calls need to be cancelled e.g. for sudden hospital appointments etc. Some agencies can ask for up to 48 hours' notice
- Have plenty of time in a care call so the carers are not rushing. We did not want dad rushed in the morning and so suggested an hour-long call to get dad out of bed, showered and dressed, then ready for his breakfast
- Have the same carer covering most care calls. Often care agencies will suggest that they introduce other carers over time so that if a carer cannot make the call, another can cover
- Introducing new carers gradually. It is helpful to get a new agency to start covering a few care calls and once they are competent and have established a good rapport to get more calls covered
- Initially showing carers what is needed at each care call. When introducing a new carer we would share the care call a few times. The first time a new agency was engaged we would show the carer what needed to be done and how, then explain everything for that care call, and ideally their manager would be present. The next care call for that time we would suggest that the carer carry out the care call with the family member prompting

- and guiding as necessary, discussing at the end how things went. Ideally during the first few calls shadow the carers and give them a written list of steps
- Carers need to listen to family members and there needs to be a good rapport between both sides
- With PSP there are often issues with communication so we would encourage carers to speak slowly and to give dad a chance to respond and this may take longer than the carers may be used to so to be patient and wait for a response. We also suggested that it may be easier for dad to nod or to squeeze their hand to show he had understood
- We asked the carers to explain to dad during the care call what they were doing. Also by keeping to a routine of doing things in a certain order and following a way of doing things that dad was used to, they and dad would get the best outcome
- If care is being provided by two carers it is important that they work together well and while one may lead tasks the other care should be supporting them.

### HOW PSPA CAN HELP

If you have care support at home and the carers have not previously supported someone living with PSP or CBD, we can help.

We have a wide range of publications which can help guide the carers and our Education Volunteers also offer training sessions to carers. Email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk) or call **0300 0110 122** for more information.



# OVERVIEW OF PSPA FUNDED RESEARCH

Research has been one of the pillars of PSPA's strategy since the charity was founded by Michael Koe in 1994. The funding of research by PSPA has been essential for the advancement of understanding PSP & CBD and identifying targets for potential treatments and a cure.

Thanks to the generosity of voluntary donations, we have been able to invest in both large and small-scale projects over the last 29 years. Current investment is focused on prioritising research which reflects people's views and priorities; supporting new research ideas in a responsive manner; targeting research in areas of high priority; funding the rising stars in research to become the academics of the future leading the way in finding treatments, and improving diagnosis and care for people with PSP & CBD.

The largest investment PSPA has made was in the running of PROSPECT-M-UK, in which we invested more than £1.3 million since the inception of the project in 2015 (see **PSPA Matters edition 2-2023, page 34 for an update**). The study produced more than 20 scientific publications to explain the potential cause-effects of neurodegeneration, the potential for molecules in blood or spinal fluid or the brain (via imaging) to diagnose PSP & CBD and explain the progression of brain atrophy while the disease

progresses. One of the biggest achievements of the research team was to unite clinicians and researchers in UK in a single network to create research collaborations. Additionally, a registry of more than 700 people affected by PSP & CBD has been created which will be invaluable when studies on pharmacological treatments to alleviate symptoms or slowdown progression become available.

The other aspect of PSPA invested research has been funding the training of clinicians in research. Three trainee neurologists have benefitted from fellowships provided by PSPA and contributed to studies like PROSPECT-M-UK and to understanding the diagnostic process from symptom onset to end of life. Growing new talent and new expertise is part of PSPA efforts to create a legacy for the committed researchers linked to the charity who are currently trying to change the research landscape.

Small Research Grants were launched in the last year to support early phase enquiries or the progression of already running studies into PSP & CBD. Three researchers are currently being supported (see **PSPA Matters edition 1-2023, page 32**) investing up to £5,000 each for research procedure investigating diagnosis and management of the conditions. A new call for researchers to request small and medium size funding (up to £100k) closed at the end of August and middle of September 2023 respectively.

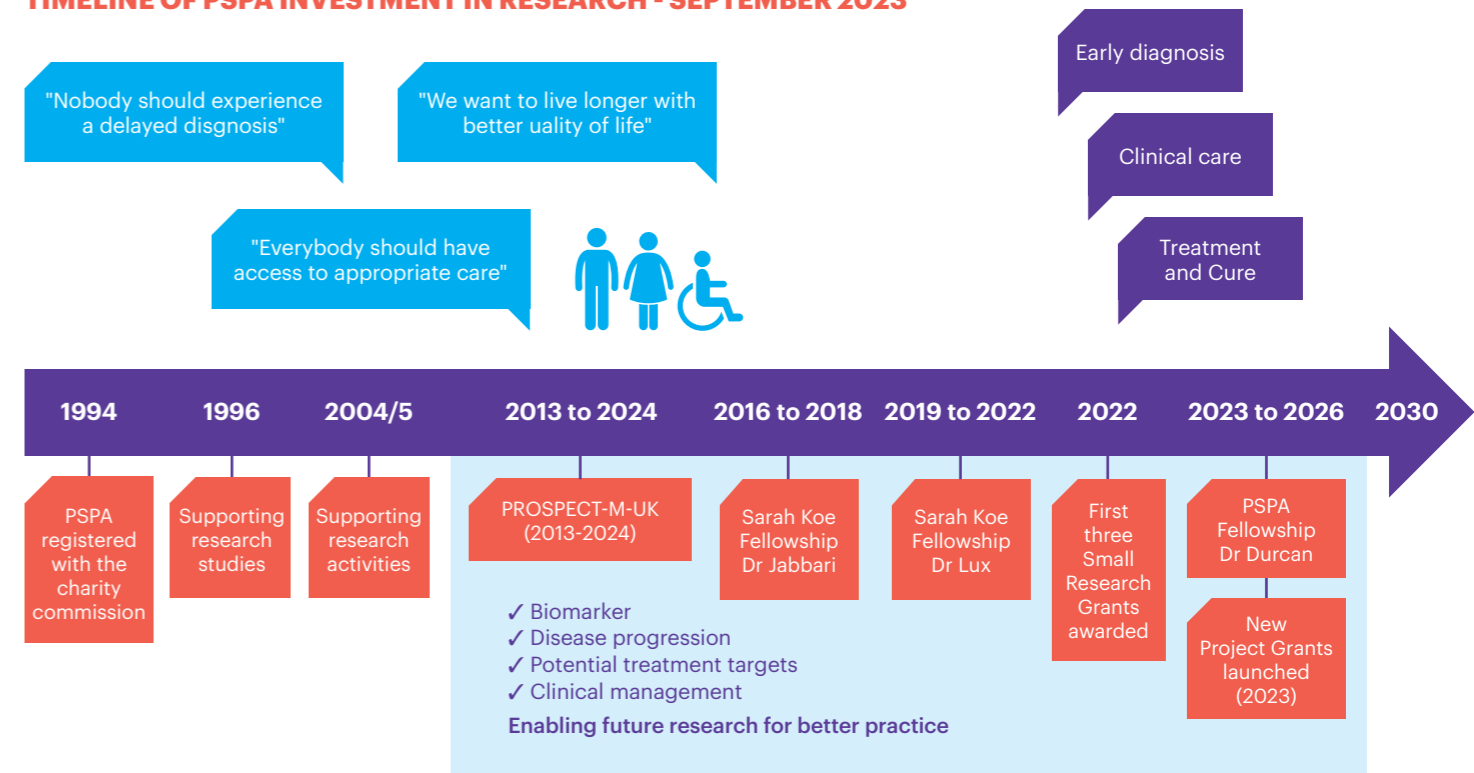
Our application process for funding complies with standards set out by the Association of Medical Research Charities (AMRC). In addition, we ensure all applications for funding over £25,000 are externally peer reviewed and adhere to clear guidance on conflicts of interest.

The chart below shows the timeline of PSPA investment in research and the forward thinking our Research Committee and Board of Trustees are committed to. Listening to people's concerns, PSPA is keen to fund research that is addressing the issues of delayed and misdiagnosis, access to treatment and care, and prolonging survival with an optimal quality of life.

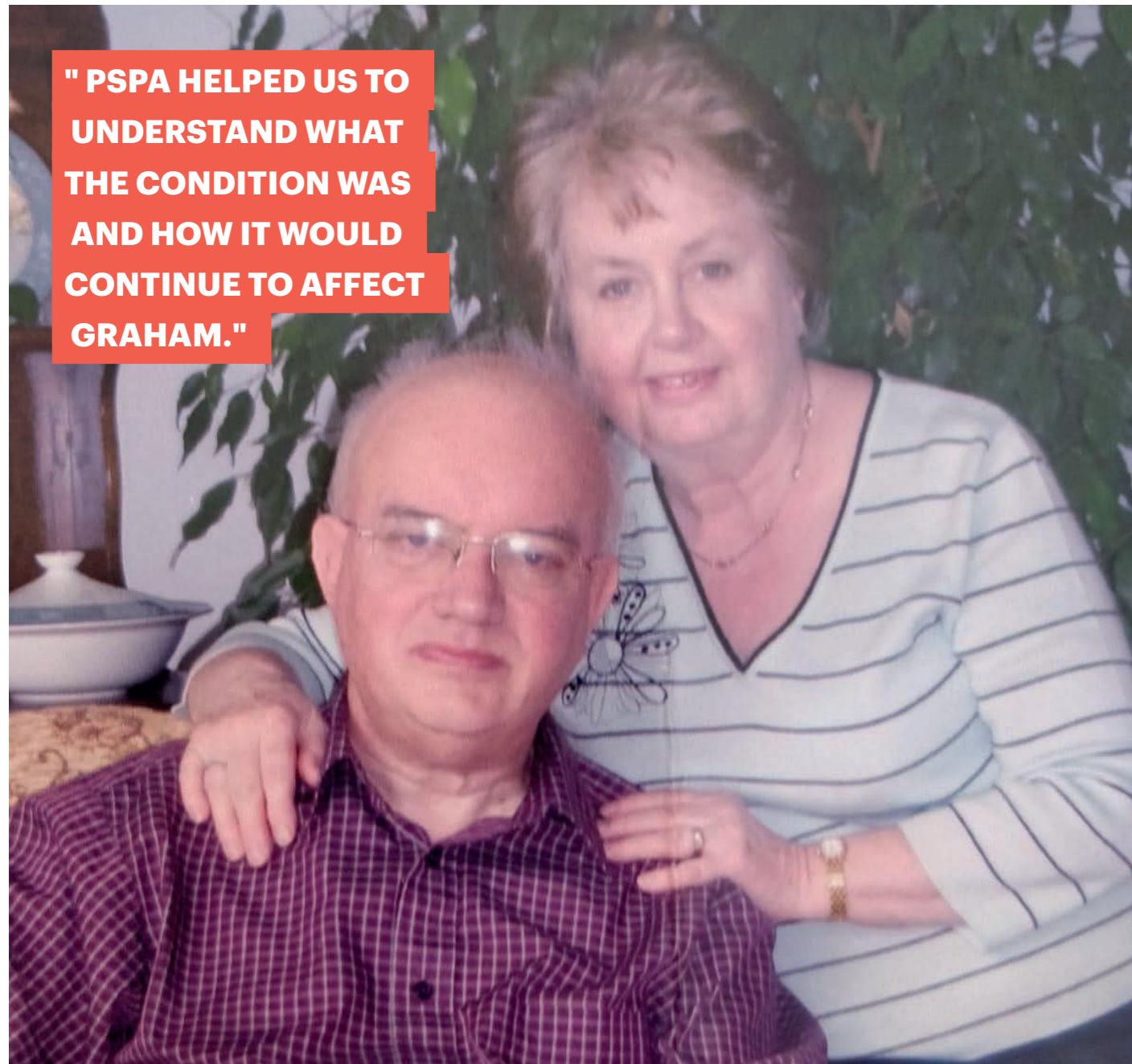
PSPA received a large legacy in 2022 specifically dedicated to promoting research activities and the Trustees are considering how to best invest the generous donation.

In addition, this October PSPA will host a major scientific event in collaboration with CurePSP (our American counterpart). Clinicians and researchers from all over the world will have the opportunity to hear from colleagues about advances in understanding and diagnosing the conditions. They will have the chance to discuss treatment targets and advances in care via roundtable discussions with pharma companies.

## TIMELINE OF PSPA INVESTMENT IN RESEARCH - SEPTEMBER 2023







**" PSPA HELPED US TO UNDERSTAND WHAT THE CONDITION WAS AND HOW IT WOULD CONTINUE TO AFFECT GRAHAM."**

## CREATE A FAMILY TRADITION WITH THE PSPA BAUBLE APPEAL

Special occasions can often see family and friends enjoying long established traditions. When you lose a loved one, those traditions can become difficult for a while.

There are many ways however, you can keep lost loved ones part of your celebrations. And during the festive season, the PSPA Bauble Appeal can provide a perfect opportunity for you remember your family member or friend, whilst also supporting PSPA in achieving our mission of creating a better future for everyone affected by PSP & CBD.

PSPA supporter Ruth Rees, shares her special traditions and how she has kept her husband part of them since his death in 2008.

"We didn't have any close family living nearby, but we were active members of our community.

This saw us regularly attending church services (with Graham also taking up the positions of organist and treasurer), being part of the singing group and enjoying suppers with friends. Particularly around the festive time.

Although we were a quiet couple, often doing things just the two of us, we did like to be around people. Out of the blue however, around a year into our early retirement, Graham started to withdraw. Instead of chatting with friends after church services, he wanted to get straight home and social occasions became limited too. I did wonder if he was depressed.

Our GP quickly referred us to a neurologist. The wait for an appointment, however, was extremely long. By the time it came around in May 2001, Graham was falling. In fact, he fell in front of the consultant.

The hospital did lots of tests. But they couldn't seem to get to the bottom of Graham's illness.

The diagnosis finally came in 2003. "It's not good news" the consultant said, as I spotted our favourite nurse getting a little upset in the background. We were there so often, staff were like friends to us.

The neurologist told us Graham had PSP and that there wasn't a cure. He gave us a leaflet and told us to contact PSPA.

PSPA helped us to understand what the condition was and how it would continue to affect Graham. They also put us in touch with Maggie Rose, the local nurse specialist, who was amazing throughout.

Graham was at home throughout his illness apart from a few stays in hospital. And with the support of the community, we continued our social traditions as much as possible, particularly around special times like Christmas.

The last two years of Graham's illness were particularly difficult though. That's when he lost his speech. I still miss our chats even now.

Although Graham died in 2008, I still keep him part of the little traditions we built.

I can't give Graham a Christmas or birthday present any more. But I can at least donate to PSPA at these special times in his memory.

Knowing I am contributing to research, and one day maybe even a cure, that has become my present to Graham. As well as a way to remember our special bond."

### DONATE IN MEMORY OF YOUR LOVED ONE

If you would like to uphold or create a new tradition, why not dedicate a PSPA Bauble to a family member or friend?

You can leave a special message to them on a PSPA bauble which can be placed on our office Christmas tree or on our virtual website tree.

Every donation received from our Bauble Appeal will help us to improve diagnosis for the 10,000 people living with PSP & CBD as well as access to appropriate support and care.

To receive a PSPA Bauble in the post please telephone **01327 322414** or email [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk)

Alternatively visit our virtual Christmas tree at [www.pspassociation.org.uk/christmas/](http://www.pspassociation.org.uk/christmas/)





**"I THINK OUR ROLE  
IN CLINICAL PSYCHOLOGY  
IS IMPORTANT TO HELP  
PEOPLE LIVE THE BEST  
POSSIBLE QUALITY  
OF LIFE."**



**DR SUSAN O'CONNELL**

## A DAY IN THE LIFE OF A CLINICAL PSYCHOLOGIST

**Dr Susan O'Connell is a clinical psychologist at Queen Elizabeth University Hospital, Glasgow. Susan works as part of a multidisciplinary team caring for people with PSP & CBD. Susan takes us through a typical day as a clinical psychologist, and explains why it's so important that mental health is treated as well as physical health.**

"Very early on in my career I saw the impact physical conditions had on the mental health of patients. It was a strong reminder that we have to treat 'the whole patient' and not solely focus on the medical management of the conditions they are diagnosed with. With every patient I see, I think about all the different roles they fulfil in their lives. They may be a mum, dad, wife, husband, granny, and it's important we help people maintain these roles as best we can, as often these are protective for mental health.

Many neurological conditions co-exist with mental health problems. Sometimes anxiety or depression can be a symptom of the illness, or mental health problems can arise because of the challenges adjusting to and living with a neurological condition, like PSP or CBD. That's why it's so important we provide holistic care to patients. I'm only one part of a bigger team, but I think our role in clinical psychology is important to help people live the best possible quality of life.

I came to Glasgow two years ago and I'm part of the Atypical Movement Disorder Team. It was recognised people with PSP & CBD have complex needs and often require more time during clinics, as well as access to a multidisciplinary team. That's why the two neurologists who lead the service, Dr Marshall and Dr Anderson, set up a dedicated clinic for people with PSP & CBD. The clinic I hold for this group of patients is separate to this dedicated clinic. We found that patients preferred to see us separately, so I now run two clinics a month for people living with PSP & CBD.

On clinic days I head to the hospital first thing to get ready for my patients. Today I'm seeing five patients living with PSP & CBD. One of these is a new patient, but I already know quite a bit about them from the previous multidisciplinary team meeting, where we go through the caseload of patients under our care.

The speech and language therapist is in clinic today for my first patient whose communication is changing. During clinic we'll do a joint assessment. We then provide some strategies for the patient and their carer, so they can continue to find ways to communicate, and to help them understand cognitive symptoms that can occur with PSP & CBD.

It's quite typical that other members of the multidisciplinary team will come in to clinic if the patient needs support in other areas. Cognitive difficulties does not always look the same from person to person, but there are some common ones like impulsivity that can lead to increased risk of harm, such as falls. We agree to look at strategies the family can use at home to reduce accidents and we will see them back in clinic again. It's nice to be able to get to know families over time and follow up on how they are getting on.

At every clinic there's a representative from the carer's centre. Having them here encourages carer's and family members to take some time to think about their own needs, which often are not prioritised. This is important because conditions like PSP & CBD can result in high care needs, especially as the disease progresses. Many of our patients remain at home, and therefore it's important we recognise and support the family, friends and carers who look after our patients.

My second patient is a gentleman who has low mood and since his diagnosis of PSP has withdrawn from many of the people and things in his life. This is a therapeutic appointment. We recognise that we cannot take away the condition, but we look to help people make space for the condition and help them focus on what in life is important to them.

I grab a quick drink before I see my third patient. This patient is attending for assessment that includes cognitive testing, to help determine capacity to make decisions about more advanced aspects of care. This can be a common question we are asked to help assess. With conditions like atypical movement disorder, people may need to make decisions about things like PEG feeding, and we need to make sure that people fully understand what making these decisions will mean for them.

After the assessment I spend some time talking to the family about the importance of supporting their loved-one to make decisions that will go in their advanced care plan, and who in the team can help support them with this. Some sessions take longer than others. It really does depend on the patient.

My final patient of the morning is new. This is another cognitive assessment, but this time it's to contribute towards the neurologist making a final diagnosis. The patient has suspected CBD, but there is a bit of uncertainty, so I'm doing a complete cognitive assessment to help build a more comprehensive picture. I also gently recommend her partner to have a chat with the carer's representative, to get an understanding of support that's available for carers.

I'm already running late so I dash out of clinic and head straight to the lunchtime meeting with the multidisciplinary team. These meetings are chaired by neurologists Dr Marshall and Dr Anderson. The specialist nurses, speech and language therapist, physiotherapists are all here along with other members of the team. We go through the caseload of patients who attended the Atypical Movement Disorder Clinic, and discuss outstanding needs or action points. I have my lunch at the meeting because straight after I have to go upstairs and see the inpatients on the neurology and neurosurgical wards, who also need input from the neuropsychology service.

The patients I see through the Atypical Movement Disorder Team are complex and even if they have the same condition they're all so variable, each with unique presentations. This is both challenging and rewarding. My work is greatly strengthened by being able to work so closely with other healthcare professionals. It means we can take a holistic approach and it results in a better service for patients.

After I see my last patient on the ward, I head to my office to update my notes. It's been a busy, challenging and tiring day, but I love what I do. It's so rewarding and I'm glad to be in a position where I can help people."





## UPDATE ON CAUSES OF NEURODEGENERATION

We know PSP & CBD are two neurodegenerative conditions. But what does this mean and how are such conditions caused? Our own Dr. Annalisa Casarin helps us understand how a brain degenerates and what can cause PSP & CBD.

It is estimated that the brain consists of 86 billion single cells, a cell being the smallest unit we can find in a living thing. Those cells are called neurons, and they talk to each other via pathways whose total length is approximately 850,000km (530,000 miles). This complex network of signals transmitted from one cell to another allows us to function properly every day. Because of this complexity, problems can arise from small changes within or around neurons. Also, miscommunication in one area can affect other parts of the brain, therefore the cascade of alterations could be quite widespread.

Many diseases or illnesses can affect neurons, and some are called neurodegenerative because they affect neurons in the brain primarily and cause neurons to breakdown. As in PSP & CBD, neurodegeneration can affect movement, sight, speech, memory, cognition and all the functions that are lost when specific neurons in specific areas of the brain are missing.

When neurons are lost, areas of the brain show signs of a decrease in size, or shrinking, called atrophy. Research and technology advances have made it possible for the human eye to look at the areas of atrophy in the brain. One among several signs of degeneration in PSP is the “hummingbird” shaped figure which shows in the brain scans of people affected. To show the parts of the brain, machines like CT scan and MRI produce virtual slices of the organ that can be looked at from different angles. In PSP, the brain tissue shows the silhouette of the bird. Why neurons start to die, and when, is still not fully understood but years of research made things clearer.

People affected by PSP & CBD often hear about TAU being the cause of their problems. What is the link between TAU and neurodegeneration? Inside neurons there are multiple organs and structures that work to keep the cell alive and connected to others. Microtubules are one component that helps transport nutrients and other substances around inside neurons and towards areas of contact with other cells called synapses. TAU, or Tubulin Associated Unit, is a protein (a building block) discovered in 1975 as the binding force of the microtubules’ components (think of the Ed’s Lace campaign as seen in **PSPA Matters summer edition 2022, page 8**, a piece of string built by several threads linked together by the aglets). At certain points in life, even years before a person shows symptoms of disease, TAU undergoes a structural modification and doesn’t work properly, microtubules start falling apart, and TAU becomes “sticky” (not folding as it should) and creates aggregates or clumps. These aggregates are common in several diseases (PSP & CBD but also Alzheimer’s and FrontoTemporal Dementia) but made

up from mutated TAU pieces with different structures, not all TAU involved are folding in the same way. Sometimes these conditions are called Tauopathies, and the patterns of tangles created by TAU have a stereotypical pattern for each disease. Clumps tend to progressively accumulate in specific areas of the brain, so disrupt different functions, a useful finding for differentiating them using imaging after symptoms appears. Although, there needs to be a significant amount of disruption to make it visible.

The mechanisms with which TAU becomes toxic to neurons is not clearly explained yet. What we know is that TAU might be toxic because it disrupts the tubules of the cells, with loss of their functions of transporting messages and substances, and TAU might be acquiring toxic properties causing damage. Also, it has been observed abnormal TAU can travel from neurons to neurons, spreading abnormalities. Creating a research model to study is not easy due to the high soluble nature of TAU (in laboratory it is not easy to reproduce TAU toxicity and its effects, it dissolves quickly) but it has been noticed there are other components in the cell that can be affected by TAU.

In recent years, attention has been also given to other neurons’ components like mitochondria. These are the powerhouses of neurons; they harvest energy from sugars with the help of oxygen. It has been shown that in PSP they work differently, maybe due to their own mutation or because susceptible to toxin from other sources. The cell will then be deprived of energy but also discharge toxic compounds around itself, called free radicals, that affects other cells. Moreover, the release of toxic factors in the space between cells activates the inflammatory cascade (the normal mechanism meant to heal the body), a process responsible for producing more components that unfortunately can cause further disruption. In a nutshell, the neurodegeneration in PSP & CBD can be caused by multiple factors, not only led by TAU mutation.

Efforts are underway targeting several treatment opportunities around this complex neurodegeneration system. Several options have been already tested and progress happens daily in the battle against neurodegeneration. Researchers and clinicians are collaborating ever more in fighting against PSP & CBD and PSPA is grateful for the contribution donors give towards this fight.

### Article Reference:

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## WHY I LEFT A GIFT IN MY WILL TO PSPA



**This year, Claire Wells took advantage of our Free Will scheme to outline her wishes for the future, including a gift to PSPA. Here Claire shares why she is leaving a gift to PSPA and what her hopes are for the future.**

"My mum, Anna, was diagnosed with CBD in 2019, she was only 69 years old at the time. We believe mum had been experiencing symptoms for around 11 years, but GPs and doctors just kept putting it down to anxiety and getting older.

We were lucky to find PSPA in a google search, the evening after mum received her diagnosis.

Previously we had felt lost in the system, with no one to turn to for information. But PSPA put us in touch with our local neurological nurse practitioner who was a huge help in terms of us accessing home adaptations, equipment and support from other professionals.

Sadly, mum died in January 2022 but her memory lives on in everything I do, including my support of PSPA.

Most recently, my support of the charity extended to leaving them a gift in my Will.

I read about PSPA's free Will Scheme in either one of their newsletters or PSPA Matters. Quite possibly both!

It was an absolute no brainer for me. PSPA were an incredible support to my mum and I.

My partner and I are not sure we want to have children so I want half of my estate to go to PSPA.

The free Will was really easy to set up. Somebody from Farewill gave me a call (although it can be completed online) and we discussed my wishes over the phone. She posted my printed Will to my home address, I had two witnesses sign it alongside me and that was that.

I hope my legacy will help to alert more healthcare professionals about PSP & CBD as mum was undiagnosed for years and years. Knowing sooner could have allowed mum to focus more on living and enjoying life whilst she could."

## THE DIFFERENCE YOUR GIFT CAN MAKE

Leaving a gift to PSPA in your Will is an inspiring way of helping us to enable positive change for people living with PSP & CBD.

There is no single type of person who might leave a gift to PSPA; you do not have to be young or old, sick, or well. We all need a Will.

So far, we have received £190,000 this year, made up of different sized gifts, given in different ways from a set amount to a percentage of an estate. Some have included property, others a rare item, other investments, or shares. Every type of gift is special and important.

Such gifts frequently feel like a chance win on the lottery; they are gifts we do not expect, usually given from families who directly understand the impact of living with PSP or CBD and want to see the change PSPA aims to bring about.

As significant as the income is, it is the amazing life stories of determination shared with us, we also find so inspiring. These are moving reminders of why PSPA exists, helping to focus staff, Trustees, volunteers and fundraisers alike, all on doing the best we can for people living with PSP & CBD.

If you are someone considering leaving a gift to PSPA in your Will, or maybe you have already made the plans to, we cannot thank you enough; your legacy will help us ensure we can create a better future for everyone affected, including improving diagnosis and access to appropriate care.

Remember, leaving a gift in your Will won't affect your spending now, so is inflation proof, but will have a lasting effect on the work PSPA are able to do. If you haven't done it already, it is certainly an idea worth considering.

If you would like to leave a Gift to PSPA in your Will here are a few tips.

You will need the charity information below:

**Charity Number in England and Wales 1037087**

**Charity Number for Scotland SC041199**

**The PSP Association**

**Margaret Powell House,**

**415a Midsummer Boulevard.**

**Milton Keynes**

**MK9 3BN**

PSPA are currently in partnership with Farewill; this is the free Will scheme that Claire (see page 20) used, and it is available to you too.

The scheme is easy, completely free, and you are under no obligation to commit to a gift to PSPA.

You can either contact Farewill by telephone, or register on their website:

[www.farewill.com/pspa-web](http://www.farewill.com/pspa-web)

[www.farewill.com/pspa-email](http://www.farewill.com/pspa-email)

[www.farewill.com/pspa-mag](http://www.farewill.com/pspa-mag)

**You can also call the Farewill team on 020 8050 2686**

This is a time limited offer running to the 31 October.



### MORE INFORMATION

Using our free Will scheme is a very straightforward process, but if you do have any questions please contact Helen Holman, Head of Fundraising at [helen.holman@pspassociation.co.uk](mailto:helen.holman@pspassociation.co.uk)





**THE LAST TIME WE HAD RUN THE EVENT WAS IN WALES IN 2019, THE PANDEMIC HAD PUT A STOP TO OUR ANNUAL GATHERING BUT AT LAST WE WERE BACK.**

## FAMILY AND FRIENDS DAY 2023

One of the challenges of a rare diagnosis is the isolation that comes from not knowing other people living with the condition. Our Family and Friends Day is an ideal opportunity to combat that isolation, enabling people living with PSP or CBD and family members to connect.

On Saturday 15 July we gathered in Windsor for our Family and Friends Day. The last time we ran the event was in Wales in 2019, the pandemic had put a stop to our annual gathering but at last we were back. How wonderful it was to be able to see old friends and new faces, and have so many people together.

PSPA Trustee Jon Garrard was our compare for the morning and introduced our first speaker Dr Negin Holland. Dr Holland, a neurologist based at Cambridge NHS Foundation Trust, gave a brilliant presentation updating the audience on the latest clinical understanding of PSP & CBD and what is happening in research. Despite it being a complex subject, her explanations were clear and understandable, soon we were learning about neurons and synapses, neuroinflammation and TAU. The presentation helped to enhance the audiences understanding of what researchers currently believe is happening to the brain in PSP & CBD and what research is currently taking place around the world.

A quick break and chance to get a treat from the 'wall of donuts' before we came back to hear from speech and language therapist Caroline Jeffries-Shaw. Caroline covered communication issues and aids as well as a section on swallowing and food. Caroline shared some handy tips on nutrition and hydration and fortifying foods. As with all sessions there was a chance for questions at the end.

Next up for a change of pace was PSPA Helpline Manager, Jules Brown. Jules challenged us all with a quiz called 'Who funds what?' where we were tested on our knowledge about where we could get funding for wheelchairs through to carers benefits. To complete the morning, we held our lucky ticket draw, everyone had been allocated a ticket with their arrival pack and one lucky winner went home with a hamper full of goodies.

After lunch the English National Ballet led us through a 'Dance for Parkinson's' taster workshop. A chance for some movement and song based around their current rehearsals for Cinderella. A carefully planned session meant everyone living with PSP or CBD could join in and it was wonderful contrast to the information focused sessions in the morning. It really did turn out to be a day for everyone.

Next year we will be planning two Family and Friends events, in the North and South of England. We hope to see many of you there. We also held a mini Family and Friends day in Belfast on 2 September for anyone living in Northern Ireland.

**HOW WONDERFUL IT WAS TO BE ABLE TO SEE OLD FRIENDS AND NEW FACES, AND HAVE SO MANY PEOPLE TOGETHER.**







# CARING FOR CARERS



When you spend a lot of time caring for someone with PSP or CBD, it can be difficult to make space for yourself. But looking after your own mental and physical health is just as important for those you care for, as it is for you.

For Davina Roberts, accessing support is essential in enabling her to be a loving carer to her husband Rhys. Davina said: "I've been Rhys' main carer since he was diagnosed with PSP in 2018.

The caring part of my life is without a doubt the hardest and most stressful bit. It's so important to publicise how tough it can be for carers and how they can get support from others. I know I like to think I can cope, but I need support to function and remain a loving carer."

Developed last year, PSPA's online monthly Carer's Support Groups have continued to grow. The groups provide a friendly environment for carers to share experiences, learn from each other and build friendships, as Davina found out when she attended a session. "It makes the world of difference to talk to carers who are experiencing the same issues. I hadn't realised quite how important this was to me, until I went to the first meeting."

As well as providing time and space for people to chat, every session also focuses on a specific topic. Vanessa Sutcliffe, a carer for her mum who is living with PSP, has found the groups to be an invaluable source of information. "Earlier this year Mum came to live with us. It's lovely having her here, and I know she's in the safest place, but our relationship has changed, partly because I'm now her carer, and partly because of how the disease has affected her.

"I went to the first carer's group in February. We collectively shared our distresses and our joys in a warm environment. It's so nice to talk to other people in a similar position. I've learned so much through the groups and afterwards I always have a long list of things to look at."

In July, we launched an online Men's Carer Support Group with 20 male carers joining. Jimmy Coelho shared his thoughts on the Carers meetings: "You may underestimate how valuable these sessions are. The feeling you're alone, seeing your partner deteriorate and dealing with the symptoms quickly vanishes when you share your thoughts and hear others' experiences."

## CARER'S SUPPORT SERVICES

PSPA has a range of services to support carers.

### CARER'S SUPPORT MEETINGS

We offer regional online meetings, men's groups, daytime and evening sessions. To attend any of our support meetings please visit our website or email [volunteering@pspassociaton.org.uk](mailto:volunteering@pspassociaton.org.uk)

### NEW CARER'S GUIDE

The guide covers what support is available to carers and how carers can connect with others. Copies can be downloaded from our website, or, for printed format, please contact our Helpline. [www.pspassociation.org.uk/information-and-support/just-been-diagnosed/pspa-publications/](http://www.pspassociation.org.uk/information-and-support/just-been-diagnosed/pspa-publications/)

### LINK VOLUNTEER SERVICE

Link Volunteers provide short-term support to carers to improve wellbeing and help navigate difficult times.

### ONLINE CARER'S PAMPER SESSIONS

Hosted by PSPA volunteer, Caroline, our bi-monthly online sessions allow you to connect with other carers while having some pamper time.

### PSPA SUPPORT GRANTS

Our grants of up to £250 are available for carers to allow you to take a break and boost your wellbeing. This may be a pamper day, gym sessions, complementary therapies or anything to improve your quality of life.

### PSPA HELPLINE AND WEBSITE CARER'S HUB

Our Helpline provides information and support to anyone affected by PSP & CBD. Lines are open 9am to 9pm Monday to Friday on **0300 011 0122**, or email [helpline@pspassociaton.org.uk](mailto:helpline@pspassociaton.org.uk).

We also have a carer's section on our website, where you can access information, podcasts and lots more.

# NEW CORPORATE PARTNERS

PSPA have a range of corporate partnerships and sponsors supporting the charity. For 2023 we are delighted two new companies are supporting us in a variety of ways. Here we introduce both company's and how they are collaborating with us throughout the year, and beyond!



## EMERALD COLOUR (EC)

EC is a full-service agency based in Basingstoke, with core skills around creative, print, design, and digital. Blending creativity with collaboration, working to support your brand. For full details about EC, please visit: [www.emeraldcolour.com](http://www.emeraldcolour.com).

EC ran a staff ballot for their 2023 charity of the year. PSPA was nominated due to an employee having a personal connection to PSP & CBD and PSPA. Since PSPA won the ballot EC have jumped into supporting the charity, primarily through challenge events, with employees signing to run the Great North Run, the Royal parks Half Marathon and the 2024 London Marathon. Quite the commitment!

We are extremely grateful EC has generously committed to supporting PSPA as their charity partner for two years, in 2023 and 2024.



## NOVENARY

### NOVENARY

Novenary specialise in wellbeing. Bringing a sensory world of aromatherapy and home wellbeing to you. Select self-care candles or bath salts to treat yourself or gift a loved one. Whether you are looking for something to stimulate your senses or help you unwind, the Novenary collection has got something to suit. Learn more about Novenary products at [www.novenary.com](http://www.novenary.com)

Novenary are supporting PSPA by donating 15% of their monthly sales for a specific period. They are also going to collaborate with us on special promos during the Christmas countdown.

The Novenary team explain: "The inspiration for this partnership came from one of our valued customers, who shared their personal experience with PSPA and its profound impact on their lives. Deeply moved by their story, we felt compelled to support this remarkable organisation in their mission to raise awareness, help, and advance research for these rare neurological conditions."



## GET YOUR COMPANY INVOLVED

From charity of the year partnerships to payroll giving, match funding, gifts in kind, sponsorship or simply having a collection tin in your office, there are so many ways to get involved in the world of corporate fundraising, just like Emerald Colour and Novenary have done with PSPA. If you would like to know more or explore opportunities please email James, our Community and Corporate Fundraising Manager at [James.Holden@pspassociaton.org.uk](mailto:James.Holden@pspassociaton.org.uk)





# MEET THE HELPLINE TEAM

To help you to get to know our knowledgeable Helpline, each edition we will be introducing a member of the team. In this edition, we say hello to Javeria, who joined the team in June.



JAVERIA SHAFIQ

"Prior to joining the PSPA team in June, I worked in different roles for the NHS. In one role I worked in the Cardiopulmonary Department at my local hospital. I was carrying out lung function testing on patients who mainly experience from asthma, COPD and cancer. I also worked with sleep apnoea patients; I was involved in the diagnostic testing for these patients as well as working on a sleep apnoea helpline. The main purpose of this helpline was for patients, family members and carers to be able to speak to a member of the team confidentially about diagnosis, treatment and managing symptoms.

I have always loved the patient contact aspect of my previous jobs and being able to meet families and carers. Working at PSPA gives me the opportunity to continue providing help and support to a wide range of people. My previous experience in working in a healthcare environment will help me build relationships with people who have been diagnosed with PSP or CBD, carers, families, and healthcare

professionals which will be beneficial in being able to support those who are living with the conditions.

I am looking forward to raising awareness for PSP & CBD and getting involved with the events and challenges PSPA will deliver in the future. As well as staying up to date with research and expanding my knowledge by attending clinics and local support groups. Most of all I am looking forward to the contact with families affected by PSP & CBD and helping them to solve problems and support them through the complex issues that the diseases present."

In my role as a PSPA Helpline Care Navigator I will cover the North-West and North-East of England. You can contact me, and other members of the team, on **0300 0110 122** or by emailing [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

**The Helpline is open Monday to Friday, from 9am to 9pm.**

# STRATEGY UPDATE – MEASURING SUCCESS

In edition one of PSPA Matters this year we outlined our new three-year strategy. Following that edition, some people have asked how we will know if we are making progress. Good question!

With a small staff team of 20 and our 150 plus volunteers there is always more work than we can do, and we have to make decisions about what will have the most impact. Measuring what we do helps us to make those decisions. We have been working on a measurement framework so we can understand progress against the strategy and to make informed decisions.

For each goal we have set strategic measures that will indicate if we are making progress towards the goal. All measures will have targets, we are collecting baseline data this year, this way we can understand current performance so we can set achievable targets for future years.

**We will publish our performance each year so you can see the progress we are making.**

**Here are some examples of the strategic measures we have set for each goal.**

<p><b>SUPPORT &amp; INFORMATION</b> Enabling people to live the best life possible</p>	<p><b>Enable people with PSP &amp; CBD and their families to live their best lives possible with high quality support and information.</b></p> <p><b>Strategic Measures</b></p> <ul style="list-style-type: none"> <li>• % growth in numbers of people with PSP &amp; CBD and their families registered with PSPA</li> <li>• % of people with PSP &amp; CBD and carers who say the support received from PSPA benefits them</li> <li>• % of carers who say attending a PSPA carers group improves their wellbeing.</li> </ul>
<p><b>RESEARCH &amp; AWARENESS RAISING</b> Improving quality of life</p>	<p><b>Improve the quality of life of people living with PSP &amp; CBD through research, education and awareness raising.</b></p> <p><b>Strategic Measures</b></p> <ul style="list-style-type: none"> <li>• The number of academic papers published because of PSPA sponsored research</li> <li>• % of PSPA income spent on research</li> <li>• % of health and social care professionals attending PSPA training who report improved knowledge or feel more confident to support people with PSP &amp; CBD.</li> </ul>
<p><b>INVOLVEMENT</b> Putting people living with PSP &amp; CBD at the heart of what we do</p>	<p><b>Putting people living with PSP &amp; CBD at the heart of what we do.</b></p> <p><b>Strategic Measures</b></p> <ul style="list-style-type: none"> <li>• The number of people involved in the PSPA services committee, public involvement in research groups and focus groups</li> <li>• Number of external consultations that PSPA service users are involved in</li> <li>• % increase in the number of people signed up to the research register.</li> </ul>

The measurement framework is part of PSPA staying focused on what matters most and making the most of the people and financial resources that we have.





**PROFESSOR HUW MORRIS**

## EXPRESS GRANT

Earlier this year, Professor Huw Morris from University College London successfully applied for a grant to continue important work mapping the journey of people with Atypical Parkinson's Disorders, which was started by the PROSPECT-M-UK study.

The Early Assessment, Diagnosis and Treatment of Parkinson's Plus Related Syndromes (ExPRESS) study is a new UK study of Parkinson's Plus syndromes, which include Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD). Along with 11 other new UK studies, it will be funded by the Medical Research Council (MRC) and the National Institute for Health and Care Research (NIHR), as part of the UK Rare Disease Platform. The study will be led by Professor Huw Morris, alongside Professor Yoav Ben-Shlomo at the University of Bristol, Professor Michele Hu at the University of Oxford and Professor James Rowe at the University of Cambridge.

The PROSPECT-M study, which has been funded by PSPA since it started in 2015, will continue recruitment and will transition and expand into the ExPRESS study.

The PROSPECT study improved our understanding of PSP & CBD and helped to identify key challenges to face in their diagnosis and treatment. In PSP patients who took part in the PROSPECT study, the delay from symptom onset to diagnosis was three to four years, and in those who had an in-depth research assessment, 90% were diagnosed accurately in life. Taking this into account the ExPRESS study aims to improve the early diagnosis of PSP & CBD and improve the accuracy of both diagnosis and prognosis.

A network of over 30 neurologists and care of the elderly physicians will be established through the ExPRESS study, including those working in areas of the UK with high proportions of non-European ancestry. With the help of the ExPRESS network, at least 500 patients with signs of parkinsonism will be recruited to the study between 2023 and 2028.

Participants and their consultants will be asked to complete a short online questionnaire each about the nature of the patient's symptoms. The questionnaires will be repeated at regular intervals up to 36 months after their primary care referral. Participants with a diagnosis of a Parkinson's Plus syndrome will have the option to take part in a face-to-face neurological assessment. This will include having blood, cerebrospinal fluid (CSF) and skin biopsy samples collected. The ExPRESS study will, like the PROSPECT study, aim to build a biobank of samples and data which could be used for important forthcoming research.

The ExPRESS study will bring together patients, relatives, researchers and UK charities including PSPA and the Multiple System Atrophy Trust (MSA) to inform and update on the progress of the research. Day-long clinical research and science research workshops will be run in 2024, the dates for which will be shared by PSPA. We hope that this network will improve the early diagnosis of PSP & CBD related conditions, enabling the development of new therapeutic trials for these conditions.

**IN PSP PATIENTS WHO TOOK PART IN THE PROSPECT STUDY, THE DELAY FROM SYMPTOM ONSET TO DIAGNOSIS WAS THREE TO FOUR YEARS, AND IN THOSE WHO HAD AN IN-DEPTH RESEARCH ASSESSMENT, 90% WERE DIAGNOSED ACCURATELY IN LIFE.**





**SHEILA BLOICE**

## PSPA LINK VOLUNTEERS PROVIDING SUPPORT IN YOUR COMMUNITY

We were proud to launch our new PSPA Link Volunteer Service in early 2023, to offer short-term support to improve wellbeing and to help people navigate difficult times.

Our PSPA Link Volunteers can offer up to 12 visits or calls to provide a listening ear, giving people the opportunity to talk through their feelings and also let them know what support is available in their local area. Volunteers also have access to all the publications provided by PSPA and information on other PSPA services. Providing this one-to-one support and information can help to reduce the isolation some people affected by PSP & CBD can experience.

People are eligible for Link Volunteer support if they have received a recent diagnosis or are going through a time of crisis. Support is also available to carers and Link Volunteers can support people with the condition and their carers, together, if requested.

Below Sheila, PSPA Link Volunteer, and Joyce, who is living with PSP, share their experiences.

### INTRODUCING SHEILA

Sheila Bloice registered to become a PSPA Link Volunteer in March and after completing her training was linked up with Joyce to offer regular support in Joyce's own home.

Sheila said "I applied to become a PSPA Link Volunteer in memory of my husband Mike who sadly died from PSP three years ago.

PSP is an exceptionally cruel condition, frequently misdiagnosed leaving families desperately seeking support.

As a Link Volunteer my goal is to assist families struggling with the challenges and reality of living with PSP & CBD on a daily basis.

Supporting Joyce on her PSP journey is immensely rewarding. Joyce is an amazing lady with a wonderful sense of humour. She is great company and still enjoys a good quality of life".

### BENEFITS OF THE PSPA LINK VOLUNTEER SERVICE

Joyce was diagnosed with PSP in April 2023 and following the diagnosis felt very anxious. Joyce's Helpline Care Navigator suggested she attend the online PSPA Newly Diagnosed Group, however Joyce felt this might be too much for her and said she would prefer to talk the diagnosis through on a one to one basis.

Following a discussion, the PSPA Helpline Care Navigator suggested Joyce signed up to receive support from the Link Volunteer Service to help her navigate her recent diagnosis. Joyce was linked with Sheila in May and they now meet face-to-face on a fortnightly basis.

**"AS A LINK VOLUNTEER MY GOAL IS TO ASSIST FAMILIES STRUGGLING WITH THE CHALLENGES AND REALITY OF LIVING WITH PSP & CBD ON A DAILY BASIS."**



### WOULD YOU LIKE SUPPORT FROM THE PSPA LINK VOLUNTEER SERVICE?

You can self-refer to the Link Volunteer Service by calling the PSPA Helpline on **0300 0110 122** or emailing [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

Referrals can also be made by health and social care professionals.

**Please note we have a limited number of volunteers in specific areas, but we are looking to expand the service. If none are available in your area the Helpline team will be happy to discuss alternative options.**

### BECOME A PSPA LINK VOLUNTEER

If this article has inspired you to become a PSPA Link Volunteer please email [volunteering@pspassociation.org.uk](mailto:volunteering@pspassociation.org.uk) or telephone **01327 356137** and make a real difference to the lives of those affected by PSP & CBD.





DR BOYD GHOSH

## PSPA RESEARCH GRANTS: SHAPING THE FUTURE STANDARDS OF CARE

With a new set of Small Research Grants due to be awarded during the autumn, we asked Dr Boyd Ghosh to explain the impact a PSPA grant has made to his team.

“What determines good care for someone with PSP & CBD? We all think we know. I certainly do. A specialist clinic, with someone who can be contacted between appointments to answer questions. Access to therapists and perhaps some degree of counselling and support. However, what evidence do we have for that? I have recently been “promoted” to a managerial level within the medical neuroscience department in Southampton and can see first-hand the pressure on our services and the lack of money and resources. We need to make the case for any resources we want to help our family and friends with PSP & CBD.

About a year ago I successfully applied for funding from PSPA to look at this question. It was only within my clinic in Southampton and on a budget. To overcome that we have involved medical and summer students to help us with the research. Our first student recruited 35 people and was so caught up with the project that she has stayed on to help us recruit more and ensure our data is clean. Without her, the study would not have started, and we would not be in the current position.

A second pupil joined us as a summer student from her biology degree to look at patients who are admitted and what effect that has on their function and quality of life. When anyone is admitted to hospital, they spend more time in bed and their ability to do things like walk around decreases. However, people with PSP & CBD seem to experience much greater reduction in their function after an admission. Some people spend so long in hospital that when they leave, they can't walk and need more care at home or in a nursing home. Why is that? Is there something that we could do differently while people are admitted that would make that negative outcome less likely? Could we do something to reduce the chances of people going into hospital in the first place? We have used the study that PSPA have funded to investigate these questions and to see if people with these diseases really do deteriorate or whether that is just a coincidence. We can then use that information to try to work out why people deteriorate more.

Our next medical student starts in September, the student will ensure we recruit more people and hopefully meeting our target of 100 people. She will be looking at the clinic and what aspects of the information we provide gives people with PSP & CBD and their family the best quality of life. Pragmatically, if people with PSP & CBD are admitted less and experience less deterioration, does that mean that they will need less care when they are discharged. Care is expensive and so if that was the case would the government and the NHS produce guidelines to say that specialist clinics must be provided for these conditions as it is cheaper for them in the long run (and of course the part that we are most interested in is that it gives the best quality of life for people with these diseases and their families). If we can demonstrate that this is the case, would doctors looking after people with PSP & CBD around the country start being asked to set up specialist clinics, rather than them constantly trying, and often failing, to persuade managers to spend some of their scant resources on their clinic?

These are difficult questions, and the situation is complex. It is unlikely that we will discover a clear answer. However, this study may help us to spot early signs or markers pointing to things that do make a difference. If that is the case maybe we can make life better for those who live with PSP & CBD and their families.”

**"WE NEED TO MAKE THE CASE FOR ANY RESOURCES WE WANT TO HELP OUR FAMILY AND FRIENDS WITH PSP AND CBD."**





## A TRIBUTE TO BOB STRAKER-COOK

Robert Straker-Cook passed away very suddenly on 15 April 2020, having been diagnosed with CBD just a few months earlier. Here Bob's wife Dawn shares a tribute to Bob by celebrating his achievements.

### CELEBRATION OF A LIFE LIVED TO THE FULL

"Born in Bristol in 1939, Bob lived with his close-knit extended family: his mother, grandmother, aunt and her husband. They all played their part in turning out the intelligent, inquisitive, creative, caring and adventurous person that he was.

Bob loved library hour at school and parallel to his progress to junior school were piano lessons. However, his main joy was his instructor's vast collection of National Geographic magazines which he devoured eagerly until the very last moment before going in for his lesson. The lessons were abandoned after two years, but they did give Bob his life-long love of classical music. The highlight of being in the 5th form was the trip to France under the Bristol-Bordeaux Schools Exchange. In Bordeaux, Bob got on well with his counterpart's elder brother, who was studying Law at the Sorbonne and was a budding concert pianist.

In 1958, Bob was accepted by King's College, Durham University, to read French and Philosophy. An academic year in Nice as "professeur assistant" was part of the degree, which was the spring-board of a whole series of adventures on his beloved Vespa.

On graduating in 1963, Bob joined the British Council as a trainee Specialist in English as a Foreign Language, with a year's trainee-ship at the Institute of Education, London; he met and wooed Dawn at this time. Teaching practice took place in London, Wales and the British Council Centre in Barcelona; after which he awarded himself a trip across Southern Spain into Morocco, across the Atlas Mountains to the edge of the Sahara. He married Dawn just 10 days before his first posting at the University of Cameroon in Yaoundé where he helped open an English Department and create a bilingual degree in English and French. There were, naturally, excursions with Dawn which included

Christmas in Spanish Guinea, a trip into the bush with a French anthropologist to visit a tribe of pygmies, and, a 3,000 miles Land Rover journey into Nigeria in the rainy season, only a month before Faye, his daughter, was born!

In 1966 came the posting to Karachi University, Pakistan. Bob was in charge of English language courses up to post-graduate MA level and a specialist course for instructors. He coordinated a government-funded survey of English language needs in Pakistan. He and Dawn made camping trips, with toddler Faye to the Sind desert, and the ancient site of Mohenjo-Daro, and en famille with Tim (born in 1967) to Afghanistan, flying on to Tashkent, Smarkand and Bokhara. An 11,500 miles journey in a converted Land Rover from Pakistan to the United Kingdom, covering 15 countries, via the Arctic Circle, with two little ones, did not deter our intrepid traveller. Bob had decided to register for doctoral studies at Edinburgh University. Bob undertook paid assignments in between study in Poland and Egypt for the British Council, and closer to home tutored foreign post-doctoral students doing research. But as funds were running low, he settled for an M. Litt (later upgraded to a PhD) in Applied Linguistics.

The Arabian odyssey followed, with British Council postings in the Yemen, Syria, Egypt, and Oman. Interesting and demanding assignments in diverse institutions. The most fulfilling was setting up English language projects in the Universities of Damascus. Aleppo and Latakia and the British Council Teaching Centre in Damascus. He part-managed the Council's cultural programme for Syria which included visits from the London Shakespeare Company, the Humphrey Lyttelton Band, and the Stan Tracey and Art Themen Quartets.

Our now married daughter was working in the Gambia with her husband and our son secured a post at the Natural Resources College in Malawi and then Tanzania. At the end of our time in Oman, we visited both our children, flying for over 12 hours from East to West Africa. By this time too, we sold our house in Edinburgh and moved to Bremhill.

Bob's final overseas post was Deputy Director of the British Council in Peru operating from Lima; he was also cultural attaché for education and was Adviser to the British-Peruvian Cultural Association. He set up Language Centres in 12 Peruvian Universities, and a British-style school in the North of Peru. Bob was offered an extension for three years to cover Bolivia in addition to Peru, but it was time to call time on this itinerant way of life: our first grandchild had arrived

and our parents were not in the best of health, so at the very end of 1996, we exited Peru via Colombia to face retirement.

Bob worked part-time as a senior trainer in business communications at Cheyney Court, a residential training centre in an opulent country mansion near Bath for over 10 years. There was now ample time to enjoy our families, make umpteen sorties to Northern Ireland and latterly Northumberland to be with our daughter, her hubby and four children, and to Tanzania, Ethiopia and Laos to visit our son, his Tanzanian wife and three children. Trips to the USA. Canada and New Zealand also featured. We so loved our Bremhill village life and got to know our neighbours better. Bob put his DIY skills to good use and hand-built a summer house to take advantage of the spectacular view.

It was on a visit to Laos and Thailand in 2015/16, we first noticed that Bob tended to get a little anxious and bothered – not quite his style. A fall off a ladder in the garden put him in hospital with compound fractures and another fall down the stairs put him in hospital again with seven broken ribs. Gradually, his speech was getting hesitant and he was slow to respond when spoken to and he was getting a little unsteady on his feet. But his mind was clear and he enjoyed reading, especially his beloved National Geographic magazines. He managed a rather demanding holiday in Morocco in 2019, and in October celebrated his 80th birthday. He was finally diagnosed with CBD at the beginning of 2020.

Though his condition was slowly getting worse, it didn't seem too debilitating and his very sudden death on the night of 14/15 April 2020, came as a shock to all. Tributes came pouring in from all over the world, colleagues who remembered his professionalism and ability to deal with difficult and challenging situations; friends who remembered his warmth, kindness, companionship and quirky sense of humour; relatives who thought of him as one of nature's nice guys and his lovely kind spirit; grandchildren who remembered his stories and tales of adventures, misadventures, whacky solutions to problems around the house, and tips on how to produce 20% wine; and his two children who will sorely miss his humorous anecdotes, kind words, hugs, winks and smiles. These all say how lucky we were to have all shared a last Christmas and the New Year together and see him revel in the merriment, food, drink and, above all, the uplifting company and love of his family."



# PSPA

## CHRISTMAS SHOP



The 2023 Christmas range is available to buy from our website!

Help create a better future for everyone affected by PSP & CBD this Christmas by purchasing your Christmas cards and stocking fillers from our website shop!



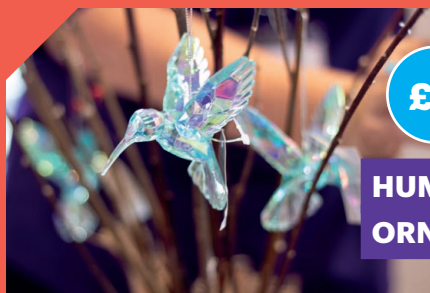
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