

# PSP **MATTERS**

SPRING 2020



**“I FELT FREE  
FROM CBD”**

## **ALSO INSIDE**

**Our New Research  
Strategy, Managing  
Carers Stress and  
Driving with PSP  
& CBD**

# WHERE THERE'S A WILL...

**We believe that with more funding we can improve diagnosis and treatment, with the ultimate goal of finding a cure for PSP & CBD.**

What if your lasting legacy could be a cure for PSP & CBD? Leaving a gift in your will could make a huge difference in beating these devastating diseases forever. Once you've remembered your loved ones, consider being part of the global fight to end PSP & CBD.



**YOUR  
LASTING  
LEGACY  
COULD  
MAKE  
HISTORY.**

[pspassociation.org.uk/fundraising/legacy](https://pspassociation.org.uk/fundraising/legacy)



## WELCOME

Last year we marked 25 years of PSPA. During the year, in both this magazine, and online, we shared key events in our history. Many people were involved in the early years of PSPA and donated their time to supporting the creation of our charity.

One of those key figures was Field Marshall Lord Bramall. Lord Bramall died last year at the age of 95 and it feels only right that we pay tribute to him and what he achieved for people with PSP & CBD.

Having joined the army at 18, Lord Bramall was awarded the Military Cross in 1945 for his bravery during the Second World War. He later became the head of the British Armed Forces.

PSPA founder, Michael Koe, served with Lord Bramall during their time in the army and asked if he would support his new charity. Lord Bramall duly became the charity's President and used his influence and standing to raise awareness of PSP & CBD. His office approached HRH, The Duchess of Gloucester to ask if she would be our Royal Patron. She accepted and continues to this day to hold that position.

While we pay tribute to Lord Bramall and will always remember his place in our history, we also take the opportunity to remember all those people affected by PSP & CBD. They are what inspire us (staff, volunteers, fundraisers) to continue to find ways to fight both of these devastating conditions. One way we will be seeking to do that is through our forthcoming new research strategy. You can read more about this on page 12 and 13.

As always, thank you for your continued support.

**Andrew Symons**, Chief Executive

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## USEFUL CONTACTS

Main contact **01327 322410**

**info@pspassociation.org.uk**

Helpline **0300 0110 122**

**helpline@pspassociation.org.uk**

Fundraising **01327 322414**

**fundraising@pspassociation.org.uk**

Volunteering **01327 356137**

**volunteering@pspassociation.org.uk**

Andrew Symons, Chief Executive

**01327 322413**

**andrew.symons@pspassociation.org.uk**

Carol Amirghiasvand, Director of Engagement,

**01327 356137 carol.amirghiasvand@**

**pspassociation.org.uk**





### EMERGENCY ALERT CARDS NOW AVAILABLE

These wallet and purse-sized cards are easy to keep on you at all times in case of an emergency.

As well as information about the symptoms of PSP & CBD and space to insert next of kin information, the cards have links to our interactive resource for healthcare professionals. This resource gives healthcare professionals easy access to the most up to date information about the conditions, meaning you'll receive the right care when you need it.

The cards are available from our Helpline  
Tel: **0300 0110 122**  
Email: **helpline@pspaassociation.org.uk**



### CHRISTMAS BAUBLE APPEAL RAISES OVER £22,000

Last year's Christmas Bauble Appeal raised more than ever before thanks to the thousands of you who donated a bauble in tribute to a loved one. As always we were very touched by reading your messages. Every bauble on our Christmas tree represented much loved parents, siblings, relatives, friends and partners.



### STAMP OUT PSP & CBD

We're raising money by recycling used stamps. Whether they're British or overseas, new or used, please send them to us and we'll turn your old postage stamps into money to support our vital work.

Stamps are sold by weight. As a general guideline we can expect to receive around £20 for one kilogram of stamps, so do encourage your friends and family, at home and abroad, to save their stamps for us. To donate, simply cut the stamp off the envelope. When cutting, leave approximately 1cm of envelope bordering each stamp.

Please send your stamps to: **PSPA**, Margaret Powell House, 415a Midsummer Boulevard, Milton Keynes MK9 3BN



### PLEASE REMEMBER TO GIFT AID YOUR DONATION

Thanks to Gift Aid, PSPA has received additional money from your donations that we have been able to invest in providing information and support to people affected by PSP & CBD, and fund vital research.

By signing up to Gift Aid, PSPA receives an additional 25% of your donation, at no extra cost to you. Gift Aid is a scheme that allows charities to reclaim tax on a donation made by a UK taxpayer, effectively increasing your donation. This means that, if you pay UK tax and agree to PSPA claiming Gift Aid, the government will give us 25p for every £1 you donate to PSPA.

If everyone who supported us in 2020 gift aided their donation, PSPA would receive tens of thousands in extra donations. Money that could be invested in research, or used to invest in our information and support services.



### JUST A REMINDER THAT FREEPOST PSPA IS ALL YOU NEED

In 2018 we set up a FREEPOST address – simply FREEPOST PSPA. That is all you need to write on the envelope. However some people have also included our actual postal address alongside the FREEPOST address. This results in PSPA receiving an extra charge of £2 per letter. So, please remember, if you are using our Freepost address, just simply write FREEPOST PSPA – it may not look like much of an address, but we promise it will get to us!



### SUMMER RAFFLE

When the days start to become longer and the weather a little brighter it can only mean one thing – our summer raffle is about to hit doormats. Entering our raffle is a great opportunity to try and win some extra cash. But, more importantly, it makes a huge difference to PSPA and helps funds our research programme as well as our information and support services. Once again there's three chances to win with the top prize set at £500. Tickets will be sent out in June.



**JAYNE TAYLOR  
AT THE GREAT  
NORTH RUN**

### DATES FOR YOUR DIARY

#### PSPA 5K

All of March

#### Virgin Money London Marathon

Sunday 26 April

#### Kiltwalk Glasgow

Sunday 26 April

#### Isle of Wight Challenge

Saturday 2 May

#### Leeds Family & Friends Day

Saturday 16 May

#### Jurassic Coast Challenge

Saturday 16 May



#### PSP & CBD Awareness Week

Monday 18 - Sunday 24 May

#### London 2 Brighton Challenge

Saturday 23 May

#### Edinburgh Marathon Festival

Saturday 23 - Sunday 24 May

#### ASICS LONDON 10K KATE, LYN, TORI



#### Virgin Money London 10,000

Monday 25 May

#### Kiltwalk Aberdeen

Sunday 7 June

#### Lake District Challenge

Saturday 13 June

#### Cotswold Way Challenge

Saturday 27 June

#### ASICS London 10K

Sunday 5 July





# NEW EVIDENCE SUGGESTS 10,000 PEOPLE MAY BE LIVING WITH PSP & CBD IN THE UK

Initial findings from the PROSPECT study have revealed there could be up to 10,000 people living with PSP & CBD in the UK at any one time, twice as many as previously thought.

The PROSPECT study, funded by PSPA uses MRI scanning, blood and cerebrospinal fluid samples, genetics, and clinical assessments to find ways of tracking disease progression, and improving diagnosis.

Baseline data from the first five years of the PROSPECT study has shown that 50% of people living with PSP had a delayed diagnosis because they initially presented with symptoms similar to other neurodegenerative conditions such as Parkinson's disease and frontotemporal dementia.

The study, led by Prof Huw Morris and Dr Edwin Jabbari from UCL, found that the different forms of PSP & CBD had distinct patterns of clinical, cognitive, MRI and blood protein results that can be used to improve early and accurate diagnosis in the clinic. Alongside UCL, the study represents a UK-wide collaborative effort with data also collected and analysed in Cambridge, Oxford, Newcastle, Brighton, Newport and Manchester.

Now baselining of the initial data collection has been completed, the study is entering into the second phase which will provide one year follow up data on disease progression in participants.

Dr Wendy Edwards, Research Manager at PSPA, said: "The initial results of the PROSPECT study provide an exciting development in our fight against PSP & CBD. PSP & CBD are regularly misdiagnosed with other neurodegenerative conditions such as Parkinson's and Alzheimer's due to the lack of specialist knowledge about these rare diseases. These latest ground breaking findings give PSPA the ammunition we need to campaign for increased awareness, better diagnosis and improved care for those living with PSP & CBD."

As the study continues Prof Morris and his team of researchers hope to discover biomarkers and diagnostic tools which will enable better outcomes for people with PSP & CBD in the future.

Prof Morris said: "With the support of patients, carers and PSPA we have completed the primary stage of the PSP – PROSPECT study. Surprisingly, recently described rarer presentations of PSP are as frequent as the classical form of PSP, indicating that the disease may be twice as common as previously thought. We hope that this improved understanding of the disease spectrum will lead to better, earlier diagnosis and ultimately to better treatments."

It's not too late to get involved in our PROSPECT study. Read page 14 to find out how.

## THE AIM OF THE PROSPECT STUDY IS TO:

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





## COPING WITH CARERS STRESS

While being a carer for someone with PSP or CBD is very rewarding, the pressure and expectations of caring can make carers particularly vulnerable to stress. There can be times when you feel you have little control over your situation or that you are in over your head.

Being a carer is a long term challenge both emotionally and physically, and when the stress of caring is left unchecked, it can take its toll on your health, relationships and state of mind. That's why taking care of yourself isn't a luxury, it's a necessity. Looking after your own emotional and physical wellbeing is just as important as making sure your loved one gets to their doctor's appointment or has their meals on time.

It's important to learn to recognise the signs of carer stress to prevent things from becoming worse. It will help you to make changes improving the situation both for yourself and the person you are caring for.

Common signs and symptoms of carer stress are:

- anxiety, feeling depressed and irritable
- tiredness, a sense of feeling constantly run down, even after sleeping or taking a break
- difficulty with sleeping
- trouble concentrating even on everyday tasks
- neglecting responsibilities, avoiding routine tasks
- feelings of resentment and impatience with the person you're caring for
- drinking, smoking or eating more
- new or worsening health problems
- cutting back on your own leisure activities, difficulty relaxing.



Feeling powerless and not being able to see a way to alleviate stress contributes to the burden. It's easy to fall into the trap of feeling stuck in the role and unable to see how you can change things. You can't always find the extra time, money or physical assistance you'd like, but you can always get more happiness and hope.

Allowing yourself to feel empowered to make changes, even small ones to improve how you feel is a good starting point. Learning to accept your situation, rather than spending a huge amount of your energy dwelling on the things you can't change and try to avoid the emotional trap of feeling sorry for yourself.

Acknowledging you've made a conscious choice to care and focusing on the positive reasons for that choice, perhaps because of your values and beliefs, or maybe to repay a parent for the care they gave you earlier in your life. You could think about the ways in which your caring role has made you stronger or brought you closer to the person you are taking care of and remember to celebrate the small victories. Remind yourself that ALL of your efforts matter, never underestimate the importance of making the person who you care for feel safe, comfortable and loved.

It's often difficult when a person has PSP or CBD for them to acknowledge and show appreciation for the care you provide due to the changes in their cognition and ability to recognise and show emotion. It's important to remind yourself that they would likely express gratitude if they were able, imagine how they'd respond if they were healthy.

Positive reinforcement doesn't have to come from the person you are caring for. Talking to a supportive family member or friend or telephoning PSPA's helpline can help when you are feeling unappreciated. Sharing how you feel and being listened to is often enough to alleviate these feelings. Do remember to speak up, don't expect family and friends to always know how you are feeling.

Leisure time may seem like an impossible luxury, but you owe it to yourself – as well as the person you are caring for - to fit it into your schedule. There is a difference between being busy and being productive - if you don't give yourself permission to rest and do something you enjoy, you'll end up accomplishing less in the long run. Taking time to de-stress and recharge your batteries will leave you feeling more energetic and focused.

To get in touch with our Helpline call **0300 0110 122** or email **helpline@pspassociation.org.uk**

## TIPS TO MANAGE CARERS STRESS

Maintain relationships, if it's difficult to leave the house, invite friends over.

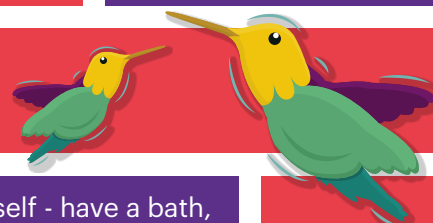


Share your feelings, it can be very cathartic.

Make time for activities you enjoy.

Sit down and take time to enjoy a cup of tea.

Feed the birds.



Be kind to yourself - have a bath, light candles, buy fresh flowers.



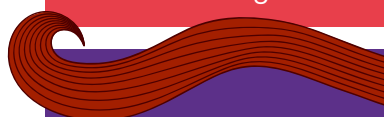
Practice relaxation - one minute deep breathing every half an hour or listen to some quiet music.



Make your bed with fresh sheets ready for a good night's sleep.

Write a list of things you feel grateful for in life and why.

Find three things to look forward to this year.



Wash and dry your hair.

Sing.

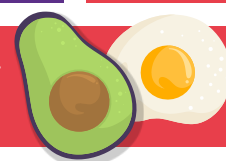
Spend 10 minutes alone.

Exercise - go for a short walk, stretch, dance.

Laugh, read a funny poem, watch a comedy, try to find humour in your day.



Eat healthy and nourishing food.



Look at old photos and reminisce.





# VOLUNTEERS MAKING US STRONGER THAN EVER

Recently we've seen a dramatic increase in the number of volunteers supporting us. Last year, our number of volunteers grew 50% to 155 people regularly donating their time.

Volunteers are vital to our charity. From overseeing how the charity is run (see page 26) to educating health and social care professionals, volunteers are involved in all aspects of our work. To help us deliver more for people affected by PSP & CBD we need to grow our volunteer support even further. Quite simply, the more volunteers we have, the more we can do.

## MICRO VOLUNTEERS

Our latest volunteering opportunity, micro volunteering, is perfect for people who find it hard to commit to a regular volunteering role. Micro volunteering can be anything from cheering on our London Marathon runners, to helping at PSPA events or reviewing our information. It doesn't matter if it's for a day a year or an hour a day.

Anjel Lancaster became one of our youngest micro volunteers when she joined her grandma, Pam at last year's London Marathon. Pam volunteers for PSPA as a Community Outreach Volunteer and also helps out at the Kent Local Group. Anjel shares why she wanted to get involved.

"My Nan has been involved with the charity for a while. I've done bake sales to help raise money but I've never volunteered before. I know what Grandad had was quite rare so I wanted to volunteer for him.

"Nan spoke to me about helping out at the London Marathon. I've never been to London on Marathon day so I was excited to see all the runners, and how all the charities were supporting them. It was cool to see all the charity signs all over the place.

"We cheered the runners at a designated cheering post and also at the after race reception. It was a very friendly atmosphere and I spoke to a few people. Everyone had been affected by PSP or CBD. I definitely want to do it again next year. For me, helping out like this is a way of keeping Grandad's memory alive."

## EDUCATION VOLUNTEERS

Christina Wigg joined PSPA as an Education Volunteer 18 months after her husband David died from CBD. Christina said: "I found out about the Education Volunteer role during one of PSPA's Local Support Group meetings.

"David had so many incorrect diagnoses. I wanted to help people to understand the disease, especially health care professionals. My first talk was at Teesside University to psychology students. I was nervous but shared my story and experience of caring for David.

"I have a busy life, with looking after my grandsons two days a week, and meeting friends, so I don't



want to get too tied down. However, the Education Volunteer role is perfect for me and completely flexible, so I can easily fit it into my life. My daughter said David would be proud of what I am doing. I think he would be too – and that is a lovely thought.”

### LOCAL SUPPORT GROUP COORDINATOR

Val Wallace decided to become a Volunteer Support Group Coordinator after her husband was diagnosed with PSP and they found there was no support locally. Val said: “We live in Stockport and had initially travelled across Manchester to our nearest Support Group. Dealing with the M60 took so long we knew attending on a regular basis wouldn’t be a realistic option for us.

“Neil’s physiotherapist told me about a group of people with PSP who were meeting up at a local hospice. After making contact with the group and securing the hospice as an ongoing venue, I contacted PSPA and that is when it all kicked off. They emailed everyone living within a 15 miles radius and the replies were so enthusiastic, I knew this group was much wanted. 18 people attended the first meeting, where everyone shared their situation and outlined any problems they were experiencing. I was so thrilled at how it went, I booked up meeting dates all the way up to Christmas.

“Being involved in the group has really provided me with something positive to focus on. I feel like I have some direction and I’m motivated to help others living in my area. I’m so glad I took the first step.”

### HELPLINE VOLUNTEER

After her father died from PSP Liz Baxter wanted to help others affected by the disease. Liz said: “After Dad died I thought, I have all this time on my hands I should give something back. Then I saw a volunteering advert in *PSPA Matters* and I thought I’d call in and see if I could be of use to someone.

“I work full time but volunteering on the Helpline doesn’t interfere too much with my private life – it is just a couple of evenings a month. The other volunteers are great and always happy to swap evenings on the rota if needed, so it is easy to commit to and be flexible.

“With both PSP & CBD being so rare and the symptoms being so unusual and at times alarming, it comforts me to know that people affected by PSP & CBD can pick up the phone and speak to someone who has been there and who understands.”

### COMMUNITY OUTREACH VOLUNTEER

When people receive a diagnosis of PSP or CBD it is life-changing. They can feel very alone, frightened and anxious about what is ahead. Having someone come along and visit you to talk things through can make such a difference.

Our Community Outreach Volunteers provide a vital support service to people affected by PSP & CBD. They are based in the community and will be in contact with people over the phone, via email or will visit them in their home. In areas where we have Community Outreach Volunteers they provide valuable support. Sadly we currently only have a small number of volunteers carrying out this role and we desperately need more.



CHRISTINA WIGG



LIZ BAXTER



ANJEL LANCASTER



VAL WALLACE

Email [volunteering@pspassociation.org.uk](mailto:volunteering@pspassociation.org.uk) or call **01327 356137** to find out more about becoming an outreach, education, helpline, micro volunteer or local group volunteer.  
[pspassociation.org.uk/get-involved/volunteering](http://pspassociation.org.uk/get-involved/volunteering)



# OUR NEW RESEARCH STRATEGY TO BEAT PSP & CBD

We know PSP & CBD are complicated conditions. Sadly, we also know very little about them. People are waiting far too long to receive a diagnosis and, once diagnosed, clinicians are unable to offer treatment options to help treat or slow down progression.

Research is happening to help improve clinicians ability to make earlier diagnoses and discover effective new treatments. We fund some of this research, and, in the future, aim to fund much more. In the last edition of *PSPA Matters* we shared the news that we are developing a new research strategy

to maximise our impact on unlocking some of the secrets of PSP & CBD. This work is well underway and we are consulting with researchers, clinicians and other health professionals alongside people living with PSP & CBD, carers and family members. In particular we are asking people affected by these





conditions to identify their top priority research questions in PSP & CBD.

Asking patients to identify their top ten priority research questions has been undertaken by other charities and is commonly used by clinical study groups of the National Institute for Health Research (NIHR) which is the research arm of the NHS. In an era of accountability, we must ensure the research we fund is relevant and that the findings will provide the evidence needed in the NHS to improve the care of people living with PSP & CBD. NHS services must

be evidenced-based and as such, if we are to help secure better care for people with PSP & CBD, we must support evidence based research which can be implemented into the NHS system. This means ensuring that research outcomes being assessed are ones that truly matter to patients.

In December 2019, Dr Wendy Edwards, Research Manager at PSPA launched a research priority study asking people living with PSP & CBD what research they would like to see undertaken. In answering the questionnaire, people were asked to think about their own personal experiences and what difficulties they faced each day living with PSP & CBD.

Wendy said: "Through funding innovative research, we aim not just to improve diagnosis and discover effective treatments, but also look to identify better ways to improve the health, quality of life and care for patients.

"The results of this study will help our charity fund research in the areas where there are gaps in knowledge. I'm excited to be leading on the development of the new research strategy and hope to tell you more about our future plans in the next edition of *PSPA Matters*."

Alongside funding research into new treatments and biomarkers for improved diagnosis, we asked people to consider research into improving the quality of life and care for people living with PSP & CBD. This type of research is aimed at helping to better manage symptoms. For example, specialised physiotherapy interventions to improve strength and mobility, speech therapies, cognition tools and improvements to swallowing and eating.

In January 2020 we launched an online version of the research priorities questionnaire. To date we've received over 130 completed questionnaires with over 2,000 research questions – many of which overlap. The questions have been edited into a shortened list for our PSP & CBD community to rank in order of priority for researchers to answer.

If you didn't get a chance to take part in the first stage of the study now is your chance to get involved. Have your say by helping to rank the questions into a priority list which will give us our Top Ten Priority Research Questions. You can do this by visiting the Research pages of our website [www.pspassociation.org/research](http://www.pspassociation.org/research)



## FUNDING FUTURE CLINICIANS

Both PSP & CBD are complex diseases. To help support research efforts so that we can learn more and turn that knowledge into treatments we must support the careers of researchers. To help build and strengthen PSP & CBD research capacity, we use some of our research investment to encourage clinicians and researchers to embark on a career in PSP & CBD.

Dr Danielle Lux is a neurology registrar and clinical research fellow at UCL Queen Square Institute of Neurology. Danielle's research study into CBD is part-funded by PSPA and CBD Solutions. Here, Danielle gives an insight into her work and why she wants to focus her career specialising in cognitive and movement disorders.

Danielle said: "This is my first time working on a research study in a more senior capacity. As a researcher it's exciting to be involved in decisions around study design, data analysis and exploring how to answer or contribute to the expanding knowledge of this complex condition and develop collaborations. As a clinician, my involvement is invaluable for developing specialist knowledge that I hope will benefit people living with CBD & PSP, both now and in the future.

"My research forms part of the UK-wide PROSPECT study led by Prof Huw Morris and we have extended this uniquely for CBD patients recruiting across Europe. Our chief aim is to understand the many different guises of CBD, track the progression and identify biomarkers to help improve diagnosis. Through identifying changes on MRI scans, cognitive profiles and blood, fluid and genetic tests, we hope to be able to map out disease markers that can be used in future drug trials to assess response.

"Throughout my career I've always been interested in the overlap between memory and movement disorders. Understanding why and how the pathology starts and then spreads as it does to involve these different functions is fascinating and we still have so much to understand about the entire area of neurodegeneration. My motivation is to be able to make patients' lives better by improving early diagnosis and finding treatments that help slow down or even halt the disease.

"Sadly there is a distinct lack of awareness on conditions like CBD & PSP even within the medical community. Both conditions can be hard to diagnose, in particular as they may mimic more common conditions like Parkinson's disease or Alzheimer's and a lack of awareness of these atypical features can cause further delays and we are likely underestimating its prevalence. Increasing awareness of these conditions is critical so that we can improve our understanding of it, but will be even more relevant in the future, when we may have treatments available.

"It can often take a while for patients to be diagnosed and may require several investigations and specialist



opinions. And while we don't have treatment options at the moment to slow down or halt progression, delays in diagnosis can cause additional stress and deny patients the ability to plan for the future or access support. However making the diagnosis is difficult with some patients diagnosed with CBD having a different but similar pathology, unfortunately also without any definitive treatment. Equally, we also know that almost half of patients who have CBD present in a different way such that they are diagnosed with something else other than CBD in life.

At the moment, the gold standard diagnosis is only made on post-mortem and we are very grateful to all the patients with PSP & CBD who agree to brain donation. This helps us in understanding how sensitive our testing is and look for features that may alert us to something else.

"Thanks to patients' commitment to research, we already have 130 patients involved in the study and will be recruiting patients for at least the rest of the year. If anyone is living with CBD and would like to be involved in our study, please ask your consultant to refer you to Professor Huw Morris at UCLH.

"We appreciate not everyone is able to come into clinic for MRI tests and other assessments. For those who want to still be involved, we have an option to be involved remotely with postal surveys and a blood test. For patients who are able to participate in a more in-depth way, their participation provides us with valuable information in the discovery of biomarkers including imaging, genetics and memory profiles. Usually patients spend a day with us and will undergo an MRI scan, lumbar puncture, eye movement assessments and cognitive tests.

"As a clinician receiving funding to undertake a study like this means I get dedicated time in my training to grow my interest and knowledge in CBD and associated conditions, probe areas of current research and develop research ideas of my own to incorporate into study design. I get to develop skills through working within a research team so that I can continue doing research throughout my career as well as taking the expertise back into my clinical practice.

"There is a lot of work being done by researchers to understand these conditions. It's incredibly rewarding to be part of this research and through collaborations and sharing data, collectively we are building up a picture of CBD we can then use to discover effective treatments and change the lives of those with CBD & PSP."



### CREATING FUTURE LEADERS IN PSP & CBD RESEARCH

Prof Huw Morris was one of the first people to receive a Research Fellowship grant from PSPA back in 1997. Since then Huw has gone on to become a Professor of Clinical Neuroscience at the Royal Free Hospital, National Hospital for Neurology and Neurosurgery and UCL Institute of Neurology. Prof Huw Morris is Chief Investigator on our UK-wide PROSPECT study, a ground-breaking project that aims to increase understanding of PSP & CBD, improve diagnosis and ultimately support more effective clinical trials.

Huw said: "I received a grant from PSPA to investigate the genetic aspects of PSP. That grant, over 20 years ago, triggered a lifelong career interest in PSP and tau research. It also helped me to secure a much larger grant from the Medical Research Council to continue the study.

"There is always a bit of tension between funding projects or people, but in reality, you need to do both. Funding someone at the start of their career will stimulate an interest in that condition. As a mentor of junior clinical fellows, I see this every day. Investing in a clinical research fellowship enables someone to focus and build up specialist knowledge. For clinicians training to be a neurologist, funding like this allows them to take three years out to understand the condition and become an expert. They will likely go on to lead clinics and research studies in the future, greatly contributing to the care of people living with PSP & CBD."



## DRIVING WITH PSP & CBD

For most of us, driving is an essential means of getting around and an enjoyable activity enabling us to discover new places and meet friends. A diagnosis of PSP or CBD does not automatically mean you have to stop driving straight away. Depending on how your symptoms affect you, you may be able to continue to drive for some time.

However you are legally required to disclose the diagnosis to either the DVLA in England, Wales & Scotland, or DVA in Northern Ireland. You also must inform your insurance provider. Failing to notify them of your diagnosis is a criminal offence and you can be fined up to £1,000. Unfortunately you may also be prosecuted if you are involved in an accident as a result of being disabled and not having disclosed your diagnosis to both the DVLA (DVA) and your insurer. Don't forget to check when your driving licence is up for renewal. DVLA recommend that you renew your licence two months before it expires.

We know that choosing to no longer drive can be a difficult decision. Practically it causes issues,

especially if you are the main or only driver in the home, but equally important is the emotional impact from the loss of independence driving can offer. If you live in England, Wales or Scotland and have chosen to give up driving or had your driving licence removed for medical reasons, you may be entitled to a free bus pass, whatever your age. You will need to contact your local council in England & Wales or local authority if you live in Scotland to find out more.

If you mainly make local trips, using a taxi could work out cheaper than running your own car. You may be able to set up an account with a local taxi company and agree a set price for weekly journeys. If you receive Attendance Allowance (AA) or Personal Independence Payment (PIP) you could choose

to spend some of it on taxi fares or other ways of getting around. Most areas will have pre-bookable community transport schemes, contact your local council or PSPA helpline to find out what is available near to you.

Railcards allow you to purchase a train ticket at a reduced price. A Senior Railcard is available to everyone aged 60 and over, and a Disabled Persons Railcard is available for people with a disability that meets the eligibility criteria. More information can be found online at [railcard.co.uk](https://railcard.co.uk)

### BLUE BADGE

The Blue Badge scheme operates across the UK and provides certain on-street parking concessions when someone has a disability or health condition that affects their walking, or a hidden disability which affects cognition and mental health.

The Blue Badge holder can be either the driver or a passenger in a car. You can use your Blue Badge in any car, including taxi's and community transport cars. Concessions usually include:

- Free parking at parking meters and Pay and Display bays (always check the information on the payment meter as places such as hospitals, supermarkets and private car parks or private roads may have their own rules)
- Parking on some single or double yellow lines for up to three hours, providing there is a 'no loading' restriction
- In London you don't have to pay the Congestion Charge if you are a Blue Badge holder but you must register with Transport for London for the 100% discount
- You can't use your Blue Badge everywhere. To check where you can park visit [gov.uk/where-registered-disabled-drivers-can-park](https://gov.uk/where-registered-disabled-drivers-can-park)

You can apply for a Blue Badge online at [gov.uk/apply-blue-badge](https://gov.uk/apply-blue-badge) or contact your local council for a paper version of the form. If you complete a paper form, remember to keep copies. You may be able to take original documents to your council office or local library to be photocopied and submitted rather than sending them in the post.

Our helpline is able to offer further information about the process when informing the DVLA/DVA about your diagnosis. Supporting letters with information about symptoms of PSP & CBD are available for you

to use when either informing the licensing agency or applying for a Blue Badge. To request a supporting letter or for more information about driving and transport, please call our helpline between 9am-5pm Monday- Friday on **0300 0110 122** or email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

**“IT’S INCREDIBLY DIFFICULT WHEN YOU HAVE BEEN DRIVING ALL YOUR LIFE BUT SUDDENLY CAN’T. IT FEELS LIKE YET ANOTHER THING THAT HAS BEEN TAKEN FROM YOU.”**

Peter Harrison shared how his wife Christine had to give up driving, but that in the end it was the right thing to do. “Christine had to give up driving last July. We’d alerted DVLA to her diagnosis and they wanted her to undertake a special driving test. In reality we both knew she wouldn’t pass.

It’s incredibly difficult when you have been driving all your life but suddenly can’t. It feels like yet another thing that has been taken from you. We had a few tears at the time. However, now she realises that it was the best thing to happen. It was too risky otherwise. It also helped me that a third party was telling her she could no longer drive, and not me telling her. Like with all things we have adjusted to this new reality.”





**“THESE ARE  
EXCITING TIMES  
AND WE  
IMPATIENTLY  
AWAIT A  
BREAKTHROUGH”**

Dr Alistair Church is a GP and Associate Specialist in Neurology who spends part of his time running a PSP & CBD clinic in the Neurology Department at Royal Gwent Hospital. Alistair has been involved in a number of drug trials and shares how he is optimistic treatment options will be available during his working lifetime.

Alistair said: “After I qualified as a GP, my wife and I moved to Wales. My wife is a dermatologist and had an office next door to a neurologist with a large and constantly growing waiting list. As a junior doctor I’d covered neurology and had an interest in the area. There was clearly a need for more clinical support so I started running a movement disorder clinic with Prof Huw Morris. Huw’s interest was in Atypical Parkinson’s, and we started seeing patients with PSP, CBD and MSA. Involvement in drug trials quickly followed. When Huw moved to UCL, I continued with the clinic and its involvement in drug trials.

“Being a GP, and seeing patients in clinic affords me the best of both worlds. As a GP you have a unique relationship with your patients. You get to know them, understand where and how they live, how they function. Whereas in hospital you get a more specialist view, and this enables you to develop more specialist knowledge.

“Before our clinic, people with PSP or CBD would have previously been seen in a general neurology setting. For patients, this would likely mean seeing a different neurologist at each hospital appointment. It is far better for people with PSP & CBD to have access to a specialist clinic, where they know who they will be seeing. I’m grateful we are able to offer this in Wales.

“Once a diagnosis has been made, or more likely confirmed, patients typically ask how long they have left. This is the hardest question to answer. It can be very difficult to predict the rate of progression. We might see some patients for years, whereas others pass through very quickly. Alongside this, by the time patients have come to me, they are likely to have been living with the disease for quite some time.

“The next typical question is much easier to answer – what can you do for me? Sadly there is currently no treatment for PSP or CBD, but there is still much we can do to help manage patients’ symptoms and maintain the highest possible quality of life. The management of PSP & CBD has evolved rapidly over the last 20 years. Back then palliative care was predominately for cancer patients and we didn’t have access to the technologies we do today.

“Treatments and interventions have been developed to help patients maintain the best possible quality of life. Sadly none of these have been shown to slow progression, but can improve the quality of their life. The nature of PSP & CBD requires access to many different areas including dieticians, speech

and language therapy and physiotherapists. Hospital based, community rehabilitation teams and palliative care teams can work well together, shifting emphasis and changing roles as the needs of people with PSP or CBD evolve. PEG tube feeding, communication devices, PRISM glasses, Botox and drugs to manage mood and impulsivity can all help manage the many and diverse symptoms of both PSP & CBD. Evidence showing the importance of coordinated multidisciplinary care is growing. Sadly at the moment in PSP & CBD care is not as joined up as in other areas. However PSPA has done an amazing job in influencing service delivery and pushing up standards. My ultimate goal would be to provide patients with access to all these services in one clinic setting.

“Before making or confirming a diagnosis of PSP or CBD I always try to understand what the patient’s expectations are. It is highly unusual for me to see a patient who has no idea what’s wrong. Usually by the time they’ve come to me they are pretty well aware of what they are facing. A large number of patients have lived for a number of years with a Parkinson’s diagnosis, but as soon as I see them it’s clear it’s PSP. When I ask what their first symptom was most say falling over backwards. That should be a red flag to all doctors considering a diagnosis of Parkinson’s disease.

“As a doctor it’s encouraging to be able to tell patients that drug trials are happening, and that there are ways for them to get involved in research if they wish to. We have just completed the PASSPORT trial where I saw two patients regularly for 18 months. I asked their wives to send me photos of their husband before they developed PSP. Seeing them enjoying life really highlighted how much the condition has taken from them.

“Participating in the trial took a huge effort from them and their wives, with regular trips to clinic. But, you could see how determined they were to do this as a way of fighting back against the disease. Watching how brilliantly their wives took care of them showed the huge impact carers have. It must be incredibly difficult to assume the role of carer. They have a huge impact on the patient’s quality of life and it’s vital they are supported.

“Sadly none of the trials we have been involved in so far have been successful. However that’s not to say that they have not been valuable. Every trial has added to our growing knowledge of both conditions. We should also be thankful that drug companies are

investing their time and resources into these trials. Without them it would be quite desolate out there.

“Our big challenge is that we are not picking up patients early enough for them to fit the criteria of drug trials. Usually drug trials require patients who are early on in their disease progression. However the difficulty in early diagnosis is hampering our ability to do this.

“The PROSPECT study has been a big game changer in terms of building our knowledge on PSP & CBD. Recent findings from the study (page 6) that has revealed many more people could be living with PSP & CBD is interesting. Larger numbers of patients can help have an impact on the care people with PSP & CBD receive. It helps to increase awareness and also drug companies are far more likely to focus on more prevalent conditions.

“These are exciting times and we impatiently await a breakthrough. I look upon my MS colleagues with envy. It took a lot of money invested in MS research, but now they have treatment options for people with MS.

“Hope is so important and work in laboratories across the world is providing that hope. We are learning so much now and our ability to understand what we are learning has improved greatly. Work is ongoing to develop biomarkers. In the PROSPECT study led by Huw they are comparing the biomarkers of 2,000 patients with Atypical Parkinson’s including PSP to further understand these conditions. The ultimate aim is to develop a biomarker that might help in diagnosing PSP. Brain imaging is also helping us to learn more about patients’ brains and the relationship between specific areas of the brain and what function they serve. Both biomarkers and brain imaging we hope will help us diagnose patients earlier, and, importantly recruit patients to drug trials much earlier.

“In ten years I hope to offer patients treatments that will help at least slow the progression of their disease. Ideally, I’d like to be in a position where I can offer patients different personalised treatment options. Something that a few years ago may have seemed impossible, but, with the work that is taking place, appears a much more realistic ambition today.”

If you would like to raise awareness of the symptoms to look out for in PSP & CBD please download our Red Flag toolkit from our website or contact our helpline for a copy.



KEN &amp; PAT ARCHER

## **“GOOD SUPPORT IS VITAL TO HELP RECHARGE MY BATTERIES”**

Just before his 81st birthday, Kenneth Archer, will be part of a six-strong crew aboard a sailing yacht for a 12 day trip from Dubrovnik, to raise funds for PSPA.

Ken is a full time carer for his wife Pat, who is living with PSP. He talks about the importance of fighting to get the right support and why respite is so vital for carers, even if it does include sailing the Adriatic Sea.

Ken said: “Pat and I retired 15 years ago. We were enjoying a full and active retirement filled with volunteering, holidays, new activities and time with family and friends before it became apparent something was wrong, health-wise, with Pat.

“During her life Pat never took a day off work through illness. Indeed, the only time she went to the GP or hospital was during two pregnancies. However, slowly and surely things with Pat weren’t as they should have been. After a number of appointments and consultations, Pat was diagnosed with Parkinson’s. A year later the diagnosis was changed to PSP.

“Thankfully we have always made sure we planned ahead for the future. Nine years ago we had downsized to a bungalow. It soon became obvious we wouldn’t be able to cope by ourselves, so we applied for a care-assisted apartment in Flint, with 24/7 care. Due to Pat’s increasing deterioration, social services eventually became involved and agreed to provide carers two nights a week so I could have some respite. This support is a lifeline and means I can take some time out during the week and recharge my batteries, something that is really important as a full time carer, whilst also having professional support workers available 24/7.



## **“PAT HAS HER GOOD AND BAD DAYS. SOME DAYS IT’S LIKE SHE’S HARDLY CHANGED, YET OTHERS SHE CAN BARELY TALK.”**

“Pat has been living with PSP for six years. Life has changed beyond all recognition. We continually have hospital appointments and are no longer free to enjoy travelling. Pat doesn’t want to fly and it’s not the same without her. However, we do focus on making the most of our time together and I aim to take Pat out every day.

“I am entirely focused on Pat. I’m able to do this by securing help from many others so I can continue, with my own interests. With a condition as complex as PSP, which is relatively unknown, you need to inform people to get the best care. Over the years I’ve found if you don’t encourage people to do things, you will be left on your own to cope. You sometimes have to fight to secure the best care, which is my priority. Pat’s welfare is paramount so I will do whatever I can to make sure she has access to all the care she needs.

“We are fortunate we have carers in 30 minutes every morning to assist Pat with washing, dressing and breakfast and every evening for 15 minutes to ensure Pat is ready for bed. Alongside this we have sensors installed so that when Pat gets out of her bed it sets off an alarm that alerts the carer, but not me, so I am able to sleep through the night, leaving me fit and able to care for Pat during the day.

“Pat has her good and bad days. Some days it’s like she’s hardly changed, yet others she can barely talk. She shuffles rather than walks and struggles to get in and out of the car. However, the biggest change is in her brain. Sadly Pat is not the woman she was. Pat was very intelligent, way above my IQ level, but not anymore. For me that is one of the hardest things to deal with.

“Pat and I have always supported various charities, and I was keen to do something for PSPA after the charity supported us. The information both on the website and in *PSPA Matters* is so useful in learning to live with the condition. Supporting PSPA is our way of saying thank you.

“Upon retiring Pat and I became active members of the Flintshire University of the Third Age (U3A). Last year I read an article about a U3A group that had sailed from Dubrovnik, where the oldest member was over 80 and had never sailed before. That sparked an idea that perhaps I could take on this challenge and raise funds for PSPA at the same time. My limited sailing experience of being on board ferries from Birkenhead to Liverpool and Dover to Calais wasn’t enough to put me off.

“After some thought I decided to embark (note my new use of sea going language) on this challenge for three reasons. Firstly to enjoy some respite from my role as carer to my wife Pat, secondly to try something new before my 81st birthday and finally (and most importantly) to raise funds for PSPA. Prior to my departure I shall be circulating these details and on my return to the UK I’m offering to speak to local groups about my experience in return for donations to PSPA.

“I’m excited about my forthcoming adventure and also at the prospect of raising awareness and funds for PSPA. Of course I wish Pat was coming with me, but I know she will be supporting me from home.”



**KEN & PAT ARCHER**



## STUDY TO HELP IMPROVE CARE FOR PEOPLE WITH PSP & CBD

Three years ago neurology registrar Dr Diane Swallow embarked on a research fellowship in Scotland, jointly funded by PSPA and the Scottish Chief Scientist Office. With the study now in its final stage, Diane shares how it will help clinicians better ensure people with PSP & CBD receive the right care.

Diane said: “Over the last three years, nearly 100 people with PSP or CBD have been recruited and followed as they have progressed with their condition. Many nominated a family member to take part alongside them, meaning we also benefited from the gathered experience of carers. For each person with PSP or CBD involved in the study, we also invited a person of the same age and gender with a diagnosis of Parkinson’s to take part, which will enable us to make important comparisons between PSP, CBD and Parkinson’s, and investigate ways to differentiate these conditions early on.

“We’ve recently completed all the follow-up clinical and MRI assessments, and are in the process of checking, analysing and interpreting the information we have collected through the various questionnaires, movement and cognitive assessments, videos and MRI scans over the last three years. As we gradually and systematically process this information, we will increase our knowledge and evidence base in PSP & CBD which in turn, we hope, will lead to improvements in diagnosis and care. We will, for example, explore the reasons for difficulties in making an accurate and timely diagnosis of PSP or CBD, allowing us to target the right health professionals with education about PSP & CBD. We will assess whether new measurement tools or imaging techniques could be used in clinics to help doctors make an accurate diagnosis of PSP or CBD. By trying to better describe how the needs of people with PSP or CBD (and their carers) change

over time, we can better ensure the right care and treatments are put in place at the right time.

“Attempting to make inroads in answering any of these important unanswered questions in PSP & CBD, would have been impossible without the partnership of individuals with PSP & CBD and their families - the true experts in these diseases. We are indebted to those who, through openly sharing their personal experience of PSP or CBD, and giving so generously of their time and energy to the Scottish PSP & CBD cohort, offer hope to those who will tread the same challenging pathway after them.”

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**“OVER THE LAST THREE  
YEARS, NEARLY 100  
PEOPLE WITH PSP OR CBD  
HAVE BEEN RECRUITED  
AND FOLLOWED WITH  
THEIR CONDITION.”**

**ROSALIND AND  
DAVID PUGH**



## **“WE WANT TO DO WHAT WE CAN TO FURTHER RESEARCH”**

When Rosalind and David Pugh read about Diane Swallow’s research taking place in Scotland they wanted to help. Since Rosalind’s diagnosis of PSP in 2017, she has been determined to do whatever she can to help further research into the condition. Her husband David explains why.

“Like with many others, Rosalind lived with the symptoms of PSP years before she knew what it was. Sadly, like many others, we soon learned how little is known about the disease. During her journey to diagnosis, Rosalind had two MRI scans months apart. The second scan was not made available to the neurologist we saw, only the radiologist, who said there was no difference between them. It was only after I complained, was I assured the second scan would be made available to the second neurologist we were referred to. She said Rosalind had a classic hummingbird pattern for PSP. It would appear some specialists are unable to identify different brain patterns, hopefully this will change with more publicity.

“A couple of years ago we read about Diane’s project in *PSPA Matters*. After experiencing a lack of awareness about the condition we were both keen to be involved. Rosalind is especially keen to do all she can to help further research into PSP and has arranged to donate her brain and spinal cord to the Queen Square Brain Bank, UCL. She knows it sadly won’t help her, but is comforted that it may help those who come after. We contacted Diane, who visited us at home and examined Rosalind. We gave Diane permission to access Rosalind’s medical files, including her previous MRI scans.

“Diane left us with a lengthy questionnaire to complete. Following this Rosalind underwent an MRI scan in January 2019, that is being repeated this January 2020. Taking part in this study is one thing we can do to add to the body of knowledge around PSP and hopefully assist Diane in formulating a means of achieving an earlier diagnosis of PSP than the medical profession are currently able to do.”



# "I FELT FREE FROM CBD"



After four years of unexplained symptoms Ruth Tillard was told she had CBD. A mum to five children, Ruth was used to a very physical lifestyle running a smallholding, riding horses and enjoying spending time outdoors. Now, at 60, Ruth and her family had to face the news that her ability to do these things would greatly deteriorate due to CBD.

Determined not to give in, and to focus instead on what she could do, Ruth decided to leave her wheelchair and jump 12,000 feet out of a plane. What's more Ruth didn't jump alone. Ruth's daughter Roxy and 87-year-old father jumped alongside her. The family hoped to raise £1,000 for PSPA. Once news got out about their plans the donations poured in, with the family raising over £10,000.

Ruth, along with husband Richard and daughter Roxy talk about the experience and how, in the face of such a devastating diagnosis, it gave them something positive to focus on.

Ruth said: "I'd always wanted to do a parachute jump. Reading *PSPA Matters* I saw how you could do it to raise money for the charity so the idea was formed. When I spoke to my family about it my daughter Roxy decided to do it with me."

Richard contacted the airfield to see if Ruth would be able to jump. Richard said: "The airfield was pretty relaxed about it and said so long as Ruth could raise her legs up for the landing she would be fine. Ruth's mobility and speech were deteriorating, but despite struggling to walk she could lift up her legs so was fit to fly.



"Since Ruth's diagnosis we try to do what we can to help maintain her mobility. Of course we've had to adapt, so rather than riding horses she now goes in a pony and trap, and we go for our weekly tandem bike ride. I found the HealthUnlocked forum very helpful for finding out ways to live with and manage the disease. Once we had organised Ruth's parachute jump I posted on HealthUnlocked and received many lovely messages, such is the nature of the supportive community that is on there."

"When we told Ruth's father about the jump he immediately said he would do it too. At 87, he needed clearance from his doctor. With clearance in place he made plans to fly from his home in the Isle of Skye and join Ruth and Roxy on the plane."

With three generations set to jump Roxy decided to set up a Just Giving page to raise money for PSPA. Roxy said: "We had no idea how much we'd raise. I thought £1,000 might be a realistic target, but it just snowballed. I created a poster of Mum in her wheelchair falling out of a plane and stuck them around the village. I also shared it on Facebook and had an article in the Parish magazine. Then, suddenly, we were in the news, with ITV Meridian covering the jump."

For Ruth the attention around the jump helped her reconnect with old friends by showing what she had and how she was dealing with it. Ruth said: "I had a lot of support from friends, including people I hadn't

seen in a while. Reading the comments on the Just Giving page gave me such a boost."

Roxy continues: "One of the things that really resonated with me is how Mum was able to show that this horrible disease will not hold her back from the things she wants to do. For all of us it gave us something positive to focus on. On the day of the jump Mum said she was nervous but she looked so cool – like a rock star. It was pretty surreal watching my mum and grandfather jump out of a plane before me."

Richard from his safe position on the airfield describes the moment Ruth broke through the clouds. "It was a nervous wait once they had disappeared above the clouds, but when I finally saw Ruth she looked serene." For Ruth the feeling was even more powerful. "I felt free. For the first time I wasn't aware of my restricted mobility, or had anyone telling me what to do. It was also pretty exciting, and was even more special to be able to do it as a family. I'm touched by all the messages we received and I'm very grateful to everyone who donated. People we hardly knew were donating - it was extraordinary."

With feet firmly placed back on the ground Ruth still has much to look forward to. "I recently became a grandma for the first time. I'm surrounded by my wonderful family and I have much to live for."

If you've been inspired by Ruth's story please visit [www.pspassociation.org.uk/events-list/skydive](http://www.pspassociation.org.uk/events-list/skydive)





## FROM FUNDRAISER TO BOARD MEMBER

A huge part of PSPA, and the charity's ability to deliver its services to people affected by PSP & CBD, is our volunteer support-base. Volunteers are involved in all aspects of PSPA, from the helpline to educating health and social care professionals. Volunteers are also involved in ensuring the charity is run and managed effectively.

Our Board of Trustees are a group of volunteers who are responsible for the strategic direction and governance of PSPA. Being on the Board demands time, commitment and ability. There are meetings to attend and board papers to read. Board members provide support to the staff team and carefully scrutinise the finances and ensure the charity is having an impact.

Every member of the Board brings with them specialist skills to ensure PSPA adheres to its charitable objectives. The latest person to join the Board is Jon Garrard. Here, Jon talks about his transition from fundraiser to Board member.

Jon said: "It's hard to believe it's been over two years now since my dad, Chris, died from PSP. I'll never



forget hearing the news. At the time the more I read about the condition, the more depressed I felt.

“Dad was a brilliant man. He was young, enjoying his retirement and suddenly everything was taken away from him. The turning point for me came when my wife Emma said that being so depressed wouldn’t help my parents and that I needed to find some positivity. Finding something positive in the face of PSP seemed impossible, but we decided to organise a Christmas craft fair for PSPA. For the first time since Dad was diagnosed, we felt like we were doing something really constructive. It was such a rewarding and happy thing to do. I liked how it made me feel, and that spurred me on to raise as much money as I could to help other people affected by PSP. I know Dad was touched by our fundraising. It was a very visible way of us showing how much he meant to us. I also saw how the charity supported my family and I wanted to give back.

“When I was first approached about the possibility of becoming a trustee I knew immediately I wanted to do it. I’m a big fan of PSPA and what the charity does. PSPA want to cure PSP, but they are also committed to supporting people who have the disease today and their families. Without its support life would have been so much harder for my family. For me, being on the Board is another way I can do whatever I can to help PSPA achieve its very highest aims and aspirations in terms of finding a cure for PSP & CBD and supporting those affected.

“I had to wait two years before I could be appointed. Looking back I understand why the charity has that measure in place for people who have lost a loved one to PSP or CBD. During the two years since Dad died I’ve hit some real low points when everything has come flooding back. I feel stronger now, and ready to use my experience in a positive way.

“Chair Simon Koe and Board member Shauna Mackenzie interviewed me to make sure I was suitable, and that my professional skills would be a good fit with the other Board members. It’s important the Board brings together a diverse set of skills to benefit the charity. Currently the Board has a neurologist and researcher, an NHS commissioner and senior business professionals. Hopefully my skills in marketing can complement this group.

“Part of my induction involved shadowing a Board meeting. It was very eye opening. Up until that point my experience of PSPA was predominately as a

fundraiser. I didn’t fully appreciate everything that goes into running a charity and all the decisions being made behind the scenes.

“Last year, when I chaired the Family and Friends Day I realised how many people assume the charity is bigger than it is. I think this is testament to the 16-strong staff team who are able to achieve so much, with such limited resources. It is motivating to think how much more could be achieved with an increase in funds.

“I’d always wanted to support a charity. My personal experience of PSP has led me to support this one. Dad was a good bloke. He did so much good during his life and is remembered for it fondly. I want to honour his memory by being the same. Many people have said to me that I’m continuing Dad’s legacy. It makes me feel good that through my efforts Dad’s torch is still burning on.”



**NADIA DOES ART WITH HER MUM LAURA TO HELP HER EMOTIONAL WELLBEING**



## TAKING ACTION TO IMPROVE DOCTORS' KNOWLEDGE OF PSP

Nadia Mendoza watched her mum Laura live with two years of unexplained symptoms, before eventually receiving a letter detailing a devastating diagnosis of PSP. Horrified at what her mum experienced and the lack of awareness of PSP, Nadia decided to take action. That action resulted in PSP being included in The Royal College of General Practitioners (RCGP) training guidance for GPs. Nadia's story shows the impact one person can have on the care of others.

Nadia shares her experience and why she was compelled to act. "My mum, like many others, had a long and upsetting journey to diagnosis. Utterly desperate for answers we paid to see a private GP. He said it could possibly be Parkinson's but would need to refer Mum to a neurologist for a confirmed diagnosis. Hearing Parkinson's was scary, but we

comforted ourselves with the knowledge it is slow progressing. We soon learned Mum had something very different from Parkinson's.

"Following Mum's appointment with a neurologist a letter was sent to her GP stating that Mum may have PSP. Despite the devastating nature of the condition



## **“ALONG WITH MUM WE ARE ALL STILL COMING TO TERMS WITH HER DIAGNOSIS. WE ARE TAKING LIFE DAY BY DAY.”**

there was no face-to-face diagnosis and Mum only found out when she went to her GP for a routine blood pressure check. There she learned about the letter. We Googled it and saw for the first time what Mum was facing. In shock, we latched onto the word ‘may’ in the letter. She ‘may’ have PSP meant she also may not have it – and with that bought hope she had something else, something more benign. We got a second opinion that left no room for doubt – Mum had PSP. Once again delivered by letter – just two lines long but utterly earth-shattering.

“I joined PSP Facebook groups and started to educate myself. I saw how Mum was not alone in waiting years for a diagnosis. I posted about how it was Mum’s eye movements that helped confirm she had PSP. I received many replies from people saying it was the same for them. Through reading the countless stories of how people received their diagnosis it became clear it was usually following an eye movement exam. This appeared to be a distinguishing feature of PSP. The effect on the eyes is significant, and a simple thing GPs could watch out for, but sadly most seem unaware.

“I collated all the first-hand testimonials and shared them with the RCGP to help GPs know what to look out for so they can refer to a neurologist promptly. Not being a health professional I was worried they wouldn’t take my email seriously. After all, I’m just someone’s daughter. The testimonials must have had an impact. In November, I received a reply stating that the RCGP would include PSP in its Curriculum Review Meeting. The RCGP Curriculum outlines the skills and expertise required to practise as a general practitioner in the UK and is what all student doctors use as part of their training. The Curriculum Review Meeting is where the content is decided

on what will be included in the RCGPs Curriculum. During the meeting it was acknowledged that PSP should be considered as one of the important conditions within the neurology topic guide.

“I’m pleased at what my initial email has achieved but it feels bittersweet. Mum still has PSP and we still face an uncertain future. However, more understanding and awareness of PSP leads to more knowledge. I hope in future, when someone sees their GP with PSP symptoms it won’t take two years before they receive their diagnosis. Receiving an earlier diagnosis means people can put provisions in place, and it takes away the frustrations of not knowing what’s wrong.

“Along with Mum, we are all still coming to terms with her diagnosis. We are taking life day by day. The silver lining is that it’s brought us closer together. My sister and I are in touch with Mum every day. We now have a daily gratitude list where every day we write three things we are grateful for and share them via WhatsApp. My sister is an artist and also encourages Mum to use art as an outlet which allows us to live in the moment for a while. Even Dad got involved at Christmas! We’re also helping maintain Mum’s independence by slowly adapting the house. We are making small changes and going at her pace.

“I want to continue to raise awareness and funds. I have lots of ideas and having seen how one email to the RCGP can make such a difference I’m motivated to do more. Focusing on what I can do helps me learn to live with PSP.”

Read Nadia’s blog detailing her mum’s journey [www.medium.com/@nadz\\_mendoza/](https://www.medium.com/@nadz_mendoza/)



CHRISTINE AND PETER HARRISON



## PETER HARRISON

In June 2017 Peter's wife Christine Harrison received a diagnosis of PSP. Devastated by the news, they set about telling family and friends. The couple's two sons, Christopher and Mark, decided to undertake a year of fundraising in tribute to their mum. Touched by their sons' efforts, Peter talks about life with PSP, how the family have pulled together and the support they've have found in the Norfolk Local Group.

Peter said: "In some ways we were lucky that Christine was diagnosed almost immediately. We were keen Nordic walkers, but early in 2017 Christine struggled to walk uphill and had trouble controlling one of her walking sticks. The GP referred Christine to a neurologist who told us she had PSP.

"I was in shock. It took us a long time to come to terms with the diagnosis. At first you expect things to fall apart quite quickly, but actually it didn't. Christine's neurologist told us about PSPA's Norfolk Local Group so we decided to go along. Linda Moore, the group coordinator was very welcoming. We learnt so much at the first meeting and have attended meetings ever since.

"Linda had started the group after watching her aunt live with PSP. During our time at the group we've met many wonderful people including Linda Iaccarino who hosts the group at her restaurant for meetings. Her husband sadly died from CBD. We do two or three fundraising activities during the year and recently learned the group has raised over £9,000 in total – a huge achievement for a small group. We're very thankful the group is there and have benefited hugely from attending it.

"We learned the importance of planning for the future. We know we want to stay in our home and are looking at adaptations we can do to make life more comfortable for Christine. At the same time, I have

to make sure we go at Christine's pace. Christine doesn't want to overdo the help, but we are well aware of what the future might hold. We aim to take these things one step at a time, not to panic, and make the most out of life.

"One of the ways we deal with PSP is to do whatever we can to help research into the condition. So far, we have been involved in five different research programmes and have donated our brains to the Brain Bank. Our sons Christopher and Mark took a

slightly more active approach to dealing with PSP. About seven months after Christine was diagnosed they announced they were going to spend 2018 undertaking fundraising challenges.

"We are so proud of them, and were thrilled to cheer them across the line at Ride London. We all pull together as a family and we're lucky that we have a lot of support around us. We aim to enjoy life for as long as we can."

#### FAMILY GREETING AFTER THE RIDE LONDON



### OUR YEAR OF FUNDRAISING

Mark said: "Mum's diagnosis provided the impetus for Christopher and I to undertake a series of challenges to raise awareness and funds for PSPA. Our original plan was to complete the London Marathon, Ride London, Snowdonia Trail Marathon and Swim Serpentine. I was to do two events, London Marathon and Ride London with my brother Chris cycling with me in London and then him doing the Snowdon and Serpentine events.

"We reckoned this would amount to about 252 human powered miles. However that all changed when, inspired by the generosity of people donating early on, I decided to raise the challenge by trying to cycle from Land's End to John O'Groats... so lengthening the mileage to just short of 1,500 miles!

"I was quite fit with past hockey playing and 'commuter' cycling to the station on my fold-up Brompton. The 2018 London Marathon (my first!) provided the focus to get back to some serious training, spurred on by the cause. As runners know, fitness can soon slip away and the winter training needed some commitment. On the day I managed a respectable 4hrs 18mins, but had hoped to beat my father's time in 1988 of 4hrs 5mins!

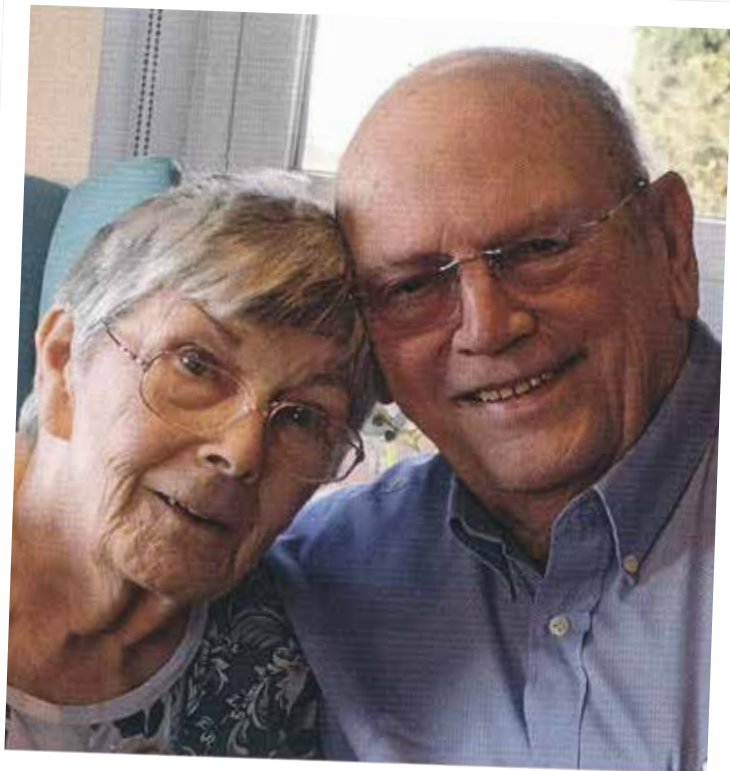
"Next was the Lands End/John O'Groats challenge that needed some serious planning as the June date loomed ever closer. I'd never cycled for more than a single day before so 14 continuous days 'in the saddle' was a daunting thought. Many of the day's rides were to be over 90 miles and this was to be mostly on my own, with no accompanying support, just what I could carry on the bike. I was lucky to avoid some severe storms on the way. Twenty five mile an hour head winds on the final legs were sent to challenge me, but I made the destination in the 14 allocated days. Friends provided great support and my wife drove all the way up to Scotland.

"My brother lives four miles from his office but regularly cycles there and back most days of the week. He has, in recent years, taken his running more seriously and has previously run the London Marathon. To run 26.2 miles on mountain tracks whilst ascending 1,685 metres takes some doing and Chris achieved this on the Scott Snowdonia Mountain Challenge taking a just over 5hrs 17mins.

"One month later we joined forces to cycle the London Ride, a first for both of us. Like the London Marathon it attracts thousands of entrants of all capabilities. We rode together for this one. It was a surprise to see Mum and Dad had travelled to London to greet us at the finish line.

"In September there was the final challenge. Neither of us are fond of swimming but my brother completed the London Swim Serpentine. That finished our year of fundraising. It was a tough year, but being able to send £5,700 to PSPA was worth it."

KEN AND DOREEN HOOTON



ROY AND SHELIA ROUTLEDGE

## A GOOD GOODBYE

Talking about dying and planning ahead may not be easy, but it can help us make the most of life and spare loved ones from making difficult decisions on our behalf. It also helps to discuss your wishes with healthcare professionals, so that you and your family can feel prepared for the future.

Roy Routledge shares how his wife Sheila left a letter for their daughter outlining her wishes and how it helped the family during a deeply distressing time.

Roy said: "Saying goodbye to my wife of 63 years was the hardest thing I've ever done. I laid my hands on her coffin and said my goodbye. The rest of the funeral passed by in a blur, but I knew we had given Sheila the simple funeral she wanted. Mind you, there were many more people than she would have ever expected even though, as outlined in her wishes, we didn't advertise it. It just goes to show how well thought of she was. We asked for donations to PSPA instead of flowers, and placed red roses on Sheila's coffin. Afterwards everyone said what a lovely funeral it was. That helped me a lot.

"Sheila had written a letter to our daughter Susan, setting out her wishes. When she died I gave it to Susan, who opened it in front of our grandsons. It helped all of us, but especially Susan and her sons to have it written down like that. My grandsons were impressed that their nan had thought about the future.

"When I received Sheila's ashes there was a little rose lapel badge inside the box. I decided to get 100 made, to give to everyone who helped Sheila and I. It seemed a nice way to thank everyone, starting with Sheila's care home. They provided Sheila with the very best care. She was happy there and it was the best place for her. I plan to volunteer there in the future, to thank them for everything



**“WHEN SHEILA WAS DYING WATCHING HOW GENTLE THE NURSES WERE WITH HER DEEPLY MOVED ME. I COULD SEE THE NURSES THOUGHT THE WORLD OF SHEILA, EVERYONE DID.”**

they did for Sheila and I. When Sheila was dying watching how gentle the nurses were with her deeply moved me. I could see the nurses thought the world of Sheila, everyone did.”

#### **BUILDING UP A RELATIONSHIP WITH HEALTHCARE PROFESSIONALS**

Ken Hooton shares how it helped to have built up a relationship with their local hospice, palliative nurses and district nurses during his wife’s life with CBD. Thanks to the coordinated support from professionals they were familiar with, Ken’s wife Doreen died a peaceful death at home. Ken said: “I always thought hospices were places people go to die. It was only when I spoke to a man caring for his wife at the Liverpool Local Group did I learn how some hospices are able to offer short stays at difficult times. Afterwards, I asked our GP to refer Doreen to the local hospice. She soon started going one day a week for day care. It was really helpful and meant I could have some rest or get the shopping.

“Doreen and I talked about her death. Doreen wanted to die at home. Thanks to the care we received, we were able to fulfil Doreen’s wishes. It helped that during the time Doreen was ill we were able to form a good relationship with the local hospice and palliative care team. The Palliative Care Consultant at the hospital also worked at the hospice so the services were very joined up.

“When Doreen received her diagnosis of CBD she was allocated a palliative care nurse. The nurse was our first point of contact and was with us right up to the very end. After a spell in hospital, Doreen was sent to

the hospice for a full assessment of her needs. It was so peaceful. The nurses would wheel her bed into the garden so she could enjoy the flowers. The hospice also organised regular carers days where you could have reflexology, hand massage and speak to other carers. I always found them very useful.

“Ten days before Doreen died the district nurses told me she was coming to the end. The palliative care nurse and district nurses worked together as a team told us to stop the tube feeds and administered morphine and other drugs to stop Doreen’s pain. My hand was held throughout. It was comforting to have someone on hand to answer any questions my sons or I had. In the morning I said good morning to Doreen as I always did. She opened her eyes, smiled and then breathed her last breath. It was very peaceful and exactly what we both wanted.

“We didn’t want a mournful funeral, but rather a celebration of her life. Despite dreading the day it was actually lovely. Doreen had a peaceful death and at our funeral, we were able to come together to celebrate her life.”

Please remember our helpline is here to support you in your journey with PSP & CBD. You can contact our helpline on **0300 0110 122** or email **helpline@pspassociation.org.uk**

KAREN DAVIES AND  
TRACY HUGHES

## SADDLE UP FOR THE WORLD'S GREATEST CHARITY CYCLING FESTIVAL

A growing group of people affected by PSP or CBD are saddling up in preparation to take part in the epic cycling festival Ride London. In August they will be joining thousands of people cycling 100 miles on closed roads through London and Surrey. While some will be keen cyclists, for many this will be their first ever cycling event. **TeamPSPA** is a diverse bunch, with widely varying ages and abilities, but the one thing that unites them is their personal experience of PSP or CBD. Two riders who took part in last year's Ride London 2019 share their experiences. Perhaps it might inspire some of you to join **TeamPSPA** and take part in the epic Ride London this year.

### "DAD CAN NO LONGER CYCLE, BUT I CAN."

Despite having never cycled before Karen Davies joined TeamPSPA in 2019 to raise money in tribute to her dad who is living with PSP. Karen said: "A few years ago, my dad Keith was a fit and active man in his late 60s. He enjoyed riding his bike, walking and was a keen gardener.

"Then he started to fall over. People often thought he was drunk. His vision worsened, he became irritable and began losing empathy for all those around him. Unfortunately that was the end of his cycling.

"One of the early signs was falling off his bike while out on a family ride. So I decided to cycle the 100 miles of Ride London, as I can still cycle, and he can't. My friend Tracy decided to ride the event with me too. Our first step was to buy bikes and start training. Neither of us had ridden before. We were out riding at 7am most weekends, finding new coffee shops to cycle to in South Wales.

"We knew we had to make it up Box Hill and Leith Hill, so our training involved lots of steep inclines. On the day we were worried about being caught by



the sweeper if we went too slowly, but the excitement and the wide flat traffic free roads meant we rode much faster than usual and had nothing to fear.

"The excitement and nerves built as we got closer to the venue, and more riders got on the tube. It was amazing to feel part of something so huge. We met another PSPA rider and swapped stories about why we were doing it. Before we knew it, we were shouting along to the countdown, 10, 9, 8...and we were off!

"We got swept along with the wave. Eight miles later we got a cheer and a wave from our husbands. The support along the route was amazing. In some towns and villages the people lined the streets ringing cowbells, it was like being in the Tour de France!

"As we rounded the last corner, there were our husbands ready to video our finish, shouting PSP at us, so that we'd spot them. Then we were over the finish line, we'd done it! We joined the throng collecting medals and goody bags and celebrated with some much deserved prosecco.

"There was a festival atmosphere in the event village afterwards, with music playing, people sharing stories and meeting up with their loved ones. I'm planning on going again this year, but this time my husband Leighton is hoping to do it too. I've talked so much about the whole experience that he entered as soon as the ballot opened. If anyone is thinking of doing it, but feeling nervous about their cycling ability, just go for it. With a bit of determination and training you'll smash it!"

### **"THIS WAS NOT ABOUT ME."**

Watching his mother-in-law Irene, live with the devastating effects of PSP motivated Dan to join TeamPSPA. Dan said: "Over the past few years the effect of this degenerative disease has sadly meant that our family, extended family and close friends have seen Irene go from a very independent confident lady to now being a shadow of her former self.

"Irene was an all-round amazing woman. Captain of the local golf club, she enjoyed Pilates and looking after her grandson, but is now unable to walk or stand unaided, has difficulty with her speech and cognitive skills, and ultimately is totally dependent on her devoted husband Dave. It's hard to comprehend how difficult and frustrating this must be for a lady who has always been so immensely capable.

"Taking part in Ride London was not about me and was entirely about Irene and trying to raise awareness and

money to fight this horrible disease. Training took over our lives and gave us something positive to focus on.

"I was up and out riding at the weekend before any of the family were even stirring. I've learnt about the joys of lycra and chamois cream that are part and parcel of any long distance ride. It was all worth it and I was thrilled to smash my initial fundraising target and raise £2,500 for PSPA."

Places are still available to ride in this iconic event. Last year our riders raised an amazing £13,000. This year, with all charity places filled, we hope to raise £30,000, which will make a huge difference to our services.

### **KAREN AND HER DAD ENJOY A RIDE IN A SPECIALISED BIKE FOR THOSE WITH MOBILITY PROBLEMS.**



All **#TeamPSPA** riders will receive a free fundraising pack and a PSPA cycling jersey. Entry costs £20 and riders are asked to raise a minimum of £500.

If you are interested and would like to find out more please visit [www.pspassociation.org.uk/events-list/ridelondon](http://www.pspassociation.org.uk/events-list/ridelondon) or email [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk) or call **01327 356132**.





## ANY TIME, ANY PLACE, ANYHOW – OUR VIRTUAL #5KFORPSPA

Our virtual fundraiser #5KFORPSPA will be returning for its third year in March. During the whole month of March families, friends and colleagues can come together and take part in a 5K to raise funds for PSPA. From babies to 90 year olds, our virtual event is perfect for anyone. Previous 5k's have involved canal walks, park runs, and even pub crawls. We even had a team of one doing it on a treadmill at home.

You don't even need to do the 5K all at once. Just 1K a day over the course of the week, along with raising at least £25 will be enough to secure your 5K medal. In fact, you don't even need to be in the UK to do it. One of last year's participants took part in what must be the first ever #5KFORPSPA in America. Christina Chow is from Oregon and decided to take part in our 5K last year following her mum's diagnosis of PSP.

Christina said: "When I first heard about the PSPA's #5KFORPSPA, I knew immediately that it was how I wanted to honour my mother and her journey. She was diagnosed with PSP in February 2019, around four years after she began to show symptoms. Our family has been on a mental, physical (mostly for mom), and emotional roller coaster, but we've also grown so much closer and stronger as a family unit. Now I know for a fact that this unit extends beyond blood relatives, as so many incredible members of our community (even people who were initially strangers!) have been so helpful in both caretaking assistance and even pushing us past our original fundraising goal! How awesome is that?"

"The experience of taking on the 5K challenge was absolutely wonderful. I heard about it through PSPA's Facebook page. My sister, who has been the primary caretaker for our mother, joined me as we hiked our way up the beautiful Southern Oregon Table Rocks. On our way up, we discussed (with some solid huffing and puffing thrown in!) the obstacles our mother's illness had created. Then, at the top, we took all of the breath-taking scenery in, sat down with our arms around one another, and reflected. The way down was actually the best part, for me, as we conversed with renewed hope and determination for the future as sisters and as daughters of such an incredible trooper of a mother and an equally amazing father.

"I will definitely be participating in another PSPA 5K, and look forward to it becoming a tradition with my sister. I highly encourage others to take part— fundraising for this charity not only shows your love for whomever the affected individual is in your life, but also contributes to resources for both the individual and families/support system/caretakers. Incredibly importantly, fundraising efforts also contribute to ongoing PSP research."

If you would like to take part in this year's virtual #5KFORPSPA register at [www.pspassociation.org/fundraising/5K](http://www.pspassociation.org/fundraising/5K) and join people from around the world united against PSP & CBD. Entry is just £5, with a fundraising target of £25 for individuals and £99 for a team of four.



CHRISTINA AND HER SISTER ELSIE AT THE SUMMIT



CHRISTINA'S PARENTS CRAIG AND PAULA



GILL DICKSON



## THE FIRST 100 DAYS

In a previous issue of *PSPA Matters* we reported how after years of campaigning in Scotland by Keith Swankie, who is living with PSP, the Scottish Government provided a grant to part-fund a new development role to help improve care and raise awareness of PSP & CBD. Gill Dickson was appointed in September 2019 and reflects on the first 100 days in the role.

Gill said: “We estimate that PSPA is in contact with one in six people living with PSP & CBD in Scotland. This compares unfavourably with the UK wide figure, which is estimated at one in three. Many health and social care professionals in Scotland have never encountered the conditions before which can lead to challenges in care coordination and families having to navigate systems themselves to find the care they need.

“Having a dedicated PSPA Manager working in Scotland allows us to maximise awareness raising and be ambitious in our plans to influence policy and support improvements in services for people with PSP & CBD. In order to reach this goal, I have had meetings with Members of the Scottish Parliament (MSPs) and also policy colleagues in neurology, palliative care and rare and undiagnosed conditions.

“Numbers of volunteers, who are so vital to increasing PSPA’s capacity, have been low in Scotland. I have visited all three current local groups in East Kilbride, Edinburgh and Aberdeen to support our existing volunteers. I have started a plan to grow numbers in education volunteering by registering PSPA volunteering opportunities online with Volunteer Scotland, and all the available regional volunteer centres. This Education Volunteer role will offer informative talks in education or community settings to help health and social care professionals understand key information about the impact of living with PSP & CBD and thereby improve their practice. This call to action has already generated some interest and we hope in 2020, when PSPA campaigns UK wide to increase our numbers of volunteers, there will be further interest and applications coming in from Scotland.



“Since September, there have been several recent policy developments in Scotland aimed at ensuring people with neurological conditions, including PSP & CBD, have the best access to care and support. Just before Christmas, The National Advisory Committee for Neurological Conditions in Scotland published an implementation plan that will drive improvement for people with neurological conditions, their families and carers, practitioners, clinicians, academics, NHS Boards, integration authorities, third sector and independent care providers. Responding to the detail of this plan in 2020, whilst collaborating with the other Scottish neurological charities, will give PSPA influencing power via the Neurological Alliance of Scotland, and Cross-Party Groups (CPGs) in the Scottish Parliament on Rare Diseases and Palliative Care.

“A meeting with PSPA/Scottish Scientific Officer’s co-funded research fellow in Aberdeen, Dr Diane Swallow, revealed that her research is planned to be published in early 2020 and will help us explore important issues around both diagnosis and care and the evidence base for treating these conditions in Scotland (page 22). This valuable information will inform how multidisciplinary teams approach anticipating people’s needs to support individuals and their families during all stages of their disease. Discussions about planning for the 2020 implementation of the research findings once published have already started with Diane.

### PLANS FOR THE FUTURE

“There is much to be done to raise awareness of PSP & CBD across Scotland. We hope to increase the reach of PSPA so that more families affected by PSP or CBD can have access to the support we provide. This work will include increasing the number of group coordinator volunteers to expand the reach of our Local Group network. Alongside this we plan to grow the numbers of Education Volunteers to help improve the skills and knowledge of health and care teams, including staff working in care homes.

“In Scotland we will be supporting PSPA’s research programme. Andrew Symons, Chief Executive and I recently visited The Anne Rowling Regenerative Neurology Clinic (a University of Edinburgh clinical research facility founded by Harry Potter author J.K. Rowling). We are looking to develop a closer relationship with research facilities like these and that people living with PSP & CBD have access to participate in research if they so wish.

“In 2020 I will be getting involved in health policy discussions and will seek to influence those discussions so they have the biggest impact on the quality of life of people affected by PSP & CBD. Examples of these policy conversations include monitoring activity from the Digital Health and Care Division who will be developing tools to support clinical decision-making. Opportunities to harness these developments for people with PSP & CBD will be explored as IT solutions may counter some of the problems of supporting people across challenging rural Scottish geography. Another example of policy involvement will centre round developments in Scotland’s new social security system delivering new forms of disability assistance as, from 2020, Disability Assistance (benefits) will begin to be delivered by the Scottish Government.

“We have some amazing PSPA fundraisers in Scotland and currently receive some funding support from several Scottish charitable trusts. My new post will build awareness with these Trusts; further increasing income from these sources in future years. We will also work with our current fundraisers to plan fundraising opportunities in Scotland through a parliamentary reception, study days and challenge events.

“With the current support from the Scottish government and the developing policy focus, there is much to be positive about when considering the future of Scotland’s health and social care delivery for people with PSPA & CBD. Using all the resources available at PSPA, I will be on hand to take up these opportunities and connect them up to people diagnosed with the conditions, so they are offered timely support from the start of living with PSP or CBD.”

Anyone wishing to contact Gill can write to her at [gill.dickson@pspassociation.org.uk](mailto:gill.dickson@pspassociation.org.uk)

**“THERE IS MUCH TO BE DONE TO RAISE AWARENESS OF PSP & CBD ACROSS SCOTLAND.”**

# HERE FOR YOU

Our Helpline Care Navigators are here to support people living with and affected by PSP & CBD. Each Helpline Care Navigator has a designated area (see map) where they can 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 a Community Outreach Volunteer or a Local Group.
- 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-5pm and 7pm-9pm.**

Tel: **0300 0110 122** or email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

# PSP/

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

T 01327 322410  
[info@pspassociation.org.uk](mailto:info@pspassociation.org.uk)  
[www.pspassociation.org.uk](http://www.pspassociation.org.uk)

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