

# PSP Matters

Winter 2018

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PSPA is personal.”



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Cover: Maxine Ridgeway, Craig Ball and Hannah Daykin

**PSPA**

PSPA is a registered charity offering support and information to people living with Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD), while funding research into treatments and ultimately a cure for these conditions. We rely entirely on donations to fund our work.

The views expressed in *PSP Matters*, published three times a year, are not necessarily those of PSPA and therefore products and services advertised or promoted should not be taken as recommendations by PSPA, who cannot be held responsible should any complaint arise.

*PSP Matters* is available as a pdf and can be downloaded from our website. PSPA Registered Charity Numbers: England and Wales 1037087/Scotland SC041199

Design by Skelton Design and printed by Newnorth Print Ltd, Bedford

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**Helpline**

The PSPA Helpline and Information Service offers confidential information, practical and emotional support to people affected by PSP & CBD.  
Mon to Fri: 9am–5pm and 7pm–9pm  
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**HealthUnlocked**

This online community provides a safe place where those affected by PSP & CBD can connect with others to share their experiences.  
<https://healthunlocked.com/psp>

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The start of the New Year can be a good time to reflect and make plans for the future. This year our plans include the development of an ambitious new strategy, so that we can help even more people living with PSP & CBD. This includes our work raising awareness and educating health professionals, alongside our support for research into both conditions.

It is vital our strategy is a collaborative effort and, most importantly, reflects the needs of people living with PSP & CBD. We have been gathering feedback, but I would like to invite you to email me on [andrew.symons@pspassociation.org.uk](mailto:andrew.symons@pspassociation.org.uk) with any views or suggestions on what our charity should be focusing on.

Part of our work on supporting more people with PSP & CBD, includes a reorganisation of our Information and Support Services, by making our Helpline the single point of contact for people affected by PSP & CBD.

We are increasing our Helpline’s capacity and scope by creating two new roles. Both the new and existing roles will become Helpline Care Navigators and will provide people with PSP & CBD a named contact to help ensure they are referred into all relevant local services.

Alongside changes in Information and Support Services, we will be aiming to recruit more volunteers, so that they can provide local support. We are appealing for people to join our committed team of volunteers. The more volunteers we have, the more we can do for people with PSP & CBD.

The New Year for me is also a time for setting personal challenges. If, like me, you are thinking of setting yourself a challenge this year, perhaps you will be interested in our new fundraiser, 5K for PSPA? You will find more information about this exciting virtual race inside this edition of *PSP Matters*.

Thank you for all you do to support PSPA. It is only through your support that we are able to fund vital research and help families affected by both of these devastating conditions.

Warmest regards,

**Andrew Symons**  
Chief Executive

## Oxford PSP study still recruiting

Researchers at the John Radcliffe Hospital in Oxford are still looking for more people with PSP to take part in their study known as OxQuip (Oxford study in Quantification in Parkinsonism).

THIS study aims to develop new ways of measuring PSP symptoms as precisely as possible so that when new drugs are ready to test, their effectiveness can be accurately assessed. During the study, you would be asked to perform some simple tasks while the researchers measure the movements of your eyes, hands and body. You would also be asked to do some tasks on a tablet computer. Testing sessions in Oxford would take around an hour and a half to two hours and take place once every three months, over two years if possible. Travel expenses will be reimbursed.

If you are interested in taking part in this study, contact Dr Chrystalina Antoniadou for more information: [chrystalina.antoniadou@ndcn.ox.ac.uk](mailto:chrystalina.antoniadou@ndcn.ox.ac.uk) or 01865 234728.

Please note that unfortunately this study is not open to people with CBD.

## Family and Friends Day

WE know how much you all enjoy our Family and Friends Days and this year we will be looking at making sure they are focused on families getting together to participate in activities, as well as learning more about both diseases. We are planning to hold our first event in May in the Berkshire area. Please check our website for regular updates. [www.pspassociation.org.uk](http://www.pspassociation.org.uk)



## Latest care information available

### Are you getting all the benefits you are entitled to?

After receiving a diagnosis of PSP or CBD, people often find that they are not aware of all the benefits they may be entitled to. To help them through what can be complex issues the Information and Support Team have put together a new information sheet *Benefits and Entitlements*. The information sheet provides concise information on benefits such as: Attendance Allowance, Personal Independence Payments, Council Tax Benefit and more.

The PSPA Helpline can also arrange

for help completing forms, if required, through their partnership with the Department of Work and Pensions Visiting Service.

### Cognition and Behaviour

For families of people living with a diagnosis of PSP & CBD, changes in their loved one's thought processes, behaviour or personality can be puzzling and frustrating. A new information sheet *Cognition and Behaviour* explains the cognitive changes, sometimes seen in PSP & CBD and looks at strategies for coping – and how to access specialist support.

These information sheets are available on our website

[www.pspassociation.org.uk/information-and-support/](http://www.pspassociation.org.uk/information-and-support/)

If you require a printed format please contact the PSPA Helpline on 0300 0110 122 or email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)



## Olympian and giant of motor racing unite to raise funds for PSP

Two sporting legends took part in a unique fundraiser for PSPA, raising over £50,000 to be invested in research into the causes of the disease.

THE fundraising lunch, held at One Whitehall Place, was hosted by Lord Coe, and organised by the Sebastian Coe Foundation. Special guest, motor racing legend Bernie Ecclestone, was interviewed by Seb, and took questions from the guests.

Under Seb's precise questioning, Bernie gave the guests an insight into some of his most satisfying deals and revealed the racing legends he believed were the best.

Seb spoke to the 150 guests about his very personal reasons for raising money

for PSPA as his mother died from PSP. As well as ticket sales, just over £50,000 was raised from a raffle to win the use of a McLaren 570S Spider worth £200,000 for the weekend, or a night for two at Hurley House Hotel.

Cameron Wood, Development Director at PSPA said: "We would like to thank Seb Coe and his charitable foundation for organising the lunch. It was a brilliant event and, along with raising a huge amount for research into PSP, it also raised awareness of the devastating impact of the disease with the guests."



Bernie Ecclestone and Lord Coe

"It was a brilliant event and, along with raising a huge amount for research into PSP, it also raised awareness of the devastating impact of the disease."

## PSP clinical trial recruiting UK participants

An international clinical trial of a potential new treatment for PSP has started recruiting participants in the relatively early stages of the disease.

As we reported via social media and e-news in the autumn, the phase II trial involves a new intravenous drug which is being developed by Biogen, a biotechnology company specialising in developing medicines for neurological conditions and rare genetic disorders. The drug is an antibody that is designed to target and remove tau, the protein that forms the tangles and clumps seen in diseased nerve cells in PSP.

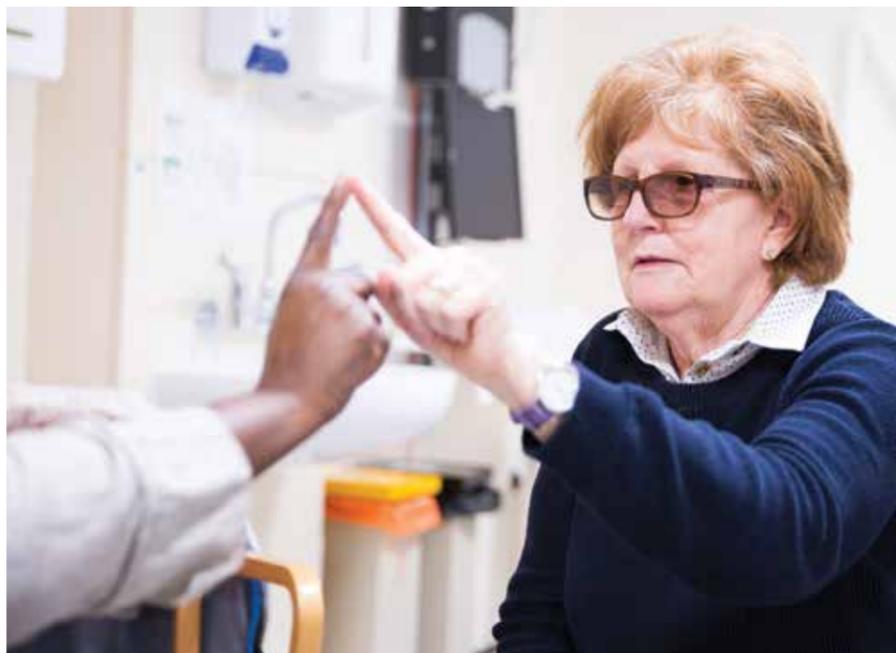
The clinical trial will involve around 400 people with PSP at centres across the world and aims to establish the safety and efficacy of the drug. It is a placebo-controlled trial, meaning that half the participants will be given the drug, while the other half will receive placebo, which looks the same but contains no active drug. Neither the participants, nor the nurses and doctors at the trial centres will know who is taking the real drug. This is an essential part of ensuring the results of the trial are robust and that any beneficial effects can be reliably attributed to the new treatment.

### Where will the trial take place?

Currently, eight UK centres for the trial have been confirmed: London (UCL), Cambridge, Glasgow, Newport, Newcastle, Brighton, Liverpool and Southampton. It is possible that more centres could be added at a later date.

### Who can take part?

Each centre will be recruiting only a small number of participants, with a target of around 30 participants for the whole of the UK; some trial



centres already have waiting lists for screening. In order to be considered for the trial, people with PSP will need to have experienced their first symptoms less than five years before enrolling and should still be able to walk with minimal assistance or independently. Unfortunately, the trial is not open to people with CBD.

The individual patient participation in the trial lasts just over a year. It is divided into a six week screening period (when all the necessary assessments will be carried out to check that you are eligible to participate) and a 52-week dosing period (when either the study drug or placebo is given) with clinic visits approximately every four weeks. Once this part of the trial concludes, there will also be an opportunity to participate in an open-label dosing period where everyone receives the study drug.

Participants will need to commit to monthly attendance at one of the trial centres, accompanied by a carer. Taking part in the trial will involve receiving intravenous infusions of the drug or placebo, along with a range of tests including MRI brain scans. If you have a pacemaker or other implant that prevents you from having MRI scans, you will not be able to take part.

There are a number of other criteria that participants need to meet. A researcher at one of the trial centres will need to go through these with you before they can enrol you for the trial.

### Where can I get more information?

You can contact PSPA Helpline: 0300 0110 122 or [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

See also our feature on clinical trials on page 12 and 13.

## 150 healthcare professionals attend our study day

'Professional advice' and 'engaging speakers' were just some of the comments we received following our annual study day.



AROUND 150 health and social care professionals joined us in Milton Keynes for the event, that was chaired by Anna Kent, Neurological Conditions Clinical Specialist. Delegates included consultants, physiotherapists, speech and language therapists, PD nurses, occupational therapists, palliative care nurses, care agency staff and paramedics.

The day opened with a presentation from Dr Luca Passamonti (pictured) *Getting the right diagnosis. It's not Parkinsons* followed by sessions on occupational therapy, cognition, research,

palliative care and information on communication aids.

Carol Amirghiasvand, Helpline and Information Services Manager said: "These events are crucial in helping to increase awareness of PSP & CBD. We are really pleased so many health professionals attended and would like to thank our speakers and all those who came along."

**2018 PSPA STUDY DAY**  
Thursday 25 October –  
Royal College of Physicians, London

### Reader survey

We produce this magazine for you so it is important for us to hear your opinions about the content of the magazine, and if you feel we should be doing anything differently. Please complete our Readers Survey and help us ensure the magazine is both relevant and informative to you.

You can either complete the freepost paper version inside this edition or online at [www.surveymonkey.co.uk/r/PSPMattersReaderSurvey](http://www.surveymonkey.co.uk/r/PSPMattersReaderSurvey)

Please complete the survey by 28 February 2018



Consultant Neurologist Prof Huw Morris

## International research symposium on PSP & CBD

We are very excited to be working with our friends at CurePSP in the USA, to organise an international research symposium on PSP & CBD, which will take place in London this autumn.

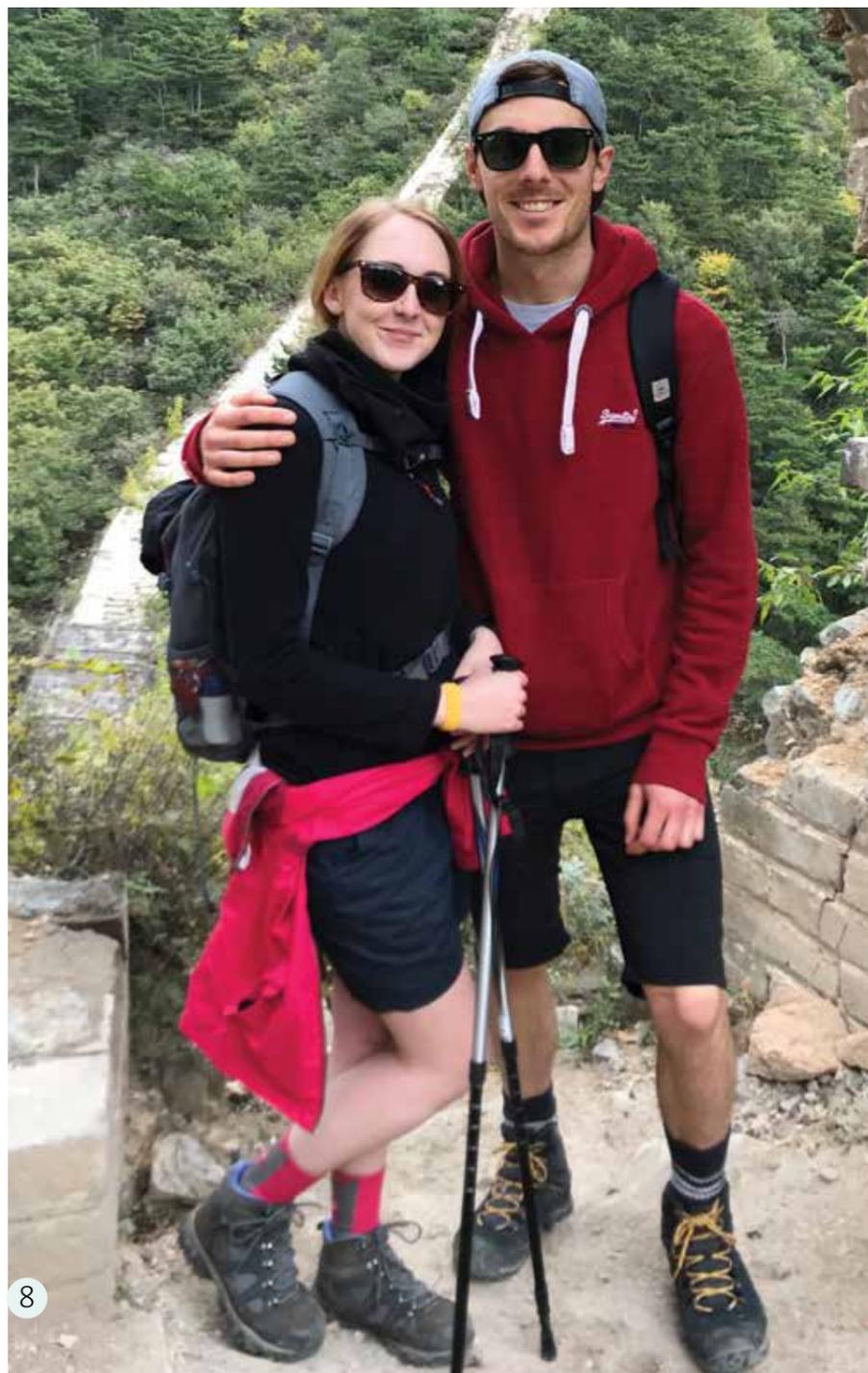
LEADING neurologists and scientists in the field of PSP & CBD research, from Europe and the USA will share their latest ideas and discoveries.

Andrew Symons Chief Executive at PSPA said: "Conferences like this provide the perfect environment for establishing new collaborations and generating new directions for studies. We are delighted to be organising the first truly international PSP & CBD research event in several years."

We will keep you updated on the event via *PSP Matters* and our website.

# “Fundraising for PSPA is personal and emotive.”

The devastating experience of PSP & CBD brought Hannah Daykin and Craig Ball together. In 2008, Hannah Daykin’s dad David, was diagnosed with PSP. At the same time, Craig Ball’s grandma May, was living with CBD.



**N**OW engaged, the couple have recently returned from an epic trek across the Great Wall of China to raise money for PSPA. Hannah speaks to *PSP Matters* about how they met and how a Christmas present led to her wearing something she never thought she would wear; a pair of walking boots.

Hannah said: “The first inkling we had that something was wrong was when Dad was at work as a heating engineer. He lost his grip of a radiator and sliced his thumb open, requiring surgery. My dad didn’t make mistakes, so it was really concerning. Eventually he was diagnosed with PSP. To say we were devastated was an understatement.

“None of us had ever heard of PSP, so I was determined to do whatever I could to raise awareness of the condition. Raising awareness was my way of trying to cope with the diagnosis. Dad was at peace with it and knew I needed to find my own way of coping. I know he was proud of what I was doing and I am so pleased he was able to see me carrying the Olympic Torch through Sheffield. He sadly died just two months later.

“Both Craig and I were studying at Sheffield Hallam University, but we never met. We did have some mutual friends and around four months after my dad died, Craig sent me a friend request on Facebook. He had seen the video my

family had made about living with PSP and wanted to get in touch.

“When I received the request, I looked through his profile and thought he was drop dead gorgeous. Then I saw he was wearing a PSPA top. I accepted his request and since then we have spoken every day, fell in love and are now engaged to be married.

“Despite being at the same university and having shared friends, it was seeing my awareness campaign that brought us together. I started my campaign the year Dad was diagnosed after being so frustrated that no-one knew about PSP. My dad had always taught me that if I can’t change something then to think about how I can make it better. I got in touch with the charity which has supported me on my journey since the beginning.

“Every year I do the annual plead with people to buy Christmas cards from PSPA and I hosted a band night in Sheffield, raising around £150. But, going to China has been my first big fundraising event and something I never expected to do.

“The Christmas of 2016 is one I will never forget. Christmas morning Craig and I were still in our dressing gowns when we swapped gifts. I gave Craig his presents first - a Hugo Boss watch and a smart coat he had wanted for ages. Then I notice Craig starts sweating and puts his hand on his forehead, riddled with panic.

“I reassure him that I love presents and basically everything about Christmas, so he shouldn’t panic - what could possibly go wrong? I open my stocking and I see all the things I like, so it’s looking promising. Then, Craig tells me to go and look on the calendar for October 2017. I can see it’s all blocked out from 7 to 15 October and rolled my eyes asking which holiday he has booked this time - being the prolific traveller that he is.

“He asks me to sit down, before



Maxine Ridgeway, Craig Ball and Hannah Daykin

he hands me a brochure wrapped in Christmas paper. I feel it and get butterflies in my stomach, convinced he’s finally taking me on a cruise where I can relax, be served champagne and get a good tan. I open it and see a brochure for PSPA and Global Adventures, who run the adventure holidays. I thought it was a wind up and frantically looked through all the material to find the booking confirmation for the cruise.

“When it was nowhere to be seen, I told Craig I didn’t understand. He didn’t say anything. At this point, he realised he has made a grave mistake. After looking through the whole brochure, I still didn’t really understand what the present was. When he told me we were trekking the Great Wall of China for five days, my confusion - having not owned a pair of walking boots in my life - turned into tears.

**“Knowing first-hand what it’s like to live with PSP & CBD, we cannot stress how important fundraising and raising awareness is to families like ours.”**

“Fundraising for PSPA is such a personal and emotive thing for me that I needed to prepare myself and this just caught me completely off-guard. He told me he didn’t need an answer straightaway and that he could get a refund and buy me some Kurt Geiger heels instead if I preferred. I don’t think he expected to wait over a month for the answer!

“Once I had spent the month deliberating about whether to go and if we’d be able to raise the money in less than 10 months, I agreed to do it because I knew what that money would mean to all the families who are going through what we did.

“I’m not a walker, nor do I have any love for outdoorsy type activities, but I bought some ugly walking boots and we made sure we walked as much as we could in preparation for the trip. We organised almost 20 people to walk with us over the Yorkshire Three Peaks on April bank holiday weekend and raised an amazing £3,000 just from that. I really struggled through and almost lay down for the Air Ambulance to come and rescue me or for the mountain goats to eat me, whatever happened first.

“For me, both the preparation and the actual trek were challenging. The whole culture is so different so you’re constantly faced with challenges. However, the incredible views more than made up for it.

“For both of us, after living through the horrendous time that we did, with Craig’s grandma’s death from CBD and losing my dad to PSP, we would never have imagined we would end up doing something as incredible as trekking the Great Wall of China in memory of them.

“Knowing first-hand what it’s like to live with PSP & CBD, we cannot stress how important fundraising and raising awareness is to families like ours. We have both lived through the horrific times that PSP & CBD have caused and we cannot imagine anyone else having to go through it. That is why we continue to raise both funds and awareness. If we can make a change, or help get that little bit closer to finding a cure, that is all we can ask for.

“As for my present for the Christmas just gone, I’m pleased to say he has learnt to stick to the list!”

# Managing your oral health

“Mouth problems can be painful, traumatic and have serious implications on general health – and they can be very challenging to treat” says Kirsty Reynolds, special care dentist. She and her colleague Nikki Craig, are part of the special care dentistry service for the Isle of Man.

SPECIAL care dentistry services (sometimes called Community Dentistry) offer support to those who, because of their disability or special care needs, are unable to access

mainstream dental services. People living with PSP or CBD may come into this category and should ask about special care dentistry provision in their area. A referral from a healthcare professional is

usually required. Kirsty and Nikki advise that oral health needs to be part of a holistic care plan for people with PSP & CBD. Here they outline some tips for good oral health.

## People living with PSP or CBD may experience barriers to maintaining their oral hygiene.

- As mobility decreases it may be difficult to get to the dentist surgery or get in/out of a dentist's chair. There are some accessible dental surgeries and, in some areas, home visits can be offered.
- Loss of movement in the hands can make opening the toothpaste or using a toothbrush tricky. In later stages, help with brushing is ideal but a person's wishes must be taken into account. It can be helpful to have a discussion early on about this issue.
- Deterioration of speech can make it challenging to explain a problem, or to show pain. Allow the person time to explain or try using a picture board. Taking cues from non-verbal responses is very important, for example, changes in behaviours around food and sleep patterns, could be due to dental problems.
- Saliva plays an important role in keeping the mouth healthy. It helps break down food particles, helps 'wash' the mouth and protects it from drying out. People with PSP & CBD may find that they are unable to swallow saliva and it builds up in their mouth, or starts to dribble out. Some medications can cause a dry mouth – your doctor or pharmacist can advise on this. Having a dry mouth can lead to an unpleasant taste in the mouth and a coated tongue. This increases the likelihood of dental decay and dryness/cracking of the tongue and lips. Drinking enough fluid and taking frequent sips of water can help. Lip balms can help moisten the lips and GPs and dentists can prescribe gels or sprays to help with a dry mouth.
- As PSP/CBD progresses it usually affects a person's ability to swallow. This can put them at higher risk of developing aspiration pneumonia. Aspiration pneumonia is a bronchial pneumonia caused by the spread of bacteria in fine droplets from the throat and mouth into the lungs during breathing and coughing. Dental plaque is a reservoir for bacteria and, if not removed by brushing, can potentially dislodge and be inhaled leading to aspiration pneumonia. Maintaining good oral hygiene and avoiding the build-up of plaque is important for people, including those who use 'PEG' feeding and will reduce the incidence of aspiration pneumonias.

## Molly and Jim's Story

Molly Boyce has PSP. She lives with her husband Jim, in South Lanarkshire in Scotland. When Molly complained of mouth ulcers Jim tried numerous routes to solve the problem. Jim consulted the pharmacist, the dentist and the speech and language therapist, but nothing was very successful. Then, explains Jim, a young doctor at his wife's surgery 'thought laterally' and asked 'why is this happening?' As a retired engineer, Jim could identify with this approach to problem solving as he had been trained to ask 'why did it go wrong?'

**“You should never stop taking medication suddenly, always discuss with the prescribing physician and see if there are alternatives that could help alleviate the side effects.”**

The doctor realised that Molly had a dry mouth and he felt this was the likely cause of her ulcers. He spoke to a neurologist who suggested looking at Molly's medication.



Molly tends to keep her mouth open which dries it and she was on a medication (Amitriptyline) which can cause a dry mouth. After discussion with the doctor, Molly stopped taking Amitriptyline Jim said: “It was like magic. Within a week, the ulcers had improved and within two weeks they had cleared completely.”

Caution, however is advised. Kirsty said: “You should never stop taking medication suddenly, always discuss with the prescribing physician and see if there are alternatives that could help alleviate the side effects.”

**Toothpaste:** Use a high fluoride toothpaste with at least 1450 ppm fluoride content. Fluoride helps prevent decay and strengthens teeth. It slows down the rate at which bacteria produce acid in the mouth. Dentists can prescribe a higher strength fluoride toothpaste which can be useful for increased protection of the teeth where someone may have increased risk of tooth decay (such as a dry mouth).

Low foaming toothpastes can be helpful if swallowing the foam created by toothpaste is a problem. These can be bought over the counter or prescribed by your dentist. Pick one that does not contain Sodium Lauryl Sulphate – this is the foaming agent.

**Spit but do not rinse:** When brushing do not wet the toothbrush – it dilutes the

fluoride and creates foam. Spit any excess toothpaste foam out after brushing and do not rinse out the mouth with water or use mouth wash, as this will remove the protective fluoride from your teeth.

Consider getting an electric toothbrush as it may be easier to use. There are special three sided brushes available which can help to clean the teeth more effectively, especially when carers are cleaning for an individual.

**Assisted brushing:** Carers may find it helpful to use the '2 toothbrush technique' to help hold the mouth open and might need to use finger protectors if appropriate. Ask the dentist to show how to help brush, as it can be difficult and they may have specific tips.

In the later stages of PSP & CBD, when teeth cleaning may be trickier due to

unpredictable clenching shut of the mouth, sliding a tooth brush in under the lip and massaging the front teeth may be all that is possible, however it is essential to keep trying to clean all the teeth, brushing at different times of day may help.

**Denture care:** Don't sleep with dentures, because gum tissue needs time to rest and leaving the dentures in can cause some fungal infections. Dentures should be brushed with soap and water and left in a small amount of water overnight.

**For further information or for help in finding a service in your area please contact our Helpline on 0300 0110 122.**



# The path to future treatments

It's an exciting time in the development of PSP treatments, with an international clinical trial already underway (see page 6) and others currently in development. The path to licensing a new treatment involves several significant hurdles, with the biggest (and most expensive) one coming at the end – the clinical trials process.



EVIDENCE from a successful clinical trial is used to get a new drug licensed and approved for use. However, before it gets anywhere near a human, a new drug must have shown significant promise in the lab and in animal studies. Researchers need to have confidence that it might be safe and effective for people to take. Even then, investing in a clinical trial is a gamble for a pharmaceutical company. Trials are nothing more than large scale experiments and many drugs that have shown promise during the early phases of testing have proven to be ineffective once they reach clinical studies. But even if that happens, the results from the trial will have provided valuable knowledge

to help researchers build up a fuller picture of PSP & CBD.

Consultant neurologist Prof James Rowe at Cambridge University Hospital said: "The new generation of clinical trials offers real hope for patients and families affected by PSP & CBD. It is not just their



Prof James Rowe

stronger scientific foundations, and use of smarter ways to detect the benefit of a drug or vaccine. The new trials are tackling PSP from very different angles, finding the weak spot in the disease that can be exploited for treatment.

"In many drug companies, the smart money is on PSP, in a way never seen before, with a domino effect on CBD research. It is a great time for patients and doctors to work together to find a cure – not everyone can take part in trials, and they can be a major commitment. But, taking part in research can also be very empowering, working closely with your medical team and taking back control against the PSP, for you and for future generations of patients."

## How do clinical trials work?

The only reliable way to prove beyond reasonable doubt that a drug is beneficial is by monitoring the effects of the drug in a group of patients and comparing their progress with a similar group not taking the drug. This means that half of the participants in the trial won't actually get to take the new treatment. Instead, they'll be given a placebo, something that looks exactly the same but has no biological effect.

## "The new generation of clinical trials offers real hope for patients and families affected by PSP & CBD."

The use of a placebo might seem unfair, but it's absolutely essential to ensure that any beneficial effects seen are entirely down to the trial drug. It can also help to highlight any increased occurrence of unwanted or even dangerous side effects in the group taking the active treatment.

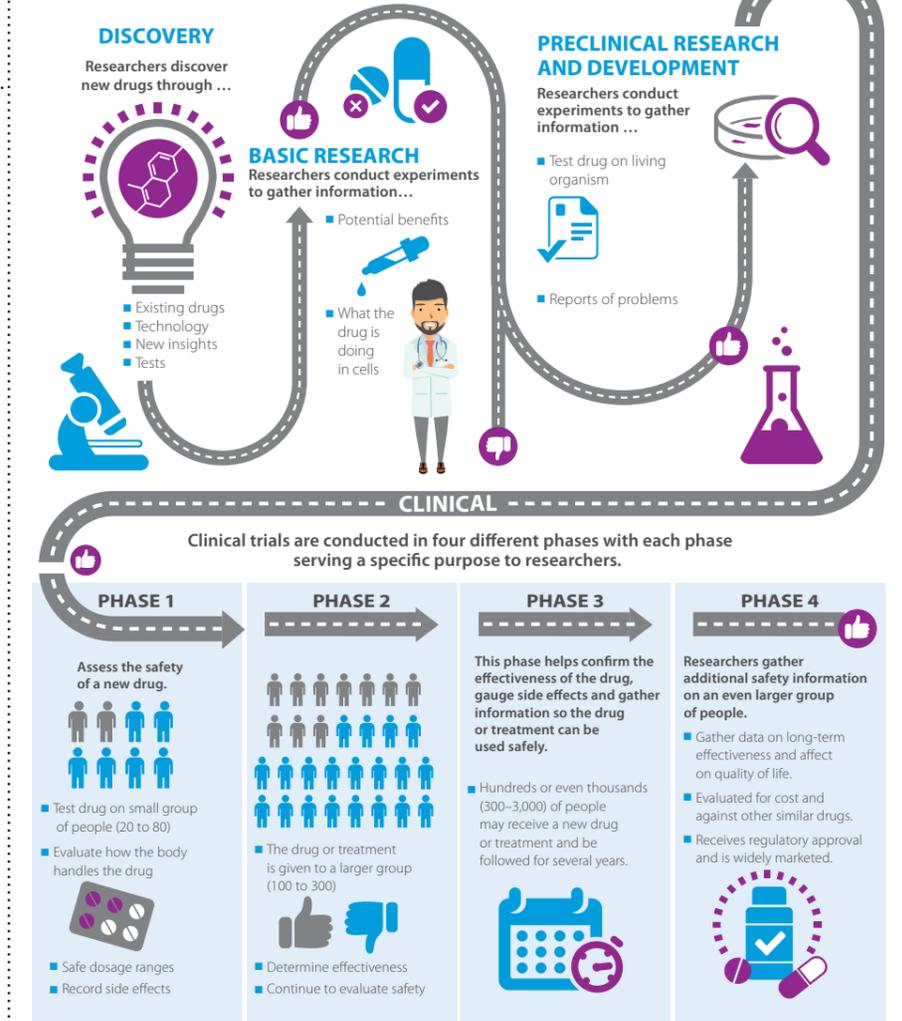
To prevent bias, participants are assigned at random by a computer to the treatment or placebo groups and for the duration of the trial neither the researchers nor the participants know who is taking the real drug.

## Count me in!

Many people jump at the chance to take part in a clinical trial, maybe in the hope that they will get access to an effective treatment, but often because they simply want to make a positive contribution to research. However, many willing volunteers find that participation is not open to them.

Strict criteria for inclusion in the trial are essential for safety reasons and to ensure that the results are reliable. Most trials require participants who are at a

## Behind the scenes of a clinical trial



reasonably early stage of the disease as this gives the treatment the best possible chance of working.

Trials also take up a lot of time and resources at the centres involved and each centre will generally only recruit a small number of participants, ideally from their local area. Taking part in a trial often involves frequent visits to the centre over several months, so it makes sense to recruit people who have the best chance of being able to make it to every appointment and complete the study without too much difficulty.

It's disappointing to find that you can't participate, but it's important to remember that trials are experiments, not treatments, and the fact that they are happening at all is still a positive step. You can make an important contribution to research by taking part in other studies or considering brain donation.

## Issues to consider if you're thinking of joining a trial:

- Are you and your carer prepared for the time and energy the trial appointments will demand?
- Can you commit to travelling to every appointment?
- How do you feel about the possibility of being on the placebo rather than the trial drug?
- Are you prepared for the risk of unpleasant or serious side effects from the trial drug?

Our new information sheet *Clinical trials* provides further information. If you would like to know more about other ways in which you can participate in research, contact our Helpline on 0300 0110 122 or [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)



Patrick and Muriel on holiday in South Africa

## “As matters went from bad to worse, our relationship became closer.”

Patrick Johnson’s wife Muriel, was diagnosed with CBD in 2007. Patrick became Muriel’s main carer and cared for her at home until the very end. Here, Patrick talks about caring for Muriel and how the experience brought them even closer together.

THE decade before my wife Muriel, was diagnosed with CBD, was one of the happiest times of our lives. I had retired from the Police at 48 and was working part-time, which involved frequent trips aboard, often with Muriel by my side.

“I first met Muriel at work in the early 60s. We were married to different people then, but ten years later, we were both single and got married in 1981. During our marriage, Muriel took great care of me and we were happy together.

“In 2006, she noticed there was something strange happening to her fingers. From there she received a series of misdiagnoses. One year later, we went to see a neurologist who told us it was likely to be CBD. Of course, we had never heard of the condition.

“When we got home I went online. It wasn’t easy reading. I kept from Muriel and her family the part about the condition being incurable and the life expectancy. During the next few years, because of the slow progression, CBD didn’t interfere too much in our lives and we continued as we had always done. However, we did put some plans in place for the future, such as moving into a retirement village.

“Eventually, the time came when the neurologist appointments and scans were becoming more frequent. Muriel became aware that CBD wasn’t going away and that it would get worse. CBD is funny that way. Nothing can happen for years and then you feel like you are falling off a cliff with a rapid deterioration.

“Becoming Muriel’s carer happened very gradually at first, with trips to the hairdressers and doing some cooking. It gradually progressed from there. One time we were on holiday in our caravan, when I could hear her crying out in pain. She couldn’t get her nightdress on. That was a milestone moment for both of us. My caring responsibilities had progressed from picking up and dropping off, to showering and dressing. From there, over time, we got to a stage where I was doing everything for her.

“That was so hard for Muriel. But, she made it as easy as possible for me and in her own gentle way, enabled me to get on with things. It makes it so much easier if you are both singing off the same hymn sheet. We shared our problems and came up with shared solutions.

“We would talk about the difficulty of getting her dressed. I took all her trousers to a tailor and had them fitted with elastic waists. With her blouses, the tailor fitted the seam from her armpit and to her wrist with poppers. This made it so much easier to get her dressed.

“I didn’t know who to ask for help. Someone suggested social services. A social worker visited and took us through everything. We had assumed we wouldn’t get any support from the state and were surprised that they don’t take the value of your home into consideration. They started to fund carer visits, which helped a lot.

“When you have good, proactive professionals involved, it makes a huge difference. Believe it or not, when Muriel got worse, was actually when things began to get better. We started to get professional help; carers, speech and language therapists, occupational therapists, social workers, physiotherapists, domiciliary dental and sight care. Each of these brought two things – assistance with everyday living and brightness in an otherwise dark time.

“Perhaps our most important guest, other than our team of carers, was the palliative care nurse. With her help, every aspect of my wife’s future could be discussed and I know that having her wishes recorded, brought my wife great peace of mind. I was also grateful I didn’t have to do it; that would have been too hard for both of us.

“As matters went from bad to worse, our relationship became closer. As she became more and more dependent on the carers and me, the more we both gained great comfort from each other.

“When you are dealing with a condition like CBD you need to have a team of people around you who really care about what they are doing and don’t just view it as a job. You need to



be told what benefits are available, and what equipment will help. For example, it wasn’t until I read in PSP Matters that if you have a wheelchair in the house, you get a discount on your council tax.

“My wife remained at home with me until the very end. Muriel’s last day started like any other. Carers came in the morning and got her showered and dressed. By this point she had lost her speech, but her brain was still active. The previous evening, we were watching a comedian she liked on TV and she was chuckling away.

“As she was sleeping after lunch I could hear she was breathing oddly. I called the nurse who confirmed she was in the last stages. I phoned Muriel’s daughter and the carers, who all rushed to be at her side. Muriel looked at each of us in turn. I really do believe, at that moment she knew what was happening and was saying goodbye. There was no pain or anguish or any discomfort at all – she passed away peacefully and at home, where she wanted to be.

“I miss her dearly. It is hard to be so needed by someone and be in such an intensive relationship as we were

and then suddenly it all stops. You lose everything. All the carers visits, the district nurses – suddenly you are in a different world.

“As much as it was a struggle, good still came out of the experience. Muriel and I were introduced to so many people who were determined to make life as near normal as possible. Many went out of their way to take care of my wife and to offer support and comfort to both of us.

**“When you have good, proactive professionals involved, it makes a huge difference. Believe it or not, when Muriel got worse, was actually when things began to get better.”**

“I would not want to go through the experience again, but I like to think it made me a better person and more attentive to the needs of others. I owe a debt of gratitude to everyone who helped. I shall always remember their acts of kindness and generosity.

“If you are now at the beginning of a journey similar to mine, I offer you my sympathy and hope that, as I did, you will get through the experience with the help of others and find yourself a better person at the end. No one deserves either PSP or CBD and PSPA warrants all the help and assistance it can be given.”

**Many people tell us that reading other people’s experience of PSP & CBD is one of their favourite parts of PSP Matters.**

**If you would like to share your story, please contact [psp@pspassociation.org.uk](mailto:psp@pspassociation.org.uk) or phone 01327 322410**

# “I knew more about PEG feeding and hoists than maths!”

When Freya Hannan-Mills, 13, was invited to create a play for the Lyric Theatre’s Gala she decided to use her personal experience of PSP. Performed by actor, Jude Law, Freya’s play *Mushy Peas and Battered Bits* was about a man with PSP, who takes a final day trip with his carer to the beach where he spent his childhood.

FREYA’S grandmother, Margaret, had PSP and lived with Freya and her mum Melanie. Melanie and Freya speak to *PSP Matters* about their experience of PSP and why the play was a great opportunity to raise awareness of the condition.

Melanie said: “It was at my daughter’s baptism when my mum, Margaret, had her first fall. She fell backwards and I remember thinking how odd, as she was standing still at the time. That was the start of many more falls, so we saw a specialist who advised me to “be a good daughter and buy better slippers.” The investigations into what was wrong continued and eventually she was misdiagnosed with Parkinson’s. Eventually she received a diagnosis of PSP.

“I wanted to look after Mum at home. At first, we had carers for a couple of hours a day. Then, with the help of PSPA, I fought for a continuing care package. Together, we influenced decisions in the area and I hope we paved the way for a much easier process for people with PSP in the future. I certainly would not have coped without PSPA. My daughter and I cared for Mum at home until her final year, when she moved into a wonderful care home, where the staff really developed an understanding of the condition.

Freya said: “I can’t remember Nana not being in a wheelchair, although I do have photos of us walking together. Nana loved her teddies and we would lie on her bed and cuddle them for hours. I loved reading to her, and she had to sit through the whole Harry Potter series. I struggle now remembering her speaking, but she would gurgle when her carers brought their dogs to work. It was terrifying the first time I saw her choking. Mum had been trained to use a suction machine and I thought it was really brave of her to be using it. In



Portrait of Gran by Freya

fact, I think Mum is the hero in all this. We seemed to spend every Christmas Day in hospital and Mum would still make them magical.” Melanie continues: “Watching Mum’s progression with PSP has been heart-breaking. I missed her voice dreadfully. You start to feel them slipping away, but each week brings new challenges and you become consumed with the practicalities, until, one day, you realise you haven’t had a conversation, or the smile has faded, or your Mum’s face is set in an almost permanent expression of worry. Once her voice went, I relied on her face and a few hand signs. When that faded too, I worried constantly that she was in pain, but thankfully she had a strong grip and could squeeze for a yes and so we worked out a code.

**“I was really lucky to be mentored by the playwright Simon Stevens and he encouraged me to write about PSP. His advice helped me to have the confidence to tackle it.”**

“PSP is little understood, even by medical professionals. I think that’s why I feel so strongly now about spreading the word. There’s so much ignorance about the condition, especially in the NHS. I can’t even begin to list the times that

really unsafe practices occurred in the hospitals. On more than one occasion I’d be photocopying PSPA information for ward doctors.

“Raising awareness of PSP is important to the family and when an opportunity presented itself to Freya, she knew what she wanted to write about. Freya said: “I had created a piece for Harts Theatre as part of a competition. The Theatre Director, Ann Akin had created a fantastic event at the Lyric Theatre in Hammersmith where it was performed. Following this, Ann was instrumental in me being invited to create a new piece for Jude Law to perform at the Lyric Gala.

“I was really lucky to be mentored by the playwright Simon Stevens and he encouraged me to write about PSP. His advice helped me to have the confidence to tackle it. I suppose it has been my entire world really, I know more about PEG feeding and hoists than maths!

“Jude had agreed to do this performance for the Lyric Gala and I knew, before I started writing *Mushy Peas and Battered Bits*, that he would be performing it. He was so lovely, very friendly and encouraging. He just really puts you at ease and is one of the team. I thought I would be intimidated, but he creates a warm and welcoming atmosphere.

“I don’t think he had heard of PSP, but he was really interested and wanted to know very specific things. He asked me a lot of detailed questions as he wanted his portrayal to be as authentic as possible. I think he did an amazing performance.

“PSP is such a hideous, difficult disease. It’s terrible for the person, but equally awful for the carers and family because it is so relentless. I have lived with this disease for most of my childhood and I’m determined to continue to raise awareness of its devastating nature.”

# How co-ordinated care should look

Is living in a small community sometimes the key to good care? Living in an area where the professionals all know each other and many of them work in the same building? Where referrals between professionals can be made face to face?

**A**NDY and Elizabeth Copp live in a small town called Keith, on the Moray Firth in the North East of Scotland. In March 2016, retired high school maths teacher Andy, 66 was diagnosed with CBD. Since then, he and his wife have appreciated the well co-ordinated and well planned care and support they have received from both their local council and local health services.

Andy was diagnosed by a local consultant who offered to arrange for him to see a neurologist in Aberdeen. The couple decided against this, feeling that key to managing was getting good local support.

One of their key professionals has been their Occupational Therapist (OT), Ailsa. Elizabeth said: "Ailsa is five star, I can't speak highly enough of her. She is so pro-active. We have never had a crisis, we have always had the right equipment in place before we need it." Ailsa has arranged a walk-in shower and other bathroom equipment, a profiling bed, a ramp at the front steps and a stand aid. Elizabeth continues: "It's so important to have a home that can cope." Ailsa has also been instrumental in bringing other professionals together. The physiotherapist now 'pops in' regularly to monitor Andy's mobility and upper body strength and the community nurses calls fortnightly and keep Andy's GP in touch with how he is.

The Speech and Language Therapist has worked with Andy on



communication issues and has lent Andy an iPad with a speech app on it. She is also looking at how Andy can continue to manage his emails despite his struggles with a keyboard due to reduced movement in his hands. This is very important to Andy as he has an enduring passion for steam trains and runs a business (Lochgorm Kits) making brass model trains.

The local Parkinson's Nurse Specialist visits which, the couple explain, is always useful and the local Parkinson's Adviser has been involved and helped with an

Attendance Allowance claim. She also liaised with Ailsa over equipment issues.

Elizabeth's needs as a carer are being addressed. Following a carer's assessment, she was put in touch with Quarriers Carer Support Service which offers support to unpaid carers across Moray. Through them Elizabeth has obtained a carers emergency card, completed an emergency plan in case she is suddenly unavailable through illness or a crisis and attended a range of courses.

It was Andy's GP who suggested



Andy raises awareness in the local media accessing the Marie Curie nursing service (which many people mistakenly believe is only available to those with cancer). The plan is that occasionally an overnight Marie Curie nurse/carer will be provided, so Elizabeth can get a good night's sleep. Marie Curie are also arranging for a volunteer to visit Andy regularly.

**"Ailsa has arranged a walk-in shower and other bathroom equipment, a profiling bed, a ramp at the front steps and a stand aid."**

Elizabeth feels the social worker and the manager of the care service have both been quick to understand their needs and to sort out concerns before they escalate. Andy now has two carers four times a day and the social worker is arranging a sitter via Crossroads Care.

For many people having a care co-ordinator is key and this is a role we know is important. For Andy and Elizabeth this hasn't really been necessary, as their needs are met through excellent individual relationships and through professionals involving their colleagues in a timely manner.

Elizabeth has shared this good practice with a local care commissioner who told her 'I now have a vision of everyone in a line holding hands, all supporting you and Andy.' "Yes" says Elizabeth "It feels just like that."

# A positive move

**"I just want to live as good a life as I can."** Pat, 71, was living alone in a 3 bedroom house when, in 2015, she was diagnosed with PSP. Concerned about the future Pat took pro-active steps to look into what housing might suit her. Having lived in her previous home for 40 years, this was quite an undertaking.

**P**AT was attending the hospice and staff there helped her obtain a flat with care staff available 24/7 and a good range of community facilities, including a gym. Pat only had two weeks to decide on the move and was grateful for this, as she feels it stopped weeks of agonising over a decision.

Initially Pat found life in her new home strange and would stay inside her flat. Slowly she started to join in activities. Pat said: "I missed my garden, so I became a garden volunteer. I'm in charge of dead heading all the flowers after they've finished blooming. I joined in more and more. I did crafts, I went on outings, made friends and then, when someone told me exercise would be good, I joined the gym."

"I checked with my consultant and he told me 'any exercise is good for you.' At that time, I was unable to walk in a straight line. I looked drunk. I was also unable to stand up from a chair without support."

The onsite gym instructor, Pat Honeyghan, is familiar with progressive movement disorders. She works in sports development for the local council, and with the falls prevention service. She talked with Pat and devised a programme for her, concentrating on using an ergonomic bicycle (with Pat sitting in a normal chair and using



pedals), upping the resistance level as time progressed. Pat's balance has improved and how she has grown in confidence.

Pat continues: "I was attending the gym twice a week, but I've just increased this to three times a week. When it's wet outside I worry about going out so using the gym replaces a walk. It is hard in the gym, but the benefits to me have been unbelievable. I walk better (still using a stick) and my fitness has improved."

"I just want to live as good a life as I can and appreciate my body as it is now. I know it can change in the future."

## You, me and PSP – Cilla’s memory lives on



A book about Cilla Dagnell’s life with PSP has been read by people across the world and has, so far, raised over £3,000 for PSPA. Through the book, *You, Me and PSP* Cilla’s legacy lives on by continuing to help others affected by the disease. With her determination and encouragement, Cilla’s husband Steve wrote the book in her memory following her sad death in late 2015.

Steve said: “When I spoke to Cilla about her illness, she said, ‘let people know by doing what you do best... go for it’... So I did. With a heavy heart, the day after she died I started to write, and since Cilla was a great diarist, many of the words in the book are very much her own.

“The response to *You, Me and PSP* has been phenomenal. I recently saw that a well-respected PSP group had included it on a list of books that may help people with PSP, and many had commented that they found our experiences helpful. The first part is about Cilla’s early life. From there, we share the impact of the diagnosis of PSP and how we managed the progression, from dealing with sight loss, advanced care planning and eventually brain donation. In fact, we cover everything someone living with PSP needs to consider.

“Cilla didn’t want to finish on a negative, so at the end we shared positive examples of things she continued to enjoy, even in the later stages of PSP. Keeping Cilla’s name alive is extremely important to me, but the most important aim of the book, is to provide people living with PSP, CBD and other neurological illnesses, useful hints and tips, as well as raising money for PSPA.

Cilla insisted that all profits go to PSPA, so I signed financial rights over to them for 25 years from publication. Conversely, I have met so many people connected to PSP, which is now my motivation for spreading the word about, *You, Me and PSP*, so that it can reach as many people as possible.”

The book is available through Amazon on Kindle and in book form as well as through the PSPA website.

# If not you, then who?

We now have an amazing team of 100 volunteers supporting us in delivering a wide range of services for people with PSP & CBD. We have some exciting plans for this year, but to put them in place we need more volunteers.

OUR aim is to double the number of people volunteering for PSPA, so we can provide people with PSP & CBD more support and raise awareness.

Chloe Cripps is a speech and language therapist and has been a volunteer for PSPA for three years, as a helpline volunteer and, a support worker. Chloe talks about her motivation for volunteering and why, for small charities supporting people with rare conditions, volunteers are vital.

Chloe said: “I started volunteering on the helpline. I found it easy to manage alongside my job and two small children. At first I was worried, how can I help people who call? I soon realised the most important thing was listening. For the majority of people, it is such a complex condition to get their head around, so talking it over helps. The most rewarding thing is when people finish the call in a better place than when they first contacted the helpline.

“PSPA asked if I would be willing to take on a support worker role. I was soon given the name of the first person to visit. Visiting someone as a support worker is very different to visiting people in my professional role. There is no tick box, no time limit, no list to work through. Instead my visit is totally led by the person I am supporting and their priorities. Most importantly of all, I am there to listen.

“There is so much need out there for this role. We need more support workers, so that people with CBD and PSP throughout the country, get access to this type of support.

“I would encourage anyone to volunteer. For me it is about meeting different people and broadening your horizons. For PSPA, without people volunteering it simply would not survive, which would be so damaging for the people we are here to support.”

We are looking for people who are good listeners and communicators, can donate a few hours



Chloe Cripps and her family

a month, want to make a difference and can be supportive. Is this you?

If it is, we would love to hear from you. Please talk to family, friends and colleagues about volunteering and pass on our details to anyone who may fit the bill. They may not have thought about volunteering before and it might be just what they are looking for.



## You just need one number for support – our Helpline

WE are reorganising our Information and Support Services, to help us focus our efforts on supporting even more people with PSP & CBD. Part of this work includes making our Helpline the single point of contact for people affected by both conditions.

Through our 2016 survey for people with PSP & CBD, we have seen the impact our Helpline has on people who have used the service. By being centrally located, our Helpline is able to provide consistent and equitable support for all our members in the most cost effective way possible. As part of the restructure, we will also be simplifying our processes so people affected by PSP & CBD will have just one point of contact in the future.

We are increasing the Helpline’s capacity by creating two new roles. Both the new and existing roles will become Helpline Care Navigators and will provide people with PSP & CBD a named contact to help ensure they are referred into all relevant local services. Inevitably, centralising this service means reducing our regionally based staff numbers, including the Specialist Care Adviser role.

Andrew Symons, Chief Executive said: “We are working hard to minimise the impact of the restructure by removing vacant roles and redeploying staff where possible to the new Care Navigator posts in the Helpline.

“In a restructure like this there are always difficult decisions to make and these will be handled sensitively and respectfully – but we need to have a sustainable cost base going forward, and to demonstrate to our supporters that we are making the best use of their donations. Our focus must always be on how we can use our resources most effectively for the people we are here to support.”

Alongside changes in Information and Support Services, we will be aiming to recruit more volunteer support worker roles, so that they can provide local support to people with PSP & CBD.

Would you like to find out more about becoming a volunteer support worker? Please contact Volunteering on 01327 356134.

Concerned about how these changes may affect you? Please contact our Helpline on 0300 0110 122.

## News from our Local Groups



### Cheerful chats

The Hertfordshire group have used the last two meetings to focus on the social aspect of their meetings. Group co-ordinator Maureen Horne, explained that members really like the opportunity to come along and socialise, and in her words: "enjoy a chat over a cuppa and cake with friends who understand." Of particular interest have been two people taking part in the Oxqip research study that is taking place at Oxford. Members learned about what it is like to take part and the processes and procedures involved. To keep everyone up to date, including those who have been unable to attend, Maureen sends out a newsletter with reminders of the next meeting.



### Hidden talents

Members of the Woking group had a fun and creative meeting trying out their artistic skills. The results were so good group co-ordinator Betty Peers, decided to make them into a calendar. The group are now selling the calendars to family and friends to cover the cost of their meetings.

### Reflections on the year

Ann Pearse, our Worthing group co-ordinator shares her reflections on the past year. "We have enjoyed catching up and exchanging helpful hints and tips. It is nice to be able to talk to people who understand exactly what you are going through, either as a person with PSP or CBD, or their carer or family member. Often another member has had a similar experience and can offer help and advice to make things easier.

"We have had talks from Carers Support West Sussex, a local Carers Health Clinician, a speech therapist, our local Parkinson's nurse, as well as Jules from PSPA.

"We have also tried to spread the word raising awareness by manning an information table at our local hospital during PSPA awareness week and two local carer's shows.

"We also raised funds for PSPA from a 5k sponsored walk, a coffee morning and stall at a fair. In addition, we were able to make a donation of £250 from donations made throughout the year at our monthly meetings and collection tins at the information tables.

"I am very grateful to all those who come to the meetings (some far afield) and those who help with the meetings. We are very friendly and if you feel you would like to join us we meet on the last Friday of the month 11.30am - 1.30pm January to November."



## Hello and Goodbye

### Leeds

PAM Bower our stalwart Leeds group co-ordinator and her committed helpers Beryl and Sid Mayhew, have after five years at the helm, decided it is time to take more of a back seat. Pam will still be attending the group, which will continue to meet at the same venue this year. Cathy Howarth will now be the main point of contact and can be reached at catherinehowarth.bowen@gmail.com The meetings will continue to be held on the second Wednesday of each month and old and new members will receive a warm welcome.



Cathy Howarth

### Sheffield

JOAN Weatherington will be handing over the reins of the Sheffield group to Sheila Bargh and June Draper, who have agreed to share the responsibilities for the Sheffield group. Joan will still be attending the group.

### Liverpool

WE are looking for a new local group co-ordinator for our Liverpool group. After being at the helm, Julia Bonner and husband Jim are leaving the Liverpool area for pastures new. A huge thank you to them for everything they have done to keep the group going. However, it may not be goodbye, talks are already happening about a new group with Kent co-ordinator Sarah Marshall in the East Grinstead area, when they are settled into their new home. We wish them all the best.

### New group on the Isle of Wight

SISTERS Becky Gell and Vikki Colenutt, will be setting up our first group on the Isle of Wight early this year. As soon as we have dates and a venue confirmed, we will be in touch to let you know.

### Moving into Northumberland

WE are now planning to develop our services in Northumberland and will be contacting everyone in the area to let them know of our plans. We are aiming to hold a meeting in the next few months to which everyone will be invited to hear about what research is taking place, have the opportunity to share experiences and knowledge and hear how we are planning to improve support for people in the area. We look forward to seeing everyone there.

## Workshops and development days for our volunteers



In September, 14 of our group co-ordinators from Aberdeen to Devon attended our local group workshop.

THE day started with a lively discussion where colleagues shared their experiences of running a local group.

Sarah Marshal, led the group in a discussion about activities during group meetings. Many ideas were put forward from craft activities to visits from Pets as Therapy.

We told the group about plans to evaluate our volunteering services and asked the volunteers to tell us about any feedback they have received. Comments were wide-ranging and all showed the positive impact of the group, with one commenting: 'the group has more impact on our lives than any of the support services.'

After this very positive session, Scott Smith, Fundraising Officer, challenged the group to come up with new ideas for fundraising. The winner was a plant potting/singing session and a lot of interest shown in a virtual race, which has subsequently been launched, 5K for PSPA.

Wendy Crofts, Volunteering Services Manager ended the day with a session on taking care of yourself with



volunteers sharing their ideas and committing to putting some of them into practice.

In November, we held a development group with a mixture of helpline assistants and support workers. The day covered topics including research, brain donation and working with other organisations. The question and answer session led to some interesting discussions.

A huge thank you to all of our volunteers that attended the two days and shared so openly your thoughts and experiences. We look forward to seeing you all again soon.

## “I felt compelled to do something in Dad’s memory.”

Chris Underwood raised £2,300 after setting himself the gruelling challenge of cycling through nine countries in just nine days – a truly incredible dare to take on! Chris tells the story of his challenge.

**A**FTER my father, Brian, died from PSP in 2016 I felt compelled to do something in his memory, something which would also raise money for PSPA.

My dad had always been a naturally adventurous type. I didn't have much experience of adventuring myself, but I did commute to work by bike, and so it struck me that perhaps a cycling challenge might be an option.

I did my research and discovered that if you kept your distances up you could cross a national border in Northern Europe every day, for more than a week on a bike. A challenge was born: 9 Countries in 9 Days.

“Just after dawn on a misty June morning I set off from home. The first day involved cycling through both London and Paris; very much an ‘in at the deep end’ approach with my first experience of cycling abroad. Shortly before midnight, after many hours of train travel, I arrived in the small Swiss town of Chur, overshadowed by the Alps, and under a blanket of torrential rain. Here I met up with my brother, who would be joining me for the first few days.



“From Switzerland we followed the turbulent course of the Rhine, over a covered wooden bridge and into the tiny principality of Liechtenstein. We chased



the Rhine further the following day, all the way to Lake Constance, stopping for lunch in Bregenz on the Austrian border, and that evening in Konstanz (Germany) at the northern tip of the lake.

“I was joined by a friend in Konstanz, as my brother had to return home, and together we headed north and into storm clouds hovering ominously over the already pretty ominous Black Forest. We spent a day crossing from one side of the forest to the other, resting in Freiburg that evening and then picking up the Rhine again the next day. We rode from there into Strasbourg.

“The following day we headed through the Vosges and then back into Germany and the Saarland, the country's industrial heart, spending the night in Saarbrücken. The next day demanded a steady climb

towards Luxembourg City.

While following the Rhine we had managed to stay relatively flat for much of the journey so it seemed ironic that as we entered the Low Countries we hit the hills. From Luxembourg we ventured through the forests of the Ardennes and into the town of Spa.

“Our final morning's cycling took us from Spa to the Dutch border near Maastricht. I felt quite emotional as I saw that the road signs were now in Dutch. There was no grand border crossing to officially denote my achievement, just a gradual fade from one language to another. I felt proud, too, not only to have achieved my goal, but in raising over two thousand pounds for PSPA. It had been quite an adventure. I like to think my dad would have approved.”



## Fundraising ball in memory of Mum

**K**ATE Pollard raised an astonishing £4,270 in memory of her mum, Christine Banner, when she organised a wonderful fundraising ball. Guests enjoyed live music, a three-course meal and a disco too. Kate said: “My wonderful mum sadly lost her battle with PSP on 14 February 2016. The day of my mum’s funeral was overwhelming for me, to see the number



of people who came to pay their respects was incredible. On that day, as the sun set, I decided I would organise an event in mum’s memory. A chance for us to get together again and celebrate what a wonderful woman she was.” The night was a huge success. Kate said: “It was such a memorable, emotional, amazing night. It was so much more than I had dreamt it would be.”

## Stamps, glorious stamps!

**S**ARAH Robinson's dad Gerald Marshall, had CBD and only lived for four years from diagnosis. Sarah describes the impact on the family and why she wants to help PSPA. Sarah said: “It was a devastating illness for him and also us, to watch helplessly, unable to do anything to stop the progression of the illness. He was very brave, never moaned and has inspired us to smile and keep going.

“I raise money for Dad’s Much Loved memorial page in lots of different ways. For the last two years, a group of us collect stamps to raise funds. I also have 20 people who collect their spare change in jars I made, called jars of hope. I sell Gerald’s daffs each September and Hope the bear gets involved too!

“I pray one day there is a cure for this devastating illness that robbed Dad of his retirement. The illness devastated our family, but it also strengthened our love



for each other to get through and support Dad. My amazing Mum never left Dad’s side, and we have all emerged stronger through their great love and bravery. I would like to thank PSPA who helped us through those dark days and we will continue to help in whatever way we can.

## Determined to run

**A**FTER two years fighting to recover fitness after a football injury left him needing major surgery on his knee, Robin Hood Half Marathon runner, Rob Hallam was greeted at the finish line by his family and young son. “This was a real challenge for me, so I am pleased to have completed the race,” said Rob. “I wanted to do something in memory of my father-in-law, Chris Yoell – and as we all live in Nottingham, this seemed a fitting choice!”

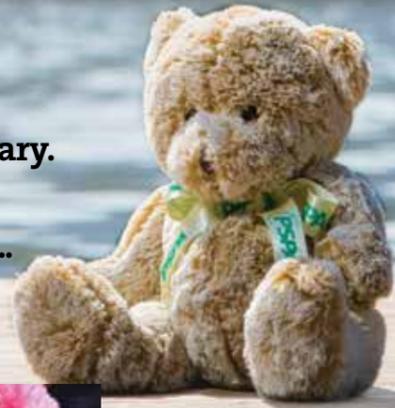


Rob's wife, Annie, is delighted that through this run – and with support from the wider family – they raised over £1000.

“Dad, received a late PSP diagnosis but the help given by PSPA was invaluable,” added Annie. “We all wanted to show our appreciation for a charity so close to our hearts – we were overwhelmed by the generosity of friends and family. Dad would have been very proud.”

# Hope's adventures

Hope, our awareness-raising mascot, now has her own diary. Here she will tell you all about the places she's been around the world, and the people she has met...



## Happy New Year!

2018 is shaping up to be something quite special indeed. Not only will I be attending some incredible events again such as the London Marathon, Great North Run, and RideLondon – Surrey 100, I will also be joining in the first ever 5k for PSPA! I've already got my running app downloaded, my new PSPA headband on, and I am ready. It's going to be quite the occasion. I can't wait to hear about all those taking part and where they will be running. It's a doddle to sign up and take part too, even for a bear.

And if a bear who ate way too much over Christmas and is in need of a little exercise can take part, then I am sure you can too! It'll be a great way to support those living with PSP & CBD.

As ever, my travels last year took me across the globe raising awareness. If I wasn't in the steamy jungles of Cambodia, I was high up in the Himalayas in Nepal. Here I

am learning the Tibetan bowl wearing my favourite happy hat when I visited Paula Nightingale in Nepal. Yes, it's difficult without opposable thumbs, but as ever, I excelled. Closer to home I got into the Christmas spirit with a visit to the Hertfordshire local group's Christmas afternoon tea. The group was treated to the afternoon by the Redbourn WI and the Redbourn Singers. Thank you very much to them for a wonderful afternoon.

I am always ready for my next big adventure, whether that's on far-off shores in the remote places of the world, or simply visiting friends and loved ones. I am always here to raise awareness and bring a smile to faces so please take me by the paw and whisk me off on your holidays or days out, and together we can raise awareness of PSP & CBD. It's what I do best!

Now I must get on with my training for 5K for PSPA.

Remember, if you'd like me to come along to your fundraising events – drop me an email [hopethebear@pspassociation.org.uk](mailto:hopethebear@pspassociation.org.uk) and I'll check my diary. Hope to see you soon. Love, Hope

# Promotions – be excited for 2018!



## RideLondon Surrey 100

29 July 2018

JOIN our biggest-ever team at the UK's biggest cycling event! #TeamPSPA will once again be at RideLondon – Surrey 100 for another spectacular day's cycling. Take in the capital through traffic-free streets before winding through the stunning Surrey countryside, then cross the finish along The Mall for a triumphant finish. Time to get in the saddle!

## Great North Run Newcastle

9 September 2018

THE world's most-famous half marathon takes place on 9 September and you can be part of #TeamPSPA! 2018 will see our biggest-ever team don PSPA colours to take part, and we just might have a place for you.

Space is limited so please be quick in registering via our website, or email [events@pspassociation.org.uk](mailto:events@pspassociation.org.uk).



2018: Bring it on!

# Your fundraising

Yet again, our loyal – and often energetic – PSPA supporters have been out and about raising funds and awareness. Big thanks to everyone who has run, jumped, sipped or cycled!

## On your marks...

Jon Clayton ran in the Spanish heat to complete the Valencia Marathon. Joined by his sister, Debbie, (who had already conquered an ultra marathon for PSPA this year) they are supporting their Dad, Norman, who is living with PSP.



Stephen Cassidy and his brother, Anthony, started - and finished - the Woburn Abbey Triathlon together, for their dad, Patrick, who is living with PSP.



Joe Wood took #TeamPSPA overseas and battled the high temperatures in the Chicago marathon.



The British 10k was held back in July, and Panay Vassilou once again donned his PSPA running vest to finish the race.



A fist pump from Jen Foulds as she finished the Beacon Bunny Run 10K. Jen wanted to fundraise for #TeamPSPA as her Mum is living with CBD.



Deb Barker crossed the finish line of the Robin Hood Half Marathon – now remembering her Dad who lived with PSP.



## Peaky

Brothers, Alex and Tom Heywood – and friends – accepted the Three Peaks challenge back in August in support of their Grandad, Noel, who lives with PSP. In his day, Noel was a semi-pro boxer – winning 47 out of 50 fights.



## A vélo

Devising his very own 'Tour de France', Andrew Helme cycled from the Channel to the Mediterranean – in just nine days!



In the Greek darkness, Patricia Vazquez Rodriguez – a PhD student from Prof James Rowe's research team at Cambridge University – completed the Thessaloniki Night Half Marathon.

Tim Ansdell ran Exeter's Great West Run last year in support of his Gramps who lives with PSP.

"It was fantastic to know I was helping such a great cause while achieving a personal goal at the same time," said Tim. "I managed to finish in 2 hours, 12 minutes for a new personal best!"



Dawn Eastwood took on the Manchester Half marathon as her friend, Emily, has recently been diagnosed with PSP. She now has her eyes on London 2019!



Christine Stanley battled through injury in the Birmingham Marathon.



£2,743

## Slurp!

There was a great turnout for a coffee morning to remember Sian Ives' son, Darren, who lived with PSP.



## Go west

Continuing her '12 events in 12 months' epic challenge, Alex Ridout recently journeyed to West Africa to take part in the Sierra Leone Marathon.



£1,300



Jamie Crawford also ran in Birmingham – finishing in less than four hours.



£570

£600

£510

£2,000

Steve Battershill completed the Manchester Half Marathon.



£2,200

£430

£350

£550

£1,050

£3,100

## ...From Lilly too

Raising funds in memory of her father, Lee Duffield, Lilly held a toe-tapping charity dance.



## Fancy footwork

Eric Maddison organised a dance at the Poplar Social Club in Accrington in memory of his wife, Irene. Thanks also to Eddie Pearson, Alison Park, David Baldwin, Eckhart Kranz and Stephanie Reickert for all their help.



£1,000

## Up and down

It was 'Man vs Mountain' as Guy Barlow took part in a gruelling 22-mile hike up, down and around Snowdon. Together with his pal, Rick, they toughed it out in memory of Guy's mum, Lynn.



£2,205

## Pedal power

Michael Richmond and his two sons, alongside lots of other family members, cycled around Rutland Water - in memory of Michael's wife, Marilyn.



£3,415

## Frilly effort

Mud, obstacles and a tutu did not stop John Carmelitano from conquering 'Muscle Acre 10k' last summer.



£450

## Groovy!

Jayden Whitehair made the world a more colourful place after he dyed his hair green and purple! Remembering his granddad, David Bill.



£400

## Virtual Run

Virtual Runner UK, which organises virtual races for charity, and Run Mummy Run, an online running network for female runners, hosted a special virtual race in October raising money for PSPA. Over 800 runners took part.



£2,000

Send your fundraising pictures to:  
Email: [events@pspassociation.org.uk](mailto:events@pspassociation.org.uk)

## Aghhhhh

Three generations of the Ferguson family fell 13,000ft – but they were not alone, they took work colleagues from Hunter Global with them!

"The dive was amazing and if you ever get a chance to do it you must," said Jo Ferguson. "We even managed to get Hope Bear attached to my dad!" In memory of Jo's Mum.



£7,000

## La-la-lah

Alison and Sammy Taylor, along with some talented students, performed at St Barnabas Cathedral, Nottingham. A professional recording of one song is available to buy from iTunes.



£2,950

## Best foot...

Niamh - and 19 others - ran and walked the Limerick Mini Marathon in memory of Niamh's mother Anne.



£840

## Fore!

Alison Heuvelink organised another successful golf day at Ludlow golf club. The winning team plus lady Captain - left to right: Val, Carl, Guy, John, Jayne and Alison.



£1,200

## Always a smile

Family, friends and carers of Chris Cooper joined together to celebrate his life with a 'Smile for Chris' fundraiser, organised by Jenny Simpson. Chris always had a smile – even on days when he didn't feel on top form.



£1,468

## How much?

Julia is an artist and printmaker who recently held a 'guess the weight of the pumpkin' competition at her open studio event.



£60

## Take a bow

Theatre student, Lisa, produced an evening of acts called: 'A Nightmare on King Street'



£875

## Doh ray me

A grand charity concert at the Church of St Michaels and All Angels, Underwood, in Nottinghamshire was organised by Will and Moira Jones.



£1,130

## Rock on

Music-loving Susan Walthall compiled her own rock concert.



£100

## Ding, dong!

Michael Shepherd hosted a musical event with a folk group and bell ringers entertaining a packed room.

£319

## Pony and trap

Trisha Luxton and her Dartmoor ponies had a fundraising and awareness adventure on Dartmoor in August – they also sold their own Christmas cards.



£2,135

## Jog on!

Henrietta Freeman and furry friend, Zebo completed the Milton Keynes 'Dog Jog'



£860

# WE'RE STRIKING BACK



**PSPA's new Strikeback Funds have been created for everyone who wants to fight back against PSP & CBD. If you want to channel your fundraising energy then our Strikeback Fund is for you. Raise funds for PSPA and we will distribute where it is needed the most.**

You can have your own fund or set one up with your family, friends or colleagues. Give your Strikeback Fund a name, register it with us and you are all set to go. You can hold fundraising activities, support our appeals, make donations and encourage people you know to do the same. Whatever you decide you will make a difference for families affected by PSP & CBD.

All the money in your Strikeback Fund will be recorded so you can see how much you have raised.



For more information, and to start your Strikeback Fund, please email the Fundraising Team [events@pspassociation.org.uk](mailto:events@pspassociation.org.uk) or call 01327 322419.

