

# PSP Matters

Spring 2016



## Diagnosing Progressive Supranuclear Palsy (PSP)



PSP is a terminal degenerative neurological condition. The difficulty in diagnosing PSP has led to the creation of red flags to act as warning signs that may raise clinical suspicion of PSP.

Think about PSP when seeing patients diagnosed with movement disorders e.g. Parkinson's disease where there has been a poor response to Levodopa, more rapid progression of symptoms and the development of clinical features not seen in Parkinson's disease.

### What to look for in a patient consultation:

- |   |                         |                                                                                                                                                 |
|---|-------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | Falls                   | Often backwards and without warning                                                                                                             |
| 2 | Postural instability    | Axial rigidity                                                                                                                                  |
| 3 | Slowness of movement    | Bradykinesia                                                                                                                                    |
| 4 | Motor recklessness      |                                                                                                                                                 |
| 5 | Eye problems            | Restricted eye movement. May describe finding it difficult to walk downstairs due to problems with down ward gaze, reduced blink, double vision |
| 6 | Speech                  | Slurring of speech, soft voice                                                                                                                  |
| 7 | Swallowing difficulties | Liquids/and or solids, excessive saliva                                                                                                         |
| 8 | Cognitive changes       | Change in personality, irritability, apathy                                                                                                     |

Inside: Take action in PSP Awareness Week

## Your stories

How PSP and CBD have affected your lives



## Research

Riding the research rollercoaster



## Starting young

Meet our young supporters



## PSP Awareness Week

Unveiling our 2016 campaign



## Care

Managing swallowing difficulties



## London Marathon

Our runners inspirational stories

**Cover:** Dr Gursaran Purewal with our Red Flags for GPs. See pages 6 and 7.

### The PSP Association

The PSP Association 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. As PSP and CBD are very similar, we often use 'PSP' as a shorthand for both.

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

*PSP Matters* is available as a pdf and can be downloaded from our website.

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# Welcome...



It's been a busy spring here preparing for the London Marathon (our biggest fundraiser of the year); planning for awareness month; and supporting more people affected by PSP and CBD than ever before.

## The PSP Association

PSP House, 167 Watling Street West,  
Towcester, Northants NN12 6BX  
Telephone: 01327 322410  
Fax: 01327 322412  
Email: [psp@pspassociation.org.uk](mailto:psp@pspassociation.org.uk)

## Local Groups:

Wendy Crofts, Volunteering  
Telephone: 01327 356134  
Email: [volunteering@pspassociation.org.uk](mailto:volunteering@pspassociation.org.uk)

## Fundraising:

Jean Kelly, Fundraising and Events  
Telephone: 01327 356131  
Email: [events@pspassociation.org.uk](mailto:events@pspassociation.org.uk)

## HealthUnlocked

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

## Helpline

The PSP Association Helpline and Information Service offers confidential information, practical and emotional support to people affected by PSP and CBD.

Mon to Fri: 9am–5pm and 7pm–9pm  
Telephone: 0300 0110 122  
Email: [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

[www.pspassociation.org.uk](http://www.pspassociation.org.uk)

 [www.facebook.com/pspassociation](https://www.facebook.com/pspassociation)

 [@pspassociation](https://twitter.com/pspassociation)

In February alone we responded to a record 355 calls to our helpline and received an influx of new joiners as many more people turn to us for help.

This suggests that our awareness raising activity is paying off and more people are learning about PSP and CBD and our charity's important work.

But there is still much more to be done and we hope, with your ongoing support, to spread the word further during our PSP Awareness Week (15 to 22 May).

This year we are specifically targeting GPs and I would urge you to take our simple 'red flags' action in your local area (see page 6). We really are relying on you to make this campaign a success so please do get involved if you can.

In the centre pages we have shared a few highlights from 2015, none of which would have been possible without your continued efforts and commitment. So however you choose to support our work, thank you.

However, it's vital that we review our activities on a regular basis to ensure they continue meet the needs of families affected by the disease.

That's why all those living with PSP and CBD and their carers on our database will receive a survey from us in the coming weeks.

Please do take the opportunity to fill it in, either online or by post, your views really do matter to us.

A handwritten signature in black ink that reads "Fergus Logan". The signature is fluid and cursive.

Fergus Logan, Chief Executive

WORKING FOR A WORLD FREE OF PSP



## Stronger together

**O**UR dedicated volunteers from around the UK joined staff to fly the flag for PSPA at Rare Disease UK events in the Senedd, Stormont, Holyrood and Westminster.

The parliamentary events were organised to mark Rare Disease Day on 29 February. This year's central theme was recognising the crucial role that patient voice plays in creating change

and improving the lives of patients, their families and carers.

We also shared Rare Disease Day activity on our social media channels. Huge thanks to everyone who helped to make our voice heard.

## Blazing a trail to earlier diagnosis

**We are proud to be involved in a new international initiative aimed at improving diagnosis of PSP.**

**T**HANKS to your generous support we have been able to contribute to the funding of a special task force, made up of around 20 of the world's leading experts in PSP, which is working towards the establishment of clear, up-to-date diagnostic criteria for the disease.

These will provide doctors with 'gold standard' clinical guidelines for diagnosis, making significant improvements on what is currently available, including clear differentiation between PSP and CBD.

The group of top neurologists, including our Research Network Chief Investigator Prof Huw Morris, met in Germany on 12 March.

Our Chief Executive, Fergus Logan, said: "Not only will early and accurate diagnosis make a huge difference to anyone affected by PSP or CBD, it will also make a significant contribution to meaningful clinical trials and ultimately to the development of effective treatments."

"It is heartening to see the international research community working together on such a critical issue."

## Guildford gathering

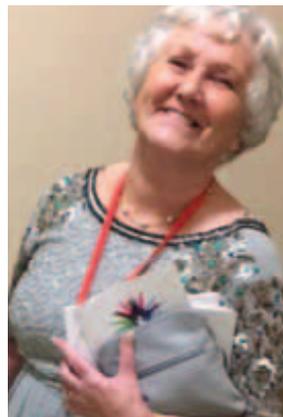
**W**E are looking forward to meeting many of you at our Family and Friends Day in Guildford on 7 May. This event has proven very popular and is already fully booked. Please contact us to be added to our waiting list, [psp@pspassociation.org.uk](mailto:psp@pspassociation.org.uk) or 01327 322410.

A Family and Friends Day will be held in northern England in the autumn. Details to follow.

## Congratulations

**W**ELL done to PSPA volunteer Doris Mason for winning the Northern Ireland Rare

Disease Partnership Community Award for her contribution to rare disease work in the nation. Doris is our Belfast Local Group Coordinator.



## Guide for occupational therapists revised

We have reviewed and republished our booklet A Guide to PSP and CBD for Occupational Therapists.

If you would like a free copy please contact our helpline, email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk) or phone 0300 0110 122.



And congratulations to campaigner Keith Swankie who was shortlisted in the Family Hero category at The Broons Awards. Keith, who lives with PSP, and his wife Sheelagh met Lorraine Kelly at the glittering ceremony.

## Raffle

Thank you to everyone who has supported our Spring Raffle. There's still time to enter! The closing date is 9 May.

# Sign up for study day

**Bookings are now being taken for our 2016 study day for health and social care professionals.**

**T**HE free event will take place at Newcastle United Football Club on 19 October and is open to all professionals with an interest in PSP and CBD.

The programme is aimed at the multi-disciplinary team and will highlight best practice. Delegates will be able to attend workshops on physiotherapy and occupational therapy; the role of the keyworker; speech and language therapy and palliative care.

Last year around 200 delegates attended our study days in Manchester

and Glasgow and more than 100 professionals have already registered for October's event.

Feedback from those who attended last year's event included:

**"I enjoyed it immensely. All the speakers were very interesting and I feel I have learned a lot."**

**"Will definitely apply new-found knowledge to practice."**

Please encourage health and social care professionals in your local area to attend. Book online at [www.pspassociation.org.uk/2016studyday](http://www.pspassociation.org.uk/2016studyday)



# Research Network update

**A huge thank you to all of our fantastic supporters who helped us raise over £56,000 for our research network appeal!**

**Y**OUR hard work and generous donations are enabling our Research Network to spearhead a leap forward in the momentum of PSP research with a unique collaboration between seven centres of expertise (see *PSP Matters Autumn 2015*).

The network's major core study, known as PROSPECT, will gather samples and data to fuel new discoveries that could improve early diagnosis and will develop understanding of disease progression, ultimately aiding future clinical trials.

The London and Newcastle centres are already up and running, recruiting patients to make regular centre visits over the next few years so that researchers can track the development of their disease for what is known as the 'longitudinal' part of

the PROSPECT study. Longitudinal study participants must meet certain criteria and so far 12 people with PSP or Atypical Parkinsonism Syndrome, and five people with CBD, have been enrolled. The other five centres in Cambridge, Oxford, Newport, Manchester and Sussex will start recruiting patients during the spring and early summer.

Meanwhile the cross-sectional arm of the study is open to anyone with a diagnosis of PSP or CBD, no matter where they live. It involves the completion of questionnaires and a one-off blood test. Thirty-five people with PSP and five with CBD have already volunteered to take part and many more would be very welcome.

Dr John Woodside, Clinical Research Co-ordinator for PROSPECT, said: "We

are so grateful to everyone living with PSP or CBD who gives up their time to participate in our study. Each participant provides us with another invaluable piece of the puzzle so that eventually we will have a much clearer picture of these diseases."

We are very excited to be able to share the news that the Research Network will soon be extending its reach into Scotland, thanks to the creation of a new Clinical Research Fellowship post jointly funded by PSPA and the Office of the Scottish Chief Scientist. Look out for further updates in the next edition of *PSP Matters*.

For more information on taking part in PROSPECT, contact Dr Woodside: [prospect@ucl.ac.uk](mailto:prospect@ucl.ac.uk) or 020 7679 4272.

# PSP Awareness Week

We are excited to unveil our 2016 PSP Awareness Week campaign and we're calling for your help to make it a success.

LAST year our supporters did us proud when thousands of you, around the UK, wore Ed's Laces to help spread the word about PSP and the Association's important work. As you know, the relative rarity of PSP means awareness of the disease is low, including in the medical profession.

**We want to change this and we need your help.**

For our 2016 Awareness Week campaign we will be focussing our efforts on raising awareness specifically with GPs.

**“An accurate diagnosis removes uncertainty and a sense of isolation for families.”**

We know GPs often find it difficult to spot symptoms of PSP and that many may not have come across the disease before. Sadly, this often means people receive a delayed diagnosis, or are misdiagnosed with other conditions.

That's why we are asking you to take action to help GPs in your local area spot red flag symptoms for PSP.

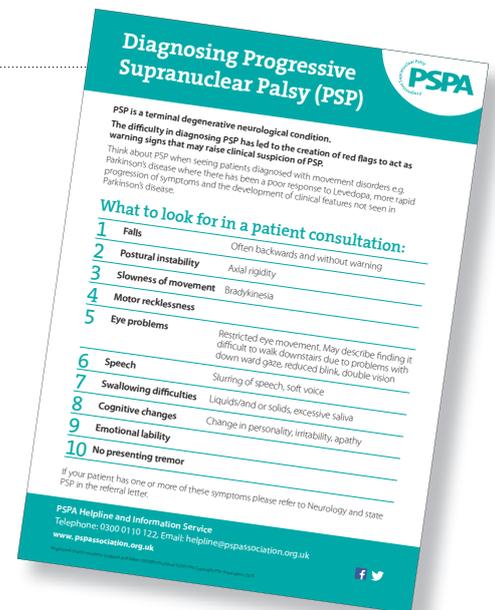
Taking part in our campaign is simple. Take a copy of our PSP Red Flags for GPs poster (enclosed with this mailing) in to your GP surgery during PSP Awareness Week 15-22 May and present it to your GP, Practice Manager or Patient Group.

This A4 poster lists 10 red flag symptoms that may help GPs spot warning signs that raise clinical suspicion of PSP.

Fergus Logan, PSPA's Chief Executive said: “Sadly time after time we hear stories from people who have waited far too long for a diagnosis, sometimes a number of years since they first spotted symptoms.

“This year our awareness week campaign aims to see more people living with PSP receive a timely referral to neurology, which in turn should speed up an accurate diagnosis.

“An accurate diagnosis removes uncertainty and a sense of isolation for families. It also means they are able to



access relevant health and social care services, receive information and support from PSPA and take part in our research projects if they wish.”

While we work hard to raise awareness all year our annual awareness week provides a focus for this activity and an opportunity for all our supporters to get involved, creating a bigger impact.

Anyone can take action and it's a simple way to make a big difference in your local area. Please encourage your family and friends to join in too.

## Delayed diagnosis: A family's experience

Terry, 72, from Grimsby, first experienced swallowing difficulties in 2009, followed by problems with mobility and mood in 2013.

Terry was a diabetic and his GP initially thought the problems were related to his medication. When changes to this didn't have any impact on Terry's symptoms the GP tried other avenues including an Ear Nose and Throat referral, numerous heart tests, and various scans including one of the arteries in his throat.

Several years since the start of symptoms, and despite

decreased mobility, Terry was no closer to a diagnosis. His GP explained he wanted to rule out all other possibilities before making a referral to neurology.

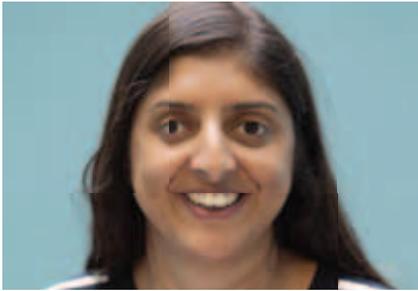
Terry's wife Liz said the ongoing uncertainty became a huge source of anxiety and frustration. She explained: “In the end I became very upset in the surgery, and asked if Terry could be reviewed privately.”

The GP finally agreed to make a referral to an NHS neurologist. Terry was diagnosed with PSP soon afterwards.

# 15 to 22 May 2016

## TAKE ACTION NOW

### Why it matters



"Using the red flag tool can only lead to an earlier recognition and diagnosis of PSP. This will have a great impact on both the patient, and their family and carers to enable them to access invaluable support, including that from the PSP Association." *Dr Gursaran Purewal, Palliative Care Consultant.*



"Having the red flag poster will not only raise awareness of PSP but will offer a quick and easy tool to encourage people to stop and think about a possible cause for the symptoms an individual is presenting with.

"The tool provides the opportunity to also highlight PSP as a condition and the PSP Association as a resource to support people affected by the disease." *Neurological Conditions Clinical Specialist, Anna Kent.*

### Take action – 15 to 22 May

- Arrange an appointment with your Practice Manager, GP or Patient Group
- Give them a copy of our PSP Red Flags for GPs
- Ask them to share it in their practice
- Let us know where you've been and send in a photo if possible
- Ask your family and friends to take the action too.

*If you have an appointment with your GP for a medical matter please take the PSP Red Flags for GPs with you, but do not book surgery time with your GP just to discuss Red Flags.*

We have enclosed a copy of PSP Red Flags for GPs in this mailing. Contact us for more copies (see below).

### Share it

Please share your PSP Red Flags for GPs pictures and news with us.

**Be social:** Tweet using @pspassociation and use the hashtag #PSPredflags or post on our Facebook page [www.facebook.com/pspassociation](http://www.facebook.com/pspassociation)

**By email:** [redflags@pspassociation.org.uk](mailto:redflags@pspassociation.org.uk)

**By post:** Red Flags for PSP, PSPA, FREEPOST RSLR-ZTGA-HHAU, Towcester, NN12 6BX

**Contact the media:** Please tell your local media about your activities and why our campaign matters to you and your family. You can find a template press release on our website [www.pspassociation.org.uk/redflags](http://www.pspassociation.org.uk/redflags)

To discuss media opportunities contact Paula McGrath, on 01327 356138, [paula.mcgrath@pspassociation.org.uk](mailto:paula.mcgrath@pspassociation.org.uk)

### Hold an event

If you have more time we'd love you to arrange a PSP Red Flags for GPs event in your area. Perhaps you could arrange a special meeting of your local group during PSP Awareness Week, or hold a coffee morning and raise funds for PSPA too.

Invite local influencers and decision makers along, including your MP or local health commissioners and talk

to them about the impact of PSP on families in your area.

Remember to give them a PSP Red Flags for GPs poster and ask them to present it to their GP.

Don't forget to send us your photos and share them on social media. Why not invite your local press along too. We've prepared a template invite on our website [www.pspassociation.org.uk/redflags](http://www.pspassociation.org.uk/redflags)

### Got a question?

Email: [redflags@pspassociation.org.uk](mailto:redflags@pspassociation.org.uk)

Visit our website: [www.pspassociation.org.uk/redflags](http://www.pspassociation.org.uk/redflags). Call us: 0300 0110 122

## Putting the wheels in motion

Professional care support can be provided by local authorities for people with PSP and CBD but it can be difficult to know when or how to ask for help.

Mary-Clare Rich, known as MC to her family and friends, was diagnosed with CBD after a lengthy series of appointments and tests and now has a care package in place at home in Ealing. Her husband Charles feels the family's proactive approach to arranging care has paid dividends.

"Once we knew the diagnosis we quickly realised the progressive nature of MC's condition," said Charles. "One of our first steps was to arrange Powers of Attorney, which has allowed me to make decisions on MC's behalf, knowing what her wishes are. This is especially important as it is now quite evident that her thinking is as sharp as it ever was but she has difficulty communicating."

However, it was a serious deterioration in MC's mobility that prompted the couple to seek more practical help.

"One Saturday morning I was working in my study while MC was out shopping," Charles explained.

"I heard 'This is the police!' from my hallway, where I found MC with four policemen, her face in a dreadful state after a fall. That spelled the end of her unaccompanied trips out.

"Within a few months and after a few more falls it was apparent that she needed someone with her any time she wanted to move about, even in the house. I was not getting much sleep



Charles and Mary-Clare Rich

because of toileting and was tied to the house during the day. This made us decide to get help, as it was also affecting my ability to run my business."

**"The big thing is that I always have people on hand, not only for day to day matters but to discuss and agree any further help as and when needed."**

Charles initially made contact with an occupational therapist (OT) at Ealing

Council who came out and assessed MC.

"Right from the start it was very easy to engage with the social care personnel at the council," said Charles. "They have been extremely helpful and eager to help throughout – little things like the contact details of a home hairdresser have been especially good. I was always kept very well informed of proceedings but I can see that social workers do have to follow due process and go by the book, so you have to help them to help you by being patient and cooperative."

Further to the OT's involvement, MC and Charles were allocated a social worker, who then visited and carried out her own assessment, including a review of Charles' needs as MC's principal

carer. A council officer also supported the couple in filling out the paperwork for a financial assessment.

"Once the social care and financial assessments had been made, it all went for approval," explained Charles. "It took around two months to get through this process. I would recommend that as soon as it is reasonably apparent that outside help is needed then the wheels are put in motion, as each stage does take some time but it is easier once you are in the system."

Initially MC had three one-hour visits from carers each day. "This freed me up to go out, as MC could be left on her

own for short periods," explained Charles. "However, it was clear after a few months that the level of care being provided was inadequate so we got in touch with our social worker again."

The care provision has since increased as necessary, with MC now receiving 12 hours of care each weekday and four-and-a-half hours each Saturday and Sunday, when the couple are also supported by their daughters.

"Having people coming into our home took a bit of getting used to, but having a big family of four children the

house has always had people coming and going," Charles said. "We have a good working relationship with the care agency and great people providing the care. I even have fun preparing meals with the carers – once MC couldn't cook any more I decided that I was going to make cooking a hobby, not a chore!"

Charles has been particularly grateful for the additional advice and support that his engagement with social services has brought.

"The big thing is that I always have people on hand, not only for day to

day matters but to discuss and agree any further help as and when needed," he explained. "Tips on local facilities and services I could use have been invaluable, as has the council's provision of somebody to look after all the financial arrangements relating to MC's care package."

"The support which we have had has been absolutely fantastic," Charles continued. "Everybody is focussed on MC's and my well-being and maintaining her life at home – it has let us live something of a normal life."

## Fact file: accessing services

### Adult Social Services

There may be a time when you need paid carers to help with your everyday activities. Adult social services can assess your needs and those of your main carer. They will help identify any help required in the home and advise on services and emergency support.

They can also arrange for an occupational therapist to assess your physical needs to help maintain independence. They will assess for a variety of aids and equipment which may include bathing aids and appropriate seating.

Services co-ordinated by social services may be subject to means testing and you may be asked to pay or contribute.

Contact your local authority to ask for an assessment. Contact details can be found online.

### Carers Assessment

If you provide support to an adult friend or family member you have the right to request a Carers Assessment. This enables you to tell social services how they can make caring easier for you. Your circumstances, income and the number of hours you provide care may affect your eligibility for services and support. An assessment will tell you what is available.

Contact your local authority to request an assessment.

### Benefits and Entitlements

You may be eligible for certain benefits or entitlements and it is recommended that you explore what is available as soon as possible.

Contact the Age UK helpline 0800 169 2081.

**NHS Services** There will be a variety of health care professionals involved in your care. Referrals happen through your GP.

### NHS Continuing Healthcare (CHC)

If your needs become more health related you may be eligible for CHC, a package of care arranged by and fully funded by the NHS. It is for people who have complex, ongoing healthcare needs. It is only available for those who meet specific eligibility criteria.

**Please note that all the above mentioned support can vary between different regions, councils and local authorities.**

**PSPA can provide support and information on any of the above, or a listening ear if you just need to talk. Contact 0300 0110 122, or [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk).**



# PSP and CBD – making valuable comparisons

**A comparison of PSP and CBD could play an important role in helping researchers establish better ways of diagnosing and tracking the progress of these and other neurodegenerative diseases.**

**D**R Marios Politis, Senior Clinical Lecturer and Consultant Neurologist at King's College London, is leading a study that will use a special type of scan, known as Positron Emission Tomography (PET) to visualise and compare some of the abnormalities present in the brains of people with both conditions.

## Sticky tangles

The behaviour, or misbehaviour, of a protein called 'tau' appears to be closely involved with the degeneration of nerve cells in PSP and CBD. Under normal healthy conditions, tau is thought to help build and stabilise scaffold-type structures known as microtubules, which run the length of nerve cells and act as train tracks for the transport of essential substances and waste products.

**“CBD patients can provide researchers with a valuable model and will play an important role in the study.”**

In CBD, PSP and other neurodegenerative diseases, tau loses its ability to associate with microtubules and instead just sticks to other pieces of tau, building up into tangled clumps (also known as aggregates).

PSP is what's known as a 'pure



*Preparing for a scan*

taupathy', meaning that tau is the only aggregate involved. CBD on the other hand has something in common with a range of other neurodegenerative diseases: as well as tau aggregates, some patients will also develop clumps of another type of protein known as amyloid. CBD patients can therefore provide researchers with a valuable model of this mixed clumping and will play an important role in the PET scanning study.

## Visualising changes

Dr Politis' study is funded by Imanova Ltd, an innovative collaboration between the Medical Research Council and three leading London universities, and makes

use of Imanova's world renowned Clinical Imaging Centre, a state of the art facility on the Hammersmith Hospital campus.

Participants in the study are injected with special tracer 'dyes', known as ligands, which bind specifically to clumps of proteins, hence making them show up clearly on the scan. This enables the researchers to visualise chemical changes in the brain. Participants attend two separate scan appointments at the Hammersmith Hospital as well as a clinical assessment at King's College Hospital.

Dr Flavia Niccolini, Clinical Research Fellow at King's, is co-ordinating the project.

“In our study we are using a ligand that specifically binds to tau aggregates for



*Dr Flavia Niccolini*

one PET scan, and then one that binds to amyloid for the other," explained Dr Niccolini. "This will allow us to visualise the distribution of the protein clumps in

people with CBD and PSP and learn how this correlates with clinical symptoms. We expect to find tau deposits in both PSP and CBD patients, whereas we expect to see some amyloid only in the CBD patients."

Researchers have suggested the prevention of protein clumping could be a good target for the development of new drugs. It's therefore important for scientists to be able to understand how the build up of clumps influences

the progression of the disease and if there are differences between pure tauopathies like PSP and conditions with mixed aggregates like CBD.

"Imaging of tau aggregates with PET can serve as an indicator of efficacy for new treatments aimed at preventing tau aggregate formation," explained Dr Niccolini. "It could therefore play a key role in generating meaningful results from future clinical trials and new understanding from our study will help to inform that process. The scans can also aid in early diagnosis of these diseases before extensive neuronal loss and clinical symptoms become evident."

### **Valued contribution**

Dr Niccolini very much values the contribution of people with CBD and PSP to her study, and we have been pleased to be able to put her in touch with some

of our members who have registered their interest in research participation via our Helpline.

"Volunteers are important to help find new and improved treatments and better ways to provide care," Dr Niccolini said. "I thank all the participants and their families for their cooperation and support. I hope the results from our study will represent a significant step forward in finding new therapies for these two diseases, as well as for other conditions such as Alzheimer's, Down's Syndrome and frontotemporal dementia."

For more information on the featured study and to find out whether you are eligible to take part, contact Dr Flavia Niccolini: [flavia.niccolini@kcl.ac.uk](mailto:flavia.niccolini@kcl.ac.uk), 0207 848 5755; or Dr Gennaro Pagano: [gennaro.pagano@kcl.ac.uk](mailto:gennaro.pagano@kcl.ac.uk), 0207 848 5682. Alternatively visit the research group's website: [www.nig-politis.com](http://www.nig-politis.com)

## **Research 'offers hope'**

Jerry Witts, a former fast jet pilot in the RAF, was diagnosed with CBD in February 2015, having experienced a growing list of symptoms for the previous five years. He lives with his wife Liz in Kent and recently decided to enrol in the imaging study.

"I am keen to help anyone else who might have this disease, and also my wife told me to take part!" explained Jerry.

"Jerry had already taken part in PSPA's Research Network study," added Liz. "I mentioned to Prof Morris (Research Network Chief Investigator) that we were keen to do more and we also registered our interest in research participation with the PSPA. One day, an email from Dr Niccolini arrived asking if Jerry wanted to join her study so we jumped at the chance."

"The enrolment process was completed really quickly by email," said Jerry. "When we arrived at the hospital for my first appointment everyone was really approachable and helpful, despite the fact that the traffic had made us late! The research centre is brand new and we could park right outside. The researcher was very friendly and asked me some questions on my own and with Liz before I had my scan with a very personable radiographer. There was a bit of a wait before the



*Jerry and Liz Witts*

scan, but I had a private room and a nurse."

Liz added: "I kept him supplied with cake, sandwiches and chocolate too!"

Unfortunately, Jerry had to withdraw from the project after this appointment as he couldn't hold his head in the correct position for the scan.

However, the couple are still very supportive of research. "I wouldn't hesitate to recommend this to anyone else," said Jerry. "It offers hope. It was disappointing not to be able to continue but we fully understand why, and we have asked if they can keep in touch with us about the rest of the project."

# A carer's perspective

Maureen Horne, from Harpenden, shares this honest account of caring for her late husband Gordon, who lived with PSP. It is a precis of a talk she delivered to health and social care professionals.

SOMEONE once said there are four kinds of people in the world:

Those who **are** carers

Those who **have been** carers

Those who **will become** carers

And those who **will be cared for**.

And at different points in our lives we may assume one or more of these roles.

For many of us, being a carer is simply part of life. It's loving someone and wanting the best for them, wanting to take away the things that are hurting, frightening them and making them suffer.

A carer is simply someone who cares.

## Everyday life as a carer

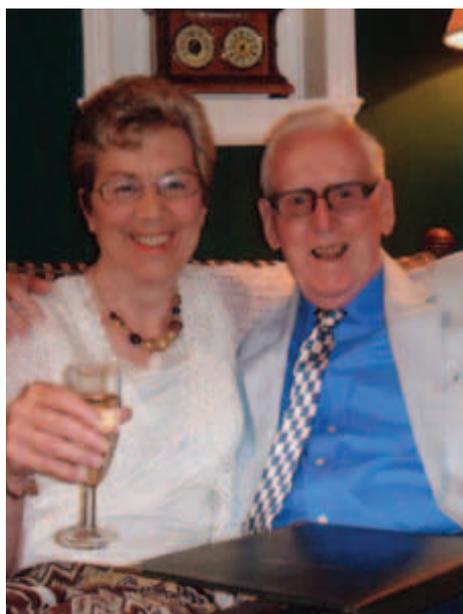
The clearest memory I have of caring is of weariness and constant vigilance; listening, looking for every sign of change or trouble brewing. The worry never subsides, it grows.

**“Ironically PSP has given my life a new sense of purpose.**

**I run PSPA's Hertfordshire Local Group and I find it very rewarding to provide friendship and support to others.”**

Fear becomes a constant companion. I used to worry every waking minute about what would happen next. How I'd cope, and what would happen to Gordon if I should have an accident or become ill.

Snow and ice were a nightmare. I just couldn't afford to fall and hurt myself. One bad winter I dressed



Maureen with Gordon

as if accompanying Scott to the South Pole and even fitted crampon like contraptions to my boots. (Not recommended for tottering around a supermarket.)

When driving I became even more cautious for fear of being involved in an accident. Gordon had always been an impatient driver and my ultra-caution really irked! I used to tell people I didn't need a satnav, I had a sat-nag!

Getting Gordon up in the morning and settled each night took longer and longer. He never wanted to go to bed early as he was afraid he wouldn't sleep, or he'd wake up coughing.

I would be so tired and desperate to get my head down but I knew it would take an hour to get him settled. I was too wound up to sleep but too exhausted to concentrate on a book. My salvation was reading poetry. I would recommend it for

weariness and bodies!

Sleep disturbance became the norm as the slightest sound would alert me.

## Regrets

Carers are not heroic and constantly patient and kind...well, this one wasn't. The perpetual state of tiredness and anxiety meant at times the milk of human kindness turned decidedly sour! I could be bad tempered, impatient, shout even, I'm ashamed to admit. But he was always so forgiving. Every single night he would say, "Thank you for looking after me today".

People tell you how admirable you are and you feel such a hypocrite thinking about when your short fuse blew, or you nursed resentment about the loss of the life you had or expected to have.

## Letting go

Admitting that care at home may not be the best solution is hard to face. Some reach a point where you have to face the realisation that you simply can't cope at home.

One day the doctor looked at me and said ...'and you need help'. I'll always be grateful to him.

Gordon's condition deteriorated very suddenly. I will always be thankful I was holding his hand when the time came. I was offered bereavement counselling and took up the offer very soon after Gordon died. I should have waited as when the days shortened and darkened the 'forever' of my situation kicked in and I was depressed.

# Chorus camaraderie

**Chris Garrard lives in Orpington, South London with his wife Margaret and was diagnosed with PSP in March 2015. Chris is a member of barber shop chorus 'The Kentones' and finds that singing with the group has a really positive impact.**

## A new sense of purpose

Ironically PSP has given my life a new sense of purpose. I run PSPA's Hertfordshire Local Group and I find it very rewarding to provide friendship and support to others and ease their sense of isolation.

Caring can test a relationship, but conversely, it can enrich it too. It makes you realise how much we can take relationships for granted, and provide the opportunity to say things to those we love before it's too late.

Caring can bring out the best in people. In my local group I constantly witness examples of loving care and devoted commitment shown by families, and it never ceases to impress me.

When caring has now become formalised, institutionalised, politicised, commercialised and regulated it is easy to forget that we're talking about one of the most basic and decent instincts that make us human...our interdependence and desire to look after those we love.

Maureen, who coordinates our Hertfordshire Local Group flew the flag for PSPA in the Houses of Parliament in December. She was invited to a thank you reception for volunteers in the St Albans area by local MP Anne Main. Maureen said: "I enjoyed the event and it gave me the chance to tell more people about PSPA!"



**“T**HE Kentones has a 40-year history and the current president was a founding member,” explained Chris. “I’ve only been part of the group for the last 12 or 13 years since I retired but I wish I’d joined donkeys’ ago – it’s great fun! I’d never done anything similar before although I did always sing in the bath and at work, where I annoyed my colleagues by getting the words wrong!”

**“I’m really proud of how the family have pulled together since my diagnosis, they’ve done really well.”**

The group has a repertoire of around 20 songs, including *A Nightingale Sang in Berkeley Square*, *Almost Like Being In Love* and songs from shows such as *Les Miserables*, and meets each week



Chris with Hope at our Kent Local Group

to rehearse. “There’s a real sense of camaraderie, we’re all mates!” said Chris. “I do walk away from rehearsals on a bit of a high. Although I tend to get a little tired now, PSP doesn’t seem to have affected my singing.”

Performances are also a high point for Chris, and a smaller group of Kentones known as ‘Acafellas’ recently sang at a meeting of our Kent Local Group. “It was good to be able to do a morning performance as I wasn’t so tired,” Chris told us. “We seemed to be well received as always – but then you only get out what you put in and we do put a lot into it!”

Chris and his family are active members of our Kent Local Group, with various family members also working hard to raise funds for PSPA. “I’m really proud of how the family have pulled together since my diagnosis, they’ve done really well,” said Chris. “It was obviously a shock at first, it’s the last thing you expect, but life goes on. I try to carry on regardless and The Kentones certainly help me to stay positive.”



Chris and his wife Margaret

# Accepting my limitations

**Austin Hewitt, 78, was something of a local hero in his native Belfast, having played rugby for Ulster and been a member of the Irish rugby squad. He has been living with PSP for over ten years and lives with his wife Betty in County Down, Northern Ireland.**

I NOTICED something wasn't quite right in 2005 when I was easily tired, slower and experienced reduced coordination with loss of facial expression. It was initially suggested this might be post-polio syndrome, as I'd had polio in 1955. However, the symptoms progressed, with difficulty in coordinating swimming strokes, stumbling, loss of balance (including on my BMW motorbike!) and difficulty playing the piano.



*Austin, Betty and family*

Two years later I had a series of scans and Parkinson's was mentioned. Our neurologist suspected something else though and recommended we see Dr Tim Lynch. He suggested the possibility of PSP.

Symptoms progressed very quickly after that. I was using a wheelchair more often. Six years ago I saw Dr Niall Quinn in London who knew immediately that I had PSP for sure. I was not allowed to drive – which I found very difficult.

Five years ago my eyes were closing and I could not read or watch TV. I had Botox injections in my eyes and at first these improved my ability to keep my eyes open but as time went on, this reduced. The consultant recommended surgery; this helped a lot and I hope to have a second eye operated on soon.

I was born into a family of great sportsmen – my father and uncles played rugby for Ireland and my brother and cousins all played at province and international level. I was interested in playing all sports: athletics, cricket and swimming in junior school with tennis and rugby added in secondary school.

I played rugby throughout my school years. I captained the team that won the Medallion Shield and played in the final of the Ulster Schools Cup. I played on the Ulster Schools team, and later, at Queens University Belfast, for the 1st XV Rugby team. My proudest moments came playing Wing for Ulster and as a member of the Irish Squad.

I retired from playing when we moved house, although continued to attend matches and my grandson now plays for the 1st XV at my old club. As I can no longer attend sporting events I watch all the rugby matches on TV, as well as athletics, snooker, bowls, tennis etc., although this can be difficult due to my eyes closing.



*Austin, bottom centre, in his rugby days*

I don't feel I could cope with modern rugby today, especially at professional level where more training is required and the game is more physical. Head injuries seem to be more of a serious issue. I would be concerned about future neurological health and I am anxious about possible injuries to my grandsons who play.

I have always been interested in water sports – swimming, bouldering, canoeing and sailing. After retiring I crewed on the Ocean Youth Team sailing around the Azores and the Canaries – a challenging and most enjoyable experience.

My other great interest was music. I played piano up to Grade 8 level and studied piano jazz at the Belfast School of Music. When my coordination deteriorated I could no longer play the piano, and have recently sold my baby grand piano. I now enjoy listening to music, especially classical and jazz.

I have lost a lot of previous pleasures in life but I have a strong Christian faith and my friends commend my contentment and patience in accepting the limitations caused by PSP.

# 'A truly magnificent experience'

**Nadia Akhtar, whose father Munir has PSP, jumped in the saddle and cycled 400km from Vietnam to Cambodia, for PSPA. The super cyclist, from Rochdale, tells her story.**

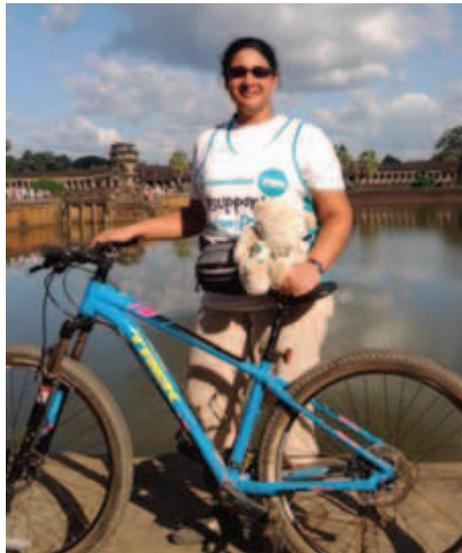
**A**FTER months of dedicated training and a great deal of momentum, I successfully completed this challenge, amidst temperatures ranging from 35-39°C throughout.

I started in Ho Chi Minh City, Vietnam and cycled through cities, across beautiful, lush green rice paddy fields, coconut plantations, past small fishing villages and rural settings, over more than 60 extremely steep bridges through the beauty of the Mekong Delta and ended up at the wonderful Angkor Wat UNESCO World Heritage Sites at Siem Reap in Cambodia.

This was a tough challenge in many ways. I was up at 5.30am daily and started cycling between 6.30am-7am, usually finishing around 5pm. The schedule was gruelling, as was the humidity at over 80%.

Most days felt as though someone had directed a powerful hairdryer in my face at the hottest possible setting!

Whilst cycling I was chased by dogs, chickens, butterflies and greeted by teams of amazingly cheery, local children of all ages, eager to practise their English



*Nadia Akhtar on her challenge*

on me as I cycled past. What better side-line support could I ask for?!

This was a truly magnificent experience. In total, I cycled 410kms. I got to enjoy some beautiful scenery and raise money for a charity I care about deeply (the half a stone I lost whilst away didn't hurt either).

**Inspired? You could follow in Nadia's tyre tracks for PSPA. This challenge is running 12-22 November and 19-29 November 2016. Contact our fundraising team to find out more.**

## Make your voice heard

*PSP Matters* is published four times a year. We welcome potential contributions for future issues. Material may be edited prior to publication.

**Please send your contributions to [psp@pspassociation.org.uk](mailto:psp@pspassociation.org.uk) or write to PSP Association, FREEPOST RSLR-ZTGA-HHAU Towcester NN12 6BX**

## Ding dong communications

**Rab Mullen shares his ingenious but simple idea to enable his wife Sarah, who is living with PSP, to call him for assistance wherever they are in the house.**

**I** WAS starting to worry that Sarah's balance was getting worse and falls were more likely but when I investigated potential solutions they all seemed quite costly. I was in B&Q when I saw a wireless door bell. I thought that if I gave Sarah the button and put the chimer in the hallway, where it can be heard from anywhere in the house, she could call me to accompany her whenever she wanted to move around, lessening the chance of a fall.

As the system is wireless, I can also move the chimer around as necessary. I keep it nearby if I'm doing something noisy like running on the treadmill and it will still work out in the garden or shed – the manufacturer states that it has a range of 100m. This means Sarah can alert me if she wants to go anywhere or needs assistance.

During the day, the button is clipped on to Sarah's walking frame, and then in the evening I move it to her bed rail. This means when Sarah has gone to bed early she can still call me even when I'm watching TV in the living room at the other end of the house. I also have a button with a different sound, which we leave in our bathroom, so I can tell where Sarah is calling from.

# 2015 in numbers - the diff

In touch with

**1,558**

people diagnosed with PSP or CBD.

**£415k**

from voluntary fundraising and events.

**40**

local groups.

**£234.5k**

donated by trusts.

**£1.131m**

income.

**35**

regional education events.

**200**

study day delegates.

**£20k**

awarded to Queen Square Brain Bank.

**9**

volunteers trained for support worker project.

**90**

London marathon runners.

To our wonderful fundraisers, supp

# erence we made together

**£1.25m**

commitment to research  
(2015-2018).

**5,252**

Facebook 'likes'.

**2,304**

Twitter followers.

**2**

parliamentary  
receptions (Westminster  
and Holyrood).

**180**

family and friends  
day attendees.

**4,000**

Ed's Laces distributed.

**1**

Scottish joint-funded  
research fellowship.

**280**

average monthly  
helpline calls.

**523**

active online  
forum members.

**882**

GP Guides  
distributed.

orters and volunteers – **thank you!**

# “Pile on the cream and healthy eating

**W**HEN Jenny Knight's late husband, Tony, developed swallowing difficulties the couple found he was still able to enjoy a varied diet, albeit with the food presented a little differently.

Along with chocolate cake and cream he enjoyed fork-mashed potatoes and cheese in his local pub and appetising soups at home.

Tony's speech and language therapist (SALT or SLT) was a huge support to them both, advising on ways of managing his increasing difficulties and liaising closely with them and other professionals. Jenny said she listened to what mattered to Tony and what suited his needs and gave permission to 'pile on the cream and throw healthy eating out of the window!'

For many people with PSP or CBD swallowing difficulties are a feature of their condition. Despite their title SLTs are the key professionals involved in supporting people to manage not just communication difficulties but swallowing ones too. The medical term for difficulty swallowing is dysphagia.

## Why do people with PSP get swallowing difficulties?

Sheila Wight is a specialist SLT in Newcastle, experienced in supporting people with PSP.

As she explained: "Swallowing is a

complex movement involving fine motor control and the timing of several sets of muscles. Food must be adequately chewed and food and liquid must be controlled in the mouth until ready to swallow.

"When the swallow occurs the airway must be closed by a flap (the epiglottis),

and the food/liquid is squeezed down the throat (pharynx), to the food pipe (oesophagus) by muscles. A 'normal' swallow is fast, well coordinated and efficient with no residue left behind."

In PSP swallowing problems occur due to the slowness of the muscles or the reduced coordination of movement, and this affects the ability to chew and swallow safely.

**“It is important that you are referred to a speech therapist following diagnosis.”**

Some people with PSP tend to overfill their mouth and/or eat too quickly putting them at risk of choking. This appears to be related to the 'impulsive' behaviour that is sometimes a feature of PSP and may make supervision at mealtimes necessary. People with PSP also often have visual problems which prevent them looking down at their plate, resulting in overloading their fork or spoon.

The short term aim of managing swallowing problems is to reduce the risk of liquids or particles of food entering the airway (aspiration). Aspiration can lead to chest infections and pneumonia. In the longer term weight needs to be monitored to ensure the individual is able to eat and drink enough to maintain their nutrition and hydration.

*Demonstrating smoothie making*



# throw out of the window...”

## What might indicate that a problem is developing?

- Frequent coughing when eating/drinking (indicating that things are going down ‘the wrong way’)
- Food being left in the mouth or falling from the mouth
- Frequent chest infections
- Weight loss
- Meals taking a long time to eat (one hour plus)
- Disinterest in food.

## How do we access help?

It is important that you are referred to a SLT following diagnosis and that you receive regular reviews. If this is not happening, and especially if any of the difficulties outlined above are appearing, request an urgent referral through your GP or consultant.

## What can be done?

SLTs undertake detailed assessments and make individual swallowing recommendations, considering safety, quality of life and the individual’s preferences about risk. The person with PSP should be involved in decision making. Educating those supporting someone with PSP of the potential difficulties is also important. Strategies suggested may include:

- Prompting a person to empty their mouth or take a pause between mouthfuls and to do a ‘dry’ swallow to clear residue
- Reminding someone not to overfill their mouth

- Modifying diet – making food texture softer as chewing becomes slower and less effective – avoiding difficult textures (crumbly, crispy or fibrous)
- Making liquids safer to swallow by adding thickening powder
- Posture is important. Sitting at a table and sitting up straight will help. If a person is unable to look down, prism glasses may be useful (free from PSPA).

## Artificial feeding

Where a person is unable to eat/drink adequately a PEG (Percutaneous Endoscopic Gastrostomy) may be suggested. This is a tube that goes directly into the stomach bypassing the need to swallow. Special feeds, water and medications can be given via the PEG.

A person can continue to eat and drink while taking ‘top up’ PEG feeds if the swallow is safe (if foods and liquids are not entering the airway).

A PEG will not be inserted against a person’s will or if they are too unwell. It is very important that the person with PSP is given the opportunity, early on in their condition, to learn more about a PEG and to make an informed choice about whether or not they would find a PEG acceptable. Their decision should be documented in their medical notes. Contact our helpline to discuss further.

**A selection of soft-food recipes are available from our helpline, [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk) or 0300 0110 122.**

## Personal insights:



For Anne Ling swallowing difficulties were an early feature. Her husband, Chris, is a great baker and Anne

finds she can still enjoy his very moist, scrumptious sticky toffee pudding and sauce. Anne finds eating from a teaspoon helps.

Mike Wareham has PSP. He finds drinking enough a struggle but he adores smoothies and finds using a



straw helps. At our Bristol Family and Friends day we had a demonstration which included smoothie making.



Presentation matters! Jenny Knight found it helped to use individual ramekins to give husband Tony’s food shape.

# Riding the research rollercoaster

Anyone who attended our Friends and Family Day in Bristol last year will remember the warmth, humour and enormous enthusiasm of one particular speaker, Patricia Vazquez Rodriguez.

**P**ATRICIA, or Patri as she prefers ('Patricia is very formal and according to my parents I am not'), is undertaking a PhD in the Department of Clinical Neurosciences at the University of Cambridge.

She is working on Prof James Rowe's PSPA-funded project, carrying out a special type of brain scan to visualise the disease-associated protein tau in people with PSP. In Bristol she fired our imaginations with wonderful descriptions of piles of tangled tau 'spaghetti' clogging up neurons.

Patri's passion for unpicking the puzzles of PSP and CBD is very evident. "When I first encountered PSP and CBD patients, I was staggered by the complexity and severity of the symptoms," she explained.

"These unique disorders really touched me and I knew if I could do a PhD I was going to focus on PSP. I wanted to try to shed some light and raise awareness."

Patri's journey from her early university education at home in Spain to the start of her PhD in Cambridge reveals the extent of her drive and ambition. "After I finished my

MA in Psychology, I wanted to improve my English, so I came to this country in 2007," she explained. "To force myself to speak English all day I got a job in a restaurant – fortunately I didn't have to take any orders because who knows what the customers would have ended up with!"

This was followed by a stint as a healthcare assistant in the Neuro Critical Care Unit at Addenbrooke's, which perhaps planted the seed of Patri's passion for changing the lives of people affected by neurological disease. She said: "That job changed the way I see so many things. There is a very thin line between life and death and we should try to do as much as we can."

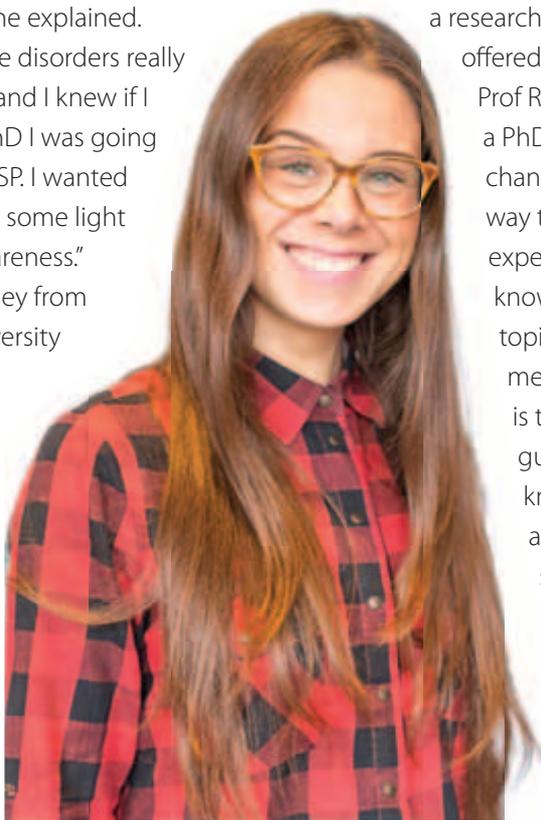
After further studies and work as a research assistant, Patri was offered the opportunity to join Prof Rowe's lab to undertake a PhD and she jumped at the chance. "A PhD is the best way to become a proper expert and to develop your knowledge in a particular topic," she explained. "For me neurodegeneration is the obvious choice, I guess because everyone knows someone who's affected, and the statistics show that in the near future the number of cases will increase. I'm privileged to be working in a lab where we are all

really driven to make a breakthrough in these devastating disorders because we are very aware of the implications for everyone involved."

Not that research is without its significant challenges. "It never goes the way you plan," said Patri. "You have to be prepared for anything, and even then there's always something you didn't count on. For example, the special contrast dye that we inject into our participants before their PET scans can only be made a couple of hours before the patient arrives. It's impossible to be 100% sure that it will pass the safety checks so when the person with PSP is making a huge effort to come in and then I cannot scan them... This is really frustrating because I'm super aware of the difficulties my participants and their carers face."

The extent of Patri's gratitude to her study participants and her enormous respect for everyone living with PSP and CBD are very obvious. "I learned a lot from the Family and Friends day in Bristol and I hope I delivered half of what I took home with me," she said.

The development of the PSP research workforce is an essential ingredient in our strategy as we move towards effective treatments. We are delighted to be funding the project that has given Patri the opportunity to undertake her PhD. She has described research as a 'real adventure', and at this stage in her career it's one that she's relatively near the beginning of. 'It's a rollercoaster,' she explained, but fortunately for the future of PSP research, Patri is up for the ride.



## Hello and goodbye

We are delighted to welcome two new recruits into the PSPA volunteering team: Ann Pearse, who is setting up a new group in Worthing, and Tim Allen, who is taking over as coordinator for our Middlesbrough Local Group.

**A**NN got in touch with us just after Christmas to volunteer her services. Ann and husband Terry, who is living with PSP, had been attending another group and enjoying the benefits but felt there was a need for one nearer to home. The first meeting for the new Worthing Local Group took place earlier this month.



*Ann Pearse and husband Terry*

Early this year, Tim Allen kindly stepped forward to take over the running of our Middlesbrough group. Tim has been a regular attendee with his mother, June, who is living with PSP and became the new group coordinator in March.

Sadly, we bid farewell to two of our long-term volunteers: local group



*Zenita Cowen and Tim Allen*

coordinators, Zenita Cowen and Christine Shepherd.

Zenita is stepping down after more than two years running our Middlesbrough group. She held the meetings as part of her role as a Parkinson's nurse from which she is now retiring.

Goodbye also to Christine Shepherd who has run our Carlisle group for four years. Christine, who is the main carer for her husband, John, is stepping down due to other commitments.

We thank them both for their time and support and wish them well.

If anyone in the Carlisle or surrounding area would be interested in taking over the group please contact Nicola.

**Please see our local group pull-out sheet for more information.**

## Local groups

### Your news and pictures...



### Stirring up support

Carolyn Ballantyne from our Hertfordshire Local Group held a Pampered Chef Party for friends and neighbours. With sales of products, donations and a raffle she raised £312 for PSPA.

Everyone had a great night and it was especially poignant as two guests had family experience of PSP.



### Bearing gifts

When Hope, our mascot, accompanied Warwickshire Local Group Coordinator, Jenny Knight, on a holiday to Andalucia with Hinckley Social Theatre & Travel Club she proved to be a very popular member of the group.

So much so, inspired by what they heard about PSPA, the club recently made a generous £250 donation to us from their charity fund.

Where will you take Hope? Follow her travels at [www.pspassociation.org.uk/hope-travels](http://www.pspassociation.org.uk/hope-travels)

**We are always looking to recruit more volunteers. Interested? Contact Nicola on 01327 322416 or [nicola.shaw@pspassociation.org.uk](mailto:nicola.shaw@pspassociation.org.uk)**

## Introducing...

### Lesley Flannagan – Gloucestershire group

**A**N unlikely mixture of chalk, cheese and cake is what gives our Gloucestershire Local Group its own unique flavour!

Since setting up the group in 2014, former nurses Lesley Flannagan and Chris O'Brien have injected their own personalities into each meeting.

**“Volunteering with PSPA has given me a purpose and what I experienced from looking after Mike can be used for the benefit of others.”**

Despite having different approaches, Lesley described how she and Chris use a combination of home-made cake and chat to create a warm and welcoming atmosphere.

She said: “Chris and I are as different as chalk and cheese but we are a brilliant team. I do all the talking and she hands out the tea and cake! I can’t overestimate her contribution.”

The firm friends, who worked together for many years on a neonatal unit, decided to start up the group to improve the experience of families affected by PSP or CBD, a desire inspired by the memory of Lesley’s late husband, Mike.

Lesley said: “When Mike died I always knew I would do something supportive. I found that being a carer was extremely isolating and my aim was to do something once a month that might make people’s lives a bit easier.

“Running the group is a bittersweet experience. I love it but I didn’t expect the emotional kickback. I have learnt a lot from the people who come, and they have my unending admiration, but I find it invariably moving and it can be emotionally exhausting. I didn’t expect the frustration of not being able to help people more but I get an intense feeling of satisfaction hearing them talk to each other during coffee time, because that’s what I desperately needed, just to talk to someone.

“Volunteering with PSPA has given me a purpose and what I experienced from looking after Mike can be used for the



*Chris O'Brien and Lesley Flannagan*

benefit of others. It is almost as though Mike living with and dying from PSP was not in vain. Behind everything is Mike, I have to make sense of what happened and doing this helps me to make sense. Long may it continue!”

Our Gloucestershire Local Group meets at St John’s Church Hall, St John’s Avenue, Churchdown, Gloucester. For more information visit [www.pspassociation.org.uk/localgroups](http://www.pspassociation.org.uk/localgroups) or contact Lesley at [florence@bogons.net](mailto:florence@bogons.net).

## Getting to know you

**M**EETING members and volunteers at our Family and Friends Days and other events throughout the year gives an incredible boost to staff at PSPA.

However, we are conscious that these opportunities are limited. So this year staff members are planning to attend as many of our local group meetings as we can.

We are looking forward to meeting and spending some quality time with you over a coffee and (hopefully) cake!

In turn, we hope you will enjoy meeting us: putting faces to names and hearing more about our roles. We will be posting details of staff visits to local groups on our events page. Contact Nicola on 01327 322416 for more information.

For more information on all local groups visit: [www.pspassociation.org.uk/localgroups](http://www.pspassociation.org.uk/localgroups)

## Louisa Roberts-West – Hampshire group

**A** FRIENDLY and relaxing atmosphere was the all-important factor for volunteer Louisa Roberts-West when she set up the Hampshire Local Group three years ago.

After losing her mother to PSP in 2006, she felt a growing determination to help others facing a similar situation and offering a comfortable place to meet and chat was key.

So it was particularly ironic when she discovered her volunteering role was taking her far out of her own comfort zone on many occasions!

However, as she admitted to *PSP Matters*, she still finds the role 'fulfilling and rewarding'.

She said: "In 2010 I recognised I might have to act upon the urge which had been niggling away at me since mum's death. I really wanted to get involved with PSPA but the timing had to be right. It was in fact another couple of years before I felt emotionally strong enough to bite the bullet and offer my help.



Louisa, second from left, and group members took part in a live TV debate hosted by Victoria Derbyshire

"As luck would have it, the timing was perfect. Plans were afoot to expand local groups for those affected by PSP or CBD. Although I was full of trepidation PSPA staff were full of encouragement. They made me understand that the only

'qualification' I really needed to set up a group was the experience I'd had of living through PSP with my mum.

"I had this idea in my head to make a home-from-home environment at our local village hall; bunches of flowers picked from the garden and home-baked cakes! I believed this relaxed atmosphere would help people feel at ease and more able to open up and chat about their experiences. Most importantly I wanted these people to come back!

**"The group feels like an extended family, each of us connected by this shared experience."**

"After nervously telephoning those in my area to tell them of my plans, I sensed their keenness to talk to someone who understood their plight and that was the impetus I needed.

"Only a small number of people attended that first group and I remember feeling quite disappointed but I now regularly welcome between 15 to 30 people each month.

"Running the group is fulfilling and rewarding. There are, of course, very sad times and moments of anguish, but more typically the atmosphere is light and uplifting. It is a wonderful thing to see - watching friendships form and hearing worries shared.

"We're joined by grandchildren, aunts, carers, sisters - sometimes an entire entourage will arrive - eager to learn from one another's experiences and to offload their worries and concerns. The group feels like an extended family, each of us connected by this shared experience. I'm humbled by the



Hampshire group meeting

determination they show to make the very best of their situation as they help one another along this difficult road.

"The group is evolving all the time - I'm lucky that occasionally I'm now helped by a local friend who lost his own father to PSP. It definitely helps to share the responsibility and at no point have I felt alone in my role. The PSPA team is fantastically supportive and always on-hand to help out with any questions.

"I never expected when I set up the group two years ago that it would take me in so many different directions! From being 'guest speaker' at a Bridge fundraiser, to raising awareness on a BBC Radio chat show, creating the opportunity for us to be on a live TV topical debate, collecting cheques, a sponsored walk along the River Test, liaising with local media, it's certainly never dull!

"I have been hesitant with each new challenge that's come my way - it's often way out of my comfort zone, but I am reminded that what we do as volunteers can and really **does** make a big difference to those whose lives have been turned upside down by PSP or CBD - and I like to think that mum would be proud too!"

## Good luck to our London Marathon runners

On 24 April Team PSPA takes on the world's most famous running race, the London Marathon!

**T**HIS year, 73 runners will head to the capital for the 26.2 mile course with the sole aim of raising as much as they can for PSPA!

Yet the focus for them on the day will

be to cross the finish line in one piece, and they will be cheered all the way by our wonderful volunteers.

Whilst the race will be very tough, the road to the start line for many of Team PSPA

began way back in the depths of winter. For many it was their personal experiences of PSP that spurred them on and inspired them to take on the worst that winter could throw at them.



### Alan Wadsworth, from Northants:

"I want to do the marathon for my Dad, Steven. He was diagnosed with PSP around four years ago which was a huge shock to us all. My Mum uses the PSP forums to talk to people and finds it a great help. I just wanted to give something back to those people who don't have help, and help the research into this illness."



### Rebecca Jones-Reading, Staffordshire:

"There are many reasons why I run for PSPA but to raise awareness for this awful disease and eventually find a cure I think sums it up."

### Liz Hancox-Eggleton, Devon:

These are Liz's muddied legs after another gruelling training run! Despite the rain and mud, Liz says, "it's worth every second as it's all for granddad."



### Justin Johnson, Dorset:

"This is my first ever marathon, and I want to prove to myself I can actually do it, dedicate the time to the training, and run the epic 26.2 miles. My stepdad, who lived with PSP, passed away in August last year, so I am honoured to raise both funds and awareness to help those who live with PSP, and their families. The help my family received from PSPA was amazing."

### **Teresa Connolly, London:**

"I am fundraising to support my friend Liz who has PSP; she tells me that PSPA has been great with support when she needs it. I am fundraising with three other friends forming 'Team Berry' who sell lots of donated stuff at car boot sales to help raise money while I train."

### **Rhian Lees, Vale of Glamorgan:**

"My partner's mother lives with PSP and I've seen first-hand what a debilitating and challenging condition it is to live with. The strain it places on Pat, and her husband Mike, who is her full-time carer, is immeasurable, but they deal with it with a smile and humour. The sooner a cure is found the better."



### **Charlotte Howarth, Leeds:**

"My dad suffers from CBD, and I am running to support a charity which gives so much to my dad and family, especially through our local support group. His struggle with the condition inspires me to push through the pain I may experience during training and the marathon itself, and I intend to push myself to my limits and beyond."

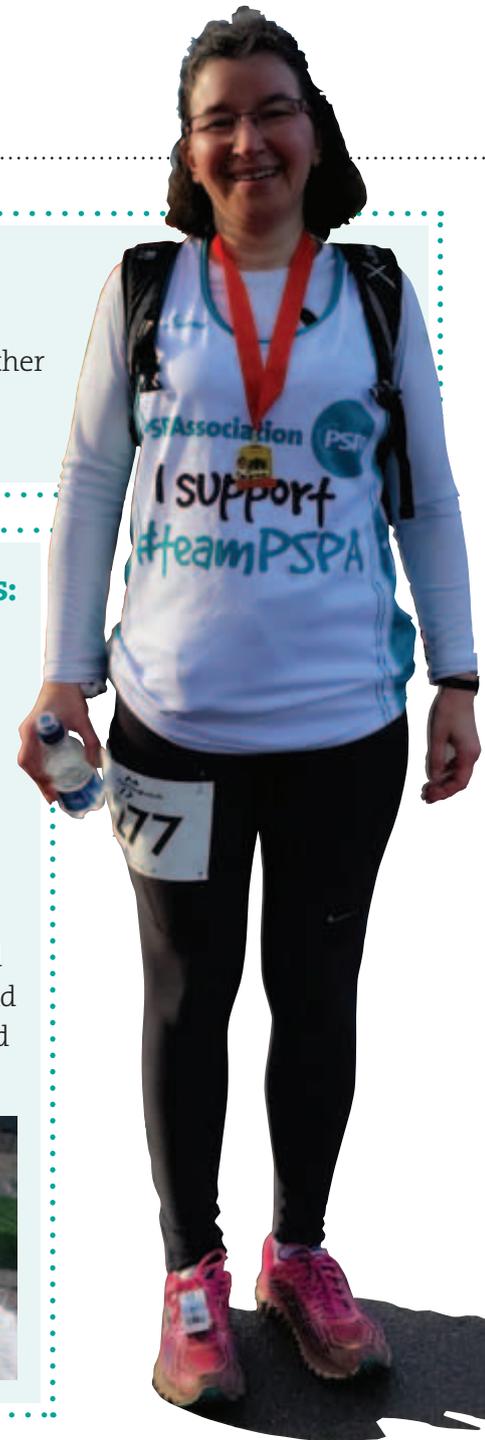
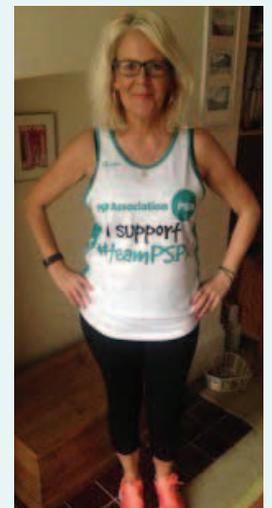


### **Emma Wasley, London:**

"I decided to run for a smaller charity like PSPA because I wanted to give back to a charity that really needs it, and may not get as much time in the spotlight as others. I'm really excited to be running my first marathon for such a great cause."

### **Sally Williams, Whitley Bay:**

Sally is running in memory of her Dad, John Stubbs. John sadly passed away in June 2008 after being diagnosed with PSP. Sally says: "My Dad fought it with a determination and sense of humour that summed him up as the incredible man he was. He was, and is, my total inspiration. This is going to be one of the biggest challenges of my life so far. I'm training hard and feeling scared but totally determined to meet this challenge. Bring it on!"



## Hope's travels

**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...**



### Hope's diary

Well, winter was pretty terrible wasn't it? Wind, storms, and if it wasn't raining, it was certainly about to. And to top it off, nature decided that daffodils should bloom alongside snowdrops, and that January is a great time of year for the trees to blossom. Just how was a bear supposed to hibernate through all of that?

The extra time though allowed me to plan the year ahead. So far I have booked trips to Costa Rica, and even Euro 2016 in France! I can't wait to watch beautiful, attacking football, so I will be annoyed if I end up at an England game. I am dreaming of all the other places I may visit this year, and I am ready to spread awareness of PSP and PSPA's important work on people's travels! My passport is up-to-date, and I have had my

jabs, so I am hoping someone will take me.

I am so excited for the year ahead. I can't wait to join my friends at PSPA for their big fundraising events like the London Marathon. I am looking forward to meeting lots of amazing people at local group meetings around the UK (not sure if I'll get to all 40) Family and Friends days (note to self must book as I know they're very popular). Then there is Awareness Week from the 15 - 22 May! This bear will be very busy.



### The Kentones

I was lucky enough to watch a barber shop quartet perform for Kent Local Group in January! Named The Kentones, they sang brilliantly, and everyone at Polhill garden centre happily contributed to a collection for PSPA, and an amazing £150 was raised! The Kentones chairman, John Sollitt, told me that they all had a great time singing.

### My Travels

Unfortunately, I had to spend some time over Christmas in the Caribbean. Dorian Cole, son of our Northampton Local Group coordinator, Val Cole, was kind enough to take me along. The sun was warm, the sand white, the sea a beautiful crystal blue. It was so tough sunning my fur and drinking those cocktails with the little umbrellas. Luckily I had a fabulous Santa hat to cheer me up.

Just returned from New York City after travelling with PSPA supporter Lisa Murphy. I took in a show on Broadway, visited Times Square, and went to the top of the Empire State Building, the first animal to do so since a big monkey climbed to the top in 1933. I don't know what became of him.

We would love to know where Hope has travelled. Send your photos and details to [hope@pspassociation.org.uk](mailto:hope@pspassociation.org.uk)  
Buy your own Hope at [www.pspassociation.org.uk/shop](http://www.pspassociation.org.uk/shop)

# Starting young

We are always impressed by the dedication and effort young members of our PSPA family put in to support us as much as they can, whether through fundraising or volunteering.

There are too many inspirational stories to share in this feature – so a huge thank you to all young people who support our work. We think you're amazing!



## NCS challenge: Sam Truman, aged 16

"When I signed up for National Citizen Service (NCS) it gave me the opportunity to make new friends. These new friends supported my suggestion of fundraising for PSPA after I had told them of how it had affected my Nana, Beryl Hambley. We all had tremendous fun in the process. Now, a lot more of those friends and their families are aware of the condition than before."



## Sponsored silence: Olivia Taylor, aged 10

"It was a massive challenge for me to keep quiet for a whole day! Me and my friend Chloe Stokes successfully managed to complete the extremely difficult challenge. PSP is close to my heart because my Grandad Baz is suffering with the devastating illness. It is upsetting for me because grandad can't speak now or do the things he used to as he was very keen to fix things. I hope the money we raised will be as unforgettable as my journey of silence!"



## Volunteer and fundraiser: Senya Kang, aged 11

"The PSPA is very close to my heart, as my granny has PSP. Helping makes me feel happy, as everyone can contribute and get involved with something. Research funds and helping people with PSP are so important to me."



## Fun run: Poppy Soden, aged 12

"I wanted to raise money for PSPA because my Nan has this condition. I am in year 8 at school and we can choose to take part in a Year 8 Challenge. As part of this we have to do some fundraising, so I thought it would be a good idea to do a 5k Fun Run with my Mum. We ended up raising over £400!"

If you are a young person and would like to support PSPA we'd love to hear from you!

We have lots of ideas and materials to help with your fundraising or volunteering, including flags, balloons and T-shirts.

Fancy being a superhero for a day? We have places to the Superhero Run in London on 15 May. Alternatively gather your friends and family for a jolly day out at Christmas and join the Santa Run!

Check out our website, [www.pspassociation.org.uk/](http://www.pspassociation.org.uk/) fundraise, call us on 01327 356132 or email [events@pspassociation.org.uk](mailto:events@pspassociation.org.uk)

## Blown away



**T**HE people of the Isle of Lewis did not allow Storm Desmond to disrupt a fundraising event organised by Cllr Alistair MacIennan in support of his friend, Ian ‘Sgadan’ MacLeod, who was diagnosed with PSP in 2013.

Battling through wind and rain, fundraisers descended upon the Barvas and Brue Community Centre to enjoy the evening – including bingo and a raffle – to raise £5,185!

Alistair said: “Despite the conditions, everyone had a fantastic time and I am very grateful to all those who attended and helped us reach our total.”



## Christmas baubles

**T**HANK you to everyone who supported our Christmas bauble appeal.

Your moving messages made a beautiful display on our office Christmas tree and together you raised £10,662 to support our work.

## Netball crazy

**H**ILLCREST netball club and Warlingham rugby club in Surrey celebrated 30 years



together with an afternoon of fun for club members and their families – while fundraising for PSPA and The Lily Foundation.

After a lunch for past and non-playing members from both clubs, the fun began with netball tournaments for all ages – including the ‘legends’ (some of whom were closer to 80 than 18 in age!).

The day was a great success and raised £224 for each charity, in memory of the netball club’s founding member, Heather Edmondson, who lived with PSP.



## Fundraising peak

**H**EADING in to the Mourne Mountains in Northern Ireland, a family group scaled seven peaks - including Slieve Donard (*Sliabh Dónairt*) Northern Ireland’s highest.

The walk, in memory of Alan Johnston from Lisburn who lived with PSP, was completed by his son Peter, and son-in-law, Jonny Calderwood. Joined by friends Mark Beattie, Richard Gamble and Ryan Crossley, who also contributed to the amazing total, the intrepid group completed the 20-mile route in 11 hours.

The Johnston family, including Alan’s

wife Lily, handed a cheque totalling £2,055 to our volunteers in Northern Ireland.



# Upcoming events

## Running teams

PSPA supporters at opposite ends of the country are in the final stages of training for their chosen fundraising challenges. Team PSPA takes on the Superhero Run in Regent's Park,



London on 15 May for the very first time, and runners including Carla Bancroft and Nicola White are sure to do us proud.

On 28 and 29 May the Edinburgh Marathon Festival takes place and father and son duo Paul and Calum Ross of Invergordon will be taking on the 10km race. We have a strong team across all distances, and cannot wait to see our runners in action. On 10 July the British 10k takes runners through the heart of London. We will be there to cheer on Team PSPA!

**We wish all of our runners the very best of luck!**

## Ride London to Surrey 100

CYCLING fever is sure to grip the nation again as Team GB cyclists go for gold at this year's Olympic Games in Rio. Make 2016 a golden year for Team PSPA too! Be part of something special, and join hundreds of others at this year's Ride London to Surrey 100 on 31 July.

The route will see you begin at the Queen Elizabeth Olympic Park, a venue that witnessed some unbelievable sporting triumphs four years ago. You will then make your way through the capital, passing Canary Wharf and Richmond Park, before entering the stunning scenery of the Surrey countryside. After tackling the world-famous Box Hill zig-zags, the route turns back to London, passing

some of its most famous landmarks, before a triumphant finish along The Mall.

Want to be part of Team PSPA? Visit our website [www.pspassociation.org.uk/fundraise](http://www.pspassociation.org.uk/fundraise), email [events@pspassociation.org.uk](mailto:events@pspassociation.org.uk) or call us on 01327 356132.

We'll send you a free cycling vest and fundraising pack.



## Diary date

### Our summer spectacular

This summer sees our very first fundraising week **13-21 August**, and there are so many ways to join in! Get in the Olympic spirit and host a games day or charity sport match. After all that fun in the sun, refreshments are sure to be needed, and a barbecue at the end of the day would be the perfect way to spend a long summer's evening whilst thinking back on your sporting achievements. It's also a good time for a thirst-quenching beer or two!

It is also schools out for the young ones, so have fun with a day of sack races, egg and spoon races, coconut shies, and three-legged races. If eating cake is considered a sport (which it absolutely should be) then host a coffee morning and sell your baked delights to raise funds. Even if you are on holiday, you can join in with the fun. The beach or a campsite would be the perfect place for a day of fundraising!

Whatever you choose to do, we have the materials to help. From balloons to flags, to T-shirts and fact cards, we will support you all the way. Keep an eye out for further details on social media in the coming weeks.

The support we receive from our fundraisers throughout the year is always amazing. For one week only, we can all come together to make 2016 unforgettable.

Call: 01327 356132

Email: [events@pspassociation.org.uk](mailto:events@pspassociation.org.uk)

# Your fundraising

## Tough guy?

Mark van der Oetelaar and his team mates ran through 'hell and high water' as he took on the flames, bogs and obstacles of a Tough Guy challenge.



£300

## Crumbs...

Melek and her friends, Naia, Kaydee and Kayan, held a cake sale at their school in memory of Melek's grandfather, Shevket Mehmed.



£300

## Sale!

Thank you to Eileen Oakenfull and her friend, Gwen, who were instrumental in nominating PSPA as charity of the year for Duston Townswomen's Guild in Northampton. They organised a mini market to raise funds.



£1,000

## In memory

Family and friends of Pamela Roberts, a much-loved mother and grandmother, and wife to Charlie, made donations instead of flowers at her funeral. Pamela's son, Cliff, said: "We think this was a really good idea, and my mother would have been delighted. What a wonderful mother we had who is loved and missed by all she knew."



£600

## Shhhhhh!

Chatterbox, Melissa Spellman challenged herself by taking part in a sponsored silence. Unfortunately, Melissa was not available for comment.

£450

## More crumbs!

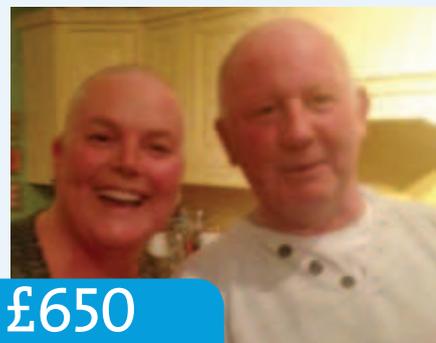
Maya Robinson, 12, helped by her Mum, Sarah, organised a break and lunchtime cake sale at her school. Lots of people helped - 23 bakers made over 600 cakes!



£211

## Facing the chop

Kelly Turnbull braved the shave and said goodbye to her luscious locks in memory of her Nan, Joyce Sargent.



£650

## On pointe

Each year The Royal Ballet Lower School hold a Christmas Jumper Charity Appeal, and this year it was PSPA that they chose to help. Organised by the Head of English, Suzanne Gunton, whose mother lives with PSP, staff and students donned festive jumpers to raise funds. Hope the Bear joined the fun, and even had her own festive tutu made for her by the school's wardrobe mistress!



£150

## Special tree

Sarah Robinson, whose dad, Gerald, lived with CBD, gave a Christmas tree a unique twist at the Christmas Tree Festival at Caddington, Bedfordshire. Gerald loved his garden, and so Sarah and family gave their tree a gardening theme. The funds raised from 'Gerald's Memory Tree' combine with Sarah's yearly fundraising total.

Sarah said: "Dad adored Christmas, so it was very special seeing his tree up again."



£2,671

## Coffee?

Cheryl Williams and her family remembered her Dad, Graham Booth, as they enjoyed a coffee morning at the end of January. Labour MP for Caerphilly, Wayne David, and Assembly Minister, Jeff Cuthbert, went along and collected fact cards and leaflets to help raise awareness.



£357

## Fundraising peak

Ally Hyland, Rhys Taylor, Daniel Crisp, and the rest of the Queen Margaret University Rugby Team hiked to the top of a snowy Ben Nevis and raised over £700! They climbed in memory of Ally's granny, Elizabeth Martin, who lived with PSP.



£700

## Singing for funds

Pupils aged 10 and 11 from Morpeth Road Primary School in Blyth, Northumberland, took it upon themselves to hold a carol concert - much to the surprise of PSPA supporter and head teacher Mike Bell. Mike and his wife are good friends with Jean Mooney, whose husband and sister both lived with PSP, and now Mike, his colleagues, and pupils, cycle the 141-mile coast-to-coast route as an annual fundraiser.

The concert raised £100 raised - adding to the cycle fund.



£600

## Brrrr!

Sarah Heward from Killin in Scotland, organised a Boxing Day dip in the village's chilly waters. Along with staff from her café, The Real Food Café, Sarah took the plunge in memory of her father, James Heward.

"The Association was very helpful... and we are very grateful to them," she said.



£1,250

## Cheers!

Raise a glass to Joanna Robinson who took part in 'Dry January' and raised £550.40. This has been match funded by her employer!

£1,100

# WE'RE STRIKING BACK



**PSPA's new Strikeback Funds have been created for everyone who wants to fight back against PSP and 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 and 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.

