

PSP Matters

Spring 2017



***IT'S NOT
PARKINSON'S***
Read about our new
campaign for PSP
Awareness Week

Also inside: NHS Continuing Healthcare · 2016 in numbers

PSP Awareness Week

Our campaign *It's not Parkinson's* focuses on diagnosis.



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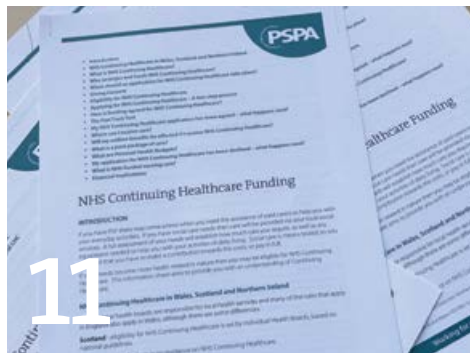
Sharing your experiences of PSP and CBD.



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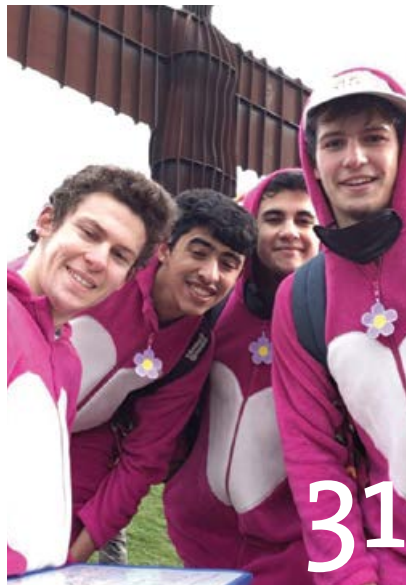
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Cover: Parkinson's Specialist Nurse, Sue Palfreeman, from the James Cook University Hospital, Middlesbrough, with a patient.

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 three 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. PSP Association Registered Charity Numbers: England and Wales 1037087/ Scotland SC041199

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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

www.pspassociation.org.uk

 www.facebook.com/pspassociation

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



It is an exciting time for PSPA.

You may recall, I was only 'standing in' as Chief Executive until a permanent replacement was found. It is now my great pleasure to inform you that the Association has appointed Andrew Symons to the position. Andrew has held senior positions in both commercial and public sectors over the past 20 years – but I'll leave him to tell you all about himself in the next edition. Welcome, Andrew.

To other matters... what's happened in the months since the last issue? Well, we met our income target for 2016, thanks to your fantastic fundraising efforts. I would also like to thank those who took part in our patient survey. Although we were pleased to see how many of you valued our support, there is always much more to do and your input helped us to focus on the areas where we can improve, and how we can work better with the NHS and Social Services. (More details in the next *PSP Matters*.)

This year, our expenditure on research is expected to hit record levels and there are indicators that we may be heading towards breakthroughs – albeit still some years away. Trials of drugs for easing some of the symptoms of PSP and CBD have received funding, so we continue to monitor their progress – of course, you will be the first to hear any news.

As I sign off, I'd like to say that it has been a great privilege for me to return to PSPA and, of course, I will continue to take a keen and active interest in our charity's progress in the years to come.

With my very best wishes,

John Chandler, Chief Executive

PSPA-funded research published

We are delighted to announce that PSPA-funded researcher Prof James Rowe and his team have published the outcomes of some of the work we supported in the prestigious medical journal *Brain*.

THE Cambridge University group used a special type of brain scan, known as a PET scan, to compare the distribution of the disease-associated protein tau in the brains of people with PSP, Alzheimer's Disease and healthy controls. PET scanning involves the use of special injected 'dyes' known as radioligands, which bind to particular substances, in this case tau, and highlight them on the resulting scan image.

The researchers were able to demonstrate that the radioligand they used showed a clear difference in the pattern of tau distribution between healthy brains, those affected by PSP and those with Alzheimer's. This means that PET scanning with this radioligand could be a useful tool in distinguishing Alzheimer's from PSP during diagnosis and in measuring the effects of new drugs.

"We are so grateful to all of our wonderful study participants and those who so kindly donated their brain tissue."

Crucially, the researchers were able to compare their scan results with the distribution of tau and other proteins in generously donated post mortem brain tissue. This meant that they were



Cambridge researchers

able to rule out the suggestion that the radioligand was binding to a substance called neuromelanin instead of tau and producing erroneous results.

PhD student Patricia Vazquez Rodriguez, who has featured in previous editions of *PSP Matters*, was heavily involved in this work and occupies the well-earned and prestigious position of joint first author on the paper.

"We are so grateful to all of our wonderful study participants and those who so kindly donated their brain tissue," said Patricia. "This progress would not have been possible without them." Here at PSPA we are also indebted to our amazing supporters for enabling us to fund this research. Thank you!

You can read the abstract for the *Brain* paper at: <https://academic.oup.com/brain/article/2951048/18F-AV-1451>

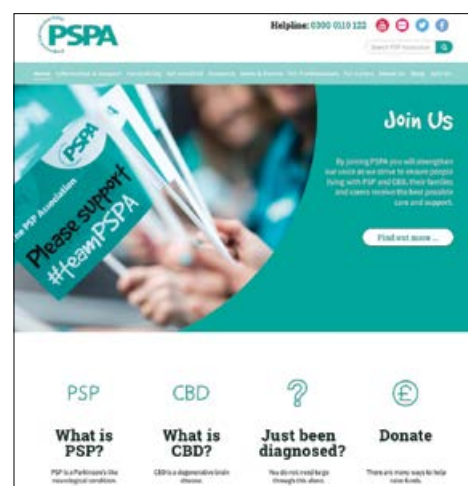
New website

IN January we re-launched the PSPA website, and feedback from supporters has been positive. The new site is far easier to navigate around than the previous version and with just a click you can easily access a whole range of comprehensive information.

New features include online forms for membership, volunteering and fundraising, and you can even register online to take part in research. There is also a full range of downloadable information on all aspects of living with PSP and CBD, and a specific area for volunteers.

The fundraising pages have also changed. We've introduced a brand new range of events for all abilities, and for those who want to organise their own events fundraising materials can now be downloaded.

It's also easy to find out events near you, from local groups to family and friends days. Volunteers also have a special area on the site where they can find out what is happening and access documents specifically for them.



If you have already used the site we hope you like it. If not please have a look at www.pspassociation.org.uk

We'd be delighted to have your feedback as it will help us keep the site up to date and in line with your needs.

Shaping future research

The PSPA, along with several other charities that support people living with a rare neurological condition, was invited to attend a meeting with a group of research physiotherapists in Cardiff.



Mr & Mrs Thomas

OUR specialist care adviser (SCA) for South of the Thames and former physiotherapist, Kathy Weston, represented the Association along with Mr and Mrs Thomas. Mr Thomas is living with PSP.

The Physical Activity for Rare Conditions Collaboration (PARCC) is to conduct some research into how best to encourage and support people living with a rare neurological condition to remain physically active.

“It’s about the professionals being aware of the condition and recognising the challenges.”

PARCC hopes that by combining rare conditions into one inclusive study, they can attract the funding required for their extensive project.

A member of PARCC, Monica Busse-

Morris, said the aim was to “identify the common issues and understand the differences (between rare neurological conditions)” and they were pleased to receive a copy of the *Pathway of Care for PSP*.

The project is to be conducted in two stages: Firstly, it will look at current practices, condition specific care pathways, regional differences, resources available, public perception and gather specific insight from charities and service users. It will also identify potential barriers to accessing facilities and participation in physical activity.

In the second stage, the project will develop an intervention or ‘tool kit’ that can be personalised for the individual based on their needs, personal choices and ability to encourage physical activity and make it more accessible.

“The research conducted by the collaboration could help people living

with PSP and CBD stay more active for longer, with potential ‘knock-on’ effects on mood and a sense of well-being,” Kathy Weston said.

Mr and Mrs Thomas also felt the day was worthwhile. “I feel this research will be really useful in highlighting the benefits of gentle activity and providing guidance to physiotherapists,” Mrs Thomas told us. “It’s all about the professionals being aware of the condition and recognising the challenges.”

The day was seen as a great success by all concerned. PARCC is keen to continue working with those who attended to ensure that their project accurately reflects the needs and challenges facing those living with a rare neurological condition.

PARCC hopes it will result in a useful, attractive resource that improves the lives of those affected.

Date for your diary: Annual Study Day 2017

OUR Annual Study day will take place this year on Wednesday 18 October at MKCC in Milton Keynes. It is open to all professionals with an interest in PSP and CBD.

The programme is yet to be finalised but will consist of a number of workshops, a presentation from a leading neurologist and his research team, with plenty of time for networking with colleagues.

Visit www.pspassociation.org.uk/for-professionals/study-days

Care information for people living with PSP, CBD and Carers

OUR publications for people affected by PSP and CBD cover a range of issues, from specific aspects of PSP and CBD, to everyday living and brain donation.

This year our Information and Support team will be developing new information sheets on many different subjects to ensure people affected by the conditions have all they need to be fully informed.

For updates visit www.pspassociation.org.uk/information-and-support/just-been-diagnosed/resources-for-diagnosed/

MRC makes major investment in PSP research

We are thrilled to announce a major investment by the Medical Research Council (MRC) in PSP research.

THE MRC have committed to over £600,000 for a new UK study that aims at improving the treatment of symptoms of PSP. Although PSP can be physically very disabling, many people are also affected by cognitive and personality changes. These can have a major impact on the quality of life and safety of the person with PSP, and their carers.

Despite the slow and stiff movements caused by PSP, people can also become paradoxically impulsive and reckless. For example, rushing to get up, cramming food while eating or 'jumping to conclusions' without enough thought for the consequences. Impulsivity is risky with PSP as it can increase the risk of falls, and choking.

The new study is based in Cambridge, with Prof James Rowe and Dr Luca Passamonti, amongst others, using the

most advanced technologies in MRI and pharmacology. They will link impulsivity to the brain's version of adrenaline (called noradrenaline), in people with PSP and in those who have donated to the Cambridge Brain Bank. The new ultra high field '7T' scanner can see detail as fine as a grain of sand, much better than traditional scanners, and in critical parts of the brain that are very unclear on normal MRI scanners.

In the second part of the study, they will invite patients to take part in a study using a drug that boosts noradrenaline in the brain, which they have shown can reduce impulsivity and reduce rigid or inflexible thinking. The MRC's decision to support this study confirms the researchers' belief in the drug's potential to improve treatments for common cognitive and behavioural problems in PSP, which will remain important even



Prof James Rowe

as new studies begin to try to slow the illness down.

Prof Rowe said: "This significant investment by the MRC reflects a growing momentum in PSP research. We are delighted that they have recognised the importance of studies aiming to provide alleviation of symptoms, generating a valuable impact on patients' and carers' quality of life."

Research participation opportunities

WE have been contacted by two research groups who are looking for people to take part in their projects.

An Oxford University group is looking for people with PSP who would be able to travel to Oxford for a two hour appointment every three months, with travel and accommodation expenses reimbursed. The researchers will be measuring your movement and cognition; there are no painful tests involved! This study aims to improve the assessment of PSP symptoms for future clinical trials and may also help with

early diagnosis. For further information contact Dr Chrystalina Antoniadou, 01865 234728 or Chrystalina.antoniadou@ndcn.ox.ac.uk

A Cambridge-based team is looking for people with PSP or CBD who live in Cambridgeshire or Norfolk. It may be possible to complete the study at home if you are unable to travel to Cambridge for appointments. The researchers would like to gather reliable data on the symptoms and progress of people living with PSP and CBD. For further information contact Dr Alexander Murley, am2505@medschl.cam.ac.uk

Specialist Care Adviser Central Region

CURRENTLY we are without a Specialist Care Adviser in the Central Region. Liz Burr has now moved on to pastures new and in her absence the helpline team will offer support to people living in this area. Please do not hesitate to contact the helpline if you need help or support.

0300 0110 122
helpline@pspassiaton.org.uk

Mon to Fri 9am - 5pm and 7pm - 9pm

Building our volunteer team

On 1 March we held our first open day here at Towcester with the aim of recruiting more volunteers to help us support those affected by PSP and CBD.

WE want to recruit and train more volunteers to take calls during the evening helpline service, and also volunteers to work with our helpline team to lend an ear with the month on month increase in calls that the team is dealing with.



At the same time, we are also looking to increase our support worker team nationally.

Following posters in libraries, an interview on BBC Northampton with Carol Amirghiasvand and Dianne Whitney who lives with PSP and her husband, Phil, articles in local newspapers and appeals to community groups, a lot of interest for the open day was generated. Local residents dropped in to find out more about PSPA and our volunteering roles and we are now hopeful that, as a result, we can begin



to build our teams, and carry on the recruitment and training throughout the rest of the year.

But... there is still room for more! If you have a few hours to spare and would be interested in finding out more about our flexible volunteering roles please call Wendy or Nicola on 01327 356134 or email volunteering@pspassociation.org.uk.

Changing views

STUDENTS from Edinburgh University have been working with PSPA on the final project for their MSc in Science Communications.

Daniel MacDougall and Molly Osborn visited the national Museum of Scotland in Edinburgh and were interested in an exhibit of prism glasses – like those used by people living with PSP.



The pair was struck by how this clever, yet simple device is a great help to those with muscular eye degeneration to change the direction of their gaze.

“Being unable to look up or down can make it difficult to read a book, eat a meal or even look at the person you are having a conversation with,” explained Molly. “Everyday tasks become much more complicated when you can’t control where you look.”

To draw attention to the ingenuity of these glasses, Daniel and Molly – as part of their degree – devised a demonstration for museum visitors on how the glasses work, along with a fact sheet for museum staff.

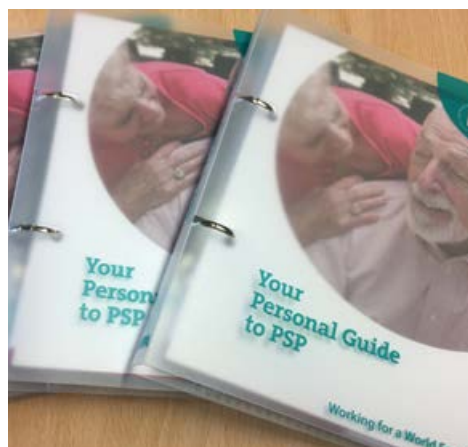
David Mills, PSP Specialist Care Adviser for Scotland helped the students on their



Students, Daniel and Molly, demonstrate the prism glasses to museum visitors

project. He said: “They were fantastic to work with and their project has real legacy highlighting both the prism glasses on display and being able to start a conversation with visitors about what the glasses are medically used for, in particular in regard to PSP.

“We’d like to thank Daniel, Molly and NMS curator Sophie Goggins for their help.”



Your Personal Guide to PSP

WE are updating *Your Personal Guide to PSP*. Following feedback we are now considering developing two separate guides, one for people with PSP and CBD and one aimed at people in a caring role. We really want to make sure we provide the right information, to the right people and would really appreciate you taking part in our short survey. Your views are really important and help us to produce useful information for the benefit of people we support.

Following your feedback we will be either keeping the guide as one updated guide or producing two separate guides.

The survey will only take five minutes of your time. If you feel you would like to help please go to www.surveymonkey.co.uk/r/ReviewofYourPersonalGuidetoPSP

If you are not able to complete the survey online please contact the helpline on 0300 0110 122.

We'd love to hear from you.

Send your news stories to editor@pspassociation.org.uk

Family and Friends Day

Family and Friends Days are a great day for a get-together in an informal relaxed setting.



THE programme is thoughtfully designed for people living with PSP and CBD, family members and carers. However, if you are a volunteer or a health care professional please feel free to join us too.

The programme includes a talk from a neurologist, a chance to put questions to a panel of health professionals who make up a multidisciplinary team and a chance to attend two workshops, one on 'Caring for the carer' and the other on 'Healthy Eating'.

"Thank you. A great day – lots of information and the opportunity to chat".

We will finish the day with entertainment provided by a local rock choir.

Are you interested in setting up a local group in this area? If the answer is yes, there will be an opportunity to

We are now taking bookings for the first of our 2017 Family and Friends Days.
Saturday 13 May
Wychwood Park, Weston, Crewe CW2 5GP
Registration and refreshments will be available from 9.30am
Programme starts at 10.00am and closes at 3.30pm

talk to a member of our volunteering team after the event between between 3.30pm – 4.00pm.

This is a free event, so book early to guarantee a place. You can book via our website www.pspassociation.org.uk
Email: psp@pspassociation.org.uk
Call: 01327 322410

We are also planning our next Family and Friends Day which will be taking place on Saturday 16 September, in the Peterborough area. The venue to be confirmed.

It's not Parkinson's, our new campaign for PSP Awareness Week 2017

Work is well underway, preparing for our awareness week campaign on 14 – 20 May, called *It's not Parkinson's*.

LAST year many of you helped to distribute over 10,000 Red Flag documents to GP surgeries across the UK, to highlight early signs of PSP and to make sure the needs of people with PSP are met.

“I have seen the impact of an incorrect diagnosis, being prescribed unsuitable medications and how little health care professionals understand PSP.

One of those was Cheryl Williams, a district nurse in Caerphilly, who targeted six GP surgeries. Cheryl's dad, Graham Booth, died from PSP in 2015. Initially misdiagnosed with Parkinson's, Graham only received his diagnosis of PSP two years later, after experiencing many falls. Thanks to Cheryl's efforts during awareness week, a GP contacted her to say that thanks to our Red Flags, she had correctly identified a patient's symptoms as possibly PSP, meaning the patient was quickly referred and received a correct and prompt diagnosis.

Cheryl said: “I have seen the impact of an incorrect diagnosis, being prescribed unsuitable medications and how little health care professionals understand PSP. I couldn't change Dad's diagnosis, but educating healthcare professionals was one thing I could do.

“I contacted six GP surgeries and produced a questionnaire asking GPs

and practice nurses five questions to test their initial knowledge of PSP. Once they had read the booklet and seen our Red Flags I went back to the GP surgeries and repeated the five questions. All of the 15 healthcare professionals I spoke to reported that they felt able to spot the symptoms and make a fast referral to a neurologist.

“Through all this I was driven by the desire to make a difference to people in the future who are diagnosed with PSP. That is why it was so heart-warming when I received an email from a GP to tell me that they had identified some of the Red Flags and sent the patient to a specialist for further tests where they have been confirmed as having PSP. Alarm bells that wouldn't have necessarily rang before are now ringing.”

We know many people with PSP are misdiagnosed and, when a correct diagnosis is eventually made, it has often taken years. Around two thirds of respondents to our recent survey received an incorrect diagnosis before being told they had PSP, and more than one third had to wait over a year for their diagnosis even after being referred to a neurologist.

This is why we are going focus on neurologists this year, as well as other specialists such as geriatricians. We will be creating an informative animation for neurologists to help them quickly identify PSP and follow up with all the advice and support that people need. Alongside this will be new awareness cards encouraging specialists to view our animation.

Cheryl Williams



How can you help?

We want to reach as many neurologists, geriatricians and other specialists as possible. To do that we need your help.

- Distribute our new awareness cards to your local Neurology departments
- Give our awareness cards to any healthcare professionals you have appointments with and ask them to share with colleagues at team meetings
- Organise an awareness stall at your local hospital
- Share our animation link via social media
- Share your story with the media

What about CBD?

PSP may be the focus of our May Awareness Week but this doesn't mean that CBD won't get its share of the attention! We are currently developing new publications specifically for CBD, including material for healthcare professionals, and will be launching these later in the year. Watch this space.

To get involved in our Awareness Week and request the new awareness cards please email notparkinsons@pspassociation.org, uk or call 01327 322410. www.pspassociation.org/itsnotparkinsons

Initial findings from latest care survey

Thank you to everyone who completed and returned the survey in 2016, either on line or by post – the response far exceeded our expectations. It was sent to all those on our data base who have either been in contact with PSPA in the past or are currently using our services.

“THIS is the first major survey we have undertaken since 2012,” explained Cameron Wood, PSPA Director of Development. “The results from that survey helped us to change the services we offer, including the introduction of the Helpline, the roles of our specialist care advisers and expansion of volunteering and volunteer-led support groups.

“It was also the catalyst for the development of the first pathway of care for PSP and CBD, which is now recognised internationally.

“We’re still in the process of analysing the results from the recent questionnaire, to ensure we get an

accurate picture of the current state of services available nationally, regionally and locally. And also the issues of length of time until diagnosis and referral to the appropriate health /social care professionals.

“The results will also help us to understand if the services provided by PSPA are in-line with the need and expectations of everyone who uses them - for people living with PSP and CBD, their family members and carers. The findings will also help us to understand how best to address education of health and social care professionals in the management of PSP and CBD.

“From the first overview, we can see that there are lots of variances regionally and locally across the UK. From diagnosis to service provision and access to services. We are now waiting for the full report and will publish the findings.

“These surveys are crucial for PSPA, as it is only with the help and honest comments from our users that we can further develop our services to ensure needs are being fulfilled. Over time, as scientific research and technology continue to change our world, we need to be able to ‘move with the times’ and constantly review all areas of our work and influence the future services provision and the role of PSPA.”

2016 Survey – early findings...

Doctors

Many people reported having to see their GP on several occasions before being referred to neurologist – with most not receiving an accurate PSP/CBD diagnosis the first time. There is a clear link between a swift neurologist referral and correct diagnosis.

Initial reaction: *Continued and further communication work needed with GPs*

Care

Despite broad satisfaction with health care there was some criticism over response times to changing needs and support for families and carer.

Satisfaction with care seems much lower amongst those who do not have a named contact/key worker.

Initial reaction: *Continued and further communication / education work needed with health and social care specialists / professionals. Greater outreach work to greater engagement with those living with PSP and CBD.*

Quality of Life

Staying active is emerging as the factor most strongly associated with enjoyment of life but a significant minority do not feel their life is valuable/worthwhile, and most do not feel in control of their situation.

Initial reaction: *Examine the outreach work of PSPA*

PSPA

Overwhelmingly, PSPA contact seen as helpful, with ‘PSP Matters’ and our helpline the most widely used services. The helpline was most strongly associated with positive assessment of contact with the Association. PSPA advisers, helpline service and local PSPA groups all feature prominently in comments about PSPA services.

Initial Reaction: *Continue to build and develop these services*

PSPA welcomes feedback and comments at any time. Please contact us with any observations, issues, complaints or compliments. Contact survey@pspassociation.org.uk

Continuing Healthcare funding... understanding the system

Across the UK there are two organisations that may be responsible for providing, or arranging, care. These are the NHS and the local authority.

NHS care is free at the point of delivery and meets health care needs. Charges may be levied for care arranged by the local authority (often referred to as 'social care'). The distinction between health and social care is blurred.

Those with complex, ongoing health care needs may be eligible for non-means tested funding to fully cover their residential/nursing home fees or to cover their care needs at home.

What is CHC funding?

NHS Continuing Healthcare (CHC) funding is the name given to a package of care that is arranged and solely funded by the NHS for individuals aged 18 + who are not in hospital but who have complex, ongoing health care needs.

There is a two-stage assessment process for CHC funding and both stages involve an assessment of needs across 12 areas (domains) of care including mobility, cognition and nutrition. The initial screening process (using the Checklist Tool) is undertaken to indicate if proceeding to a full assessment (using The Decision Support Tool) is appropriate. Assessments are carried out by Health and Social Care professionals.

Healthcare needs are met in different ways across England, Wales, Scotland and Northern Ireland. The main section of this article refers to the system in England with the systems elsewhere outlined below.

Scotland

The system in Scotland is different. In June 2015, CHC funding in Scotland was replaced by Hospital Based Complex Clinical Care (HBCCC). People who were assessed under the old system and found eligible for CHC funding continue to receive it for as long as they remain eligible.



PSPA has two fact sheets – one for families and one for the healthcare professionals involved in CHC funding assessments

Assessment for long term complex clinical care is now based on one question: 'Can your care needs be properly met in any setting other than a hospital?' If, following a full assessment the answer is yes the person will be discharged to a community setting such as a care or residential home or their own home (with care support if required). The local councils charging policy then applies and a person may need to contribute to the costs. The NHS will continue to meet any healthcare needs, free of charge. See: www.careinfoscotland.scot/ for more information or call 0800 011 3200 from 8am until 10pm, seven days a week.

Northern Ireland

In Northern Ireland there is no national guidance on CHC funding and our Specialist Care Adviser for the region, David Mills, has yet to hear of anyone in receipt of CHC funding in Northern Ireland. The local Health and Social Care Trusts can advise further.

Wales

The Welsh system is very similar to the English system. Responsibility for CHC funding in Wales lies with the Health Boards and guidance is issued to them by the Welsh government.

Continued overleaf..

CHC Funding – Key points to note:

- If you live in a residential or nursing home and receive CHC funding Attendance Allowance (AA), Disability Living Allowance (DLA) and Personal Independence Payments (PIP) stop after 28 days. This is not the case if you live at home. In all cases you continue to receive your pension although pension credit may be affected
- CHC funding is not dependent upon the Clinical Commissioning Group (CCG)/Health Board finances or whether the care is to be provided in a care home or at home
- There are no 'lifetime awards' for CHC funding. It will be regularly reviewed and can be removed if needs change
- Not everyone with a long term condition like PSP or CBD will be eligible (or become eligible) as the eligibility criteria are not based on diagnosis
- It is not permissible to 'top up' CHC funding to meet an individual's healthcare needs as CHC funding must fully meet the assessed need
- If a care home is needed CHC will choose this in discussion with the person and their family
- Keeping records and a detailed 'care diary' can be very useful when an assessment is being made.

What PSPA is doing

PSPA is now part of The Continuing Healthcare Alliance (CHC Alliance). The CHC Alliance is a group of organisations working together to improve NHS CHC for all who rely on it, now and in the future. PSPA are constantly receiving calls from people who are struggling with accessing CHC and it is important we

fight their corner any way we can.

The Continuing Healthcare Alliance has produced a new report highlighting the key problems with the NHS continuing healthcare system, and how these could be tackled. If you would like a copy of the report please contact PSPA Helpline.

Further information

The PSPA has two fact sheets about CHC funding – one for families and one for healthcare professionals involved in CHC assessments. Contact the Helpline on 0300 0110 122 for copies or further information.

Age UK produce detailed fact sheets on CHC funding and related issues. See: www.ageuk.org.uk or call 0800 678 1174

Beacon is an organisation specialising in supporting people with the CHC process. They work in partnership with, amongst others, NHS England and can offer free advice. See: www.beaconchc.co.uk or call 0345 548 0300

Care to be Different has online information. See: www.caretobedifferent.co.uk

Personal

Geoff and Marie Brooks

GEOFF and Marie Brooks live in Cheshire and are just in the process of reapplying for CHC funding for Marie who has a diagnosis of PSP. CHC funding for Marie was first considered in 2015 but following an initial screening using the Checklist Toolkit (which can be completed by any health or social care professional who is trained to use it) Marie was not deemed eligible for a full assessment.

Since then Maries' needs, particularly in relation to managing food and swallowing, have increased significantly. The district nurse has completed a further initial screening and a full

George and Veronica Mills

GEORGE Mills says "The whole experience has been like fighting a sponge," in his battle to secure CHC funding for his wife Veronica who is living with PSP. The couple, who reside in the West Country, initially attempted to secure CHC funding in August 2015 when their local multidisciplinary team felt Veronica's needs fulfilled the CHC funding criteria. Veronica was finally granted the funding in November 2016 but only after the couple had been through a frustrating process involving an unsuccessful appeal against the refusal and a fresh application having to be made.

Reflecting on his experiences George says: "The whole system needs a complete shake up, ranging from the way assessments are done (which varies from area to area) to strict adherence to time frames." He found that he had to

stories:

assessment will now take place. Geoff feels it is essential to fully involve family carers in the process as they best know the individuals needs.

“It is all rather frustrating as I know how difficult life is for Marie but it feels like decisions are made by men and women behind closed doors.”

As he says: “It is all rather frustrating as I know how difficult life is for Marie but it feels like decisions are made by men and

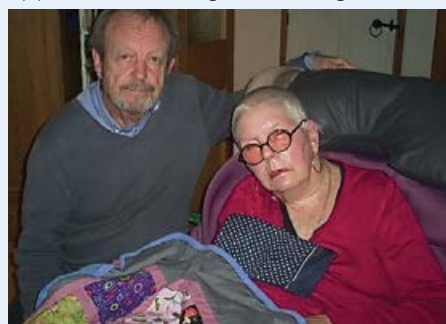
women behind closed doors.”

Geoff knows he may need to persevere to get the CHC funding put in place and expresses concerns about others who may not be in a position to challenge decisions. Geoff has made use of the Care to be Different website and talks to other families affected by PSP. He is aware that although the eligibility criteria is designed to be standard across England there are differences in interpretation in different areas. “We go to a PSPA local support group and are aware that some people there have been awarded CHC whilst Marie, who has similar or greater needs, hasn’t yet received this support.”



Geoff and Marie Brooks

chase those involved in the assessment and decision making processes to get timely responses – and to ensure he was furnished with the information he needed at each stage of the process. For example, George was not given reasons as to why the initial application had been turned down yet this was essential information which he needed to base the appeal on. There was further frustration at having to return to square one with a pre assessment for the new application. Throughout George felt



George and Veronica Mills

there was a lack of understanding of the progressive nature of PSP.

“One cannot help but feel there is a hidden agenda here, keep stalling long enough and perhaps the claimant will give up.”

George wrote to Dr Sarah Wollaston (chair of the Health Select Committee) to share his experiences and to advise her that: “It is a system full of inconsistencies, bureaucratic mismanagement and procrastination and is really not fit for purpose.” He says: “One cannot help but feel there is a hidden agenda here, keep stalling long enough and perhaps the claimant will give up.”

Georges’ advice to others is: “If you want to succeed in this process then

preparation is key – read everything you can about all the pitfalls, be prepared to fight your corner and above all, don’t give up.

“The package of help we get now is very good but ironically when we needed the most help was last year when my wife was getting up between eight and 16 times a night. That was when, in their wisdom, they determined that we did not qualify. They ignored the people who actually had day to day contact and relied on decisions taken in committee rooms.”

Although people often do experience difficulties obtaining CHC funding it can be incredibly helpful and we know of many people for whom the system works very well. Seeking advice at an early stage and understanding the system is important. PSPA are always happy to offer information and support.

Making life better

Meet Dr Lou Wiblin, a neurologist with a particular interest in movement disorders like PSP, who is investigating that enigmatic concept known as ‘quality of life’.



Dr Lou Wiblin in action in clinic at the James Cook University Hospital, Middlesbrough

QUANTITY of life is why I practise medicine” Dr Lou Wiblin explains: “Until the wonderful day when the conditions I treat have a cure, my mission is to try and make life better where I can for people living with these illnesses, patients and their families alike.”

To this end, she is conducting a research study to find out more about the impact of PSP symptoms, and those of a related disorder known as Multiple System Atrophy, on patients and those caring for them. This isn’t medical

research as most of us think of it.

“Research is important for many reasons” explains Dr Wiblin, “but not all of us will be in a lab testing cells or drugs in petri dishes. Some, like me, will be doing clinical research to see how the disease affects the person. Understanding what impacts quality of life most, and ways which could help, can allow clinicians to develop services in a particular direction to try and improve patient experience.”

But how can researchers measure such

abstract things as symptom burden and support needs? It all depends on interviews where patients and carers do a lot of talking, and Dr Wiblin does a lot of listening! “It’s a good interview if I say very little – like I say to my study participants, nobody wants to know what I think, they want to know what you think!” she says.

Developing the questions for these interviews so that researchers can dig out the information that really matters is a science in itself, and Dr Wiblin has used

special questionnaires developed over many years by doctors and psychologists to be accurate and specific.

Then, after all the talking, comes the tough part – turning people’s experiences into results that healthcare providers will take notice of. “I use a method called thematic analysis,” explains Dr Wiblin. “To cut a long story short, I code each part of the interview according to content. Patterns then start to come together and people often discuss similar things, in their own way. Hopefully particular themes emerge, which can then be presented and illustrated by pertinent quotes.”

A clear picture of the unique care and support needs of people affected by PSP and CBD is essential to open up access to improved services, a fact recognised by the PSPA’s own research strategy. Our Research Network gives researchers the opportunity to evaluate the care service experiences of a large number of people

across the country, while our Clinical Research Fellow in Scotland, Dr Diane Swallow, will be specifically assessing standards of care north of the border.

“Research is important for many reasons” explains

Dr Wiblin, “but not all of us will be in a lab testing cells or drugs in petri dishes.”

Ultimately, Dr Wiblin hopes that her work will influence how healthcare professionals deal day-to-day with people living with these conditions, making a real difference to life with PSP. “I also want to develop my own service with the insight from this work,” she tells us. “I want to achieve something like what patients and carers really need.”

If you are interested in participating in a research study, visit the research area of our website to find out more.



DR Wiblin originally went to university to study plant biochemistry but, after an inspiring stint volunteering at a local hospital oncology unit, applied to study medicine as a post-graduate. “I had never known anyone who had been to medical school so it seemed like a step into the unknown, but I loved medicine, even more than plants!” she says. “The best part of my job is interacting with patients.”

“People with this condition need all-round care, understanding and the support of a team of professionals, not just a doctor.”

Neurology was a stand-out speciality during her training. “The range of conditions, the complexity – I knew I wanted to do it,” she explains. “Movement disorder combines the challenge of diagnosis and refining treatment with needing good sense and compassion; it is holistic and multisystem. PSP is the very essence of this. People with this condition need all-round care, understanding and the support of a team of professionals, not just a doctor.”

Taking part in Dr Wiblin’s study

HILARY Miller, who is living with PSP, and her husband Alan decided to volunteer for Dr Wiblin’s study. Alan told us about their experience of taking part.

“We met Dr Wiblin at a local PSPA group event and decided that taking part in her study was a chance to help others. Hilary’s condition was so vaguely defined when she was first diagnosed, we were just told it was ‘Parkinsonism’. It feels like we need to do all we can to contribute to progress in supporting people with PSP.

“Taking part in the project involved filling in patient and carer questionnaires and talking to Dr Wiblin, who kindly visited us at home.



We spent a few hours in total with her – it was tiring, but we got through it and I feel that we successfully shared our experiences. Dr Wiblin is lovely and very caring.

“We now feel that we’ve made a contribution to alleviating the problems of others in the future.”

2016 in numbers - the diff

£1,464,500

pounds raised.

£682,500

committed to PROSPECT and the associated imaging and CSF biomarker studies up to 2019.

£20,000

awarded to the Queens Square Brain Bank.

£6,780

to fund an international task force of world leading experts on PSP working towards an improved diagnostic criteria.

£300,000

commitment to our research fellowships over three years.

3,787

people effected by PSP/CBD supported by our Information and Support Services.

3,493 Helpline calls.

715 Helpline emails.

200

health professionals attended educational event.

10,000

Red Flag fact sheets sent to GP practices across the UK.

405

copies of our GP Guides distributed.

ference we made together

145

delegates attended family and friends days.

275

local group meetings held throughout the UK.

1,600

people attended a local group.

8

new support volunteers recruited and trained.

72 runners raised

£161,488

in the Virgin London Marathon.

7 cyclists peddled

100

miles each as part of the Surrey 100 Challenge.

£50,663

was raised from the raffle and direct mail.

£190,482

was given by charitable trusts and foundations.

£407,508

was left to PSPA from generous legacies.

£156,304

given in memoriam of loved ones.

To our wonderful fundraisers, supporters and volunteers

a big thank you!

Taking a respite care holiday

“Everything is very person centred...
I found the standard of care second to none.”

WHEN Brendan Conachy and his partner Evelyn Convery fancied a short break at the end of last year they knew they needed a wheelchair accessible, well equipped venue that could offer them both a relaxing, fun time. Brendan comes from Northern Ireland and is living with PSP. Evelyn is based in Ireland and, luckily through her work for the Irish Wheelchair Association, was aware that Cuisle, the Associations’ national holiday centre might fit the bill.

Situated in Donaman, County Roscommon in the Western region of the Republic of Ireland, Cuisle offers accessible holidays to individuals (including those seeking a respite care break), couples and groups. Personal or nursing care can be provided by an onsite team if required, although it is essential to book this (and any specialist equipment) in advance. Brendan and Evelyn went as part of a group of six people but, Evelyn says: “We were both fully able to relax and enjoy time together as a couple. Brendan gets tired if we do too much but this was just perfect.” At Cuisle, Evelyn appreciated the provision of practical care support and the opportunity of some pampering. “Others helped Brendan with his breakfast while I lay in bed! Having access to wheelchair accessible transport, a pool, a spa and massage therapy were just added bonuses. I had a sauna and a neck and shoulder massage which was magic. It was all so relaxing and we had a lot of fun.”



Evelyn Convery and Brendan Conachy

Evelyn recommends the ‘lovely food’ and ‘brilliant staff’ and says: “I could not find fault in any of the support provided.”

Stays of between one and 14 nights are possible. The centre offers full board, half board and B&B packages. Mini bus trips are on offer and there is evening entertainment such as music, quizzes

and bingo. Pre bookable wheelchair accessible fishing (with tuition, fishing gear, transport and a packed lunch) is available.

“Going in a group was great. Brendan and I are going again soon with another group. We also hope to return on our own before too long.”

Further information:

Cuisle Holiday Centre – www.cuisle.ie Email: cruisle@iwa.ie Tel: 090 666 23277

Please note that the PSPA is not able to recommend holiday venues. It is important to check that your individual requirements can be met by your chosen venue. Information on UK based holidays (and some foreign based travel) is available from Tourism for All.

www.tourismforall.org who have a further website: www.openbritain.net

Long held secret

Alan Lloyd has been keeping a secret for over 80 years. It has been stashed away, out of sight, without anyone knowing (including himself!), until one day just a few months ago, his secret became public...

IT turns out that Alan is a budding artist – a bit of a master with a paintbrush! A talent that was discovered whilst enjoying a spot of respite care at his local hospice.

“Dad has never painted before in his life!” laughed his son, Andy. “None of us knew he had it in him but when he returned home with these paintings, we were all amazed – especially as Dad’s eyesight isn’t what it used to be – and shocked how good they were!”

Alan (85) lives with PSP and shares his home in Nuneaton with his wife. One day a week he visits the nearby ‘Mary Ann Evans Hospice’ where he



Alan Lloyd

has the opportunity to try his hand at new activities – he also enjoys their jacuzzi bath!

“I quite look forward to my days out,” said Alan. “The people are lovely and it’s nice to have a change of scene. It also gives my wife a well-earned break. And if it hadn’t been for them coaxing me to have a go at new things, I’d have never have known I was any good at painting! You see, you never stop learning – whatever age you are!”

Note from the Editor:

Alan’s family is wondering if these paintings might look good on a charity Christmas card – what do you think? Let us know – ideas@pspassociation.org.uk

Wedded bliss

Twenty five years after they first met former fireman Ron Randall, 81, married his sweetheart Margaret, 72, in a quiet ceremony in Cornwall in November.

THOSE attending their subsequent blessing and family party in Essex were asked by the generous happy couple for donations to PSPA in lieu of wedding presents. A cheque for £445 was gratefully received by PSPA. Everyone enjoyed the wedding cake which was designed to look like a fire engine and which had the PSP collection box right next to it!

Ron is living with PSP and Margaret provides the care and support he requires. The couple met when Margaret, then a bursar at the University of London, spotted that vandals had started a fire and called the brigade. Ron investigated the cause. Together ever since Margaret commented: “I recommend married life – we waited so many years just because we wanted to be sure we would like it.”



Their wedding cake of a LFB fire engine

Margaret and Ron now live in Cornwall where Ron belongs to a ‘blokes who brunch’ group who meet on a Wednesday. His friends from this group were the only ones aware of the wedding plans, and they made it special when the couple (married early on a Wednesday morning) popped in straight afterwards. The champagne flowed.

The continuing support of PSPA local groups



Long-term friendships forged from shared understanding and ongoing support are sometimes overlooked but a vital element of many of our local groups. In the following article, Loughborough group volunteer, Kathryn Timmons, tells *PSP Matters* how being involved has helped her and other group members:

THE Loughborough group has existed now for about five years and during that time we have had huge support from each other while living with PSP and caring for husbands or wives who were unfortunate enough to contract the condition.

“As a group, we have always tried to be positive and share what is possible rather than focus too much on the challenges. We learned a lot from each other about dealing with GPs and other professionals who, though kind and helpful, did not fully understand the particular problems of PSP.

“Also, because of the group meetings, the people we were caring for were able to take part in a social occasion without feeling self conscious about needing a cup with a lid or spilling food.

“As a group, we have always tried to be positive and share what is possible rather than focus too much on the challenges.”

“There have inevitably been several bereavements: in fact in our group now there are more of us who are bereaved than there are people still coping with life with PSP. We realise that the ongoing friendship and support is still important after death when the practical problems of everyday care are no longer there.



Friendships forged at our Loughborough group

There is still a need to talk over the difficulties we encountered and the ways in which we coped: there is a special bond and understanding which develops as a result of having lived with a rare condition. Families and friends, kind and loving as they are, do not understand in the same way as someone who has dealt daily, and nightly, with the challenges that PSP presents. An added bonus of remaining with the local group is that we can talk about the people who have died with friends who have known them in the last stages of their lives, inevitably with some sadness, but with the knowledge that they have been well cared for and loved.

“Caring for someone with PSP is more than a full time job: there is not only the time needed to take responsibility for all the practical needs but also the added burden of coordinating the visits of the various health professionals who

help to keep things going. When these responsibilities come to an end there is suddenly a lot of time in the day to be filled with other things. There are plenty of good causes looking for help, not least the PSPA: we have found the ongoing contact with the local group has helped us to look to the future and encouraged us to move on.

“We hope that as well as continuing to provide support for each other we can, because of our experience, help other people who are newly diagnosed and feeling as confused and lost as we were in the early stages. I still remember very clearly the day my husband and I were given the diagnosis. We had no idea what difficulties we were going to face over the next three years and certainly no inkling of what help might be available. Finding the PSPA website was a good start and being involved in the support group has been invaluable.”

Our education role is ready to go!

Our new Education and Awareness volunteering role is now ready to launch with a new recruitment campaign taking place throughout the UK.

BECAUSE PSP and CBD are rare and little known, we have developed this role with the aim of educating and raising awareness with health and social care professionals and other interested groups.

Volunteers taking up this exciting new opportunity will deliver education and awareness raising sessions to staff in care homes, hospices and other interested groups.

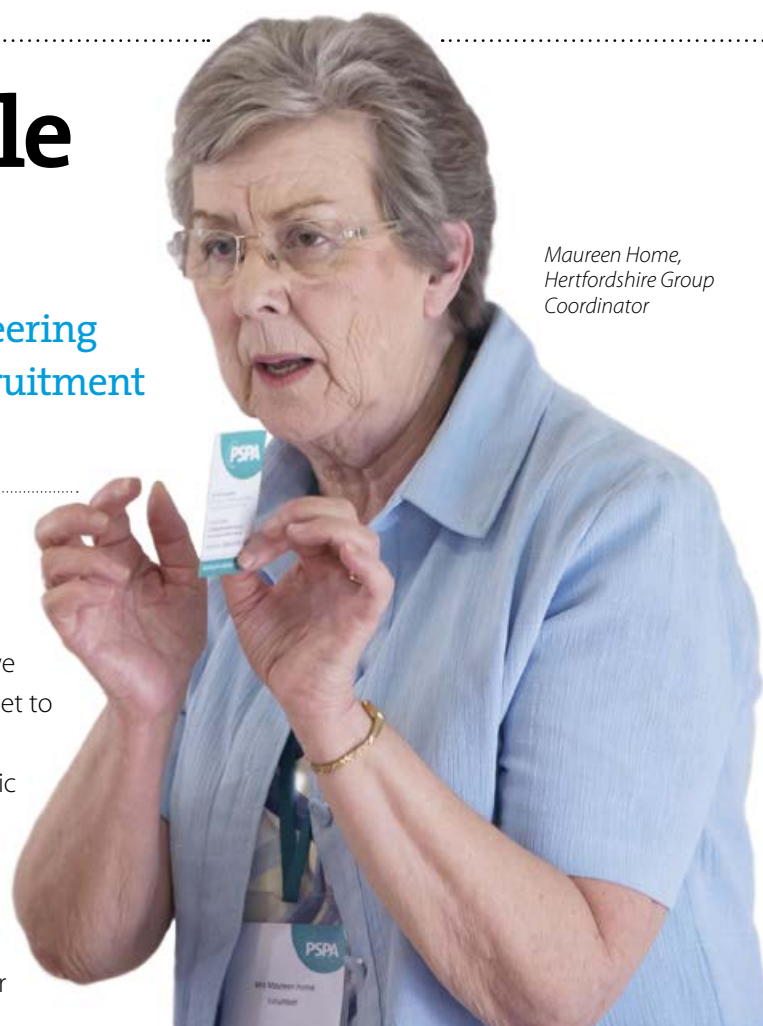
In return, volunteers could develop new skills and increase their knowledge and understanding of PSP and CBD and the wider work of PSPA.

Our specially-designed training package is now in place and involves

working through several modules online with a final practical day where we can all meet up and get to know each other.

If you are enthusiastic and enjoy speaking to groups this could be the role for you. Have a look at the full role description on our website.

Alternatively call Wendy or Nicola for an informal chat on 01327 356134 or email volunteering@pspassociation.org.uk



Maureen Home,
Hertfordshire Group
Coordinator

Are you enthusiastic and enjoy speaking to groups? Our Education and Awareness role could be perfect for you!

Linking up with local groups

AN idea to join up two areas of PSPA's work has sparked new opportunities for advancement in research.

Researchers working on PSP or CBD related studies have been linking up with our local groups to share information and talk about research participation.

The plan came about when scientists from the OxQUIP* project asked PSPA Research Coordinator, Kate Arkell, to put them in touch with people living with PSP in their area. Kate suggested a visit to our local groups would be a great way to share details of the project and

encourage people to get involved.

The idea has been taken up with great enthusiasm on both sides and to date Dr Diane Swallow was a welcome visitor at our Aberdeen group meeting



Caption Dr Chrystalina Antoniadou from the OxQUIP study talking to our South Oxfordshire group

in January and OxQUIP researchers have visited our Northampton and South Oxfordshire groups with visits to our Warwickshire and Hertfordshire groups in the pipeline. Researchers from the PiPPIN* project are also planning a visit to the Norwich group.

Kate said: "This has been a successful collaboration and a great way for researchers and people affected by PSP and CBD to meet up and share information. Huge thanks to everyone involved."

*For more information about these projects please visit the Research area on our website.

Local group roundup

THE Aberdeen group were delighted to welcome Dr Diane Swallow to their annual festive lunch on 20 January, where she was able to share news about the research project she is involved with, developing understanding of PSP and CBD in Scotland. Read more about it here: www.pspassociation.org.uk/2016/11/psp-cbd-research-fellowship-appeal/



WELL done to our Leeds group volunteers Pam Bower and Beryl Mayhew who recently set up stall at Bramhope WI AGM. They raised a grand total of £131 which included some other sales during the day and a lot of orders!

Beryl said: "I put the little cards on each table so we raised awareness as well!"



MEMBERS of our Hampshire group, along with volunteer, Louisa Roberts-West, were recently invited to the Rainbow Centre in Fareham, Hants, for a specially devised PSP taster session of Conductive Education, aimed at enabling greater independence for the individual.

"The aim of their programme is to enable greater independence for the individual."

Louisa told us: "This place came to my attention through a group member who has been visiting the centre for nine months and 'tagging' on to a Parkinson's group there. He and his wife were really impressed with the results so I went and visited last year to sit in on a group. Istvan Szucs, who runs the adult programme



at the centre came to our November support group and talked to everyone about what they do and we had a great deal of interest so they invited us along for a taster!

"The Rainbow Centre is a charity offering Conductive Education, a concept developed at The Peto Institute in Budapest which has been adapted for adults. The aim of their programme is to enable greater independence for the individual. We visited the centre in Fareham for a specially devised PSP taster session on Tuesday 31 January.

The one and half hour session was focused on posture, balance, limb coordination, voice strengthening and fine motor skill exercises. The feedback from the group was really positive and they seemed especially impressed with the reinforcing techniques used and the attentiveness of the 'conductors' (teachers), with each working at their own pace. We are working on developing a regular PSP slot at The Rainbow Centre for those in Hampshire and the surrounding area which is really exciting."

Thank you Gerry!

OUR Helpline team has bid a fond farewell to one of our original Helpline Assistant Volunteers, Gerry Jerrum, who is standing down from the role after more than three years.

But it's not goodbye as Gerry, who also did a fantastic job as chairman at our Bristol Family and Friends day in 2015, will still be involved with PSPA as a volunteer helper with the Bristol group. Thank you for all your efforts, Gerry!



Meet our volunteers

Pam Lancaster – Volunteer Support Worker

I think the Support Worker role is a lifeline. It is someone to reach out to and talk to," says Pam Lancaster, one of PSPA's first volunteer Support Workers.

Pam had already been involved for two years as a helper with the Kent Local Group when she decided to double-up her volunteering efforts by signing up for the new role.

She was inspired after realising that, while the local group meetings offered an excellent opportunity for friendship and shared experiences, there was also a need for the one-to-one contact offered through the Support Worker project.

She said: "The group is so busy, we are always trying to be in several places at once, so you can't have an in-depth conversation with anyone. With the

Support Worker role, it's much more in-depth. You can't really compare one role with another as they are so different but I enjoy them both."

Pam, who cared for husband Kenneth until his death 2010, described the positive effect of being involved in the project not only for the people she is supporting, but also for herself.

She said: "I get a great deal of satisfaction from the role. The two individuals I am in touch with are unable to get to a group so the Support Worker is much needed. It makes me feel better that I can give knowledge and a bit of comfort to them or just listen while they let off steam!

"One lady I am supporting is such a positive person and that rubs off, it has



a knock-on effect. She always says she enjoys my visits and looks forward to me going and so do I! So it's not just about giving. I feel fulfilled by that."

Could you be a PSPA Support Worker? Contact us on 01327 322416 to find out how!

Or visit www.pspassociation.org.uk/get-involved/volunteer-with-us/opportunities/support-worker

Doreen Walker – Volunteer Helpline Assistant

WHEN Doreen Walker spotted a call for volunteers in *PSP Matters* in 2013 her immediate reaction was "I can do that!"

As a former carer to husband Raymond, she felt the time was right to get involved and contacted PSPA to sign up for the newly created Volunteer Helpline Assistant role.

Doreen, who volunteers from her home in Durham, said: "It had been three years since my bereavement and that was exactly right length of time. I wanted to give something back."

"I completed the training course and I was frightened out of my wits that I would be asked something beyond my knowledge but I didn't need to worry as your role is to listen and the professionals

take up those questions the next day, so there is nothing to be afraid of.

"Volunteering with the Helpline puts you in touch with other people's emotions, how they have experienced things they are going through and you



can empathise with them.

"Many a caller has said 'It's really lovely to talk to someone who really understands' and you really DO understand.

"I feel good about it and I get a lot of satisfaction from it. If you can reach out and help people that little bit just from them talking to you then that is a wonderful way to support people."

Could you be a Volunteer Helpline Assistant? We need more volunteers to support the service by handling calls to the line during evening hours. So give us a call on 01327 322416 to find out how you could get involved.

For more information visit www.pspassociation.org.uk/get-involved/volunteer-with-us/opportunities/helpline-assistant

London Marathon

ON Sunday 23 April, Team PSPA entered the world's most famous running race – The London Marathon.

This year, 73 runners took on the 26.2

mile course with the sole aim of raising as much as they could for PSPA! Cheered on by our wonderful volunteers, runners crossed the finish line in high spirits, and in one piece! The race was very tough and

the journey to the start line began way back in the depths of winter but it was their personal experiences with PSP and CBD that spurred them on. Congratulations to all our runners – and thank you.

Sarah Watson, London

“Knowing how hard it is, not only for those living with PSP and CBD, but for their families, is what motivates me and gives me all the drive I need to help fund the support, research and the hunt for a cure. This is what I tell myself – to keep me heading out on the training runs in the wet, cold and dark! Running the London Marathon was one of the most incredible things I have achieved – and all for such a very good cause.”

Sarah's Dad, Ernest, was diagnosed with PSP when she was just 12 years old and passed away five years later.



Paola Salman, Mexico

“It is my first time running for charity and it has definitely given me greater motivation, as it is not just myself that I am running for anymore.

I have also been able to raise some awareness of the disease in Mexico.”



Chloe Anderson, Newbury

Chloe has previously taken part in a couple of running events for PSPA, as well as conquering Trekfest last year with her

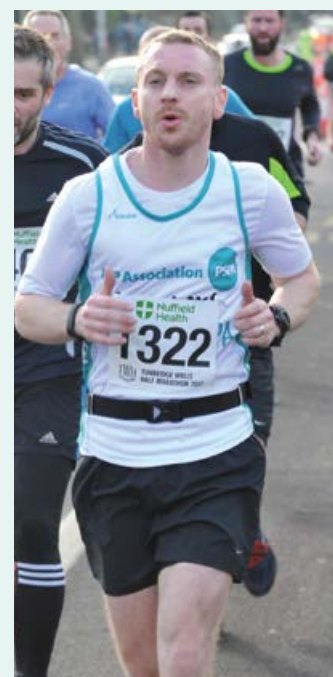


brother, Lewis. The London Marathon has presented her biggest challenge yet. “My nan, Valerie Clark, was diagnosed with PSP over three years ago now. I am running London Marathon in the hope to raise vital awareness and funds for the PSP Association.”

Rob Platt, East Sussex

“In April 2016 my Dad, John Platt, was diagnosed with PSP. It was a great shock to our family and it is clear that the PSPA is going to become very important to our family.

“I will be running as many events as possible for PSPA during 2017. My aim is to run over 230 miles in one year and try to raise over £5,000. I have no doubt already that this will be a small token for the potential support that PSPA is likely to offer us in the coming years.”





Simon Evans, Berkshire

"I want to raise awareness of PSP as well as raising as much money as I can." Running in memory of mother-in-law, Jo.

Jo Powis, Gloucestershire

"The last few years have been challenging for our family in that my lovely Mum was diagnosed with PSP six years ago. The Marathon is scary, exciting and definitely a challenge but as the quote I've chosen says: "Challenges make life interesting and overcoming them makes life meaningful"



Caroline Britton, Norfolk

"This year I ran to raise awareness of CBD. I shall be proud to fly the flag for the PSPA, and this time I have an angel by my side." Caroline remembering her dad, Bob.

Sian Pennock, Bedfordshire



Sian is running in memory of her Dad, Kieron Maloney.

"I decided to run for Team PSPA to help raise awareness and funds so that one day, others don't have to go through the same thing."

Sean Martin, London

"I am doing the marathon in memory of my Grandad Dave. He genuinely was a brilliant man. He was gifted musically and sportingly, active and always the centre of a party. It seems a general consensus from anyone that ever met him that he was one of a kind!"



Harry Chapman, Hertfordshire

"I am running the 2017 London Marathon to help PSPA continue to provide a wide range of support and information to people living with PSP and CBD. My Grandad, Paul Chapman, was diagnosed with PSP a year ago – this has inspired me to take on the challenge of my first marathon run."

Neil Anderson, West Lothian



Neil is running in support of his Mum who lives with PSP. His training included the Falkirk Parkrun, with his daughter, Eileen



James Taylor, London

"I will be running the marathon in memory of a great man who is dearly missed." His girlfriend's grandad, Gordon.



London Marathon continued

Oliver Stovin, Cambridgeshire

“As a GP, I had two patients in the last 10 years who passed away after living with PSP. I also heard how useful carers, found the PSPA.”



Lee Pearce, Shrewsbury

“This is my third London Marathon in the PSPA vest! The support and atmosphere you get at the marathon is amazing. Seeing the PSPA flags waving on Tower Bridge, and the reception we got when we arrive back, is fantastic.” Running for father-in-law, Harry, who had CBD.



Emma and Adrian Horsburgh, Hertfordshire

“We are a father/daughter pair running in memory of our mother/grandmother Ann. We're really proud to be running in Ann's memory for PSPA.”



Become a hero, and join Team PSPA at the London Marathon in 2018! Secure your place today!
marathon@psspassociation.org.uk 01327 356132

Take three

The PSPA is dependant on the dedication of its supporters who do a great job to raise the precious funds needed to maintain its services to families living with PSP and CBD.

PSP Matters always like to hear about fundraising activities and here we talk to three individuals who are committed to bringing in the cash...



Photos courtesy of RGPhotography

SCOTT SMITH has always gone above and beyond for PSPA, and The Big Brain Ball was no exception! Scott organised and hosted the evening held at the Lymm Hotel in Cheshire. There were guest speakers, a raffle and live music too.

“It went really well,” said Scott. “My main aim was for everyone to have a great night and it seems like they did – the bar didn't close until 3am!” Raising around £4,000, the event also helped to spread awareness of PSP and CBD. Then, if hosting and organising The Big Brain Ball wasn't enough, Scott ran the London Marathon – all in memory of his granddad, Ed.

FIONA BRESLIN and a host of her friends and family were 'flying without wings' back in November when together they raised over £8,000 in just one evening.

The night, named 'Brezlife', saw Fiona and her family hold their very own Westlife tribute night!

"The Breslin family are renowned for channelling their inner Westlife and performing on a night out!" said Fiona.

The Breslins joined together to sing classic hits, complete with rehearsed dance moves too! Fiona wanted to do something really special as her granddad, Edward, lives with PSP.

"Everyone had the most amazing time. PSPA is a charity very close to our family and it's the least we could do to try and support such an amazing organisation. We hope it's the first of many occasions we can fundraise and support such a fantastic charity!"



Fresh from running the London Marathon and Santa Run last year, supporter and fundraiser **Alex Ridout** has set herself a new challenge for 2017: 12 running events in 12 months in memory of her dad, Paul. Alex will be running the Great North Run in September, as well as the Sierra Leone Marathon in May!

Kicking off the year, Alex took part in the Polar Bear Dip in Canada – and, yes, it is as cold as it sounds! Alex said:

"The Polar Bear Dip was just the beginning of a New Year of fundraising for PSPA. With 12+ running events in the calendar, 2017 is promising to be a very sweaty year! But even more inspiring are those who have agreed to be involved in the madness, many of whom have never run a race before, let alone a half marathon."

First up though, was a half marathon a little closer to home – a wintry jog through London's Victoria Park back in January.



"First race DONE. A very chilly Saturday morning, 13.1miles, felt like 131! More like a post-Christmas roll than run (1 hour 45 minutes), but a starting point for the year to come. My friends Emma and Ashley kept my spirits up before I set off, and Venetia, Georgie and Rob were waiting in the pub after to rub our toes and feed us bread and beer! Thought of dad all the way round. This one was dedicated to him, and others who are living with PSP and CBD. Feeling proud of their strength and determination in their fight. xx"

Taken from Alex's race diary



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...



Spring is finally here – I love this time of year! I am really looking forward to barbecues, coffee mornings, attending lots of big fundraising events like RideLondon and the British 10k, and heading off on holidays in the sun where I can eat lots of ice cream.

Already this year I have travelled with fundraiser Laura Hudson on her epic cycle from Vietnam to Cambodia back in March. I've only just got over the jet lag and the exhaustion of cycling all those miles, so I best get writing all about our journey for my next diary entry! Watch this space!

I also cannot wait for the week 13 - 21 May. No holidays and cocktails for me though, as I will be giving my all to help with Awareness Week! This year the focus is on engaging with neurologists and improving early diagnosis. I think everyone knows just how important early diagnosis is if those living with PSP and CBD are to receive the care and support they need.

I will do the best I can to raise awareness during this week, and, of course, throughout what is to be a very exciting 2017 for PSPA!



Here I am with some guests at Scott Smith's Big Brain Ball back in February. What a night! (You can read more about it on page 22.)



I always have a great time when I visit my friend, Sarah Robinson. She is always thinking up new and amazing ways to raise awareness, and on my last visit she showed me her new creation! 'Jars of Hope' are decorated with ribbon in PSPA colours, and inside are a fact card and PSPA keyring.

The jars are then sent to Sarah's friends and family for them to collect their loose change in. I love Sarah's idea, and was only too happy to be her helper for the day!



I go to the ends of the earth to raise awareness of PSP and CBD, and that is exactly where I went when supporter (and Northampton local group co-ordinator) Val Cole, took me to New Zealand! I enjoyed horse riding, sight-seeing and was somehow convinced to go bungee jumping – EEK!

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

Love, Hope

Events upcoming in 2017

Help is at hand

If you are stuck for ideas on raising funds for PSPA in 2017, there are lots of organised events across the UK (and further afield) looking for eager participants, so how about taking part in...

RideLondon – Surrey 100

Be part of Team PSPA at the year's biggest and best cycling event! On Sunday 30 July over 26,000 riders take to the traffic-free streets of London and the twisting, climbing country lanes of Surrey for RideLondon – Surrey 100. This event grows bigger and bigger every year, and is one not to be missed!



Local Events

Remember that you can sign-up for lots of other events, including running and obstacle, throughout the UK. Events range from the Manchester Marathon to the Milton Keynes Half, the Burnley 10k to Bear Grylls Survival Race.



Superhero Run

Kapow! It's not too late to secure your spot at the Superhero Run in London's Regent's Park on Sunday 14 May. Gather a group of super friends and family and be heroes for Team PSPA!



British 10k

Pound the streets of the capital and take-in its famous landmarks on Sunday 9 July. But be quick – places go fast.

For more information and details of how to sign up, please email events@pspassociation.org.uk or call 01327 356132. So be quick to secure your place!

Be sure to check out our brand new website for a list of all of our fundraising events! Go Team PSPA! www.pspassociation.org.uk

Your fundraising

PSPA wants to thank everyone for continuing to raise vital funds. We're always keen to know what you've been doing and love to see your pictures, so please let us know!

Rock chick



£2,500

Katy Holmes raised another £1,000 with help from the Wokingham Rock Choir. In memory of Katy's Nana, Celia McMillan.

Stamping mad

Sarah Robinson, who with the help of her family and friends, collected a whopping 7667 stamps in honour of her Dad, Gerald Marshall.



£25

Jumping for funds...

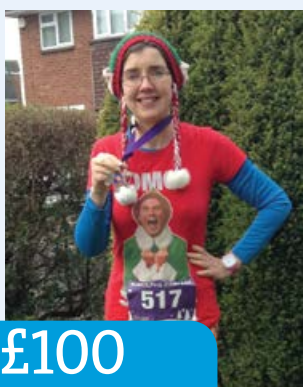


£2,300

Father and son, Richard and Rob Ravencroft also had had a wonderful day skydiving in memory of Richard's mother and Rob's grandmother, Brenda Ravencroft.

Reindeer fun?

PSPA supporter, Liz Lockhart ran the 7k Rudolph Rumpage in Painswick Beacon, Gloucestershire. She ran



through mud and over stiles, even through a field of cows which was a little scary!

£100

Proud Harvey



£274

A proud moment for Harvey Speight, as he handed over a cheque in memory of his granddad Brian Speight. The money had been raised from a coffee morning by Debbie Pointer and her colleagues at Parity Medical, Bromborough.

Coffee time

Pocklington Local Group organiser, Michael Shepherd held a Big Coffee Morning in February. Michael is a long-time supporter and fundraiser, and we thank him for all his hard work and dedication over the years.

£500

Send your fundraising pictures to:

Email: events@pspassociation.org.uk

...and running for funds

Here's Danny Foster in the Hull 10k last summer – in support of his mother-in-law, Ann Freeman, who lives with PSP.



£382

Penine – all the – Way

Lee Bhagat took on the UK's toughest and most brutal race to raise funds in memory of his father-in-law, Peter Teal. The Montane Spine Race takes in the length of the Pennine Way (all 268 miles) taking over seven days. Lee crossed some of the most arduous terrain the UK has to offer. He said: "The race was toughest thing I have ever done but loved every moment, despite the painful recovery!"



£300

Sweet enough



£62

Here is Leanne Philpott with her Nana and Grandad when she was little, and another with Leanne's son. How time flies! Leanne took part in Sugar-Free October to raise funds as her Grandad lives with PSP.

Howdy, partners!



£1,000

Julie Mitchell held a charity line dance in February.

"It was attended by non-line dancers too who all had a go and really enjoyed themselves," said Julie. "I had huge help from Kath Botta, who worked her little boots off to keep everyone on the floor all night by playing the music people wanted!" Julie's funds were raised in memory of her husband, Les.

Warwick lost!



£200

James Mabon and his Uni pals took part in a very unique event, the Warwick Lost! James and co were

blindfolded, packed into a van with no money, no phones, and with no idea where they were going. The challenge was to find their way back to Warwick as quickly as possible. James said: "We were dropped off at the Angel of the North and then it took us 21 hours to get back. We had to hitchhike and spent a lot of time sitting in service stations!" Top work, lads.

Climbing high

Friends Alex Bellew and Hetty Dawson climbed to the summit of Mount Kilimanjaro in February alongside their team of intrepid explorers. The epic trip was done in support of Alex's father, General Sir John Wilsey, who is living with PSP. Alex said: "It was MUCH harder than any of us imagined – we laughed, cried and staggered our way to the top, each of us fighting our own battles against altitude sickness and strong freezing winds. The generosity means so much to all of my family." Thank you so much to Alex, Hetty and the team for their amazing support!



£15,000

Coffee & chat

Janet Wardale held a coffee morning for her friends and family in memory of Janet's husband, Harry.



Over £350

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 or call 01327 322419.