

PSP Matters

Autumn 2017



Daring Debbie!

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Cover: Debbie Lister at the finishing line of the super tough Race for King where her dad was waiting for her. See page 27.

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

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

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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's been a busy few months here at PSPA and inside this edition of *PSP Matters* you'll see why.

There's news on research and some exciting developments - that may one day lead to treatments for PSP and CBD. You'll also be able to read about two young, PSPA-funded researchers who are promoting their work at international meetings.

Last year, we were delighted that so many of you took part in a survey to help us understand more about life with PSP and CBD. The results have now been analysed and on pages 10 -12 you can find out just what your answers told us. We'll be using the data collected to identify what we need to do to continue to deliver services that are relevant to the lives of people living with and affected by PSP and CBD. Thank you again, to all those who completed the survey.

Also inside this edition, there is useful information on how technology can aid communication, articles on preparing for a hospital appointment and also on taking supplements.

Of course there's the usual mixture of inspirational stories from our supporters and volunteers throughout the UK - without whom we really wouldn't be able to function. But we can do a lot more... so if you want to get 'on board' to raise funds or volunteer, please get in touch.

Finally, I'm sorry to mention Christmas when summer is just over, but for those who plan early (and those who don't) the 2017 card and gifts catalogue is enclosed. It has a selection of seasonal cards to suit all tastes and some well-priced gifts. All sold in support of the PSPA.

Thank you again for taking the time to read *PSP Matters*.

Andrew

Andrew Symons – Chief Executive

WORKING FOR A WORLD FREE OF PSP

PSPA-funded researchers present at international conference

Young researchers from PSPA-funded teams at UCL and Cambridge have recently been showcasing their work at a major international research conference.

THE 2017 International Congress of Parkinson's Disease and Movement Disorders took place in Vancouver in early June and was attended by leading clinicians and scientists from around the world, who discussed latest developments in the quest for improved understanding and treatments.

Dr Edwin Jabbari, our Sara Koe Clinical Research Fellow, presented some early results from his study at UCL, showing that a protein called Neurofilament Light Chain (NfL) in spinal fluid and blood may be able to predict the rate of disease progression in PSP.

This could potentially provide information that will give doctors and families the opportunity to plan ahead and put the most appropriate care and support in place. In addition, NfL can be used as a measure in future clinical trials. Importantly, Dr Jabbari has also shown a strong correlation between spinal fluid and plasma (blood) NfL levels, meaning that a blood test might be all that's needed rather than a lumbar puncture.

Dr Jabbari explains: "These are promising data. Further replication is required, but the fact that levels of spinal fluid and plasma NfL are so well correlated implies that plasma NfL may have a role in providing easily accessible early prognostic information."*

Meanwhile, PhD student Patricia Vazquez Rodriguez from Prof James Rowe's team at Cambridge University presented her impressive work on the role of neuroinflammation in PSP.

"We are so grateful to our donors and their families for making such a difference."

She used a special type of brain scan, positron emission tomography (PET), and brain tissue generously donated to the Cambridge Brain Bank, to show that the intensity and distribution of inflammation varied between PSP, Alzheimer's and healthy controls.

Patricia also demonstrated that the degree of inflammation was related to disease severity. Her results support the idea that inflammatory processes have a key role to play in the development of PSP and that suppressing this inflammation may be one possible route to treating the disease.

Studies like Patricia's that use brain images from living patients alongside *post mortem* brain tissue are complicated to perform but can be extremely effective. As Patricia told us: "Brain donations are just so important for research. We are so grateful to our donors and their families for making such a difference."



Dr Edwin Jabbari



Patricia Vazquez Rodriguez

Congratulations to both researchers! We are very proud to have had the PSPA logo displayed on the presentations.

*A more detailed description of Dr Jabbari's presentation can be found at www.neurologyadvisor.com/mds-2017/mds-2017-neurofilament-light-chain-predicts-progression-progressive-supranuclear-palsy/article/666774

Existing drugs step up in battle against neurodegenerative disease

Research published in April in the journal *Brain* and widely reported in the media showed that two existing drugs can block the death of brain cells in mice with neurodegenerative disease.

Scientists led by Prof Giovanna Mallucci at the University of Cambridge have demonstrated that trazodone, a licensed antidepressant, and 'DBM', a compound found in liquorice that is being tested in cancer, both stave off the demise of mouse brain cells by acting on a natural defence mechanism called the 'unfolded protein response'.

Many neurodegenerative diseases, including PSP, CBD and frontotemporal dementia, are characterized by the build up of tangled, or 'misfolded', proteins such as tau. The unfolded protein response is the body's attempt to deal with this by suspending protein production in the cell. However, the over-activation of this response in neurodegenerative disease may eventually lead to complete cell shut down and cell death.

Prof Mallucci's team screened many hundreds of existing drugs in the lab for their ability to reduce the unfolded protein response. They then went on to test trazodone and DBM in mice with gene mutations leading to the animal form of frontotemporal dementia. The drugs prevented the death of brain cells and the mice also improved in memory tests.

Prof James Rowe, a member of the team running PSPA's PROSPECT study and a colleague of Prof Mallucci's at Cambridge, said: "This is a very exciting



Prof James Rowe

breakthrough. There is still some way to go to show this is safe and effective in people with PSP, rather than mice, and to know when to treat people and at what dose. But, PSP is an ideal condition to test these drugs and we need a thorough clinical trial to establish whether they are of benefit for patients."

Prof Rowe also added a note of caution: "Even though trazodone is widely used in psychiatry and occasionally for symptom relief in PSP, it is not without side effects, including drowsiness and possibly some increased risk of falls, so I would recommend that it only be used under specialised supervision where clinically necessary or in a clinical trial."

New and updated resources

We have recently added some new resources to our comprehensive range of information for people affected by PSP and CBD.

General Benefits and Entitlements

This information sheet aims to provide people with an overview of the various benefits and entitlements, how and where to apply for them. Downloadable from our website www.pspassociation.org.uk/information-and-support/just-been-diagnosed/resources-for-diagnosed/ or if you prefer printed format contact the PSP helpline.

Getting the most from your appointment

A pocket reference guide with top tips to getting the most from your appointment. This useful resource comes in a credit card sized wallet, which fits neatly into your pocket or handbag. Can be ordered from the PSP helpline.

Updated information

Advance decision guidance notes for people living with PSP and CBD

Working in partnership with *Compassion in Dying*, we have now updated the information sheet, forms and guidance notes. Downloadable from our website www.pspassociation.org.uk/information-and-support/just-been-diagnosed/resources-for-diagnosed/ or if you prefer printed format contact the PSP helpline.

Guide to PSP and CBD for General Practitioners and the Primary Healthcare Team

Contact the helpline to order your copy.

PSP Helpline 0300 0110 122



Last few places available at our 2017 study day

Our 2017 study day, will be taking place on Wednesday 18 October at the Milton Keynes Christian Centre and is open to all health professionals with an interest in PSP and CBD.

THIS year's programme is 'PSP and CBD through patient and practitioner's eyes' and is aimed at the multidisciplinary team and will highlight best practice.

Last year over 150 delegates attended our study day in Newcastle and over 150 people have registered for this year's event. Feedback from those who attended the Newcastle event included:

"Absolutely brilliant – my knowledge was limited regarding PSP, but now feel confident about the differences between Parkinson's and PSP"

"The most interesting and enjoyable training I've been on in a long time"

To book your place on this year's study day www.pspassociation.org.uk/events/pspa-study-day



New diagnostic criteria published

A new set of clinical guidelines for the diagnosis of PSP has been published in the journal *Movement Disorders*.

The guidelines were developed by an international team of leading PSP experts, including PROSPECT principal investigators Prof Huw Morris and Prof James Rowe. Thanks to your generous support, we were able to contribute to the funding of this special task force for their extensive review of the literature and analysis of patient data.



The new guidelines will support neurologists in diagnosing the condition at an earlier stage and will help ensure that a wider range of symptom patterns will be recognised as PSP, reflecting the relatively recent discoveries of various subtypes of the disease. This means that more people with PSP should get quicker access to the most appropriate care and support. They could also be eligible to take part in future clinical trials, which generally demand that participants are in the early stages of the condition to give the trial drug the best chance of working.

Although the new diagnostic criteria are more complex, the expert task force believe that they should only take an experienced neurologist around 15 minutes to work through, and a web-based tool is currently in development to enable widespread implementation.

We are asking people to *Join Our Fight* against PSP and CBD

You may have seen our special magazine, *Join Our Fight*. The magazine aims to celebrate some of the stories behind the support we receive.

WE know the vast majority of our supporters and volunteers have their own personal experience of PSP and CBD. Every day they are using that experience to do amazing and extraordinary things to help others who are affected.

Chris Garrard was diagnosed with PSP at 66. His son Jon described the family's devastation and how fundraising gave them something positive to focus on. Jon said: "It didn't seem fair that Dad had been diagnosed with this horrible disease. I couldn't see a way to deal with it. The turning point came when my wife Emma said that being so down wouldn't help my parents and that I needed to find some positivity.



"Finding something positive in the face of PSP seemed impossible, but we decided to organise a Christmas craft fair for the PSPA. For the first time since Dad was diagnosed, I felt I was doing something constructive. It was such

a rewarding and happy thing to do. I liked how it made me feel, and that spurred me on to raise as much money as I could to help other people affected by PSP."

The Garrard family is just one of the many families turning personal experience into action to fight against PSP and CBD.

Across the UK there are many more, and it is thanks to them that we are able to fund more research into PSP and CBD than ever before, and continue to support families affected.

When her husband Dave Howarth was diagnosed with CBD, the news came as a complete shock to Cathy and their daughter Charlotte. It wasn't long after, the family started to fundraise. Cathy said: "Fundraising makes me feel good and it helps us focus on something positive. We really appreciate the help and support we get from the PSPA and we want to give something back."

Another inspiring person featured in the magazine is Elizabeth Birrell, who has supported the PSPA ever since her husband Ian was diagnosed with PSP. Elizabeth has raised £67,000. Elizabeth said: "When I first started fundraising I never would have thought I would have raised so much. I know there are so many charities to support and it is hard asking the same people to give all the



time. However, I have found that if you have a personal reason for supporting a charity, people want to help. Ian was a popular guy, so for many of our friends and neighbours, supporting my fundraising is a way to show how much they thought of him."

Through our *Join Our Fight* magazine we also

hope to inspire others to join us. The PSP and CBD community is a special one, made up of people living with the disease, carers, family and friends, alongside healthcare professionals and researchers. In turn, we also depend on the PSP and CBD community for its support. The larger and stronger our community gets, the more we can do for people living with PSP and CBD.

We want to encourage people to pass the magazine on to their family and friends who might be willing to help support our vital work. We know the people most motivated to help will be the ones who have seen the devastation caused by PSP and CBD.

Please contact the fundraising team on 01327 356132 or email events@pspassociation.org.uk. If you would like to request copies of the magazine to share with family and friends. Or you can simply share the link to the online version here www.pspassociation.org.uk/joinourfight

Awareness week 2017

A huge thank you to everyone who supported our *It's Not Parkinson's* campaign in May.

THANKS to those of you who completed our survey, we know that nearly half of people living with PSP received an incorrect diagnosis first, with 30% initially diagnosed with Parkinson's.

“Getting the right diagnosis, and getting it as early as possible, is vital to helping patients and families.”

Even after referral to a neurologist, more than a third of people with PSP waited over a year for a confirmed diagnosis, with 17% having to wait more than two years.

Early and accurate diagnosis is crucial to people getting the best care as soon as possible, with delays

leading to inappropriate medication and a lack of support.

That's why we worked alongside consultant neurologist Prof James Rowe to create a special animation, fronted by our Vice President Prof Sir Colin Blakemore, to highlight to neurologists, geriatricians and other specialists how they can easily identify PSP and put the right care in place.

Prof Rowe told us: “Getting the right diagnosis, and getting it as early as possible, is vital to helping patients and families. It helps people to make sense of what they are experiencing, to get started with the many ways to try to reduce symptoms, and to organise their essential healthcare and social support.”



CASE STUDY

LINDA Gray, 63 from Uxbridge was first diagnosed with Parkinson's in 2013. Two years later, she received a correct diagnosis of PSP. Linda said: “My symptoms continued to progress, but not in the way we expected with a Parkinson's diagnosis. When I was admitted to hospital, I was informed by another neurologist that I actually had PSP. To have got over the shock of being diagnosed with Parkinson's, only to discover, two years later, it was a different condition was terrible.

“I hadn't heard of PSP. For one brief moment, I allowed myself to hope that I had a condition that was not as bad as Parkinson's, one that was curable. Sadly, I soon came to learn that the diagnosis was worse, with no hope of a cure.”

How we took action:

Between you, you distributed over **1,000** awareness cards signposting healthcare professionals to our campaign animation.

We publicised the campaign via e-news to over **5,000** members of the PSPA community, including more than **2,300** healthcare professionals.

We emailed the animation directly to almost **350** neurologists and geriatricians who do not have regular contact with us.

There were over **1,000** visitors to our campaign web page during Awareness Week itself.

Our Twitter and Facebook posts on the first day of the campaign each reached over **40,000** people.



Our campaign featured on BBC *Look East* who interviewed Dianne Whitney, who is living with PSP, and her husband Phil about Dianne's experience of misdiagnosis. Prof James Rowe also explained why correct diagnosis is so important.

The animation has now been viewed over **2,000** times.



What we are doing next

OUR campaign will continue throughout the year as we target different groups of healthcare professionals, including geriatricians, physiotherapists, speech therapists and ophthalmologists, via social media and professional events. The British Geriatrics Society (BGS), the UK's professional body for geriatricians, has already supported our campaign by publishing a blog post written by our Helpline & Information Services Manager, Carol Amirghiasvand, highlighting the need for early diagnosis. The BGS shared this via Twitter with several thousand geriatricians and other healthcare professionals with a particular interest in elderly medicine, helping to raise PSPA's profile with this important group.

You can continue to request our special awareness cards to take to your local neurology department and to appointments with healthcare professionals. Please encourage your specialists to watch our animation and tell their colleagues about it.

What about CBD?

PSP may have been the focus of our 2017 Awareness Week but CBD deserves some attention too! We are currently developing new publications specifically for CBD, including material for healthcare professionals, and will be launching these later in the year.

Survey 2016



“I would like to see a great deal more advice for CBD sufferers in a nursing home about what support is available and how to access it”.

“It would be helpful if PSPA could publish a summary of all research, drugs trials etc.”

“Help making sure we are all getting the help we can and health professionals understand our condition.”

The experience and views of people living with PSP and CBD

THIS time last year we sent you our ‘Survey 2016 for people living with PSP and CBD’. The survey asked about different aspects of living with PSP and CBD, the services you receive and what you want the PSP Association (PSPA) to focus on.

We are extremely grateful to the 460 people who took the time to complete the survey. It has given us a fantastic amount of information about your experiences and the results will help us to understand where we should focus our future efforts and resources.

In this article, we share some of the findings with you, and explain how we are going to use them.

The diagnosis of PSP/CBD

We already know that receiving a diagnosis of PSP/CBD can be a long and difficult process, and the survey findings give us a clearer picture of who is affected and why it happens.

The survey shows that many GPs are not identifying symptoms early enough and therefore people have to wait too long to be referred to the neurology team. Only one in three of you were referred to a neurologist within three months of first seeing your GP about your symptoms. In fact, 31% were not referred for over a year.

Instead, many of you were referred to a range of other health professionals like physiotherapists, eye specialists

and geriatricians. Indeed, around one in ten people were seen by *at least three* other health professionals about their symptoms before they saw a neurologist.

Unfortunately 29% of you told us that you were wrongly diagnosed with Parkinson’s disease before a correct diagnosis of PSP/CBD was given.

Delays around diagnosis mean people are being prescribed the wrong medication and left with little or no support. PSPA will use these findings to raise awareness and educate health professionals across the NHS, including GPs, neurologists and geriatricians in the early diagnosis and care of people affected by PSP/CBD.

Satisfaction with health and care services

Following your diagnosis, most of you said you have been ‘satisfied’ with the health services you have received – particularly GP and neurology services. However, many of you want to receive specialist services that are not available; particularly eye specialists (20% say you want more help here), physiotherapists (16%) and counselling services (16%).

While 76% of you said, you felt you are receiving the care *you need when you need it*, one in five of you were critical about how quickly the system reacts when your needs change - and how well families and carers are supported.

Having a *named care coordinator*

seems to be a really important factor in the quality of care, but in our survey only two out of three (68%) of you said that you have someone in this role – and one in five (19%) would like this service. Moreover, over four in ten (43%) of you said that you were currently paying for professional care out of your own pocket.

We also asked you to tell us in your own words about your experiences of the health and social care system and what you would like to see change. PSPA will continue to build relationships with your local health professionals and local services to influence better understanding of the needs of those affected by PSP/CBD.

We can’t reflect all your comments here: but a couple of typical comments are below:

“More support around access and entitlements to benefits. I’m unable to work and have struggled to gain access to the relevant benefits.”

“We had 25 different carers in 79 successive visits. More consistency would help us and probably be more efficient for the agency, too.”

“When a need arises and is recognised it takes so long for anything to happen. Our funding application went in eight weeks ago – no news yet!”

continued overleaf

Preparing for your appointment

Top tips to get the most from your appointment

IT can be enormously frustrating to come away from an appointment feeling that the issues which concern you haven't been addressed or that you have been left with more questions than answers. Could preparing for the appointment help alleviate this? Our Information and Support team felt so and has produced 'Top Tips to ensure you get the most from your appointments.'



Rob and Sue Foulds

When Sue Foulds from South Yorkshire attended Prof James Rowe's specialist clinic in Cambridge the detailed preparation undertaken by her, her husband, Rob, and their daughter, Jenny, helped them gain the most from their appointment. Since Sue's diagnosis of CBD Rob has wisely kept a file of all Sue's medical correspondence. When Sue was referred to the centre in Cambridge he was able to compile a detailed history to take with them. As Rob explains: "Most of my working life I have dealt with professional people and most of these will acknowledge that they are not clairvoyant and so need to know as much as possible about, in this case, the patients they are meeting with."

A concise summary of the individual's initial symptoms, the progression of symptoms and the current situation is always helpful. Advising the professional on social circumstances can help too, for example, if a person lives alone, if their home is a bungalow or house, if they have family close by. Imaginatively Rob

included some information about how Sue's condition was impacting on him as Sue's main carer – both physically and emotionally. Rob talked about the loss of Sue's 'presence' and of the impact on his sleep pattern along with the physical efforts of providing ongoing care support.

"It's really helpful when patients come to clinic well prepared as it means the doctor can more easily understand what has already happened in the patient's journey and can spend more time in the consultation focusing on the things that are most important to them."

Keeping a diary showing how everyday living is affected can help professionals gain greater insight and understanding. Some professionals will be unfamiliar with PSP and CBD so taking PSPA literature might be a good idea.

Rob also wrote up Sue's medication regime for the team at Cambridge and says: "This was a useful exercise as the

team suggested some slight tweaks." Knowing what medication has previously been tried is helpful and could form part of the 'medical file' a family keeps and brings to an appointment. Cambridge based Neurologist Dr Richard Bevan-Jones says: "It's really helpful when patients come to clinic well prepared as it means the doctor can more easily understand what

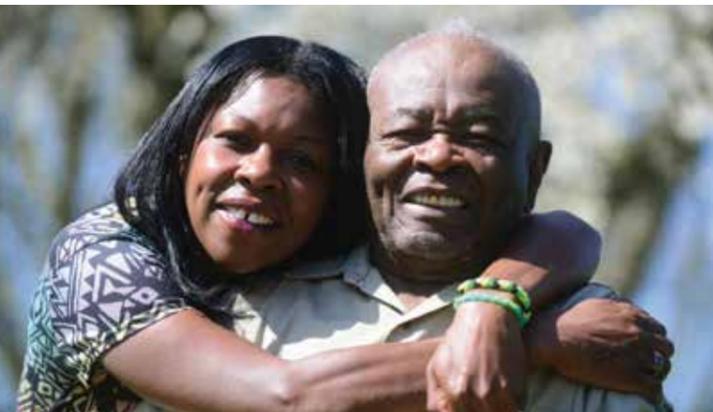
has already happened in the patient's journey and can spend more time in the consultation focusing on the things that are most important to them."

Taking a list of the professionals involved and their contact details, along with agreeing to information being shared appropriately, will ease communication between professionals and help ensure that the support offered is well co-ordinated.

Prior to the appointment try to ensure you know what the appointment is for and who you will see. If the venue is unfamiliar check journey times and parking. If possible take someone with you for support. Think about what your agenda for the meeting is and write down your questions. Ask about follow up actions and their likely time scale. Before you leave check that all your questions have been addressed.

For further information or support and copies of the mini guide contact the PSPA Helpline 0300 0110 122.

"Maybe more local groups offering support with group meetings. Giving us the chance to meet with people who are living with/carers of PSP. Offering first-hand experience or advice."



"Finding celebrities to champion the fundraising. Most of the funding comes from PSP friends and families. It needs to be spread further."



Your views on the PSP Association and its services

We also wanted to know what your thoughts were on our work at the PSPA and whether we could do anything differently.

Overwhelmingly, you said that your contact with PSPA has been helpful and the support we have given you is rated as good or excellent. For example, 52% said that the information you had received from PSPA was 'very helpful' and 35% said it was 'fairly helpful'

Our magazine *PSP Matters* is the most widely used PSPA service – over two thirds of you said you have read it, and nearly everyone said they are satisfied – particularly for the understanding it gives people of their condition and the sense of community it brings. Over half (54%) of you have used our helpline, and those who have accessed the helpline are

particularly likely to rate PSPA as useful overall. The helpline is also seen as one of our most important services. Nearly half of you place it in the top three PSPA services. It is very helpful to us to know how much you value this service, and your feedback helps us to raise money to ensure it continues.

Nearly half of you have been along to a *PSPA local group* (45%), but only one in five can make it along regularly. Most of you (86%) who have attended said that you were satisfied with the group, so we would like more people to be able to attend. You told us that the main barriers are that it's too far to travel and so we are always looking for opportunities to increase the number of groups and make them easier to get to.

We asked for your views on what the PSPA should focus on in future. Above all, you want us to continue providing

information and support (57%), and to increase knowledge of PSP/CBD among health professionals (54%). The third most important aim is to fund and promote research into causes and treatments of PSP/CBD (41%).

Finally we asked you to tell us how we could improve, and we have been reading through your comments. We will use the information we have gathered to plan future services and develop the next phase of the charity's development.

The information you gave us has been extremely helpful and we will use it to influence health services, improve what we do and raise more funds for our work.

If you would be interested in a more detailed report of the findings then please contact:

Telephone: 0300 0110 122
Email: helpline@pspassociation.org.uk

How using technology can aid communication

Communication is part of our identity. It involves the sharing of thoughts, wishes, emotions and needs. Maintaining a means of communication, even if speaking becomes difficult, is obviously important. *This is Karen's Story...*

KAREN Surtees from Norfolk is living with a diagnosis of CBD. She and her husband Mark have worked hard, alongside relevant professionals, to maximise Karen's ability

to communicate, adapting her means of communication as her CBD has progressed. They are currently working with the Communication Aid Service for the East of England (CASEE), which is one of 15 specialist AAC (Augmentative and Alternative Communication) hubs in England. These centres are funded by NHS England, to provide 'an equitable, specialised service

for those with complex communication needs.' CASEE covers Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk and Suffolk. Karen was referred to them by her speech and language therapist, and she and Mark have been delighted with the support they have received.

An individual's ability to communicate can be impaired in PSP and CBD due to a number of factors including speech problems (because the areas of the brain controlling the movement of the

tongue, lips and throat are affected), and cognitive issues that impair the ability to process information, assess it, sequence thoughts and think through a response. Restricted movements of the eye, facial and/or neck muscles, and the muscles of the hands, is also an issue.

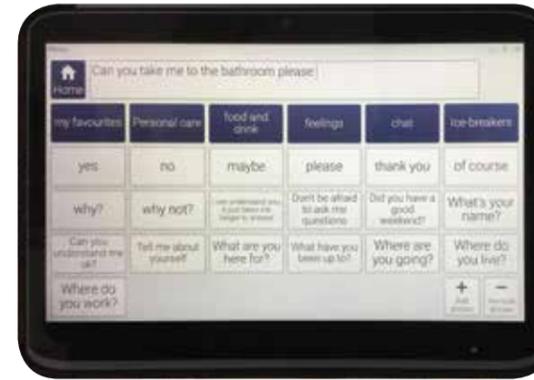
Prior to the involvement of CASEE Karen's speech and language therapist had worked through various solutions. Initially she gave Karen a simple Qwerty keyboard and the couple made a crib sheet that they perched on the back of the keyboard with key words/phrases on (for example, hot/cold, thirsty, toilet, tissue).

The speech and language therapist then showed them ProLoQuo2Go, which is a communication app (for ipads, iphones and ipod touch devices) that provides a voice for people who have difficulty speaking. Mark purchased this but they discovered it requires reasonable manual dexterity and this became problematic for Karen.

Karen then tried Predictable – an app-based voice-output communication aid that converts text to speech. This they found quite cumbersome and slow.

An eye-gaze control communication system was also tried. However, as Karen has limited head control, and her eyes often involuntarily close, this was difficult to use.

Following assessment by Charlotte Smith (Speech and Language Therapist) and Alex Kruczynska (Occupational Therapist) from CASEE, Karen was provided with a Grid Pad 13 Communication System with Grid 3 software from Smartbox and a Rehadapt floor mount and finger switch. Karen operates the system via a button that sits between her finger and thumb. The button is attached to Karen's finger



with Velcro and she uses her thumb to operate it. The system not only allows her to communicate (it has speech output) but also acts as an environmental control, meaning she can do things like turn the TV on, or switch the lights on and off, or play her talking books. Karen herself says: "It's very frustrating when your brain is working and you cannot get across your thoughts and wishes. Grid 3 is slow to use because of my condition but to me it is a godsend and gives me some of my independence back again."

There is a very useful alarm icon which Karen can use to call for assistance and which Mark can hear anywhere within their open plan home. Currently it does rely on Karen's ability to use her finger and thumb so Mark has asked the CASEE team to investigate other methods of controlling the system should Karen lose manual dexterity in her right hand.

Referrals to centres like CASEE can be made by local speech and language therapists, or by other health care professionals. They then provide specialist advice on both high and low tech communication aids and strategies. CASEE staff explain: "Following specialist multi-disciplinary assessment,

we may provide communication equipment on short term loan to trial or make recommendations on how to develop suitable low tech communication resources. If a short term loan is successful then the client keeps the device on long term loan - for as long as they need it - supported by their local therapy team."

CASEE's assessment aims to explore a client's individual abilities and communication needs to determine the best communication solution for them. "We discuss what they want to communicate and with whom, and assess how they can physically access technology. For

efficient communication, it is important to find the body movement that is most accurate, efficient and repeatable- and least effortful for the person. We also assess the impact of sensory needs such as visual or hearing difficulties. Finally, we explore the person's motivation to communicate and their familiarity with technology."

"It's very frustrating when your brain is working and you cannot get across your thoughts and wishes.

Grid 3 is slow to use because of my condition but to me it is a godsend and gives me some of my independence back again."

Charlotte and Alex from CASEE know that many clients with PSP and CBD have difficulty accessing communication aids (including those using eye gaze technology) due to their visual difficulties. "We have also

continued overleaf



found that the point at which people with PSP and CBD start to lose the ability to speak verbally, may coincide with a decline in cognitive ability. At this point learning new tasks can be particularly problematic and frustrating. Unfortunately, most communication technologies and techniques are unfamiliar and therefore difficult to learn. Using a switch for communication can be particularly challenging as it involves several skills being learnt at the same time. These include scanning, planning a movement and timing in order to be successful. However, if a switch option is identified, it enables the person to select

letters, or symbols, on a screen in order to communicate thoughts, feelings and needs. It provides a really good option for those that can use it."

Charlotte and Alex go on to explain: "Our experience has often been that low tech communication techniques, such as use of partner assisted scanning of symbol or alphabet charts, or the use of auditory scanning books, are much more successful. These enable the person to interact using a person to scan instead of a computer. This person-to-person approach enables the communication partner to support the person's communication in a

more intuitive and sensible way than a computer can. This results in more successful communications which are less frustrating and slow."

Karen and Mark have wisely taken a very open and proactive approach to addressing Karen's communication issues and have sought advice prior to the need arising. Mark stresses the importance of sharing information and ideas with others. He has particularly valued talking to other members of their local group in Norwich.

If you have any queries or need support to access services please contact the PSP Association Helpline on 0300 0110 122.

Family & Friends Day

Another successful Family and Friends Day was held in Crewe, on Saturday 13 May.

PEOPLE living with PSP and CBD, families and friends came together to enjoy an informal day in a relaxed setting.

Dr Richard Bevan-Jones spoke about the management of PSP and CBD, as well as his work at Addenbrooke's Hospital and the important

role of the multidisciplinary team. This was followed by the opportunity to put questions to our panel of health professionals, which included a physiotherapist, occupational therapist, speech and language therapist, community matron, dietitian and day hospice manager.

Following lunch, delegates were able to attend workshops on Healthy Eating and Caring for the Carer. The day ended with an uplifting performance from members of a local rock choir.

Bob Gorman, who has PSP, joined us on the day, with his wife Pat. Bob told us how much he enjoyed the question and answer session from the panel of health professionals. Pat went on to say "How nice it was to speak to other people in the same boat as us."

"We both enjoyed attending the afternoon workshops especially the one on Healthy Eating where Bob also asked a few questions. Everyone seemed to enjoy the local rock choir and it was a nice end to the day"



Dr Richard Bevan-Jones

John Holden was the lucky recipient of our 'PSPA Golden Ticket' and took home a PSPA goodie bag

To supplement or not to supplement?

WHETHER or not we are living with a health problem, many of us consider taking nutritional supplements at some point in our lives.

When facing PSP or CBD, with no drugs available to slow the progression of the condition, it's particularly tempting to try something that can be bought off the shelf in the supermarket.

Co-enzyme Q10 is a supplement that has received quite a lot of attention from the PSP and CBD community and is occasionally the subject of calls to our helpline. It's expensive stuff however! So is there any evidence to support its use in PSP and CBD and importantly, is it safe?

What is Co-enzyme Q10?

Co-enzyme Q10 is made within the body and can be found in every cell, including nerve cells. It is a bit like a vitamin and is naturally present in various foods such as meat and fish and, in particular, liver, kidney and heart. It is a key component of the cell's system for turning glucose and oxygen into energy. It is also functions as an antioxidant, mopping up harmful molecules.

Why might it help?

There is some evidence that PSP might involve problems with energy metabolism in certain parts of the brain. Supplementary co-enzyme Q10 may be able to support the energy production process and help to reduce any deficits.

What's the evidence?

Researchers have conducted some clinical trials of co-enzyme Q10 in PSP, albeit on a relatively small scale.

In 2008, German researchers published data suggesting that over the course of a 6 week study involving just 21 participants, co-enzyme Q10 supplementation improved energy metabolism in the brains of people with PSP. Study participants who took the supplement also showed a slight improvement in symptoms compared to those who took a placebo.

A more recent American trial involving 61 people with PSP showed that those who took 2,400mg of co-enzyme Q-10 per day for 12 months experienced slightly less deterioration than those who took placebo, but this difference was not statistically significant, meaning that it could have happened by chance. However, the researchers did note that many of their participants were at a relatively advanced stage of the disease due to delays in diagnosis and have suggested that the supplement might have had more chance of making a difference earlier in the course of the condition. They also wondered if there might have been a more noticeable difference between the co-enzyme Q10 and placebo groups if participants had been followed up for longer than a year.

Overall, there is no strong evidence of a positive effect of co-enzyme Q10 in

PSP, although some moderate benefit can't be completely ruled out. Studies of its use specifically in CBD are lacking.

Is it safe?

Studies of co-enzyme Q10 supplementation have shown it to be safe and well tolerated by people with PSP with mainly minor, self-resolving side effects such as stomach upsets and headaches.

How much does it cost?

Possibly the greatest risk from taking co-enzyme Q10 is a dent in your wallet! A quick internet search reveals a wide variation in pack sizes and supplement strength, so consider both when you buy. Some products provide only 50mg of co-enzyme Q10 per capsule or tablet, others as much as 300mg. Quality may also vary so use a reputable supplier.

It's worth bearing in mind that the American study mentioned above involved doses of 2,400mg per day, which is probably higher than the recommended dose on most packs.

Always speak to your GP or neurologist before taking any supplement, and particularly if you are considering taking more than the pack suggests.

For more information, contact our Helpline: 0300 0110 122 or helpline@pspassociation.org.uk

Spreading the word

We are pleased to introduce you to our first newly trained Education Volunteers

FOLLOWING the completion of some online training which includes planning and presentation skills, Janet Walch, Roger Bowley, David Oakley and Sarah Marshall were put through their paces with a day at the office here in Towcester. During the day they all prepared and gave presentations to each other as well as staff. With Val Cole and Jenny Knight, completing their training on the 12 July, we have a great start to building this new team.

They are a highly motivated group who are keen to get out and raise awareness of PSP and CBD with nursing and care homes, hospices as well as the wider community. Since completing their final training day we have already had positive responses to their offers to go along and talk to staff, and making more people aware of what it means to live with PSP and CBD and where to get more information to support them as they care for those affected.

We are of course looking to expand this service throughout the UK so if you would like to help us educate and raise awareness please get in touch with the volunteering team for more information. Telephone 01327 356134 or 01327 322416, Email volunteering@pspassociation.org.uk

"I want other people to know about PSP and CBD to make their job easier and benefit the people they care for. The training confirmed that this was a great way for me to do something using my knowledge and skills with a different audience, and the feedback I got built my confidence."

Sarah Marshall

"I am passionate about making people more aware of PSP and CBD, and particularly helping carers to understand both the physical and emotional impact on those affected but also the families. It is also a way of using my experience and skills to make a difference. I gave my first talk this week which was well received and have been invited back to talk to other staff at the care home."

Val Cole



"I just realised there was such a need. After my training, I spoke to the Care Manager at a sheltered housing complex where there was a man living with PSP. Her response was that 'any information we can get about PSP is valuable. If we have to call paramedics, it is so helpful to be able to pass on information and give them some information about the condition' so I will be speaking to all of the care team starting in September."

Jenny Knight



Hello and goodbye

SADLY, we must say farewell to Ros Gardiner who has been our stalwart supporter in the North East for many years. She not only ran the Newcastle group but also volunteered with our evening helpline service. Huge thanks to Ros, who is stepping down from

both roles. The good news is that our Newcastle group will continue with group member David Sanderson at the helm. Welcome David!

WELCOME also to new local group volunteers Tracey Plant, Pat Hamblyn, Andrea Solomon and Carol Johnston who have signed up as Local Group Coordinators during this

year and also to Jim Bruce who will be helping out with the Ayrshire group.

HENRY Scutt joined us earlier this year as a volunteer Support Worker and our six new Education volunteers Janet Walch, Roger Bowley, David Oakley, Sarah Marshall, Val Cole and Jenny Knight will be spearheading our newest volunteering project.

PSPA volunteers reach 100!

For the first time in its history, PSPA has more than 100 volunteers giving their time to the Association

FROM Aberdeen to Devon and Northern Ireland to Norwich, 120 volunteers have signed up to help us extend the services we offer to people affected by PSP and CBD.

And the ways they can get involved is growing too, with our new Education and Awareness role which was launched earlier this year.

As we continue to support existing volunteers and recruit new ones we hope you will join us in thanking all our volunteers for their dedication and inspiration.

Now the challenge is on to hit the next milestone – 200 volunteers!



Fiona McLaughlin and Doris Mason – Local Group Volunteers Our representatives in Northern Ireland, dynamic duo Doris and Fiona run the Belfast group

Rakesh Kumar – Local Group Volunteer

Multi-skilled Rakesh is not only a Senior Physiotherapist, he also runs our North Wales group, offering the occasional chair-based yoga session too!



Roger Bowley – Education and Awareness Volunteer

Herts-based Roger is one of our newest recruits, helping to lead the way with this exciting role



Alison Wood – Local Group Volunteer

Long-term volunteer Alison welcomes members in the Aberdeen area to regular meetings

Chloe Cripps - Support Worker

Chloe joined us right at the beginning of this volunteering project and offers support to people in the Bucks area



Paula Glynn – Admin Volunteer

Paula is our super-efficient office volunteer, helping out every Monday at PSPA head office



Doreen Walker – Helpline Assistant

Doreen is part of our dedicated band of volunteer helpline assistants, giving her time to offer a listening ear to anyone ringing the service between 7-9 weekdays



Help us grow. Join us now

Contact Wendy or Nicola on 01327 322416 or volunteering@pspassociation.org.uk to find out how you can get involved. Visit the volunteering section on our website for more information: www.pspassociation.org.uk/get-involved/volunteer-with-us

Local groups roundup

Northamptonshire



RELAXATION was the key message from the Northamptonshire IAPT (Improving Access to Psychological Therapies) Service when they paid a visit to our Northampton group.

Lee Johnson, Clinical Manager, and Kay, a peer support worker for the service, spoke to the group about the services available in their area.

Volunteer group coordinator, Val Cole, said: "Everyone was very enthusiastic about it and asked lots of questions."

Kent



OUR Kent group had a fun afternoon planting patio containers at their meeting last June. Group Coordinator, Sarah Marshall, said: "It was all washed down with afternoon tea and cake. Thank you to Jules (from PSPA Helpline Team) for saying a few words and offering support to our members."

South Oxfordshire



CONTINUING our successful collaboration of researchers and local groups, Dr Chrystalina Antoniadou visited our South Oxfordshire meeting earlier this year to talk to members about the OxQUIP study. Find out more about OxQUIP here: www.pspassociation.org.uk/research/take-part-in-research/others

Gloucestershire

VOLUNTEER Lesley Flannagan grabbed the opportunity to get vocal when she was invited to give a talk about PSP at a local care home.

Former nurse Lesley, who runs our Gloucestershire group, spoke to staff at The Orders of St John Care Trust Nursing Home, Millbrook Lodge, Gloucester, after one of her group members suggested the awareness raising speech.

Pictured here with Care Home Manager, Robin Wilmott, Lesley said: "I spoke to 10 health care professionals about PSP and what living with PSP could be like. It was very well received as was their question and answer session at the end. It was a very rewarding afternoon. Here's to the next time!"



New groups

Blooming Scotland: The number of local groups in Scotland is growing!

OUR Specialist Care Adviser for Scotland, David Mills, held a series of events in various locations across the country earlier this year. He invited people along to hear a talk on research, letting people know about the work and services of PSPA and an opportunity to talk about their own experiences. As part of these discussions those attending expressed an interest in meeting up again and forming a local group.

Wendy and Nicola followed this up by organising and going along to a further meeting with the aim of getting a local group off the ground.

In **East Kilbride** three volunteers agreed to share the tasks of running a local group. Kirsty Gemmell, Etta Kennedy and Christine MacLeod are holding a monthly meeting in a local hospice.

BUT it's not only Scotland that is blooming with at least three more new groups launching south of the border this year.



Eastbourne has joined Worthing and Poole in offering people living along the south coast a chance to meet up and chat in welcoming surroundings. Pat Hamblyn got in touch with us earlier this year to volunteer as Group Coordinator and the first meeting, held in May, was a great success with 16 people coming along to meet others and find out more about PSPA. Meetings continue to take place on the first Wednesday of every month at the Sunrise of Eastbourne Care Home, 6 Upper Kings Drive, Eastbourne from 2-4pm.

The same format was followed up in **Ayr** and now Carol Johnstone and Jim Bruce are holding their monthly meetings at the Education Centre in the Ayrshire Hospice.

We wish the new groups, volunteers and all those attending every success. If you would like to attend any of these meetings full details can be found on our website at www.pspassociation.org.uk/information-and-support/living-with-bsp-cbd/your-local-group/ and in the insert leaflet with this magazine.

You will be sure of a very warm welcome and have the opportunity to share your experiences, find information and support as well as sample the tea and cakes on offer.

Following a successful meeting in **Edinburgh** look out for a new group here too!

Moving up country, Tracey Plant, whose mother lived with PSP, has launched a group in **North Birmingham** in July with future meetings taking place on the third Friday of every month at the Harvest Fields Centre, Sutton Coldfield.



The North East network is also growing with the **Sunderland** group holding its first meeting on 30 June. Volunteer, Andrea Solomon, who lost her father to PSP, welcomed the new members and said: "It's lovely to be able to support others and everyone agreed it went well". The Sunderland group meets every other month at Bede Tower, Burdon Road.

Finally, plans are afoot for a group in **Carlisle** and we hope this will be up and running very soon.

For more details about all our local group meetings see the leaflet included with this magazine.



Forthcoming events

2018 Sneak Peak!

WANT to know a secret? Whisper it quietly, but you can now secure your spot at some amazing events in 2018. Join 30,000 cyclists at RideLondon – Surrey 100, run the streets of the capital at the British 10k, take on the mountains of the Brecon Beacons and the Peak District at Trekfest, or even head off on your own overseas adventure!

Santa Run

THE days are getting shorter now which can only mean one thing: Christmas is just around the corner! It's time to don the Santa suits and join hundreds of others at the annual Santa Run in Victoria Park, London, on 3 December. The Santa Run is such a great day whether you are a festive lover or a bit of a bah humbug! So gather a big group of family and friends, and join us for a jolly good time.

events@pspassociation.org.uk
01327 356132



London Marathon 2018

PLACES are still available for next year's London Marathon held on 22 April, but be quick! Places are sure to be snapped up in the coming weeks, so contact us now to secure your spot at the world's most-famous marathon.

events@pspassociation.org.uk
01327 356132



There are lots more events to join, so check out our fundraising page on our website for more info.

www.pspassociation.org.uk/fundraising/events
events@pspassociation.org.uk
01327 356132

Laura Hudson's Big Adventure

In March this year, Laura Hudson took on the epic challenge of cycling from Vietnam to Cambodia, and she took our very own Hope the Bear along with her!

THE 400km ride took her through rice fields, past ancient temples, and down muddy jungle trails, something that Laura relished. She said: "It's a trip that I am struggling to put into words when people ask me. It was such an incredible journey, filled with stunning scenery, amazingly friendly people everywhere, interesting "roads". I've wonderful memories full of emotion – I had tears in my eyes as soon as I saw Angkor Wat."

Laura started her journey way back in 2016, and it was a journey that involved some truly amazing feats of endurance. Laura took part in multiple

Tough Mudder events, and cycle rides spanning hundreds of miles, including the famous Coast to Coast ride, and even had the time for the odd cake sale! All this was in preparation for Vietnam to Cambodia, and to raise funds in memory of her Grandad Poppa. In total, Laura raised over £4,000! It was an emotional experience for Laura, and she certainly felt this at the end of her journey. "All the emotion of this 16-month fundraising/ training journey and doing it for my

Grandad Poppa all just came out at once!" So has such a tough and arduous trip put Laura off from another adventure? "I have to be honest, I was ready to do it all over again after one day of resting!"

Thank you, Laura for your quite incredible efforts!

Laura is a true inspiration, and you too can take on Vietnam to Cambodia, or another overseas adventure to support PSPA.



Go create memories!
events@pspassociation.org.uk
01327 356132
www.pspassociation.org.uk/fundraising/events/overseas-adventures

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...



Now that was a memorable summer! I loved the sunshine, the strawberries, the picnics, not to mention all those pesky flying ants at Wimbledon. Some animals eat them, but I was quite happy with my cucumber sandwiches, trifles and Pimms thank you very much.

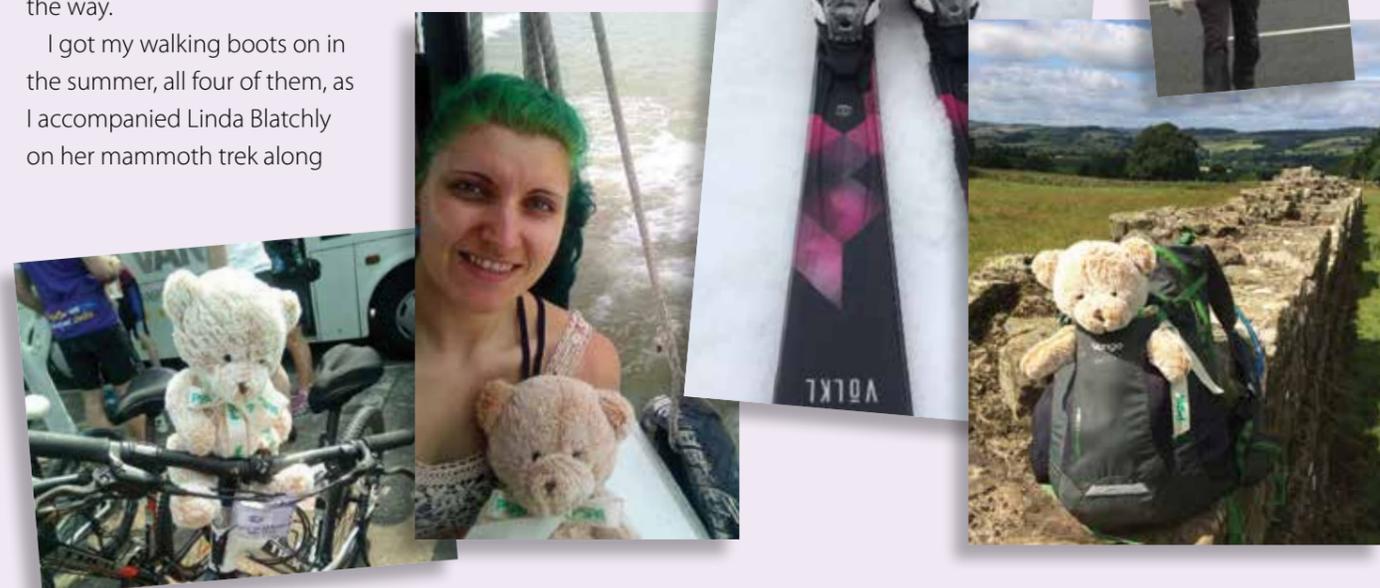
It was a busy summer for PSPA too. It all started with a very successful Awareness Week back in May, before our amazing supporters took on events such as RideLondon-Surrey, the British 10k, the Superhero Run, Trekfest, and climbing Ben Nevis. Phew! Lots of others went on their own adventures and if they could run, cycle, jump, trek, walk, eat, bake, fly, and swim for PSPA they did it! A change in season doesn't stop the fun though, and soon people will be off running the Great North Run and the Santa Run. Time to dust off the bobble hat.

I also went on a few trips myself, and they could not have been more different. I went on an epic cycle from Vietnam to Cambodia with Laura Hudson, and then went skiing with my pal Jake Arkell in Austria. It was bit nippy but luckily my skiing skills are red hot. Plus there's always time for a hot drink along the way.

I got my walking boots on in the summer, all four of them, as I accompanied Linda Blatchly on her mammoth trek along

Hadrian's Wall. Together we braved the elements, and we had a fair few thrown at us. Rain, sun, wind, as well as big climbs and sharp descents. Linda was extra brave; she attended her father's funeral the day before her departure. Linda said: "Not going to lie, there were a few tears at the end. Mum had carnations at the crematorium for people to leave on Dad's coffin, but we took a couple with us to mark the end – both of the walk and laying Dad to rest." It was a special journey and I am very thankful to Linda for taking me along.

So here's to winter. Will skip hibernation again this year as there are just too many parties, too much food, and too many people to meet. **All in a day's work for a bear.**



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

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!

Runs for Fun-ds...



£250

Clair Hurst from Wiltshire ran this year's Bath Half Marathon. "It was a great day with a lovely atmosphere and lots of support from hundreds of spectators. An experience I will remember!"



£1,000

Fiona Breslin and her family took on the Great Manchester Run in May and had a wonderful time on a day of glorious sunshine. There was even a glass of prosecco waiting at the end! This was just one of the fundraising events undertaken by the Breslins.



£655+

For Marc Warburton from Gloucestershire the Spring Bank Holiday was all about the Edinburgh Marathon Festival – 26.2 miles – **done ✓**



£500

"I did it! It was a great event and am super-chuffed with my time!" said Lisa Rosier, also from Wiltshire as she also crossed the line of the Bath Half Marathon.



££££

Super fundraiser and supporter, Sian Barlow, ran the Hackney Half Marathon in April, almost a year to the day that she will be running the London Marathon in 2018! Best of luck for next year!



£200+

Julia Roberts completed the Nottingham 10k in May. She said: "I achieved my best time of 1hr 15mins and 8 seconds! I am thrilled to bits with the amount raised."

Amongst the flowers

Anne Bass held a garden party in May in memory of her husband, Ken. It was a beautiful day with lots of cakes!



£350

Best foot...

The beginning of June saw the year's first 'Trekfest' in the Brecon Beacons. "We walked for 13 hours and 38 minutes which included a very stiff climb of 886 feet to the peak of Pen Y Fan," said Kathy Weston. "It was, without doubt, the most gruelling thing I have ever done!"



£££s

Double challenge

Richard Robinson was on home ground for the Two Castles 10k run (from Warwick to Kenilworth castles) but ventured south for the 90km London to Brighton cycle! Of the bike ride, Richard said: "The event was great, but a bit hot! I left Clapham at 6:45, arriving in Brighton at 11:15 just before the real heat of the day! I managed to pedal all the way up Ditchling Beacon - 815ft climb in 1 mile. Most people walked!"



£200+

Ready to ride

In preparation for RideLondon - Surrey 100 and Velo Birmingham, Darran Gurr held a fundraiser at work for his chosen charities, including PSPA.



£££s

JUMP!

Emma Veitch took to the skies earlier this year for a parachute jump.



£600

Pedal power

Richard Jones conquered the White Horse Challenge - cycling 150km and taking in some serious climbs!



£1,350

A team of intrepid cyclists, including Lancastrian, Sam Williams, conquered the iconic 'Coast to Coast' cycle back in May. "We enjoyed a variety of weather conditions including hail, thunderstorms and sunshine!" It took the team around six hours to complete the route.



£1,000

To the top

Lizzie Townsend from Gloucestershire, climbed Snowdon earlier in the year. Lizzie said: "It was hard work and a bit damp to say the least but we had an amazing time! More importantly, I have raised over double my target so I am super happy!"



£200+

Is Mary there?

Betty Peers held her very own 'Bake Off' back in March. *Those macarons look very tasty...*



£400

Super tough!

Debbie Lister took part in the super-tough Race to the King in the summer - a gruelling 53.5 miles of steep hills and rough terrain! Debbie said: "I did it in a time of 9hrs 49mins 12secs which made me 9th overall female! It was super challenging tackling some of the steep hills but knowing I was running it for dad, all the amazing support I have had and the fact that he and my awesome family were waiting for me at the end completely drove me through!"



£3,500

Send your fundraising pictures to:

Email: events@pspassociation.org.uk

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.