

PSP Matters

Summer 2016



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Cover: Fundraiser Rory Cunningham is greeted by his proud son after completing the 2016 London Marathon

The PSP Association

The PSP Association is a registered charity offering support and information to people living with Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD), while funding research into treatments and ultimately a cure for these conditions. We rely entirely on donations to fund our work. As PSP and CBD are very similar, we often use 'PSP' as a shorthand for both.

The views expressed in *PSP Matters*, published four times a year, are not necessarily those of PSP Association and therefore products and services advertised or promoted should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise. *PSP Matters* is available as a pdf and can be downloaded from our website. 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
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www.pspassociation.org.uk

www.facebook.com/pspassociation

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



So much has happened since spring *PSP Matters* it's been a struggle to fit everything in to this edition.

TeamPSPA once again triumphed at the London Marathon in April (see pages 24 and 25). This year we had 72 runners, all with their own personal motivation for taking part but sharing a single goal – to raise funds and awareness for PSPA.

It was an incredibly uplifting day with so many people achieving personal goals while raising thousands of pounds to support our work. There was a wonderful buzz at our post-event party, where jubilant runners celebrated with their proud families and friends, volunteer flag wavers, cheerers and support crew.

We were excited to unveil our new volunteering recruitment film in June (see pages 12 and 13). The film not only reflects how much our volunteers give to PSPA but the benefits they get in return. We rely on our volunteers for our ongoing success and we are grateful to you all.

Awareness Week was fantastically well received by our PSPA community with hundreds of you taking our PSP Red Flags action. This campaign demonstrated what can be achieved when we all pull together and how a simple action can make a big difference. Read our special feature on page 7.

With summer finally upon us, I know many of you are busy planning fundraising activities. If you need some inspiration there are plenty of ideas inside, including details of our first summer fundraising week. However you choose to support PSPA, thank you and good luck.

Fergus Logan, Chief Executive

WORKING FOR A WORLD FREE OF PSP



American author visits PSPA

WE were delighted to welcome American actress, author and CurePSP spokesperson Kathryn Leigh Scott to our Northants head office with her new book. *Last Dance at the Savoy: Life, Love and Caring for Someone With Progressive Supranuclear Palsy* is Ms Scott's personal account of caring for her husband. It is available from bookshops and Amazon with a percentage of royalties going to US-based CurePSP.

Spectacles on view in museum

A simple yet highly effective piece of optical technology that is used by many people with PSP is on display in Scotland's most visited museum.

We are pleased to have been able to donate a pair of prism spectacles to the National Museum of Scotland in Edinburgh, where they feature in the new 'Technology by Design' gallery. This is just one of ten new galleries created as part of a multi-million pound transformation of the museum, with the new displays aiming to champion excellence and innovation to inspire the scientists, engineers and designers of tomorrow.

People living with PSP often

Cognition guide updated

WE are reviewing and republishing our booklet, *A Guide to Cognition in PSP and CBD for the Primary Healthcare Team*. This is the third and final booklet to be republished in our suite of information specifically aimed at health and social care professionals. We also publish *A Guide to PSP and CBD for Occupational Therapists*, and *A Guide to PSP and CBD for GPs and the Primary Healthcare Team*.

These publications are available free of charge from our helpline, email helpline@pspassociation.org.uk or phone 0300 0110 122.

They are also available to download from the professionals section of our website www.pspassociation.org.uk



Seeking your views

IT is important that we regularly review our information and support services to ensure they continue to meet the needs of people living with PSP and CBD and those who care for them.

To this aim we have recently sent a survey to all those living with PSP and CBD with whom we are in touch.

Please complete the survey and

return it to us if you are able. By doing so you will make a valuable contribution to our work. The findings will help us to understand how PSPA makes the biggest difference for those living with and affected by PSP and CBD, and enable us to identify any areas where we can improve our support services in the future.



to see if we could offer any items that would easily tell their own story from the display case. The glasses will appear alongside iconic scientific artefacts such as Dunlop's first pneumatic tyre and Dolly the cloned sheep.

For more information about prism glasses and to request a pair, please contact our Helpline: 0300 0110 122 or helpline@pspassociation.org.uk

New specialist clinic launched

A new clinic has been set up for people living with PSP and CBD in Dorset, Hampshire and Wiltshire.

THE clinics will be run by Dr Luke Massey, who works in Poole and Dorchester, and Dr Boyd Ghosh who works in Southampton and Salisbury. Both carried out PhDs in PSP, CBD and Multiple System Atrophy (MSA). They feel strongly that although there is currently no treatment that will cure the diseases, there is still much that can be done to support patients.

Dr Ghosh said: "It is important that those with PSP and CBD have a timely diagnosis and support throughout the disease.

"The care and expertise from many professionals is key to improving the quality of life for patients. We hope that our clinic can contribute to that.

"Although patients may be referred to many agencies, such as a community physiotherapist or Parkinson's nurse, they may not always have a great deal of experience with these conditions. Our specialist clinic will enable members of the community team to 'sit in' the clinic to learn more about the diseases, while at the same time forging links with the clinic."

It is also hoped to link the clinic with palliative care services in the future.

Dr Ghosh explained: "Palliative care services are traditionally thought to be for end of life care. However, the service has changed enormously and now has the ability to help people earlier in their illness. It is hoped that with time the clinic will establish links with palliative care teams in order to provide as much support as possible to our patients."

"The care and expertise from many professionals is key to improving the quality of life for patients. We hope that our clinic can contribute to that."

As well as clinical support, the clinic will take an active role in research. The clinic is part of our PSP Research Network and will be keen to recruit willing volunteers.

Dr Massey said: "By setting up this clinic we hope to both disseminate advances in our understanding of these rare



Dr Luke Massey



Dr Boyd Ghosh

conditions and make use of the expertise in symptom management already developed throughout the region and nearer to patients' homes. We also hope that it will enable us to develop our own research programme and contribute to those of the research networks".

The new clinics are based in the Royal South Hants Hospital in Southampton on the second and fourth Friday of the month.

Anyone interested in attending should speak to the hospital doctor who manages their condition to ask if a referral would be appropriate. Those with an established diagnosis of PSP or CBD who are not under regular follow up can ask their GP to refer them directly.

Study day will highlight best practice

MORE than 180 health and social care professionals have already booked for our 2016 study day. The free event will take place at Newcastle United Football Club on 19 October and is open to all professionals with an interest in PSP and CBD.

The event is now full but we are taking registrations for our waiting list at www.pspassociation.org.uk/2016studyday

Raffle winners

CONGRATULATIONS to the lucky winners of our spring raffle. They are:

1st Prize £500: Pamela Fahey, West Bretton, **2nd Prize £250:** Roger Landells, Twyford, **3rd Prize £50:** Liz Balderson, Grimsby (re-gifted as a donation).

Thanks to everyone who bought and sold tickets, together you raised more than £17,000 to support Prof James Rowe's research. There's still time to enter our awareness week raffle! The closing date is 22 August.

Family day hits the right note

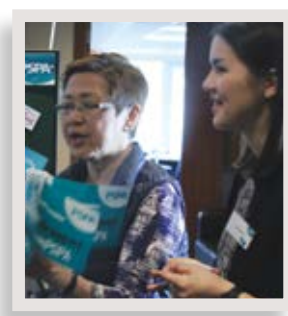
Around 85 members of our PSPA family gathered in Guildford in May.

OUR Family and Friends Day opened with an informative talk by Dr John Woodside on research into PSP and CBD, before David Gillet got our tastebuds tingling with his tasty soft food cookery demonstration.

The afternoon workshops provided an opportunity to hear tips on first aid, benefits and healthy eating, and a fun music therapy session ensured everyone left the event feeling relaxed and uplifted.

Peter Daniels, our Director of Information and Support, said it was a very successful event.

"I was particularly delighted to see so many people getting to know each other, sharing experiences and making new friends," he said. "Thanks to everyone involved for making it such an enjoyable, informative and positive day."



Our next Family and Friends Day will be held on Saturday 17 September at The Beeches, Bournville, Birmingham B30 1LS. It is free to attend and bookings will be taken on a first-come, first-served basis. Book online at www.pspassociation.org.uk or call us on 01327 322410.

Flying red flags in PSP Awareness Week

TAKE ACTION NOW

A huge thank you to our wonderful supporters who took our PSP Red Flags for GPs action during PSP Awareness Week (16 to 22 May).

MORE than 6,500 copies of our red flags document have been distributed to members around the UK to hand over to their doctors and other health and social care professionals.

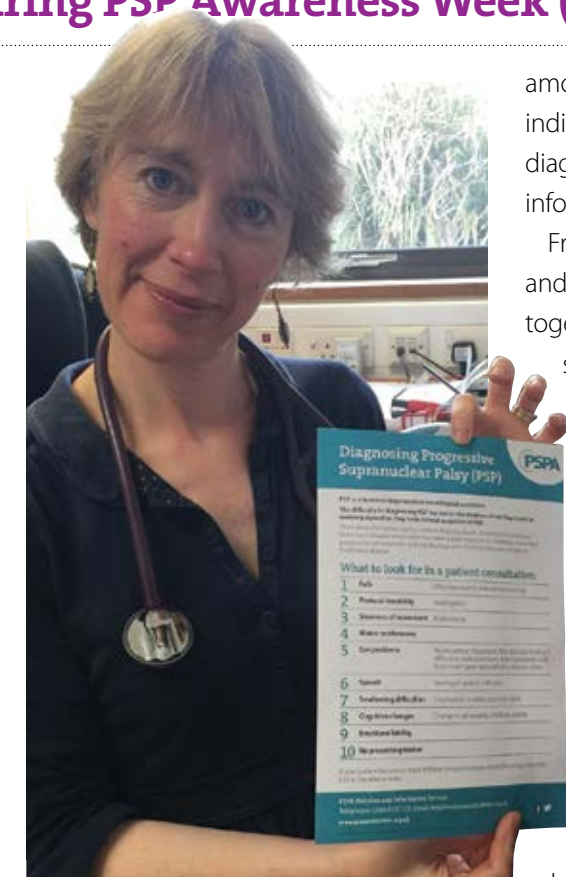
We were overwhelmed by your response including your phone calls, emails, tweets and facebook comments expressing your positive support for our campaign.

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

That's why we asked supporters to deliver copies of our PSP Red Flags for GPs document in their local area. It lists 10 red flag symptoms that may help GPs spot warning signs of PSP.

Paula McGrath, our Director of Communications, thanked everyone for making awareness week a success.

"Once again PSPA's dedicated supporters pulled out all the stops to support PSP Awareness Week and we are



hugely grateful to them all," she said.

"This year we took a slightly different approach, targeting a very specific group of people with whom we wanted to raise awareness – GPs and other health and social care professionals. Awareness

among these people is key if more individuals are to receive an earlier diagnosis and more timely access to vital information and support."

From Scotland to the Isle of Wight and Northern Ireland to the east coast, together we delivered flags to local surgeries, hospitals and Clinical Commissioning Groups (CCGs) (see our map).

"We were delighted our campaign won the backing of so many influential individuals such as health decision-makers and politicians, and also relevant organisations and professional bodies, who were able to help us reach an even wider audience," Paula added.

"This really does show that we make the biggest difference when staff, volunteers, members and supporters pull together."

While PSPA strives hard to raise awareness of PSP and CBD all year round, our annual PSP Awareness Week enables us all to focus on this important area of our work.



In the news

THANKS to everyone who contacted their local media in awareness week, including: Lesley Flannagan, from Gloucester, who was interviewed on *BBC Radio Gloucestershire*. Lesley, who lost her husband Mike to PSP, shared her personal experience of PSP and spoke about the Gloucestershire Local Group and our Red Flags campaign. Afterwards she said: "It was a wonderful experience and I would never have thought I would enjoy it as much as I did."

Joyce Freeman, from Manchester, told *BBC Radio Manchester* listeners how it took three years for her husband Henry to get a diagnosis of PSP. She also shared her story with her local edition



Christine Bycroft



Joyce Freeman

of *The Jewish Chronicle* and *The Guide* in Prestwich.

Christine and Ray Bycroft, from York, spoke to their local newspaper, *The Press*, about Christine's delayed diagnosis of PSP and her positive attitude to life.

Grantham's Gini Dellow shared her family's experience with the *Grantham Journal* and raised awareness of our Red Flags campaign. Gini's dad lives with PSP.

Carol Stanton spoke to her local newspaper on the Isle of Man.



From top: Bristol Local Group, Manchester Local Group, Leeds Local Group, North London Local Group

Local groups lead the way

A big thank you to all our local group coordinators, who not only handed out red flags in their local areas but also shared the document with their group members and encouraged them to get involved too.

Many held events too including Ann Pearse, of our Worthing group, who set up an awareness week stand at Southland Hospital in Shoreham and Alison Rose, from our Durham group, who held an awareness week coffee afternoon. Beryl Mayhew, group helper in Leeds, posted an awareness week message on her craft forum.

a copy of the PSP Red Flags for GPs and agreed to take it to his surgery."

Kathryn Timmons, Loughborough Local Group Coordinator, contacted Nicky Morgan MP for Loughborough, who tweeted her support.

Andrea Leadsom, MP for South Northants, delivered a red flag to Greens Norton doctors' surgery and Ben Howlett MP for Bath showed his support too.



Andrea Leadsom MP



Ben Howlett MP



Jenny Knight with Mark Pawsey MP

Talking to politicians

MANY of our supporters met with their MPs and told them all about the challenges of getting a PSP diagnosis and how they can make a difference in their constituencies.

Warwickshire Local Group Coordinator Jenny Knight met Mark Pawsey MP for Rugby and Bulkington. She said: "I explained about the condition PSP and he tweeted a photo of my visit. He accepted

The medical community

A WIDE range of health professionals not only welcomed our PSP Red Flags for GPs campaign but took the opportunity to share our message with their colleagues.

Thanks to the neurologists involved with our PSP Research Network for getting behind our campaign, many of whom promoted it using social media.

Rakesh Kumar, a senior physiotherapist who coordinates our North Wales Local Group, organised an awareness raising talk to around 100 trainee, junior and senior doctors, at Bangor Hospital. Rakesh also held an awareness raising stall at Sainsburys in Rhyl.

District Nurse Cheryl Williams, who lost her dad to PSP, went on a mission to tell doctors at nine GP surgeries and three hospitals in Wales about early symptoms



Cheryl Williams

of PSP. She said: "I put red flags up in GP, A&E and clinic waiting areas so that people read them whilst waiting to be seen, and could speak to the healthcare professional with any concerns about these early symptoms during their appointments. Most people I asked gladly put up posters and gave fantastic support."

We are also grateful to Southampton-based consultant neurologist Dr Boyd Ghosh who is sending a copy with every clinic follow up letter he sends to his patients' GPs, and Dr Martin Turner who promoted red flags at his Primary Care Neurology Society workshop.

Other organisations spread the word

OUR awareness week campaign won the backing of many other neurological organisations and charities.



Support from the Neurological Alliance

Rare Disease UK; The Brain Charity; Genetic Alliance UK and Parkinson's Disease Nurse Specialist Association all promoted PSP Red Flags for GPs to their members.

A number of local hospices showed their support too. Helen Miller is Education Specialist at Isabel Hospice

in Hertfordshire where a number of Community Nurse Specialists cover 30 GP practices. She provided them all with a red flag poster and a GP booklet to take to each surgery.

Thanks to the support of the Neurological Alliance, our red flags were promoted at the Association of British Neurologists Conference in Brighton.

Social media

We harnessed the power of social media to spread our #PSPRedFlags message in awareness week.

Our Twitter posts reached 27,000 people during the week and our Facebook stories reached 24,500 people.

There were 8,000 views of the PSP Red Flags page on our website and more than 200 people downloaded red flag posters online.

Your comments:

We have received really positive feedback from our members and supporters.

“ I was delighted to read the red flag diagnosis check list for GPs. I am a lay member of the local CCG, which is well attended by all our locality GPs, practice managers and others. **”**

Alison Peasgood

“ We gave a copy of the PSP Red Flags for GPs to our surgery when my wife had her regular appointment last week. Her doctor said that she would copy the page for each of the GPs in the surgery. **”**

Chris Ling

“ Our GP has photocopied this and given one to each GP in the practice. My Mum wrote and sent the list of red flags to all the doctors my dad saw over the last four years and who didn't diagnose PSP! **”**

Lynda Harris

“ I delivered some information at our local hospital in Ipswich for the professionals and patients too. When my mum was diagnosed there, there was nothing for us to leave with apart from the doctor's information which wasn't too clear...now the hospital has that extra bit of information for themselves and patients. **”**

Michelle Staunton

‘My vision just isn’t right..’

“I don’t mean to appear rude, I’m not really asleep, I don’t mean to stare and I’m really not crying” might all be said by someone living with PSP when trying to explain their visual difficulties to others.

PSP damages the nerve centres in the brain that control eye movements. The most common visual difficulties are: involuntary closure of the eyelids (with difficulty opening the eyes), an inability to look down, an inability to deal with bright lights, slow and jerky eye movements, tunnel vision, blurred vision and double vision. Due to a reduced blink rate eyes may also become very dry, sore and prone to infection. Visual difficulties are less common in CBD.

Here we take a look at what can be done to help.

Keeping the eyes open

Difficulties in opening the eyelids (apraxia of eyelid opening) and forced closure of the eyes caused by muscle spasms (blepharospasm) can be troublesome. Botox is often considered for these difficulties as Dr Helen Ling, Senior Research Associate at the PSP Research Centre, UCL Institute of Neurology, explained.

“Botulinum toxin injection is an effective and well tolerated therapy to improve involuntary eye closure in PSP. Botulinum toxin is produced naturally by a bacterium called Clostridium botulinum. This has an effect on the nerves at their junction with the muscles, acting as a blocker and preventing the release of a chemical messenger called acetylcholine that would otherwise make the muscles contract to close the eyes. Muscle spasms are reduced following



botulinum toxin injection.”

Dr Ling continued: “If the eye closure problem becomes more persistent, so the individual is spending most of their waking hours with their eyes involuntarily closed, botulinum toxin injection, close to the eyelids and around the eyes, can be given by neurologists or ophthalmologists to relax the muscles.”

According to Dr Ling, when given by experienced clinicians, most patients experience at least 50 per cent improvement and are able to open their eyes and keep them opened.

“The improvement usually begins seven days after the treatment with the maximum benefit in three to four weeks,” she explained. “Injections are repeated every three to four months with some

adjustments in the injection sites and dosage depending on the previous response of the individual.”

“The improvement usually begins seven days after the treatment with the maximum benefit in three to four weeks.”

Dr Ling advised that there are potential side effects (including bruising and droopy eyelids) and these risks should be discussed with the specialist.

Some people find using one of two different types of attachments to glasses, known as ‘Ptosis Props’ and ‘Lundie Loops’, helpful. An eye specialist can advise.

Difficulties looking up and down

Vertical Gaze Palsy is a restriction in the ability to voluntarily look up and/or down, which limits what someone can see around them. Special spectacles called prism glasses may help with this difficulty in certain situations.

Retired optical clinician Dr Anne Silk explained: “Look right down and fix your gaze on the floor. Now imagine that you want to have a conversation with a friend opposite you but you can’t look up – you can see their feet but not their face. The same might happen when you want to

watch TV. Now consider the opposite effect: your gaze is fixed looking up so you can’t read or see your meal on the table but you can only gaze at the ceiling.

“Prism glasses have the remarkable ability to transfer images through 90 degrees through the use of multiple reflective surfaces. That will bring the book or the friend’s face right into the wearer’s line of sight.”

Prism glasses are available free of charge from PSPA. They should only be used when sitting or lying down and it is not safe to walk whilst wearing them. Your local optician will adjust the sides of the frame if they are too loose or too tight.

Other common issues

Sensitivity to light: Photophobia is an aversion to bright light. Wrap-around sunglasses (from the RNIB) or tinted lenses can help. Other tips include wearing a hat (indoors and out) and adjusting the brightness on the TV.

Dry sore eyes: Your GP or specialist may advise on eye sprays or drops.

Double vision: Wearing a patch over one eye, or taping over one lens of your glasses, can help.

Your experiences

John Jones

John’s ophthalmologist picked up that he might have PSP. He explained: “My eyes are very sensitive to light so I wear sunglasses over my prescription glasses. My eyes tend to just close so people think I’m asleep. This is a great relief to my eyes (which get very sore) but I need to use my fingers to prise them open again.” John’s daughter, Dawn, praises the ophthalmologist: “After he mentioned PSP I was able to read up about it before we saw the neurologist.”



around where they did the injections, but it’s been worth it. I don’t have to keep trying to prise my eyes open. I’d tell others to consider going for it.”

Austin Hewitt

Over time botox became less effective for Austin and his specialist in Northern Ireland suggested surgery to his eyelids. Austin has had one eyelid operated on and is now able to raise his eyebrow to help open his eye and keep it open. His ability to do this is affected by fatigue but it has been successful enough for him to plan to have surgery to the other side too.



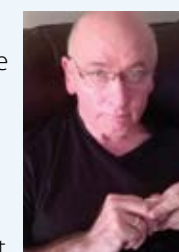
“Bob’s condition has progressed and he’s found that TV’s guilty pleasures are not quite enjoyed as they used to be and he can’t enjoy reading either. We arranged to see the eye specialist which led to Bob being certified ‘severely sight impaired.’”

The sensory team from the hospital provided the couple with lots of help and referred them to the RNIB. “Within four days we received our first talking books. Bob now has wrap-around sunglasses and glasses that are telescopic so he can try and read for a short time.” A local charity provides memory sticks of spoken news. “Every little bit of help, from equipment to advice from professionals, is definitely a benefit and helps ensure that life’s pleasures can still be enjoyed, even if they are accessed a little differently!”



Alexander Baird

Alex has had botox once and found it helpful. He plans to have it again now the effects are wearing off. “It helps me to keep my eyes open. It was uncomfortable to start with, and sore



Bob Bancroft

Bob tried botox and initially it seemed to help but later sessions didn’t seem as effective. Bob’s wife, Carla, explained:

Visual difficulties: take action

- Seek a referral to a qualified eye specialist (eg ophthalmologist) and sensory disability team.
- Raise awareness with those around you so that they understand your difficulties.
- Contact our helpline for more information and to request prism glasses, on 0300 0110 122 or helpline@pspassociation.org.uk

Lights, camera, action – meet our Team PSPA film stars

Our wonderful PSPA volunteers are enjoying new found fame.

MORE than 20 of our dedicated local group coordinators, support workers and helpline volunteers feature in our new volunteering video created by filmmaker Thomas Line.

We launched the two-and-a-half minute video in Volunteers Week (1-7 June) to thank our volunteers for all they do, celebrate their achievements and encourage others to join their team. It has already proved really popular with hundreds of views on our website and Facebook and Twitter pages.

“The volunteers at PSPA are absolutely vital in so many aspects of what the charity does and the services it provides to those affected by PSP and CBD.”

We are very grateful to Thomas, an independent filmmaker from Northampton, for volunteering his time and expertise to make the film for free.

He explained: “As a filmmaker I am always striving for new ways to challenge myself as an artist and expand my own knowledge and experiences. I became aware of PSPA through word of mouth, and with it an opportunity to volunteer my skills and expertise for a fantastic cause.

“The volunteers at PSPA are absolutely vital in so many aspects of what the charity does and the services it provides to those affected by PSP and CBD. For me, creating a film that could

acknowledge this and celebrate the brilliant work they do, why they do it and the experiences they gain from it became the focus.

“Ultimately, I hope the film will act as a tool to help expand PSPA’s volunteer base so they can continue to provide the necessary help and support to the families, friends and individuals affected by these conditions.”

Paula McGrath, Director of Communications said: “PSPA is delighted with the film which raises awareness of PSP and CBD, gives an insight into the diversity of our volunteers, the difference they make and why volunteering matters to them.

“We are incredibly grateful to Thomas and to all our volunteers who travelled from around the UK to be film stars for the day,” she said.

“We had a great time making the video with lots of laughs along the way and plenty of tea and cake to keep us going. The atmosphere of the day really comes across in the final film.”

Sadly Sue Wilson, who lived with PSP and features in the video, has passed away since filming, which makes it even more poignant.

Scott Smith volunteers with our Manchester Local Group and support worker project and is one of the 22 volunteers who feature in the film. Scott has made films for PSPA in the past.

“I would do absolutely anything to raise awareness of PSP so it was an



Left: Thomas Line and below, during filming



Watch the film

View the film at www.pspassociation.org.uk/beextraordinary

Inspired to volunteer for PSPA? We'd love to hear from you. Give us a call on 01327 356134 or email volunteering@pspassociation.org



absolute privilege to be involved in the video,” he said.

“I hope it will encourage others like me to get involved with volunteering for PSPA. It was a fantastic day and great to meet other volunteers.

“It was a little bit nerve-racking for me because I am used to being on the other side of the camera. I didn’t appreciate how nervous it can make you but I was made to feel completely at ease and I was happy to do it as I was so keen to be involved.”



Grandad's story

Amy Lane, from East Sussex, describes her grandad John's journey with PSP.

HIS routine was always the same; Tuesday with his sister, and Friday or Saturday coming to see my Dad and us, his three grandchildren. He would mow the lawn in smart trousers and a shirt, walk up to the town a number of times a day to buy his paper and sweets and often take himself out for a curry thanks to his incredible appetite for things that weren't so good for his waistline.

Early signs

The first thing to go was his speech. It was like the words were on the tip of his tongue but he could not push them out of his mouth and when they did come out, he was very softly spoken. He would say goodbye mid-sentence and put the phone down mid-conversation.

The next thing that changed was his emotions. He began to cry when he saw us and started to cry mid-conversation when talking about something unemotional.

He also became unkempt which was so unlike him. He then lost all sense of time and would often go wandering in the early hours. A catalogue of falls and hospital visits made us all realise that him moving to a nursing home was inevitable.

The diagnosis

A number of consultants, some supposedly the best neurologists in the South East, and GPs either missed the diagnosis of PSP or did not know what PSP was to diagnose it. Sadly, a very private man had to explain his symptoms over and over again, was subjected to numerous tests and, at times, we were all given false hope that we had some idea what he was facing.

When we got told that Grandad had PSP, I had no idea what it even meant. The first thing that came up on Google was the Playstation website.

We got in touch with PSPA to get some advice and guidance. PSPA were incredibly helpful and useful as were the PSP meetings, which we attended locally to us.

One time I told a consultant Grandad had PSP and the consultant had no idea what it was. Luckily, I carry PSPA fact cards but I remember the perplexed look on the consultant's face whilst he was reading it. He still wrote on Grandad's notes that he had dementia.

I am sure that had Grandad been diagnosed earlier, we would have had the benefit of earlier advice that would have made life a bit easier for him.

Unfortunately, the move into a nursing home was not a seamless transition. They already had a patient with PSP and we thought this would result in better care. Sadly, this was not the case. We moved Grandad to where he is now and he has a visitor most days.

Today

Grandad is only able to speak a few words and unable to walk without assistance. The falls have declined due to his mobility declining. He always has a terrible cough and his swallowing is a significant problem although his appetite remains incredible (and he still often has seconds for pudding!).

He seems to be at his best when he looks his best; clean shaven with aftershave, haircut and nails clipped. My sister, Grace, is a beauty therapist and is often on hand to spruce him up.



John Lane

In the six years since his diagnosis, a lot has changed for us. Grandad has become a Great Grandad following the birth of my niece, Eva. His face lights up when he sees her or a photo.

I am due to qualify as a solicitor in September and hope to specialise in private client work so that I can help families plan for the future when faced with a degenerative condition.

Heart breaking does not come close to how difficult it is to watch his decline but I take comfort in the thought this article may help others and their families through a difficult time and that through my work, I can also help families in a time of need.

Raising awareness of PSP has now become a mission for me; early diagnosis will help raise awareness of what can only be described as a terrible illness and encourage funding towards finding a cure.

Grandad may not act the same but the smile and wave when he sees us and the few times when he manages to tell me he loves me make me realise that, deep down, PSP has not taken everything away from him.

United by a flag

Two of our supporters from opposite ends of the land have been brought together by a PSPA flag.

ELIZABETH Birrell planted a hand waving flag whilst out on a sponsored walk near her home in East Neuk, Scotland... then Douglas Gray from Uxbridge picked it up four days later!

"It was a lovely surprise to hear that someone had collected one of the flags and had been in touch with the Association," said Elizabeth, whose husband, Ian, lived with PSP. "And it was touching to learn that the people who found it have also been affected by the disease."

Elizabeth is a seasoned fundraiser for PSPA and has taken part in the local Rotary Club's annual walk from Anstruther since 2010 – and over the last few years she has planted flags along the route.

"I want to raise awareness whilst also raising funds," adds Elizabeth. "It's crucial that more people hear about PSP and CBD, so by leaving a wee flag I hope others will pick them up and then find out more when they get home. I also hand out information cards whenever I can, especially at doctors' clinics and hospitals."

The flag had been at its lofty – and



Elizabeth Birrell

windy – location above Ruby Bay, Elie, for a few days before holidaying couple, Douglas and Linda Gray spotted it whilst walking with relatives who live nearby.

"It brought a broad smile to our faces," said Douglas. "My wife, Linda has recently received a PSP diagnosis, so it meant a lot to us to know that there are 'others' out there who are doing whatever they can to help 'spread the word'."

And the coincidences don't stop there... Elizabeth and Ian used to run the Craw's Nest hotel in Anstruther for over 30 years and it turns out that Douglas and his family spent many happy evenings and Hogmanys at the hotel – so their paths must have crossed before.



Douglas and Linda Gray

"We visit this area every year," added Douglas. "I hope next time we'll be able to meet up with Elizabeth – see if we recognise each other after all this time!"

Make your voice heard

We welcome potential contributions for future issues. Material may be edited prior to publication. **Send your contributions to psp@pspassociation.org.uk**

or write to PSP Association, FREEPOST RSLR-ZTGA-HHAU Towcester NN12 6BX

Keeping active

Hazel Smyth, 61, is a retired nurse who lives with her husband Ray in Northern Ireland.

HAZEL was recently diagnosed with CBD after initially being told she had Parkinson's.

"The scans suggested Parkinson's so I was prescribed Parkinson's medication," Hazel told us. "Unfortunately this just made me really unwell, to the point that I was struggling to walk and swallow, so I came off it and things improved again. That's when the doctors realised that in fact I had CBD."

There was however a rather more beneficial result from the initial misdiagnosis: Hazel was given a wristband stating 'I have Parkinson's, please give me time'. She has found this really helpful in airports or other situations where she might perhaps get a little flustered.

"People see the wristband and quickly recognise that I may need help and that they need to be patient," Hazel explained. "It takes the pressure off."

The wristband is available from the Parkinson's UK online shop.

Hazel says she tries not to think of herself as unwell. "I think the best approach is to keep doing as much as you can – I try to get on with things but just go a little slower."



Hazel Smyth

Dream big and then dream a little more

Following her late father's advice, Liz Lockhart from Chepstow achieved something way beyond her dreams.

I agreed to write this to show people that you can do so much more than you ever imagine possible. My Daddy always said to us as children 'dream big, and then dream a little more'. He didn't believe anything had limits – even dreams.

I do not have a history of athleticism. I mean yes I've had gym subscriptions, and I've swam, and got off the bus a stop earlier. But the next Paula Radcliffe I was not.

About 18 months ago I had to give up my subscription to the ladies only gym I loved. To alleviate the stress of home educating two teenagers I decided instead I would run. It was cheap! I mean it couldn't be that difficult. I probably wheezed my way around a kilometre or two once a week roughly and felt very smug.

A very special friend kept badgering me to sign up for a half marathon. Her reason was I could raise funds for PSPA, she felt I definitely had the ability. I thought she was plain bonkers. There was absolutely no way in this lifetime, or the next, I was running 13 miles. Every now and then she'd mention it, I'd pour a glass of wine and laugh it off.

In my early teens I'd been diagnosed with first one joint condition, then another; then someone had the bright idea of reconstructive surgery on my knee. It predictably backfired, and I spent a year walking with either sticks, or in a wheelchair, culminating with a month in the local orthopaedic hospital being taught how to walk again.

Right into my mid-thirties I bounced between orthopaedic, rheumatology



Liz Lockhart

and physiotherapy. Everyone had a different idea, but the general gist was I had a pretty dodgy skeleton.

In late November my beautiful friend got in touch again. Athletics for a Better World had 500 spaces for the World Marathon Championship in March. To bid for a place you had to say how running would change you, and change the/your world. She gaily announced she'd apply for me. She'd say that I would learn to

run, to be able to raise funds for a world free from PSP. I've barely won as much as a box of talc in a church raffle. There was no way I would win...

"I sniffed through the tears, that no matter how hard I was finding it, it was nowhere near as hard as Dad had found suffering from PSP."

Fast forward to 10 days before Christmas. Yes, you guessed it, I was successful! I had exactly 12 weeks to go from my rather lame pootle around the lanes to running 13 miles. I was petrified.

My rather long-suffering friend stepped into the breach. Found me a training plan, and introduced me to chi running to minimise skeletal impact. I worked my socks off. I sniffed through the tears, that no matter how hard I was finding it, it was nowhere near as hard as Dad had found suffering from PSP.

Race day was freezing, with storm force winds and biblical rain. I was probably more scared than I ever have been in my life, but I set off undeterred. I completed the course soaking wet, and absolutely ecstatic in 2hrs 49 minutes, raising £507 for PSPA. Way, way beyond my wildest dreams.

Dad and Mum had plans to visit all manner of places in the UK when Dad retired. Sadly PSP cut that dream short. I now hope to visit as many as possible completing half marathons or 10k races, raising awareness and hopefully more funds for PSPA as I go.

Mum's 'dignity and grace'

Anne McDonough from Newton-Le-Willows lived with PSP for a number of years before passing away in February.

HER daughter Susan Tickle shared with us some memories of her amazing mum and paid tribute to Anne's inspiring courage and positivity.

"Mum always dealt with this illness with real dignity and grace. She never complained, never let it get her down but instead did everything she could to learn about PSP. She armed herself with information and then made it her mission to raise awareness.

Every trip to A&E after a fall was treated

as an opportunity to educate the doctors and nurses there about PSP – many of them hadn't even heard of it. She would also chat away about it to people she came across in everyday life.

Mum did her best to maintain her independence and continue to enjoy life. She and my stepfather George had a wonderful time on a cruise last year and despite her increasing weakness and difficulty walking she was determined that they would return to their beloved Greece this summer to sit on the beach in the sunshine. She was facing up to the need for a wheelchair and adaptations to the house, but in the midst of it all she was still busy planning a holiday!

Sadly mum didn't make it to that last trip, but we knew that she would have wanted us to continue to raise awareness of PSP. Everyone at her humanist funeral was given leaflets and information – they all left the service with an understanding of what this illness involves. I will carry on where my wonderful mum left off, educating anyone who is willing to listen!"



Anne and George McDonough



Oksana and Norman

Wedding bells

CONGRATULATIONS to Oksana and Norman Johnson who were married at the Town Hall in Dewsbury, West Yorkshire, on St Patrick's Day.

The couple were joined by many family and friends including members of our Leeds Local Group and PSPA Specialist Care Adviser, Jenny Reynolds.

Guests then celebrated with the couple at a reception at Fieldhead Court, where Norman, who has PSP, lives.

Calming creativity

Creating greetings cards has proved to be a successful pastime for one of our local group members.

ROB Laver, who regularly attends the Gloucester meetings with his wife Mary, took up the hobby after being diagnosed with PSP in 2012.

Mary said: "He enjoys mixing up the colours and finds painting calming."

Each card is unique and sales have been donated to PSPA.



Research network branches out

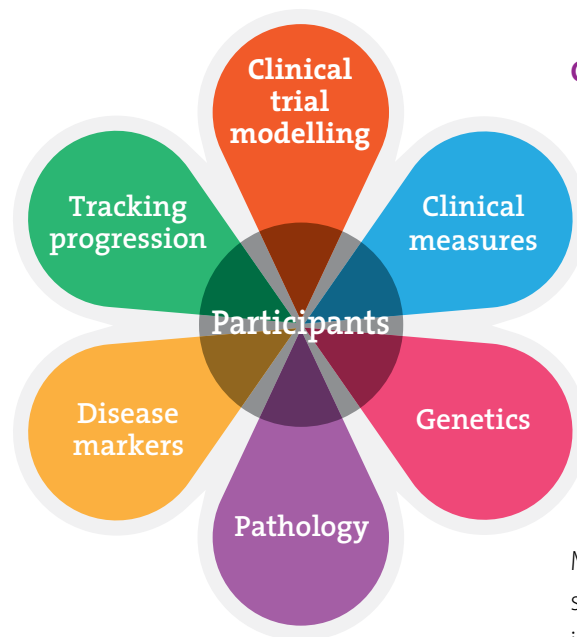
Our PSP Research Network's core study, known as PROSPECT, is now fully up and running across seven centres of expertise nationwide. As well as dramatically stepping up the pace and focus of PSP and CBD research in the UK, the project is now providing a foundation for wider studies.

Our network provides a collaborative framework, allowing centres with a strong history of PSP research to share data and samples in the quest for earlier diagnosis and effective treatments.

The network's chief investigator, Prof Huw Morris, Consultant Neurologist at University College London and the Royal Free and National Hospitals, believes teamwork is essential. "Our group brings together leading experts from many areas of biomedical research" he explained. "The rarity of PSP and CBD necessitates collaboration and we believe that the network can address some of the barriers to research and providing better care."

"It is important that we build a picture of related conditions that all fall under the umbrella of 'atypical Parkinsonism' and tease out their subtle differences."

All seven core centres are now busily recruiting study participants: nine people with PSP and six with CBD have signed up for the 'longitudinal' arm of the study. This involves visiting one of the centres several times over the course of a few years providing valuable



Aspects of our Research Network Study

data that will enable the researchers to make new discoveries based on the way that the conditions change over time. Meanwhile 39 people with PSP and nine with CBD, from Devon to the north of England, have contributed to the 'cross-sectional' part of the study, completing questionnaires and giving a one-off blood sample at their GP surgery.

Eleven healthy participants have signed up too, providing essential data and samples for comparison, but there's a long way to go, as Dr John Woodside, Clinical Research Coordinator for PROSPECT, explained: "Our target is to enrol 98 people with PSP to the longitudinal study and 98 controls. With more data collected from more people, greater comparisons can be made to give clearer insight as to how these diseases develop."

Gathering momentum

As PROSPECT gathers momentum it is growing in scope, even reaching out into Europe (see panel), and its potential impact is increasing. The structure laid down by our research network has provided a template for other studies and has attracted the attention of other funding bodies.

The MSA Trust has committed funding to allow the researchers to include people affected by Multiple Systems Atrophy in a parallel study, scaffolded by the PROSPECT infrastructure and using some similar protocols.

"It is important that we build a picture of related conditions that all fall under the umbrella of 'atypical Parkinsonism' and tease out their subtle differences" explained Dr Woodside. "It is this detail that will be critical in improving



Dr John Woodside

diagnosis across the board."

Meanwhile our campaigning activity at Holyrood last year attracted the attention of the Scottish Chief Scientist Office, who subsequently agreed to share with us the funding of a Scotland-based Clinical Research Fellowship. Newly appointed Dr Diane Swallow will recruit participants to the cross-sectional arm of PROSPECT while examining the issues surrounding diagnosis and care for people with PSP and CBD in Scotland.

"We are now seeing a much bigger drive for neurological research from the major funding bodies such as the

Medical Research Council and the NHS's National Institute for Health Research" Dr Woodside told us. "Now we are starting to establish our cohort of PROSPECT participants, we have a strong case for gaining access to these funding sources in future."

The PROSPECT team's ambitions are growing already. In addition to the seven core centres, eight secondary centres around the country are recruiting participants to the cross-sectional arm of the study, with plans for more.

Ultimately, our hope is that the work of the Research Network will create

a platform for future clinical trials as ever-increasing funding and awareness provides the momentum to edge us closer to the development of potential treatments.

Dr Woodside said "PROSPECT is addressing the key aspects of these conditions, from genetics and disease markers to how we track progression. Thanks to this study, our knowledge of PSP and CBD will dramatically increase so that we can build a more complete picture and create an accurate disease model for future trials."

Swedish funding for sister study

A sister study to PROSPECT that focuses specifically on CBD is spreading its wings into Europe thanks to funding from Swedish organisation CBD Solutions.

The European Registry of CBD and CBS (corticobasal syndrome) is a multi-national collaborative study. Like PROSPECT, it is coordinated from the Institute of Neurology at University College London and PROSPECT was used as the basis for its development. Study Coordinator Dr Ruth Lamb explained: "Our primary aim is to establish a cohort of clinically well-defined patients with CBD and CBS that will be available for future therapeutic studies."

"Patients recruited to the study will undertake a structured neurological assessment and will be invited to donate blood samples, with follow up after a year" Dr Lamb told us. "The protocols followed by the European study, including the neurological assessment, were developed from some of the existing PROSPECT protocols and will allow us to collect comparable data."

The project aims to recruit at least 150 patients over two years from more than 20 sites across Europe, plus the



Dr Ruth Lamb

existing UK Research Network centres, where participants will also join the main PROSPECT study with more in-depth tests.

Dr Lamb told us: "CBD is a rare disease so pan-European recruitment is extremely important as it helps us identify a greater number of patients. To our knowledge this will

be the largest study of CBD and CBS ever carried out and we predict that it will play a key role in facilitating the identification of disease markers while potentially providing a platform for future clinical trials."

Get involved:

To find out more and to see if you are eligible to take part in PROSPECT, contact: Dr John Woodside, Study Coordinator: prospect@ucl.ac.uk or 020 7679 4272; or PSPA: helpline@pspassociation.org.uk or 0300 0110 122.

Meet Edwin, our new PSPA-funded Sara Koe Research Fellow

Dr Edwin Jabbari is just finishing his general medical training as a junior doctor. Fortunately for us and the future of PSP research, he will undertake our research fellowship rather than ploughing straight on into a specialist registrar post.

EDWIN will gain valuable research experience and the specialist knowledge and breadth of skills that will make him an enormous asset to PSP clinical research in the future.



Dr Edwin Jabbari

He will be based at the Institute of Neurology, University College London where he trained both as a medical student and junior doctor, working alongside leading experts in the field such as Prof Huw Morris (once a PSPA fellow) and Prof Henrik Zetterberg.

Neurological conditions grabbed Dr Jabbari's attention when he was a medical student. He has become passionate about PSP and similar conditions.

"As a student I was fascinated by how

neurologists were making diagnoses based mostly on their encounter with the patient, by taking a history and examining them" he told us. "As I've gone through my training, I've realised that the sub-speciality within neurology that captures this most is movement disorders. Aside from the challenge of diagnosing and treating conditions such as PSP and Parkinson's Disease, their chronic nature means that you get to form longstanding bonds with patients and their families, which ultimately leads to more sensitive and individualised care."

During his time as the Sara Koe research fellow, Dr Jabbari will undertake a study which he hopes will contribute to tangible benefits for those diagnosed with PSP in years to come.

He explained: "Diagnosing PSP remains a challenge but on the whole we are getting better at this. What we still really struggle with is giving an early indication of how quickly and in what way the disease will progress, yet this information is vital for patients and their families who have already been through the anxiety of the diagnosis itself. My research will look into ways that we can use MRI scans, lumbar puncture and genetic testing to reliably predict and track disease progression. This approach also has the potential to identify new targets and measures for trialling new treatments."

Dr Jabbari's work will make use of our Research Network infrastructure, as his project will involve patients and

data from our PROSPECT study. He said: "PSPA's promotion of PROSPECT is an excellent example of how a patient organisation can communicate research participation opportunities to people living with the condition."

"Diagnosing PSP remains a challenge but on the whole we are getting better at this. What we still really struggle with is giving an early indication of how quickly and in what way the disease will progress."

Taking up the fellowship in August, Dr Jabbari hopes to spend his three years in post making some important contributions to PSP research, before starting his neurology registrar training. "During my time as a junior doctor in the movement disorders team my overriding feeling was one of frustration, both at the lack of treatment options and the lack of clear prognosis we could give patients and their families," he said.

"Getting this research post has certainly made me less frustrated and more driven to address these issues! I'm looking forward to meeting many more people living with PSP, hearing their stories and hopefully having a positive impact on their lives."



Hello and goodbye...

WE are delighted to welcome two new group coordinators to our volunteering team this year!

In April, Jo Catterall (pictured left) became the coordinator for our Brentwood group. Jo is a carer for her mother who is living with CBD and was already a member of the group. She is taking over from Liz Williams (pictured above right), who has stepped down from the role after three years. Despite relinquishing her role, Liz is reluctant to say goodbye to the friends she has made and has promised to continue attending the meetings as often as she can.

In Doncaster, Linda Greendale welcomed members to the first meeting at a new venue. Linda, whose husband Harry is living with PSP, organised the first meeting at Waverley Community Centre, Balby, Doncaster, in June.

For information about our group meetings please see our local group pull-out.

Offering a listening ear

OUR Helpline volunteers continue to do amazing work, providing an essential out-of-hours service.

Each volunteer spends around two to four hours per month responding to a range of calls and enquiries including what services are available, where to find a suitable holiday and, of course, providing a listening ear and emotional support.



Jackie Hill, one of the team, explained: "When a call comes through you forget all your own concerns as you listen intently to the person on the other end of the phone – it feels good knowing that you have

been there to support someone in need.

"What's two hours every few weeks? It's nothing, but the difference it can make to someone who needs support is immense."

We are looking for more volunteers to take on this challenging role. If you think you could be a 'Jackie' please get in touch with the volunteering team.



First volunteer support workers

OURfirst volunteer support workers have successfully completed their training and are now making a difference for people affected by PSP and CBD.

The support offered through this project includes one-to-one contact through home visits, phone calls or email, depending on individual need.

This exciting new project is currently offering a service limited to certain areas and to those who are newly diagnosed, living alone or facing a crisis. As we recruit and train more volunteers into this role, it will become more widely available.

If you feel you would benefit from this type of support, please get in touch with our Helpline, on 0300 0110 122, who will be more than happy to talk to you about what we can offer.

If you are interested in our support worker role, or other volunteering opportunities, the volunteering team would love to have an informal chat with you. Contact Wendy or Nicola on 01327 356134 or email volunteering@pspassociation.org.uk

Getting to know you

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

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

We are looking forward to meeting and spending some

quality time with you over a coffee and (hopefully) cake!

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

For more information on all local groups visit:
www.pspassociation.org.uk/localgroups

Introducing...

Joan Weatherington – Sheffield group

ARRANGING regular speakers for the Sheffield group meetings has proved a successful approach for retired physiotherapist, Joan Weatherington.

Joan, who has coordinated the meetings since March 2015, has used her former professional contacts to invite a range of healthcare professionals to share their knowledge with the group.

She said: "The members are more than happy to just chat to each other but it's

good to have professionals along who can answer their questions too. It's a great way of passing on information and a benefit to all the group."

Joan has also called on contacts who helped support her husband, Keith, who died from PSP in December 2013. She said: "It is a way of helping members to find out about things that they might not know otherwise. I feel very satisfied that they are getting the help they need. I always ask the group members who



Joan Weatherington

they would like to speak. We've had speakers from environmental control, a speech and language therapist, an occupational therapist and even a psychologist, who inspired a lot of questions!

"It's a very friendly group, they love meeting each other and have got to know each other very well. I think the members enjoy the friendship they get through the group. Getting to know other people with the condition and knowing they are not on their own is very important."

Marisa Brockton – Wimbledon group

THE organisation of our Wimbledon group has been a successful three-way split ever since it began back in 2012.

The smooth-running teamwork of Marisa Brockton, Jeanne Connelly and Shauna Mackenzie has ensured the group has provided a welcoming meeting place for people living with PSP and CBD in the South London area.

As part of our ongoing series of features focussing on our local group coordinators, we will be talking to all three Wimbledon volunteers in turn. This month the spotlight is on Marisa, who first became involved with PSPA when her father, Brian Robertson, was diagnosed with the condition.

She described how the combined participation of all three volunteers and a steady supply of 'epic' chocolate brownies has helped to contribute to the meetings.

She said: "It works really well with the three of us. There is someone always



Marisa and her dad Brian

doing something. The meetings are very laid-back, there is no formality. We just chat over a hot drink and share stories and information.

"Shauna makes chocolate brownies for every meeting. They are pretty epic and people do come along for them - but also for the companionship! And if people can't make it, Jeanne always follows up with amazing summaries of

what happened at the meeting.

"We see ourselves as facilitators. We are not experts, we are just there to let people talk and discuss issues."

Marisa acknowledged that volunteering with a local group can often be demanding and, at first, she wasn't even sure what would be expected of her, but that it has developed into a worthwhile and rewarding experience.

"Volunteering with the local group has been more work than I thought it was going to be but it does feel good to know you can really help people."

She said: "I didn't know if we were expected to know anything medically. I wondered what would be the point of the group if it couldn't offer that. But I quickly realised it is about providing a space for people to meet.

Local groups – your news and pictures



Congratulations to our **Leeds Local Group** (pictured above) on recently celebrating its third anniversary. Members marked the occasion with home-made cakes supplied by Group Coordinator Pam Bower and a lively discussion about new fundraising ideas.

Tim Allen, our **Middlesbrough Local Group** Coordinator, gave a talk about PSP to Stockton Unitarian Church. Church members kindly fundraised for PSPA for a year and Tim's mam, June Allen, together with group member Irene Ridgeway, were delighted to collect a cheque for £511. June and Irene are both living with PSP.



Our new **Worthing Local Group** got off to a great start in April when more than 20 people attended the first meeting. Group Coordinator, Ann Pearce, gave a warm welcome to new members at The Durrington Community Centre.

Regional meetings

WE have recently held two regional meetings to give families affected by PSP the chance to meet staff and find out more about PSPA.

We welcomed more than 15 people to our recent Worcestershire regional meeting.

Held at Lower Smite Farm in Hindlip in April, the session included information about the Association and our local group network. PSPA's Specialist Care Adviser

(SCA) for the central region, Liz Burr, was also on hand to answer any questions.

More than 15 people attended our regional meeting in Poole, Dorset in June attended by consultant neurologist Dr Luke Massey and Jane Stein, SCA.

Regional meetings take place in areas where we do not currently have a local group. The sessions offer people a chance to meet staff, find out more about our work, and experience a local group meeting.

They did us proud!

A massive thank you and congratulations to our 72 London Marathon runners for their incredible achievement.

FROM novice to experienced runners, they all saw months of gruelling training pay off to raise tens of thousands of pounds to support our work in our biggest fundraiser of the year.

"I felt both humbled and privileged to be there with the other runners and all the volunteers, it was brilliant!"

The event just wouldn't be the same without dozens of energetic cheerers, who willed our runners on every step of the way around the course and gave

them a rousing welcome back at our post-race reception.

We were delighted to meet so many runners, their proud families and friends at our reception, to thank them in person, hear their inspirational stories and celebrate their success together.

Justin Johnson ran in memory of his step dad, along with Matt Ironside and Sam Potter.

He said: "I felt both humbled and privileged to be there with the other runners and all the volunteers, it was brilliant! I felt so proud wearing my vest, I kept looking down

at it throughout for motivation and it really put everything into perspective!

"Running for such a personal reason was the best boost – especially at those horrible late teen miles."

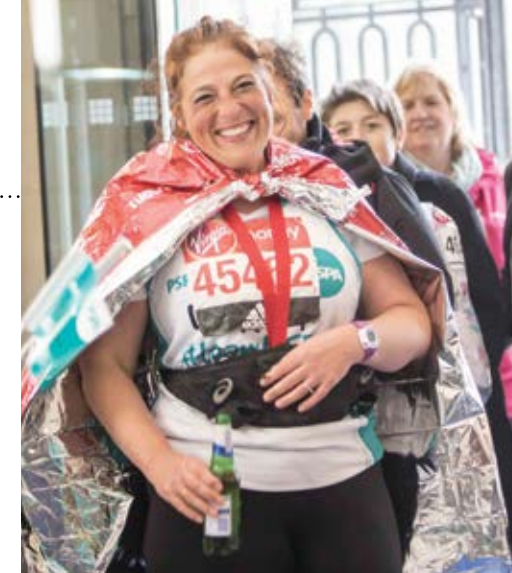
Feeling inspired?

We'd love you to join #TeamPSPA at next year's London Marathon.

Sign up now www.pspassociation.org.uk/londonmarathon



Justin Johnson



London Marathon 2016 Roll of Honour

Hani Abidi	Matthew Heaven	Richard Piggford
Laura Brown	Gabrielle Hine	Sam Potter
Sarah Buxton	Nikki Hodges-Smith	Jeremy Ramsden
Darren Chappell	Victoria Holland	Edward Reed
Teresa Connolly	Joanne Homes	Alex Ridout
Luke Courtney	Charlotte Howarth	Amanda Salter
Edward Craig	Matthew Ironside	Viraj Sanghai
Rory Cunningham	Joe Jennings	Gary Sloman
Paul Davis	Justin Johnson	Helen Sprason
Katie Davis	Rebecca Jones-Reading	John Sutton
Thomas Davies	Mike Jump	Lindsey Thomas
Amy Decaro	Rhian Lees	Mark Thomas
Elizabeth Eggleton	Heather Martingell	Sebastian Tusa
Charlotte Elms	Andrew McAvan	Tristan Tusa
James Evans	Clare McCarthy	Alan Wadsworth
Nick Fellows	Anthony McCann	Gary Walker
Paul Fleming	Elaine McGlynn	Josh Walker
Sarah Fletcher	David Meer	Sarah Walker
Joseph Gilman	Mickael Metayer	Emma Wasley
Terry Gilmartin	Wilma Milton	Steven Watson
Suzanne Glowala	Sabrina Monforte	Mike Wenn
Jennifer Gunn	Joanne Moore	Sally Williams
Jema Hart	Annette O'Donnell	Matthew Woodruff
Dan Heaven	Chris Overland	Elen Woodward

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...

Summer is finally here! I am so excited for the big PSPA events such as August Fundraising Week (13-21 Aug), RideLondon-Surrey 100 (31 July), and the Great North Run (11 Sept). Plus it isn't long until the Olympics begin, and I can finally show off my pole vaulting skills.

I'll need a rest after all that excitement, maybe I'll even need a holiday, and I am so very ready to be swept away to exotic, and not so exotic climes all around the world. I have my paws crossed that a family will take me with them and take lots of photos of me for the PSPA community to see.

It has already been a fantastic year so far. I have been to the jungles of Costa Rica and down to London to

join our amazing marathon runners. I was, quite simply, brilliant, and I smashed my PB by over an hour. It took a lot of training to get so fit, and the taxi ride halfway through really helped. When I reached the PSPA reception at Carlton House Terrace, I had a lovely massage, a cup of tea, and a nice sandwich (no salmon, though).

To see so many PSPA supporters was just fantastic – I am so proud of our runners, and the astounding efforts they put in to raise as much funds and awareness as possible. I hobbled home a tired but very happy bear.

Research

One of my highlights so far this year was my visit to Cambridge University where Patri Vazquez Rodriguez, a student working on a PSPA-funded project, showed me around the labs. I had a scan, had bloods taken, and gave a talk on the importance of funding for research into PSP and CBD. She was a lovely host, and I also got to practice my impeccable Spanish. Merci... oops, I mean gracias, Patri!

We would love to know where Hope has travelled. Send your photos and details to hope@pspassociation.org.uk. Buy your own Hope at www.pspassociation.org.uk/shop

My Travels

My passport has hardly been put away so far this year. I had an amazing time in La Palma taking in some spring sunshine, then it was off to Costa Rica for a tour of the country. I rode a horse through the dry forest, zip-wired through the jungle, met toucans, poison dart frogs, sloths, and howler monkeys in the rainforest, before a close encounter with some Cayman crocs on the Caribbean coast. I dipped my paws in the Pacific, took in the San Jose skyline, and spoke to many locals about PSPA. All that and I only needed one diarrhoea tablet!



Upcoming events

August Fundraising Week

JOIN in the fun between 13-21 August, and raise as much as you can for PSPA!

Fundraising comes in all shapes and sizes, so no matter how big or small, we'd love for you to take part in August Fundraising Week. Host a charity barbecue for friends and family, get in the Olympic spirit and enjoy a games day or sport match, or sit back and relax and enjoy a wine and cheese evening – perfect for a summer's night.

It would also be great to have the

young ones involved, and as it's 'schools out', have fun with sack races, egg and spoon races, coconut shies, and three-legged races. No matter what your age, cake is sure to be a favourite, so gather a group of friends and enjoy a bake sale, or coffee morning!

No matter how you choose to help PSPA, we will supply you with all the materials you need to make your event stand out. Ask us for balloons, flags, T-shirts, fact cards and leaflets, and we'll post out them to you straight away.



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

A royal run

IT was a wonderful race. I really enjoyed it – Erik De Haan, Team PSPA Runner 2015

Autumn may seem a while off yet, but not for Team PSPA runners in this year's Royal Parks Half Marathon!

London's most scenic running event on 9 October, is a special occasion, and we wish all of our runners the very best of luck.

Join Team PSPA, and be part of this iconic half marathon.

A jolly day out



WHAT better time to start thinking about Christmas than the height of summer? Applications for this year's wonderfully jolly Santa Run are now open. This is a perfect event for groups of family and friends to take part. With distances of both 5k and 10k, the race is open to all abilities, plus you get a free Santa suit!

To take part in any of these events, or to find out more call us on 01327 356132, or email events@pspassociation.org.uk



Strikeback against PSP and CBD

OUR new Strikeback Funds have been created for everyone who wants to strike back against PSP and CBD.

They are easy to set up, just name your fund, register it and you're ready to go! You can channel your fundraising energy, either on your own, or with your family, friends or colleagues to help fightback against these dreadful diseases.

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

Email strikeback@pspassociation.org.uk, call 01327 322419 or go to www.pspassociation.org.uk/strikeback

A runaway success

THE sun shone on what was an amazing day of running in the South Downs on 22 May.

"I'm blown away with all the positive feedback, and it looks like that they all want the event again next year!"

Organised by Ken Finlay, whose wife Mary lives with PSP, over 500 runners took part in the event, with races taking place over 1km, 5km, and 12km.

Those cheering the runners on were entertained by the many stalls and attractions that made the day even more special, including cake sales, raffles, a barbecue, and even bouncy castles.

The event came on the final day of our PSP Awareness Week, and every runner was handed a goody bag complete with PSPA fact cards.

Ken said: "I'm blown away with all the positive feedback, and it looks like that they all want the event again next year!"

Thanks to Ken, around 500 more people now know about PSP and CBD, and we are very grateful to him, and his team of volunteers.



Bar Mitzvah marvel

THIRTEEN year-old Noah Shulman-Miller from London decided he would celebrate his Bar Mitzvah in May by supporting five charities, and PSPA was lucky enough to be one of them.

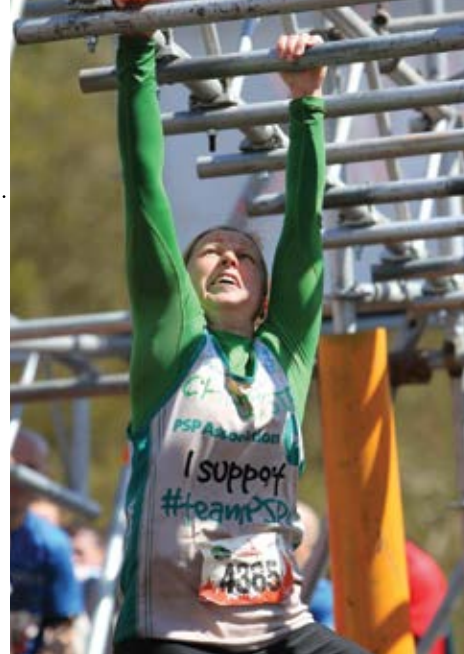
We are close to Noah's heart as his mum, Sarah Miller, lost her mother, Judy, to PSP.

Noah decided he would take on nine big challenges to raise funds, and so far he has raised over £3,000!

Supported by his family and friends, Noah has taken part in a 2km swim

with his mum, walked 25km along the Thames crossing 16 of its bridges, cycled 23km around Ashfield Cycle Circuit, taken part in an 18km stadia challenge, been on a 16km walk to 30 of London's iconic landmarks, and walked a further 13km from Bevis Marks to New North London Synagogue.

After all that he still had the energy to take part in the 5km Great Ormond Street Hospital Race for Kids. With ascents of Mount Snowdon and Scafell Pike planned, his amazing fundraising journey is sure to hit the heights once more. We



Triple challenge

CHRISIE Coyle, from Brighton, completed three challenges in three consecutive months, and raised nearly £350 for PSPA!

In March she abseiled down the Spinnaker Tower in Portsmouth, in April she ran the Brighton Marathon, which she followed with a Tough Mudder event in May.

Of the Tough Mudder, Chrissie said: "The orange wires give off little electric shocks and made me fall over which I thought was very funny. I liked it much more than the marathon, and most of it I enjoyed!"

Chrissie is inspired to support PSPA by her mum Mo Lumsden, who was diagnosed with PSP in 2012.



Noah Shulman-Miller

are all so proud of Noah's efforts, and his commitment and determination to help those in need are admirable. Well done Noah!

Sugar-free fundraising



Maya, Sarah and Zachary

IF you thought running a marathon was tough, then how about giving up chocolate, sweets, and biscuits for 365 days!

For a whole year, Sarah Robinson from Luton and her children Maya, 12, and Zachary, eight, went without their favourite snacks to raise funds for PSPA in memory of Sarah's Dad, Gerald Marshall, who sadly passed away last July after living with CBD.

Supported by Sarah's husband Simon,



Luton Christian Fellowship Friday Night Club

who ran a half marathon for the family's campaign, and the Luton Christian Fellowship, particularly Victoria Joyner who runs the kids' Friday Night Club (FNC) there, the Robinsons raised over £4,000!

Victoria said: "The other children at FNC have been giving their spare change at the end of every Friday night as they have been so inspired and amazed by Maya and Zachary's commitment. On the last Friday we had a onesie night, and

managed to raise an extra 50 pounds, and this all added up to £225.55."

The challenge ended on 9 May, on what would have been Gerald's 71st birthday, and to mark the occasion the family enjoyed a meal out with plenty of chocolate pudding for dessert!

Sarah said: "Hopefully this money can help PSPA in some small way. We would have been lost without you."

A huge well done and thank you to the Robinson family.

Gearing up for RideLondon – Surrey 100

THIS year sees Team PSPA take on the Prudential RideLondon-Surrey 100. Our riders will see city streets give way to country lanes before looping back into London to cross the finish line at The Mall.

A number of our cyclists will be pedalling for loved ones lost to, or living with, PSP. They include:

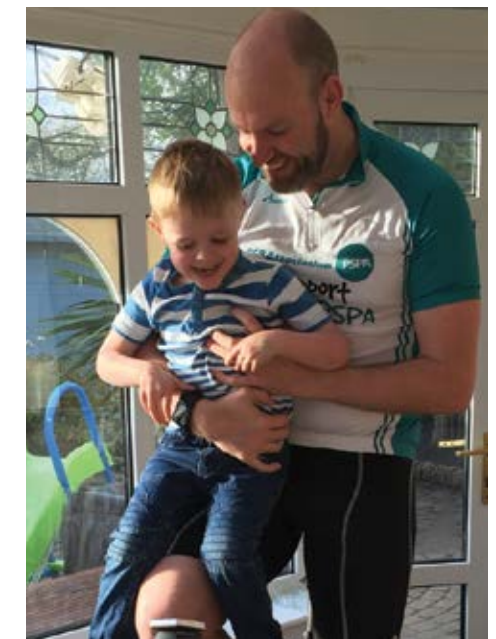
Dave Trevaskus from Weston-Super-Mare, Somerset: "My father-in-law lived with PSP and passed away three years ago. This is my small way of showing support for my wife's family and many others."

Clare Sellors and **Emma Bond** from London: "Our mother and grandmother,

Susan Peacock, lived with PSP for seven years which was sad and painful for us. PSPA was very helpful at the time, and we have been so impressed by how much it has grown as an organisation in terms of providing support and advice, and in its ground-breaking and very exciting research."

Darren Ford from Haywards Heath, West Sussex: "My dad lives with PSP, and in the last 12 months the symptoms have progressed. Dad will be with me in my mind for every pedal stroke during that day."

Best of luck to all our cyclists for 31 July. It is sure to be an unforgettable journey.



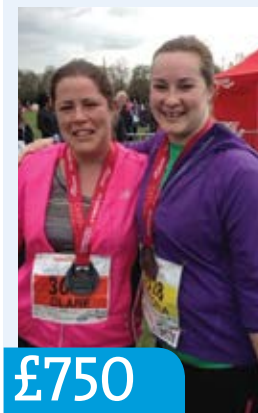
Dave Trevaskus

Half marathon heroines...

Super fundraiser Verna Gill raised a further £204 for PSPA by running the Coventry Half Marathon in February. Verna also ran for Zoe's Place, a Coventry-based charity, and was joined by her daughter Feebi.



£204



£750

The Cambridge Half Marathon presented Clare Robinson (pink jacket) with the opportunity to run her first ever long-distance race, and she ran a great time

of 2 hours 40 minutes! Clare ran in memory of her grandmother Valentine Saunders, who sadly passed away from PSP in 2015. She has raised £750!

... and a hero too!

Daniel Spellman completed the Leeds Half Marathon in May, and raised over £1,000! Daniel was cheered on by his dad and mum, Susan, who lives with PSP.



£1,000

Cakes into cash

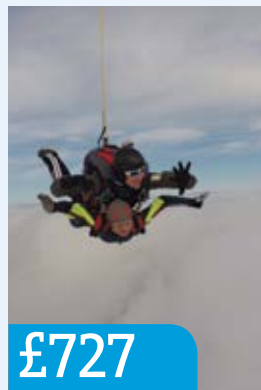
Once a month Duncan Shephard holds a charity coffee morning at home. In March, PSPA was his nominated charity and everyone in attendance was interested to hear about PSP and CBD. Duncan's helpers Jean, Daphne and Lynne served up a large selection of gorgeous cakes and £201.28 was raised.



£201

Flying fundraisers

Kate Glover wanted to do a challenge for PSPA which was exciting and scary. She chose skydiving and raised £727.



£727



£450

Darren Cooper took to the skies in February to raise funds for PSPA in memory of Bernard Cooper who lived with PSP. Darren raised a fantastic £450.

Cheque mates

We were delighted to welcome Maureen Horne and Barbara Crabb from our Hertfordshire Local Group to our Towcester offices. Our lovely volunteers delivered a cheque for £1,000 kindly donated by The Wenlock Lodge. Thank you!

They also received £1,000 from Dean, the Very Reverend Dr Jeffrey John. The money was raised by St Albans Cathedral Mission Giving and the cheque presentation was held in the Cathedral's crypt.



£2,000

Run Forrest, RUN!

Zoe Dillon ran the Manchester Winter Run in memory of her Dad, Charles Dillon. Running with Jack Murphy, Lasse Christensen, and Peter Knaggs who made up Team Run Forrest Run, Zoe and her team raised £900!



£900

Marathon men

Thank you to Ben Skinner and Ed Lawrence who ran the Paris Marathon in April for family member William Finlayson who is living with PSP. So far, they have raised over £2,000.



£2,000

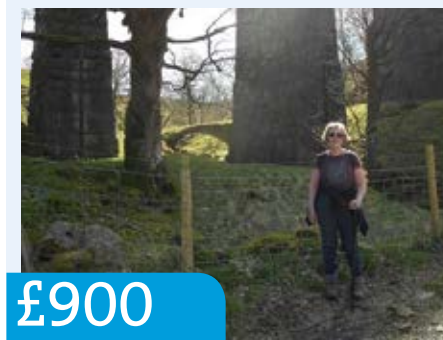
Gordon Easton ran the Greater Manchester Marathon in memory of Alan McGuinness and raised £816 for PSPA. Well done, Gordon!



£816

Quite a way...

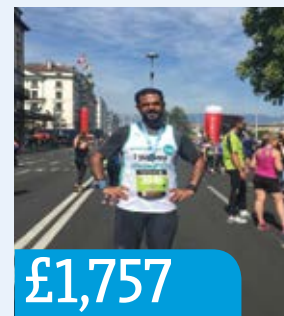
PSPA volunteer Sue Beech walked the 79-mile Dales Way in April and raised £900. Well done, Sue!



£900

More marathon men

Ameer Khanbhai took part in the Geneva Marathon, Switzerland, and raised £1,757.38.



£1,757

Tom Brown from Yorkshire ran for PSPA when he took part in the Greater Manchester Marathon in April. Tom raised £135!



£135

Vanessa's run

Vanessa Procter ran her very own marathon after she was unable to take part in the London Marathon due to an administrative error on our part. As thousands ran the capital's iconic course, Vanessa took to the countryside, much to the delight of her family and friends, those who donated to her Just Giving page, and all at PSPA. We are grateful to Vanessa for not letting the disappointment discourage her from running. She will take on the Great North Run in September.



Muddy money

Ed Morgans, Trevor Hearn and team took part in Tough Mudder, and they raised nearly £500. Trevor said: "The four of us that started managed to make it round, and first timers did it in four hours. We were looking rather damp and cold at the end. It was an amazing day."



£500

Mountainous achievement

In April, Lancashire's Steven Ball took part in a Three Peaks Challenge in memory of his Mum, May Ball. With their fundraising target of £1,000 met successfully, Steven and his team could focus on scaling the UK's highest peaks. After tackling the snows and -13°C temperatures of Ben Nevis, Steven said: "The next 24 hours were a whirlwind race through Scotland, England (scaling Scafell Pike at 2am in pitch black conditions), and finally Wales. I now understand the real meaning of the words endurance and exhaustion."



£1,000

MAKE A LASTING DIFFERENCE



Making a regular donation to PSPA ensures we have a steady income and gives us the confidence to forward plan everything we do.

Your generosity enables us to commit to funding vital research into PSP and CBD and to continue providing information and support to families affected by the conditions through our helpline and local groups.

By becoming a regular giver, you are making a positive lasting difference to people living PSP and CBD and those who care for them.

- £10 provides a copy of *Your Personal Guide to PSP*
- £20 pays for one person to attend our Family and Friends Day
- £50 funds laboratory equipment for a day's research



It's quick and easy to set up a regular donation to PSPA
Visit: www.pspassociation.org.uk/donate
Call: Gail Cheeseman on 01327 322419
Email: gail.cheeseman@pspassociation.org.uk