

PSP Matters

Winter 2017



Inside: Respite care, its importance and benefits

Respite care

How it can help and how to access it



Volunteering

Welcome to new volunteers



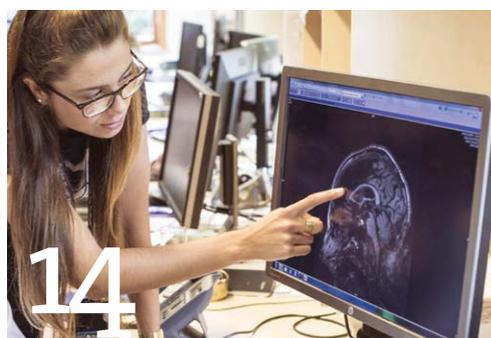
Thanks to you

Our energetic fundraisers



Study day

Health and social care professionals come together



Research around the country

Where and what's happening in our Research Network



Santa run

Our largest ever group take part for PSPA

Cover: Steve and Anne Ruddick share their experience of using respite care.

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.

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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)



As some of you may know, Fergus Logan has moved on after six years as the Chief Executive of the PSP Association, and it is the right time to thank him for the work that he has done to drive us onwards and upwards.

So who am I? I started working for our Founder Michael Koe back in 2005 on a part-time basis to expand the support that we gave to families, and I left after a period as the interim Chief Executive after handing over to Fergus, who could then focus on the task full-time. History has repeated itself, and I am now back as Chief Executive, again until the right person can be recruited for the long term.

So what has changed in the intervening six years? Our new Research Network is trailblazing the search for answers in PSP and CBD, increasing our understanding of the disease progression and bringing closer the point when an effective treatment becomes a reality. We are now in contact with 2,000 families trying to manage this condition. Our volunteer programme has expanded from an idea to almost 100 of you supporting those affected by PSP and CBD through our local group network, helpline and support workers. My sincere thanks and appreciation go out to all of you who are involved, for the support you give to families and each other, and for your enthusiastic fundraising. We have no statutory support, and without your continuing fundraising efforts we would be far less effective. Our focus for this year is providing more opportunities across the UK for family and friends to get involved in raising funds. You can find our more by visiting the website at www.pspassociation.org.uk

I also want to reassure you that I am not here just to keep the seat warm for my successor. I have invested too much over the years in this great project for that. After the successful launch last year of our 'Red Flags' for GPs to ensure that people with symptoms of PSP are referred to the right specialist, we will be focusing on earlier and accurate diagnosis, and this will be the theme of awareness week in 2017. We are also nearing the completion of a review to see how we can further improve our support to families, both directly and by educating health and social care professionals you will hear more of that in later issues.

I wish you all well for the coming year and I look forwards to renewing some old friendships.



John Chandler, Chief Executive

WORKING FOR A WORLD FREE OF PSP

Network researchers share progress



Research fellow Dr Ed Jabbari and network co-ordinator Dr John Woodside chat to colleagues over lunch at the meeting.

LAST October, our Research Network Principal Investigators (PIs) gathered for a meeting at the Royal Society of Medicine to share their progress and discuss potential new avenues of exploration. With all seven network centres now recruiting participants to the groundbreaking core study, PROSPECT, this was an excellent opportunity for the lead researchers to share plans for their particular areas of expertise, be that genetics, brain imaging or biomarkers.

The value of the network's collaborative nature was clear, with researchers able to quickly share and access the large amounts of samples and data needed for easier comparisons and more rapid progress. Participant numbers are already well into three figures, which would previously have taken a centre working alone several years to achieve.

There were updates on how the blood samples collected during the PROSPECT study will be used in genetic research and how the large amounts of detailed

clinical data will also allow scientists to link the genetic information to what is actually happening to the patient. We also heard how a special secure computer network will be used to share highly detailed brain images between centres.

With PROSPECT's infrastructure and protocols already helping to get additional projects, such as the European CBD registry (see *PSP Matters* Summer 2016), off the ground, the researchers discussed how the network is in a strong position to negotiate for additional sources of funding and to become a hotbed of further studies, possibly including a clinical trial.

Thanks to your generous support, the Research Network is really starting to 'up the pace' of PSP and CBD research in the UK. As one of our Principal Investigators, Prof James Rowe, put it: "The PSP Association should be proud of coordinating the research community in this way." We couldn't have done it without you!

New information sheets

For people living with PSP and CBD: *A Guide to Tissue Donation for Research* – This information sheet explains how donated tissue may be used and how to go about arranging for donation.

For health and social care professionals: *NHS Continuing Healthcare- Guidance Notes for Health and Social Care Professionals* – This information sheet is to provide guidance to health and social care professionals involved in the CHC assessment process.

Contact the PSPA helpline on 0300 0110 122 for more information.

Three cheers

OUR Helpline volunteering project has celebrated its third anniversary!

The project, launched in 2013, has proved to be a huge success enabling people to access this vital service every weekday evening.

A big thank you to all our volunteer Helpline Assistants and the Helpline staff for supporting them.

If you would like to find out more about becoming a volunteer Helpline Assistant contact Wendy or Nicola on 01327 356134.



'Huge momentum' at symposium

ALMOST 150 delegates from across the globe gathered in Jersey City, USA, at the end of October for the annual international research symposium organised by our colleagues at American charity, CurePSP.

"This symposium has brought together the best minds in neurodegenerative science from quite a few countries."

Described by CurePSP as 'surpassing all expectations', the event featured speakers carefully selected for their outstanding work in the field of neurodegenerative disease research. With last year's attendance doubled, it's clear that there is a growing impetus within the international research community to work together to put an end to PSP, CBD and related conditions. Here at the PSP Association, we are keen to work alongside CurePSP and other



international partners to build on this in the future.

Dr Alex Klein, Cure PSP's Vice President – Scientific Affairs, said: "This symposium has brought together the best minds in neurodegenerative science from quite a few countries. This interest in the field has a huge momentum behind it and I can see the event being even bigger next year, bringing the key players in neurodegeneration research together to find a cure for these devastating diseases."



Red Flags Campaign 2016

AS we mentioned in our autumn issue, Red Flag posters were sent to over 10,000 GP practices around the UK. We hope that now every GP's surgery in the UK has received a Red Flag. Carol Amirghiasvand, Helpline and Information

Services Manager said: "It will take some time before we know whether this has improved referral times to a neurologist and the time to diagnosis. We hope to be able to measure the impact of this successful awareness raising by early 2018."

Crowd Funding for the future of research

MANY of you will have received our autumn appeal for support for our exciting Research Fellowships at University College London and the University of Aberdeen.

Thanks to our funding commitment, young neurologists Edwin Jabbari and Diane Swallow will spend the next three years investigating key factors around diagnosis, progression and standards of care. Not only will they complete valuable work, they will also be laying the foundations for future careers in PSP and CBD research, making a massive difference to continued future advancement in the field.

For the first time we are using Crowd Funder to promote our appeal online. This means that you can not only make a donation via Crowd Funder yourself, but you can also easily spread the word among friends, family and colleagues by using Crowd Funder's straightforward sharing options for Facebook and Twitter. The link can also be emailed.

Visit www.goo.gl/TQMmpU for the London fellowship and www.goo.gl/Xlg0oL for the Aberdeen fellowship. Thank you for your support!

Volunteers' Annual Workshop

MORE than 20 volunteers joined staff at the annual volunteering workshop which took place at Coleshill, Birmingham on Saturday, 8 October. It was a good opportunity for everyone to catch up with familiar faces and get to know new ones!

A packed programme included a lively, hands-on session on basic First Aid training, which received great feedback.

During the afternoon session, helpline volunteers and support workers joined Carol Amirghiasvand, Helpline Manager, and Jules Brown, Helpline and Information Services Officer, to learn more about Corticobasal Degeneration (CBD) and the impact it has on the family.



“Recently we have seen more people contacting the helpline with CBD and it is clear we all need to increase our knowledge to be able to support people affected by this condition.”

Carol Amirghiasvand

Another successful study day

More than 150 health and social care professionals supporting families affected by PSP and CBD around the UK attended the PSPA study day in Newcastle.



“Very good event. All the speakers were lively and seemed very committed and passionate about the subject”

“Great care and attention to detail – good broad but deep coverage obtained by the workshop methodology”

“Everything ran smoothly and efficiently”

“Very well organised”

“The most interesting and enjoyable training I’ve been to in a long time”



THIS free event was held in October at St James Park Football Stadium, Newcastle. The event was open to all professionals with an interest in both conditions and included consultants, physiotherapists, PD nurse specialists, speech and language therapists, care workers, commissioners, social workers and community matrons.

The day opened with a presentation on PSP and CBD from Dr Neil Archibald,

followed by four workshops where delegates had the opportunity to learn more about the management of PSP and CBD. Workshops included Palliative Care, Speech and Language Therapy, Physiotherapy and Occupational Therapy and the Role of the Keyworker. The day concluded with an update on Research by Dr Louise Wiblin.

Peter Daniels, PSPA’s Director of Information and Support, said: “We

were delighted to welcome so many professionals to our study day. Thanks to everyone who attended, particularly our speakers for sharing their expertise.”

The 2017 Study Day will take place on Wednesday 18 October in Milton Keynes. More information will follow in later issues of PSP Matters.

Respite Care: What is it, how might

Providing the best possible care to a loved one often brings real rewards with a sense of pride and achievement.

BEING a carer (as well as a husband, wife, partner, son, daughter, relative or friend) is a demanding role and the progressive nature of PSP and CBD can mean it is an increasingly difficult one.

Anne and Steve Ruddick live in North Somerset. Steve has a PSP diagnosis and is cared for at home by Anne with some support from paid carers. He has respite care in a local nursing home for one week in every six.

“It was heart breaking the first time I left him...I felt so guilty. Even now, the first day he’s in respite I find it hard and have to make sure I have something planned for that evening.”

“Respite is for me but it’s part of his care package” says Anne. “These weeks are essential to Steve’s welfare. I’m the most important person in Steve’s world. He accepts that I need these weeks off to rest, recuperate and live a bit. Nobody can do a 24 hour a day job, seven days a week without burning out.

“It was heart breaking the first time I left him...I felt so guilty. Even now, the first day he’s in respite I find it hard and have to make sure I have something planned for that evening. But now I no longer feel guilty. I see it as an essential part of his care. It was only after Steve had had two or three respite care breaks that I really



Steve and Anne Ruddick

realised how much I needed it.”

Anne continues, “Respite breaks allow me to live again, and not to have constant worry. Not having to ‘clock watch’ is the biggest thing. You can relax. You have time to do other things, go out for a meal, see friends, enjoy a glass



of wine. It’s lonely being a carer. You feel better able to cope psychologically when you know you will be released, at a set time, from the pressure you’re under. Booked respite is very important.”

During a recent respite care break Anne went to visit her son at his house for the first time in five years. “I suddenly realised I’d missed five years of seeing my granddaughter grow up in her own home. Sadly their home isn’t accessible for Steve so they visit us but it’s not the same.”

Anne and Steve have been able to use respite care creatively. Recently their

it help and how do we access it?

Carers UK statistics reveal that 83% of all carers feel stressed. But as Age UK says, 'Having a break doesn't mean you are letting down the person you care for.' The reverse is often true. Respite care can help maintain a carer's ability to care for their loved one at home, or help someone decide if an alternative best suits their needs. PSP Matters has taken a look at the experience of one couple.

daughter, Karen, arranged a respite care stay for Steve at a nursing home near her in Devon. This allowed Anne to spend time with Karen at her home and for the three of them to go out together to the theatre (something Anne couldn't have done with Steve unaided). Anne explained, "That week Steve and I were able to be a couple without me having to do any of the caring; that was really special."

Anne advises other families to try to organise respite 'the minute you need it.'

Thank you, Anne and Steve for your honesty in this article.

What you need to know...

What is respite care?

- Respite care is temporary care designed to give carers of people with varying types of special needs a break from their caring responsibilities
- Respite care can be for a few hours or days or weeks
- It can be provided in a range of diverse settings including an individual's own home, another person's home, a residential care home, a nursing home, a hospice or a holiday centre
- Respite care can be arranged in advance or in response to an emergency.

How is respite care funded?

(There are some differences between England, Scotland, Wales and Northern Ireland - your local council can advise on these)

- If someone has been assessed as being eligible for Continuing Health Care funding (which is non means tested, NHS funding for those with complex nursing needs) there will be no charge for respite care and an agreement will be reached as to the frequency with which it can be offered
- Many hospices offer regular day centre support. Some offer emergency and/or occasional respite care breaks. There is no charge for hospice services. Your GP can arrange a referral to the hospice. Most hospices support

people through the duration of a life limiting condition, not just at the end of life

- Respite care breaks can be arranged in an individual's own home or in residential or nursing homes following an assessment of needs by your local Adult Social Care department (or its equivalent). A 'means test' usually applies so you may have to fully, or partially, fund the break (the value of your home is not included in this means test)
- Home-based respite care can be arranged privately with individual carers or care agencies. Residential or nursing home breaks can also be arranged and funded privately by directly contacting the homes concerned. Your Adult Social Care department can supply lists of local homes and agencies and details of their inspection reports.

Where do I go for more information?

- Your local council's Adult Social Care department (or its equivalent) has a responsibility to supply information and assess needs. A carer can also ask the department to carry out a Carers Assessment. This can identify a need for respite care
- Ask a specialist nurse
- Ask at a local Carers Centre
- Contact the PSP Association Helpline on 0300 0110 122

Who's who?

Meet our local coordinators, Pam Bower from Leeds and Nicola Daykin of Nottingham.

Hello Pam!

As with many of our local group coordinators, Pam Bower has personal experience of how lonely caring for someone with PSP or CBD can be.

When her husband, Malcolm, was diagnosed with CBD more than ten years ago there was very little in the way of support.

So when she was asked about volunteering as a local group coordinator, Pam was keen

to help people have a more positive experience and agreed to set up a local group in Leeds.

She said: "When I joined the



Pam with her late husband, Malcolm



Pam Bower, right, Leeds group coordinator with Beryl and Sid Mayhew, Leeds group helpers

Association there was no helpline or specialist care advisers. It was quite isolating, especially as people hadn't heard of CBD.

"I'm glad I made the decision to volunteer, running the group has been a really positive experience and it's my nature to help people whenever I can. I just wish there had been a group like this when Malcolm was alive.

"I always emphasise support group meeting is a bit of a misnomer because we are an informal get together with home-made cakes and tea and coffee. Everyone seems happy with what we do so we don't intend to change anything!"

The Leeds group has celebrated its third anniversary and in that time Pam, together with group helpers, Beryl and Sid Mayhew, has provided a welcoming and friendly environment for people affected by PSP and CBD to meet up and share experiences, information and companionship. Pam said: "Sid and Beryl didn't know anything about PSP or CBD but they just got involved because they

are those kind of people. Beryl is good with figures and offered to do the group finances and Sid does a sterling job, he carries the heavy stuff and then he goes into the kitchen and starts serving the tea and cake. They are just stars!"

"I'm glad I made the decision to volunteer, running the group has been a really positive experience."

Fundraising has also been an important element of the group's activities, with many group members

and family getting involved in different ways. Pam and Beryl raised more than £3,500 by using their skills to make and sell their hand-knitted scarves.

Other group highlights have included arranging a visit from the local MP which helped lead to a PSPA awareness raising event at Westminster. Then, group members Dave and Cathy Howarth had their fundraising efforts recognised when they received an invitation to a Garden Party at Buckingham Palace and invited Pam to

join them.

Pam said: "Our MP, Stuart Andrew, had seen an item about Malcolm and me in the local newspaper and got in touch. He came to our meeting and that led to the PSPA event at the Houses of Parliament. That was a huge positive!

"Dave and Cathy are brilliant. They really participate at meetings, they are a great family" she added.

But, for Pam, it is the regular meetings and the support that is given through them that is the most rewarding aspect

of volunteering.

She said: "I feel I am a friend to people who come to the group. I really feel that I am helping them and helping to raise awareness. At the last meeting a new couple came and they so enjoyed the meeting. Everyone made them welcome and made them tea. They said they didn't feel alone anymore and when I told them what they would get by joining the Association they were just thrilled. I went away from that meeting thinking it is all so worthwhile."

Hello Nicola!

FOR Nicola Daykin, our Nottingham Group Coordinator, volunteering with PSPA regularly inspires a wide range of emotions.

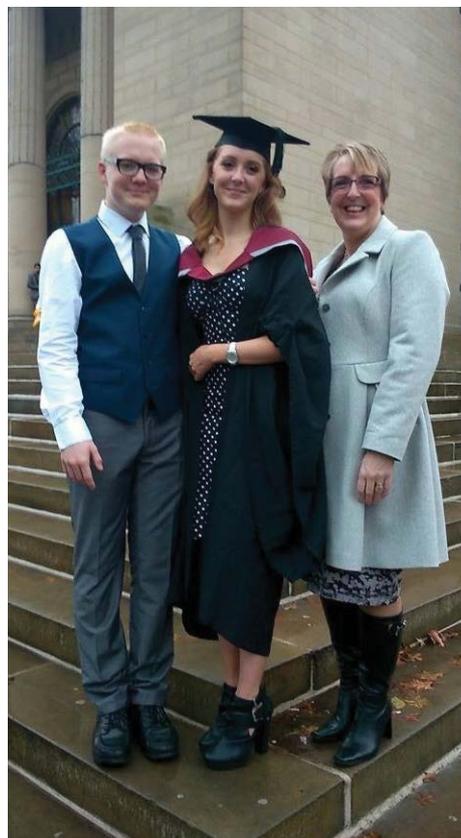
Nicola, who cared for husband David until his death in 2012, admits running the monthly meetings can bring stresses and strains but that it is also an immensely rewarding experience.

And now, the mother-of-two is happy to share the news that her family's involvement with PSPA has brought about an unexpected joy.

"I love being involved with it all because what you do others will benefit from. I find that very rewarding."

She was over-the-moon when daughter, Hannah, who featured in the PSPA video, Hannah's Story, broke the news that she had become engaged to her long-term partner, Craig Ball. The couple's romance got off to an unusual start after Craig, who lost his grandmother to PSP in 2009, spotted the video on the PSPA website and decided to contact Hannah.

Nicola described the shared happiness



Nicola with daughter Hannah and son George

on hearing about the future nuptials. She said: "Through such sadness, two families living 100 miles apart now have the most wonderful news anyone could want".

Through her own understanding of PSP, Nicola is aware of how much can be gained by supporting people living through a similar situation. But what has surprised her is the overwhelming sense

of privilege at being given a chance to share others' experiences.

She said: "As group coordinator you are privileged in that people trust you to walk this journey with them. It is a very personal journey and they trust you enough to walk alongside them even if it is only for a few hours every month. I feel it is a passion (for me) because of what we went through.

"My group is very supportive and caring to each other. We have lots of fun and laughter, let's face it, it has to be a crazy group because I'm the coordinator! But people are also respectful and sensitive to each other's needs.



Nicola Daykin

"I love being involved with it all because what you do others will benefit from. I find that very rewarding."

Thanks to you

The PSP Association relies on its fundraisers to maintain and develop new services and support for all those living with PSP and CBD. Here we meet some of those brave, intrepid and energetic people who have welcomed the challenge of the great outdoors...

Aiming high Fiona and Alison Turner

SISTERS, Fiona and Alison, scaled the heights of Ben Nevis back in October and were rewarded with breath-taking views, stunning scenery and a huge feeling of accomplishment. Together they raised over £2,500 in memory of their Mum, Margaret, who lived with PSP.

Fiona and Alison said: "Our Mum was an amazing wife, mother, gran, auntie, colleague and also a friend to all who

had the privilege to know her."

What made the climb all the more poignant was that Alison and Fiona's parents were engaged at the top of Ben Nevis in 1965. Margaret and Rob married a year later, meaning that 2016 was the year of their 50th wedding anniversary.

Fiona said: "It was a fantastic day. We had

brilliant weather, and couldn't have asked for a better experience. We can't thank everyone enough for their support and donations."

"We had brilliant weather, and couldn't have asked for a better experience. We can't thank everyone enough for their support and donations."



Physical Force Bill Searson

TAKING on some seriously tough events throughout 2016, Bill Searson handed over £844 after running and cycling across the UK.

Both Ben Nevis and Snowdonia were conquered, and the Hollymoorside 10k completed, leaving time to cycle the 105 miles from Chesterfield, Derbyshire to Filey, East Yorkshire and also take part in a triathlon in Perranporth, Cornwall!

"I decided this year to enter several physical challenges and raise funds for PSPA because my dad, Leslie, has been diagnosed with this condition," said Bill. "I want to say a big thank you to everyone who donated."



China Challenge Kathy Weston

HEALTH and Social Care
Professional and Fundraiser
Kathy Weston recently trekked
the Great Wall of China, raising nearly
£3,500.

It was a life-changing experience for her, and she is so pleased that she took on the challenge for PSPA.

“Some of us faced fears we didn’t even know we had, but there was always someone to get you through it.”

“I can scarcely begin to describe what an incredible experience it was,” said Kathy. “When you felt like you were flagging a bit someone would give you a boost, and jelly babies are great at helping you along! The camaraderie within the group and with our guides was brilliant fun and, at times, we stood on the wall helpless with laughter.”

The going did get tough for Kathy, but nothing was going to deter her from tackling the route head-on.

“It wasn’t a walk in the park! Some of us faced fears we didn’t even know we had, but there was always someone to get you through it.”

Would you like an adventure like Kathy’s? How about climbing Kilimanjaro, riding the rapids of the Zambezi, walking the timeless sands of the Sahara Desert or cycling from Vietnam to Cambodia? If you fancy an overseas challenge for PSPA, let us know!



PSPA has a dedicated team to offer advice and support to all fundraisers. Whether you need information on how to publicise your own activities, want to join an organised event or to check details on insurance or health and safety matters, please email events@pspassociation.org.uk or call 01327 356132.

More information is also available at www.pspassociation.org.uk

Research around the country

Our Research Network has brought together some of the country's leading centres of neurodegenerative disease research. As they forge ahead with the Network's flagship PSPA-funded study, PROSPECT (see News page 4), here's a peep into some of the other research activity that's underway...



Cambridge researchers study an image

London

UNIVERSITY College London is the hub of our Research Network and the main centre for the PROSPECT study. It's also the home of our Sarah Koe Clinical Research Fellowship, a post currently occupied by Dr Ed Jabbari.

"We still really struggle with giving an 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," said Dr Jabbari. "My research will look at ways that we can use brain scans, lumbar puncture and genetic testing to reliably predict and track disease progression."

He will use a bank of existing samples and scans, as well as those collected from PROSPECT participants, to investigate biological markers that may reflect the intensity of the disease in a particular individual and give an indication of how their disease will develop.



Dr Ed Jabbari

Oxford

RESEARCH Network Principal Investigator, Dr Michele Hu and colleagues at the Oxford Parkinson's Disease Centre are embracing smartphone technology and its potential application to medical practice. Working with Dr Max Little (Aston and MIT University), they have developed an easy-to-use smartphone app that can be used by patients at home to collect data on the progression of their symptoms and, while the original version has been designed for Parkinson's Disease, Dr Hu believes that adaptation for use in PSP will be possible in the future.

The app uses seven different tests to measure voice, tremor, walking gait and reaction times. Whereas it is normally very difficult for researchers and clinicians to monitor progression when they only see patients once every few months, the app can be used daily to collect information on how an individual's symptoms are changing over time. Dr Hu said: "This is a pragmatic, easy test that will ultimately provide doctors with a much more accurate picture of how their patient's condition is developing and could even support diagnosis."



Dr Michele Hu



Cambridge

RESearch Network Principal Investigator, Prof James Rowe and his team are at the forefront of brain imaging research and have access to cutting-edge scanning technology at the Wolfson Brain Imaging Centre at Addenbrooke's Hospital. In PSPA-funded projects, they are investigating how particular types of brain scans, known as PET and MRI, can be used to accurately diagnose disease and monitor progression. Their work should ultimately enable these scans to accurately reflect the efficacy of new drugs in future clinical trials.

"We are already seeing some exciting results from our PET scanning study, including significant differences in the images of PSP patients compared to other diseases like Alzheimer's, and we're connecting the PET signals to evidence from the Cambridge Brain

Bank," says Prof Rowe. "We have also started the collection of top-quality MRI scans from across the country for the PROSPECT study, using a new and secure computing infrastructure in place across the network sites."



Prof James Rowe

Newcastle

DR Lou Wiblin is part of the team at our Newcastle Research Network Centre. Alongside her work with PROSPECT



Dr Lou Wiblin

participants, she is also carrying out a study to better understand how the symptoms PSP and a related condition, Multiple System Atrophy, impact upon patients' and carers' quality of life. This involves carrying out extensive interviews, sometimes at peoples' homes.

Dr Wiblin says: "Part of my drive to do these interviews and analyse them thematically was to try and 'describe the indefinable', the personal experience of patients and carers. This sort of aspect is very hard to capture with just rating scales and surveys alone, and I am hopeful that these interviews will provide a real perspective for doctors and care providers."

The project will also investigate the need for palliative care and Dr Wiblin hopes that eventually her results will help neurology services to plan care better and ultimately improve patients' experiences.

Aberdeen

WE are delighted that the Scottish Chief Scientist Office has joined us in funding a Clinical Research Fellowship in Scotland. Dr Diane Swallow will spend the three years of the fellowship looking into the reasons for delays in diagnosis and assessing quality of care. She also aims to establish the number of people with PSP and CBD in Scotland.

"This fellowship is a wonderful opportunity to undertake research that should provide rapid practical benefits to people affected by PSP and CBD" said Dr Swallow. "It should also help inform service planners and other researchers. There is relatively little ongoing research in PSP and CBD in Scotland at present, which means that there is tremendous capacity for growth."



Dr Diane Swallow

Local group roundup



HAMPSHIRE group coordinator, Louisa Roberts-West organised a visit from Jackie Murray from The Hampshire Princess Royal Trust for Carers at a recent meeting. Jackie was able to tell the group more about services available to carers in the county.



OUR Liverpool group members enjoyed a post-meeting lunch at The Liner Hotel on 2 November. This friendly group meets every second month at the city centre venue. If you would like to join them contact group coordinator, Julia Bonner, at juliabonner29@gmail.com.



A warm Welsh welcome awaited around 18 people who attended the first meeting of the new Carmarthenshire group in October, held at the Whitland Town Hall. Welsh language can also be spoken at these regular meetings, so ymunwch gyda ni. Croeso i bawp!

Hello and goodbye



TWO volunteers from South Wales have joined our team. Liz Halpin-Williams, whose mother, Margaret, is living with PSP, is coordinating the new Carmarthenshire group, helped by Sheena Halpin-Williams. Welcome Liz and Sheena!

WELCOME also to John Kavanagh who offered to set up and run a new group in Poole after attending our regional event earlier this year. John, who is a carer for his wife, Elizabeth, will hold the regular meetings at Sainsburys Alder Heath.

For more details about our meetings see the Local Group insert.



SADLY, we say farewell to Ruth Keeble, who set up our Solihull group last year, and has handed over the role of coordinator to Hannah Wilson after the group's December meeting.

Also 'cheerio' to our Dundee coordinator, Kirsty Gemmell, who also stepped down at the end of last year.

Kirsty has been involved with the group for a number of years but is moving away from the area to take up a new job in Glasgow. We wish both volunteers the very best of luck and our thanks for all their involvement with PSPA.

If anyone is interested in taking over as group coordinator for Dundee, please contact Nicola Shaw on 01327 322416.

I really enjoy running the group. I get a lot of personal satisfaction from the feeling I am helping others and making a difference for them

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

A listening ear is a comfort in itself

Running the group has been more rewarding than I could ever have imagined

It's great to have someone say how much you have helped at the end of a call, you may seem to have said very little but you were there to listen when it was needed most

By working together, we can make a real difference to people affected by PSP and CBD.

Could you offer people a warm welcome?

Our local groups provide a welcoming and friendly place for people affected by PSP or CBD, including family and friends, to meet up on a regular basis to share experiences, information and just chat.

Becoming a **Local Group Volunteer** is a fantastic way to join a rapidly growing group of volunteers, help your local community and make a real difference.

Become a Helpline Assistant

Our volunteer helpline team offers a vital service providing information and support to people calling our helpline during the weekday evenings.

Each **Volunteer Helpline Assistant** has been trained to offer a supportive and helpful 'listening ear' to callers including people living with PSP or CBD and those who care for them, health and social care professionals and PSPA staff and volunteers.

Could you help us to provide regular contact?

For many people, living with PSP or CBD is an isolating experience. Although we have a network of local groups dotted around the country, we are aware not everyone can get to them or want this kind of interaction. Our Support Worker project offers people regular contact either by phone, email or home visits.

Support Worker Volunteers provide confidential emotional support and accurate information to enable people to make informed choices.

How you get involved depends on the skills, experience and time you have to offer and the volunteering role you choose to carry out, but you can be certain that it will have an impact on improving the lives of people affected by PSP and CBD.

Apply online at: www.pspassociation.org.uk/support-us/volunteer or to find out more about our volunteering roles contact Wendy or Nicola on: tel: 01327 356134 email: volunteering@pspassociation.org.uk

Looking ahead to 2017

Here we are again... heading towards another New Year, a time for reflection on what has passed but also an opportunity to plan for the future – perhaps set new goals and targets, aims and objectives.

Many PSPA supporters have already thought about what they can do to support PSPA and committed to fundraising challenges in 2017. If you would like to do something to help, but are short on ideas, here's some to get you thinking!

Events for 2017

Whether you want to run, cycle, trek, or climb your way to fundraising glory, there is an event to suit you!

New Year Special!

One too many mince pies over Christmas? New Year's Resolution to lose a bit of weight? Then sign up to the 'Pound for a Pound' challenge. Devised by fundraiser and supporter, Jon Garrard, you can ask your friends and family to sponsor you pound for every pound you lose in weight. Visit www.pspapoundforpoundchallenge.co.uk



British 10k Sunday 9 July

Last year's PSPA places sold out very quickly, so you'll need to hurry if you want to confirm your place on the starting line for this run around the magnificent city of London.



Ride London-Surrey 100

Sunday 30 July

Last year's 'RideLondon-Surrey 100' was a big success but together we can make 2017's event even more of a triumph! The RideLondon is now a major event on the UK calendar, and you can be part of it with 'Team PSPA'.

Superhero Run Sunday 14 May

Join thousands of other superheroes at Regent's Park, and take part in the annual Superhero Run! Whether you are a bat, a Wonder Woman, a spider, or simply super, we'd love you to be part of Team PSPA!



Edinburgh Marathon Festival 27 /28 May

With distances ranging from marathon to 5km, the Edinburgh Marathon Festival offers something for everyone. Join thousands of others and make your way through Scotland's beautiful capital city.

Trekfest Brecon Beacons 3- 4 June; The Peaks 2- 3 September

Trek either 25km or 50km through some of the most stunning landscapes in the UK for PSPA! Sign up for Trekfest and enjoy spectacular scenery and a real feeling of accomplishment.

New for 2017 Challenges closer to home

This year gives our fantastic fundraisers the chance to take part in more exciting and varied events than ever before! And even better, is that you can now find an event much closer to home. Have a look at the website or call the Fundraising Team – contact details below.



If running is your 'thing'...

Marathons and half marathons available include those in Manchester, Bristol, Chester, Milton Keynes, and even Amsterdam!

We have lots of half marathons and 10ks to choose from too - Yorkshire to Yeovil, Lincoln to London, via Plymouth and Paris, there is sure to be a running event for you!



How about a jump?

If that is all too much for you then let gravity do all the work! Strap yourself in, prepare yourself to feel as free as a bird and bungee jump for PSPA!



Or do you prefer some obstacles?

Take on the challenges of the world-famous 'Bear Grylls Survival Race', plough through Mudnificent's perilous quagmires, emerge victorious from the flames and freezing waters of 'Tough Guy: The Original', escape the zombie hordes at the 'Zombie Evacuation Race', or dash through clouds of colour at 'The Colour Vibe'. Take your pick!

THESE are just a few of the many fantastic challenges and events that are now available - whether you run, jump, swim, or cycle your way to the finish line, we will support you all the way! Alongside our annual events like the London Marathon and Awareness Week, we also have a new partnership with 'Sport for Charity', that offers lots of local running and challenge events – near you!

All fundraisers receive a fundraising pack and free PSPA

running vest or t-shirt, plus many other promotional goodies!

So don't let 2017 get ahead of you. Start planning your events now! Remember, if getting sweaty isn't to your taste perhaps a coffee morning might better fit the bill.

However you want to help PSPA, we will help you!

For more information please call: 01327 356132 or email events@pspassociation.org.uk or contact us via the website – www.pspassociation.org.uk.

Good luck to...

Scott Smith

Date for your diary: Saturday 18 February as Scott is organising 'Ed's Big Brain Ball' at the Lymm Hotel, Warrington.

The evening kicks off with welcome drinks canapés, followed by a three course meal with after-dinner coffee, speeches and live entertainment and a DJ until midnight. Of course, there will be also be exciting raffles and games! This will be a night to remember - a brilliant occasion for PSPA.

For more info please email Scott at BigBrainBall@yahoo.com

Laura Hudson

Laura is gearing up for the epic cycle from Vietnam to Cambodia. In preparation, Laura has taken on several Tough Mudder events, cycled hundreds of miles, held cakes sales and dance-a-thons to raise funds and awareness of PSP and CBD.

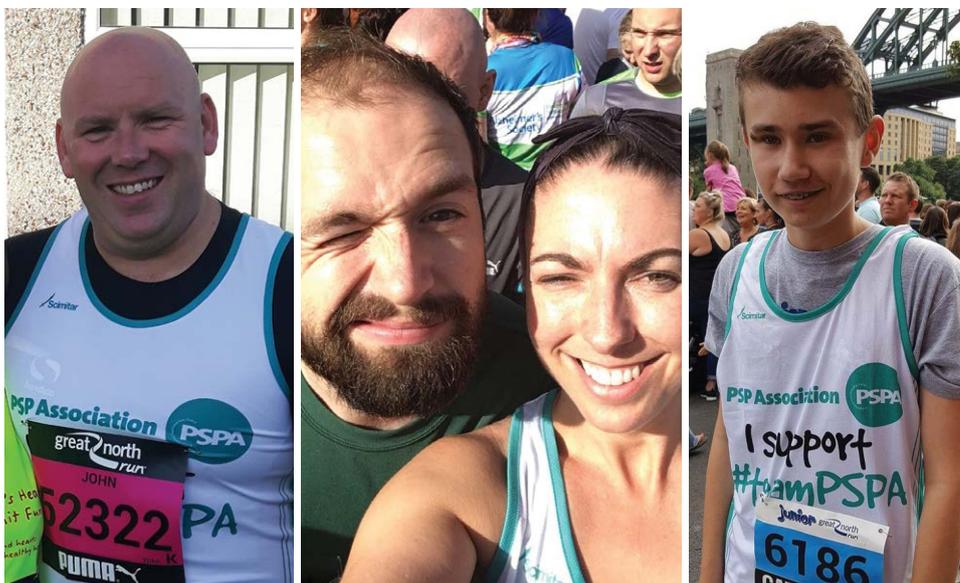


More ways you have helped

It always amazes us the lengths that PSPA supporters go to in their fundraising activities – proving that whatever your hobby or interest, there’s a way to help others whilst you enjoy your particular favourite pastime. So, sling the clubs in the car, lace up the trainers or put on a hat, here’s a round-up of some of your fundraising events..



“What an amazing feeling! Thank you again for letting me represent your charity, it was a great honour!”



Top left: Antoinette Oglethorpe, top right: Carol Johnson, bottom left: John McKenns, bottom centre: Stevie Lyth and Lisa Bird, bottom right: Ellis Moore

Great North Run

THE world’s most famous half marathon was completed by 13 Team PSPA runners. Thomas Whittle ran in memory of his father, Ian Whittle, who lived with PSP. Thomas said:

“The run was great and I managed to finish which was the main thing, and raised £2,400 – that was more than I expected, so that was great too!”

Other runners included PSPA supporter and fundraiser Lisa Bird, who ran alongside Stevie Lyth in 2:23.09, were sponsored for over £600.

Kelly Ruddy also took part, finishing in 2:56.00. Kelly said: “What an amazing feeling! Thank you again for letting me represent your charity, it was a great honour!”

Joining the team was Vanessa Procter who will be running the London Marathon for PSPA again next April. “It was hot but it was brilliant!” she said. “I really enjoyed it and the atmosphere was very similar to the London Marathon.”

Carol Johnson competed in memory of her friend, Doreen Lane.

“I had an amazing day! I finished the run in 2 hours 45 minutes and have raised over £600,” said Carol.

Away from the main race, PSPA was lucky enough to be represented in the Junior Race (on the previous day) by Ellis Moore. Ellis remembered his Uncle, John Mooney, and collected over £250.

Thank you Thank you Thank you Thank you Thank you Thank

Thames Bridges Trek

FOUR hardy souls battled heavy rain as they took on the Thames Bridges Trek - a 25km route crossing 16 London bridges.

Taking part for 'Team PSPA' were Navpreet Juty alongside her friend, Electra Wallington - with sponsorship of over £250.

Leigh Mitchell and Mark Hanson also trekked, in memory of Leigh's dad, Leslie. "We had a great day although it was a bit wet. We are already planning to do it again next year!" said Mark. Leigh and Mark raised over £1,000.



Top: Leigh Mitchell and Mark Hanson, bottom: Navpreet Juty and Electra Wallington



New Zealand Golf Day

OCTOBER saw the return of the annual PSPA charity golf day held at the New Zealand Golf Club, Surrey, organised by PSPA founder, Michael Koe. On a clear and crisp morning, 67 golfers took to the fairways to 'hit' the £3,265 fundraising total.

Trophies were presented when all had returned to the 19th hole, and the team to emerge victorious was 'Gordon's Guildford Healthcare' made up of Paul Robinson, Steve Dacey, Andy Norman and Iain Pickering.

Royal Parks Half Marathon

ON a glorious autumn day in the Royal Parks of London, thousands of runners gathered to take part in this iconic event.

Team PSPA was well-represented and did an exceptional job in raising both awareness and funds. Rob and Liz Platt (who between them are taking on every PSPA running event!) ran some great times, as did Sarah McKeown, Charlotte Swain, and mother and daughter, Katherine and Tiffany Leftwich. Rachel Heath also competed - raising £3,300 by taking on this challenge.



Top: Rob and Liz Platt, bottom left: Rachel Heath, bottom right: Sarah McKeown

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

Hope's adventures

Hope, our awareness-raising mascot, now has her own diary.

Here she will tell you all about the places she's been around the world, and the people she has met...



Happy New Year!

I skipped hibernation once again this winter, not only to indulge at Christmas, but also because I was far too busy helping our amazing supporters raise funds and awareness for PSPA.

I've travelled to **Spain** with Tracy, Aaron, and Kodi Shackcloth to Tarragona and Barcelona. I visited an ancient Roman amphitheatre, then it was off to the Camp Nou, home of F.C Barcelona.

(They offered me a three-year contract, but I said I am dedicated to the PSP Association.)

It was wonderful to travel with the Shackcloths. Tracy is a PSPA supporter as her Mum lived with PSP. Tracy said: "My son wanted Hope to accompany us on our summer holiday to raise awareness of the condition." I was very pleased to do so!



And whilst I mention football, I met a couple of handsome players at a photo shoot with our charity partners, **Northampton Town F.C.** This is me with David Buchanan and Marc Richards who played a vital role in securing the Cobblers' promotion from League 2 last season. They were very pleased to meet me and were only too happy to hear about everything we do at PSPA.



I also donned a red hat to join the fun at the **Santa Run** – cheering on our biggest ever 'Team PSPA'. (I was nice and warm but it was a bit chilly for the others!)

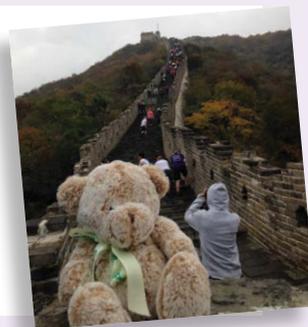


Late last year I was lucky enough to attend the **PSPA Study Day** held at St James's Park, home of Newcastle United! Bears don't usually associate with magpies, but I was very pleased to attend and met lots of amazing health and social care professionals, who work tirelessly to help those living with PSP and CBD. It was a very special day.

Here I am in Thassos, **Greece** with supporter, Lisa Murphy. I saw ancient ruins, a lovely beach, beautiful mountaintops and a peaceful olive grove. I also met some locals and told them all about PSP and CBD!



Here I am with Kathy Weston at **The Great Wall of China**. I had so much fun walking along the battlements and up the steep staircases, and the scenery was amazing. We had a marvellous time together. No pandas though.



I would love to go on holiday with other PSPA supporters, so am hoping some lovely people might take me away with them this year (hint, hint!). I travel light and even though I say it myself, folks love me! I am only too happy to meet them and increase awareness of PSP and CBD.

If you think you have room in your case for me, please email me: hope@pspassociation.org.uk.

Love, Hope

PS Just heard... I'm off to Vietnam and Cambodia with fundraiser Laura Hudson in March! Yay!



FANTASTIC OFFER

PSPA Challenges for only £99!

sign up now!

PSPA Association has lots of charity spaces available for incredible sporting challenges for a fundraising target of just £99. All you need to do is choose your challenge, decide whether you want to do it on your own or as part of a team and pay a registration fee of £25, which goes towards your fundraising total.

It really is that simple! Below is a selection of challenges available.

Runs

- Supernova Run 5K** – 1 April
- Hull 10k** – 18 June
- South Downs Trail Half Marathon** – 17 June
- Manchester Half Marathon** – 15 October
- Milton Keynes Marathon** – 1 May
- Chester Marathon** – 8 October

Obstacle

- Spartan Beast Edinburgh** – 22 July
- The Gauntlet Games Brighton** – 29 July
- Mudnificent7 Warwickshire** – 12 August
- Bear Grylls Survival Race Cambridge** – 5 August
- Bear Grylls Survival Race Manchester** – 9 September
- Bear Grylls Survival Race London** – 29 September
- Zombie Evacuation** – 5 November

*To see an extensive list of local events go to sportforcharity.com/charity/psp-association
When you sign up for one of our challenges you will receive a PSP Association running vest, fundraising pack and advice from our dedicated team.

For more details or to sign up call our fundraising team on 01327 356132 or email events@pspassociation.org.uk

*Please note not all events listed will be part of the £99 Challenge offer.

Your fundraising

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

On me 'ead



£1,000

Eccles' Adam Whitehead organised a charity football tournament at the Trafford Centre, Manchester. Fundraising for both PSPA and St. Anne's Hospice.

Aghhhhhhh!

Sisters, Kate Conroy and Carly Woodward took to the skies for PSPA. "We were pretty nervous as neither of us had done a skydive before, but we loved it and want to do it again!" Kate and Carly fundraised in memory of their grandad, Fred Glover.



£2,300

Down South



Over £700

Deborah Godfrey took on the mighty South Coast Challenge in August, a gruelling 100km route along the South Downs Way.

Eeek!

Daredevil, Amanda Fox from Bootle, rode the world's fastest zip wire in Snowdonia, in support of her Nan, Sylvia, who lives with PSP. Amanda whizzed along at speeds in excess of 100mph as she raced over a vast quarry, complete with lake!



Over £500

Jazzing it up



£400

Jazz maestro, Richard Exall held a musical extravaganza in Olney, Bucks in August. Playing to a room of over 100 people, he and his band, 'Richard Exall's Shooting Stars' were raising funds for PSPA and Cardiomyopathy UK. Alongside the great music, a tasty carvery and a raffle.

BBQ

The soggy autumn weather was happily avoided back in September when Richard Freeman held a charity barbecue at his home in Hull. Forty friends and family joined together for Richard's wife, Ann, who lives with PSP.



£350

Three peaks

Gaynor Gormley, and her sister, Gail, marched through mist and drizzle as they conquered the Yorkshire Three Peaks Challenge in September, to remember their Dad, Ray.

Gaynor said: "We wanted to mark the 1st year without him by attempting the 26-mile hike over the green and pleasant land of Yorkshire, the county where my Dad's life began 62 years ago. We had an amazing time. Such a fantastic experience despite the painful recovery!"



Over £300

Highland fling



£3,750

Our thanks go to the Harpenden Lions who chose the PSPA as one of their Charities of the Year and raised funds at their Highland Gathering. Accepting the cheque were Maureen Horne and Barbara Crabb from the Herfordshire Group.

Tri-athlete

Nichola Green swam, cycled and ran her way to glory as she completed a UK Triathlon.



Over £200

Dancing in the street



£2,200

Super fundraiser and long-time PSPA supporter, Elizabeth Birrell from Anstruther, Fife, held a street party to raise funds for both PSPA and The East Neuk Wheelchair Appeal. It was a fabulous day of live music, raffles, fish and chips, a barbecue, face painting, and cake stalls. A special mention to the local scout group for providing two marquees and to G. & J. Wilson Fishmongers who donated six stone of haddock!

Best Foot



£500

Andrea Eaton walked the 25½ mile Test Way in October in memory of her Mum, Tessa Tate. Supported all the way by her local Rotary Club, Andrea said: "I did it! It was a very well organised walk, and you can walk for whatever charity you wish. The company was great and the views were amazing."

Glorious mud

Jason Milsom led his two sons, George and Samuel, around the daunting Tough Mudder course in Cirencester. Jason took part in memory of his Mum, Pat, who lived with PSP. He said: "It's done! It was a hard day, and I'm blown away by how many people gave money."



£1,000



Your fundraising

Running for funds



OVER £500

Katherine Balmer had a merry time at the Robin Hood Half Marathon in September – in memory of her Grandma, Iris Burgoine, who lived with PSP.



£1,400

Tom Bryant went over the line in the Cardiff Half Marathon in October. "It was a brilliant experience, I really enjoyed it! I will definitely be doing it again," said Tom, who ran in support of his Dad, Nigel Bryant, who lives with CBD. Nigel spent 30 years in the police force and has a Queen's gallantry medal for saving a life.



£500

Amy Jones completed Great South Run at the end of October in memory of her Grampy, Michael Bird.



OVER £300

Carolyn Leggat and her 'Nursery Nutters' team ran the Baxter's 10k. The team, including Louise McLeish and Lisa Fairly, were supporting Carolyn's dad, Richard Pirie, who lives with PSP. Carolyn said: "I have been blown away by the generosity of my friends, running buddies and family." The girls were joined at the end by Gary Leggat, and Glynis Leslie. Glynis, in support of PSPA and the British Heart Foundation, had taken part in the Banchory Beast, a 10km obstacle race, the day before taking part in the Baxter's 10k!



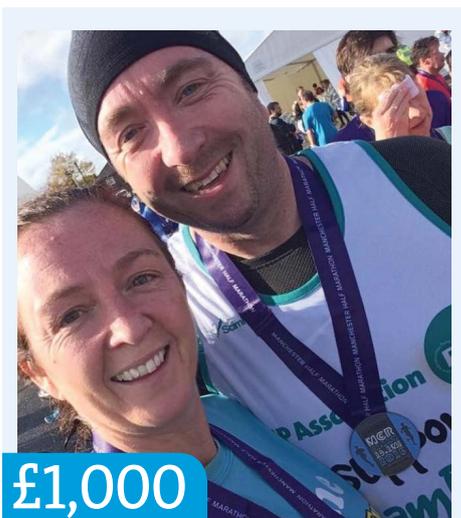
£2,300

Erica Wigg competed in the Kielder 10k in October, running for her Dad, David, who lives with CBD. Erica's sister, Alice Whitworth, did the Sheffield Half Marathon alongside her husband, Sam.



OVER £400

Running in memory of her friend, Terry Brand, Jacqueline Elson-Whittaker took on the Plusnet Yorkshire Marathon in October. Jacqueline said: "The week preceding the marathon and weekend was an amazing and overwhelming experience. I organised a bake sale and that alone demonstrated how people work together for a cause. It wasn't just me but friends, family and colleagues who helped me out." It was a real test of endurance for Jacqueline, as she had not done much running before. "Despite lots of training and preparation, it was one of the hardest physical and mental tasks that I have ever done!"



£1,000

Tony Mooney and his sister, Lynne Doyle, ran the Manchester Half Marathon in memory of Tony's father-in-law, Brian McDade, who lived with CBD.



£400

Fiona Moncur also finished the Cardiff Half Marathon. The weather was very kind to the runners - Fiona said: "It was a lovely sunny day. Perfect for running!"



OVER £400

Super Helen Hobbs ran the Great South Run, the 33rd event in Helen's fortyb4forty challenge. Helen is raising funds in memory of her Nan, Jean Watts, who passed away in January 2015 after living with PSP.

Santa Run 2016

On 4 December at London's Victoria Park, Team PSPA's largest ever group of runners took on the fabulously festive Santa Run!

THE runners took on the course on a beautifully crisp winter's day, and all had an amazing time raising funds and awareness for PSPA. Kerry Baker ran to support her Mum who was diagnosed with PSP 18 months ago, and was supported by Jenny Tanton, and 8-year-olds Joe Tanton-Baker and Fred Tanton-Baker.

Another family group included Rebecca Flanagan who ran with her two sisters Patsy Oliver, and Roseanna Munroe, plus brother-in-law Dion Oliver. Together they raised well over £2,000! The family affair continued as Charlotte Townsend ran with her Mum and sister, Jane Townsend and Hannah Townsend. Completing the line-up were good friends Alex Ridout and Emma Wayman who enjoyed running in familiar surroundings before they take on the Sierra Leone Marathon in May!

Sign up now to guarantee your spot at next year's Santa Run! Email: events@pspassociation.org.uk Call: 01327356132



Huge well done and thank you to all those who took part for PSPA



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.

