

PSP Matters

Winter 2016



Inside: Hospice care • Accessing information and support

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Cover: Terry and Jacqui Bock and their dog Henry visit Katherine House Hospice. See page 8.

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.

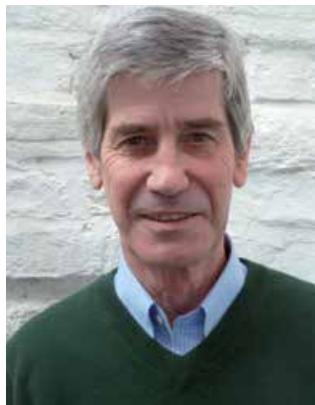
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PSP Matters is available as a pdf and can be downloaded from our website.

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Welcome...



Here we are at the start of a new year, and there's a real buzz at PSPA as we make exciting plans and set ambitious goals for 2016.

The PSP Association

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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

But it's also important to take time to reflect on what we achieved together in 2015, and what a busy year it was!

We spoke with parliamentarians at Westminster and Holyrood; met hundreds of you at family and friends days; informed health and social care professionals at our study days (page 6); and shared the latest in PSP research at a London reception (page 5).

We grew our local groups network, developed our information and support services (see page 16) and made a major investment in our PSP Research Network.

Quite simply, none of this would have been possible without you, our amazing supporters around the UK who tirelessly devote your time and energy to PSPA. Thank you.

While we made great strides in 2015, I know with your continued support we can achieve so much more.

This edition of PSP Matters is packed with ideas on how you can raise funds and awareness, or volunteer your time. If you need more inspiration, take a look at our pages on Facebook and Twitter.

So why not set yourself a challenge, have some fun, and feel the warm glow that comes from knowing you're making a difference for so many families affected by PSP and CBD.

A handwritten signature in black ink, appearing to read "Fergus Logan".

Fergus Logan, Chief Executive

WORKING FOR A WORLD FREE OF PSP

MSP visits Aberdeen Local Group

Our Aberdeen Local Group welcomed local MSP Dr Nannette Milne to a recent meeting where she met families affected by PSP and CBD and learned more about the conditions.

DR MILNE was invited to the meeting by volunteer group coordinator Alison Wood. Alison contacted the former doctor after she attended PSPA's awareness raising event in Holyrood in June.

Alison said the group was delighted to welcome Dr Milne (Conservative & Unionist Party North East Scotland) who is a member of the Health and Sport Committee.

"She was lovely and it was a very positive afternoon. She was keen to hear about issues that matter to our members who felt they were genuinely being listened to."

She explained: "She was lovely and it was a very positive afternoon. She was keen to hear about issues that matter to our members who felt they were genuinely being listened to.



Dr Nanette Milne MSP is pictured with members of our Aberdeen Local Group

"Dr Milne has also told us she is keen to receive more information on PSP and CBD and the work of the PSP Association.

"The group members were really pleased she came and listened to their experiences – it gave them a boost."

Speaking after the meeting, Dr Milne said: "It was really very interesting to meet the Aberdeen PSPA Local Group and to hear at first hand the experiences of patients and their families.

"PSP and CBD are clearly very difficult conditions to live with both for sufferers

and their carers. Both conditions are rare and difficult to diagnose.

"With the ongoing debate surrounding the planning for the integration of health and social care services in Scotland, now is the time to consider the best provision of services to PSP and CBD patients and their families."

Topics discussed included the need for more timely diagnosis and improved support post-diagnosis. Dr Milne also heard how the quality of services and support varies depending on where people live.



Simon Koe

Chair of PSPA's Board of Trustees, Christopher Kemball, has handed over the reins after five years in the role. Simon Koe took over as Chairman at a meeting of the Board in London in November. Simon is the eldest son of Sara Koe, who was the inspiration behind PSPA being formed in 1995. He has been on the Board of Trustees for 17 years.

Raffle winners

Congratulations to the lucky winners of our summer raffle:

First prize £500: M Read, Taunton

Second prize £250: S Jackson, Chapel-en-le-Frith

Third prize £50: E Gray, Thames Ditton.

Huge thanks to everyone who bought and sold tickets. Together you raised £14,930 towards our PROSPECT-MR research study. The study is being led by Cambridge University researcher Prof James Rowe, as part of our PSP Research Network. We really appreciate your ongoing support.

New development in potential drug treatment

RESEARCHERS from the Gladstone Institutes in California have discovered that a drug already in use for the treatment of arthritis can prevent the toxic accumulation of tau protein in an animal model of neurodegenerative disease.

The scientists were studying a mouse model of frontotemporal dementia (FTD) which, like PSP and CBD, involves the damaging accumulation of tau in nerve cells. In a study published in *Nature Medicine*, they show that a drug called salsalate, which is related to aspirin, could prevent the build up of tau and protect against some of the symptoms of disease in the mice.

Salsalate is already undergoing testing in people with PSP in a Phase 1 clinical trial in the USA. The main aim of this early stage of testing is to establish that the drug can be safely tolerated by people with PSP over several months but the trial may also give some preliminary indications as to whether salsalate has any positive impact.

Awareness Week 2016

Thanks to you, our 2015 PSP Awareness Week was a huge success – and with your ongoing support we know we can build on this in 2016.

For this year's Awareness Week (Monday 16 May to Sunday 22 May) we'll be asking you to help us get our message out to GPs and other health and social care professionals.

Better awareness of PSP and CBD within the medical profession is vital if we are to achieve our aims of earlier diagnosis leading to more timely access to support and services.

Please pop PSP Awareness Week 2016 in your diaries.



From left: Maureen Horne, Carolyn Ballantyne and Prof James Rowe meet HRH The Duchess of Gloucester

Royal Patron attends research reception

Our Royal Patron, HRH The Duchess of Gloucester, met PSPA volunteers, fundraisers and supporters at a reception in London.

The event on 11 November, was held to update supporters on our PSP Research Network, the focus of our investment in research.

The invited guests heard presentations from leading PSP researchers Prof Huw



Our expert panel

Morris, Prof James Rowe and Prof Nigel Leigh. The event was chaired by Sir Colin Blakemore, Professor of Neuroscience and a trustee of the Association.

He said he was impressed by PSPA's strategic commitment to research and explained the charity has a crucial role to play in bringing researchers together.

"Research is often a very competitive business with people beavering away in their own labs, loathed to share their research – that's not good for progress" he said. "Through the PSP Research Network there is a willingness to share data and collaborate with colleagues."

We have committed £872,000 to the PSP Research Network between now and 2018. Thanks to everyone who has donated to our recent appeal. To date you have raised £15,285.

There's still time to make a gift, visit www.pspassociation.org.uk/donate

Buzz at professionals' study days

More than 200 health and social care professionals supporting families affected by PSP and CBD around the UK attended our study days in Manchester and Glasgow.

OUR free events, held in October, were open to all professionals with an interest in the diseases.

Around 160 delegates joined us at The University of Manchester and a further 60 at the William Quarrier Conference Centre in Glasgow. They included consultants, GPs, physiotherapists, PD nurse specialists, speech and language therapists, social workers and commissioners.

The focus for this year's study days was Improving Quality of Life and topics for learning included PSP research, challenging behaviour, pain management, oral hygiene, continence management and nutrition.

Peter Daniels, PSPA's Director of Information and Support, said: "We were delighted to welcome so many professionals to our study days. Thanks to everyone who attended, particularly our speakers for sharing their expertise.

"The feedback was really positive, with delegates telling us they had learned a



great deal about how best to support those affected by PSP and CBD in their local areas. There was a real buzz around the room too with everyone keen to share their knowledge and experiences with others."

This year's PSPA study day will be held in Newcastle on 19 October.

More information to follow.



What delegates told us:

"Very well organised event, great support staff."

"Interesting and stimulating event. Really good to network with other clinicians who work with patients with PSP."

"Very informative well organised day with good mixtures of talks and opportunity to network."

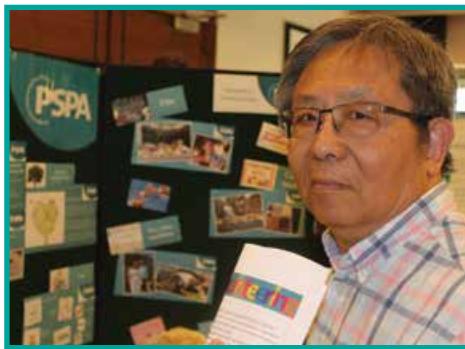
"I enjoyed it immensely. All the speakers were very interesting and I feel I have learned a lot."

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



Friendship and learning

We were delighted to meet so many families affected by PSP and CBD at our recent Family and Friends Days.



AROUND 115 people in total joined us in Cambridge in September, and Bristol in November.

Both days provided an informal opportunity for people living with PSP and CBD, their families and those who care for them to come together to learn more about research and care, the work of PSPA and to meet others affected by the diseases.

Peter Daniels, PSPA's Director of Information and Support said they were very successful events.

"A big thank you to everyone who came along to our Family and Friends Days, particularly our presenters who gave their time to share their knowledge and experience with us all."

"It was wonderful to meet so many members of our PSPA family, many of whom had travelled a long way to join us, and to see everyone sharing experiences and making new friends."

Future PSPA events will be advertised in PSP Matters and on our website www.pspassociation.org/events, Facebook, and Twitter.

"A big thank you to everyone who came along to our Family and Friends Days, particularly our presenters who gave their time to share their knowledge and experience with us all."



Hospice care – strength and comfort in difficult times

"Like many other people we thought hospices were only for patients with cancer towards the end of their lives," says Terry Bock who has PSP. "But Katharine House Hospice cares for patients with other conditions too, including neurological, cardiac and respiratory ones."

THE support they offer Terry, who lives in Oxfordshire with his wife Jacqui, and many others is very special but thankfully also very typical of modern hospices across the UK. As their day hospice manager, Mel Mobley, explained: "It's not only about the patient, it's about supporting the whole family, and it's about looking at the physical, social, emotional and spiritual wellbeing of the individual and taking a holistic approach."

Hospices are mostly run by charitable organisations but in some cases hospice care is provided by the NHS. However, hospice care is a style of care and much of that can be provided by a local hospice in your own home (or a care home) as well as in a day hospice or as a hospice in-patient.

After a career in the army and local government, Terry first noticed difficulties while playing golf 10 years ago. He explained: "I started to limp when walking around the golf course."

In 2008 Terry was diagnosed with Parkinson's Disease, but in 2011 his diagnosis was changed to PSP. Soon after, Terry was introduced to Katharine House Hospice near Banbury where he sought guidance with completing an Advance Decision to Refuse Treatment (ADRT).

A Clinical Nurse Specialist in Palliative Care from Katharine House Hospice visited him and Jacqui at home as did a Consultant in Palliative Medicine.



Terry Bock enjoys painting in the hospice's art room

Terry explained: "They gave a great deal of assistance in writing down my wishes in a format that is sufficiently detailed. At all times I was asked if I understood the ramifications of my wishes."

"Jacqui and I were then invited to go to the hospice and were immediately struck by the friendly and inviting atmosphere. We completed the ADRT and I was given the opportunity to attend the Day Hospice programme for one day a week, initially for eight weeks. After this I was offered a week's in-patient care."

"The hospice works really well with the help of many volunteers, including Mabel, the dog."

This gave the hospice the chance to monitor the progression of Terry's condition and provided a break for Jacqui from her full-time caring role.

Terry recognises the importance of support for Jacqui. "I feel like a three-year-old as I am getting much slower and I'm finding day to day life more difficult," he said. "It's hard work for Jacqui as I need her help with nearly everything I do. It's not called 'progressive' (as in PSP) for nothing. The staff at Katharine House Hospice are wonderful and highly professional. The care I receive is cheerful and helpful and everyone is treated with privacy and dignity."

The range of services hospices offer will vary. For example, some do not have an in-patient facility. Katharine House Hospice has been innovative in setting up a Neurology Support Group. This came about through collaboration with the Motor Neurone Disease Association and once a month brings together people living with a neurological condition and their families.

Terry and Jacqui look forward to this

meeting. "There is usually a speaker to talk about topics of general interest plus tea and cakes and a relaxing hand massage. And Henry, our dachshund, is welcomed to the meetings too!" Terry explained.

Terry currently attends the Day Hospice. He is struck by the wonderful support offered by the hospice's team of volunteers. "The hospice works really well with the help of many volunteers, including Mabel, the dog. On the days I visit the Day Hospice I am collected in the morning by a volunteer, greeted by staff, join others for coffee, spend time in the art room (with volunteer tutors) and chapel, enjoy a three-course lunch followed by an activity like a quiz, have afternoon tea and a chat and am then brought home. There are also beautiful grounds to enjoy which are tended by volunteers."



Mabel is a regular visitor

to go and are looking at setting up the technology to allow me to watch the ceremony."

Terry and Jacqui sum up their feelings about Katharine House Hospice: "It doesn't feel like a hospital. There is a feeling of calmness and tranquility with no one rushing about. We have found the support and care from Katharine House Hospice invaluable. Others with PSP or CBD might also gain peace of mind from their local hospice. They have given us strength and comfort in difficult times."

Finding your local hospice:

There are around 200 hospices across the UK with new services being developed all the time.

See: www.hospiceuk.org or call 020 7520 8200. Alternatively ask your GP/specialist nurse or the PSPA Helpline 0300 0110 122.

Getting a referral:

People are usually referred by a health or social care professional (often their GP) but individuals and families can approach most hospices themselves. Hospice staff will work with others involved in your care including your GP. You can request referral at any time. There is no charge.

Research without the lab coats

When most of us think about research, images of labs, test tubes and people in white coats tend to spring to mind. PSP and CBD research is surely all about using cutting edge science and technology to find a cure – isn't it?

In fact, there's a completely different aspect to research, one that can potentially make a bigger impact on the lives of people living with PSP today. Healthcare research is of huge importance in providing the evidence needed to persuade policy makers and care providers to make changes to the care and support available to patients. Rather than studying the underlying biology of disease and searching for potential drug treatments, researchers working in this area evaluate how quality of life and wellbeing are influenced by access to particular healthcare services and interventions.

Crucial evidence

Professor Irene Higginson of the Cicely Saunders Institute at Kings College London is the Chief Investigator of the OPTCARE Neuro clinical trial, funded by the National Institute for Health Research (NIHR). This trial aims to find out if patients with serious neurological conditions, including PSP, would see an improvement in their symptoms as a result of earlier intervention by palliative care teams, who are experts in symptom management and supportive care.

Prof Higginson explained: "The quality of life for patients with long term neurological conditions is vital, and yet we don't do enough to improve it. Palliative care is often only offered when the disease reaches a very advanced stage, whereas it can in fact provide



Researchers use interviews to analyse patients' experiences

"The quality of life for patients with long term neurological conditions is vital, and yet we don't do enough to improve it."

a continuum of care from diagnosis onwards. We want to test whether earlier provision can improve quality of life and reduce the stress on patients and their families. If it can, clear evidence for this will be crucial if we are to convince care commissioners of the benefits to patients and influence future service delivery."

OPTCARE Neuro will evaluate a brand

new short-term service that provides around three appointments, at home or in hospital, with specialist palliative care teams who can provide additional support to address not just physical symptoms but also social, emotional, spiritual and psychological issues too. Study participants will be randomly assigned to receive this service, over and above their normal care, either as soon as possible or after 12 weeks so that the researchers can get a clear picture of the difference made by early intervention.

Sharing experiences

Healthcare research often focuses on participants' quality of life and whether

it can be enhanced by the care service or intervention in question. However, unlike levels of a substance in blood or patterns on a brain scan, this is far from black and white and not straightforward to measure. The researchers rely heavily on careful analysis of patients' and carers' experiences and often make extensive use of interviews. All OPTCARE Neuro participants will take part in interviews at six week intervals for around six months. Some will also take part in more in-depth discussions about their experiences.

Dr Nilay Hepgul is the Trial Manager for OPTCARE Neuro. She explained: "Our trial uses a mixture of methods to collect data, but interview content is extremely valuable to us. As palliative care is person-centred and will draw upon different professionals from a multi-disciplinary team depending on each person's needs, we feel it is very important to hear the views of our participants via interviews. We are very grateful to participants for taking the time to talk to us and share their experiences."

Unlocking improved care

In this age of evidence-based medicine, a clear picture of the unique care and support needs of people affected by PSP, CBD and similar conditions is essential to open up access to improved services, a fact recognised by the PSP Association's



Dr Nilay Hepgul

own research strategy. The establishment of our Research Network (see *PSP Matters*, Autumn 2015) gives researchers the potential to evaluate the care service experiences of a large number of people with PSP and CBD across the country.

"Our trial uses a mixture of methods to collect data, but interview content is extremely valuable to us."

Meanwhile, Dr Hepgul is hopeful that OPTCARE Neuro will make a difference: "Our trial will help us understand whether this short-term integrated palliative



Prof Irene Higginson

care approach can be routinely used to improve care quality. If we show it to be effective, there is the potential for it to be beneficial for a wider range of conditions and in more diverse care settings."

OPTCARE Neuro is running across five centres: London, Nottingham, Brighton & Sussex, Liverpool and Cardiff. Participants must meet certain eligibility criteria.

For more information and to find out if you are able to participate, please contact Trial Manager Dr Nilay Hepgul or Trial Administrator Debbie Tonkin. Telephone 0207 848 5578 Email optcareneuro@kcl.ac.uk



Jackie and Charles Kirk

CASE STUDY:

Charles Kirk from Nottingham was diagnosed with PSP in early 2015 and has been taking part in the OPTCARE Neuro study since the autumn.

"I decided to take part in the study in the hope that it might help somebody else in the future," explains Charles. "The care support has been very good; it's certainly been helpful for both me and my wife, Jackie. Everybody's so nice and kind and the appointments give me something to look forward to. It's brilliant to talk about everything with the researchers. They are completely non-judgmental and I've never felt embarrassed talking to them about anything. I'm really glad I volunteered."

Accept help when you need it

Peter Grant, 81, cares for his wife Margaret, 78, who lives with PSP. He explains how life is a little easier since professional carers started to visit their Driffield home.



Peter and Margaret Grant

MARGARET was diagnosed with PSP in 2010. Before that we'd noticed she found it difficult to judge distance. She would drop the pans on the floor before she'd reached the shelf to put them on, and she scraped the car a few times. Then she started falling backwards. At first she was thought to be having mini strokes.

We went to the falls clinic where they realised it was a neurology problem and sent us to Scarborough Hospital. The neurologist there diagnosed PSP.

After the diagnosis we had two or three years where we busily did everything we could together, including going on cruises. But that isn't possible now as the progression is much quicker.

Continuing Healthcare funding kicked in about six weeks ago and this has

made a big difference for us.

Since we have been in the system it's been brilliant. It was the neurology nurse, Sandie Wade at St Catherine's Hospice in Scarborough, who linked us in, pointed us in the right direction for assistance and has helped us to fill in different forms.

We now have an arrangement with Marie Curie where someone comes in overnight three times a week, although sometimes there have been others with a greater need and it's only been once a week.

It makes such a big difference as I have to get up quite often with Margaret in the night. As she's not weight-bearing it's quite a lengthy job, hoisting and turning her and taking her to the loo. It can take 20 minutes every time I get up, and that can be up to five times a night.

The Marie Curie nurses come in from 10pm to 7am. We have a chat; quite often they keep me talking in the evening when I'm keen to get off to bed!

Before the night service started I was shattered. As well as caring for Margaret I have the house and a large garden to look after, and the meals to cook.

Carers have also started to come in during the day, which means I can pop out, and a cleaner comes in for a couple of hours a week so that helps too.

Margaret and I go to the Pocklington Local Group with our daughter Libby, who lives in Driffield and our other daughter Helen Dibb is also a member of Leeds Local Group.

I sing with a local choir, The Middle 8 Singers, and the members are all very attentive. Margaret used to be a member until she couldn't sing anymore and they have all been very caring. I still try to take her to concerts so she can relive it.

Since Margaret has had PSP I've learned that you have to be able to accept help from people, and push for it if you don't get it.

"Since Margaret has had PSP I've learned that you have to be able to accept help from people, and push for it if you don't get it."

You also have to get used to people coming into your home to help, as it's your own little place, but if you are pleasant everyone can get along well. Although I don't know what the neighbours must think with so many ladies visiting our house!"

Thankful for magical memories

Seventy-nine year old Yvonne Pacitti from Aberdeen was diagnosed with PSP in 2012. In June 2015 her family were delighted that, somewhat against the odds, she was able to join them to celebrate the wedding of her granddaughter Kim. Yvonne's daughter Dawn Walker told us about the special day:

In the four months running up to the wedding, mum's health had taken a bit of a turn for the worse. She had lost a lot of weight and was very tired and we all thought it was touch and go that she would be able to join us on the big day.

To see the look on Kim's face when she came down the stairs to see her grandma sitting waiting for her is a memory I will never forget. My parents have been such an important and inspirational part of Kim's life and upbringing that it meant the world to her to have mum there. (Unfortunately my dad passed away when Kim was 11, so he was with us in spirit!)

After discussions with the fantastic care team at mum's home, we arranged for a carer to escort mum to the wedding with the help of a family friend. If it wasn't for the genuine care and support from her carer that day then I don't think any of it would have been possible. Mum had a front row space for her wheelchair during the ceremony and managed to stay for the photos, speeches and toasts before she became too tired.

The day was truly magical to say the least and to have mum by our side felt like a miracle. It was wonderful to see the pride on her face too. We will be forever thankful for our memories of the day.



Yvonne Pacitti with daughter Dawn Walker

The Butterfly Scheme

AHOSPITAL stay can be an overwhelming experience. Dozens of staff can pass through a patient's life in one day, with a confusing array of information to give, or questions to ask. This can be even more daunting if you have a diagnosis of PSP or CBD and are experiencing issues with memory or slowness of thought.

You may be interested to know that there is a scheme, adopted by almost 150 hospitals in the UK, which provides a system of care to support patients who have a diagnosis of dementia or who simply find that their memory is not as reliable as it used to be.

The Butterfly Scheme was created

by Barbara Hodkinson, a former family carer whose mother had dementia. It is an opt-in system which is available to anyone in need of memory support. The staff in these hospitals are trained to use a system of care which promotes safety and well-being, regardless of how reliable a patient's memory is. You can request that care by opting to display a special butterfly symbol; the staff then know what to do to help you. The staff will be aware of whether you have a dementia diagnosis or simply need support because of your memory.

To find out more about the Butterfly Scheme please visit www.butterflyscheme.org.uk/

Neck massager provides relaxing relief

At the end of 2014 Maureen McAlister from East Kilbride happened to spot a Medisana neck massage cushion on sale for around £15 in her local Lidl. She decided to buy it for her husband Tommy who is living with PSP and tells us it's one of the best things she's ever bought for him. Maureen explains: "Tommy's neck and shoulders visibly relax when I turn it on and his complaints about neck pain have reduced. It's the first thing he asks for when I visit him at the care home – he calls it his 'wee German machine'. Even the staff have commented on how relaxed he is when it's on."

Your stories

Inspired by an athlete seen on the internet, mum-of-two from Hampshire, Helen Hobbs, decided to raise funds for PSPA by committing herself to running 40 events before her 40th birthday – here's how she's getting on...

THE deadline is February 2017 for Helen to register her 40 races – that's one every two to three weeks!

"Ummm... it is a tough challenge but one that I am relishing!" said Helen. "I only took up running last year but really enjoyed it, so joined a local club. I have been taking part in a few Park Runs and other club events – having completed five of my target 40 so far. I am training to increase the distances and plan to do the Southampton half marathon next April."

Helen is running in memory of her grandmother, Jean Watts.

"I just want to share my experiences with others. It helps me to share my thoughts and will hopefully inspire others to take on their own personal challenges."

"Nan lived with PSP for three years and her illness affected everyone in the family. So, I want to raise money for the Association to support and provide information to those who are diagnosed with PSP, and their carers," she said.

Joined by fellow club members, Helen



Helen Hobbs

hopes to further her running career by logging some good times for races of various lengths, and to keep her training on course, she is also writing a blog.

"I just want to share my experiences with others," added Helen. "It helps me to share my thoughts and will hopefully inspire others to take on their own personal challenges. Many of my friends

and running buddies are encouraging me and will keep me going through next year – I'm determined to reach my goal!"

Helen has created a JustGiving page: www.justgiving.com/Helen-Hobbs2 and to monitor Helen's progress, read her blog at <http://2014runningchallenge.blogspot.co.uk>. Helen is also using #fortyb4forty on Twitter.

HOW PSP AND CBD HAVE Affected YOUR LIVES

Walking 5k a day for 50 days before a 50th birthday was the challenge set by one PSPA supporter.

LISA Gregory, from Buckinghamshire, put her best foot forward to spend a good deal of the summer treading a well-worn route around her home village to clock-up an impressive 250k (over 150miles!).

"I walked in memory of my Mum, Joy Whitmarsh, who lived with PSP – I know she would be very proud."

"As my big birthday was approaching, I knew that I wanted to take part in a fundraising event and to remember those who would not be there to celebrate my milestone," said Lisa.

"A friend had taken on a similar challenge and my husband cycled across Britain in just nine days last year. So I took inspiration from them and came up with this idea."

Lisa is a keen walker and heads off into the countryside with friends most weekends – many of whom joined her on her daily jaunt.

"I rarely walked alone," added Lisa. "My family and friends were really supportive and encouraged me at every step. During the 50 days we had a special holiday and I was delighted that my husband and two daughters accompanied me as we walked along some of the beautiful beaches in Mauritius – it was lovely!"

"I walked in memory of my Mum,



Lisa Gregory

Joy Whitmarsh, who lived with PSP – I know she would be very proud. The PSP Association helped us when needed – giving us vital information and support. It is great to contribute to such a worthy cause and help fund vital research. I hope my small effort will support others and their families and maybe inspire more people to get fund raising too."

Lisa raised over £1,000 and her employer, Barclays, match-funded this amount – so boosting the donation to over £2,000.

Make your voice heard

PSP Matters, PSPA's magazine is published four times a year. The Editor is always interested in your comments, hints and tips, and welcomes potential contributions for future issues. Material may be edited prior to publication.

Please send your contributions to psp@pspassociation.org.uk or write to PSP Association, FREEPOST RSLR-ZTGA-HHAU Towcester NN12 6BX

No one need face a diagnosis of PSP or CBD alone

Thanks to PSPA no one need face a diagnosis of PSP or CBD alone. We provide information and support for families affected by the diseases and help them access services to enable them to achieve the highest quality of life possible.

Someone to talk to

We know that receiving a diagnosis of PSP or CBD can often make people feel isolated, misinformed and worried.

The need for some reassurance that they are not the only one out there is very important and also sometimes someone to talk to outside of the family environment can be very helpful.

PSP and CBD are life changing conditions and our team of experienced Helpline and Information Service staff and volunteers are dedicated to helping people make these changes as smoothly as possible.



Helpline staff Carol Amirghiasvand and Julia Brown

Helpline and Information Services Manager, Carol Amirghiasvand, explained: "We know from talking to people that the service has made a real difference to how people cope in the future and we've done a lot of talking! In fact we have received just over 7,500 calls in the past three years.

"We want people to know we are here



Our helpline staff and volunteers

for them every step of the way."

The service offers support to anyone who has been diagnosed with PSP or CBD, their carers, families, health professionals working in the field of PSP/CBD and association volunteers. Contact can be via phone, email or letter.

Feedback has included:

"I spoke to you on several occasions and genuinely do not know how I would have coped at the time without you. You were always supportive and informative and helped steer me through a very difficult time for my husband and me." "I should like to thank you for making

me feel much better this morning, realising that we are not alone and there is help available to get us through this difficult time."

Our friendly team work very closely with our regional services and attend PSPA's larger events.

"We want people to know we are here for them every step of the way."

The helpline is currently undergoing an accreditation process with the Helplines Partnership and this will be completed early this year. The accreditation will mean we have demonstrated we

are committed to quality and offer a professional service.

We regularly review the service we offer and strive to improve it wherever we can. An essential part of this review involves seeking the opinions of people who use the helpline. If you can spare some time for feedback please email helpline@pspassociation.org.uk. Your input is invaluable.

We provide information and support in the following ways:

- Listen to you and talk through a situation
- Make suggestions and explore options that are available
- Talk through benefits that are available and signpost to appropriate agencies
- Offer information on management of symptoms
- Tell you about people and services that are there to support you
- Put you in touch with other relevant local and national organisations
- Send you leaflets and information sheets on the condition
- Direct you to further sources of information
- Put you in touch with the Specialist Care Adviser for your area
- Link you to your local group, where available.

Our evening helpline is only possible thanks to our wonderful volunteers who answer calls Monday to Friday between 7pm and 9pm. We currently have 10 helpline volunteers but we're keen to recruit more. If you're interested in joining our helpline team we'd love to hear from you. No experience is necessary and full training is given for this rewarding volunteer role. The next training course will take place in the spring.

Meeting others at local groups

Our network of local groups is rapidly growing and, thanks to our fabulous volunteers, we now have 40 groups around the UK.

Local groups provide the opportunity to meet other people living with PSP/CBD, carers, family and friends, health and social care professionals and to share information, encouragement and refreshments.

Many of the groups, which are run by volunteers, invite visiting speakers such as benefits advisers, Parkinson's nurses or other health and social care professionals, to share expertise on managing PSP and CBD on a daily basis.

Local group members have told us:

"Being with people who fully understand the symptoms of PSP/CBD and talking to people who can empathise is such a relief - it creates a

sense of friendship too."

"Practical hints and tips are quickly forthcoming which has been enormously helpful."

"It made us realise that we were not alone. Before we found out about the events, we knew nothing of the support that was out there. New ideas and practices are often discussed, which means we leave the meetings with new purpose."



To find your local group, or if you're interested in setting one up in your area, please refer to the insert with this magazine, or contact our helpline.

Trustworthy and up-to-date information

We publish a very comprehensive range of publications including booklets and information sheets relating to PSP/CBD. Resources are available for people affected by both conditions and for those involved in their care.

These are regularly reviewed and updated to ensure they are accurate, trustworthy and up to date. They are free of charge.

We provide information on a range of topics relating to everyday living and managing symptoms. Our publication Your Personal Guide to PSP is designed for those living with PSP and their carers.

All our information sheets are available as hard copies from our

helpline and can also be downloaded from our website www.pspassociation.org.uk/publications





Finding friendship and support online

Through HealthUnlocked we provide a safe place where those affected by PSP and CBD can connect with others and share their experience online.

Our forum is growing all the time and we now have 492 active HealthUnlocked members who share their experiences of PSP and CBD and offer each other friendship and support.

Take a look <https://healthunlocked.com/psp>

Getting together at Family and Friends Days

Our popular Family and Friends Day provide an opportunity for a get together in an informal and relaxed setting.

The events move around the UK and the programmes are designed for all those affected by PSP and CBD, including family members of all ages, carers and friends. Our volunteers and interested health and social care professionals are also welcome.

Those who come along to our Family and Friends Days can learn more about PSP and CBD and the work of the Association, while meeting others affected by the disease. See page 7

Comments from those attending our Family and Friends Days include:

"A very relaxed and friendly environment with lots of interesting and useful information. It was lovely to meet others affected by PSP & CBD."

"I really enjoyed meeting everyone and getting lots of helpful information and it was lovely to put faces to voices."

"Thank you all for another super day. It is so good to meet other families with similar issues."

Future Family and Friends Days will be advertised on our website
www.pspassociation.org.uk/events



Our journey with PSPA

Susannah Treherne, from Oxfordshire, contacted PSPA after her dad David from High Wycombe, was diagnosed with PSP in April.

"When the consultant told us dad had PSP and there is no cure we were shell-shocked. I googled PSP on my phone whilst still in the hospital and saw PSPA. I immediately rang the helpline.

"I spoke with Julia, who was incredible. I will never forget how kind she was. She arranged to send out information packs, which we received the next day. This was

the start of our journey with PSPA.

"We were put in touch with Jan, our Specialist Care Adviser (SCA), and soon felt so much more informed.

"We've had many phone conversations with the helpline and SCA since. The Association has also sent us information to give to health professionals, many of whom have never heard of PSP and a Guide to PSP for our GP, which was really useful.

"We wouldn't be able to cope half as well if it wasn't for the Association. It

can be very difficult to see the wood for the trees.

"I recently attended my first Association event, the Family and Friends Day in Bristol, with my mum Kathy. We found all the presentations topical, informative and helpful to us. We were very impressed with the organisation of the event, the kindness and friendliness of all those we spoke with and we were made to feel very welcome throughout the day.

"We remain very much indebted to PSPA."

Support in the regions

Our regionally-based Specialist Care Advisers (SCAs) work with PSPA's Helpline and Information Service to provide support to people living with PSP or CBD and their families, and to raise awareness of the needs of people living with these conditions.

SCAs are experienced health and social care professionals (not employed as nurses) who are able to take a broad view of a person's situation.

We are currently in touch with almost 2,000 people affected by PSP and CBD, and wherever you live in the UK there is a SCA for your area.

"Good planning and coordination by these local professionals is essential and can help prevent a crisis arising."

We know that good management of PSP and CBD can involve contact with many professionals, from many agencies, at different stages of the condition.

SCAs aim to ensure that people living with PSP or CBD and their families have an understanding of their condition and have ready access to the help and support they need from local professionals.

Peter Daniels, PSPA's Director of Information and Support explained: "Good planning and coordination by these local professionals is essential and can help prevent a crisis arising. SCAs work to build good relationships with key health and social care professionals in their area including Parkinson's nurse specialists, neurology nurse specialists, neurologists, community matrons, neurological therapy teams, CHC assessors and hospices."

Our SCAs aim to maintain telephone



David Mills
Scotland & NI



Liz Burr
Central



Jane Stein
South West and
South Wales

Meet our specialist care advisers



Jenny Reynolds
North and North
Wales



Jan Wilderspin
North of the
Thames



Kathy Weston
South of the
Thames

or email contact with families to review current situations and to help with planning for likely future needs. They can act as an advocate, making referrals or checking on situations where necessary. They are there for carers and family members too and try to ensure their needs (both practical and emotional) are also addressed and met.

SCAs also work on more complex cases referred by our Helpline. For example, when there is a crisis with a carer's health, or a hospital admission, or where a person has been refused a service such as CHC funding.

Peter added: "Because PSP and CBD are rare conditions and many health and social care professionals may not have a detailed understanding of them, part of the SCA's role involves education and

awareness raising.

"They will liaise with local staff on an individual basis, discussing needs and supplying literature but they also arrange study days and events throughout their region. SCAs may also be involved in local groups such as Neurological Alliances and in Neurology Awareness events run in conjunction with other voluntary agencies or the NHS/Social Services."

SCAs work with other PSP Association staff on larger scale events – including our Study Days and Family and Friends Days - and with our volunteer and fundraising teams to expand and develop our range of services.

To contact your local SCA please give the Helpline a call on 0300 0110 122, or email helpline@pspassociation.org.uk

Local Groups

What's happening in a local group near you...

Pop-up meetings

PSPA is trialling a new 'pop-up' approach to local groups meetings

Since November some of our local groups have been 'popping up' at one-off venues.

"The idea came about following feedback which showed that although some members want to attend a local group, travel to the venue can often be too far or too difficult," explained Volunteering Services Coordinator, Nicola Shaw. "By moving the meetings around a locality, we hope more people will be able to access

this valued service."

Initially, the pop-up approach will take place in more rural areas but the Association is also looking for volunteers to arrange meetings in cities where there is not currently a local group: central Birmingham or Glasgow, for example.

"By moving the meetings around a locality, we hope more people will be able to access this valued service."

"Pop-up meetings will also help us to pinpoint areas which have the greatest

interest in a local group," added Nicola.

"We will consider making the meetings a permanent fixture where attendance is high."

Devon was the first county to take on this approach when Group Coordinator Carla Bancroft held the first pop-up meeting in Barnstaple.

Information on local groups can be found on our website, check the events page for more details about pop-up meetings near you. If you are interested in setting up and running such a meeting in your area, contact Nicola on 01327 322416 or email: nicola.shaw@pspassociation.org.uk for more details.

First anniversaries



Congratulations to our Devon Local Group members on celebrating their first anniversary with tea and cakes - of course!

The group makes a real difference to families affected by PSP and CBD.

Happy first birthday to our Gloucester Local Group too!

Group members marked the occasion with a super Hope cake made by Group Coordinator Lesley Flannagan's daughter, Liz Lockhart.



Bling!



Creative Karen O'Brien, Morecambe Local Group Coordinator, is making and selling PSPA bracelets to raise funds and awareness – in memory of her mum.

Bracelets cost £5 each, plus p&p, with all profits to PSPA. Order yours from Karen at karen.obrien5@btinternet.com

Talking about research



'No cure is not the same as no treatments.'

That was the message Cambridge researcher, Dr Ian Coyle-Gilchrist gave to around 40 people at Hertfordshire Local Group's meeting in September. He also gave an update on his PIPPIN study. The meeting was organised by Group Co-ordinator, Maureen Horne. Ian is pictured with Dr Graham Fothergill, whose wife has PSP.

Find your local group
[www.pspassociation.org.uk/
local groups](http://www.pspassociation.org.uk/local-groups)

Gathering together

On a sunny autumn day in October, 15 group coordinators from as far afield as Aberdeen and Devon gathered near Birmingham for our annual workshop.



Local group coordinators and staff at our workshop

"It was a full day starting with lively discussions about what was going well and what challenges there have been over the last year," reported Volunteering Services Manager, Wendy Crofts. "A lot of new ideas came from the conversations and it was a great opportunity for people to share their thoughts and experiences."

The workshop included discussion on how to manage different situations, a quick tutorial on new forms and processes, and a presentation from Paula McGrath, Communications Manager, on how everyone can be involved in raising awareness and help to make the Association 'heard'.

"The whole day was very constructive and provided plenty of opportunities for

"A lot of new ideas came from the conversations and it was a great opportunity for people to share their thoughts and experiences."

getting to know each other and sharing experiences. The feedback was really positive," said Wendy. "It was also great to see so many of our volunteers and this year we are looking forward to the launch of our support worker project, the introduction of our new education volunteer role and, of course, the continued growth of our local group network."

We are always looking to recruit more volunteers. Interested? Contact Nicola on 01327 322416 or nicola.shaw@pspassociation.org.uk

Hello!

Welcome to Val Cole, who joins the volunteering team as coordinator for our Northampton Local Group.

VAL is already a familiar face at the group, as she has been a member since 2012 along with her husband Eddie, who lived with PSP.

She said: "It was good to go to the meetings to chat to people in a similar situation and for Eddie to go out and meet people. It was a great support and he enjoyed it."

Sadly Eddie passed away in January 2015 but Val has continued to attend the meetings and is also enjoying her new role.



Val Cole

"I just wanted to use my skills and knowledge to help others," added Val. "I already knew most of the group members so that has made it easier."

Val is also taking on a short-term administrative project at head office and in 2016 she will be 'trailblazing' for our new support worker project as Volunteer Team Leader for Northamptonshire.

Northampton group meetings take place on the last Saturday of each month at the Richmond Care Home, Bridge Meadows Way, Grange Park, Northampton NN4 5EB. Contact Val at val.jameson@yahoo.com for more information

Volunteering

Introducing...

Julia Bonner – Liverpool Group

WITH The Liner Hotel as the regular venue, it's no surprise that Liverpool group meetings are always held in a 'shipshape' style.

"Volunteering with PSPA is very worthwhile and the support and help from head office is fantastic."

Volunteer Coordinator, Julia Bonner has 'captained' the get-togethers since September 2014 but it was chance and a willingness to help that initially got her involved with PSPA.

She said: "I attended a Christmas concert for PSPA at The Liner in 2013. I just offered to help and it went from there. I have volunteered in the past and it helps that the group is like a well-oiled engine, it runs itself."

Despite not having any personal connection with PSP or CBD, Julia and husband Jim regularly give their time so that members can access the friendship and support of others in similar circumstances and they have both thoroughly enjoyed the experience.

"Volunteering with PSPA is very worthwhile and the support and help from head office is fantastic," added Julia.



"I didn't have any expectations about volunteering, I just got on with it! You don't have to be a superhero, you just have to be caring and patient."

Liverpool group meetings take place at The Liner Hotel, Lord Nelson Street, Liverpool, L3 5QB. Take a look at details of all our local groups on our website or contact Julia direct at juliabonner29@gmail.com for more information.



DIANNE Davies was at a loss for someone to turn to when her late husband, David, was told he had PSP in 1999. But a 'phone call from the founder of PSPA offered comfort that she has never forgotten.

Those 'amazing' words from Michael Koe and a wholehearted desire to help others have been the inspiration for Dianne, Shrewsbury Group Coordinator,

Dianne Davies – Shrewsbury Group

to become one of the Association's longest serving volunteers.

She said: "Michael rang me when David was diagnosed and I will be forever grateful for that. No one had heard of PSP so I desperately needed to talk to someone who understood and he was amazing."

"I really get a lot of satisfaction out of it. I know what I went through with David and it isn't easy."

His well-timed comments encouraged Dianne to attend her local PSPA meetings where she initially helped out making teas and coffees. She remained a loyal supporter for many years and when the group needed a new coordinator, she stepped into the role.

She said: "I said I would do it (run the

group) for a little while but it's been five or six years now! I love it and I think I must be the longest-serving volunteer at PSPA.

"I really get a lot of satisfaction out of it. I know what I went through with David and it isn't easy. I was once on the receiving end and really looked forward to those meetings. So, if the members enjoy the meeting then I go home on a high and think it is all worthwhile. I feel that I would do anything I can if it can bring someone some help."

"I have really been so grateful for my volunteering. I'm amazed I am still doing it as I don't like talking in front of people but I think if I can do it, anyone can!"

The Shrewsbury group meets at The Hamar Centre, Royal Shrewsbury Hospital, Mytton Oak Road, Shrewsbury. For more information, contact Nicola, on 01327 322416

Janet Smith and Janet Norbury – Manchester Group

AFIRM friendship and steady mutual support has been the key to success with our Manchester Local Group volunteers.

Janet Smith and Janet Norbury were already long-term friends when they teamed up to set up and run the group in September 2013.

So when we asked them to tell us about their volunteering experiences with PSPA, a joint interview seemed the perfect approach! This is what they told PSP Matters...



How did you first get together to set up the Manchester group?

Janet S: "Janet was already a friend when my father (Edmund Wibberley) was diagnosed with PSP. We decided to set up a local group after attending a PSPA Friends and Family Day. She was a great support from the start and throughout my father's illness".

Janet N: "We were strong friends anyway. We have got stronger as a result (of the group) and now it's just part of what we do".

Has running a local group been what you expected?

Janet N: "We have made a lot of friends through it. I didn't go into it with any expectations, so it has all been plain



sailing, we just go with the flow! I think that if we just help one person then we have achieved something."

Janet S: "We only had a couple of people who attended at first but it's a strong group now. We have all made friends and it's a very happy group. It's been a very positive experience.

"It's become more like a family. We can just sit and chat and have a laugh, not necessarily about PSP. Everyone is in the same situation and it's a relief to just talk about other things. The social side of it is really important. But the support is there if people want it and there can be a support in just chatting!"

What high points have you had with the group?

Janet S: "A big high point was when Janet (Norbury) contacted our local MP, Kate Green, to draw a raffle prize at our annual

afternoon tea in 2013. She came to that event and then again the following year to spend time chatting to people. She kept in contact with us and my son, Scott, and it all ended up with the Ed's Lace launch at the Houses of Parliament."

Janet N: "I just looked in our local paper and found her email address. I didn't realise she was the Shadow Health Secretary for the Disabled, so it was a double whammy!

"I would never have thought when we set up this group that we would get involved with our local MP but we aren't going to let her go now!"

What would you say to anyone thinking about volunteering with PSPA?

Janet N: "Just give it a try because there are people who want your help and local groups are also great for raising awareness. My family have all got involved and now they all know about PSP."

Janet S: "Go ahead! If it doesn't work at first, carry on, because it will take off. Don't have any expectations. When dad was poorly there was nothing for us. We were so alone and no-one understood. We felt that if we could just help someone (through a local group) it would be a bonus and that is what we have found ever since."

The Manchester group meets every other month at St Mary's The Virgin Church Hall, 13 Vicarage Road, Urmston, M41 5TP.

Contact Janet Smith at pspamanchester@yahoo.co.uk for details about the next meeting or visit our website.

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

Fundraising

New for
2016!

Hope's travels

Hope, our awareness-raising mascot now has her very own diary. Here she will tell you all about the places she's been around the world, and the people she has met...

Sunday 11 October 2015

Royal Parks Half Marathon, London



Sarah Fletcher and Hope

For a bear, Sundays usually mean sleep. Though not today. I was awoken far too early, before I was stuffed inside a small bag where I spent the next two uncomfortable hours travelling to London (I have a friend from Peru who lives there, and he speaks highly of the place). I like trains too, and it would have been nice to have gazed out of the window at the countryside whilst sipping on a chai latte, and nibbling on a grr-nola bar (*classic bear joke there. Diary, I apologise*). Oh well.

My spirits were lifted though upon arrival. To see thousands of people all running together to raise funds for charity does wonders for a bear's spirits, and it made me very proud to see our inspirational Team PSPA runners giving

their all. I had my photo taken with some lovely people, and, despite them being sweaty, their faces as red as Hyde Park's autumn leaves, it made me really cheerful. I wished a happy birthday to Sarah Fletcher, who's Nan, Beryl, had CBD. I also congratulated Luke Courtney on being the first back to the PSPA sign!

My journey home (stuck in the bag again) was made so much easier knowing that, through the marvellous efforts of our runners, lots of funds were raised to help those living with PSP and CBD.

Sunday 6 December

Santa Run, London



Sue and Hannah Kitson with Liam Whitby and Hope at the Santa Run

Plenty of Christmas spirit on show today! It was tough being wrapped up in my coat, hat, and scarf, eating mince pies and drinking mulled wine whilst our Team PSPA Santas braved the winter chill to raise funds. Proud of them all! I'd have taken my hat off to them, but, well, it was a wee bit chilly.

My travels



I had a busy autumn travelling around the globe raising awareness for PSPA. I've been to Washington D.C, where I met an important human historical figure. I met some lovely pumpkins in Canada, showed just what a bear can do when I took part in an Ironman challenge in Mallorca, Spain, and tasted some very nice wine in Seville! Here are some of my snaps.

To see where Hope has travelled visit www.pspassociation.org.uk/hope-travels and click on the red balloons. We would love you to share where you have taken Hope.

Email photos and details to hope@pspassociation.org.uk

Buy your own Hope at www.pspassociation.org.uk/shop

Turning used stamps into cash



PSPA needs your stamps! Please collect used postage stamps and turn them in to cash for your favourite charity.

Send your used stamps direct to:

**Paul Roebuck, PSP Association,
Fundraising Stamps Ltd, 59 Mitre Copse,
Bishopstoke, Eastleigh, Hants SO50 8QE**

Alternatively request your free pre-paid and pre-addressed envelopes at www.fundraisingstamps.com

Please leave no more than 1cm of envelope around each stamp and do not trim too close to avoid damaging perforations.

We collect both UK and overseas stamps and receive £11 per kilo to fund our vital work.

Fundraising tips *giftaid it*

However you choose to raise funds for us

please remember to sign-up for Gift Aid. This is a great scheme where the tax man adds 25p to every pound you raise – and it's simple to join.

Also, it is always worth checking if your employer runs a match-funding scheme. Many businesses now are willing to match the amount raised by their employees from their fundraising exploits!

New year – new challenge

THE New Year is a time of planning for the year ahead, and setting targets and goals, including New Year's resolutions. But this year, how about making them really count, and help raise funds for PSPA at the same time?

Asking friends and family to sponsor you along the way is a great incentive, and of course, it means making a difference to those living with PSP and

CBD as well. Whether you are trying to shed some undesired post-Christmas weight, quitting smoking or drinking, getting fit, or even giving up your favourite comfort foods, New Year's resolutions can raise lots of funds.

January is also a great time to get involved with fundraising heading into the year ahead. In 2016, there are many things you can do to support PSPA.

Here are some ideas to get you started...

How about getting sponsored to...

- Stop smoking
- Give up drinking for a whole month
- Lose some of those extra pounds
- Get fit
- Forego your favourite snacks
- Go without television, computer games, or even your smartphone.

· Summer fêtes

· Garden parties

· Raffles

· Charity sport matches (football, cricket, rugby etc)

· Quiz nights

· Fancy dress discos and karaoke

· The £10 Challenge – make as much money as you can from just £10!

There are lots of other events to help fundraise – really anything you like, but here are some ideas...

- Cake sales
- Coffee mornings

Or perhaps you could spare some of your time to volunteer for PSPA? There are plenty of local groups who would be more than happy to welcome new faces in 2016.



Fundraising

Choose your challenge for 2016

Some fantastic challenges await our fundraisers in 2016. Whether you run, cycle, climb, trek, walk, or swim your way to fundraising glory, there is something for you! No matter how tough or how challenging the events, those that take part are not only left with a great feeling of achievement, but also a tremendous feeling of pride.

If running is your thing

You could take part in the Royal Parks Half Marathon; a glorious run through London's resplendent royal parks awash with autumnal colour. For those seeking shorter distances, there's the British 10k London Run and the Edinburgh Marathon Festival also has courses that cater for all abilities.

For festive fun, there's the Santa Run through London's Victoria Park – don the free Santa suit and beard then run, walk, or jog the 5k or 10k courses – in your own time.

Seeking a tougher challenge. Why not take part in a mud run such as Tough Mudder or the Hell Runner. Despite the mud and wet, these events are rapidly growing in popularity!

How about...

Virgin Money London Marathon:

24 April

The world's most famous running event, the London Marathon is our biggest fundraising event of the year! A dedicated team of PSPA staff and volunteers will be cheering the team on, and will be there at the end to welcome home courageous fundraisers.

Edinburgh Marathon Festival:

28/29 May

Full Marathon: £50

Fundraising Target: £500

Half Marathon: £30

Fundraising Target: £360

10km: Fundraising Target: £180

5km: Fundraising Target: £100



"It was hard, but the encouragement of the crowds saw me round."

Kirsten James, London Marathon runner and fundraiser

Hairy Haggis Relay: £50
Fundraising Target: £500 per team

British 10k London: 10 July

Registration Fee: £15

Fundraising Target: £180

Royal Parks Half Marathon, London:

October

Registration Fee: £30

Fundraising Target: £395

Santa Run, London: December

Registration Fee: £22

Fundraising Target: £100

Tough Mudder:

This events take place at varied times at multiple locations. Please check their website for details.
www.toughmudder.co.uk

Prefer to pedal?

The Coast to Coast cycle is 136-miles of seaside vistas, stunning mountains, tranquil lakes, and rolling moors. Or if you are feeling especially intrepid, then maybe London to Paris?



"I completed the London to Paris bike ride under the Eiffel Tower. It was an amazing finish line!"

Joel Barnett, cyclist and fundraiser

How about...

London to Paris: 13 April – 17 April

Tour de France Edition Route 1

8 June – 12 June

Tour de France Edition Route 2

20 July – 24 July and 14 – 18 September

London to Surrey 100: 30/31 July

Registration Fee: £35

Fundraising Target: £550

Coast to Coast: 11 – 14 August

Registration Fee: £99

Fundraising Target: £790

Edinburgh Night Ride: 21/22 June

Registration Fee: £34

Fundraising Target: £160

Land's End to John O'Groats:

10 – 22 May and 30 August – 11 Sept

Registration Fee: £99

Fundraising Target: £1,600

Stepping out

2016 sees the return of Trekfest, a challenging event but one that caters for all abilities. Other walks and treks include the London Trekathon, the 24 Peaks Challenge (reach the summit of 24 peaks in 24 hours), and scaling Ben Nevis, the UK's loftiest peak.

How about...

24 Peaks Challenge:

3 – 5 June and 16 – 18 September 2016

Registration Fee: £75

Fundraising Target: £650

Ben Nevis: 30 September – 2 October

Registration Fee: £75

Fundraising Target: £510

London Trekathon: 24 September

Registration Fee: £25

Fundraising Target: £100 minimum

TrekFest:

The Beacons: 4/5 June

The Peaks: 3/4 September

25km trek:

Registration Fee: £35

Fundraising Target: £140

50km trek:

Registration Fee: £45

Fundraising Target: £300

75km trek:

Registration Fee: £50

Fundraising Target: £400

100km trek:

Registration Fee: £60

Fundraising Target: £460

17 November – 4 December

Registration Fee: £399

Fundraising Target: £3,120

Zambezi Blast, Zambia:

10 – 17 September

Registration Fee: £399

Fundraising Target: £3,600

Kilimanjaro, Machame Trail, Tanzania:

18 – 28 February, 18 – 28 August and 6 – 16 October

Registration Fee: £399

Fundraising Target: £3,650

Cycle Vietnam to Cambodia:

5 – 15 March and 19 – 29 November

Registration Fee: £399

Fundraising Target: £2,950

Feeling adventurous?

Once-in-a-lifetime overseas challenges include walking the Great Wall of China, cycling from Vietnam to Cambodia, trekking the Sahara Desert, or tackling the rapids of the Zambezi. These are challenges that will live with you forever.



“One of the highlights of the trip was getting to the top of the dunes.”

Paul Maxin, Sahara trekker and fundraiser.

How about...

The Great Wall of China Trek:

7 – 15 May and 15 – 23 October

Registration Fee: £349

Fundraising Target: £2,750

(Airport Tax: £250)

Sahara Trek, Morocco:

18 – 23 February & 24 – 29 November

Registration Fee: £175

Fundraising Target: £1,700

Everest Base Camp, Nepal:

10 – 27 March, 8 – 25 September and

New for 2016

This year, PSPA has 20 places in Ride London to Surrey 100! Beginning at London's Queen Elizabeth Olympic Park, the route goes from cityscape to Surrey's stunning countryside!

Cycling is fast becoming one of the biggest participation sports in the UK. In fact, there are now over 8.7 million cyclists nationwide! Cycling is a fun way to fundraise, but with the sport now so popular, spaces for the Ride London to Surrey 100 will fill up fast!

Or how about a skydive? Available all year round, multiple venues
Registration Fee: £70 (reimbursed through sponsorship) Fundraising Target: £395

Do your own thing

Of course, if you have any fundraising ideas of your own, then please feel free to run with them; we will support you all the way! If you have your own challenge event in mind, please let us know, and we'll make sure you have all you need in terms of fundraising tools. Call us on 01327 356132 or email events@pspassociation.org.uk



“What an amazing group of people all raising money for their charities.”

Carla Bancroft, 24 Peaks Challenge

Fundraising

Fundraising – over the border



Trudy Kennedy on her triathlon

LEVEN members of a family, from three generations, joined together for what was to be the last time with Albert Bennett, who lived with PSP, to take part in the Great Scottish Run.



Albert Bennett with his family

Albert, from Dundee, was wheeled around the 10K course by his son-in-law, Andy Jenkins and even got out of his wheelchair to step over the finish line to the cheers of the crowd.

His grandson's wife, Cheryl Jenkins, had

defied the odds to take part. Just four months previously she experienced a spinal puncture whilst giving birth to her baby boy, leaving her unable to walk.

Cheryl said: "It was a fantastic day! Everyone in team 'Granddad Bennett' completed their races and lots of money was raised for PSPA. For me, to go from being unable to walk to completing a half marathon in just four months was amazing!"

"Sadly Albert passed away just six days after our marathon. It really is testament to how strong Albert was crossing that line and it made the day even more special as it was our last time all together as a family. What better way than to do something for him and the cause?"

Albert and Andy were joined in the 10k by Albert's wife Margaret, his grandson Grant and Grant's girlfriend Louise. Completing the half marathon

TRUDY Kennedy, from Campbeltown, Argyll and Bute, completed a triathlon in July to raise almost £10,000!

Her swim took her across the Sound of Gigha, to Point Sands near Tayinloan. From there, she cycled down to Campbeltown, before running back across the peninsula to Machrihanish.

"Everyone who supported on the day or took part in any of the events, either by swimming, biking, or running alongside me, or following the day with cheers from cars along the way, deserves a big thank you," said Trudy.

The incredible feat was inspired by Trudy's mother, Marie Kennedy, who lived with PSP.

"Raising money for this event will help support research into a cause, and help other families," she said.



Cheryl and Andrew Jenkins

with Cheryl, were Albert's daughter, Margaret Jenkins and his grandchildren, Andrew Jenkins and Chantelle, Holly and Erin Bennett.

The family also took a collection at Albert's funeral, raising a further £300.

Having a ball of a time for PSPA

THE family of a man living with CBD organised their first ball to raise £4,000.

Cathy Howarth, from Horsforth, Leeds, and her daughter Charlotte, sold 150 tickets for an autumn charity ball in October.

Dave Howarth was diagnosed in 2011 and Cathy said raising money for PSPA is a way of demonstrating gratitude for the support they received.

"We didn't know what CBD was until Dave was diagnosed. We'd never even heard of it," she explained. "Fortunately, PSPA has been there to help us and we want to help them in return, so we can offer others hope for the future."

The ball has boosted the amount Cathy, Charlotte and their friends have raised over the last two years to more than £10,000. Dave and Cathy are also dedicated to raising awareness of CBD and their efforts have won the support

of local MP Stuart Andrew, who also attended the ball.

"Charlotte and I have both completed sponsored runs and we recently did the Three Peaks Challenge with a group of friends," Cathy explained.

"Everyone has been so generous. The idea of the ball was that it was an evening where people can come along and enjoy themselves, rather than giving us money for our sponsored events."

Dave said: "Everybody said they had a fantastic evening. I'm proud of Cath for the amount of organising she did and then standing up and taking the microphone, something she's never done before and she did it with some ease."

"It all came together with the help of a few non-PSPA friends and Pam, Beryl and Sid from the support group. The room looked fabulous and everybody got dressed up and had a marvellous time."



Cathy and Dave Howarth, top right, organised a fantastic ball



Clockwise from top left: Luke Courtney, Clair and Jeremy Ramsden, Sarah Watson, Sarah Fletcher and Hope

Royal congrats!

WELL done to all our runners who took part in the Royal Parks Half Marathon in Hyde Park in October. It was a perfect day for running. Competitors Luke Courtney and Clair and Jeremy Ramsden were putting in the practise for April when they will run the London Marathon for TeamPSPA.

Up for sale

OUR first PSPA eBay auction took place in October with some fantastic items donated by generous supporters.

The highest bid of £100 was for Hope the PSPA Bear who was signed by One Direction's Niall, Liam and Louis and was donated by the Acton family. Our bidders had some fun too, the Bowley family were unknowingly bidding against each other for our England Rugby World Cup winners 2003 signed frame and the signed Leicester Tigers Jersey!

Thanks to all bidders.

Your fundraising

Running for cash

Julie Anderson took on the Great North Run, wearing a PSPA vest bearing the inspiring words 'For Mam'.



£650

Sophie Dickinson also completed the race, cheered on by family and friends, as well as the Leeds Local Group.



£526

Jan Airlie ran the Great Scottish Run in memory of her mum, Myra.



£756

Family fun

Ruth Soden, whose mum lives with PSP, and 12-year-old daughter Poppy, ran the Milton Keynes 5k fun run. Poppy ran a time of 35 minutes, and completed the run just behind her mum.



£400+

Cheque this out

Supporter Francis Burke delivered a cheque to PSPA head office in Towcester.



£100

Coffee time

Janet Wardale held a successful coffee morning. There was a bring-and-buy stall, and friends and neighbours who attended enjoyed lots of tasty cake.



£400

Dropping in

Rob Spenceley, his daughter, Charlotte and sister-in-law, Sharon Brandenburg, skydived from 13,000ft watched by Rob's mum, Pam, who is living with PSP



£2,302

... and again!

Good friends, Carol Johnson and Trina Dugdale took to the skies for tandem skydives.



£1,700

Loose change

Rhonda Bolton saved her loose change each time she went shopping and donated £15 to PSPA.



£15

Top sale

Richard Freeman, his daughter Lindsay Foster and her family ran a stall at St Nicholas Church, Hull. Richard's wife, Ann, was diagnosed with PSP last November.

Lindsay's auntie knitted cute bears wearing PSPA coloured T-shirts and they held a raffle and sold badges and wrist bands.



Quiz time

Keri Johnston from Bonnyrigg, held a quiz night and raised awareness of PSP. Keri had plenty of fact cards and leaflets to hand out and by the end of the night everyone had commented on how worthwhile it was with some even inspired to plan their own fundraising event!



£1,000

Fun-draiser

Barbara Brown from Cambridgeshire held a fundraising event where her daughter, Linda, designed and sold her own gingerbread houses, and her son, Stephen, travelled all the way from Florida to attend to a range of activities – from cake stalls to silent auctions. All were there for Barbara's husband, Mike, who lives with PSP.



£2,300+



£115

Up hill...

Carla Bancroft took on the 24 Peaks Challenge, and was rewarded with spectacular views, and stunning scenery, but only after a day of low cloud, high winds, and heavy rain!



£1,416

Getting jiggy

Rita Menzies from Gillingham, Kent, held a night of Scottish Ceilidh Dancing – everyone had a marvellous time!

£250

The Liver gang

A group of Liverpool teenagers undertaking the National Citizenship Scheme (NCS) held a fundraising week in aid of PSP. The group, led by Sam Truman who lost his Nana to PSP, held events such as sponsored walks, raffles, a sponsored dance-a-thon, and an afternoon tea and bingo event for the local community.



£1,000

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.