Issue number 74

www.pspassociation.org.uk

PSP Matters

Spring 2018

Rather than travel over an hour to her nearest group, Betty decided to start her own

Also inside: Page 10: Prof Huw Morris on care and research in PSP

Saddle up
FOR THE WORLD'S GREATEST CHARITY CYCLING EVENT

RIDELONDON – SURREY 100
29 JULY 2018

Join #TeamPSPA and ride alongside 25,000 cyclists past famous London landmarks, along traffic-free roads before heading out into the stunning Surrey countryside. Then it's downhill all the way to the finish line along The Mall in front of thousands of cheering fans.

events@pspassociation.org.uk
www.pspassociation.org.uk/events

FIGHTING BACK AGAINST PSP & CBD IS PERSONAL

PSPA

PSP House, 167 Watling Street West,
Towcester, Northants NN12 6BX
Telephone: 01327 322410
Fax: 01327 322412
Email: psp@pspassociation.org.uk

Helpline

The PSPA Helpline and Information Service offers confidential information, practical and emotional support to people affected by PSP & CBD.

Mon to Fri: 9am–5pm and 7pm–9pm
Telephone: 0300 0110 122
Email: helpline@pspassociation.org.uk

HealthUnlocked

This online community provides a safe place where those affected by PSP & CBD can connect with others to share their experiences.
https://healthunlocked.com/psp

Volunteering:

Wendy Crofts, Volunteering
Telephone: 01327 356134
Email: volunteering@pspassociation.org.uk

Fundraising:

James Murphy, Fundraising and Events
Telephone: 01327 356131
Email: events@pspassociation.org.uk

Cover: Betty and Steven Peers

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The fight starts here

This is an exciting time for PSPA. Our work continues on organising the International Symposium on PSP & CBD, by bringing the world's leading researchers and neurologists together, cementing our place in the global fight to end both conditions. We continue to build relationships with pharmaceutical companies currently undertaking clinical trials in PSP and we have secured funding to create the country's first CBD care pathway. All this activity is underpinned by an ambitious new strategy, focused on doing more for people with PSP & CBD.

One of our greatest challenges is raising awareness, with around 40% of people still misdiagnosed initially, and many health professionals unaware of PSP & CBD. The economic situation remains uncertain, with continued cuts to social services and increasing demands on the NHS, putting more pressure on charities to support our communities. This is all happening alongside a challenging fundraising environment with many charities competing fiercely for donations from the public.

To face these challenges we need to build a strong brand that unites and brings together everyone affected by PSP & CBD. The more people who join our community, the wider will be our sphere of influence, and the stronger we will be against the challenges we face.

We are working with a leading branding agency, Brandpie, who have offered us their internationally renowned services free. The Brandpie team have been consulting with the PSP & CBD community to help them develop PSPA's brand, to make us more visible as a charity so that we can tackle the challenges identified above. One family member they spoke to said: "At the moment, the PSPA brand doesn't feel strong enough to take on such a big, terrible disease." This is something we must and will change. With your continued support, we will be strong together in the face of these devastating conditions.

Thank you

Andrew

Andrew Symons
Chief Executive

Scottish Fellowship study ready to recruit participants

OUR jointly funded research study with the Scottish Chief Scientist Office has begun recruiting people with PSP & CBD from across Scotland.

The study, entitled 'Improving diagnostic and care pathways in PSP and CBD' is being conducted by Dr Diane Swallow, a Neurology Registrar and Clinical Research Fellow based at the University of Aberdeen.

The study will look at the routes to diagnosis and care pathways of people with PSP & CBD in Scotland, to find out how diagnosis and care could be improved. The study will also involve the carers or families to learn more about the support that carers of people with PSP & CBD require.

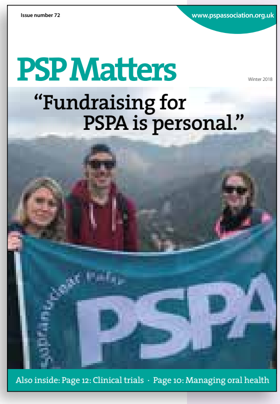
Dr Swallow said: "We hope the study will help us find ways to improve the diagnosis of people with PSP & CBD, by finding out how, when, and to which specialities, people present. We will also test new assessment tools to see if these could improve diagnosis. By understanding the range of symptoms which affect people with PSP & CBD, and how these different health needs change over time, we can learn how to better provide the right care, interventions and support to people with PSP or CBD, and their families, at all stages of the disease."

The study is open to everyone in Scotland with PSP or CBD at all stages of their condition. For more information about the study contact Dr Diane Swallow on 01224 437121. Any information you provide will be kept confidential and only used by members of the research team.

Your views on *PSP Matters*

"I feel so alone sometimes until I see the inspiring stories from others who have personal experience."

"Knowing my husband is not the only one living with this disease, I don't feel so alone."



Thank you to everyone who completed our reader survey. Alongside people living with PSP & CBD, it was great to see so many carers and family members reading *PSP Matters*. It is wonderful to see how well the magazine is received and we were especially delighted over 60% of you share the magazine with family and friends.

The reason most of you read the magazine is for information on how to help manage the condition. Personal stories were also rated highly and many of you have asked for more because they help to reduce the feeling of isolation. It is also clear you want more research news and updates, as well as information on what services we provide.

What we will do now

Following your suggestions, from now on we will include:

- an interview with a prominent neurologist and researcher in every edition (page 10)
- articles on palliative care, advanced care plans (page 24) and brain bank donation (page 22).
- article on how to start a support group (page 14).

In future editions we will also include articles on:

- cognition
- communication aids
- benefits and funding advice
- choosing a nursing home
- more information on CBD

If you would like to share your story, or if you have further suggestions on how we can develop *PSP Matters*, please email psp@pspassociation.org.uk

Symposium update

WORK continues alongside CurePSP on our International Research Symposium on PSP & CBD, to be held in October.

The event will bring together PSP & CBD researchers from around the world and our exciting programme is now finalised, with around 20 presenters confirmed for the one day event.

Speakers will be sharing the latest developments from their various fields of expertise including neuropathology, biomarkers, genetics and clinical studies.

"Conferences like this provide the perfect environment for establishing new collaborations and generating new directions for studies," says Andrew Symons, PSPA's Chief Executive. "We are delighted to be organising the first truly international PSP & CBD research event in several years."

We will be reporting from the event via social media, our website and sharing highlights in future editions of *PSP Matters*.

PSPA

Name

Address

Tel no.

Unsold Tickets, Cash, Counterfoils should be returned to promoter by 30 May 2018.

Any money received after this date will be treated as a donation and will be used to fund our work.

PSPA

Registered Charity Number 1037087 / SC04119
Promoter: The PSP Association, 167 Watling Street West, Towcester, Northants NN12 6BX

TICKETS £1 EACH

SPRING RAFFLE

1st Prize: £500 Cash · 2nd Prize: £250 Cash · 3rd Prize: £50 Cash

Draw will take place on 1 June 2018
Registered with South Northamptonshire Council

www.pspassociation.org.uk
Thank You and Good Luck

Our spring raffle is here with your chance to win £500

EVERY ticket sold helps us provide information and support to people affected by PSP & CBD, fund research and educate health and social care professionals.

Last year Christopher Allon used his winnings to take his family on a much-needed holiday to the Yorkshire Moors. “My wife Jackie had PSP so I always buy raffle tickets to support PSPA and help try and find a cure. It never crossed my mind I might win! Winning was a lovely surprise during a difficult time and with the winnings I booked a holiday for my family.”

Like many of you, supporting PSPA was personal for Christopher after his wife was diagnosed with PSP. It was also personal for Verna whose Dad had PSP. Verna Gill decided to sell as many tickets for PSPA to help others. Verna said: “When I received the raffle tickets I knew it was an easy way to raise money for the charity. My colleague and I decided to sell the tickets together. We went everywhere we could think of to sell them. It was also a great way to raise awareness because people always ask what it is. We sold over 200 tickets which felt brilliant.”

Whether you buy one ticket or more, you are helping PSPA raise vital funds to invest in ground-breaking research, like our UK-wide PROSPECT trial. The money raised will also help fund our Information and Support service, including our Helpline.

To order some raffle tickets please contact raffle@pspassociation.org.uk or 01327 356132. For the first time ever you will be able to see the winners drawn live on Facebook at 1pm on 1 June.

“I would actually pay a subscription for *PSP Matters*.”

IT was wonderful to see that some of you who responded to our *PSP Matters* survey valued the magazine so much you would pay a subscription for it.

We are determined to keep producing a high-quality magazine for you and everyone affected by PSP & CBD. If you would like to contribute towards the production of the magazine for one year a suggested donation of £5 would help enormously, but any amount would be welcomed. If you would like to make a donation please visit our website www.pspassociation.org.uk/donate or call 01327 322419.

How can we do more?

AS previously reported we have developed a new strategy to help us focus our efforts on supporting more people with PSP & CBD than ever before.

We will be implementing ambitious new plans to increase our fundraising capabilities in order to provide more support to people affected by both conditions, raise awareness, educate health and social care professionals and fund research into effective treatments. To do this we need to develop a strong brand to help us stand out and encourage others to join us. Developing a strong brand can be an expensive process for charities, but PSPA secured the free support of top branding agency Brandpie, through the agency’s charitable foundation.

PSPA was selected from five shortlisted charities to receive £50,000 of support. Brandpie has worked on major brands and is one of the top branding agencies in the country. As part of their work to develop a strong brand for PSPA they have spoken to a number of people living with PSP & CBD, family members, carers, fundraisers and health and social care professionals. The majority of people they interviewed said they would like PSPA to be more dynamic in the fight against PSP & CBD. Taking the views of the people from the PSP & CBD community they are developing a new identity.

We hope to share this with you in a future edition of *PSP Matters*.

FROM HALLUCINATIONS, TO WHEELCHAIRS AND BENEFITS HEALTH UNLOCKED FORUM COVERS IT ALL

www.healthunlocked.com/psp

FOR many people affected by PSP & CBD the HealthUnlocked forum provides vital information on a range of topics from carer's allowance, lasting power of attorney, incontinence and finding a nursing home. However, it is not just information people find there, but vital support, and, for many, valued friendships.

A post by Amanda Teasdale asking if people would be interested in meeting up led to a meeting in London. Three forum regulars who attended the meeting, share their thoughts on the lifeline the forum has given them.

Amanda Teasdale said: "The HealthUnlocked forum has been an absolute godsend to me. Sadly, my Dad has PSP. Without the forum and the amazing people on there, we wouldn't have known about attendance allowance, or continuing healthcare. We wouldn't have known how the hospice can help. I thought hospices were just there for when you die, but this is not the case and they offer so many wonderful services.

"I wouldn't have had anywhere to vent my anger, concerns, or just talk to others who understood. Day or night there is always someone to offer advice, point you in the right direction or just listen. The members are the most loyal and wonderful people who know exactly what you going through. Many have become friends.

"I suggested a meet up and on the 6 March we had the most wonderful get together. People travelled from all over the country just to meet their online friends. The virtual hugs we've sent online were suddenly real and so very overwhelming. More than once I had to hold back the tears. Words cannot actually express the genuine love I felt that day.

"No one appeared nervous, although I know some people were beforehand. One person even told me they started walking to the venue and nearly walked away, but once they stepped inside they felt so welcome and their nerves disappeared. To be among a group of people that you've never actually met and only talked to online wasn't in the least bit strange. It was like meeting the family you'd never met.

The first Forum meeting on 6 March held in London

"Everyone shared their stories, their grief and sorrow, but there was also lots of laughter, exactly what the meeting was about. I came away absolutely buzzing from the day. My mum, who has never been on the forum, was quite astounded at the friendliness of everyone. We are now hoping to have regular meets in London monthly or three monthly.

Anne Ruddick travelled from Bristol to attend the meeting. Anne started posting on the forum following her husband Steve's diagnosis of PSP. Anne said: "I have never been one for forums and had no idea that this one would change my life the way it has.

"Reading a post from someone crying out for help because they were upset they had shouted at their husband who had PSP compelled me to reply. I remember typing that surely it is normal to shout at your husband on occasion. Soon there were many other responses saying the same thing. It was wonderful to see the lady reassured what she did was entirely normal and understandable. This is when I realised being part of this forum was exactly what I needed. It is a safe space where there's always someone to talk to, even at 3am.

"One day I hit a brick wall and cried out for help. It wasn't long before I received it from people who understood what I was going through. Typing out your thoughts can be quite therapeutic. It also helps to know someone is listening. No one really knows anything about PSP. I remember during one hospital stay Steve saw 14 different doctors and nurses (I counted them) and not one had ever heard of PSP. So, to come to a place where everyone knows about PSP is very reassuring.

There are so few of us affected by PSP & CBD we need to stick together."

"As well as gaining help and support, I have also made many new friends. I'm even going to China later this year with one lady whose husband also died of PSP.

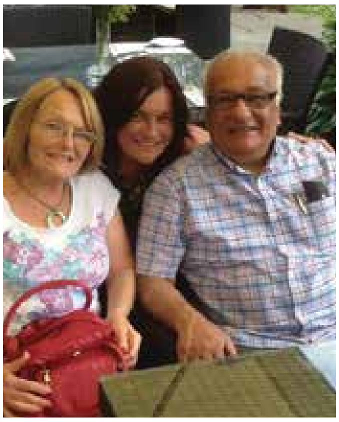
"I'm still on the forum even though Steve has now died. I don't want to leave my friends; we have become family. Many of them are still caring for loved ones and I feel I can help them. It comforts me to think every painful lesson I learnt could now help someone else.

"There is so much humour on the site. When you first open the page, you can barely see because you are crying so much, and by the end, you still can't see but it is from crying with laughter."

"When Amanda first posted about the meet up immediately I thought 'I am there'. Being able to meet up with everyone and put faces to names meant a lot. There are so few of us affected by PSP & CBD we need to stick together."

Another forum member who attending the meeting was Kevin Sheffield. Kevin's wife Liz has PSP. When Liz could no longer post on the forum due to her progression Kevin started posting for her and saw for himself how much it helped.

"Amanda and I had talked about meeting up. I thought it was a brilliant idea. We have shared a lot of heartbreak so it is nice to meet people and have some fun together.



Amanda and mum and dad

Kevin and Liz Sheffield

Anne and Steve Ruddock

"When Liz first showed me the forum I saw there was a strong network of people sharing a lot of good information. There is a lot of acceptance on the forum and a complete absence of judgement, even if people disagree it is courteous and respectful of differences.

"Liz spent some time sharing what it was like to suffer PSP, in response to some posts by carers who were struggling with the demands being made on them. Sadly, their partners were no longer at a stage where they could explain why they were making such demands. I posted Liz's explanation and was deeply moved by the numbers of carers who said it provided them with a real insight into the condition and how their partners must also feel.

"There are a number of people on the forum with really good specialist expertise who help signpost people towards help. As a retired Mental Health Social Worker and Psychological Therapist, I have a good understanding of the NHS and can help people with advice. I am always cautious to advise that they must always check with their health professionals, but I do try to give people a lot of support in a way that is helpful, as do many others on the site.

"PSPA provides great support to people affected by PSP & CBD and the forum sits alongside it very well. It is separate to PSPA, but the two complete each other. On the forum, we can share our experiences and fears. We can get help with issues, or just get support at 2am. We can stay anonymous if we choose. At the same time we have PSPA there to support us and provide us with accurate and relevant information."

YOU JUST NEED ONE NUMBER FOR SUPPORT

0300 0110 122

In the last edition of *PSP Matters* we reported that we are increasing the Helpline's capacity by creating new roles. Last year the Helpline received 5,621 enquires, an increase of 39% on the previous year.

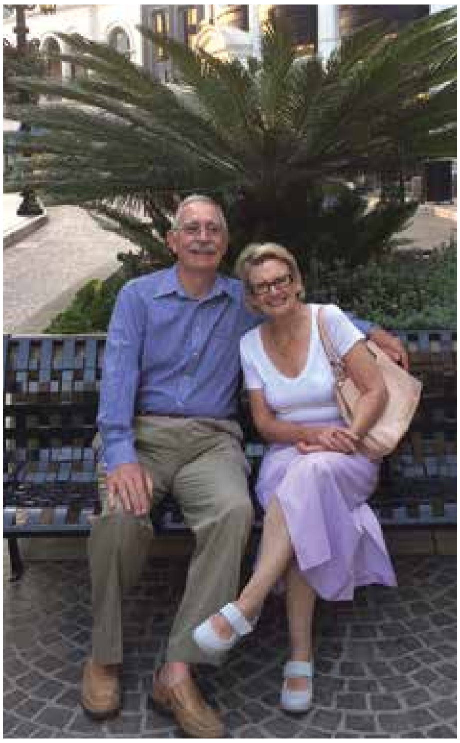
Following his wife Yvonne's diagnosis of PSP, Stephen Buck called the Helpline for support.

"I would call my wife Yvonne the human dynamo because of her ability to juggle so many things. But, around two years ago it started to become obvious something was wrong.

"With Yvonne's mobility clearly deteriorating we decided to retire and move back to Hampshire, where we had fond memories growing up. The process of moving really exposed Yvonne's symptoms. We arranged to see a neurologist who told us Yvonne had PSP. The diagnosis meant we both had to come to terms with the revelation it was serious, but we have been frightened to ask too much about its progression ever since.

"Two weeks later I called the Helpline and was told about the ways PSPA can support us. The next day I received an information pack. I decided to call again, to see how we could manage PSP. That call resulted in us accessing financial support that has made a huge difference to our lives.

"The Helpline explained the benefits we could apply for and even arranged someone from the Department of Work and Pensions to come to our home and help us make the application. We then received a follow-up call from the Helpline asking if they had visited us yet. Without the help and guidance from PSPA we wouldn't be where we are today.



Stephen and Yvonne on holiday in LA

"It is a great comfort to know that there is an organisation that understands what you are going through and exists to provide support and comfort in the face of this disease.

"From making that initial call to the Helpline, we now have Attendance Allowance for Yvonne, Carer's Allowance for myself and a blue badge. With this extra financial support, we were able to get a car suitable for Yvonne, enabling us to go on frequent trips to the coast, making the most of our time together."

Timea Matyus is a Helpline volunteer.

"In Hungary I was a speech and language therapist. I was very interested in how speech and language therapy worked here, so I would observe therapy sessions. One of the therapists I was observing talked about her volunteering work for PSPA on the Helpline. It really motivated me to think about volunteering.

"When I read more about the charity's work I was really inspired. I had heard about PSP before. When training to be a speech therapist many of my observations were with people who had PSP. I saw the challenges they faced. So, I was thrilled to hear about a charity looking after people with PSP & CBD.

"My training soon started and I spent the day watching how the Helpline worked. The next week I was set up with a phone and ready to take my first call. I remember it vividly. The lady was worried her condition was progressing too quickly. She was already experiencing sight loss and communication difficulties. She felt very isolated and alone. She told me that she had a neurologist appointment the next day, she just didn't want to hear what they had to say. She needed someone to help calm her down and thankfully, by the end of the call she was much calmer.

"Recently I took a call from a lady whose husband had PSP. He lived in a care home and his condition appeared to be changing day by day. Some days he was fine and then others he could barely open his eyes. The lady felt that she didn't know how to manage it. She needed some strength. After talking it through, she felt better. It feels good when someone ends the call in a better place than they were at the start of it.


Timea Matyus

"In the evening, I find the calls are not usually about asking for specific information, most people just want someone to listen.

"I do up to two evenings a month, so in total it is four hours of volunteering. I do it because I want to help people.

> **"Without the help and guidance from PSPA we wouldn't be where we are today."**

"After one phone call, you can feel that you are making a big difference. The gift of being able to give someone a peaceful night is priceless. I can imagine how hard it is for many to pick up the phone. Especially because so much information can be found on the website. But, we are here to listen whenever they have any doubts, or are simply having a hard time."

The Helpline can provide:

- Information on life with PSP & CBD
- Symptom management
- Benefits and entitlements
- Emotional and practical support
- Linking to local NHS services
- Contact details for local support (this may include a volunteer support worker or a local support group)
- Information on PSPA
- Signposting to other sources of information and help.

0300 0110 122

helpline@pspassociation.org.uk

We offer a confidential telephone and email service.

We are open Monday to Friday from 9am-5pm and 7pm-9pm.

Please leave a message on our answerphone if we are unavailable and we will get back to you.

"OUR KNOWLEDGE IS STARTING TO TRANSLATE INTO DISCOVERING POTENTIAL NEW TREATMENTS FOR PSP."

Prof Huw Morris is a Consultant Neurologist and is Chief Investigator on our UK-wide PROSPECT study, a ground-breaking project that aims to increase understanding of PSP, improve diagnosis and ultimately support more effective clinical trials. We asked Huw what attracted him to neurology and how research has increased our knowledge of PSP.

"THE brain is the most complex organ we have. I have always been fascinated by the way the brain processes information and, importantly, how it breaks down in patients with neurological conditions. When I started my training in neurology, the focus was very much on making a diagnosis and managing symptoms. Over the last ten years the focus has started to shift towards discovering treatments to tackle the progression of the disease.

"This is a big change in approach and it relates directly to the huge amount we have learnt in the last 20 – 30 years. We still don't know what causes PSP, but we do know that it is likely to relate in part to genetic risk factors which ultimately lead to the accumulation of abnormal tau protein. When I first started doing research in 1997 there had not been any large scale trials for PSP. Since then there have been several large scale studies across multiple sites.

"One of the most important discoveries so far for PSP has been the identification of the tau protein. When the tau protein becomes sticky it clogs up the nerve cells. We have also seen that in some families, spelling mistakes in the tau gene can cause a neurodegenerative condition very similar to PSP. This knowledge of the disease mechanism provides new targets for drug therapies. This includes the tau antibody approach that is currently being explored by pharmaceutical companies.

"Our knowledge is now starting to translate into possible new treatments, with a number of clinical trials being set up for PSP and other neurodegenerative conditions. I think, over the next ten years, we will see an even greater focus on selecting patients for clinical trials and enabling people to receive the best treatments.

"Research has also helped us to improve the diagnosis of PSP. Due to our increasing understanding about the condition, the diagnostic criteria have been revised to be broader because we now know that people have varying types of PSP, different to the classical form. However, diagnosis remains a challenging area and I know many people with PSP have been initially misdiagnosed. One problem is that the disease features are not specific to PSP, with some people initially having symptoms that are similar to Parkinson's disease. One of the ways we are trying to improve diagnosis is by developing biomarkers. We are currently comparing the biomarkers of 2,000 patients with Parkinson's and PSP to see how they are different. The ultimate aim is to develop a blood test that might help in diagnosing PSP.

"Brain imaging allows us to visualise patients' brains

and, therefore, understand the relationship between specific areas of the brain and what function they serve. We can see the ways certain parts of the brain wear down in PSP, particularly the areas that control eye movement and balance. We see how when the disease gets worse the patient develops more symptoms. This appears to be happening because abnormal tau protein spreads between the nerve cells in the brain. So, if we can stop it being taken up by the next cell it may stop the progression. One of the current clinical trials is looking to test the effectiveness of an antibody that aims to "mop up" the tau protein as it spreads.

"Research funded by PSPA has made a big difference to our understanding of the disease and in the drive to develop new treatments."

We (and other sites in UK and around the world) are still in the process of recruiting participants, and we expect to know if the trial was successful in two – three years' time. Patients need to be in the early stages of the disease and need to visit a trial centre regularly for lengthy appointments, so it is a big commitment from them to be involved.

"Increasing awareness of the condition is also important and we need to ensure people are being referred to neurology/movement disorders clinics promptly. The care people with PSP receive does need improving. There are far fewer specialist centres for PSP than for other neurodegenerative conditions. We also need to have more therapists and doctors with a special interest in PSP, and more patients with access to co-ordinated multi-disciplinary care. It is heartening to see how the developments in research have a positive impact on patient care. In the UK, there were just seven specialist centres for PSP. Since the start of the PROSPECT study, a further 20 centres have joined the network, so there is a big interest in wanting to do more to help patients. Complementing NHS support are the PSPA's services for patients. The charity's local support groups provide excellent information and support to patients.

"PSPA has made a huge impact on research into PSP. Research funded by PSPA has made a big difference to our understanding of the disease and in the drive to develop new treatments. PSPA's funding has paved the way for new drug trials in the UK and its initial funding has allowed us to successfully apply for other grants, so the charity's money has gone a long way. I know that this is down to the dedication and commitment of those who have been personally affected by PSP. They are very much a big part of the research effort to end PSP and I am optimistic about the road ahead."

Families come together for virtual event

Earlier this year we launched our 5K for PSPA virtual race. Our event proved to be the perfect opportunity for family and friends to get together. Across the country 400 of you walked, ran or were pushed through parks, roads and towns, raising over £10,000 for PSPA.

TWO of our youngest runners were six year old Toby and his younger sister Edie, three, who decided to take part after watching their dad, Alan Wadsworth run both London and Brighton Marathons for PSPA. Fundraising is personal for the family after Alan's dad Stephen was diagnosed with PSP. When asked why they wanted to do the race Toby said: "I am running for charity and to make Grandad better" while Edie replied that she was running "to help Grandad get better as he is really really sick."

Janet Smith along with colleagues from Poppies Dental Practice and other supporters

Toby Wadsworth

Alan said: "We have always been very open with the kids about their grandad's PSP. They are very much on this journey with us. My dad was able to get to know Toby, but sadly by the time Edie came along he wasn't able to interact with her. I'm sad he wasn't able to get to know her, but fundraising as a family has brought us closer together and provided us with something positive to focus on.

"The kids see me go out three or four times a week for training runs so, when they saw 5K for PSPA, they wanted to do it. I think Toby was attracted by the medal and Evie liked the headband. Evie has been training for the last month – doing practice runs around the house in her headband – it's hilarious to watch.

"My motivation comes from my mum, she is a trooper. Without fail she visits Dad in the home every day. She has sacrificed so much to care for him. I know she has used the Helpline and so I wanted to give something back to the charity. Also, I want to help others who may not have the support Dad thankfully has.

"While the kids were preparing for their 5K, I decided to find my next run for PSPA. After completing three marathons, it needed to be something big to convince people to part with their money again. So, my next run is the London to Brighton ultra-marathon at 100km. It will be tough, but I want to be part of the effort to cure PSP, and running is one way I can do that."

Jean Tucker and her family decided to

take part in honour of Jean's husband John who is living with PSP. Jean said: "We couldn't have coped with our situation without the support of PSPA. They are always on the end of a phone if you need help.

"From reading *PSP Matters* I see how important money is to the charity and the difference it makes. The only way we can continue to get information and support we need, and read about developments in research, is by supporting PSPA. That is when I first started to think of doing something.

"I saw the 5K for PSPA fundraiser and thought this is one way we can say thank you and help others affected. When I told my family about wanting to do it, they told me to 'go for it, we are with you all the way'.

"Soon, more and more people wanted to join our 5K walk. It started off with my daughter, granddaughter and sister. Then word spread and friends, nieces and nephews and more grandchildren took part. It was a real family event and a lovely get together. John came too, and led the way in his wheelchair.

"It feels really positive to be coming together as a family to raise money for PSPA. What started as a fundraiser turned into a family get together."

It wasn't just family members taking part in our virtual race, but colleagues, including Janet Smith's teammates from Poppies Dental Practice in Manchester. Janet wanted to do something in memory of her dad who had PSP. Janet said: "PSPA is a charity very close to my heart. As soon as I saw the leaflet in *PSP Matters* I wanted to take part. We walked the 5k and all really enjoyed it. It felt good to do something together for such a good cause."

Verna Gill

Helpline team brace the blizzard to do 5K for PSPA

Following her Dad's diagnosis of PSP Verna started fundraising. "I am a warrior for PSPA and I will do anything for the charity."

> **"What started as a fundraiser turned into a family get together."**

"Information from PSPA was vital in helping us make the most of life. If it hasn't been for *PSP Matters*, we would never have known about things that made such a difference to Dad, like prism glasses or having Botox to help keep his eyes open.

"I cared for my dad until the very end. When he died, it left a huge gap in my life. A gap I have now filled with fundraising. I thought once Dad died I would stop fundraising. But I have found that fundraising is providing me with a focus. This charity is so close to my heart and my life is now built around it.

"Taking part in the 5K for PSPA was another opportunity for me to raise money. Our journey has been heart-breaking, but now I just want to help others as much as I can."

To see more photos visit www.pspassociation.org.uk/5kforpspa

VOLUNTEERS ARE VITAL

PSP Matters speaks to three volunteers about their very different roles within PSPA.

Local group co-ordinator - Betty Peers

WHEN Betty Peers' husband Steven was diagnosed with PSP she looked for a local group but the closest one was miles away. Thinking there must be others in this area living with PSP, Betty decided to set-up a group herself. Betty said: "I decided, rather than travel over an hour to my nearest group, I would start one in my own town instead.

"After speaking to PSPA it seemed the main requirements for starting your own group were finding a venue and the ability to make tea. I found a local church hall for £40 a month. We fundraise to cover the costs of the venue and bake cakes to bring to the meetings.

"Working with PSPA, we made sure everyone in the area knew about the first meeting. Four wonderful friends from my church volunteered to be group helpers.

"Three years on the group has grown from 12 to 31 people. We invited a Parkinson's nurse to talk, who, subsequently, told the local neurologist about a new support group in Woking for people affected by PSP & CBD. He is now referring people to the group.

"To be able to spend this time together, once a month, helps to beat the isolation that can come with living with a condition no one has heard of. I want people to come along and not feel that they are different, that they will be judged, or feel uncomfortable. I also want carers to know that they are not the only ones struggling. I want us to have fun together.

"We do some fundraising to go towards the group. In October, we ran a painting competition. We had a lot of fun, with everyone creating a piece to submit. I got an artist friend to select 12 paintings to put into a calendar. My daughter Lucy, who is a graphic designer, created the calendar and we printed 150 of them at a cost of £500. The calendars were sold at the group and we made nearly £700 profit. It just goes to show how something as small as that can actually raise a lot of money.

"We also did a bake off that was so popular we will definitely do it again this year. I invited three judges to come along, and taste all 20 cakes before selecting the winners. We asked people for a suggested donation of £5 and raised over £400.

"Doing smaller fundraising is always enjoyable. It means everyone can be involved and it doesn't take too much time or effort. The money we raise pays for the venue and for specialists to come in and run sessions like Pilates or first aid training. Raising money to cover the costs of the group is actually really easy. I think if people saw how easy it is to set up and run a local group more would do it.

"Supporting PSPA is my way of trying to find some good out of a devastating situation. My family feel the same. Last year we climbed Snowdon, raising over £2,500. It felt good to donate the money to research, so that it might help people diagnosed in the future. We

Betty and Steven Peers

TO OUR WORK

have to work together to eradicate this horrible disease.

"Raising awareness is also very important. People really have no idea about PSP. Seeing how people ignore Steven because he is in a wheelchair and can't speak is devastating. I know his brain is as active as it ever was and I can imagine how frustrating it must be for him. As we progress with PSP, life is getting harder. Being a carer can be frustrating and hard. It is physically and emotionally demanding. It can get you down, but I am a very positive person. Our faith keeps both of us going and our wonderful friends who are always there for us.

"When I met my husband when I first moved to London to do my nursing training I never thought this would be our future. However, it is the life we have now and we must do whatever we can to make the best of it."

Betty's top tips for starting a group

Start one close to your home. It is likely there are people nearby who don't want to travel far to a group either.

- Don't worry about how other groups are run – do it your own way
- You don't need big numbers, a small group provides just as much support
- Find a venue – church halls are perfect
- Get some helpers who like to make tea and talk!
- PSPA will help you contact people
- Picking up the phone is always better than email

Support worker - Val Jameson

"AFTER Eddie died I thought I never want to hear about PSP ever again. But then I thought I can't just sit here and feel sorry for myself, I want to have a purpose in life. Eight months after Eddie died, I took over the co-ordination of our local support group, did some volunteering in PSPA's office and took on the new support workers role.

Val and Eddie Jameson with proceeds from the sale of his Ford Capri

"As a support worker, I will adapt how I support the person based on their needs. Recently one couple rang me from home and were both quite depressed. I went to visit them and spoke to them individually and together. I referred them to NHS Improving Access to Psychological Therapies for extra support. It was heartening to see how, following the additional help they received, they were able to manage better.

"Being a support worker is a good way to utilise my background in nursing and as a health visitor. I am used to going into people's homes and helping to find practical solutions or signpost to places that can help. Or, if that is not required, it may be just to be there and listen. It is nice when you build up a rapport with someone, you become more like friends and they often tell you things they perhaps wouldn't tell their own family.

> **"Being a support worker is a good way to utilise my background in nursing and as a health visitor."**

"Unless you have had experience of PSP or CBD it is very difficult to expect people to support our charity. I really think it is down to those of us who have seen the devastation it can cause to raise money to support others affected and fund research. Eddie sold his old Ford Capri to raise money for PSPA. My son Andy and grandson Liam cycled through Cambodia and Vietnam for PSPA. Liam also recently did the Edinburgh marathon. My youngest son Dorian held a fundraising gig with his band in London and I have done afternoon cream teas. It is our way of fighting back, because we can't let PSP & CBD win."

Education volunteer - Roger Bowley

"MY wife, Margaret died of CBD in September 2016. Since her death, I wanted to keep busy and do something to help solve some of the problems she faced. We were very unclear about how to manage CBD for a long time. Now, having lived with the condition for six years, I have picked up knowledge that I'd like to use to help others. When I saw an article in *PSP Matters* appealing for volunteers to help educate people about CBD & PSP, I thought I could do that.

> **"Now, having lived with the condition for six years, I have picked up knowledge that I'd like to use to help others."**

"I always introduce my talks to health care professionals by describing the day I first realised something was wrong with Margaret, back in June 2012. We were walking in the grounds of Highclere Castle, when I took a short cut into some long grass. Margaret wasn't following and I could see she couldn't lift her feet adequately.

"When the eventual diagnosis of CBD was made we left the appointment in a fog. Neither of us knew anything about CBD and Margaret was not keen to read about it on the internet, although after researching the condition, our daughters realised the severity of it. However, we still didn't realise the impact it would have on our lives and how we would manage its progression.

"Despite CBD, Margaret and I would have fun. I would always try to take her out to places like the cinema, so that she would have other things to look forward to besides a visit from the bowel nurse! Our daughters were also a great support and we visited them while we could in Harpenden and France, where they live with their families."

"When I talk to healthcare professionals about caring for people with CBD & PSP I always use PSPA's care pathway leaflet, as it is very clear and includes all the disciplines people may need support from.

"Having spent so many years caring for Margaret, giving talks helps me to feel I am creating something positive out of what was a devastating situation. I wrote to a number of care homes offering to speak. When many didn't reply I soon realised the importance of using places you already have a relationship with. So, I contacted the home Margaret was at, and also spoke to people in the local support group about where they or their relatives stayed. I also contacted the Hospice of St Francis who invited me in to speak.

"The hospice was holding a neurological seminar and they particularly wanted to know about caring for someone with a neurological condition. Following my talk, word got around and I have been to a number of hospices in Hertfordshire.

"I want to help professionals learn more about PSP & CBD and, particularly, how important it is for services to be joined-up and coordinated."

Volunteer for PSPA and join a powerful and dedicated group of people, united by their experience of PSP & CBD and determined to fight the devastation they cause. If you have energy to share please contact Wendy Crofts Volunteer Development Manager, on 01327 356134 or email volunteering@pspassociation.org.uk

Roger and Margaret Bowley

The highlight of our week

JOYCE Freeman and her husband Henry loved music. So it was natural that music therapy provided them with a break from the challenges of PSP.

"Ever since we first met at a graduate's event in Manchester, where I was playing the piano, we have sang, danced and performed together. My marriage of 53 years to Henry has been a very happy one. Sadly, the singing, dancing and performing has come to end thanks to PSP.

"Henry, myself and a friend formed a group called Three's Company. We would travel all over performing in clubs and homes. Henry was an excellent singer. Life was wonderful until some very strange things started to happen to Henry, but he didn't appear to notice. It was only after his diagnosis of PSP that it all became clear. Things like walking through puddles suddenly made sense, because he couldn't actually see them. And of course, the falls that anyone affected by PSP is so familiar with.

"Even after his diagnosis, he was very stoical and never complained. Getting to the point of a diagnosis was traumatic. I had to fight to get one. Eventually the diagnosis was made when he was in hospital due to repeated falls. I will never forget how one kind doctor took me into a side room and carefully explained PSP. While I was in shock, his kindness made the news slightly more bearable.

Joyce and Henry Freeman

"PSP turned our lives upside down. There were many crisis points and Henry had got to the stage where he needed two carers, 24 hours a day. I just couldn't manage. He moved into a nursing home. The care he has received there has been fantastic.

"Henry moving to a home was devastating for all of us and his progression seems to be rapid. However, our relief from the challenges of PSP came in the form of music therapy. Thanks to the fundraising committee at the home, they raised enough to secure the services of a music therapist. Henry soon began one-to-one sessions with David Robinson, the Nordoff Robbins music therapist. David is so talented and really connects with people.

> **"PSP turned our lives upside down. There were many crisis points and Henry had got to the stage where he needed two carers, 24 hours a day."**

"Every week he visits Henry with an individualised programme of music specially chosen to encourage Henry in singing. David plays the piano for us whilst Henry sings and I often sing alongside him as well. These sessions soon became the highlight of our week. In the early sessions, Henry's voice was largely unaffected. His deep baritone voice would travel around the home – the carers loved it. But, although gradually it has disappeared, David always adjusts his own playing to encourage whatever Henry feels able to do. Some days Henry just moves his lips, other times you can still hear a shadow of his former voice.

"We will continue to look forward to our music therapy sessions for as long as we have left together. Henry is not suffering. He always accepted his diagnosis. I look at my husband now and I'm proud to have married such an inspiring and talented man."

"MANY ASPECTS OF ANTHONY'S MOBILITY ARE BETTER THAN THEY WERE BEFORE."

Ann's husband Tony Bartlett was diagnosed with PSP five years ago. Following a fall, Tony spent two weeks in hospital. By the time he returned home he had very limited mobility. Ann talks about the difference exercise has made in Tony regaining his strength and mobility.

"WHENEVER I read any description of the progress of PSP, it is almost always a case of gradual loss of functions with little that can be done to halt the decline. Through exercise we have tried to delay that decline.

"The progress of Anthony's disease has been relatively slow until last summer he suffered the familiar deterioration in walking, with frequent incidents of 'freezing' and 'juddering' small steps. Transferring from chair to chair or to bed was becoming increasingly tricky.

"His mobility was helped by the use of a 'Ustep' walker indoors and a wheelchair when out and about.

"Then Anthony had a nasty fall, which led him to spending two weeks in hospital. Although Anthony had no permanent physical damage, two weeks lying in bed had a serious effect on his mobility.

"When Anthony got home he needed two people to do his personal care. He needed a turntable to transfer from bed to wheelchair, and a wheelchair in the house. He could barely use his walker for any distance.

"We were determined we would make every effort to regain as much of the mobility he enjoyed before his fall. I discovered a local physiotherapy practice with experience in neuro-rehab. Since July, Anthony has had intensive physio twice a week and all his carers (including me) have followed the exercise programme.

"The results have been very encouraging. Not only has Anthony regained the mobility he enjoyed before his fall, but many aspects of his mobility are now better than they were. His balance is better, his ability to transfer from walker to chair or bed, and to walk a short distance unaided has improved. His freezing and juddering steps happen less often, his walking and his stamina in general has also improved.

"This has enhanced Anthony's quality of life. Of course, we have no idea how long he will continue to improve or when the inevitable decline in his mobility will reassert itself, but for the moment we are enjoying all the things that his current level of mobility allows him to do."

Rakesh Kumar is a Clinical Specialist Physiotherapist at Ysbyty Gwynedd Hospital in Bangor. He describes how exercise can help people living with CBD & PSP.

"Living with a long term and progressive condition like PSP or CBD can suppress people's energy for living and even potentially make them more vulnerable to infections by dampening their immune system.

"Often the first thing people stop doing is moving, especially when regular exercise becomes intolerable. But gentle exercise, starting with just a few minutes a day, coupled with correct breathing patterns, can become very effective.

"Physical exercises stimulate glands and organs, helping them to produce the soothing, healing chemical balance needed to feel well.

Exercise improves circulation by sending oxygen to the brain and muscles.

"Probably, the most powerful aspect of these exercises comes from breathing. However, breathing typically becomes distorted in people with PSP & CBD, and this exacerbates the condition, causing anxiety, deeper depression, stress or fear. The physical postures and breathing exercises encourage deeper and more natural breathing. Increasing the body's intake of oxygen also works to improve one's mood.

Rakesh Kumar, Clinical Specialist Physiotherapist

"Combined with a healthy diet, regular exercise and medication is something people can do to help try and take some control over how they feel. Even if you can't exercise, a 10-15 minute walk or marching in one place can help you to clear your mind and relax. For people who can't stand up, they can use a pedal exerciser. Ask your physiotherapist about pedal exercisers, they are very effective in strengthening muscles in the legs and arms.

"Don't worry about not doing enough – get started by building a bit more physical activity into your daily life now. Even a small change can boost your morale, give you a sense of achievement and help you feel better. Exercise takes many forms. Playing with the grandchildren, dancing, walking, chair aerobics, yoga, Tai Chi, Pilates and even gardening are all forms of exercise. Water based exercise is often recommended because water increases buoyancy and weightlessness. The resistance water provides is also good for muscle strengthening and less fear of falling. In addition, exercising in warm water can help muscles feel relaxed and less painful.

A physiotherapist can help you to:

- Customise an exercise regime to meet your needs. A home exercise programme can help maintain or improve strength, flexibility, co-ordination and balance.
- Evaluate and treat mobility problems by helping you learn the proper ways to move and walk.·
- Evaluate and treat walking problems, loss of balance, and falls- due to problems with eye movements, particularly downward gaze. Using head movements to help move the eyes, specific eye movement exercises, balance exercises, and new walking techniques can all help with fall prevention. People with PSP & CBD tend to fall backwards, so rolling walkers with weighted fronts and heel wedges in shoes can often limit falls by helping to keep the centre of gravity forward.
- Teach you to do stretching. People with CBD often experiences involuntary hand levitation (commonly known as alien hand syndrome) and need regular stretching of the arms.

Simple relaxation technique

Try the following tense-relax exercise as you sit in a comfortable chair with your eyes closed:

- Inhale through the nose; tighten the muscles in knees, calves, ankles, feet, and toes. Hold the tension, then relax and exhale.
- Inhale, tensing all of these parts as well as the abdomen, pelvis, hips, and thighs. Hold them taut, then relax and exhale.
- Tense the muscles in the neck, shoulders, arms, elbows, waist, hands, fingers, chest as well as muscles in chest and legs. Hold the tension, then relax and exhale.
- Finally, starting with your scalp, face, and head, tense all the body muscles. Hold the tension, then relax and exhale. Feel how all of the tension has melted away from your body.
- Rest in the stillness for six-eight minutes without falling asleep.
- Awakening the body mentally by imagining glow of light enhancing the inner energy of the body.
- Awakening the body by gentle wiggling toes, hand muscles and head.
- Gentle massage with tip of fingers on the face, back of neck and head scalp.

“MY MUCH-LOVED VESPA IS BEING REPLACED WITH AN AUTOMATIC.”

“MOST people’s worst nightmare is receiving a horrible diagnosis. By the time I was 53, I had received two. In 2004 I was told I had non-Hodgkins lymphoma. Just 12 years later, I was told I also had PSP. Dealing with the news that my life is going to be cut short is hard. My wife and I were happy. I enjoyed my job at Honda and we loved to spend time with the grandchildren and going on holiday.

“The first PSP symptom I noticed was when my handwriting got very small. Initially I thought it was carpel tunnel. Then I thought it might be connected to my lymphoma. When I started to trip at work the backward falls struck me as particularly odd and felt very scary.

“I was diagnosed with Parkinson’s. Receiving that diagnosis was actually a relief. But the relief didn’t last long and when it was confirmed I actually had PSP, I was gutted. But what can you do? We had to get on with things and try to make the best of it. The rest of the family have taken it quite hard. I keep telling them that I was told that the average length of survival with lymphoma was eight years and I have had it now for 13, so the doctors don’t always get it right.

“After receiving my PSP diagnosis, I contacted PSPA. They were really helpful and informative. I have since called the Helpline a couple of times when I feel a bit low. After speaking to them I feel better and they give me a boost. Knowing there is support out there, from people who know and understand the condition, provides me with some comfort.

“My wife has now become my carer, along with continuing her work at a special school. The list of things I can’t do is growing by the day. I can’t spread butter on my toast, I fall on a daily basis. This condition is slowly taking me.

> **“The research currently happening makes me feel optimistic and fills me with hope for the future.”**

“My voice is getting weaker and it is affecting my confidence. People think I am drunk when I slur my words. I do carry a card that explains what PSP is and this does help. Eating in front of people is becoming embarrassing. I end up wearing most of the food. Eating out is now something I dread. The one activity I am clinging onto is walking my dog. It is really important to me to continue to do this. He is great company during the day and I love our walks together.

“I am still driving thank god, but what I drive has had to change. I’m trying to adapt to these changes. My much-loved Vespa is being replaced with an automatic car. This is just one of the many adjustments we will have to make. Selling the Vespa will be hard, but no harder than when I sold my Harley Davidson after my diagnosis of PSP. A big heavy bike like that and a neuro

> “Selling the Vespa will be hard, but no harder than when I sold my Harley Davidson after my diagnosis of PSP.”

degenerative condition are not a good combination.

“Planning ahead is now more important than ever. We are in the process of moving to a two bedroom bungalow with a downstairs toilet. I have also done a power of attorney and my funeral plan. It has given me peace of mind to know that it is all sorted and that my wife won’t have to arrange everything herself.

“Adapting to my new life with PSP is not just about stopping activities, thankfully it has also been about finding new ones. I now do Tai Chi once a week. I am the youngest one there, but I really enjoy it and have made some good friends. What isn’t helpful though is comparing my progression with others. When I do, I feel I am accelerating worse than everyone else.

“I am waiting for a referral to the PSP specialist centre in Southampton. The care I have received so far has been good. The local neurological nurse is really helpful, as is the physiotherapist who is helping me with my lower back pain and the speech and language therapist who has given me exercises to increase the volume in my voice. I have found them all to be proactive. They are helping me to be as independent as possible, something that’s very important to me.

“PSP is a nasty disease and finding a cure is urgent. I am on the PROSPECT trial, and I am prepared to help push forward research into PSP in whatever way I can. I think it is vital people support PSPA so they can find the cure we all desperately want. The research currently happening makes me feel optimistic and fills me with hope for the future.”

THE PRIDE AND JOY OF DAD'S LASTING LEGACY

Alison, an occupational therapist, describes the process of her dad Ken Short's donation to the Brain Bank and the comfort his lasting legacy has given the family.

"HAVING 'the' conversation is not easy, but it is important to be able to achieve a good ending. This came into sharp focus when, three years after his diagnosis of PSP, my dad got sepsis. There were no clear plans for Dad's good ending. We hadn't had 'the' conversation and by this stage, Dad had lost his ability to communicate and no longer had the capacity to make complex decisions about his care and end of life plans. So 'the' conversation between my mum and I began.

"Mum told me she had ripped up his donor card because she didn't like the idea of him 'being messed with'. As both a health professional and a daughter I was cross she had taken the decision away from Dad. I decided to document his wish to be a donor in a personalised care plan for his care home, to help them understand and support him.

"The next time we discussed it was when Mum, an avid reader of *PSP Matters*, told me about an article she had read about brain donation. I contacted the Queen Square Brain Bank at the Institute of Neurology, although I was certain that because Dad had not given permission for this type of donation, and because his donor card no longer existed, there would be no way of enabling him to donate.

"I spoke to the brain donor scheme co-ordinator Lynn Haddon. Kind, patient, knowledgeable and compassionate, she was able to answer any question I threw at her. I found out that if it had been Dad's intention to be a donor, despite not being able to sign the consent form, we [his family] could.

"This was a huge breakthrough, but I encourage anyone thinking about brain or any kind of organ donation not to leave it to chance. Discuss your wishes with your family so that you can make an active decision.

"When the information about brain donation arrived Mum and I made a pot of tea and read it together. Of course, there were tears, but it was incredible to be with Mum and to experience how her attitude changed about what an amazing gift Dad could offer through brain donation. We called Lynn who spent time talking

Ken Short

“I would like to encourage others to consider making a donation to the brain bank. There is great need for us all to donate.”

things through with Mum. There was no pressure at all and we filled in the consent form and sent this off knowing that any time we could reverse the decision. We felt very supported.

“I then made sure that the people at Dad’s care home, including his care manager, GP and the undertakers all knew what needed to happen when he died in order to donate. This is vital because speed is needed to protect the integrity and quality of the brain donation after death. Again, this was made easy as the information from the Brain Bank was so accessible and easy to share with others.

“When Dad died the system for enabling the brain donation to happen was all co-ordinated by the Brain Bank. It was so smooth and we were kept in touch by Lynn with what was happening at each stage of the process. This was very personal and a great help in our confidence and trust in the scheme.

“We as a family are so proud of my dad, Ken. He has left not only memories, but also, through his skill as a master craftsman stonemason, many physical works. His masonry and carving work lives on today in the Houses of Parliament, Buckingham Place, the Roman Baths and even the parliament buildings in Bermuda. But, he really has left a legacy through his brain and spinal cord donation which will contribute to world-wide research. At the celebration of my dad’s life we played Rockin’ All Over The World by his favourite band Status Quo. With his contribution to world-wide research into PSP, this song felt especially apt.

“I would like to encourage others to consider making a donation to the brain bank. There is great need for us all to donate – people with and without neurological conditions are needed to register for donation.

“People without a neurological condition provide vital ‘controls’ giving researchers an understanding of the normal appearance and function of the brain, for comparison with the brains of people with PSP. I have already registered mine.”

“IT ISN’T ABOUT ONE PERSON SWOOPING IN TO SAVE THE DAY.”

Katherine Lawson is a clinical nurse specialist and describes the difference multi-disciplinary care can make and why everyone should think about advanced care planning.

“IF you’d have asked me three years ago what PSP was, I’d have looked at you blankly. I’ve been a nurse for 12 years and only when I got the job as a Clinical Nurse Specialist did progressive supranuclear palsy become part of my vocabulary.

“Specialist Palliative Care Teams work with patients diagnosed with many forms of conditions. We have a multitude of drugs at our disposal, which we use to deal with symptoms such as pain, sickness, confusion and fatigue. But, it’s not just about that. We look at the whole person, often called taking ‘a holistic approach’.

“This isn’t about one person swooping in to save the day, it’s about building up a network of support around the patient and their family. This is made up of members of the multi-disciplinary team, including GPs, district nurses, carers, day hospice staff, benefits advisers, clinical psychologists, occupational therapists, physiotherapists, specialist nurses and consultants. Not every patient will need every service, but we work together to support one another in order to best serve our patients.

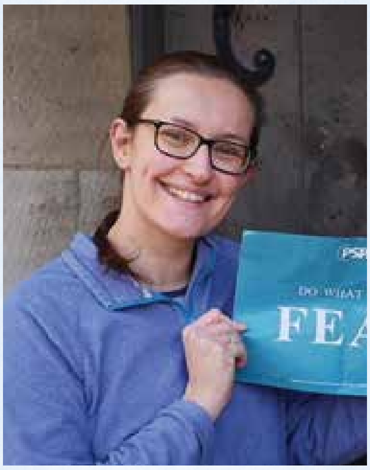
GOOD LUCK TO OUR LONDON MARATHON RUNNERS

Alexander Bak and Paul Richardson, Surrey

“Neither Paul nor I have run very far before, so we thought we’d start our training early. I suppose you could say that nothing gets in the way of training and trying to raise as much money as we can.”

Analia Aguirre, Buenos Aires

“My mother teaches children in Argentina with neurological problems, so I think that my passion to run for PSPA comes from her, and all the good work she does for those who need support.”



"One important role of a specialist palliative care team is facilitating Advance Care Planning (ACP). When we talk about ACP many people worry that this is simply about stopping treatments and leaving people to deteriorate. This is thankfully not the case. ACP is about making your wishes known. It's about making decisions while you're still well enough to do so and documenting them, so that medical professionals and your family are able to respect your wishes and care for you how you would like. It covers many topics from resuscitation, where you wish to be cared for as you get more poorly, where you want to die and your wishes for after death, such as organ donation and details about your funeral.

"It is very distressing for families to see their relatives deteriorate and I believe making an ACP is one of the greatest gifts we can give to our family. They will be able to look back after our death and know that they did things the way we wanted. You can get more information on ACP from your GP, district nurse, local hospice or palliative care team. None of us are promised a tomorrow and as a healthy 33 year old, I have already documented many of my own wishes.

"My first patient in this role was a lovely lady with PSP. Along with her dedicated family, a wonderful specialist palliative occupational therapist and a fabulous team of carers, she was able to remain at home in a familiar environment, just as she and her family wished. I learnt so much from her and from her loving family, in essence we learnt about the condition side by side. I owe a lot of my knowledge and understanding about PSP to her.

"During my three years in palliative care I've now looked after three patients with PSP. Most recently I met a wonderful man who had, in his prime, run the London Marathon. He ran it in less than four hours too, no mean feat. Finding this out led to a growing sense of interest… could I do it too? At this point I'd run two half marathons, but both very, very slowly. I was not a runner, I was a determined plodder who always thought marathon runners were crazy. I think it's safe to say that I wasn't created as a long-distance runner, but I was created to be inquisitive and determined so, somehow, the idea was born.

"Supporting PSPA seemed like a natural thing to do. It's a cruel disease that not enough people understand and more needs to be done to raise its profile. A vital part of PSPA's work is in supporting research. This research will hopefully mean that clinicians will better understand the disease process, patients will be diagnosed faster and who knows, one day we'll be working on a cure?

> **"It is very distressing for families to see their relatives deteriorate and I believe making an ACP is one of the greatest gifts we can give to our family."**

"Every time I go and visit my patient, I find myself updating him on my training and although he can't talk to me anymore his broad grin and thumbs up lets me know that he's proud of what I'm doing (or maybe he's just amused!). When I go out for training runs in the rain, get cramp in my legs or lie awake wondering how on earth I'm going to cover such a ridiculous distance the thought that keeps me going is that my patients make this much effort just to get out of bed in the morning. I owe it to them to get to that finish line and every bit of that glory and the shiny medal will be for them. If there's a glass of bubbly waiting, I might just have that for myself."

Beccy Jones-Reading, Staffordshire

"The marathon continues to be both a physical and mental challenge for me yet I want to help those with a greater challenge still. Having met people living with PSP & CBD I just want to help find a cure for this horrendous disease for as long as I can."

David Major, Hampshire

"Like many who have just turned 30, I must prove my youth and run a marathon. Or two...

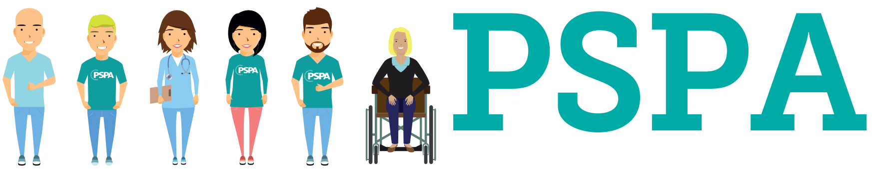
I am privileged to be running the London Marathon, which I have ALWAYS wanted to do, and I am also running the Barcelona Marathon the month before! I first came across PSPA when my girlfriend's grandmother was diagnosed with the disease a couple of years ago. I am running to raise funds and awareness of this little known illness."

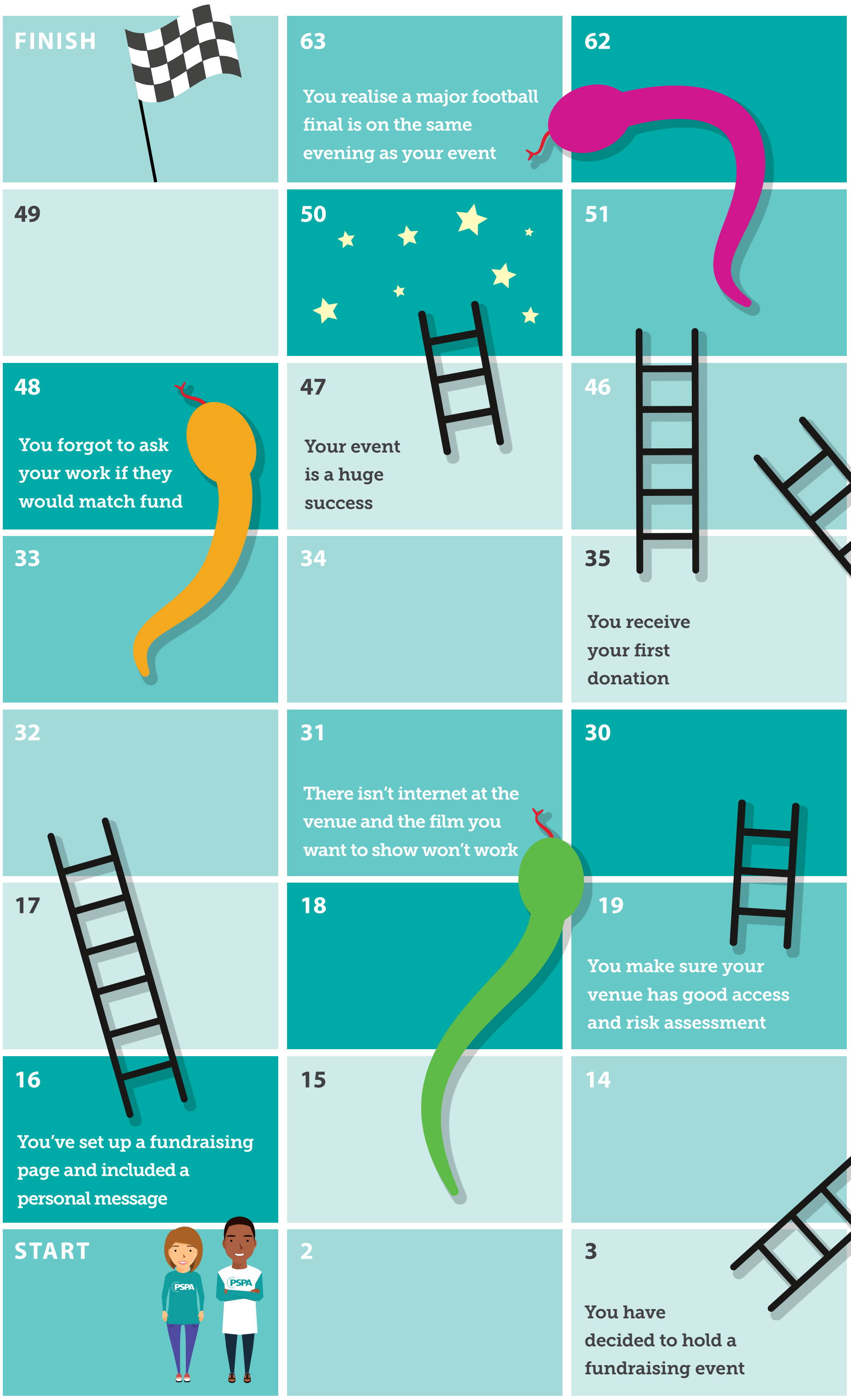
Join #TeamPSPA and fight

IT is thanks to our amazing team of supporters we are able to provide our Information and Support service to everyone affected by PSP & CBD, raise awareness and educate health and social care professionals, and we are able to fund world-class research.

They are a dedicated team of fundraisers. They are a diverse group all united by one thing – their personal experience of PSP & CBD. Would you like to join them?

Our brand new fundraising pack is ready with inspiring stories and advice on how to fundraise for PSPA. To help get you started, why not play this game of snakes and ladders so you can see some of the tips for success and also the pitfalls (snakes) to look out for!





63 You realise a major football final is on the same evening as your event

48 You forgot to ask your work if they would match fund

47 Your event is a huge success

35 You receive your first donation

31 There isn't internet at the venue and the film you want to show won't work

19 You make sure your venue has good access and risk assessment

16 You've set up a fundraising page and included a personal message

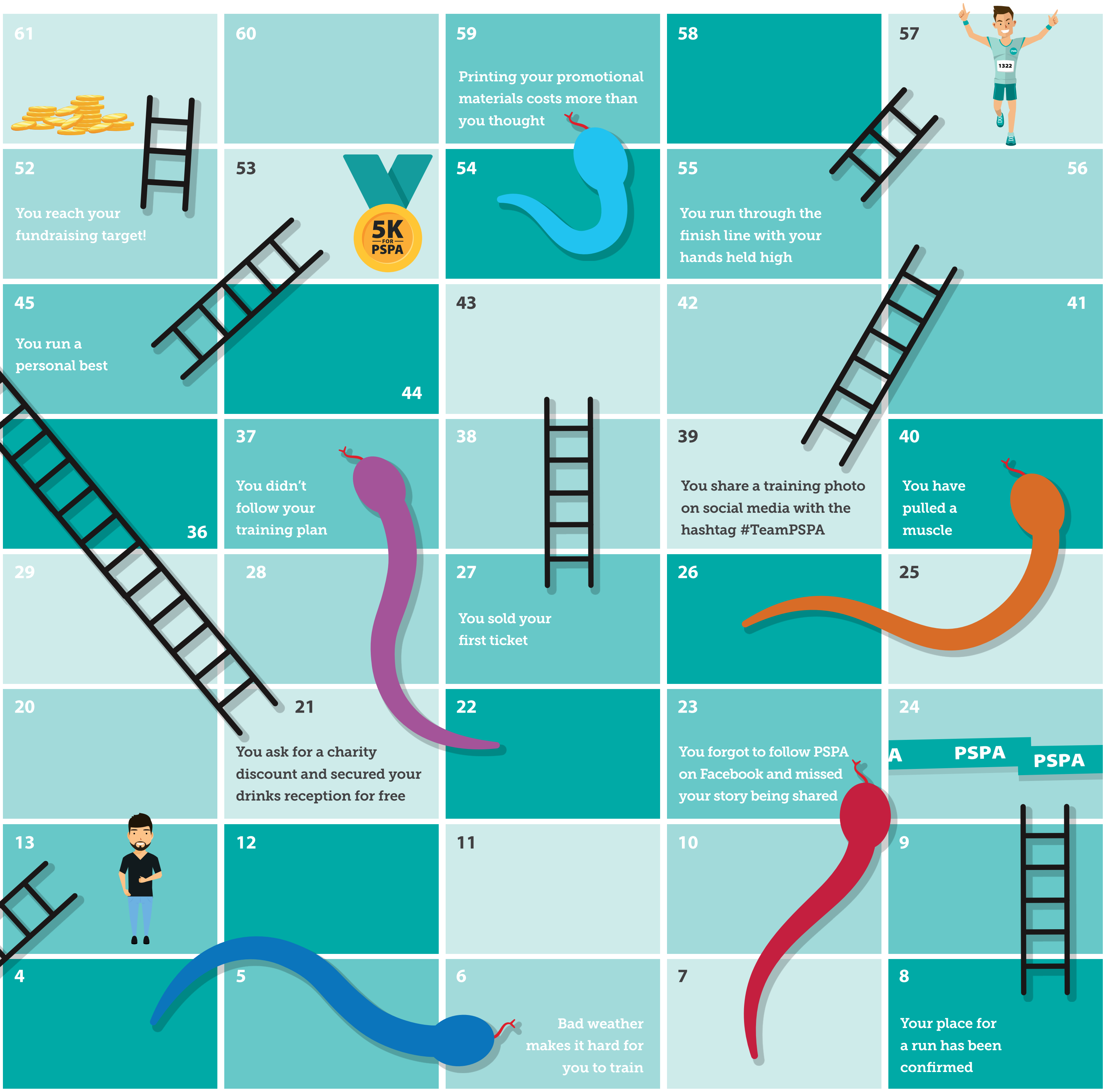
3 You have decided to hold a fundraising event

To join the fight against PSP & CBD order your pack today from the fundraising team – telephone 01327 322419 or download from **www.pspassociation.org.uk/fundraisingpack**

back against PSP & CBD

Snakes and Ladders

The money you raise will go towards supporting people with PSP & CBD and funding research.
There are many ways to maximise your fundraising.
Why not play our PSPA Snakes and Ladders to help you fight back in the best way possible, together we will beat PSP & CBD.



61

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59 Printing your promotional materials costs more than you thought

58

57

52 You reach your fundraising target!

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54

55 You run through the finish line with your hands held high

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45 You run a personal best

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43

42

41

36

37 You didn't follow your training plan

38

39 You share a training photo on social media with the hashtag #TeamPSPA

40 You have pulled a muscle

29

28

27 You sold your first ticket

26

25

20

21 You ask for a charity discount and secured your drinks reception for free

22

23 You forgot to follow PSPA on Facebook and missed your story being shared

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6 Bad weather makes it hard for you to train

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8 Your place for a run has been confirmed

TRASH TO TREASURE

AS the old adage goes: 'One Man's rubbish is another man's treasure' – and one PSPA fundraiser certainly agrees. Alison Taylor, from the Nottingham Support Group has raised over £2,000 by selling unwanted items on eBay. Here she tells *PSP Matters* how it works.

"I started using eBay to sell clothes and odd bits I wanted to clear from my house and was stunned at what people would buy!" explained Alison. "Anything from rabbit hutches to handbags, shoes and china ornaments.

Result! Alison bought this jug at an auction for £50, then sold it on eBay for £156 – the profits coming to PSPA!

"Then, as people around me heard what I was doing, they would offload anything they didn't need and I'd have a go at selling it. The best of these was a cup, saucer and plate set that was cracked, crazed and discoloured - that sold for £45. It was rare, apparently!"

Alison believes that anything will sell if the price is right. "You have nothing to lose but PSPA has something to gain! I have mainly sold china - as that's my 'thing', so packaging is key to ensure items arrive in one piece! Our local supermarket offers used wine boxes which are perfect as a small parcel through Royal Mail (and are free!). I also use my shredded documents - again a good way of recycling.

"The key to success is to be honest. Take good photos, point out any problems and give a clear description - I usually search for items like the ones I'm going to sell and use that wording to help inform mine!"

Alison started her fundraising in memory of her mum, who lived with PSP. "I try to organise an event every year - either a garden party or for 2017, I held a concert in Nottingham. Along with eBay and other efforts, last year I raised £5,000.

"For me it's all about spreading awareness of PSP & CBD – the more people who know, the easier it will be to attract more volunteers and raise funds, therefore we will be able to afford more research. It's all a big circle!"

Need to know...

- Auction sites, like eBay, are easy to use and allow you to sell your wares to customers across the globe
- As a seller, you give a description of the item, take a photo and put it up for sale
- Buyers then make bids (like a traditional auction) and the highest bidder wins
- Postage and packing fees (calculated by the seller) are also paid for by the buyer
- The item is then posted when the payment has cleared

On eBay, a percentage of sales can be donated to a charity by using a 'donation account' – the seller chooses the amount and also pays reduced eBay costs. (Alison gives 100% to PSPA, so pays no eBay fees).

But Alison warns that you just need to make sure you charge enough postage to cover your costs and remember that if using 'PayPal', it will also charge you a fee, so you need to build this in to your price.

GOOD LUCK TO OUR LONDON MARATHON RUNNERS

Lydia Stringer, Lichfield

"I am doing this to raise awareness of PSP. I hope one day there will be a cure, and that other people won't have to live with this frightening disease. Ultimately, I am doing this for my Mum, who is my inspiration. I have the most wonderful parents who have shown me life goes on no matter what and have given me the courage and confidence to run the marathon."

Domingos Ferronato, Brazil

"I run marathons to overcome challenges. And I'm going to run the London Marathon with the help of PSPA."

TURNING A PASSION INTO A FUNDRAISER

For enthusiastic computer gamer, Natasha Clarke, using her hobby was an enjoyable way to raise funds and awareness...

IT'S a pastime enjoyed by millions of people across the world and one where individuals can pit their skills against others who might be thousands of miles away or just next door – it's computer video gaming.

Whether battling with medieval knights, space creatures or weapon-bearing warriors, players build experience and expertise to master the intricacies of what can be very complicated games.

"I enjoy playing on the Xbox with my husband," said Natasha. "We compete against each other and also other people - it's good fun! My grandad lived with PSP and I have been thinking about raising money, in memory of him and ways to do it. So, we came up with a 24 hour gaming marathon!"

One dark evening on a Friday in February, Natasha donned her headphones and made herself comfortable to settle in for her day and night of gaming. "I had great support from my family and friends" added Natasha. "My husband stayed up with me for most of the time - only taking a two hour snooze and my step-dad was online to monitor my progress and advise me when to take breaks.

"Throughout the 24 hours, other gamers watched and cheered me on. One gave me a mention via 'Twitch' (a streaming app) that has over 100,000 viewers – so they all knew what I was doing and why. I have had loads of really good feedback."

Natasha raised £750 and with Gift Aid the final total was well over £800.

"I couldn't have done it without my husband - it meant a lot to him too, as his Nana is also living with PSP. I still can't believe how much I managed to raise for PSPA – it's incredible!"

If you could do #JustOneThing for PSPA what would it be?

COULD you put up an awareness poster in your local GP surgery, do a cake bake sale, sign up to make a regular gift, hold an educational talk or perhaps, become a volunteer?

This PSP Awareness Week on 1-7 May 2018 we are asking the PSP community to do #JustOneThing for PSPA. Whether you decide to volunteer, fundraise or spread the word about PSP, it all helps to support our vital work. Even the smallest action can make a big difference, especially if the whole PSP community takes part.

We have come up with some ideas on how you can be part of our national #JustOneThing campaign. Please do tell us what you have planned, or even better, share on social media with the hashtag #JustOneThing.

- Host a coffee morning
- Share your personal experience of PSP
- Join our research register
- Send our red flag document to your GP surgery
- Invite a health professional to your local group
- Do a talk on PSP
- Send our *It's Not Parkinson's* animation to all your contacts

For PSP Awareness Week let's bring the PSP community together to fight the devastation caused by PSP.

Robbie Ma, Hong Kong

"I am a father of two kids. Marathon is a kind of modelling. You need to set the target in the right direction, train hard and try your best to reach your target, then you will be the champion!"

Kimberley Bessant, Gloucestershire

"I felt very passionate that I wanted to run the London marathon for a charity where the money I raised would make a big difference. It has also allowed me to raise more awareness about PSP & CBD in my local community."

Jose Motta Garcia and Alexandre Diniz, Brazil

"Running is more than just physical exercise. It's a lifestyle. And, if you can run for a great cause, it becomes complete."

Local group

PSPA Local Groups not only provide an opportunity to meet others affected by PSP & CBD but also want to fight back against the diseases – and fundraise.

Members of the Leicester Local Group visited the home of Leicester City Football Club, The King Power Stadium, for a birthday concert organised by the Ross family – in memory of Jim Ross.

"The concert was very good," commented one of the organisers, Edna Ross. "Most said it was the best time they have had for a long time! There were two acts, a fun raffle and great music with lots of dancing and laughter."

Other Leicester Group members, Michael Richmond and his son Kristian, took on a cycling challenge last year – and Kristian will also be running the London marathon on behalf of PSPA.

On the run for £2250

Helen McGillivray ran the Spanish Cordoba half marathon in support of her father who is living with PSP.

Help from my friends

Kirsty Gemmell, from East Ayrshire, knows just what it is like for families affected by PSP.

As well as supporting her mum, who is living with PSP, Kirsty has volunteered at the Local Group in Dundee, is now helping at the group in East Kilbride and also master-minded successful fundraising events – with ex-work colleagues helping her to raise £1,132.

Kirsty said: "I would like to thank everyone for their incredible support in raising this amazing amount for PSPA." Kirsty's ex-work colleagues explained that they were all looking for a challenge, which started off with the idea to do a sponsored walk. One colleague said: "What began as a short stroll soon turned into a 5-mile trek with more staff and friends signing-up than had been anticipated. Before long, the group had other events planned, including a 'Pakora and Pancake Day'. Amazingly, 50 pancakes were flipped and served within an hour and 250 pakoras were eaten too!"

But the fun didn't stop there, home-made brooches were sold, donation boxes were scattered around the office and before long, PSP was the main topic of conversation.

As well as having fun raising money, Kirsty and the group have been able to raise awareness of PSP with people who hadn't heard of the disease.

Weekend fundraiser

It was two days packed with fundraising events for PSPA supporter, Gabriella Raimo.

Along with friend, Linda Vaughan, the pair organised a coffee afternoon and raffle to raise over £1,200 in support of Gabriella's grandfather, Lord Garfield Davis who is living with PSP. This total will be matched by Linda's employer, Barclays.

The next day, Gabriella and a large number of her family took part in the Heaton 5K Park Run in Manchester. So far, their 'Just Giving' page has clocked up well over £1,500.

"We started fundraising to not only raise money but also to make people aware of the condition," said Gabriella. "Being a nurse, and not having heard of PSP, I felt by fundraising we would be able to explain and let more people know exactly what the condition is and symptoms it starts with.

"My Grandfather has given so much throughout his career to the public and charity, we wanted to give something back to him, in hope that one day a cure can be found."

In training

Family group, Chris and Pete Draper and their daughter, Jo Pike, are getting ready to take on the marathon.

"Mum and dad are running with me and remembering my father-in-law, Russ. This will be their 5th and 3rd marathons respectively! As a non-runner, this is a huge challenge for me, and the massive running journey I have been on over the last few years has seen me lose over six stone so far!"

Nom, nom...

Linda Blatchly showcased her skills when she baked and designed these gingerbread houses. Linda builds her creations throughout the year for events such as Easter, birthdays and Christmas. For every order received, Linda makes a donation to PSPA.

Chop! Chop!

Young Pip Lockhart lost her locks to raise £150 in memory of her grandfather, Michael Flannagan. Pip also helps her grandmother, Lesley, with running of the Gloucester Local Group.

WE'RE STRIKING BACK.

PSPA's Strikeback Funds have been created for everyone who wants to fight back against PSP & 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 & CBD.

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

Progressive Supranuclear Palsy
PSPA

For more information, and to start your Strikeback Fund, please email the Fundraising Team
events@pspassociation.org.uk
or call 01327 322419