

PSP Matters

Autumn 2016



Inside: Home from home, choosing the right care

Home from home

Residential and nursing home care



Your stories

Our supporters' inspirational stories



Your fundraising

Celebrating your amazing achievements



Take control

Healthy volunteers in research



Striking back

Our new Strikeback Funds



Volunteering

Meet our local group coordinators

Cover: Chris Orford, who lives with PSP, and her daughter Ann enjoy the gardens at Abbots Leigh Manor Nursing Home.

The PSP Association

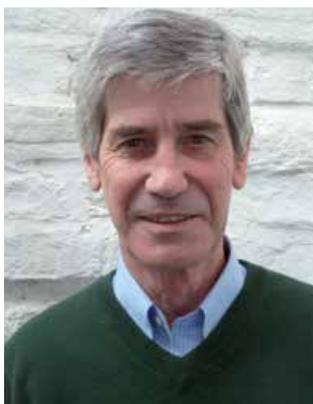
The PSP Association is a registered charity offering support and information to people living with Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD), while funding research into treatments and ultimately a cure for these conditions. We rely entirely on donations to fund our work.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

The views expressed in *PSP Matters*, published four times a year, are not necessarily those of PSP Association and therefore products and services advertised or promoted should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise.

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

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The nights are drawing in, which means summer is over, and what a busy one it's been!

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

Hundreds of you, across the UK, have taken advantage of the longer, warmer days to raise funds and awareness for PSPA.

You've barbecued and baked, held fetes and fun days, run, trekked, cycled and all sorts in between to bring in the coffers that help us make a positive difference for those affected by PSP and CBD.

While we feature many of your smiling faces in this magazine sadly we can't include you all. On behalf of everyone at PSPA a big thank you to all our supporters.

Earlier in the year we launched our new Strikeback Funds. These enable families, friends and colleagues to channel their energy and see all the money they raise recorded in one fund in their loved one's name. On page 21 you can read how this has brought a positive focus to one family's fundraising efforts. If you're interested in setting up a Strikeback Fund we'd love to hear from you.

The shorter days also mean the festive season is fast approaching and we've enclosed our Christmas Catalogue, packed with new gift ideas and Christmas cards.

As always, the profits from sales help to fund our information and support services and research activities so please look through the catalogue.

Enjoy the magazine, and thank you for your continued support.

Fergus Logan, Chief Executive

Friendship and learning

We were delighted to welcome members of our PSPA family to a recent event in Birmingham.



AROUND 60 people attended our Family and Friends Day on 17 September.

Dr Richard Bevan-Jones gave an update on research and our friends from the British Red Cross provided tips on first aid for carers.

Families also watched a soft-food cookery demonstration and received dietary advice before enjoying a rousing performance from members of Birmingham and Solihull rock choirs.

Thanks to all those who attended for making it a successful and enjoyable day.

Details of future Family and Friends Days will be promoted in *PSP Matters* and on our website.



Brain bank funding agreed

WE are delighted to be donating £20,000 to the Queen Square Brain Bank at University College London. This follows on from similar donations in previous years to support the bank's research



programme with brains generously donated by people with PSP and CBD.

In 2015 the Brain Bank received 14 brains donated by people with PSP, an increase from the previous year. It is now extending its work on the condition, including an exciting new four-year project that will undertake extensive analysis to better understand the processes at work in brain cells affected by PSP.

Prof Tom Warner, Clinical Director of Queen Square Brain Bank, said: "The study of brain tissue plays a critical role in understanding how brain cells die and identifying potential ways this can be treated. Brain banking is becoming an increasingly costly process and we are extremely grateful to PSPA for contributions towards our running."



Red flags campaign latest

THANKS to you, thousands of copies of our PSP Red Flags for GPs were handed over to doctors and other health and social care professionals around the UK during our PSP Awareness Week in May.

Last month we followed up our campaign action by mailing a further 10,000 PSP Red Flags to GPs and Practice Managers around the UK.

The document lists 10 red flag symptoms that may help GPs spot warning signs of PSP.

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

Peter Daniels, Director of Information and Support said: "We know that far too many people often wait years for a diagnosis of PSP and are often misdiagnosed in the meantime. This causes worry and uncertainty for families and means they experience an unacceptable delay in accessing vital information and support services.

"We hope our PSP Red Flags for GPs will enable more GPs to spot key signs and symptoms of the disease and speed up a referral to a neurologist and the time to diagnosis."

Winners named

CONGRATULATIONS to our latest raffle prize winners and thanks to everyone who bought and sold tickets. Together you raised more than £12,000 to support our vital work.

The lucky winners were:

1st prize £500. Anne Bass, London.

2nd prize £250. Felicity Lloyd, Northants.

3rd prize £50. Juliet Tait, Leeds.

They have been notified.

Feeling festive?

OUR Christmas Collection 2016 is now available to order and features a wide range of Christmas cards and new gift ideas.

Orders can be placed by phone, email or post. Browse the catalogue enclosed with this mailing, or visit www.pspassociation.org.uk/shop

Your views matter

WE recently sent a survey to all those living with PSP and CBD that we are in touch with.

More than 30 per cent of the 1,470 surveys mailed out were returned, which is a great response. A huge thank you to everyone who shared their experiences and views, you have made an important contribution to our work.

The responses are currently being analysed and we will share key findings with you when these are available.

We will use the information to help us to best understand how PSPA makes the biggest difference for those living with and affected by PSP and CBD, and enable us to identify any areas where we can improve our support services in the future.

Your chance to take control

Think that you can't contribute to a research study because you don't have PSP or CBD? Think again.

HEALTHY volunteers, known as control participants, are essential to most areas of medical research because they help define the limits of 'normal'. Whether researchers are looking at brain scans, blood tests or even brain tissue, it would be impossible for them to know what signified the onset of disease and its progression without having healthy samples as a benchmark for comparison.

Key to reliable data

Patricia Vázquez Rodríguez is a PhD student working on Prof James Rowe's PSPA-funded research at the University of Cambridge. She and the team rely on healthy volunteers undergoing the special type of brain scans around which their research is centred.



Patricia Vázquez Rodríguez

"Our work would simply not be possible without healthy controls," Patri said. "Comparing their results with our patient cohort is key to interpreting our data reliably. It means that we can identify the disease-related changes that are extremely important in addressing the research questions of our study. Both patient and control groups are essential for us to draw our conclusions."

Recruitment challenge

Just as research studies require certain numbers of people with PSP and CBD to ensure the reliability of their results, so they also need a good-sized group of healthy participants – a handful won't be enough.

"We normally try to recruit the same number of controls as patients, which for the scanning study is 20-30," explained Patri. "In order to be able to make really good comparisons we are always trying to match participants with PSP or CBD with controls of the same gender, age and educational level, which is not always easy to achieve."

Finding all of these healthy, willing volunteers can be a bit of a headache for researchers.

"The control group is generally the most challenging in terms of recruitment," said Patri. "We approach the family members of our lovely participants and they are often very



A researcher at Queen Square Brain Bank

keen, but sometimes the commitment is just too much. We are always mindful that they are busy looking after their loved ones and coming to research appointments can be tricky and stressful."

A precious gift

One extraordinarily valuable resource that researchers are crying out for is healthy brain tissue, donated by someone who does not have neurodegenerative disease after they have passed away.

"I would really encourage people to think about registering to become a donor, it's such a precious gift."

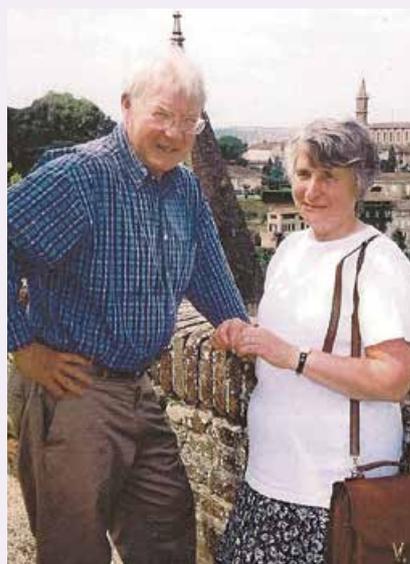
Patri also uses this in her studies as it is a vital part of understanding the changes that take place in the brain as a result



Doing something to help

KATHRYN Timmons is our Loughborough Local Group co-ordinator. Her husband George lived with PSP and generously donated his brain to the Queen Square Brain Bank when he passed away in 2014. Kathy has decided that she too would like to donate her brain for use as control tissue. She told us about her motivation and experiences with George's donation.

"It makes sense that, in order for research to be



George and Kathryn Timmons

successful, researchers need to be able to compare brains which are healthy with those that are affected by neurological disease. I hope that my brain will still be healthy when I die and might help in the search for better diagnosis and medication which, if it doesn't cure, might alleviate some of the more unpleasant features of PSP. When I watched my husband deteriorate I felt very helpless to

do more than try and make life as pleasant and normal as possible; this is something I can do that might help. Both our sons are in agreement

and will do what is necessary for me.

"Our experience when George died was positive and I hope encourages other people to consider brain donation. He had already signed all the consent forms and this obviously made it much easier. I also had to give consent but this

was easily dealt with by phone and email. George's body was moved to the pathology department at the hospital in Leicester for the procedure to be carried out but the funeral director was able to collect him very soon and it caused no delay in funeral arrangements. It was very important to George to be able to make a contribution to research that might help someone else."

of PSP and CBD as compared to normal 'wear and tear'.

She explained: "I need to be able to look at the areas of the brain particularly affected by these conditions and know how they appear when they are healthy."

Patri uses tissue from the Cambridge Brain Bank as well as requesting samples from other sources such as London's Queen Square Brain Bank, which PSPA helps to fund (see page 5). However, both banks are continually urging donors without neurological disease to sign up.

"It is so difficult for me to track down healthy brains," said Patri. "I would really encourage people to think about registering to become a donor, it's such a precious gift." Brain donors are still able to donate organs for transplant.

So remember, if you don't have PSP or CBD: researchers need you too! The next breakthrough can't happen without you.

Be a research control

Healthy volunteers can register their interest in taking part in general research via our Helpline: 0300 0110 122 or helpline@pspassociation.org.uk

For more information on taking part in the brain scan study at Cambridge, contact Robert Arnold, Research Assistant: 01223 768003; or Patri: pv283@medschl.cam.ac.uk

For more information on registering for brain donation, contact: Cambridge Brain Bank: 01223 217336 or brbank@addenbrookes.nhs.uk Queen Square Brain Bank: 020 7837 8370 or l.haddon@ucl.ac.uk

Home from home?

A look at residential and nursing home care

“I’ve been surprised by the lifestyle I’m able to have here,” said Chris Orford who has PSP and lives at Abbots Leigh Manor Nursing Home near Bristol. “If someone’s unsure I’d say come and try it out.”



Enjoying the gardens at Abbots Leigh

CHRIS is a retired midwife. She was living alone when she was diagnosed with PSP and had the support of carers three times a day prior to her move. She and her daughters, Ann and Catherine, agreed she should try nursing home life after one particularly bad fall.

Chris’s daughters researched the options and liked Abbots Leigh. Ann said: “Abbots Leigh is keen to make residents feel it is their home so friends and relatives are always welcome.”

Gut feeling is important when making choices. As Age UK advises in one of its fact sheets: “Remember that the care home is your relative’s new home and

should offer everything we all expect from our homes – a welcoming, safe and positive place to live.”

For Chris her trial stay was a two way thing – she was checking out the nursing home and they were assessing her. The fit had to be right, and luckily for Chris this one was.

Chris reflected: “Once I’d settled I realised the move had taken a lot of worry away, both for me and my daughters.” Both Ann and the Nursing Home Manager, Kathy Bauer, are glad that Chris was able to fully communicate when she moved to Abbots Leigh. It has allowed staff to understand the person she is and to appreciate her personality and history.

Activity and flexibility are two important things a care home can offer residents. Chris has found she enjoys the gardening club, films and mindfulness sessions. It suits her to have a quiet morning and a more active afternoon and staff respect this and work to a routine that suits her.

The activities coordinator, Gill, has a good relationship with Chris and has helped her to host two of the PSPA Bristol local group meetings at Abbots Leigh. The meetings enable Chris to feel connected to others who fully understand what living with PSP is like. Manager Kathy feels that they also help staff learn more about PSP from listening

to the experiences of different families.

Kathy explained that staff take care of practical concerns and quietly manage medical issues so that residents can concentrate on other things.

“Their families are not carers but are free to spend time with their loved one whilst remaining as involved as they, and their loved one, wish them to be,” she explained. “With a progressive condition potential concerns can be anticipated and an increased level of care can be introduced as soon as it is needed. Equipment and support are readily available.”

Kathy knows that caring for someone with PSP can prove challenging. She said: “We have regular reviews with the multi disciplinary team, our residents and their families.”

Managing risks such as falls and swallowing difficulties have to be balanced with accepting the residents wish to make choices. PSP is, as Kathy explained, “an illness that takes away so much of a person’s ability to look after themselves.” However, she added, “our home is homely and the environment and gardens remind us that each day can be positive.”

“With a progressive condition potential concerns can be anticipated and an increased level of care can be introduced as soon as it is needed.”

Chris’s caring family visit often and liaise well with staff. Maintaining a good relationship with the home’s manager and staff is vital.

Not everyone’s experience of a move to a care home is a good one and families need to be alert to things that may indicate a problem – for example,



Chris is made to feel special

a change in mood, expressions of fear or unhappiness, or signs of neglect. Concerns should be raised with the manager and issues which are serious or ignored should be reported to Social Services and the inspecting authority. People with PSP or CBD can be very vulnerable, especially in later stages of the condition, when communicating may be difficult.

Ideally a move into a care home should be planned and not the result of a crisis.

A try-out day or respite stays can give a useful insight and planning leaves people feeling more in control of their future.

Nursing homes and residential homes differ in that nursing homes must employ qualified nurses and are able to manage more complex care routines than a residential care home. Residential homes do not need to employ nurses and may not undertake certain aspects of medical care. People with PSP are advised to look at either a nursing home or a home that is dual registered (so it has both nursing and residential care beds) so that the risk of a need to move as the condition progresses is minimized.

Relatives may express regret, or guilt, that a move to a care home is needed. But it’s about meeting need and a caring environment can be provided in a range of settings. As Chris’s daughter Ann said: “There have been many times when Mum has been made to feel special at Abbots Leigh.”

Find out more:

Funding is complex. Some people may be eligible for full funding through NHS Continuing Healthcare Funding (where complex healthcare needs exist) or from their Local Authority.

All residential and nursing homes are regulated and inspected.

- In England – Care Quality Commission www.cqc.org.uk, 03000 616161
- In Wales – Care and Social Services Inspectorate www.cssiw.org.uk, 0300 7900 126
- In Scotland – Care Inspectorate www.careinspectorate.com, 0345 600 9527
- In Northern Ireland – Regulation and Quality Inspection Authority www.rqia.org.uk, 028 9051 7500

Further information:

- Social Services/health care professionals
- PSPA Helpline – helpline@pspassociation.org, 0300 0110 122
- Age UK has region-specific fact sheets including detailed information on funding – www.ageuk.org.uk, 0800 169 6565
- Independent Age – www.independentage.org, 0800 319 6789

Taking fundraising

Our fundraisers are truly an inspiration. Join the likes of Rob, Liz, and Laura, and sign up for one of our challenge events, or even for one of our epic overseas adventures. Go on a voyage of discovery for PSPA, and inspire others to take on the challenge. Your journey awaits! Contact us at events@pspassociation.org.uk or phone 01327 356132

Brother and sister Rob and Liz Platt are taking on a huge challenge over the next year, running 150 miles between them for PSPA.

THE duo are showing their support for their father, John, who has recently been diagnosed with PSP.

Liz said: "Our dad is an absolute legend and fighter. He has had a tough two years but fought his way back from the illness a couple of times. He made it to South Africa to walk me down the aisle and a week later met his newest granddaughter.

"There is a lot of life in the old dog yet! We hope that by taking on this challenge

we can inspire him to keep up the fight and stay positive."

"Our dad is an absolute legend and fighter. He has had a tough two years but fought his way back from the illness a couple of times."

Rob will take on every one of our running challenges starting with the



Rob Platt



The Platt family

Royal Parks Half Marathon in October.

He has also signed up for the Santa Run in December, the London Marathon in April, the Superhero Run and the Edinburgh Marathon, both in May, the British 10k in July, and finally the Great North Run in September. Liz will take part in all except the Santa Run and the London Marathon.

For this monumental challenge, Rob and Liz have set up their very own webpage where they will upload blogs and vlogs with training updates and reports on the events.

to the extreme

Super fundraiser Laura Hudson will tackle the Vietnam to Cambodia cycle ride in March next year, a gruelling six-day, 400km ride through sweltering jungle.

Laura is taking on one mammoth challenge after the other. So far she has cycled the Coast to Coast Whitehaven to Sunderland route, a 50-mile route around Norwich, and tackled numerous Tough Mudder events, even completing two in a weekend!

If that wasn't enough, Laura is also partial to donning a fancy dress outfit, but whether dressed as a chicken or a dinosaur, she still manages to cross the Tough Mudder finish lines with a smile.

Laura said: "It was very surreal on the second day to be running a Tough Mudder again, and it didn't really sink in! I set myself a fundraising target of £600 to run the Sunday dressed as a chicken which I luckily hit. I had a great time, and got a lot of mentions from other



Laura is no chicken

runners, and from the comperes on the microphones at different obstacles."

One of the obstacles is a daunting run through a field of dangling wires charged with 10,000 volts of electricity!

No problem for Laura though. "Once you have completed your first Tough Mudder you get to bypass the Electroshock Therapy obstacle, but I enjoy the thrill of running through it and would never skip it!"

"I'm fundraising for PSPA as my Grandad, Poppa, lost his six-year fight with PSP in 2008."

Laura is planning more, less strenuous, fundraising events to help her reach her total for her big cycle ride in March and will also be on Series Three of Ninja

Warrior UK airing in January.

Laura's incredible feats of endurance are inspired by her Grandad, David Hudson, known to his family as 'Poppa'. He sadly passed away in 2008 after a six-year fight with PSP.

"It was hard to understand why he had got PSP, what it was, and to watch such a strong man become so quiet and lost in his body," said Laura. "Raising a substantial amount of money for a very personal charity means an awful lot to me and my family, knowing how much help and support PSPA gives to families like ours."



David Hudson



Laura with other 'Mudders'

Make the most of what you can do

Mick Sampson, from Somerset, hasn't let CBD stop him from travelling and enjoying a safari in South Africa.



Mick, far left, enjoying sundowners on safari

IN August 2014, following several visits to various consultants and an MRI scan, I was diagnosed with CBD.

My wife Clare had been making enquiries about holidays and top of her 'bucket list' was a safari holiday. She commented that she would not be doing this on her own and, after much research, booked a trip in northern South Africa.

In March 2015 we flew overnight to Johannesburg and then stayed in four different safari lodges for three nights at each, the last being in the Kruger National Park.

At each location we had our own lodge with veranda (one with a spa pool). Most days started with an early morning game drive until about 10am when we returned to the lodges or other locations for breakfast. Other trips took place during the day with further game drives in the afternoons and early evenings. On several late afternoon trips we stopped in the bush with the driver producing sundowners and snacks which we had as the sun set.

Despite my reservations at the start, the trip was everything we wanted.

We saw, at close range, every type of wild animal you could wish for; including lions, leopards, rhinoceros, water buffalos, giraffe, zebras and all the different antelopes and gazelles. We will remember forever a herd of about 20 elephants passing either side of the vehicle within touching distance, a leopard in the branches of a tree eating its prey and watching a pack of African wild dogs harrying zebras.

“On several late afternoon trips we stopped in the bush with the driver producing sundowners and snacks.”

Game drives were in open 4x4s which provided great views and, providing you are reasonably able to climb two steps, access was easy and help was provided. Although we did some walking over rough ground I was able to cope with this and the ability to walk distances was not essential. Travel between lodges was in a minibus (and trailer for the luggage).

The holiday was all-inclusive and included collection from, and return

to, home from Heathrow. This made life a lot easier, particularly as we live in South Somerset. Our group of six was met at Johannesburg and we were accompanied by a guide the whole time.

I found a one-off insurance cover for both my wife and I, with my CBD and other conditions, for £250.

Not everyone is as fit as I am, but make the most of what you can do. Holiday insurance is available but problems can arise if you are awaiting specific tests or treatment. It's best to wait until you have the results before applying for cover.



Elephants at close range

If you need any information on travel companies, the trip etc please contact me via the PSPA helpline.

Also, some while ago my consultant recommended Tai Chi and I have been attending classes in the village. This helps considerably with balance and eye-limb coordination.

You can even take part sitting down or using a chair for support. I feel this, combined with assistance from our local Parkinson's Physiotherapy Department and other treatment, has resulted in a slow progression of my condition. I would recommend Tai Chi to any who can manage it.

All the best travelling!

A happy and wonderful lady

Jon Battershill continues his wife Theresa's story published in autumn 2015 *PSP Matters*.

WHEN I last wrote Theresa was enjoying going to the hospice where she joined in with art therapy. She had some very troublesome symptoms with incontinence and an adverse reaction to catheters but good cognition.

In December 2014, the neurologist said Theresa was mid stage with complications. By September 2015, he considered she was advanced. She had no standing strength and palsy to the upper body and hallucinations.

We went to Revitalise for a break in mid-September and on a trip to London. Theresa didn't enjoy it. On the way back the disabled van went around a corner and a wheel on the wheelchair broke. It took three of us (including a paramedic) to get Theresa back to the respite home. She was convinced we had been hit by a fire-engine, refused to take her medication and I called the hospice.

“The nursing home was brilliant. The staff raised the morale (of both of us), got the food and drink correct, and wouldn't stop feeding me cake.”

They were brilliant and travelled from Kent to Essex the next day and Theresa was admitted to the Ellenor hospice.

Theresa was fast tracked for Continuing Health Care and we left the hospice for a nursing home. I still feel guilty that I failed to look after Theresa at home until the end of her illness, but I was reassured by the neuro rehab nurse, hospice and nursing home staff that this was the right thing to do.



Theresa enjoying her son's wedding day

The nursing home was brilliant. The staff raised the morale (of both of us), got the food and drink correct, and wouldn't stop feeding me cake. We both did better.

We had support from the wonderful Reverend Sarah, family and friends and spent some really good afternoons just chatting in a room overlooking the Kent countryside. The staff always remember Theresa smiling and she never complained. One downside is that once in a nursing home the NHS would not fund a wheelchair. I bought a highly specialised tilt/recline wheelchair, which we gave to the nursing home.

But there was more confused thinking and vivid hallucinations.

By March 2016 the family, led by my future daughter-in-law, made a bold decision that we would try to get Theresa to her son's wedding on 6 May 2016.

Theresa wasn't told as we didn't know if she would make it. But on the day, she knew she was leaving the nursing home for the wedding. The nursing care

given that day was the highest I saw on the five-year journey. A huge fuss was made of Theresa and a senior care worker accompanied her. She managed to get to the start of the reception.

The day after the wedding a major cognitive decline began. Occasionally she was able to give a short clear message. I was told to get out and use my brain and to get specific presents for my sons and daughter-in law.

Theresa passed away peacefully with her son and myself with her.

The neurologist thought the symptoms that arose after the wedding were most likely PSP-related.

The speed of decline was unusual, and it is likely there was a trigger. Perhaps, as one of the nursing home carers said, she reached her goal of getting to the wedding, and then let go.

Whatever happened, just look at the picture. It shows a happy and wonderful lady. We left the nursing home very proud of Theresa, and what we, the hospice and nursing home had achieved.

Let the tomorrows take care of themselves

Lynette Dellar, from Wokingham, explains how art has helped her cope with CBD.

MY big shock began in June 2016. Two years prior to my diagnosis I noticed strange things happening with my right hand. I began to drop things, cutting vegetables became a problem, putting on jewellery and certain clothes was difficult.

My GP referred me to a neurologist and after a nerve conduction test I was operated on for carpal tunnel. There was no improvement and I developed pain in my shoulder and was referred to an Orthopaedic Specialist who operated. This was followed with weeks of physiotherapy. With no improvement I was referred for more nerve conduction tests and a brain scan.

When I returned to see the neurologist my husband was working in Africa so I asked a friend to take me and, fortunately, to come in with me. Intuition told me I was about to get not so good news, I was right.

The diagnosis was CBD. I needed to 'Google' to understand the disease and the implications. I Skyped my husband in Kenya to relay the dreadful news, not an easy task as he had lost his brother to cancer. Tears were shed. We had another hurdle to jump but together with our wonderful son who is partially deaf we can, and do, cope every day with the awful effects this disease.

My saving grace came when I was contacted by Sue Ryder Day Hospice in Wokingham. The staff there showed me that there is a life after being diagnosed terminally ill.

Barbara, a volunteer, suggested I try painting watercolours. I laughed, how could I paint? I am right handed and that is the arm that no longer works, and my art teacher at school suggested I gave up art and take history as she felt I was no good at art.



One of Lynette's paintings

I am now painting watercolours and loving every minute of it. I think my paintings are pretty good (excuse me if I blow my own trumpet) and I am incredibly happy it has given me a new lease of life. A huge thank you to Sue Ryder and the wonderful staff and volunteers who gave me the courage to re-find my life which has meaning and purpose again. Barbara's encouragement has meant a lot especially as I am painting left handed - perhaps I should have tried that when I was at school!



Lynette Dellar and husband Richard

Living with CBD is awful. It is a degrading, lonely disease that robs you of everything. It takes away your dignity, confidence and most of your will to carry on. You begin to feel you are a burden on your family and friends and try to hide away. I have wanted to end it all but the hurt I know would devastate my loved ones and this outweighs the pain and fear.

Most days are happy and care free. My art brings me the freedom to lose myself in each picture. I can be happy and a whole person minus the ailments. I will fight to the bitter end and enjoy happy times with family and friends.

I have many a 'pity party'. I am the only one invited and the tears roll off my cheeks but it's my time to wash the pain away and make the most of the time God is granting me. I feel blessed to have time to make amends where necessary and pour out love to my precious family and friends.

I want each day to count towards a day closer to finding a cure eventually for PSP, CBD, Parkinson's and MND. To all the sufferers, be strong, don't let your disease rule you. Fill each moment with positive thoughts and let the tomorrows take care of themselves.

I am going to be positive and fill my days with painting, laughter and fun family times. I have a lot of living to do, so beware the 'Tazmanian Devil' (nickname for my alien arm) and 'Damit' (my leg with a will of its own) I am fighting back!

You, Me & PSP

Cilla Dagnell had a passion for life and love. An energetic and flamboyant character, she filled her days with adventure and laughter, fun and friendship.

SADLY Cilla's life was to be cruelly cut short when she passed away from PSP in 2015.

But her memory lives on in the newly-published *You, Me & PSP*, an honest, open and often humorous account of Cilla's fascinating and colourful world, both before and while living with PSP.

Cilla was a prolific diarist and blogger and many of the words in the book are her own. It was mostly written during Cilla's lifetime and, when no longer able to speak, she gave her husband Steve's words her approval with a 'thumbs up'.

"I was determined to put my all into this book for Cilla's sake, I did not want her story to go unheard."

The book does not shy away from difficult topics, Cilla was adamant they should be included. Neither does it attempt to give advice. Instead it shares hints, tips and information drawn from personal experience.

Page by page, Cilla and Steve selflessly take us through the physical symptoms and emotional impact of PSP, so that we may learn from their experiences.

"Never in a million years could I ever have imagined myself in the role of 'carer'". Steve shares his innermost feelings as he strives to balance his unfolding role of carer, with that of husband.

In his foreword to the book, our President Charles Guthrie, Baron Guthrie of Craigiebank writes: "Thanks to the devoted couple's openness throughout the book, many families



Cilla Dagnell and husband Steve

affected by PSP will no doubt find comfort in their reflections alongside practical information on issues such as communication, feeding and planning for the future."

Steve is delighted to see the book in print.

"I was determined to put my all into this book for Cilla's sake, I did not want her story to go unheard. I firmly believe it will help expand the knowledge of PSP," he said.

It was Cilla's wish that proceeds from book sales should be donated to PSPA. Copies cost £10.99 plus £2.60 p&p (UK only. Overseas postage costs advised on request). To order, please email YouMePSP@pspassociation.org. uk or call 01327 322410 to make a card payment. Alternatively, send a cheque made payable to PSP Association to PSP Association, 167 Watling Street West, Towcester, Northants, NN12 6BX. Please include your postal address and contact telephone number.

Hospice solves wedding dilemma

When Terry Bock's son, Andrew, married his partner Charmaine Terry was determined not to miss the event.

TERRY'S PSP meant he was unable to travel to Colwell for the ceremony in June.

But Terry and Katherine House Hospice nurses found a solution that enabled him to see the whole event.

He booked in to the Hospice's Inpatient Unit for respite care, and hospice staff joined him to watch the ceremony and speeches.



The happy couple

Terry said: "With the help of the hospice staff, a link was set up so that I could see and hear the reception and speeches, which were very amusing. Two friends, one of whom works voluntarily at the hospice, came along to keep me company and when the Master of Ceremonies asked everyone to raise their glasses and drink a toast to me we all enjoyed a glass of bubbly, so I felt included in the happy event.

"A video was taken of the wedding ceremony, which we're looking forward to seeing and reliving the occasion."

Meet Diane, who will be taking our research programme forward in Scotland



Dr Diane Swallow

We were delighted that our awareness event at Holyrood last year led to the creation of a new research fellowship in Scotland, jointly funded by PSPA and the Scottish Chief Scientist Office.

NEWLY-recruited fellow, neurology registrar Dr Diane Swallow, will spend the next three years based at the University of Aberdeen investigating the issues surrounding diagnosis and care for people with PSP and CBD across Scotland.

Since her early medical training, Dr Swallow has made use of numerous opportunities to expand her experiences in neurology research and it has become central to her career.

“To me, research feels a very natural facet of what it is to be a doctor,” she explained. “It’s a means by which clinicians and patients collaboratively try to ask and answer the important questions in order to further our knowledge and evidence base.”

“As a student the brain was, for me, the most interesting part of the body and of medicine. I’m thankful that an early interest in academic neurology was encouraged while I was still at medical school and that I’ve had opportunities since then to contribute to projects in movement disorders.”

Diane will look into the extent and reasons for delays in the diagnosis of PSP and CBD and compare the quality of care

received by patients in Scotland with PSPA recommended standards. She also aims to establish the number of people living with these conditions in Scotland.

“This fellowship is a wonderful opportunity to undertake research which should provide rapid practical benefits to people affected by PSP and CBD and which should also help health service planners and other researchers,” explained Diane.

“It is my day to day interactions with people with neurological conditions and their families that has made me want to commit to working with this group of people.”

She also shares our excitement in extending our research activity north of the border. She explained: “Scotland is an ideal country in which to do long-term population-based research like this, especially in rarer conditions like PSP and CBD. It has a large (but not too large)

population, excellent general practice and hospital care systems and relatively small number of neurology centres, which aids collaboration. There is also relatively little ongoing research in PSP and CBD in Scotland at present, which means that there is tremendous capacity for growth.”

A fellowship like this is not only about completion of the project itself but is also an investment in the future of PSP and CBD research, as Diane herself explained: “Ten years from now I hope that I will still be playing a role in driving forward our evidence base for treating these conditions. I hope that I’ll also be in a position to provide opportunities for medical students and junior doctors to participate in research, as that was such a formative period for me.”

Like so many of our researchers, Diane is clearly inspired by those living with PSP and CBD. “It is my day to day interactions with people with neurological conditions and their families that has made me want to commit to working with this group of people” she said. “There is much to admire about their resilience and optimism as they manage the challenges of living with progressive disease.”

Local group roundup



Friendly faces in Hampshire

There was a fantastic gathering of families affected by PSP and CBD for our Hampshire Local Group meeting in July. SCA Kathy Weston paid a visit to the group.



Popping up in Alcester

Cakes were the centre of attention when Warwickshire group coordinator Jenny Knight held a pop up meeting in Alcester. There was a good turn-out, despite a mix-up with the room.

Jenny said: "The room we had planned to use was unavailable so we had to use a very small lounge. As you can see from the photo it was a bit of a squeeze - I couldn't fit everyone in the photo!"



Celebrations in Leicester

Our Leicester Local Group had a lovely meeting in June when families took part in a raffle and enjoyed celebrating a 45th wedding anniversary.

Hello to our new volunteers

WE are pleased to welcome Susannah Treherne to the PSPA volunteering team.

Susannah contacted us to offer her services in setting up a group in South Oxfordshire and the first meeting at the Sue Ryder Hospice, Nettlebed in July got off to a great start.

Susannah was inspired to set up the group after her father, David Asirvatham, was nursed at the hospice until his death from PSP earlier this year.

She has also been instrumental in pioneering a new approach with the group working collaboratively with the hospice. PSPA will work with Sue Ryder



Susannah Treherne and her mother, Kathy Asirvatham



Hannah Wilson and Ruth Keeble

staff to help engage group members in other suitable activities taking place at the hospice.

The next meeting will take place on 28 November.

Our Solihull group has a new face! Hannah Wilson will be teaming up with coordinator, Ruth Keeble, at the monthly meetings. Hannah works with the Patient and Family Support Team at the Marie Curie Hospice in Solihull, where the meetings take place.

Welcome Susannah and Hannah!

New online training for volunteers

IN the last two years we have recruited and trained helpline and support worker volunteers. These volunteers are enabling people affected by PSP and CBD to access the help and support they need at a time that is suitable for them.

Training is costly and time consuming and requires people to be available for a weekend residential course. We know this is not suitable for everybody and sadly this has meant that some really good potential volunteers have not been able to train and volunteer with us.

To overcome these barriers we have now converted our existing training into a package that can be completed via email at any time.

The benefits of this type of learning include:

- It's self-paced – the programme can be completed around other commitments and the module-based design allows volunteers to go through

smaller chunks of training that can be absorbed for a while before moving on.

- It can work from any location and any time. This can make learning possible for people who would not have been able to attend a residential course due to home or family commitments.
- Volunteers will not have to wait to start their training.

Each volunteer also receives a workbook to complete with questions to answer, and space to record their thoughts and queries. We currently have ten volunteers going through this training and we will be arranging a day for all of us to get together before they take up their new roles.

If you are interested in our helpline or support worker roles, please call Wendy for an informal chat on 01327 356134 or email wendy.crofts@pspassociation.org.uk. Further information can be found on our website.

Introducing Karen O'Brien – Lancashire group

Raising awareness and funds for PSPA has become a family affair for Karen O'Brien, our Lancashire (formerly Morecambe) group coordinator.



Karen O'Brien and her grandson Harry

FOR the past two years, Karen and husband Tony have teamed up to organise meetings in Morecambe and Preston and the couple also help out with daughter Louise's regular fundraising events.

“When my mum had PSP I felt really isolated, I didn't know where to go or what to do.”

The inspiration for the family's commitment is Karen's mother, Jean, who died from PSP in 2010. Their

dedication increased with the discovery that Louise's grandmother-in-law had also been diagnosed with the disease.

Karen said: “As a family we are very much involved. Louise organised a family fun day earlier this summer and is now organising a bowling event for PSPA. Tony is a big help – he comes along to every meeting and carries everything for me. He likes to chat and he makes a brew for everyone. I'm just proud of my family!”

The close-knit family's contributions continued when Louise suggested making bracelets for PSPA after her mother had enrolled in a jewellery-making course.

Karen said: “I've never done anything like it before and I was amazed by the response. I must have sold over 100 now.”

Karen first got in touch with the Association after she spotted a call to action on Facebook and decided the time was right to get involved.

She said: “I saw an advert asking for volunteers so I signed up. When my mum had PSP I felt really isolated, I didn't know where to go or what to do. I was desperate for some kind of communication. I felt if there was a group (in our area) it would help people feel less isolated.

“Volunteering has meant an awful lot to me, just knowing that I am helping out. Even if it's only one or two people who turn up for the meetings, I've still really enjoyed it. Volunteering makes me feel brilliant to be honest! I'm not very mobile but it's still something I can do.”



Supporting PSPA

The next meeting will take place on 12 November 2016 from 1pm to 3pm at Barton Grange Garden Centre, Garstang Road, Brock, Preston, PR3 0BT.

For more information about Karen's PSPA bracelets contact: karen.obrien5@btinternet.com

Introducing Michael Shepherd – Pocklington group

As a long-time volunteer with PSPA, Michael Shepherd is proud to call himself 'Mr PSP of Pocklington'.

MICHAEL, who has run the Pocklington group for more than 10 years, never misses a chance to help raise awareness of PSP and CBD and has become well-known in his home town as a result.

He said: "I never leave home without being fully equipped with PSPA information cards and leaflets. Someone might ask me at any time about PSP so I carry a bag with general information in it. If anyone asks me 'what is this PSP?' I can hand them a leaflet.

"I was even invited to speak on local radio because they wanted someone to come on and talk about PSP and they knew exactly who to contact. I am Mr PSP in these parts!"

Michael's mission to spread awareness and raise funds began when his wife, Shirley, was diagnosed with PSP.

"People have made good friends through the group and they are always asking after each other."

He said: "Shirley started being poorly around 12 years ago and my volunteering began when we started doing coffee mornings with all my church friends in Pocklington. The whole town wanted to support Shirley. They all rallied round because we were so well known through our local church. Even though Shirley has been gone for six



Michael Shepherd

years now, they are still supporting me!

"I have a wonderful team of volunteers with the group too. People have come and gone as time goes by but we are a great team and they are fabulous helpers.



Michael with Shirley

"The Pocklington group is a bit boisterous and noisy but there is friendship and companionship too. People have made good friends through the group and they are always asking after each other."

Michael is one of PSPA's longest serving volunteers and even in his ninth decade, he still relishes the challenges volunteering brings.

He said: "Volunteering just takes over your life but in a good way. I've been a busy person all my life and when you are retired (and I'm 81!) you can't just do nothing.

"Being involved with PSPA means that there is always something there for me to do. That has meant a lot to me. I never intended to become a volunteer – it just happened!

"Sometimes I think 'why do I do this?' and the answer is 'I don't know' but I still do it. If there is a need, you just get on and do it!"

Hope's adventures

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



Autumn has arrived and with it my favourite season! I love the colours, smells, and frosty mornings, though the fattening up for winter is a bit of a pain. Now I have to eat four cakes instead of three every day, and the chocolate bar count has gone through the roof. Luckily, I had a very energetic summer, travelling lots of miles and meeting many different people, so I just about got away with it.

I've travelled across the UK, from Cornwall to Norfolk, and all in between. I even took in a few games at Euro 2016 in a cold, rainy Paris. I watched Spain v

Italy and hosts France v world-beaters Iceland, and met some amazing people from lots of different countries. I also had time for a bit of sight-seeing, and took in the Eiffel Tower, the Arc de Triomphe, and strolled along the Champs-Élysées.

Back home, my friend Sarah Robinson sends me out to

people who take me on holiday with them in exchange for a donation to PSPA. I pose for photos and raise awareness! Remember to take me on your adventures and together we can spread the word about PSP and CBD.



Harpenden Highland Gathering

As a special treat I thought I'd share with you the lovely words of Maureen Horne, who I joined at the Harpenden Highland Gathering (see page 22).

"Hope, as Chieftain of Clan PSP, presided over the day. She was a little miffed that there was no opportunity for her to demonstrate her unique Sitting-Down Highland Fling but she attracted much admiration, especially from the younger visitors. Some expressed surprise that she

was wearing her sunglasses on such an overcast, drizzly morning but we pointed out that she is called Hope for good reason and in due course her optimism was rewarded with afternoon sunshine which brought out the crowds!"



Wimbledon

Swanning around SW19 is always a highlight of my summer. In the members' enclosure, Annabel Croft was lucky enough to meet me and pose for a cuddly photo. I had a great day watching the ladies' quarter-finals, and very much enjoyed the champagne and strawberries and cream. Game, set and match PSPA.



RideLondon-Surrey 100

Here I am at the RideLondon-Surrey 100 back in July. It was a brilliant day, and it was great to cheer on Team PSPA as they took on the mammoth ride. I know that everyone at PSPA is proud of them all. I joined in using my special bicycle. It is very similar to a normal bike, only it has four wheels, an engine, a roof, doors, and a kind driver who knew where he was going.



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

We're striking back

Our amazing fundraisers now have a new way to focus their fundraising energy thanks to our PSPA Strikeback Funds.

STRIKEBACK Funds have been created for everyone who wants to fight back against PSP and CBD and enable fundraisers to see the combined total they have raised from events, activities and donations.

Supporters can name a Strikeback Fund, register it with us, and all the money raised by family, friends and colleagues in their loved one's honour will be recorded in the central fund. We will then distribute this money to where it is most needed to support our activities.

Lucy Peers is one of our first supporters to set up a Strikeback Fund. She registered the Team Peers fund in support of her dad Steve, who was diagnosed with PSP in 2014.

Lucy, from London, said: "Seeing him finding it increasingly difficult to walk, talk and do every day things has been hard, and it's easy to feel helpless.

"I have a lot of admiration for my mum who started a PSPA local group in Woking, allowing others living with/ caring for someone with the condition to share their experiences and support one another. We decided to raise funds that PSPA could effectively use to help cover the cost of the room hire – £500 a year.

"As we started planning our fundraising I was amazed by how many friends and family wanted to join us to do something for my dad, hence Team Peers was born," she said.

Lucy said the Strikeback Fund has



Team Peers

given the family's fundraising efforts a welcome focus.

"The day after our first fundraising event, we were already talking about what we could do next. I like the idea that the Strikeback Fund gives us something to build on in the future

and, as we're all spread out around the country, we can continue to raise money together in a central fund."

In June Lucy was joined by seven family and friends for a trek up Snowdon, which raised over £2,500.

"As we started planning our fundraising I was amazed by how many friends and family wanted to join us to do something for my dad, hence Team Peers was born."

"We couldn't see a thing from the top due to fog and rain, and we arrived back soaked through! But it was an amazing experience, and worthwhile not only to raise money for PSPA, but also to raise awareness of this relatively unknown condition amongst the friends and family who donated," said Lucy.

Team Peers are already busy planning their next event to strike back at PSP and CBD.

"We have a few keen bakers amongst us, so perhaps we'll arrange a bake off!" said Lucy.

To set up your Strikeback Fund visit www.pspassociation.org.uk/strikeback, call us on 01327 322419 or email events@pspassociation.org.uk

Kicking out at PSP and CBD

YOUNG martial arts enthusiast Matthew Thompson and his friends quite literally kicked out at PSP and CBD, in fact they did it 10,000 times in 10 minutes.

The team from Kim Chung Do Kwan Taekwondo Club in Newton Aycliff, County Durham, raised a magnificent £600 for PSPA.

Matthew's grandfather Gordon Douglas, 79, lives with PSP and 11-year-old Matthew and his friends really wanted to raise funds and awareness for PSPA.

Matthew said: "We had been collecting five pence pieces in a jar but we wanted to do something bigger. I love martial arts and it is always very exciting when my grandad comes to watch."

A huge well done to Matthew and his kick-tastic friends.



Matthew and his grandfather Gordon

A taste of Scotland

KILTS and cabers, pipes and pibrochs, tartans and whisky tasting, traditional Scottish dancing. Where are we? In the Scottish Highlands? Wrong!

Quintessentially Home Counties Hertfordshire was where all these and more were on show in July at the annual Harpenden Highland Gathering.

For many years now, this event has been staged for charity by the Harpenden Lions Club and this year one of the three chosen charities to benefit was PSPA.



Our PSPA stand

Pipe bands came from near and as far as Truro to compete, as did dancers, young and younger, and the 'heavy mob' who tossed cabers and hurled hammers. There were sheep dog trials, ferret races, falconry and even a Celtic Rock Band.

Best of all, there was the PSPA tombola stall which proved a real draw thanks to the generosity of the Herts local group who donated so many tempting prizes.

PSPA staff members Jean Kelly and Gail Cheeseman, and Herts local group coordinator, Maureen Horne, kept the



Jean Kelly with David Heritage, Deputy Mayor, and John Powell, Lions President

tombola tumbling and handed out prizes. Those who didn't win were offered a PSPA mug, badge or T-shirt and everyone was given information cards and leaflets explaining PSP /CBD and the work of the charity.

Not only was it a great fundraiser for PSPA but also an opportunity to raise awareness on a large scale. Over 5,000 people attended and by the time the last strains of the pipes and drums faded away thousands more people had been made aware of PSPA, seen our logo, read about us in their programmes and taken away our information and merchandise, as well as our tombola prizes.

Now we keenly await the news from Harpenden Lions of PSPA's share of the final proceeds and we are extremely grateful to them for having given us this great opportunity for raising our profile as well as funds.

Where there's a will

OCTOBER is Free Will Month. If you are aged 55 years or over you can have your Will written or amended for free in October. If you would also consider leaving a gift to PSP Association it would make a real difference to the lives of people with PSP and CBD. Look out for participating solicitors.

10,000 selfie challenge

PSPA fundraiser and keen runner Lewis Anderson, from Newbury, has dreamt up a fun, and rather daunting challenge.

He plans to take 10,000 selfies with other runners and supporters while dressed in costumes ranging from the Honey Monster to a Storm Trooper.

Lewis will run as many events as he can in his costumes, snapping selfies along the way.

“PSPA is very close to my heart as I have seen first-hand the effect the condition can have on the entire family.”

He said: “I’ll put the pictures up on my PSPA 10,000 Selfie Challenge Facebook page for people to tag themselves in and share.”

Lewis’ Nan, Valerie Clark, lives with PSP. He said: “I have started this challenge to help raise awareness and funds for this incredible charity. PSPA is very close to my heart as I have seen first-hand the



The Honey Monster visits PSPA

effect the condition can have on the entire family.”

Lewis even made time to head along to PSPA HQ in Towcester to meet the staff and introduce them to the Honey Monster!

Kicking off new partnership

PSPA has successfully applied to be a charity partner of English League 1 side Northampton Town FC for the 2016/17 season.

The Cobblers amassed a club-record equalling 99 points on their way to the League 2 title last year, and with it secured promotion.

Our partnership with Northampton Town promises a huge boost in awareness and funds and we are grateful to the club for selecting us as a partner.



Collecting at the Cobblers

Good luck



Santa Run

Festive fun

THE festive season is just around the corner and it can only mean one thing, it’s time for another Santa Run!

Fancy a jolly jog around a wintery Victoria Park, London on 4 December. There’s still time to sign up. Email events@pspassociation.org.uk or call 01327 356132 to get involved.

Whether you choose to run the 5km or 10km course, you will receive a free Santa suit!

Great challenge

OUR Specialist Care Adviser Kathy Weston will be walking into history when she takes on the unique challenge of trekking the Great Wall of China this month.

The five-day adventure will see Kathy scale watchtowers and mountains, and climb along the world famous battlements to raise as much as she can for PSPA.

It is sure to be an arduous and unforgettable experience for Kathy, and we wish her luck.

Well done!

Best of British

IN July, 12 Team PSPA runners took on the British 10k in London. Chris Garrard, who lives with PSP, inspired his son Jon and niece and nephew Sarah and Chris, to run and together they raised a fantastic £3,000!

Kayleigh Gunner also took part, and raised £200 in memory of her Grandfather Norman Gregory.

Also running were Lana Fry, Matthew Brooks, and Tessa and Adam Betterton. Together they raised over £1,000 in memory of Grandfather Roy Archer. Tessa said: "Running is my absolutely least favourite thing to do and I'm not very



Chris, Chris, Sarah and Jon Garrard

good at it. After losing my grandfather to PSP in December I wanted to do something to help PSPA which brings so much hope, help and support."

On their bikes

THOUSANDS of cyclists took on the wide roads of London and country lanes of Surrey on a glorious summer's day for RideLondon-Surrey 100. Team PSPA included Dave Trevaskus, who rode in memory of his father-in law, David Clifton.

Also on the team was Darren Ford,

whose father lives with PSP. Others included Fiennes Davey, whose dad Charles lives with CBD, and supporter Roger Green. Long-time PSPA supporter Charles Peacock led a team made up of wife Sarah, sister Clare Sellors, and niece Emma Bond. Of the event, Emma simply said: "I loved it!"



Clare Sellors

Fiennes Davey

Roger Green

Charles Peacock

Dave Trevaskus

Darren Ford



North of the border

PSPA runners took part in the Edinburgh Marathon Festival's marathon and 10k event in May!

Running the 10k were father and son Paul and Calum Ross, brother and sister Ashleigh and Owen Rose, and Jonny Whiteman, Johnny Scott Mercer, and Gavin Stevenson (pictured above).

They ran in memory of Paul's dad, John Ross, who lived with CBD and raised nearly £450.

A huge well done also to George Findlay and David Meer for completing the marathon event.

The big one!

JOIN Team PSPA for next year's London Marathon, and be part of our biggest fundraising event! Nothing can beat the feeling of crossing the finish line after a gruelling 26.2 mile run through our iconic capital, and the funds you could raise really will make a difference.

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

Justin Johnson, Team PSPA marathon runner 2016

Your fundraising

More tea?



£2,142

Supporting her husband, Gerry, who lives with PSP, Marie Duffy held an afternoon tea at their home - helped by a host of friends and family.

... in to the night



£420

Andrea Solomon organised a fun fundraiser that lasted well into the night! There were football matches, raffles and cake stalls, as well the unique PSPA tent - all in memory of her dad, Brian McKenna. "This was our first fundraiser but won't be our last," said Andrea.

Star turns



£473

Jess Bright from Ashford, Kent and her confirmation group friends staged a variety show - inspired by Jess' grandmother Joan, who lives with PSP. They presented a cheque to PSPA trustee, Sarah Marshall.

Quizzing

Fiona Leask held a fundraising day and quiz at her office - also taking the opportunity to hand out PSPA fact cards.

£820

Umm, errr



£550

Bangor Rotary Club put their heads together for a quiz night. PSPA Volunteer, Doris Mason accepted the cheque from Rotary President, Paul Hatty.

Mufti



£420

Staff at Tarmac dressed-down for the day. Employees, Beccy Reading-Jones and Maggie Hodder presented the cheque to PSPA's Fundraising Manager, Jean Kelly.

One lump or two?



£300

Rachel Wood and friends organised a coffee morning at the Wollaston Methodist Church near Stourbridge, in memory of Helen Tomkins who lived with CBD.

Big fun...

Louise O'Brien from Morecambe organised a family fun day with bouncy castles, hog roasts, cake stalls, sunshine and smiles.



£1,800

Your fundraising

Running for funds...



Harriet Bullard from Chippenham, Wiltshire, ran the Bath Half Marathon earlier this year and also the Clanfield Challenge.



Wendy Wilson, Marie Witherall, Stacy Montague and Anna Syrett dashed through the Colour Run at Windsor – in support of their colleague, Stuart Smith, whose father, David, is living with PSP.

Becky Renton, alongside Michelle Renton and Shannon Purdy, ran the Hull 10k in June.



Mark Kelsey remembered his mother-in-law, as he completed the Humber Bridge Half Marathon.



Newmarket's Andrew Rice galloped the Newmarket 10k in memory of his Dad, John. "I am very motivated to help PSPA in any way I can," said Andrew.



Jane Newsham, alongside Steve Newsham, Gemma Ruddy, Clarke Newsham and Elysse Bartlett, enjoyed the Blackpool Fun Run – running for Jane's auntie, Lynn Barlow, who lives with PSP.

Alex Murgatroyd is running in various events throughout the year. Here he is at the Pudsey 10k – a month before he took on the Leeds 10k.



Pedal power...



Team Acton (PSPA supporters, Andrew, Oliver, and Charlie) had a great day on the London to Brighton cycle ride.



Julie Hannam led a team of her colleagues on a 70-mile cycle ride from Carnforth to Blackpool. The weather was on their side and the team had a marvellous time. "The cycle was a success," said Julie. "There were a few falls and I ended up on roads that I never knew existed!"



Tom and his friend Craig, pedalled from Land's End to John O'Groats, for Tom's mum-in-law, Hazel, who has PSP.

Best foot...



£1,000

Londoner, Dom Hammond and his Dad, Derek, who is living with PSP, marched from the capital to Brighton.

Formal nosh-up



£1,500

A black tie dinner organised by the Abbotts Group, welcomed special guest, Rugby World Cup winner, Neil Back MBE.

Thanks to David and Anissa from Cantell and Company and Brook Kingston Lodge Hotel, for their generous support.

For rent



£1,395

Shelagh Finlay and family from Northern Ireland, came up with the bright idea of providing helmet storage and camping pitches to the bikers at the NW200 Motor Cycle Road Race - in return for donations.

House for sale



£100

Stella Arnold donated a doll's house to sell at the local Pocklington Group. Local PSPA supporter and antique dealer, Gregg Huber, was more than happy to inform Stella that it was worth £100! The house was built in 1906 by Stella's grandfather, and has been in the family ever since.

Scouting for funds



The 1st Neston and Box Scout Group held many fundraising activities, including an overnight hike where the scouts were rewarded with bacon sandwiches in the morning! The group was inspired to fundraise by group leader Matt Mullins, whose grandfather lives with PSP. "I suggested we support PSPA as I hadn't heard of the charity until my Grampy was diagnosed - the scouts agreed to raise funds and awareness."



£1,000

Chloe and Lewis Anderson crossed the Brecon Beacons at the first Trekfest of the year. Here they are at the top of Pen y Fan (2,907 feet) just 12km into their 25km route! Chloe will also be running the London Marathon next year.

Send your fundraising pictures to:

Email: events@pspassociation.org.uk

At the top

The rain and fog did not deter Sue Brown and her family atop Ben Nevis in memory of her Mum, Josephine Leonard. "The weather wasn't kind at all!" commented Sue. "It rained continuously but it didn't stop us!"



£2,000

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.

