



VOLUNTEERING

**STARTS
PSPHERE**

Figure 1

YEARS OF PSPA

SPECIAL ANNIVERSARY EDITION

WHERE THERE'S A WILL...

Researchers believe that within the next ten years a cure to PSP & CBD will be found. To achieve this we need to continue to fund world-class research.

What if your lasting legacy could be a cure for PSP & CBD? Leaving a gift in your will could make a huge difference in beating these devastating diseases forever. Once you've remembered your loved ones, consider being part of the global fight to end PSP & CBD.



**YOUR
LASTING
LEGACY
COULD
MAKE
HISTORY.**

pspassociation.org.uk/fundraising/legacy



WELCOME

This year is a special one for PSPA, as we mark the charity's 25th anniversary. A significant anniversary like this gives us the opportunity to reflect and look back on key milestones in our history. On page 16, you can read our interview with PSPA Founder, Michael Koe, who shares his experience of setting up the charity and growing it into what it is now.

Michael's interview is followed by a timeline, highlighting some of the big events that have taken place over the years. When I first saw the timeline, it struck me how much of a role PSPA has taken in research – something the PSP & CBD community should be very proud of.

We wanted to celebrate some of the PSP & CBD community who have been involved in our charity from the early years. Di Davies and Michael Shepherd are two of our longest serving volunteers. Both became involved following their partners diagnosis of PSP. The similar theme in the stories is their dedication to helping others affected by PSP & CBD – something I know all our wonderful volunteers and supporters have in common.

Enclosed in this edition you will see our 2018 annual report, detailing everything we did last year. It was a busy year for PSPA. We held the largest ever international research conference, created the first professionals guide to CBD and committed to fund the next stage of the Prospect study. All these achievements would not have been possible without your support.

Thank you for being part of our special community.

Andrew Symons
Chief Executive

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KEITH AND HIS FAMILY

£25,000 GRANT AWARDED BY SCOTTISH GOVERNMENT

After years of campaigning by Keith Swankie, who is living with PSP, we are thrilled to announce the Scottish Government has awarded us £25K to support a new development role in Scotland to create partnerships to improve care and raise awareness of PSP & CBD.

Andrew Symons, Chief Executive of PSPA said: "We are really pleased the Scottish Government has recognised the need for this role, and supported it with a generous grant after several years of tireless campaigning by Keith Swankie. Too often, people affected by PSP & CBD face difficulties using NHS services because staff are unaware of these conditions.

"The Development Manager will raise the profile of PSP & CBD with the Scottish Government, NHS Scotland and other neuro-degenerative charities to educate health and social care professionals in best practice treatments. The aim is to improve the quality of life for people affected by these conditions in Scotland, and reduce the burden on their carers."

We will continue our work to improve care for people with PSP & CBD in the rest of the UK, through influencing and educating health and social care professionals and developing care guidelines that clearly map out the care people with PSP & CBD should receive. If you would like to support this vital work email volunteering@pspassociation.org.uk

IMPROVING OUR SUPPORT TO YOU – OUR VITAL VOLUNTEERS

Our volunteers are a key part of PSPA's ambitions to achieve even more for people living with PSP & CBD over the next three years. One of our strategic goals is to grow our capacity to support more people affected by PSP & CBD, and fund more research. In order to do this, we have restructured PSPA's central functions.

The Volunteering, Information & Support and Helpline functions have been merged into one Engagement Team under the leadership of Carol Amirghiasvand, who has been promoted to the role of Director of Engagement.

Carol's new role will be responsible for improving our engagement with volunteers and the wider membership. Carol will also focus on recruiting more volunteers to increase and strengthen our PSP & CBD community. Gemma O'Connor, Engagement Officer, will be supporting Carol on our ambitious volunteer recruitment drive. Our Local Groups will now be supported by the Helpline Team, headed up by Jules Brown who has been appointed to the role of Helpline Team Leader.

The aim of this restructure is to help build solid foundations in order to provide you, our valued volunteers, and our wider community, with increased support and improved communication.

If you have any questions please contact our Helpline on **0300 0110 122** or helpline@pspassociation.org.uk

INCREASE YOUR DONATION AT NO COST TO YOU

Thanks to Gift Aid, PSPA has received additional money from your donations that we have been able to invest in providing information and support to people affected by PSP & CBD, and to fund vital research.

By signing up to Gift Aid, PSPA receives an additional 25%, at no extra cost to you. Gift Aid is a scheme that allows charities to reclaim tax on a donation made by a UK taxpayer, effectively increasing your donation. This means that, if you pay UK tax and agree to PSPA claiming Gift Aid on your donation, the government will give us 25p for every £1 you donate to PSPA.

If everyone who supported us in 2018 gift aided their donation, PSPA could receive thousands in extra donations. Money that could be invested in research, or used to invest in our information and support services.

So, if you make a donation to PSPA, and you are a UK taxpayer, please remember to Gift Aid it – it makes a huge difference!



SPOTLIGHT ON: HAMPSHIRE LOCAL GROUP

Jade Donnelly, specialist physiotherapist, ran an exercise session at a Local Group meeting in Hampshire, where people could do as much as they were able. Exercise can help to keep muscles strong. It can help improve flexibility and mobility and can be beneficial for people with PSP & CBD.

The Hampshire Group is co-ordinated by Louisa Roberts-West, who created the group six years ago. Louisa's mum died of PSP in 2006. Following her personal experience of PSP, Louisa knew she wanted to create a group in Hampshire, to provide local support, once she was ready.

Louisa said: "I always knew in my heart I wanted to do something for people with PSP. A few years after mum's death, I got in touch with PSPA about setting up a new group. I visited a group to see how it was run, and whether I was able to take it on emotionally. Seeing people with PSP for the first time since Mum was initially very hard.

"After the visit I was determined to set up the group. Our local village hall was really accommodating and is in a lovely spot by the river. I believe the environment you hold the group in is important. I wanted

to make the group feel like a home away from home.

"We held the first meeting with just three people. I very nearly called it quits. But, gradually word of mouth spread and the group grew. At the beginning, I used to think it was important to get guest speakers to every meeting. However, I soon learned that while people like to learn things from health and social care professionals, they are also just as happy getting support from one another if there's no guest speaker.

"Everyone joins in with the running of the group and brings biscuits and cakes. It is very much 'our' group.

"Over the years I've realised it is not my job to make everyone happy. Sometimes the mood of the meeting is happy and joyful, other times, perhaps when we have lost people, it isn't. Naturally there are times that impacts on me, like when we have a succession of people who pass away, one after the other. But, when new people walk through the door it gives me the impetus to keep going."

Would you like to share what is happening at your Local Group? Please email a photo and some information to info@pspassociation.org.uk

MOTH AND RAY WINN



MEET RAY AND MOTH

“In that desperate moment, it seemed the most obvious step to put one foot in front of the other.”

In the same week Moth Winn received his diagnosis of CBD at just 53, Moth and his wife Ray were also told they were being evicted from their home, due to a bad investment. Faced with a progressive, incurable disease, and no home, the couple threw some belongings into their rucksack and set off on a 630 mile walk along the South West Coast Path, leaving their old life behind. Two years later, Ray wrote a critically acclaimed book about the experience, *The Salt Path*. Ray tells *PSP Matters* of their incredible story and how walking appeared to hold back the progression of Moth's CBD.

Ray said: “Our family home was a small farm we had restored from a ruin. We'd lived there for 20 years, raising our two children and devoting all our time to its restoration. Moth had always worked outside in very physical jobs, so when he first developed a pain in his shoulder, we put it down to the physical stresses of his work. The pain gradually got worse and his left arm started to feel numb.

“Moth's GP thought it could be ligament damage from when he fell off the roof. Two years were spent going back and forth to consultants and having numerous tests and scans. That's when we were told by doctors they believed he had CBD. It was devastating. We had never heard of CBD and

we didn't understand how, what we thought was shoulder damage, could actually be a disease that would progress in the way it would. Moth was just 53 – far too young to be diagnosed with something like this.

“The diagnosis of CBD came just a few days after we had an eviction notice to leave our home. We couldn't believe how our life was changing so much and so rapidly. How could this be happening to us? Suddenly the whole framework and structure of our life was gone within a week, including our future. We couldn't see a way forward.

“We had given our life over to the farm house. From a pile of stones, we had turned it into a holiday business. It was our children's home. Yet now, we were going to be made homeless. The day the bailiffs banged on the door we were hiding under the stairs. We knew we had to leave, but we weren't ready to take the final step, knowing we would never return to our home. Just then I spotted a book on top of a packing case about a man who had walked the South West Coastal Path. In that moment, we decided to throw some things in a rucksack and set off on a long walk until we had a plan for the future. It seemed the most obvious thing to just put one foot in front of the other and follow a line on a map.

“THE DIAGNOSIS OF CBD CAME JUST A FEW DAYS AFTER WE HAD AN EVICTION NOTICE TO LEAVE OUR HOME. WE COULDN’T BELIEVE HOW OUR LIFE WAS CHANGING SO MUCH AND SO RAPIDLY.”

“Moth’s consultant said there was no treatment for CBD, but that if he could stay active it might help him stay mobile for a little longer. We seized on that, almost like a lifeline, as a way to limit the progression of CBD. We travelled to Minehead in Somerset. The first few days were hard for Moth. He couldn’t put his coat or rucksack on without help and struggled to get in and out of the tent. But we kept pushing on and slowly things began to change.

“After walking about 200 miles over a few weeks we noticed he was walking easier and he could put on his rucksack without help. His muscles were getting stronger. One night we were camping on the beach after watching dolphins in the bay, but at 3am the tide was coming in – fast. We had to grab our fully erected tent, with everything still in it, and run up the beach with it above our heads to higher ground. Afterwards we couldn’t believe how Moth had managed to do it. It seemed like a miracle. When he was diagnosed with CBD we were told it was a downward spiral, but time spent walking in nature was affecting his health in a positive way.

“We walked until mid-October when it started to get too cold to stay outside. We were offered a shed to stay in, in exchange for helping the owners with its conversion. During that period when we stopped

walking, Moth’s deterioration was fast. When we had completed the project, and the weather improved, we turned back to the path. We really thought we were now on a slope to the end, because his decline had been so rapid. But, in a few short weeks, his health returned and once again he was walking better than he had walked before. Surely this can’t be a coincidence.



CAMPING ON THE BEACH



"We walked for three months, spending nearly 100 nights on the path. Although we lost our home, we didn't think of ourselves as homeless, but soon we were faced with people's preconceptions and fears about homelessness. When we told people we met along the way why we were walking the path and that we had lost our home, they would physically recoil from us. It was a shock to experience. To save ourselves from having to encounter that reaction, we changed our story to say we had sold our house. Suddenly we were inspirational. The difference between losing your home and selling it was incredible.

"Two years after we finished the walk, I began to realise it hadn't just been a physical journey but a huge emotional journey too. During the walk I had kept notes scribbled in a guide book. I started to write them up, so that when Moth's illness progressed, I could stick it in front of him and say 'look what we did'. I didn't show anyone until it was finished and gave it to Moth for his birthday.

"My daughter read it and encouraged me to find a publisher. I really couldn't see the point – who would be interested in a 50-something woman who had never written before? I did however write an article for *The Big Issue* magazine. The response to the article was so positive it prompted me to send an email to a few agents I had Googled. One week later I signed with an agent who sent my manuscript to Penguin Books. Next came a book deal. It was all so quick and unexpected.

"One of the most moving things about the whole experience happened a couple of months after *The Big Issue* article was published. I was walking along

the coastal path and saw someone coming towards me with a backpack. He didn't look like the average backpacker, with his facial piercings and a yellow high-vis waterproof. I asked him where he was going. He said he'd been sleeping rough in Exeter and had read an article in *The Big Issue* about a woman who had taken to the coastal path after she became homeless. He decided if she could do it, so could he. And, with walking, he had found a new determination to change his life.

"Moth is really proud that our story can be read by people who can take a tiny bit from it and possibly use it to influence their own lives. His health isn't as good as when we were walking, and, this winter has been hard, but he is still in a much better state than the consultants and scans said he should be. We have a number of long walks planned for this year and living close to the coastal path we walk on it every chance we get.

"Moth graduated last year with a degree in horticulture and garden design. It took three years of very hard work but he did it. He is determined to fight every single day and not give in. When he got that diagnosis, he said 'I'm not going to sit in a chair and wait for it to come. I will work to keep what I have'. He continues to do that and is always stretching himself mentally and physically. I think that is the key to where he is now.

"The response to *The Salt Path* has been incredible, it seems to have really resonated with people. When I wrote the book, it was a personal thing, I wasn't thinking how other people would be affected by it. To know our journey has touched people in the way it has is really incredible."



THE SALT PATH

"I came across *The Salt Path* when attending a PSPA Local Group. This book takes you on a journey of emotions. I was humbled by Moth's and Ray's strength. As a physiotherapist, it made me think about the physical challenge Moth embarks on. How he copes with the intensity of covering the distance. The challenge to his balance when walking in the wind and on uneven terrain. The impact of carrying his backpack day in and day out on his strength.

"Everyone can benefit from exercise. Being physically active can help both physical and mental health, but having a neurological diagnosis can make exercise less accessible and activity more challenging.

"Part of my role in the Atypical Parkinsonian Service, is to advise on exercise and symptom control in progressive neurological diseases. I work with Dr Boyd Ghosh and Dr Luke Massey, neurologists with a specialist interest in PSP & CBD. Together, we work closely with community-based teams advocating early therapy input and ongoing reassessment.

"What role does exercise and physiotherapy have? There is little research into the effect of physiotherapy and exercise for people with PSP & CBD. Can therapy maximise and maintain function for longer? As a physiotherapist, I would say yes. Reading *The Salt Path* highlighted the benefits of physical activity on Moth's symptoms and mental wellbeing. But how much activity is needed? Every patient is different, presentations can vary, and deterioration rates differ. We are all individuals and must be assessed and treated as such.

"As we get older, our muscles start to deteriorate. Balance is also affected. Reduced strength and poor balance put you at a greater risk of falls and this is without a diagnosis of PSP or CBD. Safety is paramount, being assessed by an appropriately qualified professional is important when obtaining advice on exercise. As therapists, we need to consider the physical symptoms as well as fatigue, apathy and impulsivity and what impact these features have on activity.

"More research is needed into what exercise strategies best benefit those with PSP & CBD. Research into Parkinson's demonstrates that exercise can improve gait, balance, tremor, flexibility, grip strength and motor co-ordination. Exercise in the over 65's, focusing on strength and balance programmes has been shown to be effective in preventing falls. Seated exercise can help general fitness and flexibility, but only exercise in standing can influence balance.

"Ray noted that Moth's deterioration was rapid when he stopped walking for periods on the coastal path, demonstrating the benefits of the activity to his body. Not everyone can take to the coastal path, but as a physiotherapist I believe there is a value in keeping active."

Jade Donnelly

APS coordinator and Specialist physiotherapist, Southampton General Hospital



MAKING DECISIONS AROUND EATING AND DRINKING WITH PSP & CBD - THE IMPORTANCE OF QUALITY OF LIFE AND ADVANCED CARE PLANNING

PSP & CBD affects people in different ways, but a common symptom is its impact on your ability to swallow. In this article, Elinor Blair, a Speech and Language Therapist (SLT) and Dietitian Heather Pratt, help to explain some of the issues and options for people who have problems eating and drinking.

Many people with PSP & CBD develop swallowing difficulties as the disease progresses. This is because the areas of the brain which control the movement of the lips, tongue and throat are affected. As eating and drinking is such a central part of our lives, this can be a distressing development. However, with forward planning there are ways in which your healthcare team can support you, your family or carers to reduce anxiety, and help make mealtimes as safe as possible.

EARLY SIGNS OF SWALLOWING DIFFICULTIES INCLUDE:

- Taking a long time to clear your plate during mealtimes
- Weight loss
- Leaving bits of food in your mouth and finding it hard to swallow.

LATER SIGNS INCLUDE:

- Becoming short of breath during mealtimes

- Coughing and or choking when eating or drinking
- Repeated chest infections which may occur if food or fluid goes down into the lungs instead of the stomach (this is known as an aspiration pneumonia).

If you or your carers notice any of these problems, ask your GP to refer you urgently to the Speech and Language Therapy (SLT) Team who will be able to carry out a thorough assessment of your swallowing ability either at home or in clinic. It may be beneficial to have an x-ray (or Videofluoroscopy) assessment of your swallowing. The SLT will be able to provide you with recommendations around food and fluid preparation (which may involve modifying the consistency of your food), equipment that may help you eat and drink more safely, and strategies to help make your mealtimes as enjoyable as possible. The SLT will also make a referral to the Dietitian if required for support and advice to ensure that you are maintaining adequate levels of nutrition and hydration.

The Dietitian will complete an assessment, looking at areas including your eating pattern, the amount and types of foods you are having, and your weight history. They would then offer advice tailored to your food preferences, lifestyle and any other dietary needs. If you have lost weight, they may provide advice on how to increase your calorie and protein intake through enriching your diet and having nourishing drinks. They may also recommend that you take oral nutritional supplement drinks if you are unable to meet your needs through diet.

If your swallowing becomes increasingly difficult or distressing, your healthcare team will discuss alternative, non-oral methods of feeding. This will involve being fed via a tube directly into your stomach, which is called a gastrostomy. This requires a small operation which can usually be performed under light sedation. The procedure is called a PEG (percutaneous endoscopic gastrostomy) or RIG (radiologically-inserted gastrostomy), depending on how the tube is inserted. The decision to have a gastrostomy is yours, and the team will be there to provide as much information and support as you need. It is helpful to make a decision before you need a gastrostomy (i.e. before your swallowing becomes too difficult) so that everyone involved in your care understands your wishes.

If you do decide to opt for a gastrostomy, a referral will be made to the Gastroenterologist who will give you more detailed information about the procedure and aftercare. As with all operations there are some risks involved, such as infection, but you will be well advised by your medical team and you can of course change your mind about the procedure if you feel this is not the right option for you.

FREQUENTLY ASKED QUESTIONS WHICH MAY HELP YOU WITH DECISION MAKING:

Will I be able to carry on eating by mouth once the PEG is inserted?

This depends on your swallowing ability. It may be that the gastrostomy is initially used as a 'back up' to oral feeding and then becomes your main way of getting nutrition. You may decide to continue eating and drinking small amounts orally whilst acknowledging that you are at risk of developing a chest infection. This is known as 'Risk Feeding' and your healthcare team can advise further on this.

Is a gastrostomy difficult to look after, will it get in the way?

Your healthcare team will show you, your family and carers how to look after the tube once it is fitted. Before you are discharged home, you will be given training on the ward. The tube is discreet and can be tucked underneath your clothes. Your healthcare team will let you know when it is safe to have a bath or go swimming – usually a few weeks after the tube is placed.

Who will help me with the gastrostomy when I'm at home?

Some people can manage their feeding themselves, and others need support, for example if they have hand weakness.

If you live alone you can be supported by home carers or district nurses with your feeds. If you are concerned about how you will manage your feeds, discuss this with your healthcare team before the tube is fitted so they can help you to arrange support.

We hope that this article has been helpful, if you have further questions please contact PSPA's helpline or speak directly to your healthcare team.

For more information please visit our website **pspa.org.uk** or contact the helpline and request *PSPA Tube Feeding* information sheet.



ELINOR BLAIR



HEATHER PRATT

To hear directly from people who have had a feeding tube fitted go to **www.mytube.mymnd.org.uk**

The website is an educational website and offers an insight into living with a feeding tube. It also outlines other alternatives and can help you decide what option is best for you.



**“PEOPLE SAY ISN’T IT TIME
YOU WALKED AWAY? BUT, I
COULD NEVER DO THAT.”**

Michael Shepherd has been a volunteer for over 15 years, following his wife Shirley’s diagnosis of PSP. Shirley died 11 years ago, but Michael remained determined to continue to support local families by co-ordinating a Local Group.

“My wife Shirley was a lovely lady, so kind and gentle. Sadly, PSP took away all that. Shirley had symptoms of PSP for around two years before it was diagnosed. Initially we had no idea what was wrong. Doctors and consultants didn’t either. Those two years were a struggle.

“My son-in-law who works in psychiatric health suggested we travelled down to London to Queen Square, to the department of neurology and neuroscience to see if they could shed any light on what was wrong with Shirley. It was there we were

told Shirley had PSP. While the consultant could tell us what was wrong, he was unable to tell us what we could do to make Shirley better. We left the appointment better informed, but with the words ‘no cure’ ringing in our ears. At that stage Shirley’s brain and thinking process was already badly affected by PSP. She knew what was happening, but didn’t seem able to question it. I have since seen that with many PSP patients over the years.

“Armed with the knowledge Shirley had PSP, the first thing we did was organise a coffee morning at our

church to raise money for PSPA. People came from all over, including Devon! That was how well Shirley was thought of. I remember that day well. We were selling cakes and cards. People would hand me over £20 and refuse the change. We raised over £1,000. My volunteering for PSPA started at that event, and has continued ever since.

"We began to organise regular coffee mornings. Somehow, those coffee mornings turned into a Local Support Group. In the early days of Shirley's illness, I had travelled 60 miles to a PSPA Local Support Group in Barnsley. I saw the value in the group, how it provided local people with support and information. Indeed, I learned so much about PSP from that one trip. Driving back home I was determined to help create a group that could provide the same level of help.

"I went into town to search for a venue to hold the meetings. The room I found 15 years ago is the same room we meet in now – the Pocklington Community Room. People appeared from everywhere – all over the North East of England. I remember one lovely man, a GP, Dr Jolly. He was one of those patients who refused to give in. He was determined to do as much as he could, for as long as he was able. He was very inspiring in how he lived with PSP.

"Organising the Local Group isn't arduous. People who attended the group soon became personal friends. Over the years people have come and gone, but the warm atmosphere has always stayed the same.

"I have seen many changes in the 15 years I have been a volunteer. The Helpline has been an important development. In the old days, there was nowhere for people to ring. Now they can have information and support, and simply someone to talk to. I also think the expansion of the healthcare professionals' educational training is a very good development.

"When Shirley died, I couldn't just walk away from PSPA. When you have seen a family member go through it, I think you need to do something to help. I don't know when a cure for PSP or CBD will be found. What I do know is, if this horrible illness is going to be beaten, it will only be through people personally affected raising money and volunteering.

"I remember clearly at a funeral it dawned on me how closely affiliated I was to PSPA. There was a big pot full of donations people had left at the back of the church. I suggested to the funeral director he send

it to PSPA. He told me 'Mr Shepherd, you are Mr PSP in these parts so I will hand it to you to send', so I sent it to the office. I'll never forget that. People often say to me 'Michael, isn't it about time you walked away? Haven't you done enough?' But there is no way I could do that."

"I HAVE SEEN MANY CHANGES IN THE 15 YEARS. THE HELPLINE HAS BEEN AN IMPORTANT DEVELOPMENT."

We have a number of Local Groups across the UK but we could do with many more. If you think you could set up one of these amazing groups or even help at an existing group please contact volunteering@pspassociation.org.uk or call Carol Amirghiasvand, Director of Engagement on **01327 356137**

PSPA
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LONG SERVING VOLUNTEER, DI DAVIES

Di's husband David was diagnosed with PSP in 1998 and died in 2003, just four and a half years later. Since then Di has volunteered for PSPA. Having served for over 21 years, Di is one of our longest serving volunteers and is determined to continue, for as long as she is able to help others affected.

"When David and I married he was 60. He was a farmer. A big strong man, he could always be a bit clumsy and moved awkwardly. But, I gradually noticed he was getting worse, with the occasional fall thrown in.

"For his 65th birthday we invited neighbours from the hamlet where we lived to a party. David wore his wedding suit. That's when I first noticed how much weight he had lost. During the party someone commented on how unwell he looked. The following week I made him go to the GP. David had never been to the GP in his life, the doctor couldn't even find his notes.

"His blood test came back negative, but I insisted on going with him to a follow-up GP appointment. I used to be a GP's secretary, so I was familiar with the system. The GP asked what I had noticed and I told

him David could no longer walk in a straight line. He tested David and saw for himself how unsteady he had become.

"He agreed something was wrong and referred us to a neurologist. The six months referral time to see a neurologist was far too long to wait, so we paid to see one the following week. The neurologist took one look at David and told him he had PSP. Naturally, we had never heard of it. He gave us a leaflet with a contact number for Michael Koe, who, at the time was running PSPA from his home.

"Two days later Michael called. He was amazing and I shall always be grateful for that call. I had no idea what we were up against, so speaking to someone who knew about the condition, and had personal experience in caring for their loved one, made such a difference. Michael shared how he had cared for his

wife Sara and told me to call anytime. That call set me on a path to help people also faced with PSP. I saw the difference talking to someone who had been there meant to me, so I wanted to do that for others.

“With David, things got worse very quickly. Soon it became obvious he could no longer farm. He had to get rid of his beloved cows. It was a horrendous time. We auctioned off the cows first, followed by machinery.

“Watching his old life being dismantled like this must have been unbearably hard for David. Not that he ever complained or asked ‘why me’? He was the easiest person in the world to take care of. I nursed David for four and a half years. He had a PEG fitted, was on a ventilator, could no longer see or speak. In the end he was bedridden. Our very old cottage became impossible for him to live in, but every time I mentioned moving into a bungalow he’d refuse. He had lost his farm, he didn’t want to lose his home too. David was a big man. Looking back, I can’t believe how I actually lifted him after his many falls.

“Maggie Rose, one of the first employees at PSPA, got in touch. She had helped nurse Sara Koe and started the Local Group in Shropshire. I attended the very first meeting and helped make teas and coffees. When I was asked to co-ordinate the meetings I didn’t hesitate. I’ve done it ever since. Remembering the impact of Michael Koe’s call, I wanted to try and have that impact on other families. I approached my GP surgery with information and asked them to give my number to anyone diagnosed.

“Over the years there have been many developments. The creation of the Helpline I think, has been especially valuable. It is so much better now that people have a

number they can ring for support and information. “I can’t believe I have been involved with PSPA for 21 years. I love it and it means so much to me because it has played such a huge part of my life. I am doing this for David. He was such an incredible man. Very quiet, but also very brave and stoic. I don’t know how much longer I can continue to volunteer, but I am determined to keep going for as long as I am able. Those of us who have been there need to stick together.”

“WATCHING HIS OLD LIFE BEING DISMANTLED LIKE THIS MUST HAVE BEEN UNBEARABLY HARD FOR DAVID. NOT THAT HE EVER COMPLAINED OR ASKED ‘WHY ME’? HE WAS THE EASIEST PERSON IN THE WORLD TO TAKE CARE OF.”



DAVID AND DI ON THEIR WEDDING DAY



DAVID AND DI WITH THE GRANDCHILDREN



**“WE WERE SO UPSET THAT
NO ONE SEEMED TO KNOW
OR CARE ABOUT PSP.”**

When Sara Koe received her diagnosis of PSP, both Sara and her husband Michael were surprised and shocked at how little awareness and support for those affected existed.

Driven by their own devastating experience, they decided to set up a charity from their kitchen table with three aims: promote and sponsor research into the cause, treatment and cure of PSP; raise awareness among the general public; and provide information and support across the UK for families affected. Michael explained how PSPA began and how it helped give him a focus after Sara died.



"My wife, Sara and I moved from London to Gayton Manor, a beautiful Grade I listed building in South Northamptonshire. It was where we had planned to spend our retirement and where our story with PSP really began. During the renovation, Sarah hit her head on the corner of some scaffolding and needed a couple of stitches. However, either because of or just after that, Sara began to have problems with balance, speech and swallowing, all of which got steadily worse.

"Her balance became very poor with unexpected falls. She developed a dislike of bright lights and

found it difficult to look up and down without moving her head. Then her problem swallowing worsened. I took her to the doctor and local neurologist – no one seemed to know what the problem was. It was suggested by one doctor she possibly had early onset Parkinson's. That was the closest she got to a diagnosis until my son Jamie got in touch with Prof Martin Rossor. He invited Sara to spend a week in The National Hospital for Neurology in Queen Square, in London. Prof Rossor and Prof Andrew Lees finally made a firm diagnosis of PSP. Hearing that diagnosis was pretty bleak. I had to try and explain to Sara their diagnosis and its implications as I drove her back to Gayton.

"I learnt there was a PSP Association in Baltimore. There was talk that Dr Irene Litvan there was close to a cure. I flew over to Baltimore while our sons came to look after Sara. Unfortunately, upon arriving it soon became clear that there was no potential cure. By the time I returned home, things had got worse. Sara's swallowing had deteriorated and her propensity to fall increased. It was quite frightening for her.

"We tried everything from alternative medicines to special therapies, like laying on hands to see if anything would slow the progression of the disease or even stop it. Sadly, all turned out to be –for her anyway - a waste of time (and money!). Both Sara and I were upset that no one knew, or seemed to care much about PSP. Progressive Supranuclear Palsy is a difficult and awkward name for what is a particularly nasty brain disease. We were keen to do something to draw public attention to it and help others living with PSP. We also were determined to raise awareness and funds for research into this devastating disease.

"A year before Sara died, I asked our local MP, Michael Morris if he would be willing to help us set up a new charity. He agreed to do his best and chair such a charity. Many other friends also helped, including Sir Michael Carlton Smith who was then CEO of Marie Curie and James Stanford who was Chief Executive of The Leonard Cheshire Foundation. My neighbour Sir John Greenaway offered to become our treasurer. Soon we had a committee and held our first ever meeting at the Marie Curie offices in Belgravia. We each put in £25 and the charity began. Despite her rapid progression with PSP, Sara managed to come to our first meeting. We agreed on the charity's objectives.

“WE ESTABLISHED AN OFFICE IN AN OUTBUILDING AT MY HOME. THAT CONTINUED TO BE THE CHARITY’S OFFICE FOR THE NEXT 15 YEARS, UNTIL WE OUTGREW IT AND MOVED TO A BIGGER BUILDING IN TOWCESTER.”

“Sadly, it was around that time we realised we could no longer live in Gayton Manor, with its stone stairs and steps. It was just too big for Sara and I to cope with, along with our four boys and a dog. So, we sold and moved to nearby Wappenham to a smaller and more manageable house. We had a through floor lift fitted so Sara could take her wheelchair upstairs, but all the time she was getting worse. In January 1995, she died in Northampton General Hospital where she had been admitted a couple of days before. My son Jamie, who was visiting, and I drove sadly back to the hospital, where I had said goodnight a few hours earlier – she was just 54. It was a miserable time. During those dark days after Sara died, PSPA saved me. It took a huge amount of my time and effort, and was something positive to focus on.

“We established an office in an outbuilding at my home. That continued to be the charity’s office for the next 15 years, until we outgrew it and moved to a bigger building in Towcester. Prof Andrew Lees became our Chief Medical Adviser. Prof Martin Rosser, joined our Medical Advisory Panel. We later set up the Sara Koe Research Centre next to Andrew’s offices.

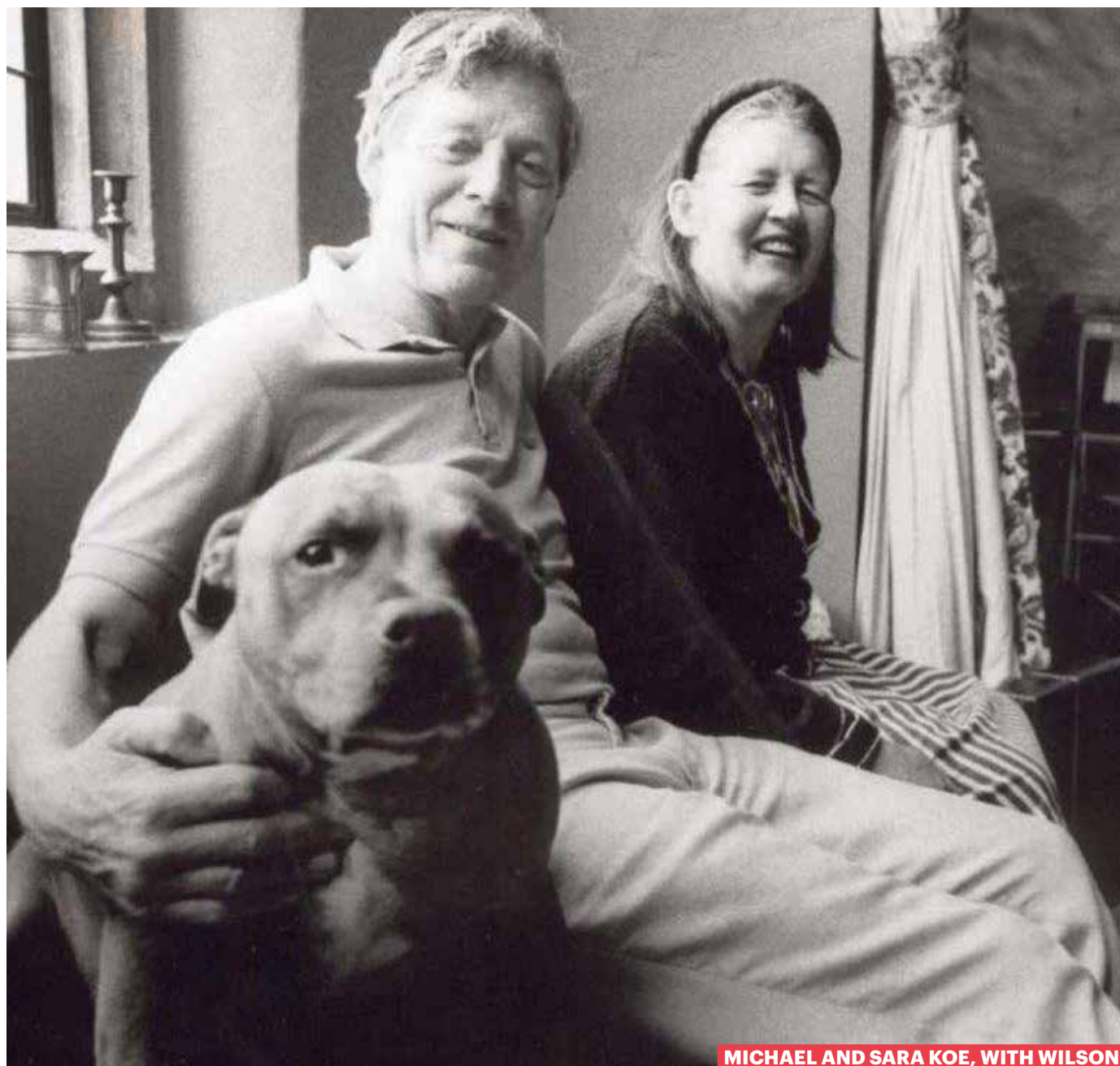
“Field Marshal The Lord Bramall, whom I had served with, became President. His office approached HRH, The Duchess of Gloucester to ask if she would be our Royal Patron. She accepted and attended one of our early fundraising events at Grosvenor House Hotel

in London. I’m very happy to say she is still our Royal Patron today.

“Our first major fundraising event was the Magnolia Ball in Stowe School. Sara loved magnolias and asked for them to be our emblem. This event helped us raise worthwhile funds and was a brilliant setting for some of our further events, including medical workshops.

“My four sons, Simon, Jamie, Richard and Digby helped raise funds by running the London and New York Marathons. Richard, with some friends, later took part in the Marathon des Sables, one the toughest events, involving three marathons across the Sahara while carrying food and bedding over a hundred miles in the scorching desert sun. Before their first marathon, I contacted Seb Coe and asked if he would ‘coach’ my four sons immediately outside The Houses of Parliament, as a PR exercise to help raise awareness. I’d booked a photographer and the training session ended up in the newspapers. At this stage, Seb had no personal connection with PSP, but in a quite extraordinary coincidence, a few years later, his own mother would receive a diagnosis of PSP and sadly die from it. He went on ‘Who Wants to Be a Millionaire’ and raised some £62,500.

“We employed two nurses, Maggie Rose and Grace Lewis, and started to set up Local Support Groups. We wanted these groups to be run by local people and for those in the area with PSP and their



MICHAEL AND SARA KOE, WITH WILSON

families to be supported by the local community. I remembered what it was like when Sara was diagnosed with PSP, so I was happy to contact anyone with the disease to tell them about the charity and how we could help them. Now that role is fulfilled by our Helpline.

"Of course, over the last 25 years there have been lots of changes. The charity is now based in Milton Keynes, its CEO is Andrew Symons and my eldest son Simon is now its Chair. It supports many more people with PSP, and now those with the closely related CBD too. I am very happy that Simon is now its Chair, with an impressive group of Trustees. He keeps me up to speed about what is happening.

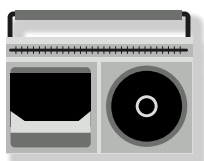
"I was delighted to attend the impressive research symposium held last October at the Royal College of Physicians, with world-leading neurologists from America and Europe. Our Patron HRH The Duchess of Gloucester came to open this two day gathering and I was very happy to listen to the many top neurologists speak at the two day event. It really bought home to me the impressive progress being made in research into the cause and cure of these devastating brain diseases. Effective treatment and cure are moving tantalisingly closer, something I know we all long for."

25 YEARS OF PSPA



1993

Sara Koe diagnosed with PSP by Prof Martin Rosser



1997

Seb Coe presents BBC Radio 4 Charity Appeal

1995

PSP Association-led Local Group set up in Liverpool, closely followed by groups in Northern Ireland, Merseyside and Kent



1999

Dr Nath's research, funded by PSP Association, into the prevalence of PSP, establishes over **5,000** people are living with PSP in the UK

2001

Magnolia Ball is held, raising **£25,000**, attended by Royal Patron HRH The Duchess of Gloucester

2003

Total research spend **£600,000**. The charity aims to spend a minimum of one third of its income on research



2005

PSP Association holds a medical workshop in London

2007

PSP Association moves into PSPA House in Towcester



1996

First research workshop held in Kent

1998

New office established in Michael Koe's outbuilding



2000

Clinical trial investigates effectiveness of Riluzole in people with PSP



2002

HRH The Duchess of Gloucester opens the Sara Koe PSP Research Centre

2006

Clinical trial in Valproic Acid in people with PSP



2004

The October Club, made up of a number of high profile companies, hold a dinner raising many thousands

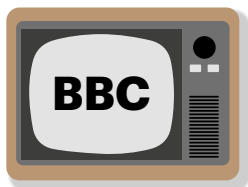


1994

PSP Association registered with Charity Commission

PSP Medical Advisory Panel formed, chaired by Prof Andrew Lees





2009

BBC documentary A Short Stay in Switzerland is aired, based on Dr Anne Turner decision to go to Dignitas



2011

Pathway of Care for people with PSP developed



2013

First Family and Friends day in Sandbach



2015

Launched **PROSPECT** Appeal to fund the most ambitious research study into PSP & CBD to date



2017

Funded a brain imaging co-ordinator at Cambridge University



2019

Secured **£25,000** grant from The Scottish Government to fund a role to raise awareness and improve care



2010

Researchers collaborate on a whole genome analysis genetic study to identify genetic risk factors for PSP



2014

Received **£187,000** from gifts in wills



2012

Helpline and online forum Health Unlocked launched

Volunteer led support groups set up in Norwich, Brentwood and Northampton

2016

Survey discovers half of people with PSP & CBD are misdiagnosed



2018

Launched new brand, PSPA – and move to Milton Keynes

In conjunction with CurePSP, organises the world largest research Symposium on PSP & CBD.

Developed first professional guide to CBD



PSPA NEWS



2008

PSP Matters is created to provide information to people with PSP & CBD



“A PROACTIVE APPROACH TO CARE MAKES A BIG DIFFERENCE TO PATIENTS AND THEIR FAMILIES.”

Dr Boyd Ghosh is a consultant neurologist in Southampton and Salisbury. Dr Ghosh set up the region's first clinic for patients with PSP & CBD. Here he shares why co-ordinated care is so important for people with PSP & CBD, and how being proactive can help patients avoid hospital admissions.

“During a superstring theory lecture the realisation dawned on me that while interesting, it was perhaps not very useful in real life. I was studying natural sciences at the University of Cambridge and had recently volunteered at a holiday camp for adults and children with disabilities. That experience resonated with me and directed me towards a career that would have a direct impact on people - medicine. Early on in medical school I knew I wanted to specialise in neurology - it appealed to my logical brain.

“I wanted to understand what made people do the things they did and what was happening in the brain. After working in Bristol as a neurological fellow, I applied to Cambridge to do a PhD. After a discussion with Professor Rowe, I started my PhD in social cognition in patients with PSP. Part of my PhD involved lots of visits to PSP patients for the research, which is when I really appreciated how horrible the disease was. Following my research, I moved to Southampton as a registrar to complete my clinical training. My

“I KNEW WHEN I’D FINISHED MY TRAINING I WANTED TO RUN A CLINIC FOR PEOPLE WITH PSP & CBD.”

earlier experience with PSP patients stayed with me and I knew when I’d finished my training I wanted to run a clinic for people with PSP & CBD.

“Once I became a consultant, I set up a monthly clinic in my own time where colleagues could seek advice when treating and caring for people with PSP & CBD. After running this for a year, it was obvious that there was huge demand, but I couldn’t run a big clinic on my own. Luckily Dr Luke Massey, a consultant neurologist at Poole and Dorchester hospital, had been asked by his Trust to set up a specialist service. Luke contacted me and we agreed to hold clinics for PSP & CBD.

“While setting up the clinic we informed PSPA’s Local Group. Word soon got around and within six months we were at full capacity. As the clinic became more established, we secured agreement for a clinical coordinator to help us. In setting up the clinic there were lots of models we could have followed. In London, patients have in the past seen a speech and language therapist, dietitian and physiotherapist all in one visit. Here, we needed a different model because our patients come from a wide area. We therefore designed our clinic to interact more closely with the local therapists and palliative care team so that they have access to local support.

“Through the clinic we want to invigorate other professionals’ interest in PSP & CBD to improve their care. For example, if we can secure interest from professionals like ophthalmologists, we can encourage

them to change from feeling there is not a lot they can do, to finding more innovative ways to help people.

“Patients often tell me that they find it hard dealing with professionals who have no idea what PSP & CBD are. The benefit of our service is that not only do we know about PSP & CBD, but we are able to be proactive about what we can do to help patients and what decisions they may have to think about in the near future.

“This proactive approach to care makes a big difference to patients and their families, and keeps people out of hospital and at home, where they want to be. Patients may come to clinic and mention that they cough when they take a drink. Rather than waiting for it to get worse, we will ask the speech and language therapist for a baseline assessment. Once we have that, we can quickly identify if the situation changes and be proactive about managing the symptoms. This then helps to prevent the patient choking, or being admitted to hospital because they can’t swallow.

“Being proactive means we can have early conversations about important issues. This is important, because later on the patient may find it hard to tell us what they want. For example, we suggest patients get to know the palliative care team early so that the patient and their family know them if they need them later. Another example would be equipment like wheelchairs and stair lifts which take a long-time to source. If we can talk to



the physiotherapist or occupational therapist about equipment before the patient needs it. It means the whole service can provide seamless care when the patient feels they do need extra support.

“While this idea of coordinated multidisciplinary care seems to make sense, there is no research evidence that it provides benefits for patients or the health service. Unfortunately, if there is no evidence then it is very difficult to persuade the NHS to provide this care around the country. As a result, I am looking for funding to carry out research into this type of clinic and care. If I can prove the advantages, then it would be much easier to ask for NICE guidance on PSP & CBD, meaning all patients, wherever they live in the country, would be able to access this type of care.

“We do have some initial information that shows the benefits of coordinated, multidisciplinary care to patients with PSP & CBD. Following the appointment of our clinic coordinator, we undertook a service evaluation by asking patients with PSP to rate their quality of life. Despite their condition worsening, patients reported no worsening of their quality of life. This suggests that this type of coordinated care may help improve or maintain a patient’s quality of life. However, this information is only in small numbers of patients and I would like to get much more rigorous information. In addition, I would like to investigate resource utilisation. How often do patients with PSP & CBD see their GP? Are paramedics repeatedly being

called out because of falls? How many emergency admissions are there? In the NHS, you have to prove financial benefit. I want to show that by being proactive we can reduce emergency admissions.

“There is a lot of opportunity for local groups to get involved and support this type of work. They can help inform and educate local professionals, but also, they could potentially get involved in any future research by doing questionnaires with people living with PSP & CBD. More information means more chance to change the way services are run.

“When I first started there were very few medical conferences about PSP or CBD. Very little was invested in research and there were no clinical trials. This situation has dramatically changed. We have seen a marked increase in specialist centres, many of whom are actively involved in drug trials, offering the hope of slowing down the disease. Research into PSP & CBD is accelerating, and many young researchers are now looking to specialise in this area. More geriatricians are interested and are now actively looking at how best to support patients. Just recently two consultants contacted me who want to set up specialist clinics. This shows a growing focus on both supporting people with PSP & CBD, and tackling the symptoms of the diseases. There is still a lot of work to do, but with the growing interest in PSP & CBD, I am hopeful that in the coming years treatments will be found to help slow progression.”



DEVELOPING OUR SERVICES WITH HELP FROM PEOPLE WHO MATTER THE MOST

It is vital we involve people living with PSP & CBD, their carers, families and friends in how we develop our information and support services. Local Groups provide the ideal place to get people's thoughts and over the past few months, Director of Engagement, Carol Amirghiasvand, has attended a number of meetings around the country.

Carol said: "Being able to ask people who are experiencing and living with PSP & CBD for their ideas on how we can develop our services is really important. I have gained so many ideas and insights from the meetings I've attended so far and I'm very grateful to everyone who contributed to the discussions."

Carol attended the Hertfordshire Local Group to ask for opinions on our new Lay Guide for CBD. Suggestions were put forward regarding a title for the booklet, layout and what people thought should or should not be included in it. Feedback from the group will be used to inform the development of this new resource.

Existing resources were also discussed, including *Your Personal Guide to PSP*. Due for review, the group discussed how the resource could be developed, including different formats to make it more user friendly.

At the Northampton Local Group, Carol discussed our Volunteering Service. We offer a number of services supported by volunteers, so it is important we provide what people find most helpful. The group spoke about the importance of being able to attend a Local Group and how much they enjoyed meeting others and sharing information and advice. The group were asked what would have made their journey with PSP or CBD easier with regards to support and Carol was able to take away a number of suggestions put forward.

Carol said: "We want to really develop how we involve people affected by PSP & CBD in our work. We would like to start a database of people who could occasionally offer just a couple of hours, to be involved in future PSPA projects.

"This could include either attending focus groups, taking part in individual user testing, local awareness raising or other work PSPA may be doing. It would be an ideal opportunity to get involved and does not require the commitment of regular volunteering. I'd love to speak to anyone willing to be involved in this and become one of our new micro volunteers."

If interested, please contact Carol on **01327 356137** or email **volunteering@pspassociation.org.uk**



SHORT FILM AND PLAY FOCUSES ON THE IMPACT OF PSP

Since her Nana died of PSP, Freya Hannan-Mills, 15 has been determined to raise awareness of the condition through writing. Freya has now created a new play, *Swallow*, based on her experiences of living with and caring for her Nana, Margaret.

As previously reported in *PSP Matters*, the play started out as a piece for Jude Law to perform at the Lyric Hammersmith Gala. It has since been developed into both a full length piece and a short film.

Freya said: "I feel really strongly that carers in this country are marginalised, having lived with PSP and witnessed its consequences on my family, it was something I really wanted to explore dramatically."

An extract from *Swallow* was performed by Olivier award winning actress Denise Gough at the Everyman Theatre, Liverpool before premiering at the Tristan Bates Theatre in Covent Garden. The play centres on Paula, a single mum who is looking after her own mum and her daughter, it explores Paula's feeling of guilt, exhaustion and isolation as she tries to

keep it all together with little outside support. It isn't all doom and gloom though as the family share stories and we see their close bonds.

Freya is thrilled that *Swallow* has also been filmed with direction by Ethan Graham and has been entered for the Cannes Festival 2019. "I feel incredibly lucky that it is a story that has resonated with people and that so many fantastic actors such as Jude Law and Denise Gough have worked with me on it. I try to tell everyone I can about PSP as I understand how important it is to bring greater understanding of the illness. My thoughts are with everyone who is currently dealing with it, I think you are all warriors."

To see updates on *Swallow* and upcoming performances visit Freya's website at freyahm.com



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Registered charity number No.
England and Wales 1037087, Scotland SCO41199



LIVING WITH CORTICOBASAL DEGENERATION

CBD: what to expect from your care



**STARTS
CARE HERE**

CBD: WHAT TO EXPECT FROM YOUR CARE

As part of our plans to improve information resources available to people affected by CBD, we are launching a new publication: Living with Corticobasal Degeneration -CBD: what to expect from your care. This publication closely follows the launch earlier this year of our Professionals Guide to CBD and Red Flags for CBD.

Carol Amirghiasvand, Director of Engagement explained: "We've always supported people living with CBD, but have never had information specific to the condition. We have tended to put CBD under the same 'umbrella' as PSP and we know that this sometimes was frustrating for people living with CBD. So this is the start of us making sure we recognise how important it is to talk about it as a separate condition and when we produce new information now, we talk about PSP & CBD and not just PSP."

With the help of those affected by CBD, we developed the new pocket-sized guide. The booklet will help

those with the condition have open discussions about their care with health and social care providers and gain better outcomes at appointments. It will also help people access suitable support at the right time. It could also be shared with others to raise awareness of CBD.

The guide is the ideal size to be carried in your pocket, wallet or purse and is available in printed format as well as on-line <http://tiny.cc/feq45y>

To order your copy please contact the helpline.

Telephone: 0300 0110 122

Email: helpline@pspassociation.org.uk



YOUR FUNDRAISER, YOUR WAY

Throughout the year, our amazing fundraisers are taking part in national fundraising events by running, cycling, hiking or walking to raise money for PSPA. But what about the ones who don't want to do something quite so physical, or want to fundraise 'their own way'? Thankfully #TeamPSPA is a diverse bunch and we have seen growing numbers of people, personally affected by PSP & CBD, use their own interests and talents to raise funds. From masquerade balls, to bake sales many of our #TeamPSPA heroes have created their own fundraising events.

Organising your own event can be a great way to support PSPA and our fundraising team are on hand to help you plan your fundraiser, your way. The first step is to decide what you fancy doing. Almost anything you enjoy can be turned into a great fundraiser. Perhaps you are a keen runner, or maybe baking is more your thing. You may want to take on a personal

challenge and push yourself to achieve something you never thought possible.

Sally Whitaker and husband Sam, held a quiz night, with interval games of 'sit down bingo' and 'heads & tails'. The evening finished off with a raffle with prizes donated by local businesses. The couple

wanted to do something because Sam's dad, Tony, had PSP. Speaking about his motivations for raising money Sam said: "PSP is incredibly rare and any funds raised will go a long way to researching and better understanding the condition." The couple have raised nearly £1,700, an amazing amount!

Georgie Irwin, and her mum Denise Hunt, decided to 'Drink Tea for PSP'. Georgie's nanny, Joyce, was diagnosed with PSP in 2018. They are fundraising, and raising awareness, in the hopes of limiting the misdiagnosis of PSP & CBD. Their full day of baking paid off, with a fantastic £620 raised by their tea drinking supporters. Georgie said: "We really wanted to put on an event my nan could be part of. That's where the 'Drink Tea for PSP' idea was born! It was a wonderful day which people of any age could get involved with and I was utterly blown away by the kindness shown on the day. From raffle prizes, to delicious bakes and generous cash donations, it really boosted my fundraising total and motivation."

George Findley and Liza Reekie hosted their own running event, with over 60 runners taking part. With bespoke medals donated for the event, and sponsorships by local companies, it was an event on a big scale and the perfect example of a community coming together! George said: "It was wonderful so many companies supported us and helped us to raise not just money, but also awareness of PSP. The run was in memory of Liza's dad Ian Burrell and my cousin Lil Gimmetstad. We are delighted to raise over £600 to invest in research."



GEORGIE IRWIN AND HER NAN, JOYCE

IDEAS FOR FUN FUNDRAISERS

Coffee Morning

Simple idea that will get everyone buzzing

Quiz Night

There's no right or wrong answer here – everyone loves a good quiz

BBQ

This will definitely make your fundraising sizzle

Afternoon Tea

Pour a cup of tea, for PSP & CBD

Dress down at work

Easy money maker

Bake Off

Soggy bottom or not, it's the tastiest fundraiser

Tee off

Get in the fundraising swing! Golf days are one of the most lucrative fundraisers

Fundraising evening

Bigger commitment, but well worth it

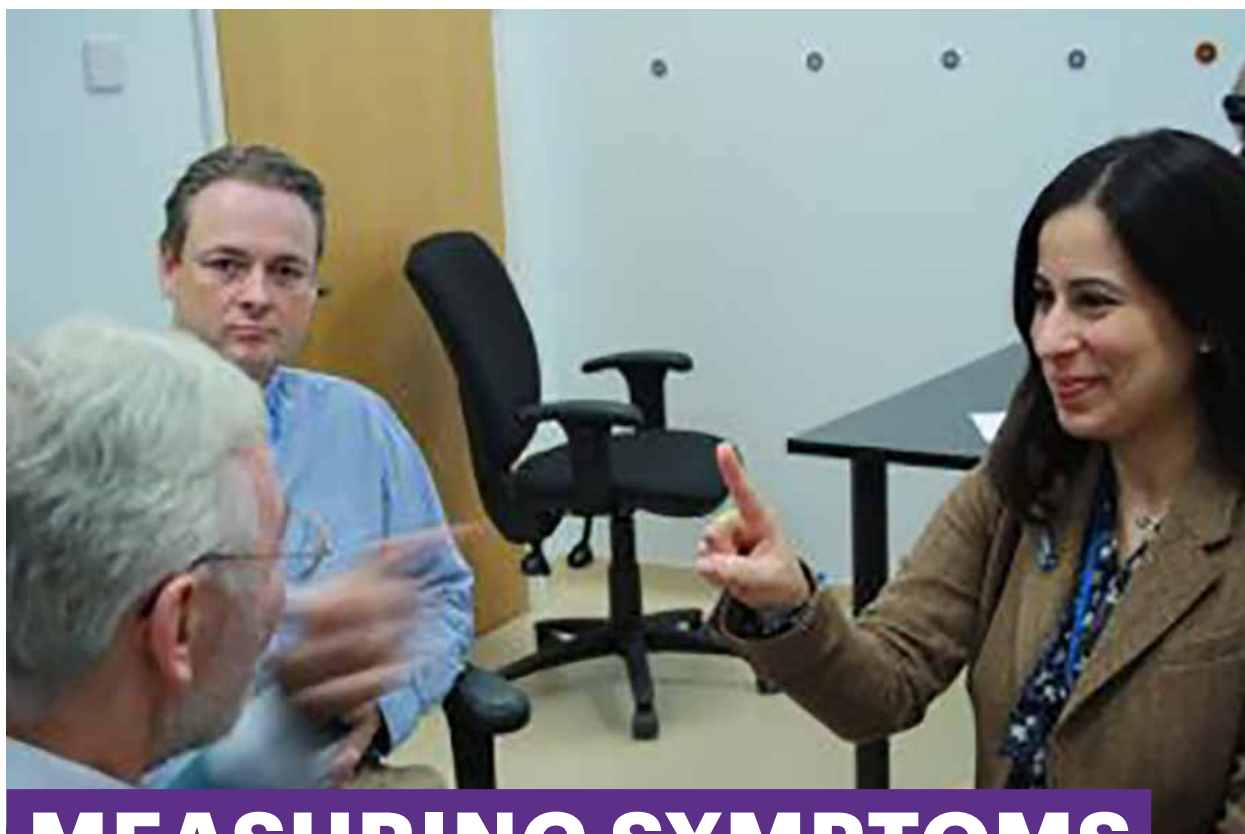


CONTACT OUR FRIENDLY FUNDRAISING TEAM

Don't forget that we are here to help you with your fundraiser. We can help to generate ideas for fundraisers, and how best to plan them. We will also send you our handy fundraising pack, along with some merchandise, to get you ready for the big event! Contact a member of our fundraising team now on **01327 356132** or **events@pspassociation.org.uk**



GEORGE FINDLEY AND LIZA REEKIE AT THEIR RUNNING EVENT



MEASURING SYMPTOMS

Associate Professor Chrystalina Antoniades is leading a study at Oxford University to develop new ways of measuring PSP symptoms, so that when new drugs are tested their effectiveness can be accurately assessed. Dr Antoniades decided to do this study after first coming into contact with people with PSP and realising how little we knew about their progression, and how hard it can be to accurately identify people at the early stages of the disease.



"I wanted to set up a trial to very closely follow people for a long period of time. When I was at Cambridge University, I was fascinated how people with PSP looked so different at the later stages of the disease, yet at the beginning

they looked the same as people with Parkinson's, with the only notable difference being eye movement.

"I remember talking to colleagues about how little we knew about eye movement abnormalities. Parkinson's and PSP patients looked the same, but once you looked closer and asked them to follow a pen with their eyes, I realised the differences were quite large. When I moved to Oxford University I was given the

opportunity to pursue my own interests and set up my own research group within the Nuffield Department of Clinical Neurosciences. When I received funding from UCB, a pharmaceutical company, I started my study to measure PSP symptoms.

"From the very first day I got in touch with PSPA, I have received nothing but support. I know the charity is very small, so I am especially grateful. The charity clearly prioritise research and have helped enormously with recruitment to OxQUIP.

"Treatments available for people with PSP can only help manage symptoms and there is nothing currently preventative or disease slowing. However, there has been a dramatic increase in the number of new clinical trials in PSP and this is very encouraging.



When new drugs are developed we need to assess them quickly and be able to rapidly identify the ones with the most promise. We can only do this by understanding how the disease progresses and by having a standardised way of measuring symptoms. For future clinical trials we would like to be able to use our progression markers to see the impact drugs are having on patients.

“We are following patients for three years at a first instance and will identify measures to mark their disease progression. We ask patients to perform simple tasks to measure the movement of their hands, eyes and body. Advances in technology are making a big difference in our ability to track and measure progression and we are working with two companies in the States who are using their technology on people with PSP for the first time.

“Patients are asked to do a number of tasks on a tablet to measure their cognitive performance. This replaces the previous approach where a researcher interprets the patient’s cognitive performance themselves. The benefits of using the new technology is it totally remove any subjective bias by the researcher, and the results will be directly managed against standard clinical scales.

“We ask patients to come for two hours, every three months, so it is quite a commitment from them. We



always aim to take our time in case people get tired. The feedback we receive shows that people actually enjoy attending and it helps them to do something positive. They are aware this research may not help them, but it may help those who are diagnosed with PSP in the future.

“PSP may be a rare disease but it shares many areas similar to dementia or Alzheimer’s, so if you have a disorder like PSP, you can learn a lot about the accumulation of the tau protein that can be applied to Alzheimer’s. Therefore, researchers are not just investing in PSP, but also a condition like Alzheimer’s that affects many hundreds of thousands of people.

“We are now at the stage where we are starting to analyse our data from the last couple of years. Analysing this volume of data will take around six months, and then we will be publishing our results in peer-reviewed journals. Once the results have been published, we will be sharing our findings with everyone who took part in the study and will be freely sharing our findings on our website, always anonymously.

We are hopeful that the results will help pharmaceutical companies to design future trials. They will be able to measure the effectiveness of the drugs they are testing by using our biomarkers, thereby directly seeing how the drugs are affecting patients.

“WE ARE HOPEFULL THE RESULTS WILL HELP PHARMACEUTICAL COMPANIES TO DESIGN FUTURE TRIALS.”

MAREN AND HER HUSBAND, CHRIS



A SECOND CHANCE

For Maren Wilmott-Borberg and her ex-husband Chris, a diagnosis of PSP rekindled their love for each other. They spent Chris' last two years together, where Maren cared for him until the very end. Maren talks about how PSP brought them back together and what she has learnt from caring for Chris.

Maren said: "By nature and having served as an officer in the Royal Air Force, my husband Chris was a very disciplined man. He was a fiercely critical and independent thinker, with a deep love for literature which he taught at one of the London Colleges after he left the Air Force. We had three children and were together 13 years until our marriage ended. Despite the divorce, we were still very much a family and when his work allowed it, Chris stayed nearby so he could be around for the children.

"Chris was not a drinker, but one day watching him walk up the hill, I honestly thought he must have had a drink or two. His gait looked so strange. Something else the children and I noticed was the uncontrollable laugh. It was child-like, and certainly not at all like Chris. He began to have frequent falls which became very concerning. Chris was also disciplined with food, yet, contrary to his life-long aversion to sweet things, he developed a taste for them and would also eat anything put in front of him to the last crumb. These changes were so weird. Eventually he had a

consultant appointment and an MRI. Then he was confronted with the diagnosis of PSP.

"He had attended the appointment with one of our daughters, but uncharacteristically he called me within the hour of having been diagnosed, telling me that while all life has to come to an end, he never thought it would end this way. He was rather shocked. We all were. At the time he was living by himself.

"The children decided we should take turns to cook for him in the evening. I did my fair share and absolutely loved it. About a month later, he was at the point where he needed someone to be with him during mealtimes, so I started to take his daily lunches over until someone was found to do the job 'professionally'. Fortunately no one was found. It was a beautiful time in my life and there was nowhere else I would rather be.

"We got close and our new relationship started from there. One of our daughters had started to build a

flat for Chris in her basement. But, you can't build in a hurry and PSP won't wait. I have a large Victorian house, with wide corridors that accommodates a wheelchair easily. It made sense for Chris to move in with me while the flat was being built.

"Two days after moving in, Chris announced he didn't ever want to leave. The build on the flat stopped and Chris remained at home with me until the end. He was so happy here and we discovered a lot of joy in adversity. Every moment we looked forward to seeing each other. A newly discovered love, this time on a different level, deeper than ever, yet still based in the past and intensified in the present.

"I became Chris' main carer. We were fortunate that all our children live close by. I was greatly helped by our children who were always around. Each in their own way comforted Chris.

"Our children cared so much for Chris and would encourage him strongly, for example, not to eat toast anymore for fear of him choking and couldn't believe that I would let him. When he asked the consultant he was told, 'you have full capacity and you know the consequences. If that is what you want to do, do it.' Chris did want to do just that and smirked every time toast was put in front of him. He never did choke, and he gave up toast of his own accord, when he no longer felt able to tolerate it.

"In the beginning, I was at my wits' end trying to find information on PSP. We didn't know who to contact for help. We could not travel to the mainland to join any groups. So I rang PSPA and asked 'what do I do about this and that and the other?' The helpline was fabulous. Two days later a Parkinson's Nurse appeared on our door step. Finally, we were getting information and support. It made a big difference.

"Despite PSP, life was lovely. We both decided to get married again and for Chris to know that he had my undivided love, care and commitment. Equally I felt in a strange way cared for and protected. We married at our home in November 2017 and Chris died May 2018. I wished we had had a little longer together. I wish I could have cared for him longer. I loved being there for him and he loved that I was there. There was not one moment where I resented the 'work', rolled my eyes or sighed because he rang the bell again. I knew minute by minute what he needed/wanted and what would make him more comfortable. So often we laughed and giggled our way through the day. We had such a sense of togetherness and trust.

"The sudden death of my beloved sister shook us both. When I returned after a few days from her funeral in Germany, I could see how much Chris had deteriorated. Within five days he died. When I returned, I looked at him and put my head down in front of his eyes, he smiled and despite his right hand being useless, he pulled it from under mine with all the strength he could master and placed it on top. I can feel it today. That was the last loving gesture between us. He was not able to respond anymore. Chris wanted to die at home. We wanted to respect his wishes, but I would advise people to find out what dying at home can mean and how it will work.

"Sadly, by the time a Local Group was established on the Isle of Wight, Chris was unable to attend. I went alone and was saddened to see younger people in the same situation as Chris. At the same time, I have never before met such a wonderful, caring, supportive group of people. There is no personal agenda – just friendship and support. I instantly felt at home with them.

"My advice to people with PSP and their families is to 'please push for everything you need'. With PSP you don't have the luxury of time. We know how stretched our NHS is, but when Chris had been measured for a bespoke wheelchair it took eight months. He finally received it just two weeks before he died. Needless to say that he refused it.

"My PSP life with Chris was full of love, fun, banter and laughter and the occasional crying together. I became his voice. I fought for Chris. Chris' mind was as sharp as ever, but he could not speak anymore. Anyone who loves someone who is dying, needs to fight for their rights. Chris had faith in me and we had faith and trust in one another."

"There were also times when outside forces could make Chris' life more uncomfortable than was necessary. He endured carers who were not trained at all, never mind 'end of life' caring. He experienced times in which 'caring' was far from 'dignified'. One carer refused to leave me alone with Chris in his room. She also objected to us speaking German together. Even noted it in her daily journal "Maren has spoken to Chris in German again!" Chris and I have ALWAYS spoken German together. It was HIS wish. Small in comparison, but in Chris' and my life these objections zoomed large. However, the blessings outweighed some of the negative caring aspects. This is a different chapter and I am fighting for the rights of others now."



THOUGHTS OF LOVED ONES PUSH #TEAMPSPA ACROSS THE FINISH LINE

Seventy four runners took part in the London Marathon to raise money for PSPA. Many managed to get a personal best, most had personal experience of PSP or CBD, and all crossed the finish line.

The London Marathon is a big fundraiser for PSPA. Last year it raised £157,000 for the charity and we hope this year will do the same. While some of our runners like Gary Walker (who clocked in at an impressive time of 3 hours and 6 minutes) our experienced marathon runners, a large number had never run before. It was seeing the devastation caused by PSP or CBD that motivated them to put on trainers and build up the miles in their legs.



Self-described running novice Jess Martin describes how she previously wouldn't even run for a bus, but then her gran's death from PSP motivated her to do something in her memory. Jess said: "Two years ago, my gran sadly died from PSP. It was horrible to see her deteriorate and to see the symptoms of PSP - from struggling to keep her balance, to struggling to swallow food.

"At first, I kept thinking she'd get better. When she died the hurt, upset and shock I felt was something that I will never be able to explain. My gran was my rock. It was hard to lose her. After she passed away, I kept thinking how can I spread what PSP is about and do something so that people don't have to go through what I went through? That is when it hit me. I will run the London Marathon in aid of PSPA. As a running novice, I'd never even ran for the bus. I was nervous but I felt good about making Gran proud."

To help keep Georgie Irwin's spirits up during the marathon, mum Denise Hunt recorded a number of supportive messages from family and friends, including from Georgie's gran who is living with PSP. Before the marathon Georgie could hardly run. Georgie said: "I am a self-confessed non-runner and six months ago I could barely run for 10 minutes! But watching my mum's strength as she strives for greater awareness of PSP inspired me to go big and when the opportunity presented itself I didn't hesitate to take it. I was proud to wear my PSPA vest

with pride across 26.2 miles of London. Hearing my Nan's voice as I headed for the start line put the 26.2 miles into perspective for me - a timely reminder that the challenge ahead was nothing compared to the thousands being diagnosed with PSP every year. It gave me the extra push I needed to run for her and all the other families living with PSP & CBD."

Paul Farrell decided to run in memory of his gran, who died from PSP 12 years ago. Paul said: "Around four years ago I ran the bath half marathon with my mum for PSPA. We raised £1,000 and I set the London Marathon as my next ambition. So far £3,000 has been raised which feels good.

"The marathon was as hard as it gets and I'm still walking down the stairs like I'm drunk, but it was an amazing experience and the PSPA cheering point at Tower Bridge was a highlight. I'll also always remember the welcome to the reception as I collapsed onto a chair grabbing a Mars bar."

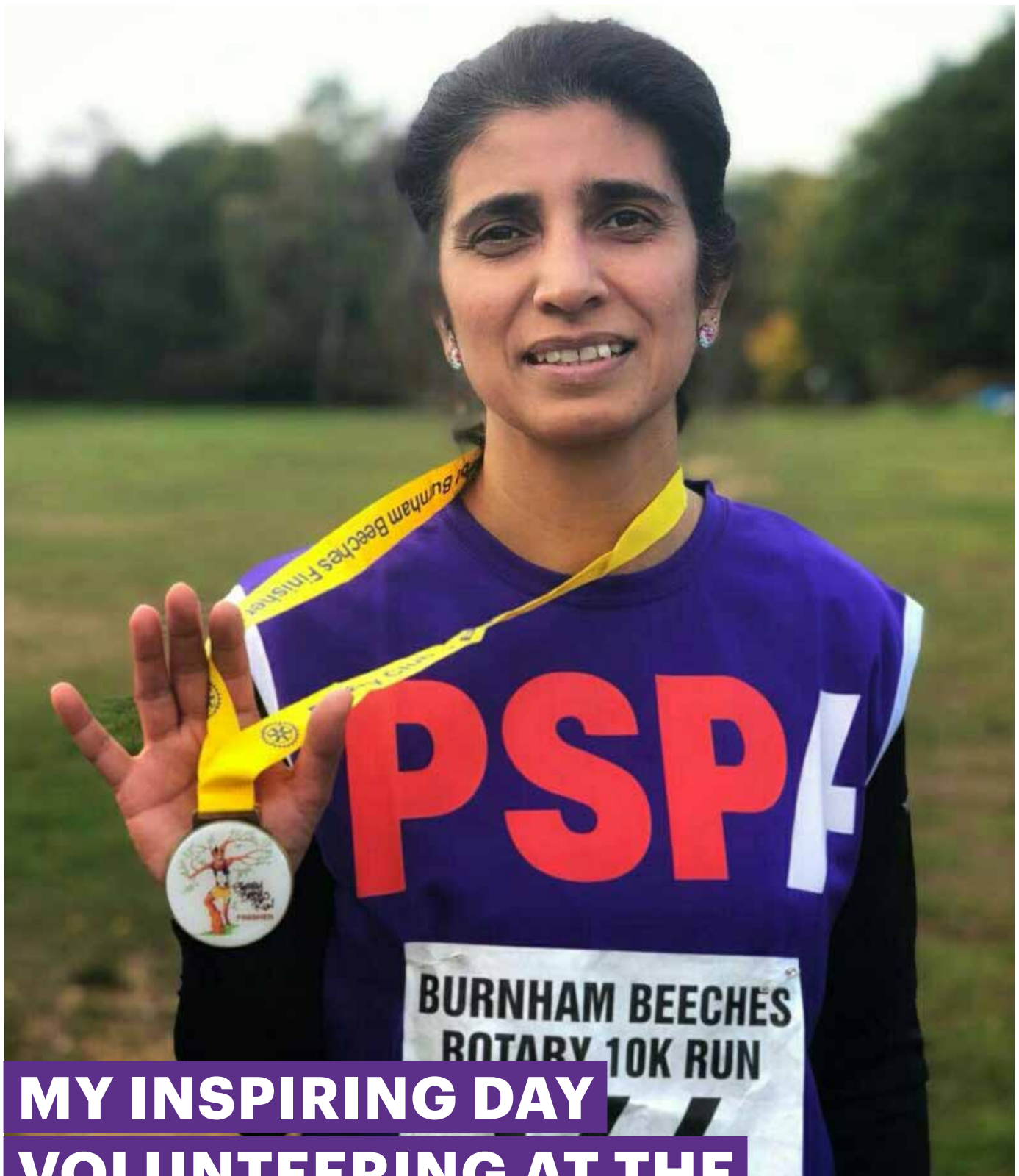
Thank you to all the amazing runners who trained through the long winter months and raised so much money for PSPA. We are hugely grateful. Our special thanks also go to the amazing volunteers who stood at our two cheer points, and reception, to cheer our runners across the finish line.

FEELING INSPIRED?

You can be part of this amazing event for next year. You have two chances to apply for the 2020 London Marathon.

Visit **ballot.virginmoneylondonmarathon.com** to apply via the official public ballot, if you get a place via this route, you can still run for the PSPA and it means we can maximise the numbers of runners. To apply direct visit **pspassociation.org.uk/events-list/london-marathon-2020** or contact **events@pspassociation.org.uk** or call **01327 356132**.





MY INSPIRING DAY VOLUNTEERING AT THE LONDON MARATHON

Volunteer and #TeamPSPA member Eram Osman gives an insight on what it is like volunteering at our biggest fundraising event, the London Marathon.

"I woke up early, with a sense of excitement, as well as nervousness. This was going to be my first experience of volunteering for PSPA. I have a keen interest in running and to honour my mum's memory, I wanted to support everyone who was running for #TeamPSPA at the London Marathon.

"I arrived at Carlton House Terrace, a beautiful and historic building near the finishing line, and was greeted by PSPA's fundraising team.

"Everything was so well organised, and all the volunteers were really friendly. We worked together to get everything ready: balloons had to be filled with helium and tied with ribbon, all the tables in the eating area were dressed with PSPA balloons and brochures. The upstairs hallway and lounge areas were branded with merchandise, and the central banisters and stairs were decorated with bunting and balloons. Carlton House was ready for the runners and their families.

"Just after midday, we had a debrief and everyone was given a role: some of the volunteers went to Tower Hill to cheer the runners on, others were asked to greet the runners at the finishing line and bring them up to street level. I was stationed at the top of the steps and had the job of escorting the runners to Carlton House. The hallway entrance was lined with volunteers with banners and whistles to welcome home the runners. We all swapped positions throughout the day to make sure everyone got a rest and didn't have to stay in the same place for too long.

"While I was waiting for runners in the entrance hall, I was honoured to meet Michael Koe, the founder of PSPA. We had a lovely chat and it was emotional for me, because this was the first time I had encountered other people who were directly affected by PSP.

"I met so many interesting people from PSPA and learnt a lot about the charity. Cameron, the Director of Development, explained about the research and how PSPA works with other organisations across Europe and America, and I was delighted to hear about the positive progress that is being made. I spoke to the chair, Simon Koe, about his role. He explained about the early days when his father set up the charity, how family and friends supported it, and how he ran the London Marathon to raise money. We spoke about marketing and rebranding, and how PSPA will grow and become a stronger charity in 2019. In the afternoon, I learnt about the Helpline and how calls have increased in the past few years. I heard how the team support people with PSP, CBD and their carers.

"At around 2.30 pm, the first runners started to cross the finish line and make their way over — it was so exciting to see them coming up the stairs! I've never done a marathon so I don't know what it feels like, but you could clearly see their joy and pain — it was certainly an amazing achievement.

"I spoke to one of the runners whose father had recently passed away and it was hard, because I could relate to every word he said. On the other hand, it was lovely to see so many families together and for the runners to have somewhere to sit and recharge in a beautiful environment.

"As the day drew to a close around 5.30pm, the volunteers started to clear up and take down all the balloons, bunting and pack away all the stands, posters and brochures. It was time to say goodbye to everyone I had met. As I walked to the underground station, the whole day unfolded in my mind. There was so much energy and positivity throughout the whole day. It was a day of learning and taking an interest in what PSPA does and what its goals are and how I can do my bit to help.

"Sadly, I became aware of PSPA when my mum was diagnosed in 2008. In my experience, getting involved in a charity for personal reasons can only magnify your passion and enthusiasm. All you want to do is make a difference, and that difference can only be achieved working as a team with others who share the same passion.

The more I get involved with PSPA, the more I realise that while too many people are going through what my family and I went through, so many people are doing something about it by raising awareness and money for vital research and above all trying to be positive. I really loved volunteering and I'm going to do it again next year. It's a very long and tiring day, but it's definitely worth making the effort to get involved."

"GETTING INVOLVED IN A CHARITY FOR PERSONAL REASONS CAN ONLY MAGNIFY YOUR PASSION."



PSP & CBD AWARENESS WEEK CAMPAIGN FOCUSES ON MAKING OUR VOICE LOUDER

PSP & CBD have been ignored for too long. During PSP & CBD Awareness Week on 20 – 26 May 2019 we aimed to #Unmute these devastating diseases. With your help, we launched our #Unmute campaign to create a movement across social media during the week, to raise awareness and focus attention on PSP & CBD.

Sadly we know most people, including healthcare professionals, are not aware of PSP & CBD. We know many of you are frustrated at the lack of awareness they face on a daily basis. PSP & CBD have been ignored for too long. Our #Unmute campaign, for PSP & CBD Awareness Week focused on making noise about these silent diseases.

As part of the campaign, we asked everyone in our PSP & CBD community to take a short, selfie shout video on their phone to share across their own social media accounts, tagging @PSPAAssociation and use the hashtag #Unmute during PSP & CBD Awareness Week.

Last year, in London a small but powerful group of people affected by PSP & CBD came together to make their own selfie film as part of the campaign. Each had their own personal reasons for travelling to London that day, and for doing their bit to raise awareness. Amy Silver's dad is living with PSP. Amy has done some fundraising for the charity and is passionate

about raising awareness. Amy said: "I felt inspired by the #Unmute campaign and knew I needed to get involved, due to the importance of getting knowledge of PSP out into the world as nobody knows what it is.....this included myself until my dad was diagnosed!

"When your loved one gets diagnosed with PSP, slowly, but, surely your whole world changes, but, the world around us doesn't as it knows nothing about PSP. This is why we need to get it out there as much as humanly possible. The thing that worries me most is the misdiagnosis that many people receive as even GPs don't know enough about it.

"I'm hoping that the more people know about PSP & PSPA, more fundraising will take place which will allow more support for families, more research and eventually possible treatments. We all need to get on board to help change this and social media is the easiest and most effective way of doing so.

"Taking part in the filming was very daunting as I've never done anything like it before, but, I was made to feel so welcome and at ease, I actually enjoyed the experience. It was lovely to meet people involved in PSPA and other people in similar situations, along with others that out of the kindness of their hearts just want to help even though they aren't directly affected by

a family member suffering from this horrible disease. PSP is heartbreaking for all involved."

Sisters Purvi Patal and Sheetal Rush wanted to get involved following their dad's diagnosis of PSP. Purvi said: "My father has PSP and I wanted to help raise awareness. There are very few people who understand and have knowledge about the condition, making it even more important to bring attention to it."

Sheetal added: "PSP has been silent for too long and we need to #Unmute it. I've been personally moved by everyone I have met within the PSP community. It's important to raise awareness so that other families like ours know where to go for information and support."

Craig Bell's gran died of CBD. Craig and his fiancé Hannah Daykin, travelled down from Wigan to be part of the filming. Craig said: "When my gran was diagnosed with CBD no one had a clue what it was. She had to see several professionals. She was even told by one that she'd be walking and on her holidays again in no time. They had no idea what it was. That's why I want to raise awareness and give something back to the charity that really helped her out in her time of need."

Talking about the day, Hannah, whose dad died of PSP said: "Although it was a strange experience and Craig and I were both out of our comfort zones, it was great to be able to be part of the new campaign. And to do it together was brilliant, as before, we were two separate families doing our bit for PSPA, but coming together our voice is much louder!"

Lucy Peers' dad is living with PSP. Lucy said: "It was great to see so much enthusiasm and activity to raise awareness of PSP & CBD That, and meeting others who have had similar experiences, made me feel less isolated and more positive about what we can do to fight against it. It really is a horrible condition and I'll do whatever I can to help (even if that involves shouting into a camera which was hugely uncomfortable for me!)."



AMY SILVER

CRAIG BELL AND
HANNAH DAYKIN

PURVI PATAL AND SHEETAL RUSH



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