

PSPA



YOUR #TEAMPSPA FUNDRAISING GUIDE

Join our fight against
PSP & CBD

HOPE *STARTS*
HERE

THANK YOU

FOR CHOOSING TO SUPPORT OUR VITAL WORK

TOGETHER WE ARE

- Supporting individuals and families living with PSP & CBD.
- Educating health and social care professionals aiding earlier diagnosis and better care.
- Advancing research into treatments that can stop the progression of PSP & CBD in its tracks.

Whether you've chosen to walk, run, cycle, sail, bake, make or host a gala dinner, your support is invaluable to our fight against PSP & CBD.

We know organising an event, training for a challenge and raising awareness of PSP & CBD takes a lot of time and effort. That's why we've created this guide to help give you the inspiration, tips and information you need to make your fundraising easy, and more importantly, a success.

We wish you the best of luck with your fundraising and look forward to supporting you along the way.



Your PSPA Fundraising Team



DAD CAN'T RIDE HIS BIKE NOW, BUT I CAN!

Karen Davies and her friend Tracy Hughes joined #TeamPSPA for Ride London in August 2019. Together they raised more than £2,684 including Gift Aid for PSPA.

"Dad was a fit and active man in his late 60s, enjoying riding his bike, walking and gardening. Then he started to fall over. In fact, one of the early signs of dad's PSP was him falling off his bike on a family bike ride.

"Dad can't ride his bike now but I can, which is why I decided to ride the 100 miles of Ride London with my friend Tracy. Neither of us had ridden before so we were out riding at 7am most weekends, finding new coffee shops to cycle to in South Wales and cycling up lots of steep climbs to prepare us for making it up Box Hill and Leith Hill. On the day we were worried about being caught by the sweeper if we rode too slowly, but with the excitement and the wide flat traffic free roads, we rode much faster than usual, so had nothing to fear. The support along the route was amazing and having got swept along the wave, we were over the finish line in what felt like no time."

"If anyone is thinking about doing Ride London but is feeling nervous about their cycling ability, just go for it. With a bit of determination and training, you'll smash it!"

HOW YOUR MONEY WILL HELP FIGHT PSP & CBD

Everything we do is funded by donations and fundraising activities undertaken by people like you.

THANKS TO #TEAMPSPA WE HAVE BEEN ABLE TO...

Provide emotional and practical support to approximately 5000 people via our Helpline

Launch the PSPA Support Grant service to help improve peoples' quality of life

Learn more about PSP & CBD by promoting and funding research



Here's just a few examples of how your fundraising will help to fund our work and deliver on our promise for the right care today and the cure tomorrow.

£25
Could cover the cost of a GP Guide to PSP & CBD and Red Flag posters for a local surgery, aiding faster, more accurate diagnosis and encouraging referrals to specialist neurologists

£250
Could provide a grant to someone living with PSP or CBD for equipment that will improve their quality of life

£100
Could go towards funding a Family & Friends Day for people living with PSP & CBD ensuring they know they are not facing the disease alone

£1000
Could enable researchers to analyse research data to help us better understand PSP & CBD and how they progress

I REALLY APPRECIATED, AND ALWAYS WILL, THE GUIDANCE I GOT FROM PSPA'S HELPLINE WHEN MY DAD WAS DIAGNOSED WITH CBD. IT WAS A WORLD I DIDN'T KNOW ANYTHING ABOUT BUT VERY QUICKLY NEEDED TO DO SO. THANK YOU FOR THE SUPPORT YOU PROVIDE. SUZANNE

RED FLAGS FOR PROGRESSIVE SUPRANUCLEAR PALSY (PSP)



PSP is a terminal degenerative neurological condition.

The difficulty in diagnosing PSP has led to the creation of red flags to act as warning signs that may raise clinical suspicion of PSP.

Think about PSP when seeing patients diagnosed with movement disorders e.g. Parkinson's disease, where there has been a poor response to Levodopa, more rapid progression of symptoms and the development of clinical features not seen in Parkinson's disease.

PSP – what to look for in a patient consultation:

- | | |
|---------------------------|--|
| 1 Falls | Often backwards and without warning |
| 2 Postural instability | Axial rigidity, easily loses balance |
| 3 Slowness of movement | Bradykinesia |
| 4 Motor recklessness | Impulsive, despite problems moving |
| 5 Eye problems | Restricted eye movement, up/down. May find it difficult to walk downstairs with down gaze. Reduced blink, double vision, 'glare' |
| 6 Speech | Slurring of speech, gravelly or lower voice and progressive word finding difficulties |
| 7 Swallowing difficulties | Liquids/and or solids, excessive saliva |
| 8 Cognitive changes | Change in personality, irritability, apathy |
| 9 Emotional lability | Appears to cry or laugh even if not upset |
| 10 No presenting tremor | |

If your patient has one or more of these symptoms, please refer to Neurology and state possible PSP in the referral letter.

PSPA Helpline and Information Service
Telephone: 0300 0110 122, Email: helpline@pspassociation.org.uk
www.pspassociation.org.uk



Registered charity numbers: England and Wales 1037087/ Scotland SC041199 Copyright PSP Association 2021

RED FLAGS FOR CORTICOBASAL DEGENERATION (CBD)



CBD is a terminal degenerative neurological condition.

Diagnosing CBD can be difficult, but it is important to get an early accurate diagnosis. There are RED FLAGS to help diagnosis, or for making a referral to a specialist.

Remember to think of CBD in patients diagnosed with Parkinson's Disease, if the illness and treatment response is not typical. Be suspicious of CBD if the patient shows little response to levodopa or who develops extra features below, or worsens rapidly.

CBD – what to look for in a patient consultation:

- | | |
|-------------------------------------|--|
| 1 Highly asymmetric presentation | Which is progressive
One side affected much earlier and worse than the other |
| 2 Apraxia | Clumsy, awkward hands |
| 3 Dystonia | Odd posture of hand, foot, arm or leg |
| 4 Myoclonus | Quick involuntary jerks |
| 5 Alien limb | Reaching or grasping automatically |
| 6 Speech | Slurring or distortion of speech, halting, stuttering |
| 7 Cognitive and behavioural changes | Change in personality, irritability, apathy, low mood, difficulties with organisation and planning |
| 8 Poor response to levodopa | Sinemet, Madopar |

Unlike PSP, patients with CBD are less likely to experience eye or balance symptoms. Problems with swallow can occur, usually in late stage disease.

If your patient has one or more of these symptoms please refer to Neurology and state possible CBD in the referral letter.

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EIGHT TEAMS FROM DIFFERENT UNIVERSITY OF CHESTER DEPARTMENTS TOOK PART IN A GREAT BRITISH BAKE OFF INSPIRED COMPETITION, RAISING £340 FOR PSPA.

Heather Johnson organised the contest with her colleague, Lisa Weaver. Heather said: "I had been keen to do something to raise money for PSPA as the charity has been a great support to my dad since he was diagnosed with CBD several years ago."



I SAW PSPA'S CALL OUT TO HOLD A FUNDRAISING TEA PARTY AND AFTER DISCUSSING IT WITH A COLLEAGUE WE DECIDED TO HOLD A CHESTER GREAT BAKE ON COMPETITION.



MORE THAN 55 PEOPLE, FROM NOVICE BAKERS TO KITCHEN EXPERTS, WIELDED THEIR ROLLING PINS FOR THE COMPETITION AND MANY MORE GOT INVOLVED WITH TASTING AND VOTING FOR THEIR TEAM BAKES - IT WAS FANTASTIC!



ORGANISING AN EVENT OR TAKING ON A CHALLENGE CAN BE A LOT OF FUN.

It can also help raise awareness of PSP & CBD and much needed funds for PSPA too.

To help get you started, here's some key tips and information you will need to think about:

WHAT Hobbies and interests of yours, as well as for those around you, can be a great starting point when deciding what to do for a fundraiser.

TOP TIP - Get inspired with our #TeamPSPA Fundraising ideas (page 10) or check them out on line on www.pspassociation.org.uk/a-z-of-fundraising-ideas/

WHERE How many people are you aiming to attract? What facilities will you need? And what are the costs? Could you hold an event at home or an activity at work, or is your event big enough to justify hiring a local community room or hotel meeting room?

TOP TIP - Remember to plan for all weathers!

WHEN Choosing a weekend for your event or activity can help to maximise attendance as well as fundraising on the day.

TOP TIP - Remember to check if there are any big sporting fixtures or local events taking place on your preferred dates before you book it in.

WHO Use our press release template and your Facebook, Twitter and Instagram profiles to help spread the word about your event or activity. Give it a personal touch by sharing why you have chosen to fundraise for PSPA and remember to use the **#TeamPSPA hashtag** so we can share details too.

TOP TIP - Take plenty of photos during the event. Sharing them on social media or with local press can help top up your fundraising after the event.

HOW Plan how you will raise money from your event, activity or challenge. Will you gain sponsorship, charge an entrance fee or hold a fundraising raffle or auction?

Keep any costs as low as possible. Ask for discounts on your venue hire and supply costs or approach local attractions and businesses for prize donations. Check if your employer operates a Matched Giving Scheme. This can help to double your fundraising as well as to boost their profile. We can provide supporting letters if they are needed.

7 TOP TIP - Setting up an online fundraising page is a really simple way to boost your fundraising. Messages from your supporters will help to keep you inspired too!

ON THE DAY Look and feel the part during your event or challenge by stocking up on our **#TeamPSPA** merchandise. A sponsorship form, a gift aid form and posters are already included in our pack. If you need more or if you would like some bunting for your venue, toppers for your cakes or wrist bands to help aid your fundraising, get in touch at **fundraising@pspassociation.org.uk**.

TOP TIP - Wear a t-shirt, running top or cycling shirt during your event or challenge so people can spot you when cheering you on or if they need help.

AFTER Make sure you thank everyone who has supported your event or challenge. One of the most satisfying parts of fundraising is counting up the donations and declaring a grand total.

Remember to bank the money you've raised once it has all been totted up:

Pay using a credit or debit card at www.pspassociation.org.uk or by calling **01327 322414**. Then, Pay by cheque to **FREEPOST PSPA** or automatically via your online fundraising page.

TOP TIP - Make your fundraising go further by encouraging your supporters to tick the Gift Aid box on your sponsorship form and including their full name and address. Donations from UK tax payers are eligible for an additional 25p per £1 from the Government.

Please remember... Raffles are governed by different rules. For example you may need a special license if drawing the winner(s) on a different day from when the tickets are sold.

You may need **Public Liability Insurance** for your event. If you are holding it at a venue, check if your activity will be covered by their insurance. If not, get in touch to see if we can help.

Health and safety will be your responsibility. Complete a risk assessment to highlight any potential dangers and what can be done to minimise the risks. If needed invite a trained first aider.

If your event involves the preparation of **food and drink**, be aware of hygiene regulations and any licensing you might need to serve alcohol or play music. Guidance is available from your local council.

Be careful of any data you collect via sponsorship forms, attendance lists and raffle and auction wins. **General Data Protection Regulations** mean you cannot share any information or photos without permission.

If you are planning a **collection** in a public space you may need a licence from your local council. On private land be sure to ask permission from the manager or owner.

We encourage you to use our logo and charity number when promoting your activity. For any guidance on how to use them, please email **fundraising@pspassociation.org.uk**.

MUM'S STRENGTH INSPIRED ME TO GO BIG

In 2019 Georgie Irwin ran the London Marathon in honour of her nan who was diagnosed with PSP, raising £3,600 for PSPA in the process.

Georgie said: "Receiving my nan's diagnosis was devastating but also a relief to finally be able to put a label on something we'd been trying to understand for around four years. I was so in awe of the way my mum sprang into action, both in terms of making sure my nan was getting the care she needed but also giving up the little free time she had to become a Education Volunteer for PSPA. I wanted to do something big to help and that's when I signed up for the London Marathon 2019. I am a self-confessed non-runner and before I started training I could barely run for 10 minutes! But knowing how important it is to raise awareness of PSP kept me going through the long, dark training runs.

"Raising £1,600 seemed as terrifying as the race itself, however, through a couple of organised fundraising events and the kindness of people around me, I somehow managed to fly right past the £1,600 mark. I'd highly recommend hosting fundraising events, such as coffee afternoons and pub quizzes, as it's the perfect opportunity to raise money but also talk to lots of people about PSP & CBD.

"The London Marathon itself is a truly amazing day, one that I will never forget. Those last few miles were extremely tough and I can still remember how heavy my legs felt as I crossed the finish line, but knowing the good it was doing in terms of raising awareness and how proud my nan was going to be kept me going all the way."



RAISING AWARENESS AND HOW PROUD MY NAN WAS GOING TO BE KEPT ME GOING ALL THE WAY



GO SOLO

Help us to get closer to a cure by...

- Getting sponsored to walk, run, cycle or swim for PSPA
- Being bold with a sponsored head shave or by giving shaving up
- Challenging yourself to face a fear with a sponsored sky dive, bungee jump or hot coal walk
- Give to PSPA regularly via Payroll Giving or by setting up a direct debit.



GET TOGETHER

Fight misdiagnosis of PSP & CBD by...

- Hosting a tea party with your friends and family or at work
- Help us raise aware by sharing our campaigns on facebook and twitter
- Holding a fundraising quiz night in your local community
- Organising a memory walk in honour of a loved one.



FUN FOR ALL AGES

Help give hope to everyone affected by PSP & CBD by...

- Holding a sponsored dress down (or up) day at school or at work
- Organising a fundraising concert, car boot sale, car wash or 5K for PSPA event
- Competing with friends and colleagues in a bake off competition
- Hosting a fun treasure hunt at your local park
- Get a local company fundraising for PSPA or consider leaving a gift in your will to PSPA



STILL NOT SURE HOW YOU WANT TO FUNDRAISE FOR PSPA?

Take our fun quiz or read through our 'A to Z' of fundraising ideas for more inspiration. pspassociation.org.uk/a-z-of-fundraising-ideas/

RELATIVES AND OUR COMMUNITY WERE SO SUPPORTIVE

"When I first heard about the 5K for PSPA event on Facebook, I know immediately that was how I wanted to honour my mother and her journey. She was diagnosed with PSP in February 2019, around four years after she began to show symptoms.

"The experience of taking on the 5K challenge was absolutely wonderful. My sister, who has been my mum's primary caregiver, joined me for a hike up the beautiful Oregon Table Rocks. On our way up, we discussed the obstacles our mother's illness has created. Then at the top, we took all of the breath-taking scenery in, sat down with our arms around each other, and reflected.

"The way down was the best part for me, as we conversed with renewed hope and determination for the future as sisters and as daughters of such an incredible trooper of a mother and an equally amazing father.

"Our blood relatives and incredible members of our community have been so supportive and pushed us past our original fundraising goal.

"I will definitely be participating in another 5K for PSPA and look forward to it becoming a tradition with my sister. I highly encourage others to also take part as it not only shows your love for whomever the affected individual is in your life, but it also contributes to the resources for individuals and families as well as ongoing PSP research."

Christina and Elsie Chow proved you don't need to be in the UK to take part in our virtual 5K challenge. Together, as well as taking on the Southern Oregon Table Rocks hike, they also raised £1,200 For PSPA.



ON OUR WAY UP, WE DISCUSSED THE OBSTACLES OUR MOTHER'S ILLNESS HAS CREATED. THEN AT THE TOP, WE TOOK ALL OF THE BREATH-TAKING SCENERY IN, SAT DOWN WITH OUR ARMS AROUND EACH OTHER, AND REFLECTED.



LOOK THE PART

We have a wide range of kit and merchandise that can help you feel part of #TeamPSPA, help you raise extra funds and make your event or activity really stand out.

We will send anyone taking part in a challenge a #TeamPSPA t-shirt and flags to help your friends and family cheer you on during the event.

Take a look below for anything else you might need for your fundraising:

CLOTHING



#TeamPSPA t-shirt
£10



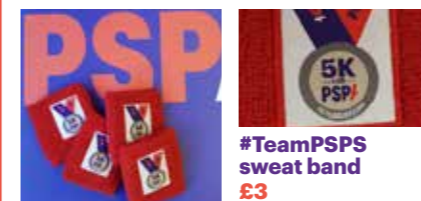
#TeamPSPS training top
£10



#TeamPSPS cycling jersey
£25



#TeamPSPS running vest
£8



#TeamPSPS sweat band
£3

FUNDRAISING ITEMS

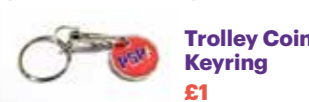


Orange or Purple wristband
£1



Pin badge
£2

Cake toppers
£1



Trolley Coin Keyring
£1

OTHER GOODIES

Water bottle
£6



Mugs
£6

To order any additional items please visit: www.pspassociation.org.uk/fundraising/shop/

I WANTED TO HELP CONTRIBUTE TOWARDS A CURE FOR THE FUTURE



Felicity Winslade wanted to do something good for others and make a difference in the world.

Inspired by her Grandad who was diagnosed with PSP, Felicity asked for donations to PSPA in return for having approximately 10 inches of her hair cut off which she donated to The Little Princess Trust.

Wanting to fund a cure for the 'Grandad's of the future', Felicity's fundraising exceeded her expectations as her friends and family donated £400!

"It all started when my grandad got diagnosed with PSP, and from that day on I knew I had to do something about it to potentially help my grandad and lots of other people too. I found out if I cut my hair I could raise money and give the money to PSPA for them to research and help find a cure. I also donated my hair I had cut off to a different charity that makes wigs for sick children. I was determined to do it, so that's what I did and here I am today having lovely short hair and a good feeling inside me. I only set out to raise £100 that's two days of research but I raised £400 that means eight days people can be paid to do research to help lots of lives."



**FUND A CURE FOR THE
GRANDAD'S OF THE FUTURE**

OTHER WAYS YOU CAN GET INVOLVED

We always need more people to join our fight against PSP & CBD.
Here's a few more ways that you can get involved in our work:

VOLUNTEER YOUR TIME

Volunteering is a really rewarding way to give something back to your community whilst meeting new people and building your skills set too.

We have a wide variety of roles to suit all interests and availability, including:

- Micro volunteers to help support our events
- Helpline volunteers to help provide information and support to people living with PSP & CBD
- Education volunteers to help spread awareness of the symptoms of PSP & CBD
- Office volunteers to help support our staff team.

Email volunteering@pspassociation.org.uk



COLLECTIONS IN YOUR COMMUNITY

Help raise awareness of PSP & CBD and much needed funds by distributing **collection tins** in your area.

Speak to your local post office, hairdresser, pub, corner shop or community rooms to get their permission, then email us at fundraising@pspassociation.org.uk for more information



USE SOCIAL FOR GOOD

PSP & CBD are little known diseases.

Use your **Facebook, Twitter and Instagram** profiles for good by sharing information to help raise awareness of the symptoms and how PSPA can help.



Thank you for joining #TeamPSPA

Contact us

PSP/



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01327 322410



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**STARTS
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