

# #BEAWARE OF PSP & CBD

HOW YOU CAN GET INVOLVED IN PSPA'S  
2023 AWARENESS ACTIVITIES.



[pspassociation.org.uk/information-and-support/awareness-tools](https://pspassociation.org.uk/information-and-support/awareness-tools)

Facebook: **PSP Association**

Instagram: **@teampspa**

Twitter: **@PSPAAssociation**

# PSPA





We're excited to be launching PSP & CBD Awareness Week from 17 to 23 June 2023.

This year, we have plenty planned to ensure everyone can have the opportunity to get involved.

In our 2022 survey of people living with PSP & CBD, you fed back that raising awareness of the conditions to health and social care professionals is a top priority. That's why, we've made it a core goal of our new strategy and the prime focus of our awareness plans this year.

I will be taking part in a Walk of Hope with the team in Milton Keynes on 20 June and visiting my local opticians (dressed in my PSPA branded t-shirt) to drop in our new Red Flags poster. I hope you too can be part of some activities and I look forward to seeing the impact we can make together.

Together, we can improve diagnosis for the 10,000 people living with PSP & CBD, saving time, resources and helping patients get the care they need faster.

Keep reading to learn how you can help more people #BeAware of PSP & CBD!

**PSPA CEO**

## HELP OPTICIANS LOOK OUT FOR PSP

As part of our commitment to improving diagnosis, this year we are highlighting the Eye Red Flags of PSP to opticians and ophthalmologists.

To raise awareness with opticians, we have created a new Red Flag poster (see the back page of this booklet), listing all the early eye symptoms they can keep an eye out for, during routine eye examinations.

The aim of sharing this important new resource, is for opticians and ophthalmologists to aid diagnosis by advising any patients exhibiting symptoms, to speak to their GP. This may include requesting a referral to a Neurologist for further investigation.

### HOW OPTICIANS HAVE HELPED

Katy Butterill knows all too well the importance of spotting those all-important eye changes.

Katy's mum was diagnosed with PSP in 2020. After multiple visits to the GP, and whilst waiting for a neurology appointment, Katy's mum's eye issues were picked up during an optician appointment:

**"My mum had been to the GP several times over balance issues but nothing conclusive had been found. Eventually they did refer her to neurology but there was quite a wait. During this wait, the GP suggested going for an eye test.**

**"The optician picked up on limited eye movement and said she would do a report for the GP. As a result of this mum was referred to a neuro- ophthalmologist and the appointment came through quite quickly. In the ophthalmology report, PSP was mentioned for the first time. This diagnosis was confirmed later when mum finally had her neurology appointment."**



### HOW YOU CAN HELP

You can help spread awareness, by sharing our new Eye Red Flag poster with your local opticians or taking it with you, when you visit your ophthalmologist.

To help us keep track of where the posters are being taken, please log where you dropped off the poster on our website awareness map.

[pspassociation.org.uk/information-and-support/awareness-tools/raising-awareness-across-the-uk](https://pspassociation.org.uk/information-and-support/awareness-tools/raising-awareness-across-the-uk)

**If you would like more Eye Red Flag posters, you can**

- Download a copy from our website: [pspassociation.org.uk/information-and-support/awareness-tools](https://pspassociation.org.uk/information-and-support/awareness-tools)
- Contact us to receive copies in the post: Ring **01327 322410** or email [info@pspassociation.org.uk](mailto:info@pspassociation.org.uk)

## SHARE YOUR EXPERIENCE OF PSP & CBD LOCALLY:

### 1. CIRCULATE A #BEAWARE CAMPAIGN PRESS RELEASE

We want more people to #BeAware of PSP & CBD. To do that we want to ensure more people can see and read about the conditions in their local area, and even nationally.

To help, we've created a template press release you can adapt so you can share your personal experience with your local newspaper, magazine or radio station. To personalise the release, just fill in your own experience of PSP & CBD or details of your Walk of Hope event in the blank sections.

See page 6 for the full template press release.

### 2. SHARE AN IDEA FOR RAISING AWARENESS

Another way we can help you raise awareness in your community is with our newly launched PSPA Awareness Grants.

The aim of the Awareness Grants is to harness the ideas, skills and experience of people living with PSP or CBD, health and social care professionals, volunteers, and supporters to help raise awareness in their communities. Ideas big or small are welcome.

**You can apply for an Awareness Grant of a maximum £2,500 to help do one of following in your area:**

- Raising awareness to improve diagnosis
- Raising awareness to improve the quality of care and support
- Raising awareness of the services and support people living with PSP or CBD are entitled to and how to access those services
- Raising awareness to improve the resources allocated to supporting people with PSP or CBD in the health and social care system.

## WHAT CAN YOU APPLY FOR?

**We don't have an exhaustive list, but to give you an indication of what a grant could help you with:**

- Publicity materials
- Writing a book about PSP or CBD
- Developing learning materials
- An information session for a specific community
- Travel and accommodation to speak at a conference or workshop.

## APPLYING FOR A PSPA AWARENESS GRANT

If you have an idea about how you can help raise awareness and need some funding to make it happen, then go to our website to find out how to apply.

The deadline for applications is midnight Thursday 31 August 2023.  
[pspassociation.org.uk/information-and-support/awareness-tools](http://pspassociation.org.uk/information-and-support/awareness-tools)



## STEP UP AWARENESS IN YOUR COMMUNITY

Throughout the summer, raise awareness of PSP & CBD in your area by holding a Walk of Hope.

Our Walk of Hope is an awareness raising 5km walk or wheelchair push. You can take part in a local event or host your own walk with your friends, family and colleagues.

The beauty of this awareness raising event, is you can organise it to suit your needs. Walk or push 5km in one go, or break the distance up into smaller chunks across a number of days. You can maybe even organise a relay so you only need to complete a portion of the walk yourself.

View public Walk of Hope events you can join at  
[pspassociation.org.uk/information-and-support/awareness-tools](http://pspassociation.org.uk/information-and-support/awareness-tools)

To help you raise funds whilst taking part in a Walk of Hope, we've included a template sponsorship form in this pack. Photocopy the form and get your friends, family and colleagues to sponsor you to complete the 5km walk or wheelchair push. See page 7.

## BUY OR SELL RAFFLE TICKETS IN YOUR COMMUNITY

You can help to raise awareness of PSP & CBD in your community by buying or selling our #BeAware Raffle tickets in your community from the end of June.

Selling raffle tickets can be a great conversation starter. It can enable you to share your experience of PSP & CBD, ensuring people #BeAware of the conditions.

This year we are encouraging supporters to buy or sell 40 #BeAware Raffle tickets to help us improve diagnosis for the 10,000 people living with PSP & CBD in the UK.

The #BeAware Raffle prizes include 1st prize: **£500** 2nd prize: **£250** 3rd prize: **PSPA hamper**

If you would like to receive a supply of #BeAware Raffle tickets, please email [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk) or call 01327 322414.

## LOOK THE PART THIS PSP & CBD AWARENESS WEEK

You can look the part this PSP & CBD Awareness Week with our range of PSPA branded goodies.



View the full PSPA Shop range at:  
[pspassociation.org.uk/fundraising/shop](http://pspassociation.org.uk/fundraising/shop)



# TEMPLATE PRESS RELEASE

**[HOME TOWN/CITY NAME]** LOCAL HELPING PEOPLE **#BEAWARE** OF RARE BRAIN DISEASES

**[HOME TOWN/CITY NAME]** is helping residents **#BeAware** of two rare brain diseases called Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD) this June.

**[ADD IN YOUR NAME]** from **[ADD IN THE AREA OF YOUR TOWN/CITY]** wants to help more people to **#BeAware** of the two conditions to help mark PSP & CBD Awareness Week. To do this **[ADD IN FIRST NAME]** is sharing their own personal experience of PSP & CBD/hosting a Walk of Hope event so more people can **#BeAware** of the early signs and symptoms of the conditions.

PSP & CBD are rare neurodegenerative diseases caused by the loss of nerve cells in the brain. Over time, this causes problems with balance, speech, cognition, vision and mobility. Both conditions are terminal and currently there is no treatment, nor a cure.

The aim of the **#BeAware** of PSP & CBD campaign, coordinated by the charity, PSPA, is to improve diagnosis for the 10,000 people living with the conditions in the UK.

Currently, 60% of people living with PSP & CBD are misdiagnosed with other conditions, including Parkinson’s disease, depression and stroke. By raising awareness of the symptoms of the two conditions, PSPA aims to improve the diagnosis journey, saving time, resources and helping people get the care they need faster.

**[ADD IN YOUR FIRST NAME]**, said: **“ADD IN A QUOTE DETAILING YOUR DIAGNOSIS JOURNEY AND HOW THIS IMPACTED ON YOU, YOUR FAMILY AND ACCESS TO APPROPRIATE CARE AND SUPPORT. IF YOU ARE HOLDING A WALK OF HOPE EVENT, SHARE DETAILS OF THE DATE AND LOCATION. YOU MIGHT ALSO LIKE TO SHARE THE DIFFERENCE YOU HOPE SHARING YOUR EXPERIENCE/HOLDING A WALK OF HOPE EVENT WILL MAKE.**

Rebecca Packwood, PSPA CEO, said: “Our recent survey of people living with PSP & CBD highlights diagnosis of PSP & CBD remains problematic. Largely, the cause of delays to diagnosis is a lack of awareness of the two conditions, even among the medical community. We want this to change.

This year we have launched the **#BeAware** campaign to raise awareness of the early signs and symptoms of PSP & CBD, to help improve diagnosis. In turn, we hope earlier diagnosis means people living with PSP & CBD will receive appropriate care and support which is coordinated, has continuity, and is compassionate.”

PSP & CBD Awareness Week takes place between 17 and 23 June 2023.

For more information about the **#BeAware** campaign and how people can get involved, please visit: [pspassociation.org.uk/information-and-support/awareness-tools](https://pspassociation.org.uk/information-and-support/awareness-tools)



# OFFICIAL SPONSORSHIP FORM

E: [events@pspassociation.org.uk](mailto:events@pspassociation.org.uk) T: 01327 356132 **Please return to:** Freepost PSPA

## INCREASE YOUR DONATION AT NO ADDITIONAL COST!

**Thanks to the Gift Aid scheme, PSPA can reclaim 25p for each £1 you give, increasing its value to £1.25.** If I have ticked the column headed ‘Gift Aid’, I confirm that I am a UK Income or Capital Gains taxpayer. I have read this statement and want PSPA to reclaim tax on the donation detailed below, given on the date shown. I understand that if I pay less Income Tax/ Capital Gains tax in the current tax year than the amount of Gift Aid claimed on all of my donations, it is my responsibility to pay any difference. I understand the charity will reclaim 25p of tax on every £1 that I have given.

**Connected Persons:** Sponsorship payments towards the cost of an event made by people who are connected to the participant (e.g. wife, husband, civil partner, son, daughter, parent, grandparent or grandchild) will usually fail the donor benefit rules and so will not qualify for Gift Aid. This is because HMRC perceives there to be a personal benefit of the experience (e.g. skydiving, climbing Kilimanjaro).

**Remember: Full name + House name/number + Address + Postcode = giftaid it**

## PSP & CBD:

- at least 10,000 people are living with PSP & CBD in the UK
- leaves people unable to balance, walk, talk, eat, swallow, drink and see.
- has no cure

## PSPA:

- provides information and support to people affected by PSP & CBD
- funds vital research into PSP & CBD
- raises awareness of PSP & CBD

Name \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

You’re fundraising for people living with PSP & CBD by \_\_\_\_\_ Date \_\_\_\_\_

FULL NAME	ADDRESS (Please write clearly and give your full address, including postcode, or we can't claim Gift Aid)	POST-CODE	PLEDGE	GIFT AID	DATE COLLECTED	CAN WE CONTACT YOU ABOUT OUR WORK AND ACTIVITIES?*		
						By post	By email	Email address
Anne Sample	21c Watford Rd, Luton, Beds	LU11LT	£10	<input checked="" type="checkbox"/>	14.05.18	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	anne.sample@any.com
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**TOTAL AMOUNT RAISED**

**DATE DONATIONS GIVEN TO PSPA**

# EYE RED FLAGS OF PROGRESSIVE SUPRANUCLEAR PALSY (PSP)

Progressive Supranuclear Palsy (PSP) is a severe neurological condition which changes many ocular and oculomotor functions. These easy-to-check eye red flags could speed up detection and treatment.

On average it takes three years to get a diagnosis of PSP. To improve diagnosis and access to relevant care and support, we have developed a list of red flags for opticians and ophthalmologists that may raise clinical suspicion of PSP.

If you see these red flag signs, you may want to suggest a visit to the GP. The GP can look into possible causes, and consider a specialist referral.

## 1. EYE MOVEMENTS

- Limited up or down range of eye movements
- Trouble voluntarily shifting gaze up or down
- Slow or curved vertical saccades

## 2. EYE LIDS

- Difficulty in opening the eyes.
- Tendency to not blink ('stare' look)

## 3. FIXATION

- Square wave jerks (involuntary, horizontal, saccadic intrusions that interrupt fixation).

To learn more, you can read the article on the link, left which includes a film to illustrate what the eye red flags look like.



PSPA is the UK's leading centre of knowledge, experiences and support for people living with PSP or CBD, their families and health and social care professionals.

**PSPA Helpline and Information Service**  
Telephone: 0300 0110 122  
Email: [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)