



20 May 2019

### **New campaign seeks to #Unmute ignored diseases**

A powerful new campaign to be launched at the start of PSP & CBD Awareness Week on Monday 20 May seeks to end the silence around two life limiting neurological conditions.

Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD) are cruel and devastating neurological diseases, leaving people unable to balance, walk, talk, eat, swallow, drink and see.

The majority of people, including many health and social care professionals, are not aware of PSP & CBD. Nearly half of people diagnosed received an incorrect diagnosis first, with many having to wait a year or more for a correct diagnosis. People affected by PSP or CBD are frustrated at the lack of awareness they face on a daily basis. During PSP & CBD Awareness Week on 20 – 26 May 2019, national charity PSPA, wants to raise awareness by asking people affected by PSP & CBD to share (and broadcast) their frustrations on social media.

Hundreds of people affected by the similar conditions will be creating their own shouting film, in an attempt to #Unmute PSP & CBD. The charity hopes this will create a movement across social media during the week, to raise awareness and focus attention on PSP & CBD.

Chief Executive of PSPA, Andrew Symons said: “PSP & CBD robs affected people of their voice. Through this campaign, we want to give those voices back. We need to focus more attention on these ignored, but devastating, conditions. Due to the lack of awareness and information surrounding them, people are deprived of a timely diagnosis and then, once diagnosed, have to contend with the fact that most professionals involved in their care have no knowledge about their condition. This needs to change and why we need to be loud about PSP & CBD.”

Amy Silver decided to get involved in the campaign following her dad’s diagnosis of PSP. Amy said: “When your loved one is diagnosed with PSP, 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, especially to health professionals. It is so frustrating when they haven’t heard about it.

“I’m hoping that the more people know about PSP & PSPA, the more fundraising will take place which will allow more support for families, more research and hopefully future treatments.”

The charity hopes people support the campaign even if they have no personal experience of PSP or CBD. To take part, all people need to do is 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 the week. The more people who do it – the louder we will be about PSP & CBD, and the more likely we can raise awareness.

### **Ends**

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## Notes to editors

- PSPA is the only national charity offering advice, support and information to people living with PSP, while supporting research into treatments and ultimately a cure.
- PSP & CBD are caused by the progressive death of nerve cells in the brain, leading to difficulty with balance, movement, vision, speech and swallowing.
- PSP & CBD are associated with an over-production of a protein called tau in certain areas of the brain.
- The average life expectancy is around seven years from onset
- There are no effective treatments and no cure.
- To find out more about PSPA visit [www.pspassociation.org.uk](http://www.pspassociation.org.uk) or find us on Facebook and Twitter.