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## News Release

For immediate release

# Nation takes 'Afternoon Tea for PSP' in the UK's First National PSP Awareness Week 5<sup>th</sup> – 12<sup>th</sup> April

The UK's first ever 'National PSP Awareness Week' will take place from 5<sup>th</sup> -12<sup>th</sup> April.

To mark this special week The PSP Association, the only UK charity dedicated to helping people with PSP, is aiming to hold 10,000 Tea Parties across the UK. There are at least 10,000 people in the UK who have PSP. Each 'Afternoon Tea for PSP' therefore represents the life of a person with PSP.

PSP (Progressive Supranuclear Palsy) is a devastating brain disease that progressively robs its victims of their ability to walk, talk, see, swallow, eat and drink. In the later stages of the disease patients are confined to a wheelchair or are bed-bound, unable to communicate with the world around them, yet remain mentally alert. On average patients die within seven years of the onset of the disease. PSP can strike anyone regardless of gender, race or social class although it tends to appear in the over forties. The cause of PSP is unknown and there is no effective treatment.

Across the nation well known celebrities and local dignitaries will be attending Tea Parties in their areas.

Tea Party guests will be invited to drink '**Tea for Treatment**' or '**Coffee for Care**' to increase awareness about PSP and help raise money to fund research to develop a treatment for PSP; provide essential care and support for thousands of people with PSP; and to fund the charity's PSP specialist nurses who provide free help and advice to people with PSP and their carers 24 hours a day, 365 days a year.

Staff at The PSP Association's Headquarters in Towcester, Northamptonshire will hold their own 'Afternoon Tea for PSP' on Tuesday 8<sup>th</sup> April. The event will be hosted by the local MP, The Rt Hon Tim Boswell.

Tim Boswell (MP) said, "I am looking forward to hosting my first ever 'Afternoon Tea for PSP' – it will be a fun event and a great opportunity to promote the work of the charity at a local and national level. As Chair of The PSP Association's All Party Parliamentary Group I have been involved with The PSP Association for some considerable time and know what a lifeline the charity is for people with PSP and their families and carers. 'Afternoon Tea for PSP' is a fantastic initiative and will result in increased awareness and knowledge about the disease amongst the general public, as well as the medical and healthcare professionals. This should result in fewer people being misdiagnosed or going undiagnosed which, in due course, will improve their chances of receiving appropriate care and support."

Amongst the local dignitaries and national celebrities invited to The PSP Association's Towcester 'Afternoon Tea for PSP', which includes an impressive list of Bishops, Lords and Knights, is former Olympic gold medalist and Chair of the 2012 Olympics Committee Sebastian Coe (Lord Coe) who is a close supporter of the work of The PSP Association and one of its Vice Presidents.

The Lord Coe (Seb) said, "The information, advice and support the charity offers to PSP sufferers and their families is invaluable. My own mother suffered from PSP from which she died in 2005, so I have first-hand experience of this devastating and fatal disease and know how important the work of the charity is. I am doing all that I can to raise awareness of PSP, to ensure that everyone living with PSP has access to the care and support they need, and that more research is undertaken to enable earlier and better diagnosis of PSP as well as the development of an effective treatment. Hopefully, a cure will eventually be found."

Jane Hardy, Chief Executive of The PSP Association, said, "'Afternoon Tea for PSP' is a great way to increase the nation's awareness of PSP, raise money for the charity's much needed work and at the same time have fun. And it's so simple – just get together with a few friends, family or colleagues at work and have a Tea Party. It can be as elaborate or simple as you want. Guests can make a donation for every cup they drink, or just make a donation at the end of the party. It's amazing what a cup of tea can do to help people with PSP."

As part of National PSP Awareness Week The PSP Association will be holding an Open Day at its headquarters at 167 Watling Street, Towcester on Wednesday 9<sup>th</sup> April (10 am – 4pm). Visitors will have the opportunity to learn more about PSP and the work of the charity and to drink 'Tea for Treatment' or 'Coffee for Care'.

**- Ends -**

For more information please call Dr Angela Wilson on 0774 979 5172.

For general information about PSP and The PSP Association please call 01327 322410 or visit [www.pspeur.org](http://www.pspeur.org).

## Notes to Editors

- The PSP Association was established as a registered charity by Brigadier Michael Koe, OBE and his wife Sara in 1994, shortly before she died from PSP in 1995. They were appalled to learn that so little was known about this disease and established the charity to “conquer PSP through effective research, education, welfare and communication”.
- ‘Afternoon Tea for PSP’ is symbolised by a Magnolia flower. This was the favourite flower of Sara Koe, the charity’s co-founder and, since her death from PSP in 1995, the 8<sup>th</sup> April has been known as Magnolia Day.
- Since The PSP Association was established in 1994 it has:
  - developed a unique UK-wide Nurse Specialist Service to support PSP patients and their carers.
  - helped over 2,000 families with members suffering from PSP
  - invested more than £2m into research into PSP.
  - established the Sara Koe PSP Research Centre, the first PSP research centre in the world, based at the Institute of Neurology, 1 Wakefield Street, London.
- PSP is thought to affect more than 10,000 people in the UK at any one time but the true number is likely to be much higher, as it is often misdiagnosed as a stroke, dementia or Parkinson’s disease and frequently goes undiagnosed in older people resulting in unnecessary suffering.
- The number of cases of PSP is set to rise significantly with the changing demographics and an ageing population.
- PSP claimed the life of *Daily Mail* columnist Nigel Dempster in 2007, and Dudley Moore died from the disease in 2002.
- J.N.P. Watson, author and former polo correspondent for The Times, died from PSP in February 2008.
- Case studies are available for interview - to demonstrate the devastating impact that PSP has on patients and their families and carers.

## *Working for a world free of PSP*

The PSP Association. Registered charity 1037087

**Patron:** HRH The Duchess of Gloucester GCVO **President:** General the Lord Guthrie of Craigiebank GCB, LVO, OBE  
**Vice-Presidents:** The Lord Coe KBE; Sir Michael Carleton-Smith CBE DL; Professor Colin Blakemore FRS  
**Chairman:** Brigadier Michael R Koe, OBE **Chief Executive:** Mrs Jane Hardy, FCIB, FRSA  
**Hon Treasurer:** Mr Peter Glithero, FCA