



The PSP Association,  
167 Watling Street West,  
Towcester,  
Northamptonshire  
NN12 6BX

Email: [psp@pspeur.org](mailto:psp@pspeur.org)  
[www.pspeur.org](http://www.pspeur.org)

## News Release

**For immediate release 26/10/07**

### **Top Banker to Head up Brain Charity**

Jane Hardy, formerly Head of Banking at Cahoot, has been appointed as the new CEO of The PSP Association, the Towcester-based national charity fighting to make life better for people with Progressive Supranuclear Palsy (PSP).

PSP is a devastatingly cruel 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. There is no treatment. Patients are destined to a living hell before dying on average about seven years after diagnosis. The cause of the disease is unknown and it can strike anyone regardless of gender, race or social class although it tends to appear in the over forties.

Jane, who sadly and only recently lost her own mother to PSP, followed shortly by the death of her husband from cancer said, "Mother and George dying so close together made me re-evaluate what was important to me in life. I wanted something good to come out of the deeply harrowing years I'd been through. What I gained from these dreadful life events is first hand knowledge, experience and understanding of the pain and suffering, and the obstacles and frustrations that beset caring for people with a terminal illness. I know what others in a similar situation are going through and I want to make things better for them. It was by chance that I saw the advertisement for a new Chief Executive for The PSP Association and instantly knew this was the job for me. I couldn't believe my luck when I was appointed. In my new role I will be able to fulfil my personal ambition - to make a real difference to the lives of people with PSP and their families".

Jane takes over from Brigadier Michael Koe, OBE, who founded The PSP Association with his wife Sara shortly before her death from PSP in 1995. Following Sara's earlier diagnosis the Koes were appalled to learn that so little was known about the disease and set up the charity to 'conquer PSP through effective research, education, welfare and communication'.

Since 1994 the charity has supported PSP sufferers and their families helping over 2,000 families and investing some £2m into research which it is hoped will lead to a greater understanding of PSP and its causes, and to an effective treatment and ultimately a cure. An important part of the charity's work is to raise awareness about PSP amongst the general public and with healthcare professionals as many people with PSP go undiagnosed or are misdiagnosed. As a result they can often receive treatments that make the symptoms of the disease worse.

In June Brigadier Koe successfully completed the purchase of property in Towcester and moved the charity from an outbuilding at his home in Wappenham to new Headquarters at PSP House,

167 Watling Street West. Funding for PSP House which was opened by HRH the Duchess of Gloucester in October, was achieved in part by a legacy from Mr William Stanley Megenis and Lord Coe's (Seb) winnings on TV's 'Who wants to be a millionaire?' Lord Coe's mother died from PSP in 2005.

The Charity's move to new Headquarters coincided with Michael Koe's planned decision to step down as CEO. He will succeed Sir Michael Carleton-Smith as Chair of the Charity.

Brigadier Michael Koe said, "It is with a mixture of relief, sadness and hope for the future that I hand over the day-to-day running of The PSP Association to Jane Hardy. The Charity has grown explosively over the last few months and is well poised for further expansion. I am confident that Jane is absolutely the right person to take the Charity forward with fresh ideas and new momentum."

Armed with her personal experience of PSP and formidable financial expertise Jane is set to lead the charity in the next phase of its development. She said "This is a tremendously exciting time for the charity and for people with PSP. Brigadier Koe has put in place the foundations for the charity to grow. We are now set to make his dream a reality and do so much more to improve the lives of people with PSP."

One of Jane's priorities will be to address the lack of much needed hospice care for people towards the end of their life with PSP and indeed other neurological conditions such as Parkinson's and Alzheimer's Diseases. Jane said, "Having experienced the wonderful hospice care that was available to George as a cancer patient [in his case at Willen Hospice], I want this to be available to PSP patients too. There is no reason why people with these dreadful terminal diseases should have such different end of life experiences when their needs are so similar. If I compare the end of life care that my husband and my mother received, the difference between the two is like comparing heaven with hell. This is not right or fair and The PSP Association will be spearheading a national campaign to address this injustice."

Funds to support the work of the charity are raised through donations and by local and national fundraising events, many of which are supported by local people. The charity's next big national fundraising event will be its Christmas Carol Service, to be held in London on Thursday 13<sup>th</sup> December at 6.30pm. Lessons will be read by Lord Coe (Seb), Mrs Holly Bellingham, John Sutton, Lord Guthrie, Professor John Hardy and Michael Koe. The Carol Service will be followed by a reception with mulled wine and mince pies at which guests will have the opportunity to meet with Jane, staff from the charity and to mingle with celebrities and VIPS. The Carol Service is a wonderful event to round off a day's work for commuters or a day's Xmas shopping in London. All are welcome. Tickets for the Carol Service, priced at £12.50, are available from PSP House (telephone 01327 322419 or email [psp@pspeur.org](mailto:psp@pspeur.org))

For more information about PSP or the work of the charity please call 01327 322410 or email [psp@pspeur.org](mailto:psp@pspeur.org) or log on to the website [www.pspeur.org](http://www.pspeur.org)

**- Ends -**

For further information please contact The PSP Association on 01327 322410 or email [psp@pspeur.org](mailto:psp@pspeur.org)

### **Notes to Editors**

- PSP is thought to affect up to 10,000 people in the UK at any one time but the disease is often misdiagnosed and wrongly treated as cases of dementia, stroke or Parkinson's disease. PSP frequently goes undiagnosed in the elderly. The prevalence of PSP is set to rise with the changing demographics and an ageing population.

- Former Olympic gold medallist Sebastian Coe has close experience of the devastating effects of PSP, resulting in his own mother's death from this disease in 2005. He is a close supporter of the work of The PSP Association and a Vice – Chairman of the charity.

- The PSP Association runs a unique UK-wide Nurse Specialist Service to support PSP patients and their carers as well as local Support Groups across the UK.

## *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