

Press Information

- 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 from the onset of the disease; however from diagnosis to death is usually between two and four years.
- PSP is one of the last really harmful diseases for which there is no effective treatment. The cause of PSP is unknown and it can strike anyone regardless of gender, race or social class although it tends to appear in the over forties. PSP is frequently misdiagnosed as dementia, stroke, or Parkinson's disease resulting in the wrong treatment which can exacerbate the disease and all too often goes undiagnosed in older people resulting in unnecessary suffering.
- PSP is thought to affect some 10,000 people in the UK but the actual number is likely to be much higher as it is often misdiagnosed and goes undiagnosed in the elderly. The number of cases of PSP is set to rise significantly with the changing demographics and an ageing population.
- 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.

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 3,000 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 claimed the life of *Daily Mail* columnist Nigel Dempster in 2007, and talented actor and concert pianist 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.

For further information contact:

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Working for a world free of PSP

The PSP Association. Registered charity 1037087