

## **PROGRESSIVE SUPRANUCLEAR PALSY (PSP)**

### **About the Disease**

PSP is a degenerative brain disease. The cause is unknown and there is as yet no effective treatment and no cure. PSP affects progressively a patient's vision, balance, mobility, speech and ability to swallow. In some cases, it can also cause personality changes and behavioural problems. As it progresses, wheelchair and other mobility aids may be required, with tube feeding and 24 hour nursing care possibly needed in the later stages. It mainly affects those aged over 50, but patients in their late 30's have been positively diagnosed.

Leading neurologists estimate that there could be up to 10,000 cases of PSP in the UK today. However, correct diagnosis, especially in the early stages of the condition, is difficult and until recently many health professionals were unaware of the disease and diagnostic criteria had not been set. Recent research indicates a prevalence of PSP in the UK similar to Motor Neurone Disease, a more widely recognised neurodegenerative disease.

Many PSP patients still remain undiagnosed, or misdiagnosed as having Parkinson's or other related conditions. As many other neurological conditions are much better understood, PSP patients and their carers can be left feeling desperately neglected and isolated.

### **About the PSP Association**

The PSP Association was formed some 10 years ago, and it aims to:

- Carry out and promote research leading to an understanding of the causes of PSP, to improve diagnosis, and to find effective treatment and ultimately a cure.
- Raise awareness of PSP within the Health and Welfare Services.
- Support patients and carers by providing a 24-hour telephone help line manned by qualified nurses with a specialized understanding of PSP, and coordinating local support groups across the UK.

The PSP Association also provides similar services for sufferers of Cortico Basal Degeneration (CBD), a rarer, but similar condition.

### **Further Information**

If you would like to find out more about PSP and the PSP Association then please contact the Regional Development Officer for the East Midlands, Maureen Fowler.

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