

Abstracts

The Progressive Supranuclear Palsy Association's Sixth International Medical Workshop

INTRODUCTION

The PSP Association

The PSP Association, formerly known as 'The Progressive Supranuclear Palsy (PSP) [Europe] Association', was registered as a charity in the United Kingdom in April 1994 by Sara and Michael Koe, after the former was diagnosed as having this disease. Sadly, Sara died from it in January 1995.

The Mission of The PSP Association is the conquest of Progressive Supranuclear Palsy. Its three main objectives are to promote research into PSP worldwide, provide information and support to patients, afflicted families and carers and engender awareness of the disease and the Association particularly in the UK and across Europe. The Association has come a long way in the past 13 years. Its achievements have included sponsoring:-

Some £2m of Research including:

- the first PSP Research Centre in the world, known at the Sara Koe PSP Research Centre, at the UK National Hospital for Neurology
- prevalence studies in the UK into PSP confirming a figure of at least 6.4 per 100,000 of population
- to date, six International Medical Workshops
- cutting edge research into diagnostic markers and cause, effective treatment and eventual cure of this devastating disease

For more information about The PSP Association, please email us at psp@pspeur.org or visit our website at www.pspeur.org

Raising awareness of PSP amongst relevant health and welfare professionals is currently The Association's top priority; for, recent research confirms PSP to be at least as common, and most neurologists would agree, at least as nasty as its better known 'cousin', Lewy Gerig's or, as it is called in the UK, Motor Neurone Disease. PSP nonetheless remains little known and tucked away in the shadow of Parkinson's Disease, a clinically, pathologically, and biologically distinct and different disease. Until it is recognised both within the medical profession and by the general public for what it is, a devastating and relatively common neurodegenerative disease, patients will not receive the support they need commensurate with its prevalence and nastiness.

The PSP (Europe) International Medical Workshops

The PSP Association's first 'brainstorming' International Medical Workshop was held in 1996 at the Marie Curie Cancer Institute near Oxsted in Surrey. After this very successful event, the Association held, in 1999, 2001, and 2003, three additional International Medical Workshops at Stowe School in Buckinghamshire.

The PSP Association held its Fifth International Medical Workshop (IMW) at the National Hospital for Neurology and Neurosurgery, Queen Square, on Friday, 8th July 2005, in what could be described as difficult circumstances. For on Thursday, 7th July 2005, a terrorist attack took place in London very close to the hospital where, the next day, 80 leading scientists from around the world had been invited to the 1-day PSP Association sponsored IMW. The hotel, into which delegates were booked, was closed off during the morning after the bus bomb, but they were able to access the hotel through the underground rear entrance from Queen Square. The Workshop accordingly went ahead as planned and was felt by all who came, despite the necessary 'ad lib' and 'ad hoc' arrangements, to be a great success.

Our sixth Workshop was also held at Queen Square in more benign circumstances. The focus of the Workshop was on 'Clinical Drug Trials into PSP'. Once again, Professor Colin Blakemore, Chief Executive of the Medical Research Council, gave an encouraging opening address after which, Chaired by Professors Andrew Lees in the morning (two sessions) and John Hardy in the afternoon (three sessions), presentations on selected themes were followed by focused discussions on each theme.

The morning sessions looked at the Natural History of PSP, trial design, patient selection, surrogate markers for diagnosis and symptomatic drug therapies for PSP followed by 'The Lithium Story', the evidence for its use both for PSP and across tauopathies. The afternoon session looked at other candidates for tau phosphorylation inhibitors, other possible disease modifying treatments, the current Valproic acid trial in France and control of PSP clinical trials in the UK (DeNDRoN) and across the European Union. This was followed by a session on stem cell research possibilities and an overview of why Basic Science advances in neurodegenerative diseases haven't yet translated into bedside treatments. The Workshop concluded with an open discussion.

A dinner was held for delegates that evening at the Rifles Club in Davies Street.

Andrew Lees, MD, FRCP and Brigadier Michael R Koe, OBE

*Chairman, Medical Advisory Panel, Chief Executive
The PSP Association The PSP Association*