

## **Symposium 2009 Summaries**

### **What is PSP and CBD, and the Lithium Clinical Trials - by Dr Huw Morris.**

This session aimed to establish common understanding about PSP and CBD. In addition to covering an overview of symptoms, disease progression and the accompanying morphological and pathological changes in the brain, the session updated delegates on the potential use of Lithium as a treatment for PSP and CBD, one of the few drugs with the potential to slow the progression of PSP, though tolerability by patients is sadly proving difficult to establish.

### **Overview of sponsored research – by Dr Angela Wilson.**

This session gave an understanding of PSP research - past, present and future. Specifically, the lack of research before the establishment of The PSP Association; the charity's efforts to build research capability and capacity over the past 15 years, and, going forward, the need to identify research priorities (involving patients and carers) and develop a National PSP Research Strategy to maximise research effort.

### **Imaging and biomarkers - by Dr Luke Massey.**

Early diagnosis of PSP and CBD can be difficult due to the wide variety of symptoms in the early stages and the lack of a diagnostic test. Dr Massey explained that conventional magnetic resonance imaging (MRI) has so far proved unsuccessful, but showed that new high-powered MRI may offer a way forward. Progress towards finding suitable biomarkers to aid effective diagnosis was also discussed.

### **Genetic Aspects of PSP and CBD - by Professor John Hardy, FRS.**

Participants learnt about the role of genetics as a risk factor for PSP and CBD and, whilst there is a genetic link, there is currently no actual evidence supporting the view that these conditions may also be caused by environmental (toxic) components or head injury. Current research is seeking to better understand the genetic components of PSP, such as the H1/H1 genotype and specific H1 sub-haplotypes, and whether an individual's genetic make-up gives an increased risk of developing PSP when combined with exposure to some as yet unidentified environmental factor(s).

### **Managing swallow with PSP and CBD - by Dr Tom Hughes.**

Swallowing is often affected in PSP, increasing the risk to patients of choking, infection, dehydration and/or malnutrition. This session explored therapeutic options and the need for Speech and Language Therapists to be part of the multidisciplinary team approach in the management of PSP and CBD.

### **Caring for PSP and CBD - by Mrs Sylvia Denton, CBE.**

Though caring for someone with a long term or debilitating illness can be rewarding, it can be physically and emotionally exhausting and carers often struggle without the help and support they need. In this session, Sylvia Denton, former President of the Royal College of Nursing, explored the challenges and practical aspects of being a carer. She identified, in particular, the vital need to develop a support network, access outside help and avoid carer burnout. Caring is an increasingly important issue on the political agenda and the government's national strategy for carers, to improve recognition for the important work they do and the practical and financial support made available, was acknowledged.

### **Balance and mobility issues - by Ms Lori Quinn.**

The progressive nature of PSP can lead to problems that affect all aspects of daily living. Balance and walking are affected and falls (often backwards) can be a major problem affecting quality of life, as can joint stiffness and the associated risk of contractures. This session explored the importance of early intervention by therapists, particularly Physiotherapists, to develop and regularly review exercise programmes; and Occupational Therapists, for advice and access to environmental aids for stability and to reduce the likelihood or severity of falls.

### **Eye movement in PSP and CBD – by Dr Adam Zermansky.**

Unlike most other brain diseases, PSP affects the area above the nuclei which controls balance and eye movement. Visual difficulties are therefore a common feature of PSP and can sometimes be early clinical signs. This session explored the different symptoms, when they appear and the implication this has for disease progression and outcome. Therapeutic options for symptom management were discussed.

### **Hospice and palliative care - by Dr Jo Hayes.**

This session explored end of life care issues including the importance of early intervention, the current lack of provision for end of life care for neurological conditions, and the impact on carers / families of what can become a 24/7 care situation. The use of hospice/ palliative beds to give respite care for carers was explored. The changing population demographics means that in future there will be more people over the age of 60. As age is the only known risk factor for many neurological conditions, so the numbers of people suffering from these conditions will increase, putting immense pressure on existing health systems. Going forward it is essential that these needs are planned for with adequate 'end of life' care provision.

### **Palliative Care -The Future in Wales - by Baroness Finlay.**

Baroness Finlay spoke of the strategic Welsh plans developed to ensure that those who require palliation are adequately provided for, and it was encouraging to note that this included up to 40% of available care being provisioned for those suffering from neurological conditions.