Hi my name is Boyd Groome (age 48), I am a recipient of the Bi-monthly newsletter for the PSP support group. In the last edition it was interesting to read the personal experience/story section (along with the other interesting articles!). Given that a great deal of discussion revolves around the carers/partners of PSP suffers, I would like to take this opportunity to share my short perspective as a PSP Challenger.

I use the word ‘challenger’, as I feel that the words ‘patient’ and ‘suffer’ have too many negative connotations! I was diagnosed with PSP approximately 5 years ago (at the young age of 43). This diagnosis came after a battery of examinations by my neurologist and his colleagues at the QEH (Adelaide). I was referred initially due to a balance problem experienced on shiny floor surfaces. This balance issue, together with a general slowness in movement (i.e. I use to run marathons, half marathons, and compete in triathlons), resulted in me seeking medical advice.

After ruling out a range of medical conditions, my neurologist suggested that I was in the early stages of PSP. Like many, the first source of information I went to was the Internet – not a smart move! Information gathering, asking questions, and having family with a medical background assisted in this process. I attended the first conference at the Kingston Medical Centre (Melbourne) regarding PSP. Once again, I was on a search for answers. The conference was well attended by a range of health professionals, carers and PSP patients. At this stage I didn’t include myself as a ‘patient’ – I suppose you could call it denial – one of the many stages along this journey of acceptance. Although informative, I came away feeling somewhat saturated by negative information regarding the stages of the condition and how to support the family and carers, however very little time was given to the person themselves, i.e. their feelings of frustration, anxiety and uncertainty. Yes these feelings and emotions were acknowledged, however an insight from a person diagnosed with PSP was lacking.

After this conference, I sought the professional advice of a clinical psychologist in a bid to gain a benchmark of my level of cognition – this to me was critical, given my age, family situation, and employment. Whilst there was an indication of depression, and slowness in recall of information, there appeared to be no other memory issues.

For my next source of information gathering I was off to my specialist to request an MRI scan of the brain. Unfortunately the results were not as promising. This MRI scan reveal a reduction in size of the brain consistent with the diagnosis initially given by my neurologist and his colleagues.

As mentioned above, it is almost 5 years since the first diagnosis of the condition. At present I have been able to maintain my employment (Disability Adviser for Department of Education), and through a positive approach, maintaining a high level of fitness and general understanding from those around me, I have and will continue to rise to the challenges presented by this complex condition. I believe there are others worse of than myself, and through my work and support of my godson who is autistic and profoundly deaf, I have been able to put my condition to the background in a bid to empower those experiencing greater challenges than myself!

Given that the majority of medical documentation re PSP focuses on individuals aged 60+, I thought that readers may like to gain an insight into the thoughts of a younger challenger of the condition. I wish all of the readers well in their search for total wellbeing – what ever this may be!