An Interview With Marion Carlisle

Q:	Tell us a little about yourself and your polio journey

My mother is very sure I had polio when I was 2 (1960). She said it was the worst week of her life, though I was not hospitalised. I recovered with slight walking impediment for a year. Then apparently nothing until I was 39 when symptoms started: unexplained temperature rises, progessive fatigue.

Q:	When did you first realise you had PPS?

I self-diagnosed P.P.S in 2003 (age 45) after reading Dr. Bruno's *'The Polio Paradox'*. So much in his book rang bells. There was the gradual onset of unexplained symtpoms in my late '30s. The fact that all blood tests fell into the 'normal' range and yet I could hardly function at all sometimes.

Q:	How did you get a diagnosis?

I've been living in West Wales since 2002 and haven't had any official diagnosis or seen any expert in the field. My local GP accepted my self-diagnosis but apart from prescribing Q10 on the NHS, I've had no medical help.

Q:	What has helped you to cope?

I've been following protocol for M.E. / C.F.S patients, ie pacing, supplements and a low carb / high protein diet for many years. Accepting limitation rather than fighting it has been a key. Although I don't need physical aids and can walk OK, new arm weakness means I don't lift heavy things – including a half-full kettle. A background in meditation, being in the 'here and now' as much as possible helps me to accept what I can't change. Perhaps mental fatigue is the most challenging – not able to read or engage socially when I'm very exhausted. Then re-charging the batteries, alone and doing nothing is the only help.

Q:	Is there anything that our members can help you with currently?

Yes, I wonder if any other members have experienced constant tingling sensations, like pins and needles. This tingling started just in the soles of my feet, then progessively moved up my body. This used to disappear with prolonged rest. Now the tingling never goes away and is my whole body, including my head. I also experience a strong pulse in my adrenal area, especially in the night and on waking. There seems to be no medical reason for this.

Q:	What one piece of advice would you give to other polio survivors?

I know I'm not facing challenges like many polio survivors. I can walk and have been working part-time musically for the last 10 years, finding more strength by sticking to the diet and supplements protocol. So advice? Not really. I'll just say that feeling empowered – in whatever way that means for a person – is vital. Celebrating ones talents, however small. Enjoying the world around – the elements, the natural world and being able to receive and give to others. Also spiritual gifts are so important. Through undergoing limitation (not something I'd wish on anyone), I'm more receptive to the essentials in life. There is a silver lining in having to let go ambition!