

## **THE FOUNDING OF THE SCOTTISH POST POLIO NETWORK (SPPN)**

In the late 1990's I began to experience the late effects of polio. I wrote about this time in my book "A Balanced Way of Living; Practical and Holistic strategies for Coping with PPS". This is how I felt then ;

" I had always led a very active life in spite of having had polio as a baby and wearing a caliper as a result of the disease. Even though I managed to achieve a great deal there were always more hurdles to overcome - gaining a degree, travelling, learning different skills including those involved in becoming a mother; all of these experiences

were rewarding but there were always, metaphorically speaking, more mountains to climb! When I was 30 I embarked on training to become an acupuncturist and after 3 years gained my license to practise. Working full time with 4 kids under 10 was challenging but did not phase me - I even found time to go swimming every other day and gave time to various committees! Of course I was on a merry go round that got faster and faster until it spun out of control. My poor old body was not prepared to keep up the hectic pace I had set it and with the symptoms of PPS becoming too strident to be ignored, I finally had to let go of pushing on and give myself a break."

At the time of writing those words at the end of the twentieth century, thanks to the techno revolution that had recently given us the internet, I was able to gather much information about PPS but still felt very alone in my search for answers. As I spoke to other polio survivors and recorded their stories to include in my book I began to realise that there were many of us out there and that we needed to get ourselves organised!

Billy was one of the first polio survivors that I interviewed for my book and I wrote ;

"Billy from Glasgow, is also finding a need to fight on behalf of polio survivors and he was in the process of setting up a polio support group when I spoke with him.

He had only recently heard of PPS but had been struggling with his health for years. Finally, due to an article in a local newspaper, he was relieved to discover that the label of PPS could explain the underlying cause of his deterioration. When Billy contracted polio at 3 years old, he was put into an iron lung and when he came out it was to find that he needed to wear calipers on both legs. As he got older he managed to get by with only one caliper and being the fighter that he is, he "went into automatic" as he put it, working hard as a housing manager for the local council and bringing up 5 children. This tendency to get on with life and take on its challenges without a moment of hesitation, is by no means curtailed now that Billy finds himself in a wheelchair in his forties as a result of PPS. He is "angry and annoyed" to find that many health professionals have not heard of PPS and wants to change this for himself and other polio survivors by campaigning for more awareness of PPS."

Meeting with Billy and hearing his story was in fact the start of the SPPN although neither of us realised it at the time!

Thanks to the sterling work of Hilary Ann Boone (Hallam as she was then) and through her organisation the Lincolnshire Post-Polio Network - LINK-PIN--I connected with another Scottish polio survivor-- Agnes Walker from Edinburgh. Agnes had a wealth of experience when it came to practical organisational skills and it soon became clear that she and I and Billy should all get together and see if we could create a support group of some sort. And that was how 20 years ago the core group that became the SPPN met to share experiences as polio survivors with PPS and also to have a laugh, a blether and light refreshment at a very cosy pub just outside Stirling. A few more local polio survivors members joined us from Glasgow and like Topsy our group grew and grew!

As time went by we formed a committee and thus the SPPN became a registered charity. From those very early days we decided not to be a “moan and groan” group. Although we were there to share our frustrations with regards to living with PPS and also with regards to the lack of support from the medical world we decided at that first meeting that we were not there to have a griping session! Our commitment from the start was to campaign to raise awareness of PPS and to act as a source of advice for new and existing members, other polio survivors and their families. Furthermore we were keen to campaign for a central “one stop shop” to provide treatment for PPS. In effect our aims and objectives were and still are; to give people who have had polio the most up-to-date information about Post Polio Syndrome, to inform medical professionals of best practice, to campaign for recognition of Post Polio Syndrome and to ensure the model of best practice and conservation of mobility is practiced.

In all of this we were very much supported and advised by the very helpful Dr Richard Bruno, a research and clinical psychophysiological trained at the New York State Psychiatric Institute. In 1984 Bruno founded the International Post-Polio Task Force, which promotes PPS research, education and treatment in 25 countries. Dick Bruno had helped me hugely to write the “science” part of my book so it was natural to ask him to be the patron of the SPPN and we were delighted when he agreed and he has continued as patron of the organisation to this day.

The founding of the SPPN was exciting stuff and I loved being part of it all. However eventually I decided I could no longer remain on the committee –I needed to “walk my talk” and stop taking on too much –again! With family and my acupuncture practise commitments I needed to let go of all that I had helped to initiate and it was a wrench but it had to be done. Nevertheless I feel proud that the SPPN continues through the hard work of so many good people.

In 2005 the SPPN took its campaign to the Scottish Parliament where it became well supported for many years by the marvellous MSP Margo MacDonald until her death . She is sorely missed and no one has replaced her in our challenge to get better support for polio survivors in Scotland. Now with the Covid pandemic taking top priority I fear our voices will not be heard by those in power who could help. And as time goes by we survivors of polio are fewer. But on we go and every year the SPPN holds a conference (not this year due to Coronavirus!)to which many polio survivors come and hopefully they go away feeling advised, informed and supported. From the day when Billy, Agnes and I met together and decided we needed to do something to help ourselves, the SPPN has put information about PPS out there to help those experiencing the late effects of polio. It also informs medical professionals of best practice --some of whom were not even born when polio epidemics were around and thus need some input from us polio survivors! And thanks particularly to Hilary Ann Boone for being the link that connected me with other Scottish polio survivors all those years ago!

Vicki McKenna is the author, as acupuncturist and polio survivor of “A Balanced Way of Living; Practical and Holistic strategies for Coping with PPS”.

To purchase a copy see [www.postpolioinfo.com/balanced\\_way](http://www.postpolioinfo.com/balanced_way).