

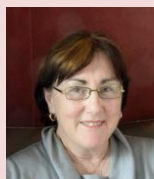
Parkinson's is all about balance

Sara Riggare

organiser being Christine Belford, Chief Executive Officer of Parkinson's South Australia. Australia is a country of less than 24 million people spread across six states and two territories. 400 people attended the conference, more than was expected. There were seven people from New Zealand and one person from England as well as participants from throughout the country.

I came away with positive impressions about the future for most people with Parkinson in Australia. The services available vary from state to state. Not surprisingly this annoys some people. They notice what they lack in comparison to others. Of particular note are the challenges of meeting the needs of those in very isolated areas. However, though each state is independent there have been positive moves to build national cohesion and work together on common issues. It was good to note the positive working relationship between the Parkinson research organisation Shake It Up Australia, and Parkinson's Australia.

The Conference byline 'In This Together' is also the banner used by the State and National Organisations. Internationally it is increasingly being acknowledged that we need to see all members of the Parkinson Community as significant and equal players in working for better treatment and a cure for Parkinson's. 'In this Together' captures this vision well. Achieving results for people affected by Parkinson's will come about with us recognizing that we are all in this together, researchers, practitioners and people living with Parkinson's.



Dilys Parker was diagnosed with Parkinson's in 2008 while she and her husband John were living in the UK. They have now returned to New Zealand. Dilys is a World Parkinson Congress Ambassador and is also involved with Parkinson activities in NZ locally and nationally. Parkinson related activities plus family occupy most of her time. She and John share their house with extended family as they have what she calls boomerang children who keep returning home.

"Mummy, is Parkinson's contagious?" In her own way my daughter, Frida, had been interested in Parkinson's research since she was about five or six years old. And rightly so, as she was only 4 months old when I was diagnosed. "You have Parkinson's," the neurologist said, "Have a nice day." The neurologist's words literally made me feel like I had fallen into a black hole . . . I thought that I would never smile again.

In fairness, my diagnosis of a neurological disease on that day not long after my 32nd birthday, was not like a bolt out of the blue. I had known that there was something wrong with the way my body had been responding since my teens. Nevertheless, hearing from an expert, a neurologist, that I, the mother of a beautiful baby girl, had an "old person's disease" did come as a shock to me.

My darling Frida is now a very clever and funny 12-year old with a beautiful singing voice who makes me smile a lot, every day. And I have long since climbed out of that black hole. Frida has always known that I don't move as well as other parents, and that I sometimes get tired and need to rest. We talk very openly about Parkinson's in our family, and I think that she feels comfortable enough to ask me anything Parkinson-related.

Five years ago, having spent a considerable amount of my time after my work as an engineer on learning about Parkinson's, I decided to try making my disease my day job. I wanted to combine my patient experiences with my engineering skills; my dream was to work together with researchers to try to improve the quality of life for people with Parkinson's. Encouraged by my husband, I applied to enter a masters program in health informatics at Karolinska Institutet in Stockholm, where I am now a doctoral student with my field of research as selfcare in Parkinson's. I am looking at how we can use our own observations to learn about and improve our condition,



sometimes aided by different kinds of technology like apps, sensors or other devices.

My most difficult Parkinson's symptom is freezing-of-gait, and I am exploring this problem from a lot of angles. I find that physical activity and customised exercises helps, and I also read a lot of scientific articles to learn as much as I can. Both Frida and my husband are very engaged and often help me try out new options that might help. It is very true that Parkinson's not only affects the person with the disease, but the whole family, and probably more so when the children are not yet grown up.

When walking around town, Frida is like a watchdog, constantly looking out for potentially difficult situations where I might freeze. She is really good at it and very often warns me even before anything happens. She is very quick at helping me when needed, and I really appreciate that. But of course, I would prefer it if she didn't have to help me, which is my biggest motivator - I do everything I can to stay well for Frida's sake - I want her to not have to help me when we are out walking!

I would love for my daughter to NOT know as much about Parkinson's as she does; but since I

cannot take away Parkinson's from our family, I think it is very important to be open about what Parkinson's is and how she can help me if so desired. Just the other day, Frida told me that she doesn't think my Parkinson's is a big problem to her, and I take that as a confirmation that I am doing something right and haven't put too much Parkinson's in her life even though I made my disease my career. I seem to have found the right balance between life with Parkinson's in the family and researching Parkinson's at work, which is very good. Because Parkinson's is all about balance. Literally.



Sara Riggare, an engineer by training, experienced her first symptoms of Parkinson's in her teens but was not diagnosed until her thirties. A committed patient advocate, she is currently a doctoral student at the Karolinska Institutet working towards her PhD on personal health observations.

