



My MS journey began almost 30 years ago when I was in my mid-20s. I was a graduate Architect working in the design office of a Construction Company in Hastings. It started with a weird tingling sensation in my feet. After several visits to my GP and other health professionals, I was referred to Neurology at Hastings Hospital and after a lumbar puncture, it was concluded I had 'probable' Multiple Sclerosis. MRIs were pretty new then and I wasn't eligible for one under public funding so I lived with having probable Multiple Sclerosis and constantly tingling feet (and torso by then).

About 5 years on my next exacerbation hit - tingly hands, not great for an Architect that drew by hand. By then Hawke's Bay had an MRI scanner and that confirmed my Relapsing Remitting MS diagnosis.

That pattern continued, an exacerbation every 4 or 5 years; continued tingling sensation, balance and coordination issues, fatigue, bladder and bowel control issues, foggy memory - thankfully no eyesight issues. I have been on Baclofen for many years and it certainly helps with spasticity.

Mid 2008, I attended an MS family Camp in Hawke's Bay with my 2 preteen kids. At that camp was the MS Waikato Client Services Manager, Liz, who was sussing out how the camp was run. Little did I know I would shift there the following year!

Moving to Hamilton the support from MS Waikato was great. My new partner knew little of MS and MS Waikato information evenings were a good way for him to learn more. However, with the slow progression of my disease and NZ system of funding drugs I was never eligible for any disease modifying medications.

Around 2015, another exacerbation (big fatigue hit and leg strength issues), another trip to Neurology and the news I still wasn't eligible for any funded meds. The Waikato DHB were about to take part in a double-blind MS trial, I jumped at the opportunity. I was on Beta interferon for the first 15 months of the trial and then the trial drug RPC1063 (now known as Ozanimod) on open label trial for about the next 6 ½ years, regular MRIs show I haven't had an exacerbation since.

Sadly, my mobility has deteriorated in the last few years, but I lived with MS without being on any meds for a long time. I started on Fampyra to help leg strength a few years ago when I discovered the generic version cost made the non-funded medication much more accessible. I stopped taking it for a few days recently and it certainly makes a difference for me.

By the end of the Ozanimod trial, criteria for funding of MS medications in NZ had changed and I started on Ocrelizumab just over six months ago. Have just had my second 6 monthly infusion, I am feeling good and very positive about my journey going forward.

I still work full time as an Architect, all my work is now on a computer, and I am lucky my chosen career doesn't involve a lot of physical activity. My partner David works part time and supports me hugely.

We love travel and purchasing my Travel Scoot has been an absolute game changer.

I have long been an active Rotarian; but have become a little less focused on Rotary as I became more involved with MS Waikato. I am now in my second year as Chair of the MS Waikato Trust Board and am thoroughly enjoying the role and 'putting something back'. I am in awe of the support that Liz and Karen give to our members and the fantastic way Janet manages to source funding to help run our organisation.

Keith

To make a donation - <https://fundraise.msanz.org.nz/faceofms/MS-waikato>