# *The Insidious Disease (Scleroderma) - Lynne Lamerton-Quinn*

*In 1992 I was diagnosed with Scleroderma. The diagnosis came after blood tests ordered by a dermatologist who was treating me for an ulcer on my finger. I had been suffering from Raynaud's Phenomenon for about four years.*

*My son had just started school and my daughter was in Year 2. I was 44years old. We knew a colleague who had been diagnosed with scleroderma so we were aware of some of the visible effects but not much else. After the numerous tests – lung function, chest CT scans, ECG, stress echo and blood tests at St Vincents Hospital, Sydney, I was put on a monitoring schedule where I saw the specialists every three months.*

*At that time my only concern was that I had Raynaud's and that I began to feel the cold much more. I could still do my daily three kilometre walk and keep up training my softball and hockey teams at school. One day in early 2001, on my morning walk, I became so breathless I couldn't continue. My doctor recommended me to the Scleroderma Clinic at Westmead where I underwent further test and was diagnosed with Pulmonary Arterial Hypertension (PAH). I remember reading that this was one of the associated illnesses of Scleroderma and that it caused heart failure. I was devastated.*

*I was prescribed Bosentan immediately but, of course had to do the six minute walk (which I still dread) and have a stress echo. At that time I could walk 480 metres without any stopping and my pulmonary pressures were 42. I now walk 100 metres, with a few stops and my pressures are in the 70's. My medications have changed several times and I've been on a trial drug which has helped a lot.*

***What really bugs me about this illness?*** *Winter! Taking so much medication and the fact that I won't ever go into remission. Also, I was always an active person, played a lot of sport – was playing hockey at the time I was diagnosed – loved to swim and walk. I really miss the fact that I can't go walking or chase my grandchildren. I miss catching that wave and going to places that require me to climb a large flight of stairs. I miss being able to use my fingers properly because of the painful ulcers. And I miss teaching.*

***How do I cope?*** *I stop to look at things or pretend to send a text to disguise my shortness of breath when I do go for a walk. I have a mobility scooter which is my independence – trips to the shop, doctor, hairdresser etc. I am able to still do most of my housework - in double the time it used to take - and I still enjoy "pottering" in my garden.*

*I have always had a positive attitude to most things and have found that this has been an enormous help. In 2011, I had an operation and contracted pneumonia following the anaesthetic. I then developed pulmonary emboli, had gross oedema, started bleeding internally and contracted a severe bowel infection. I was hospitalised for four weeks. I'm sure that it was the support from family, friends and staff and my positive attitude that helped pull me through.*

*There are times when "Why me?" creeps in but it doesn't last long and when it does I always have someone I can talk to or just "hang out with".*

*I am very lucky. I have a wonderful family – close and extended – and a tremendous group of friends. I also have a great group of people – doctors (specialist and GP), nurses, administrative staff and psychologists looking after me. All these people help to keep me positive through their love and care.*

*I have a grandson, 3 and a granddaughter, 2 and I intend to be a happy, loving Grandma for a long while yet.*

***Acknowledgements***

*I would like to thank the Autoimmune Resource and Research Centre for giving me the opportunity to share my story.*

*Keep your chin up,*

*Lynne Lamerton-Quinn*

## *Many thanks to Lynne for sharing your story.*