Good morning.

I have been living with scleroderma for 6 ½ years and this is my story.

Up until the fall of 2004 I had been a healthy, active person. I had an exciting and demanding career in the pharmaceutical industry, my children had grown and were on their own, and I was active in my local community. I travelled and enjoyed many hobbies. Becoming ill with a rare disease was something that I had never considered. My grandmother was still going strong, living in her own home at the age of 101 and I assumed I'd follow in her footsteps.

In October of that year I started experiencing some strange symptoms. My hands and feet began to swell. At first I had no pain, but as the swelling increased the pain began and it was an effort to move from sitting to standing. Breathlessness was soon added to the mix.

Thus began a much closer relationship with my family doctor. Instead of an annual visit I was now in his office every two weeks or so, feeling ill and frightened. I was still working, but feeling vague and exhausted I had to work harder and longer just to maintain the quality of my work.

After a variety of tests, one blood test provided my family doctor with a clue. He told me that he thought that I might have something called scleroderma, a rare disease that he had only seen three times before during his 25+ year career.

As you can imagine, I was shocked to hear that I might have a disease that was completely unknown to me. I immediately began to research and the information I found, combined with how terrible I felt, convinced me that I would not survive. And at that point I still had not advanced to my worst days with this disease.

On the May long weekend of 2005, I was having a shower when I couldn't raise my arms to wash my hair. I couldn't breathe and the strength seemed to seep out of my body and go down the drain with the water. Dripping wet, I got back into bed and stayed there. Fortunately my sister called later that day and next thing I knew she was there insisting on taking me to Emergency at my local hospital. We both thought that I must have severe pneumonia.

My resulting hospital stay provided me with confirmation that I did, in fact, have scleroderma with pulmonary fibrosis. Then, within 6 weeks my kidneys began to fail.

As the disease progressed my skin tightened until it felt as though it was two sizes too small for my body. Combined with swollen hands and feet, and breathlessness with any exertion, it was difficult to complete even the simplest task. My planned and happy life seemed a distant memory.

That was six years ago next month, but thankfully time and excellent medical care have kept my situation stable for now. I try not to think too far into the future.

My experience could have had a terrible final outcome. But during my hospitalization I had the good fortune to meet a Respirologist who recommended that I request a referral to the Firestone Institute at St. Joseph's Healthcare in Hamilton, and I believe that referral saved my life.

Scleroderma is an incurable disease, that's the bad news. The good news is that many of the symptoms, even the most life-threatening ones can often be managed if caught soon into the disease. The tricky part is to be fortunate enough in finding a doctor who recognizes and understands scleroderma and is knowledgeable about the various current treatment options.

Several of the medications that have returned quality of life to me did not exist a generation ago. In fact, it was not so long ago that scleroderma patients with kidney failure did not survive. It is since the advent of ACE-inhibitors, used to manage the sudden high blood pressure that causes kidney failure, that scleroderma patients can live well and have this symptom managed successfully.

I find it serendipitous that in May 2005, the month and year that I was diagnosed, the results of the Scleroderma Lung Study was presented at the American Thoracic Society. This was the first randomized, double-blind, multicenter study to show effectiveness for a drug in the treatment of scleroderma lung disease. It was also shown to improve skin tightness is some patients. Because of its side effects this drug is used cautiously, but for me it proved to be the silver bullet, stopping my fibrosis in its tracks and reducing the skin tightness quickly and dramatically. However, like most medications used to treat scleroderma, it is not 100% successful in all patients.

Scleroderma is not well known at this time amongst the general public or even the medical community. The formation of the Hamilton Scleroderma Group gives great hope that this will change. I know that the Scleroderma Society of Ontario is working hard to spread the word through its own communication vehicles and events.

Finally, I am truly thankful that I've had the opportunity to receive scleroderma treatment and care at St. Joseph's, specifically by Doctors Cox, Khalidi, and Carlisle. I'm hopeful and optimistic that a cure can be found for scleroderma for future generations and that this gift from the SSO will assist in improving the lives of people living with scleroderma everywhere.

Thank you.