



Let's give hope to Canadians with Scleroderma!

(Stats show 1 in 2500 have Scleroderma)

I saw walks happening across Canada so I stepped up to the plate to organize the walk-Alberta 2016. I live here in Sylvan Lake; I have Scleroderma, CREST and Systemic; I have had this disease for nearly 25 years. Over most of these years, I have known one other person with

Scleroderma; my twin sister Helen G in Manitoba - A familial connection?? Or the same trigger??? The AB Walk of 2016 changed so much.

Prior, I hesitated to talk about the disease, I was embarrassed...I met a friend of a friend who had Scleroderma so we met for coffee. So awkward, we were so different with Scleroderma. **She thought I did not look sick but inside I was.** But compared to her pulmonary issues plus others, who was the better off? I fought to keep this Scleroderma thing to myself but it was not working.

- I'd been struggling with tired/achy feelings that didn't go away,
- Esophagus/motility issues, swallowing hence eyes watching my slow eating, and dry mouth
- And then much later, A-Fib happened one day, which my electrophysiologist said had been caused by fibrous scarring, which was eventually cured by targeted scarring with a heat tool to the pulmonary veins where the A-Fib originated; I did my part with a medical study

I did however, have some health issues that showed up on the outside of my body:

- Reynaud's in my hands, white/dead man's fingers, which I did not like anyone to see,
- Very sore fingers which meant many trips to the ER, hard to start IV's, "You have what?"
- Swelling on my lower arms/hands, and bands of red, tight skin on both of my lower legs.

12 years ago, I was still in the "work for pay" world, I'd get unkind comments: "You're just like Michael Jackson???" but I thought wearing one glove was good if only one hand was cold; the Reynaud's did not mix well with the air conditioning inside. And on a personal level, people that knew about my Scleroderma would always ask, "how are your hands?" which I would get quite tired of becausethe disease was so much more!

I now take a proactive view of Scleroderma, my big goal is to increase public awareness, get the word out about SUPPORT. I feel there is so much to be done.

- I am involved with [Scleroderma Canada](#) (since 2015) and now on the executive
- I am keen to 'find' more patients and offer them support. I've discovered:
[Scleroderma Patient-Centered Information Network](#) [McGill University & Jewish Canadian Scleroderma Research Group](#) [General Hospital, Montreal](#)
- I've learned along the way how to cope with the disease also where to get info
- I've tried to take a holistic approach to treatment, by balancing exercise with physical ability, non-prescription meds along with prescription meds
- And most importantly a questioning mind, keeping abreast with medical options and still wondering why not much is done, the AB patient registry is not maintained, no special departments in our hospitals, staff do some research on their own

MY MOTTO: BE POSITIVE HAVE COMPASSION SPEAK OUT