

I have had scleroderma since June 2018. But for the past ten years, I was wondering what was wrong with me healthwise. I am a professional translator, cook and, for the past five years, grower of organic culinary lavender. Agriculture, small fragrant blue flowers, bees, the tides, agrotourism, my children are grown so, full sun responsibly since 2016.

The disease settled down quietly on one leg which became red "mottled-like", to eventually spread to my thigh. In 2009, I showed it to my family doctor who didn't know what it was. So I said, never mind, I won't be wearing shorts in summer. No problem.

In 2018, I joined a local Christmas Market here in Baie-Saint-Paul. My forehead was horribly itchy and I had a burning sensation. The plaque went from my forehead to my brow, and the following week it reached one eyelid, which became swollen and closed. Very pretty for a public market ☺ And my wrist and forearm, had linear plaques. Plus, I was always sick – one bout of flu after another – we try this for the forehead, that for the wrist, antibiotics for my cough. Nothing worked.

I had also moved my mother from Montreal, she was slowly falling into dementia at 90 years old. I was her only landmark. The clinic told me that I was exhausted, that I was suffering from depression. Not at all! Finally, at my fifth visit, the nurse welcomed me before I saw the doctor. She asked me what was wrong with my hands, "nothing", I said. "yes", she said, "show them to me." She inspected them for at least 5 minutes. The next day, she called and told me I had to see a rheumatologist.

I went alone. My rheumatologist took my left arm, turning it to look at my elbow, then my knee. Her assistant did the same. Of course, any trace of what I'd had on my forehead and left arm was gone after four months. After examining my cuticles with a probe, she explains that I have an overlap of scleroderma and / dermatomyosite. Bravely, I tell her that I don't really have time to be sick. That I would fight against these diseases I didn't even know. I jump on my computer as soon as I get home: phew, bad news this scleroderma. It is then that I found the Scleroderma Quebec. I didn't know anyone who had "that".

Recently, I had the leasure of being chosen to participate with the group SPIN-COVID. I loved it. I met people like me for the second time. I am happy to have new friends! We learned to smile again together in spite of the disease and COVID-19. From now on, we will stay in touch via WhatsApp. We share a sense of belonging.

I take Apo-hydroxyquine (an antimalarial), Oméga 3, and Amitryptiline for pain. That's all.

The only thing I surrendered to the disease is the freedom to go outside in full sun without being protected to the max. And I won't talk about my first sunburn. On the tops of my feet. Horrible. I avoid the lavender field between 11:00 a.m. and 2:00 p.m. In summer, I drive with a light chale over my left side.

I have become a skier during nice weather only. Same thing for other sports. And following my doctor's recommendation, I cut solanaceae from my diet to maybe help fight rheumatism. Gluten also. I cheat sometimes: life is short and nothing is more reassuring than a good "air" of toast.

I consider myself lucky: the disease progresses rather slowly. But I see. I notice. I do my best to stay in shape. And nobody in my circle knows about it except my husband, my children, my best friends. This is my coming out, with you. Looking forward to meeting all of you.

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