RARE VIEWS

Scleroderma

Maureen Sauvé was diagnosed in 2002 with Scleroderma, an autoimmune connective tissue and rheumatic disease that causes inflammation in the skin and other areas of the body. Since that time, she has had a tremendous impact as an advocate for people living with Scleroderma in Ontario, across Canada, and internationally. Maureen is currently the Vice President of Advocacy and Public Relations for Scleroderma Canada and Co-Chair of the SPIN Patient Advisory Board, which was launched with seed funding from the Scleroderma Society of Ontario and Scleroderma Canada.

Q. **Looking back from the time you were diagnosed, is there something that you would have done differently or wished you had learned sooner?**

A. My greatest regret was not fully appreciating the impact of this illness on my daughter, Lauren. She was ten years old when I was diagnosed. I was putting her to bed one night and she asked me, "Mommy, are you going to die?" I replied, "We are all going to die someday, but I don't plan on dying any time soon." I thought this was the best answer I could give her at the time. She saw the changes...lack of energy, weight loss, difficulty eating and heightened emotions in the house, but over time we all adjusted to a 'new normal'. However, when she was about 15, she seemed to be angry with me all the time. I later learned that Lauren thought that I was a hypocrite because whenever people asked how I was doing I said I was "fine" but, in truth, there was nothing fine about Scleroderma. Lauren had been doing her own research on the internet but didn't want to talk to me about it.

Q. **How has living with Scleroderma affected your day-to-day life?**

A. Managing my energy, difficulty sleeping, dexterity issues with my hands, and managing reflux are among the myriad of ways in which Scleroderma affects my day-to-day life. The reality of the day to day living with this disease is that you cannot predict how today or tomorrow will go. Some days are fabulous, and you can almost forget that you have an illness. Other days are exhausting grinds as you try to get through the list of 'must do's'. Starting the day exhausted is hard. This is challenging for others to understand, as you don't always look as ill as you are.

Q. **Other than a cure, what do you think is needed to help the Scleroderma community?**

A. Better education and awareness for healthcare providers is needed. This is a complex disease that is complicated to treat, and not all healthcare providers have sufficient knowledge. This is a tremendous concern and underlines the critical need for treatment by multi-disciplinary teams.

Q. **How can stakeholders help advocate for patients and caregivers with Scleroderma?**

A. Raising awareness and understanding of the complexity of this rare disease is needed. There is a tendency to look at the individual aspects of this illness in isolation. Our patients need multi-disciplinary teams to formulate treatment plans that consider the totality of the illness impact. There is also a critical need for greater speed in accessing treatments in this community in terms of both health-related quality of life and mortality. This is a tremendously complicated illness with many co-morbidities. We cannot look at one element of the disease, such as Pulmonary Hypertension, in isolation when making treatment and funding decisions. We have argued for some time that some of the barriers to treatment that may make sense for someone with idiopathic disease, do not make sense within our patient population that have co-morbidities. For example, someone suffering from Pulmonary Arterial Hypertension and Interstitial Lung Disease should not have to wait for 6 months taking a treatment that isn't working, before being allowed access to the more expensive drugs that are available. These step therapies do not always make sense for our patients with faster progressing disease and higher mortality rates.

Q. **What advice would you give to someone who is in the initial stages of diagnosis?**

A. Do not imagine the worst. There are treatments that help you manage the effects of the disease, and new treatments in development. There is hope! Get referred to a doctor who has a special interest in Scleroderma. They are the most up to date on treatments and research. The first two years are probably the hardest as you and those you love adjust to your new reality. Be patient with yourself and others as you learn to wrap your head around the uncertainties that you will have to live with. Find a support group because they are a tremendous resource as you learn to cope with the day-to-day impact of Scleroderma.