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## My Journey: Lee Durdon, President and Founder, Sjogren's Society of Canada



Sjogren's Syndrome is the second most prevalent autoimmune disorder that few have heard of. Sjogren's takes an average of 5–9 years to be diagnosed. Sufferers may not look sick on the outside adding to the delay in diagnosis. Affects 430,000 Canadians; 3 x more than Multiple Sclerosis and Lupus; and 9 out of 10 are women, but men and children also suffer.

After a long road and finally being diagnosed with Sjogren's Syndrome several years ago, I was fortunate to find excellent doctors and excellent care, but it still wasn't enough. As many of us living with Sjogren's are all too well aware of, just as we seem to get one symptom under control, another equally annoying, disruptive, painful symptom appears or an unwanted one returns again. The unpredictability of Sjogren's is particularly difficult to live with. So goes the journey.

I felt I owed it to my husband and family but more importantly, I owed it to myself to find a way to try to live a better life or even have a life with Sjogren's. I needed to find support from other people with the same disease that could understand the daily difficulties and the emotional roller coaster that I was experiencing. I'd never heard of Sjogren's before, I didn't know anyone with this weird disease that I couldn't pronounce nor were there any resources available.

This group's inception started out of pure frustration and selfishness. Little did I know at the time that the secret to helping me was by helping others!

With debilitating fatigue and many systemic problems, I reluctantly started the first support group in Ontario in 2005 with the support of my doctors and the US based Sjogren's Syndrome Foundation. I felt for the first time that I could cope and live with my disease even with its ups and downs with the support from others. My wonderful specialist was agreeable to my idea of inviting a US specialist to do Medical Grand Rounds at McMaster University Medical School. I arranged healthcare professionals to speak to our group.

People came from all over Ontario to my Southwestern Ontario support group and I soon realized that much more was needed in Ontario and Canada and as a result, the Sjogren's Society of Canada (SjSC) was formed in 2006. An excellent multi-disciplined Medical Advisory Board comprised of leading experts was recruited and a dedicated Board of Directors was formed. The Sjogren's Society was incorporated in 2008 and became a Canadian Not-for-Profit Organization intent on improving conditions for people living with Sjogren's Syndrome and putting a human face on this debilitating, and all too often, dismissed disease. The SjSC's mandate is to provide patient support and education; increase professional and public awareness; support and raise funds for Sjogren's related medical research and a cure.

Sjogren's ("SHOW-grins") syndrome is a systemic disease in which the body's immune system mistakenly attacks its own moisture producing glands. The hallmark symptoms are dry eyes and dry mouth, but it is a systemic disease, affecting multiple organs causing extreme fatigue, muscle aches, arthritis, low grade fever, nerve damage, thyroid inflammation, lymphoma, reduced quality of life and other incapacitating complications.

Nine out of ten patients are women ages thirty-five to sixty-five, but children and men can also suffer from the disease. It is not easily diagnosed and on average, can take five to nine years. Tennis player, Venus Williams was finally diagnosed in 2011 with Sjogren's Syndrome after searching for almost six years. Sjogren's syndrome is often misunderstood, misdiagnosed and underestimated.

Although symptoms may vary individually, we can say that living with the hallmark symptoms of Sjogren's alone impacts every aspect of a person's life including everything one enjoys doing, needs to do and their involvement in society.

About 50% of the time Sjogren's syndrome occurs in the body alone, and 50% of the time it occurs in the presence of another connective tissue disease such as Rheumatoid Arthritis, Systemic Lupus, Scleroderma and Polymyositis/Dermatomyositis. All instances of Sjogren's syndrome are systemic, affecting the entire body.

Most people have suffered in isolation trying to cope with their myriad of symptoms never having met another person with Sjogren's. Awareness is the key to earlier diagnosis and improved quality of life; while delayed diagnosis causes more serious side-effects such as organ damage, life-threatening complications and lymphoma in Sjogren's syndrome patients.

Awareness goes hand-in-hand with research. We have funded nine small, but important studies, in our short existence. Much more is needed. New treatments and therapies need to be found.

We host an annual national conference each spring and in 2013, we held our first multidiscipline accredited conference (CME and CE) for professionals. We continue to increase our support groups across the country. In 2012, we were awarded a grant to provide an interactive webinar workshop for current and prospective Support Group Leaders and Contact Persons; and an interactive educational webinar on Sjogren's Syndrome, and for many across Canada, this was their first opportunity to learn about Sjogren's and know that they are not alone. The third part of the grant was to develop a video/public service announcement on Sjogren's Syndrome to help increase awareness about this overlooked and complicated disease which affects so many Canadians.

I continue to hear from people with a wide-range of issues. Their individual Sjogren's symptoms may vary but the stories remain the same. They have never heard of Sjogren's before nor met anyone else with the disease. People have difficulties accessing knowledgeable doctors and specialists; had their symptoms dismissed or been told it's all "in their heads" and/or been told that there is nothing that can be done; healthcare professionals – including those in emergency say, "you have what? I've never heard of that before". Many healthcare professionals still believe that Sjogren's is dry eye and dry mouth and how bad can that be!!

This group has grown and morphed into something much larger than I first dared to dream but there is so much more work to be done. We have made a tiny dent. Conditions simply need to improve for people living with Sjogren's and those seeking diagnosis in Canada. Sjogren's needs to become a household name! ...And so the journey continues...

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**Affecting up to 430,000 Canadians!**

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