SJÖGREN’S SYNDROME FACTS

Sjögren’s syndrome (“SHOW-grins”) is now recognized as the second most common rheumatologic disease yet the public, and many in the medical community are still unaware of this serious condition.

Sjögren’s syndrome is a chronic autoimmune disease in which white blood cells attack the moisture-producing glands. The hallmark symptoms are dry eyes and dry mouth, but it is a systemic disease, affecting many organs and may cause severe fatigue. It can spread throughout the entire body.

Sjögren’s syndrome is estimated to affect up to 1% of the population and the Canadian Arthritis Society estimates that there may be as many as 430,000 Canadians affected by the disease. Ninety percent are women between the ages of 35 – 65 but children can also be affected. This multi-faceted disease is difficult to diagnose and manage. On average, it can take 5 - 9 years for diagnosis. Sjögren’s is often misdiagnosed, under-diagnosed and under-estimated.

It is sometimes confused with Multiple Sclerosis or other autoimmune diseases as symptoms are similar. This major women’s health problem is under-diagnosed, under-treated and misunderstood by most professionals and virtually unknown by the Canadian public.

The severity of symptoms among Sjögren’s patients varies almost as much as the symptoms themselves. For some, their symptoms are so severe that chronic fatigue or the inability for those with dry eyes to work in front of a computer forces them to leave their careers and go on long-term disability. Severe dental decay can also occur. From dental care and implants to over-the-counter eye drops and medications to alleviate the painful symptoms, Sjögren’s is an expensive disease to manage.

Other common symptoms include dryness of the skin, lungs, vaginal tissues, sinuses and gastrointestinal tract; joint and muscle pain; swollen glands; chronic fatigue and numbness.

There is an increased risk of developing non-Hodgkin’s lymphoma (lymph node cancer). There is a 44 times greater incidence of non-Hodgkins in Sjögren’s patients as compared to the general population. Lymphoma may occur in up to 10% of patients. Additionally, about 50 percent of Sjögren's patients have another autoimmune disorder like lupus or rheumatoid arthritis.

Often times Sjögren’s symptoms may come and go or don’t seem severe enough to warrant a visit to the doctor. Patients may talk to their dermatologist about a rash or their ophthalmologist about their dry eyes, but because the physicians are not interfacing or may be unfamiliar with Sjögren's, it may take a while for the pieces of the puzzle to come together.

One of the obstacles to diagnosing Sjögren's is that there is not one simple test to identify it. Fortunately in 2002, a set of objective criteria was developed to identify Sjögren’s. Through subjective and objective measures which include patient interviews, blood work, a lip biopsy and tests that determine salivary and lacrimal (tear) function, doctors are able to determine if patients meet four of six criteria to make a diagnosis of Sjögren’s.

Finding a physician who is familiar, current or knowledgeable about Sjögren’s can be problematic. It is not easily diagnosed as Sjögren’s can mimic other diseases such as multiple sclerosis and lupus. The “invisibility” of the disease may add to the delay in diagnosis or not to be taken seriously by professionals. Additionally, lack of awareness adds to delayed diagnosis causing more serious side-effects such as organ damage, life-threatening complications and lymphoma in Sjögren’s syndrome patients.
Although the criteria are important in identifying many people with Sjögren’s syndrome, it is far from perfect and may miss many people with the disease. We anticipate that a new, more comprehensive set of diagnostic criteria will be developed in the next few years that will include systemic factors.

This multi-system disease requires many specialists and doctor appointments to manage it. Sjögren’s can be a costly disease as there are few treatments. Patients rely on expensive over-the-counter products that often provide minimal symptomatic relief, at best.

People take saliva and lacrimal tear secretions for granted but when flow is reduced, it can have some life-altering consequences. Imagine if you were unable to do your normal activities including using the computer, reading, walking, running, gardening or an activity with your family because your eyes were so painful it prevented you from participating. Imagine if your mouth was so dry it felt like it was filled with cotton balls and it was painful to swallow and talk. That describes part of daily life for people with Sjögren’s syndrome.

The exact cause of Sjögren’s is unknown but it’s believed that people inherit genetic tendencies to develop an autoimmune disease and that environmental triggers, such as a virus, bacteria, or even chemical exposure, could start the disease process. Sjögren’s is a chronic disease, meaning that it lasts a lifetime so treatments are designed to manage the symptoms, not address the underlying cause. We are hopeful that future treatments will be developed for Sjögren’s syndrome to keep the disease under control.

In 2006, determined to make a difference for newly diagnosed patients and people living with Sjögren’s syndrome, the Sjögren’s Society of Canada was formed by patient, Lee Durdon.

Sjögren’s Society of Canada is a volunteer organization and our mandate is to reach out and provide support and education for Sjögren’s syndrome patients and their families; increase professional and public awareness of the disease; and raise funds for, and spark much needed Sjögren’s syndrome related medical research, and find a cure.

Early diagnosis and proper treatment can prevent serious complications and greatly improve the quality of a person’s life. Increased awareness, education and research into the disease, and developing new treatments are the keys to helping thousands of Canadians suffering from Sjögren’s syndrome.

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*Working Together to Conquer this Serious Autoimmune Disease  
Affecting up to 430,000 Canadians!*