

**Testimony for the Compassionate  
Allowances Outreach Hearing on  
Autoimmune Diseases**

**Sjögren's Syndrome**

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Autoimmune Diseases – Sjögren’s Syndrome (1)

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Thank you for considering my experience with the second most common autoimmune rheumatic disease, **Sjögren’s syndrome**. I had never heard the term until, after years of seeking a diagnosis for my symptoms, I was referred to a Rheumatologist for extensive blood tests in 1997.

My story starts sixteen years prior to that in 1981, when I first noticed multiple occasions of dry, gritty-feeling, very red eyes; dry, bleeding nose; dry, cotton-like mouth and painful bleeding mouth sores; dry skin and extreme dry vaginal area, causing bleeding during intercourse with my husband and just walking. I suffered countless urinary tract infections. I was thirsty all the time and had to drink water, even throughout the night. Also, my energy would come and go. I had always been energetic, but it seems that suddenly, I could go “like a house a-fire” one day and “crash” the next, to use my husband’s terms. There were times that I could not raise my arms to wash my hair or walk upstairs due to weakness and fatigue. In 1989, I fell from a foot stool and broke both wrists, tailbone and neckbone. There was no evidence of osteoporosis. A few years later, I was walking and stepped on a manhole cover and broke my ankle. Again, there was no evidence of osteoporosis. I was on no medication. I was not a diabetic. Later I realized this was due to neuropathies caused by Sjögren’s where I couldn’t feel the ground beneath my feet.

I went to my eye specialist every time I experienced bleeding eyes (blood vessels burst in the eyes). He sent me home with non-prescription eye drops and told me to be careful of how much time I used the computer.

I went to my family doctor for multiple nosebleeds, and he passed it off as “just dry nose,” to pinch my nostrils to stop the bleeding and use vaseline for lubrication. I tried a series of vitamins in hopes of gaining more energy.

Whenever I went to my dentist for regular check-ups, the hygienist would ask what I was eating and drinking to have such a surprising build-up of plaque. I was told to rinse with salt water, floss and brush more often. I was asked to come for regular cleaning twice a year, which progressed over the years until now I go four times a year for cleaning. My dental plan partially covers one cleaning per year. I spend a lot of time in doctors’ offices.

I went faithfully to my gynecologist for regular check-ups. He did not support the use of hormones following my hysterectomy in 1979 and instead prescribed an over-the-counter vaginal cream for the dryness. Nothing stopped the bleeding.

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Because of an insurance change with my employer, I had to change gynecologists. This, finally, started me on my way to a proper diagnosis. My new gynecologist said I had a lot more going on than just vaginal dryness and recommended hormone replacement therapy which did help with the dryness. (But even before hormone therapy became controversial, I discontinued the prescription because of undesirable side effects. Sensitive reactions and side effects to medicines are not uncommon in Sjögren’s.) He then referred me to a rheumatologist.

The rheumatologist ordered extensive blood tests and declared that I had lupus or Sjögren’s and told me to contact the Arthritis Foundation for literature to read about those autoimmune diseases. He told me to stop chewing my gum which contained sugar and would increase my tooth decay. I felt like I was on my own because each question I had for him, he shrugged and didn’t give an answer. While I was relieved to have a name put on all these multiple symptoms, I was very frustrated and started investigating on my own. I read a short discussion of Sjögren’s in a Rheumatoid Arthritis pamphlet. There was nothing on Sjögren’s anywhere to be found in our local library, but I did find a paragraph on it in a medical dictionary. That’s when I realized the need to learn more about this puzzling and devastating disease.

In the course of a conversation with a client, my daughter found out that the client had been diagnosed with Sjögren’s and could recommend a good rheumatologist who knew about the disease. I waited four months for an appointment and was very grateful for his knowledge about Sjögren’s and interest in my case. He did even more extensive blood tests to determine which autoimmune disease I had and concluded that due to my symptoms it was Sjögren’s syndrome. He has recommended the prescription medication plaquenil for the fatigue, but with my history of allergic reactions to medication, I am hesitant to try it. He urged me to find an eye specialist and a dentist who had knowledge of the disease. He also referred me to the local Sjögren’s support group, so I could meet other patients with this disease.

The first thing I did was to return to my former eye specialist (who is well known and respected) and let him know that my eye condition was actually a result of extreme dryness due to Sjögren’s. Because of his lack of knowledge about the disease, he seemed unconcerned with my problem. My next step was to find an eye specialist who knew about Sjögren’s, and I was referred to a wonderful group of eye specialists who are very knowledgeable about the disease. They did a Schirmer eye test that showed such dry eyes that the litmus paper used in the test was completely dry. They also performed the Rose Bengal dye staining test which definitely pointed to extremely dry eyes. They put in temporary ductal plugs, then permanent, but one fell out. So now my lower eye ducts have been cauterized to keep whatever moisture I do produce in the eyes longer.

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I use a series of non-preservative over-the-counter eye drops four or five times a day. I perform eye scrubs twice a day, wear wrap-around sunglasses by day and clear motorcycle glasses on a windy night. Cold air hurts my eyes and has curtailed my ability to walk outdoors. One of the eye gels I used at night produced a rash and swollen eye lids. It took over two years of treatment and referral to university eye and dermatology clinics before we found out from my daughter’s rheumatologist in Virginia that the eye gel I had been using at night was the culprit. I was allergic to the preservative in the gel.

Next, I found a local dentist who taught at the Baltimore Dental College and was knowledgeable about Sjögren’s and urged me to have regular dental cleanings four times a year due to the plaque build-up. Between us, we have kept the incidence of new cavities to a minimum. It was recommended that I use two kinds of fluoride every day. I have found that special dry mouth products are available that contain no drying alcohol and are very helpful in keeping my mouth refreshed. The special gum is refreshing and keeps my mouth moisturized without adding sugar. My mouth sores are better.

I was then treated by Johns Hopkins dermatologists for a skin rash sometimes called Cutaneous T-cell lymphoma. I drove twice a week for light box treatments to their Green Spring facility. Prior to a diagnosis, I saw eight different dermatologists for the rash and used as many or more different prescribed or over-the-counter creams with no relief. While this type of lymphoma is unusual in Sjögren’s, the link with other lymphomas is clear, especially with B cell non-Hodgkin’s lymphomas, which occur in about 7% of those with Sjögren’s.

As for my energy level, I am now seeing an Internist/Integrative Medicine Specialist who has placed me on a course of supplements that are helping with my energy. I do have relapses and Sjögren’s flares that are debilitating and just have to give in to them by getting complete rest. I’ve learned to pace myself during the day and the importance of proper bed rest. Recently, I was very weak and had to give up most of my activities for a period of time due to fever, weakness, general malaise and an adverse reaction to an antibiotic. Thank God, I’m over that period now and have resumed former activities.

Ongoing symptoms include a form of peripheral neuropathy where I cannot feel my fingertips or toes and feet. I have pushed an elevator button and thought it was broken until someone else came along and pushed and it lit up. When I get up in the morning, I cannot feel the bottoms of my feet and my feet burn constantly. I am subject to sinus infections and have to take extra precaution by using nose sprays and humidifiers to moisten the air. My taste buds are compromised and I tend to oversalt, or dislike, food. I still experience urinary tract infections. I have to keep water with me at all times. Sometimes, I am immersed in brain fog where I am unable to bring up names and places that are very familiar.

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I have learned that autoimmune diseases run in families, and I am concerned about my children and grandchildren. In fact, my daughter has been diagnosed with Sjogren’s syndrome and Raynaud’s. We think that my mother died of kidney failure in 1990 due to Sjogren’s. This was undiagnosed at the time of her death even though she had all the classic symptoms of Sjögren’s.

As long as I am able, I will lead our local Sjögren’s Syndrome Foundation Support Group. We meet in the Baltimore area four times a year. There are many people in my support group who suffer much more than I do from this disease. Sadly, there are a few people missing from our group due to death from lymphoma and other symptoms associated with Sjögren’s. A few examples follow.

We have a fellow who was a court stenographer whose eyes were so dry and damaged due to Sjögren’s that he had to leave his job. He has been in and out of the hospital the past year for serious side effects from a drug used to treat his sinus infections. We have people in our group who depend on walkers to get around due to weakened leg and foot muscles and neuropathies associated with Sjögren’s. Some of us have debilitating joint pain that requires more than over-the-counter drugs to get relief, if any. Some people have to wear sunglasses indoors due to the light strain on their dry eyes. We are susceptible to corneal ulcerations and infections.

We also have people in our support group with symptoms that frequently overlap with Sjögren’s such as Raynaud’s syndrome and who suffer from other autoimmune diseases in addition to their Sjögren’s. (Sjögren’s occurs in conjunction with other autoimmune diseases more often than any other such disease.) Due to the lack of saliva, we have difficulty swallowing and suffer from heartburn and reflux esophagitis. We face abdominal pain and stomach upsets, gastroparesis and autoimmune pancreatitis. Some of us have abnormal liver function tests and may suffer from chronic active autoimmune hepatitis or primary biliary cirrhosis. Some have vasculitis that can accompany Sjögren’s.

The face of Sjogren’s is deceiving – we don’t look ill. This is a silent disease where our disease is not obvious. Unless we have extremely swollen salivary glands, one cannot see the war going on inside our bodies. One sage put it this way: “If I look so good, why do I feel so bad?”

Each one of us suffers in varying degrees from the dryness of Sjögren’s, but the one thread that affects each one of us is the **fatigue** brought on by Sjögren’s syndrome. When you are unable to pick up a pencil due to extreme fatigue, you are unable to do any job whether at home or in the work force.

Thank you.