Sjögren’s Fast Facts

- Sjögren’s is pronounced “SHOW-grins”.
- The hallmark symptoms of Sjögren’s syndrome are dry eyes, dry mouth, fatigue and joint pain, but the disease is systemic, affecting the entire body.
- Sjögren’s is one of the most prevalent autoimmune disorders, striking as many as 4,000,000 Americans.
- Nine out of ten patients are women.
- The average age of diagnosis is around 40 although it can occur in all age groups and in both sexes.
- Early diagnosis and proper treatment may prevent serious complications and greatly improve the quality of life for individuals living with Sjögren’s.

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What is Sjögren’s Syndrome?

Sjögren’s (pronounced SHOW-grins) syndrome is a chronic autoimmune inflammatory disease in which moisture-producing glands are damaged, significantly decreasing the quantity and quality of saliva and tears. The disease was first identified by a Swedish physician, Henrik Sjögren, in 1933.

Although the hallmark symptoms are dry eyes, dry mouth, fatigue and joint pain, Sjögren’s may cause dysfunction of other organs, affecting the kidneys, gastrointestinal system, blood vessels, lungs, liver, pancreas, and the nervous system. Patients also have a higher risk of developing lymphoma. Sjögren’s is one of the most prevalent autoimmune disorders, striking as many as 4,000,000 Americans. Nine out of ten patients are women.

About half of the time Sjögren’s occurs alone, and the other half it occurs in the presence of another connective tissue disease such as rheumatoid arthritis, lupus, or scleroderma. All instances of Sjögren’s syndrome are systemic, affecting the entire body. Symptoms may plateau, worsen, or, uncommonly, go into remission. While some people experience mild discomfort, others suffer debilitating symptoms that greatly impair their functioning. Early diagnosis and proper treatment are important — they may prevent serious complications and greatly improve a patient’s quality of life.

Visit www.sjogrens.org to learn more about Sjögren’s and the SSF.

What are the symptoms of Sjögren’s syndrome?

Symptoms vary from person to person but may include a dry, gritty, or burning sensation in the eyes; dry mouth; difficulty talking, chewing, or swallowing; a sore or cracked tongue; dry or burning throat; dry, peeling lips; a change in taste or smell; increased dental decay; joint pain; vaginal and skin dryness; digestive problems; dry nose; and fatigue.

Who is most likely to develop Sjögren’s syndrome?

Nine out of ten Sjögren’s patients are women. The average age of diagnosis is around 40, although it can occur in all age groups (including children) and in both sexes.

Is it easy to diagnose Sjögren’s syndrome?

Sjögren’s often is undiagnosed or misdiagnosed. The symptoms of Sjögren’s syndrome may mimic those of menopause, drug side effects, or medical conditions such as lupus, rheumatoid arthritis, fibromyalgia, chronic fatigue syndrome, and multiple sclerosis. Because all symptoms are not always present at the same time and because Sjögren’s can involve several body systems, physicians and dentists sometimes treat each symptom individually and do not recognize that a systemic disease is present. The average time from the onset of symptoms to diagnosis is over four years.
**What kind of doctor treats Sjögren’s?**

Rheumatologists have primary responsibility for managing Sjögren’s. Patients also are seen and treated by specialists such as ophthalmologists, optometrists, dentists and others as necessary to treat their various complications.

**How is Sjögren’s diagnosed?**

It can be difficult to diagnose Sjögren’s. No single test will confirm the diagnosis and, Sjögren’s may appear in many different forms in different patients. Physicians may conduct a series of tests and ask about symptoms. An international group of experts has formulated classification criteria for Sjögren’s which will help your doctor arrive at a diagnosis. These criteria consider dryness symptoms, changes in salivary (mouth) and lacrimal (eye) gland function, and systemic (whole body) findings.

**Blood tests you may have include:**

- ANA (Anti-Nuclear Antibody): Found in 70% of Sjögren’s patients and people with other autoimmune diseases.
- RF (Rheumatoid Factor): Antibody found in 60-70% of Sjögren’s patients and people with rheumatoid arthritis.
- SS-A (or Ro) and SS-B (or La): Marker antibodies for Sjögren’s. 70% of Sjögren’s patients are positive for SS-A and 40% are positive for SS-B. Also found in lupus patients.
- ESR (Erythrocyte Sedimentation Rate): Measures inflammation. An elevated ESR can indicate an inflammatory disorder, including Sjögren’s syndrome.
- IGs (Immunoglobulins): Normal blood proteins, usually elevated in Sjögren’s.

**The eye tests include:**

- Schirmer test: Measures tear production.
- Rose Bengal and Lissamine Green: Use dyes to examine the surface of the eye for dry spots.

**The dental tests include:**

- Salivary flow: Measures the amount of saliva produced over a certain period of time.
- Salivary scintigraphy: A nuclear medicine test that measures salivary gland function.
- Salivary gland biopsy (usually in the lower lip): Confirms lymphocytic infiltration of the minor salivary glands.

Your physician will consider the results of these tests and his or her examination to arrive at a final diagnosis. Further research is being conducted to refine the diagnostic criteria for Sjögren’s and to help make diagnosis easier and more accurate.

**What treatments are available?**

Currently, there is no cure for Sjögren’s syndrome. However, treatments may improve various symptoms and prevent complications. Prescription medicines for dry eyes and dry mouth are available. A number of over-the-counter products may also be used to alleviate different types of dryness. Immunosuppressive medications are used to treat serious internal organ manifestations.

**Will I die from Sjögren’s syndrome?**

Sjögren’s syndrome is serious but generally not fatal if complications are diagnosed and treated early. Sjögren’s patients must be monitored carefully for development of internal organ involvement, related autoimmune diseases, and other serious complications. In particular, patients should be aware that the incidence of lymphomas (cancer of the lymph glands) is significantly higher in people with Sjögren’s compared to the general population.

**Is there a cure?**

Not yet. But with your help, there will be.
Ways Sjögren’s syndrome may affect the body

- Neurological problems, concentration/memory-loss (brain fog)
- Dry eyes, corneal ulcerations, and infections.
- Difficulty swallowing, heartburn, reflux esophagitis
- Recurrent bronchitis, pneumonia, interstitial lung disease
- Arthritis, muscle pain
- Stomach upset, gastroparesis, autoimmune pancreatitis
- Vaginal dryness, painful intercourse

- Dry nose, recurrent sinusitis, nose bleeds
- Dry mouth, mouth sores, dental decay; difficulty with chewing, speech, taste and dentures
- Dry skin, vasculitis, Raynaud’s phenomenon
- Abnormal liver function tests, chronic active autoimmune hepatitis, primary biliary cirrhosis
- Peripheral neuropathy (numbness and tingling in the extremities)

Visit www.sjogrens.org to learn more.
Add your voice to the cause!

Join the Sjögren’s Syndrome Foundation today and provide another voice to increase awareness, educate others, and encourage research. With your help, we can conquer Sjögren’s!

To sign up as a member and start receiving our newsletter, complete the information below and send this form, with your check or credit card information, to the Sjögren’s Syndrome Foundation, c/o BB&T Bank, PO Box 890612, Charlotte NC 28289-0612 or by fax to 301-530-4415 (credit card payments only). Make checks payable to Sjögren’s Syndrome Foundation.

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