

What is the Sjögren's Syndrome Foundation?

The Sjögren's Syndrome Foundation (SSF) is the only national non-profit organization dedicated to fighting Sjögren's syndrome through research, education, and awareness. SSF supports and educates patients and their families, increases public and professional awareness, and encourages additional research into new treatments and a possible cure.

Join the SSF today and receive these great membership benefits (and much more)!

- ▶ *The Moisture Seekers* newsletter. Regarded as the outstanding source of current information on Sjögren's syndrome, this monthly newsletter contains the latest information on Sjögren's syndrome, practical tips for daily living, and answers to medical questions from the experts.
- ▶ Access to a network of knowledgeable volunteers and local support groups. These knowledgeable and empathetic individuals and fellow Sjögren's syndrome patients are invaluable sources of information about Sjögren's syndrome and the Foundation's activities.
- ▶ Exclusive access to the members-only section of www.sjogrens.org featuring resources unavailable to other site visitors such as archives of the most popular newsletter articles, our online product guide, and daily survival tips.
- ▶ Members-only discounts on a variety of products and services such as *The Sjögren's Syndrome Handbook, 3rd Edition (2004)* and registration for our educational conferences.
- ▶ Providing the Foundation with one more voice to increase awareness, educate others, and encourage research – all of which help in the fight to conquer Sjögren's syndrome. Annual membership donations ensure that the SSF can support its ongoing programs, including support groups, patient and professional education, and the funding of research.

of experts has formulated classification criteria for Sjögren's syndrome 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 syndrome 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 syndrome 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.

Sjögren's Fast Facts

- ▶ The hallmark symptoms of Sjögren's syndrome are dry eyes and dry mouth.
- ▶ 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 late 40s although it can occur in all age groups in both sexes.
- ▶ Sjögren's syndrome is treatable. Early diagnosis and proper treatment may prevent serious complications and greatly improve the quality of life for individuals living with Sjögren's syndrome.



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What is Sjögren's syndrome?

www.sjogrens.org

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 and dry mouth, Sjögren's also may cause dysfunction of other organs, affecting the kidneys, gastrointestinal system, blood vessels, lungs, liver, pancreas, and the nervous system. Patients may experience extreme fatigue and joint pain and have a higher risk of 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.

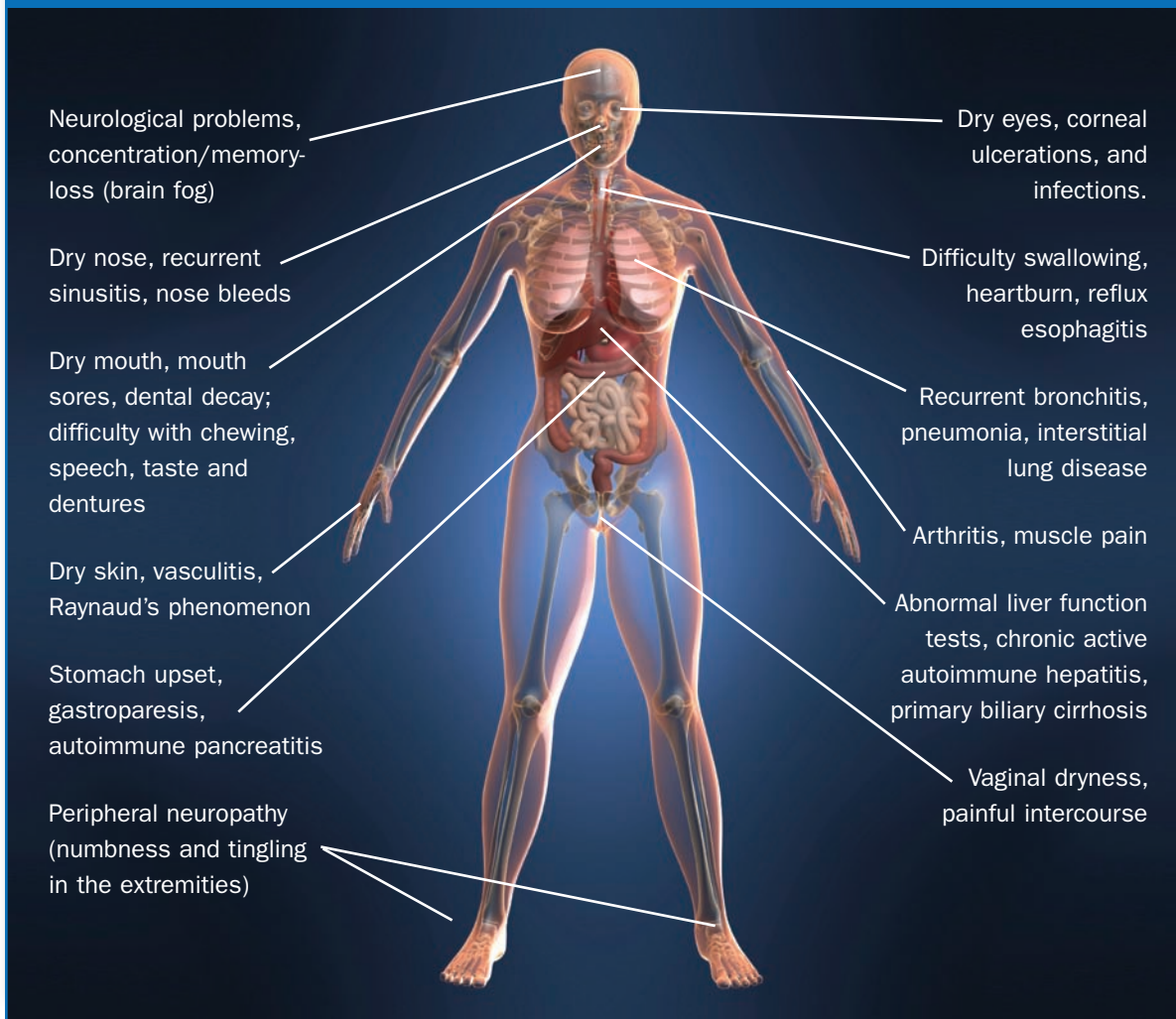
About half of the time Sjögren's syndrome occurs alone, and the other half it occurs in the presence of another connective tissue disease such as rheumatoid arthritis, lupus, or scleroderma. When Sjögren's occurs alone, it is

referred to as **"Primary Sjögren's."**

When it occurs with another connective tissue disease, it is referred to as **"Secondary Sjögren's."** 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.



Ways Sjögren's syndrome may affect the body



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 the late 40s, although it can occur in all age groups (including in children) and in both sexes.

Is it easy to diagnose Sjögren's syndrome?

Sjögren's syndrome 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 six years.

What kind of doctor treats Sjögren's?

Rheumatologists have primary responsibility for managing Sjögren's syndrome. Patients also are seen and treated by specialists such as ophthalmologists, optometrists, dentists and others.

How is Sjögren's diagnosed?

It can be difficult to diagnose Sjögren's syndrome. No single test will confirm the diagnosis and, since it is a syndrome, Sjögren's syndrome may appear in many different forms in different patients. Physicians may conduct a series of tests and ask about symptoms. An international group



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 syndrome!

To sign up as a member* of the Sjögren's Syndrome Foundation, 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. *All membership donations are tax-deductible.*

Dues:

\$32 US

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*Membership includes a one-year subscription to *The Moisture Seekers* monthly newsletter and a host of additional benefits. Visit www.sjogrens.org or see reverse to learn more about the benefits of SSF membership.