

**Sjögren's ("SHOW-grins") is a systemic autoimmune disease that affects the entire body.**

- Profound fatigue, joint pain, muscle pain
- Dry eyes, corneal ulcerations and infections
- Dry nose, recurrent sinusitis, nose bleeds
- Dry mouth, mouth sores, dental decay, difficulty with chewing, speech, diminished sense of taste
- Swollen, painful parotid/salivary glands
- Difficulty swallowing, heartburn, reflux, esophagitis
- Vasculitis, dry skin, lymphoma and other blood cancers
- Recurrent bronchitis, interstitial lung disease, pneumonia
- Abnormal liver function tests, chronic active autoimmune hepatitis, primary biliary cholangitis
- Interstitial nephritis, renal tubular acidosis, glomerulonephritis
- Peripheral neuropathy, Raynaud's
- Stomach upset, gastroparesis, autoimmune pancreatitis
- Irritable bowel, autoimmune gastrointestinal dysmotility
- Interstitial cystitis
- Vaginal dryness, vulvodynia (women); chronic prostatitis (men)

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**sjogrens.org**

## The Sjögren's Foundation

Founded in 1983, the Sjögren's Foundation is the only national non-profit organization leading the fight against Sjögren's on behalf of all patients. Our vision is to create a community where patients, healthcare professionals and researchers come together to conquer the complexities of this disease.

**Be your own best advocate by becoming a member of the Foundation to support our vital work and receive these exclusive benefits:**

- A New Member Welcome Packet with helpful information about Sjögren's, local support groups, and the Foundation.
- A subscription to our patient newsletter, *Conquering Sjögren's*. Printed six times a year, our newsletter contains the most up-to-date information from leading experts.
- Access to the member-only section of our website, which features archived issues of *Conquering Sjögren's* and the Sjögren's Foundation Product Directory.
- Receive ongoing information about upcoming clinical trial research in your area.
- Discounts on Sjögren's-related books and merchandise from the Foundation's store, as well as registration discounts for our educational conferences.
- Most importantly, your membership helps fund ongoing Foundation programs and provides one more voice as we work to transform the future of Sjögren's.



**Visit [www.sjogrens.org](http://www.sjogrens.org) to take control of your health and sign up as a member today!**



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## WHAT IS Sjögren's?



## WHAT IS Sjögren's?

Sjögren's ("SHOW-grins") is a systemic autoimmune disease that affects the entire body. Along with symptoms of extensive dryness, other serious complications include profound fatigue, chronic pain, major organ involvement, neuropathies, and lymphomas.

Although many patients experience dry eye, dry mouth, fatigue and joint pain, Sjögren's can also cause dysfunction of organs such as the gastrointestinal system, blood vessels, lungs, liver, kidney, pancreas, and the central nervous system. Patients also have a higher risk of developing lymphoma, and heart block can occur in fetuses when a mother has Sjögren's. Today, as many as four million Americans are living with this disease.

Sjögren's may occur alone or in the presence of another connective tissue disease such as rheumatoid arthritis, lupus, or scleroderma. All instances of Sjögren's are systemic, affecting the entire body. Symptoms may plateau or worsen overtime.

While some people experience mild discomfort, others suffer debilitating symptoms that greatly impair their functioning. That is why early diagnosis and proper treatment are important — as these may prevent serious complications and greatly improve a patient's quality of life.

## What are the symptoms someone may notice before getting diagnosed?

Presenting symptoms vary from person to person but some of the most common symptoms patients may experience include:

- Dry, gritty, or burning sensation in the eyes
- Increased dental decay
- Dry mouth symptoms including difficulty talking, chewing, or swallowing
- Dry or burning throat or mouth
- Joint or musculoskeletal pain
- Sore or cracked tongue
- Vaginal and skin dryness
- Digestive problems, including reflux
- Neuropathies
- Profound fatigue

In addition, Sjögren's may accompany other autoimmune diseases such as lupus, rheumatoid arthritis, and scleroderma. Physicians should also take note that not all patients will present with symptoms of dryness.

## Who is most likely to develop Sjögren's?



The average age of Sjögren's diagnosis is **40 YEARS**. It can occur in ALL AGE GROUPS (including children) AND IN BOTH SEXES

## Is it easy to diagnose Sjögren's?

Sjögren's can be challenging to recognize or diagnose because symptoms of Sjögren's may mimic those of menopause, drug side effects, or medical conditions such as lupus, rheumatoid arthritis, fibromyalgia, chronic fatigue syndrome, 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 2.8 years.

## How is Sjögren's diagnosed?

Unfortunately, there is no single test that will confirm the diagnosis of Sjögren's and thus physicians must conduct a series of tests and ask about symptoms the patient is experiencing.

Physicians will use a number of tests to determine a Sjögren's diagnosis.

### Objective tests used in diagnosis include:

- **Blood tests you may have include:**
  - **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.
- **Eye tests most commonly used include:**
  - **Schirmer test:** Measures tear production.
  - **Rose Bengal and Lissamine Green:** Use of dyes to examine the surface of the eye for dry spots.
- **Dental tests most commonly used include:**
  - **Salivary flow:** Measures the amount of saliva produced over a certain period of time.
  - **Salivary gland biopsy (usually in the lower lip):** Confirms lymphocytic infiltration of the minor salivary glands.

### Subjective questions used in diagnosis may include:

- **Ocular Symptoms\***
  - Do your eyes feel dry?
  - How long have you been experiencing dry eye?
  - How often do you use artificial tears each day?

- **Oral Symptoms\***
  - How long have you had dry mouth?
  - Do you experience salivary gland swelling?
  - Do you need liquids to swallow food?

*\*These questions are a sampling of questions a physician may ask a patient.*

In addition to objective and subjective testing, your physician will also take a complete medical history as well as discuss your various symptoms you may be experiencing. Your physician will then consider the results of all these tests and his/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 kind of doctor treats Sjögren's?

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

## What treatments are available?

Currently, there is no one medication to treat Sjögren's. However, there are treatments that may improve various symptoms and prevent complications. Prescription medicines for both dry eye and dry mouth are available. Physicians may also prescribe immunosuppressive medications and/or immune modulators to treat serious internal organ manifestations or fatigue. In addition, a number of over-the-counter products may also be used to alleviate different types of dryness and chronic pain.

The Sjögren's Foundation is working on ensuring clinical trials take place so that new therapies are developed to treat Sjögren's. The Foundation is proud of our work in this area, as we feel we are getting closer to having an approved therapy for Sjögren's. Visit [www.sjogrens.org](http://www.sjogrens.org) to learn more about the Foundation's work in clinical trials.

The Sjögren's Foundation encourages patients to visit [www.sjogrens.org](http://www.sjogrens.org) to print, review and bring our Clinical Practice Guidelines to your healthcare providers. These peer-reviewed and endorsed guidelines will give them a roadmap for potential treatment and management options.



Scan this QR code to view, print or download our Clinical Practice Guidelines.

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