

# Sjögren's Disease Fact Sheet

- Sjögren's disease is a serious and systemic autoimmune disease that presents with symptoms of extensive dryness (eyes, mouth, skin), profound fatigue, and chronic pain. Other serious manifestations can include major organ involvement (e.g., kidney, lung, heart, pancreas); neurological symptoms (peripheral neuropathy, dysautonomia, migraines, aseptic meningitis); and lymphoma.
- People with Sjögren's disease are 44 times more likely to develop lymphoma than those who do not have Sjögren's disease.
- Sjögren's is the 2nd most common rheumatic autoimmune disease in the United States. Affecting as many as four million Americans, Sjögren's is three times more common than better known related diseases such as lupus and multiple sclerosis.
- Ninety percent (90%) of adults diagnosed with Sjögren's are women, and 10% are men. In pediatric cases, the female predominance is less skewed. Historically, Sjögren's has been considered a disease of older women, contributing to delays in diagnosis for men, children, and younger women. The disease has been recognized across nearly all racial and ethnic groups.
- Diagnosing Sjögren's is difficult and can often take years for a person to receive an accurate diagnosis. This is because the disease presents differently in people living with Sjögren's, with a wide range of symptoms that can mimic other conditions and diseases. The disease has also been misunderstood and misrepresented as only a dry mouth and dry eye disease that affects older women. Proper awareness is essential for accurate diagnosis and treatment.
- Diagnosis can also be difficult because people with Sjögren's may not share all of their symptoms with a single healthcare professional (e.g., not telling their primary care provider about their dry mouth and cavities, or telling their optometrist about their peripheral neuropathy, etc.). Because the U.S. healthcare system provides treatment by specialty, many patients are used to sharing information only about that specific area of their body.

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- Sjögren's can occur on its own or with another autoimmune disease such as lupus, rheumatoid arthritis, or scleroderma. Sjögren's and lupus are closely related and approximately 30% of people living with Sjögren's disease have lupus and vice versa. Fifty percent (50%) of all people with Sjögren's have features of other autoimmune diseases, even if there is no formal diagnosis of another disease.
- We need to learn more about Sjögren's to better diagnose, understand, and treat the disease. Historical research shows that Sjögren's is a disease in which white blood cells attack and damage the moisture-producing glands in a person's body. Recently, we are learning that Sjögren's also attacks small fiber nerves.
- There is no specific treatment for Sjögren's although healthcare providers often prescribe immune modulating drugs (such as hydroxychloroquine) or immune suppressants (such as methotrexate or rituximab). Healthcare providers also prescribe anti-inflammatory eyedrops, such as cyclosporine, to reduce ocular inflammation to control dryness. Over-the-counter products, such as eyedrops and oral moisture aids, are used for comfort.
- There is no known cure for Sjögren's.
- Currently, there are no FDA-approved therapies for Sjögren's, but multiple potential therapies are in clinical trial, bringing hope that patients' quality of life can improve soon.
- The Sjögren's Foundation is the only national nonprofit organization dedicated to increasing research, awareness, and education for Sjögren's. The Sjögren's Foundation's mission is to:
  - Support Sjögren's patients and their loved ones through education, resources, and services
  - Provide credible resources and education for healthcare professionals
  - Serve as the voice for all Sjögren's patients through advocacy and awareness initiatives
  - Lead, encourage and fund innovative research projects to better understand, diagnose, and treat Sjögren's