



Sjögren's Syndrome Foundation

The Sjögren's Syndrome Foundation (SSF) is the only non-profit organization focused on increasing research, education and awareness for Sjögren's ("SHOW-grins"), one of the most prevalent autoimmune disorders, affecting as many as four million Americans, with an estimated 2.5 million patients currently undiagnosed.

Sjögren's 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.

Founded in 1983 by Elaine Harris, a frustrated patient, the SSF's mission was simple: help patients cope with their Sjögren's, increase awareness, and support research efforts. Today, the Foundation's mission remains the same. Headquartered in Bethesda, MD, it has grown into a multi-faceted organization that provides patients, caregivers, health care providers and others with helpful information and resources to aid them in managing this debilitating disease. The Foundation is also internationally recognized for its leadership and support of research, education, patient care, advocacy and developing new therapies to make a difference in the care and treatment of Sjögren's patients.

In 2012, research of newly diagnosed Sjögren's patients showed that it took an average of over five years for them to receive an accurate diagnosis. That year, the Foundation launched an ambitious *5-Year Breakthrough Goal* to shorten the time to diagnose Sjögren's by 50 percent for patients diagnosed in 2017. Thanks to the efforts of the Foundation, and its dedicated group of Sjögren's Awareness Ambassadors to increase public and professional awareness of Sjögren's, today it takes an average of three years to receive a correct diagnosis.

An integral part of achieving this goal involves ensuring a comprehensive understanding of Sjögren's by healthcare professionals. The SSF works closely with health care providers to ensure quality and consistency of care for the assessment and management of patients with Sjögren's. In 2016, The Foundation, with the assistance of hundreds of physicians and dentists developed and published the first U.S. [Rheumatology Clinical Practice Guidelines for Sjögren's](#) and [Dental Caries Prevention Clinical Practice Guidelines in Sjögren's Patients](#). In addition to providing standard of care guidelines for systemic Sjögren's, these guidelines, along with previously published [Clinical Guidelines for Ocular Management in Sjögren's Patients](#) will help to standardize patient care by giving physicians a roadmap of how to treat and manage their Sjögren's patients.

The SSF has a strong advocacy and research arm to improve the lives of those with Sjögren's. This includes working with legislators on issues of importance to Sjögren's patients, such as increased federal funding for research, coverage of expensive over-the-counter drugs and products used by Sjögren's patients, access to specialists and treatment under managed care, better coverage from health insurance companies, and protection of patients' rights. The Foundation also works closely with agencies that are part of the U.S. Department of Health and Human Services (DHHS) to encourage increased support of research into Sjögren's.

For more information, visit www.sjogrens.org or call 1-800-475-6473.