# Press Release

**World Sjögren’s Day – 23 July**

**Sjögren’s Syndrome is a hard-hitting disease**

***The burden of Sjögren’s is wide and real although invisible***

In honor of World Sjögren’s Day, Sjögren Europe helps to spread the word to increase awareness about this invisible and hard to diagnose disease, which is one of the most prevalent but still lesser known autoimmune diseases.

Sjögren’s patients often feel misunderstood because most of the debilitating symptoms are not visible to others and the disease is often not recognized largely due to a lack of awareness. “By increasing both public and professional awareness, the goal is to reduce diagnosis time and to advance research on the cure for this disorder” says Mrs. Alice Grosjean, President of Sjögren Europe. “It is also about recognising the burden that this disease represents in the lives of Sjögren's patients” she adds.

Sjögren’s Syndrome is a systemic disease & its debilitating symptoms are felt throughout the entire body. Although the primary symptoms are dry eyes, dry mouth, fatigue & 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. Women are nine times more likely to develop Sjogren’s than men and diagnosis usually occurs around the age of 40.

Unfortunately, because the symptoms vary from person to person, and the disease often occurs in the presence of or mimics other diseases (such as lupus, rheumatoid arthritis, menopause, allergies or multiple sclerosis) Sjögren’s is often misdiagnosed or overlooked. Typically, it takes three years (and sometimes much longer) to obtain a Sjogren’s diagnosis once symptoms are noticed.

As a systemic disease, symptoms may remain steady or worsen overtime. There is no one single progression of the disease and this can make it challenging for patients and their physicians. While some people experience mild discomfort, others suffer debilitating symptoms that greatly impair their functioning. Early diagnosis and proper treatments are important as they may prevent serious complications and greatly improve a patient's quality of life.

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. Over-the-counter products may also be used to alleviate different types of dryness. Immunosuppressive medications are available to treat the serious internal organ symptoms. New treatments are being investigated and hopefully will be available in the near future. On average patients are prescribed upwards of 8 medications to treat the wide range of symptoms.

Rheumatologists have primary responsibility for managing Sjögren’s Syndrome. Patients are also seen and treated by specialists such as eye care providers, dentists and other specialists depending on a patient’s complications, while the big picture is often missed.

During World Sjögren’s Day on July 23rd, Sjögren Europe will post on its social media pages its new campaign about the invisibility of the disease and the burden it represents in the lives of Sjögren’s patients to help raise awareness and educate people about this hard hitting disease and how it affects the lives of those who live with it.

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***About Sjögren Europe***

Sjögren Europe, a federation of national associations representing Sjögren’s patients, was established in Switzerland in 2019 and is governed by Swiss law. All Board members, except one, suffer from Sjögren’s.
Board members are all unpaid volunteers and there is no separate paid secretariat. The Medical Board of Sjögren Europe consists of well known European experts

Its key objectives are:

* To increase visibility, attention and solutions for Sjögren’s Syndrome
* To be considered a vital partner and an additional force to address the numerous unmet needs
* To raise awareness on the disease
* To articulate patient voices throughout Europe
* To foster patient involvement in research

Sjögren Europe is a member of EURORDIS and a co-opted member of EULAR PARE.

Its activities include organizing an annual congress, webinars and workshops; promoting Sjögren’s month in April and World Sjögren’s Day on 23 July, producing a newsletter; and maintaining a social media presence, eg Facebook, Instagram, website etc.

***About World Sjögren’s Day – 23 July***

**World Sjögren's Day** was created to commemorate the birthday of Dr. Henrik Sjögren, the Swedish ophthalmologist who discovered Sjögren's in 1933.

World Sjögren’s Day helps to put a face on the millions of people who live with this disease or suffer from symptoms and have yet to be diagnosed. It aims to increase awareness of Sjögren’s Syndrome while also stressing the need for further research, additional diagnostics and new treatments. On this day, patients, their families, and friends join together and have their voices heard.