



[www.sjogreneurope.org](http://www.sjogreneurope.org)



# Sjögren Europe

Sjögren Europe is a European federation of national patient associations representing Sjögren's patients. Its purposes are to:

- achieve more visibility, attention, and solutions for Sjögren by promoting the advancement of knowledge, research, information, treatment, and care
- foster patient involvement and participation in scientific research, medical, health and political institutions, pharmaceutical industry, and social areas, and
- increase awareness about Sjögren at all levels.

Sjögren Europe was created in February 2019 in Switzerland by several patient organisations throughout Europe. Sjögren Europe members are national patient organisations or groups representing Sjögren's patients.

Sjögren Europe is led by a small group of patients who are also involved at a national level and aware of other Sjögren's patients experiences and reality.



Sjögren Europe does not have direct contact with, or provide personal information or support to patients: this is the role of national associations and groups. Sjögren Europe's main role is patient advocacy, which is the inclusion of the patient perspectives in healthcare systems and raising awareness about the disease.

Sjögren Europe offers the opportunity to merge the voices, perspectives and needs of patient communities from different countries at European level and to bring a ray of hope to patients with Sjögren. This is Sjögren Europe's mission: work together and be accepted as an equal partner by all stakeholders in the sector in order to build a better future for patients with Sjögren.



# More visibility, attention, and solutions for Sjögren

Sjögren Europe key objectives are to:

- Increase visibility, attention, and solutions for Sjögren
- Empower national patient organisations and groups in Europe
- Be considered a crucial partner and an additional force to address the numerous unmet needs
- Raise awareness of the disease
- Articulate patient voices throughout Europe
- Foster patient involvement in research and health care systems

You can keep updated with Sjögren Europe activities by checking our website [www.sjogreneurope.org](http://www.sjogreneurope.org) where you can find different information and subscribe to our newsletter.

# Sjögren

Sjögren is a heterogeneous systemic disease characterized by dry eyes (xerophthalmia) and dry mouth (xerostomia). Dry eyes and dry mouth are disabling symptoms that have a strong impact on the quality of life.

However, Sjögren is so much more than dry eyes and dry mouth: it can affect the whole body.

There is no cure although there are symptomatic and systemic treatments for the symptoms.





# The European patients' community perspective

Sjögren is a disease with diverse clinical expression, prognosis, and a multidimensional complexity.

*Diagnosing, treating, following up and researching Sjögren remains a significant challenge which is equalled by the lack of acknowledgment and recognition that it is a devastating disease, affecting patients physically, mentally, emotionally, socially, and financially. Quality of life is dramatically impaired. Patients must lead their lives with a disease lacking effective and specific treatment that has them living daily with invisibility, unpredictability, and unimaginable suffering.*



Although Sjögren is isolating for sufferers, the wider European patient community is aligned when identifying the numerous unmet needs. They clearly state that a huge and borderless lack of knowledge and understanding prevails and seems to persistently fuel misunderstandings, misdiagnosis and/or delays not only in diagnosis but also in access to treatment and care.

Inadequate or non-existent quality knowledge and information about the disease is a barrier to early diagnosis resulting in delayed referral to rheumatology. The journey to reach a diagnosis is still an odyssey in many countries as patients find difficulties in being understood and end up walking on their own, and at their own cost, on a pilgrimage between medical specialities, trying to find answers to the different symptoms that they do not know how to manage.

The lack of understanding of the systemic nature of Sjögren and the lack of appreciation of its heterogeneous nature frequently leads to poor advice, inappropriate care, and underestimated burden. Patients are often dismissed because doctors cannot relate to the symptoms or are not taken seriously and labelled as anxious - many reported symptoms are still hung on the 'mental hook'. Lack of understanding from family, friends, co-workers, and employers leads to a heavy emotional burden fuelled by



relationship difficulties, not to mention poor disease outcomes.

The classification of Sjögren as a syndrome may contribute to underestimating what it actually is: a disease. Lack of consensus on disease prevalence and incidence across Europe highlights the need for reliable, updated, and harmonized data.

Facilitating access and signposting patients to a multidisciplinary team is a 'must' as is active and mutually fruitful collaboration between doctors. A key role of healthcare professionals is to enable patients to take a more active role in their healthcare.

Educating patients, caregivers, and public is essential to fight widespread disease stigma. Because Sjögren is typically considered a condition of middle-aged women, men and young people may be underdiagnosed and, consequently the disease may become more severe.

Fatigue and cognitive dysfunction cause the greatest patient reported disability and remain a massive unmet need, poorly addressed and validated. This need **fails** to be recognised when applying for disability. Furthermore, this fatigue results in lower work output and relates directly to difficulties in reconciling work and Sjögren's. Communication between patient and doctor is not good enough: difficulties in understanding the disease and treatments remain, and sensitive topics such as family



sexuality, intimacy, self-esteem, and mental health are still taboo and, consequently, overlooked.

Receiving adequate support from a variety of sources is crucial. For this reason, engagement of patients with patient organisations, particularly when newly diagnosed, should be promoted. Lived and experiential knowledge should be complementary to evidence-based knowledge and has the potential to make a significant difference to patients' lives.

Striking disparities exist across countries in access to care and treatment, standards and continuity of care, quality of healthcare delivery, drug and health services prescription availability and reimbursement, and regular

follow-up plans. In some countries access to rheumatology is very delayed, limited, or non-existent. A similar situation applies to medical specialities such as ophthalmology or dentistry.

Overall, a different approach is needed: the future of Sjögren's is collaborative work. Active and synergistic involvement of patients, clinicians, and scientists in the definition of unmet needs and areas of future research is crucial to achieve successful outcomes in clinical medicine. It is time for change.

Summary of *Vieira A, Grosjean A, Stone L, Oosterbaan M, Bouillot C, Koelewijn-Tukker J, Antonopoulou K. "Sjögren's: the European patients' community perspective". Clin Exp Rheumatol. 2021 Jul 6. Epub ahead of print. PMID: 34251305.*

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