

## World Sjögren's Day - July 23

### Chronic fatigue is associated with reduced quality of life

Chronic fatigue is one of the most common symptoms of Sjögren's and clearly differs from the usual fatigue according to Sjögren Europe. "We describe it as an incessant, fluctuating and unreliable lack of vitality that is beyond one's control. Not everyone experiences it the same way, but fatigue is undoubtedly a permanent part of patients' lives. It is a debilitating symptom related to a reduced quality of life", mentioned Alice Grosjean, President of Sjögren Europe.

Teri Rumpf PhD, a Sjögren's sufferer, has identified 15 types of chronic fatigue in her recently [revised article](#):

1. **Basic or baseline fatigue** is a continuous presence for many Sjögren's sufferers.
2. **Rebound fatigue** is a reminder that I have done too much.
3. **Sudden fatigue** can hit you anywhere, at any time.
4. Forecasting changes in the weather is a side effect of **Weather-related fatigue**
5. **Molten Lead phenomenon** is a predictor of a really bad day
6. **Tired-wired** when you are physically exhausted but your mind is still whirling
7. Unpredictable **flare-related fatigue** can last for days or weeks
8. **Fatigue related to other physical causes** feels like climbing up a steep hill when you are walking on flat ground
9. **Fatigue impairs concentration** encloses me in a thick cloud of cotton wool.
10. **Stress, distress, anxiety or depression** create emotional fatigue that can be as exhausting as physical fatigue
11. **Fatigue that comes from not sleeping well** getting to sleep and staying asleep can be a challenge for Sjögren's sufferers
12. **Fatigue that comes with normal ageing** it still hurts that I cannot keep up with friends of the same age
13. **Fatigue that comes from a chronic illness that just won't quit** it is easy to be "sick and tired of being sick and tired" when Sjögren's just does not go away
14. **Fatigue that comes from trying to keep up with family and friends who don't have a chronic illness** my body won't co-operate and I can't keep up
15. **Doctor fatigue** repeated clinical visits and tests are exhausting

"Sjögren Europe want to contribute to increasing awareness and recognition of fatigue as a major factor in Sjögren's and promote understanding that Sjögren's is a systemic disease. To mark World Sjögren's Day, Sjögren Europe and its members – the national patient associations, have posted the 15 types of chronic fatigue on social media. With this, we hope to highlight an issue that is often misinterpreted and treated so badly", said Alice Grosjean.

Sjogren's affects the whole body. Many patients experience dry eye, dry mouth, joint pain and fatigue. However, the disease can also cause other serious complications such as chronic pain, organ dysfunction, neuropathy and lymphoma. Women are nine times more likely to develop Sjogren's than men and the diagnosis usually occurs around the age of 40.

The etiology of the disease is unknown. Genetic and environmental factors, such as relatively common viral infections, appear to play a role in its onset. The disease is caused by the production of antibodies, and immune cells that attack the connective tissue, that of the exocrine glands especially, such as the lacrimal and salivary glands. This results in long-term inflammation of these glands leading to dysfunction, destruction, and a reduction in the production of saliva and/or tears, as well as by the swelling -sometimes- of the salivary glands.

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### **About Sjögren Europe**

Sjögren Europe, a federation of national associations representing patients with Sjögren, was founded in Switzerland in 2019. All members of the Board - except one, have Sjögren's. The members of the Board are all volunteers and there is no paid staff. The Scientific Committee of the Federation consists of renowned medical specialists in Sjögren's Syndrome.

The main objectives of **Sjögren Europe** are:

- The strengthening of national patient associations
- Updating and increasing the knowledge and awareness of all (patients, caregivers, medical community, governmental agencies, health professionals, pharmaceutical companies and the general public)
- The achievement of an optimal care system, psychosocial support and quality of life for all patients with Sjögren's in Europe
- Involvement of patients in decisions, programs, strategies, etc. that affect patients with Sjögren's in Europe
- The collaboration, participation, and involvement of patients in clinical trials but also the implementation of research and research projects related to the disease and the publication of their results
- Sjögren Europe is member of EURORDIS and a supporting member of EULAR PARE.

### **On World Sjögren's Day- July 23**

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

World Sjögren's Day aimed to put a face to the millions of people living with this disease or suffer from symptoms and have not been diagnosed and aims to raise awareness for Sjögren's, while stressing the need for further research, quicker diagnostics and new treatments. This day, patients, their families, and friends come together around the world to make their voices heard.