

world sjögren's day 2021: a 3-axis campaign about fatigue

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fatigue

Fatigue is one of the most prevalent and disabling patient reported symptoms of Sjögren's. Fatigue in Sjögren's clearly differs from ordinary tiredness. We describe it as an ever-present, fluctuating, and nonrelievable lack of vitality being beyond one's own control. Not everyone experiences it in the same way, but fatigue is undeniably a permanent part of patients' lives. It is a debilitating symptom which is associated with reduced health-related quality of life.

world sjögren's day

Every 23 July is World Sjögren's Day (WSD), which is dedicated to raise awareness about this condition. For WSD 2021, Sjögren Europe decided to focus on fatigue, with the hope to bring forth a topic often misinterpreted and poorly addressed.



In order to contribute to increase awareness and acknowledgment of fatigue as a major factor in Sjögren's and promote a growing knowledge that Sjögren's is a systemic disease, various activities

and informative material related to fatigue were presented in honour of WSD 2021.



The campaign was disseminated over a month between June and July, culminating with WSD and it was posted on a dedicated webpage on Sjögren Europe's website www.sjogreneurope.org/wsd, on different social media channels and in a newsletter. It was also disseminated by our members and other patients' communities.

a 3-axis campaign about fatigue

The campaign was organised in 3 axes, in order to present fatigue from 3 perspectives:

1) the medical perspective

A webinar about fatigue was organised with a rheumatologist from UK specialised in Sjögren's, in order to better understand fatigue.

2) the psychological perspective

A self-help booklet on targeting chronic fatigue in Sjögren's was published with a Dutch psychologist

who was involved in the development of treatment programs and international guidelines for the treatment of fatigue and pain in RMDs. In this booklet, he offers tips for targeting fatigue: personal factors that can influence fatigue are mapped and it explains how those factors can be tackled.



3) the patient perspective

The core of the campaign is to raise awareness about patients' fatigue and express the different ways in which it manifests itself, as experienced by patients. The article by Teri Rumpf, a Sjögren's patient and psychologist from the US, "15 types of Sjögren's fatigue", was shared in a visual campaign available in 13 European languages.

One type of fatigue per day was shared with an expressive picture, the pictorial name of the fatigue and a short sentence summarizing the fatigue. The complete description was shared in addition.

These publications aim to help patients feel understood and validated in their experience of



fatigue, and to put into words what they live and feel so they can better express it to others.

results

The campaign had a great impact and a lot of visibility. In July 2021, just on Sjögren Europe Facebook page, it had more than 50'000 views. The visits on our website more than doubled to reach 500 visits a day.

This campaign allowed many patients to feel less alone in the face of fatigue as it made visible the invisible, to incorporate them into the discussions and to initiate a rich dialogue. We noticed an increased presence of young people and men during the campaign which is probably due to their representation in the photos.

The involvement and contribution of our member organisations was critical to the success of our campaign. They helped with the translations and the dissemination and made the campaign their own, allowing patients to unite for WSD.