

DISCLOSURES

Conflicts of Interests: None declared



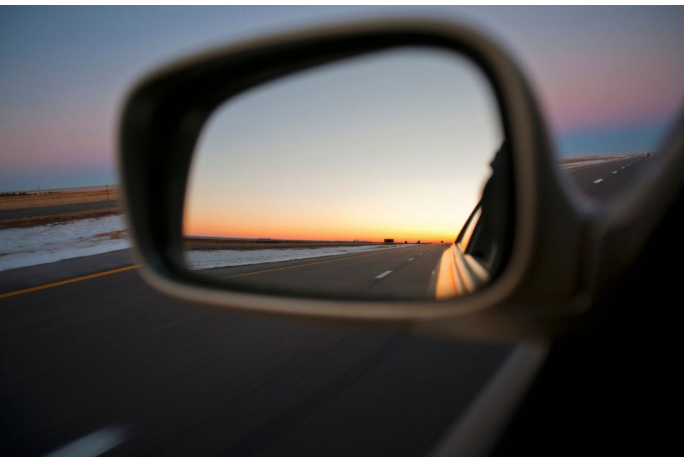
Picture taking is **ALLOWED during my presentation
(including presented slides)**



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Sjögren Europe: Review of its first three years of activity



Alice Grosjean
Sjögren Europe President

EULAR Congress
June 2022
Copenhagen



Sjögren Europe was founded three years ago on 23 February 2019 by several European patient organisations representing Sjögren's patient to help to address the lack of **visibility, attention, and solutions for Sjögren's**.



What are the first achievements and contributions of Sjögren Europe?

How many of you have heard
about Sjögren Europe?

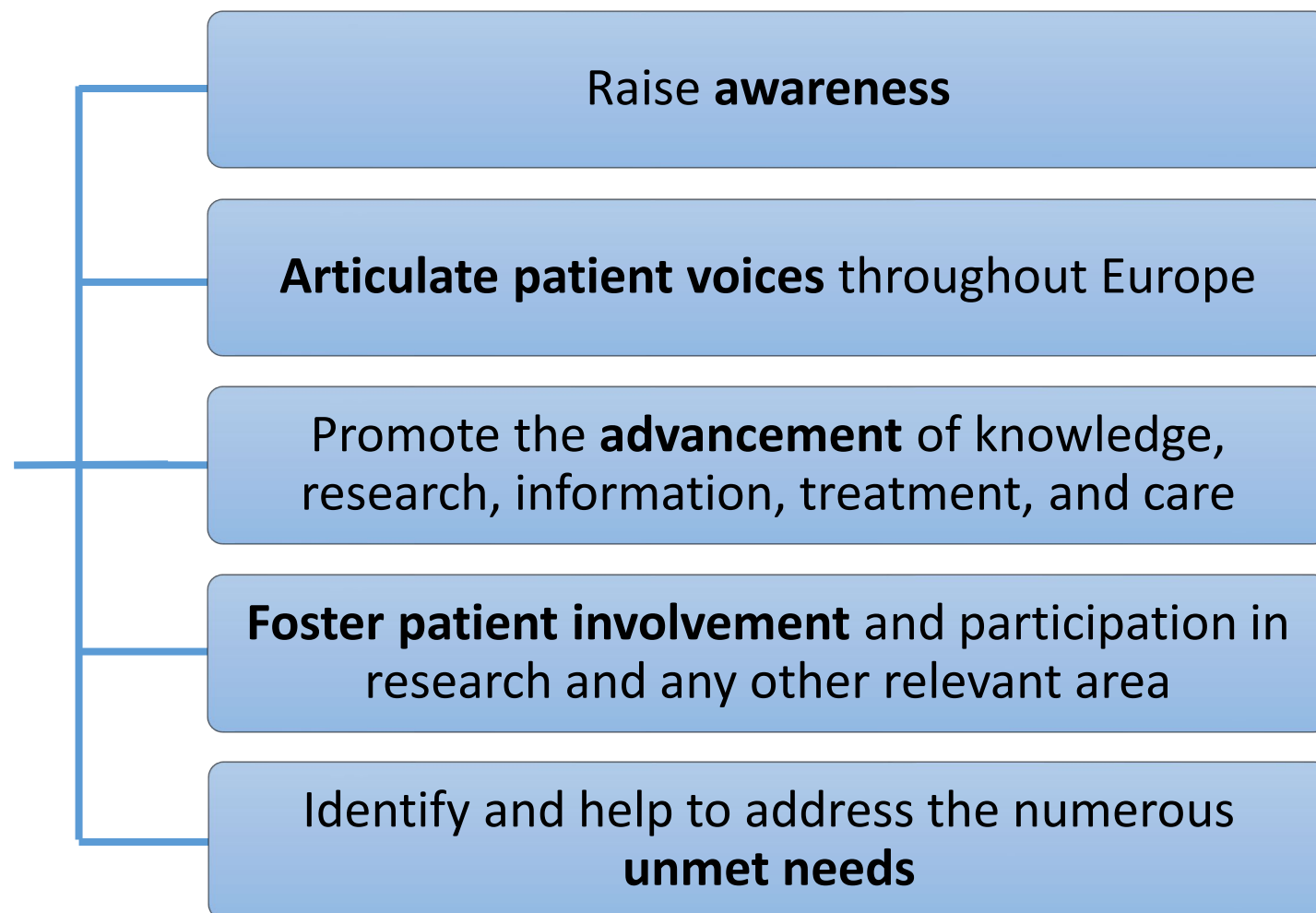
How many of you had heard
about Sjögren's before hearing
about Sjögren Europe?



Sjögren Europe's purpose



By patients for patients in Europe



What we did these 3 first years

Finding one's bearings and the right rhythm during the first years of an organisation's life is a challenge in itself.

The Covid-19 pandemic has made this process even more difficult.

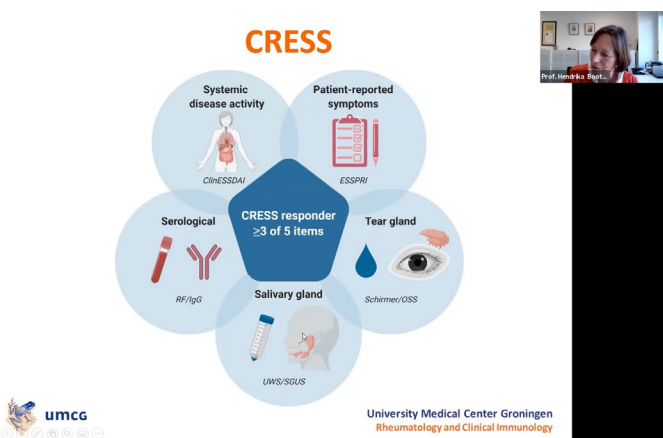


Our first goal was to organise a first face-to-face European patient conference about Sjögren's.

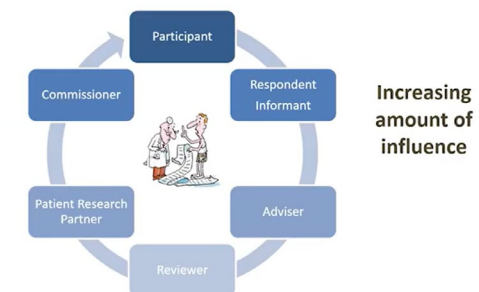
This meeting had to be postponed.

However, we were able to adapt and develop a range of activities.





Patient roles in scientific research



ADDRESSING THE CHALLENGES IN DRUG DEVELOPMENT

Primary endpoint

ESSDAI and ESSPRI: current measures selected as primary endpoint:

- Consensually developed and validated
- MCID available

Limitations of ESSDAI:

- Promising recent trials, however many trials failed due to lack of sensitivity
- Does not measure symptomatic improvement
- Only relevant for patients with moderate to high systemic activity disease

Limitations of ESSPRI:

- No clear effect detected to date on ESSPRI in most of current clinical trials

Need for a unique score to measure both systemic and symptoms and include important but not well captured features (i.e. glandular function)

Patient stratification

- Heterogeneous patient population
- Recent work showed 4 subgroups of patients based on symptoms
- Could respond differently to treatment

Need for stratification biomarkers to optimize design of clinical trials

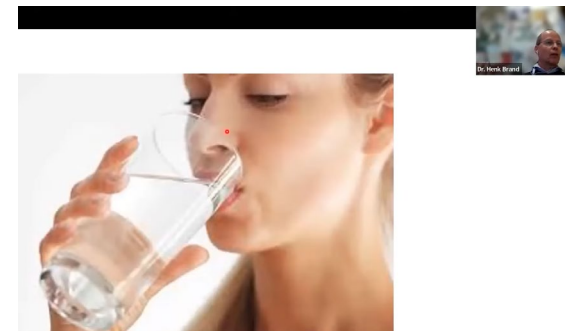
Evaluation of all features of pSS

- Symptoms are very variable from day to day
- No objective measure of fatigue, one of the three most important symptoms of pSS
- Lack of validated procedures for evaluating improvement of glandular function

Need for more assessment procedures validated in pSS

necessity

efpia



Water does not really help....

We organised a series of informative webinars on different topics by leading European experts for patients and others interested in the subject.

We have organised various awareness campaigns such as a campaign for Sjögren Awareness Month in 2021 for which we have created 2 awareness videos and published several testimonials.





15 TYPES OF FATIGUE
by Teri Rumpf, Ph.D.

5 **Molten Lead phenomenon**
is a predictor of a really bad day.





15 TYPES OF FATIGUE
by Teri Rumpf, Ph.D.

9 **Fatigue impairs concentration**
encloses me in a thick cloud of cotton wool.



We also created a 3-axis campaign about fatigue for World Sjögren's Day 2021 which won the Best Practice Award at the 2021 PARE Conference, and during which we shared the patients' perspective on fatigue in publications in 13 languages on social media.

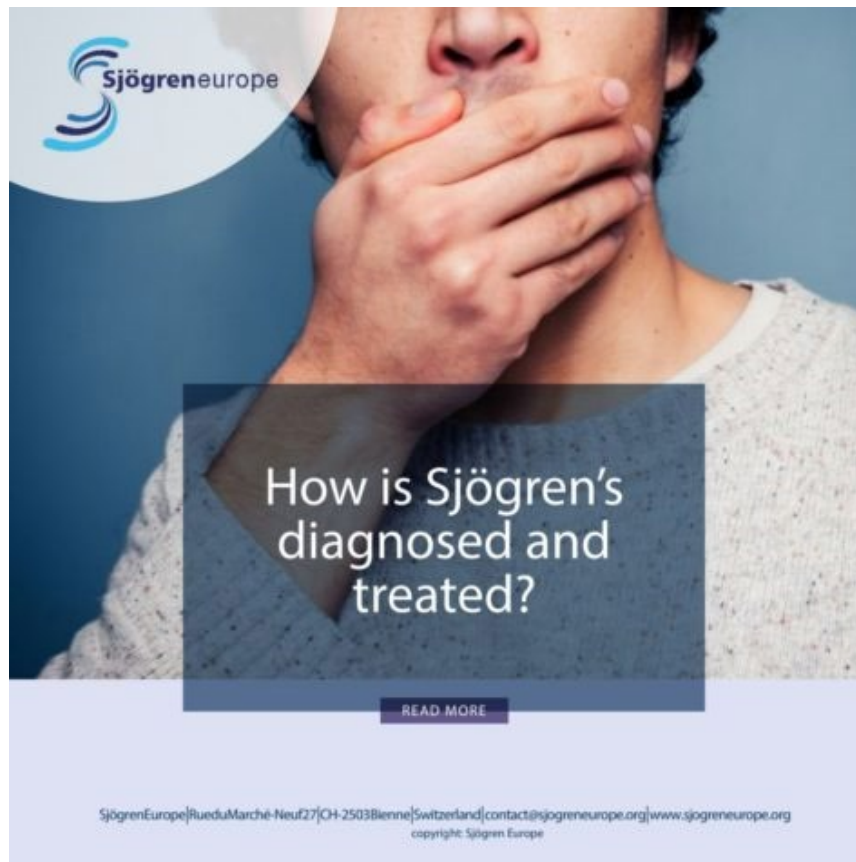


What is Sjögren's?

Sjögren's is a disease that is characterized by an inflammation of glands leading to dry eyes (xerophthalmia) and dry mouth (xerostomia). Dryness can also affect other parts of the body inside and out (nose, genitals, lungs, skin, etc.). Sjögren's can affect the whole body. Patients with Sjögren's often experience extensive fatigue and chronic pain.

[READ MORE](#)

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How is Sjögren's diagnosed and treated?

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We published a booklet about fatigue developed by a specialist and produced 3 informative leaflets for patients.

We also subtitled 2 videos made by one of our members in 10 European languages to disseminate quality information that many patients miss.



We have been involved in various research projects, working groups and patient panels and have been able to bring the patient perspective to various stakeholders on many occasions.





Despite the limited contacts, we were able to create strong links and rich discussions that stimulated our creativity.

Sjögren Europe has become a privileged partner, recognised, and appreciated by the various stakeholders. Patients with Sjögren's are better represented at the supranational level.





It is our members, the national patient organisations, who by their trust give us our legitimacy. In return, Sjögren Europe has been able to inject a new energy and dynamism that can be felt at the different national levels and that opens up many perspectives and opportunities.

We have been able to strengthen our presence and visibility with patients on social media, where our audience is constantly growing, as well as in the rheumatology field with researchers, clinicians, industry, and associations such as EULAR.





The resumption of face-to-face contacts is eagerly awaited to consolidate the links already created and to feed the richness, relevance, originality and diversity of our discussions and activities.

Last words (for today!)

How it looks...



And how it feels...



Thank you!



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