

Setting up a European Federation of Sjögren's Syndrome patient associations: how we built up Sjögren Europe in less than one year



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Background

Despite its considerable prevalence among connective tissue diseases, Sjögren's Syndrome has been devoted less research, interest, time and effort compared with other close conditions. Active and synergistic involvement of patients, clinicians and scientists in the definition of unmet needs and areas of future research is crucial. *

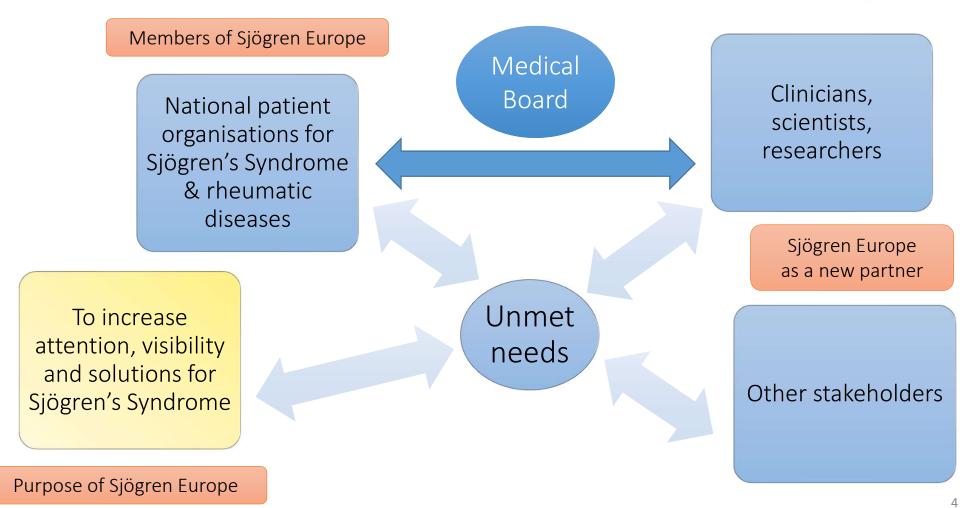
* Romão V. C., Talarico R., Scirè C. A., et al *Sjögren's syndrome: state of the art on clinical practice guidelines* RMD Open 2018; 4:e000789. doi: 10.1136/rmdopen-2018-000789



Why setting up Sjögren Europe? **Raise awareness** Articulate patient voices throughout Europe Foster patient involvement in research Etc. Help to address the numerous By patients for patients in Europe unmet needs

Landscape









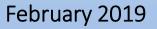


Key dates

April 2018 - 14th International Sjögren's Syndrome Symposium (ISSS) in Washington D.C.

Emergence of the idea of a European Federation June 2018 - EULAR Congress in Amsterdam

Decision to set up Sjögren Europe



Constituent Assembly of Sjögren Europe with 10 countries involved



Key milestones

April 2018 – 14th ISSS in Washington D.C.

Face-to-face meetings with European Patient Advocates

Strong wish to build a better future for European patients with Sjögren's June 2018 – EULAR Congress in Amsterdam

meetings

Networking Information & experiences

gathering (Lupus Europe, FESCA, etc.)

Decision to set up Sjögren Europe Summer 2018 First contacts with other associations Choice of a name Drafting of the By-Laws Fall – 2018 Logo design Networking Learning from others (EURORDIS Council of European Federations)

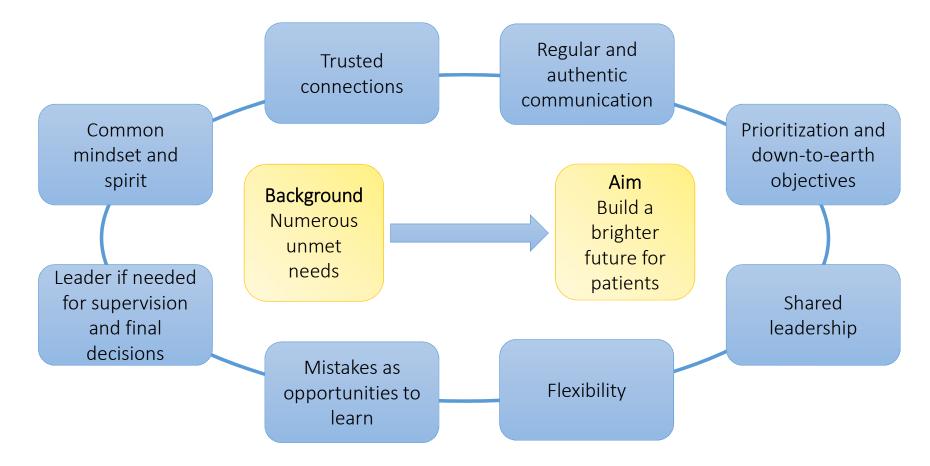
Winter 2018 – 2019 Creation of the website Invitation to other associations to join Set up of the Medical Board

February 2019

Constituent Assembly of Sjögren Europe

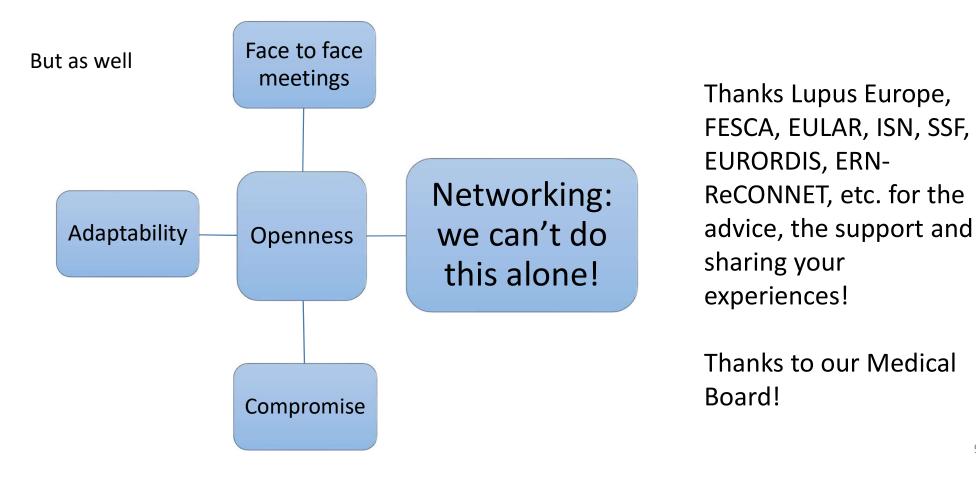


Key Ingredients for the setting up of Sjögren Europe 1/2





Key Ingredients for the setting up of Sjögren Europe 2/2





Results

On the 23rd of February 2019, Sjögren Europe was formally set with 10 countries as founders.

Being flexible not only allows patients with extensive fatigue to do work for the federation but also leads to lean and efficient procedures and tasks: patients must save energy.

An enthusiastic and supportive environment makes the commitment sustainable and meaningful.

Face to face meetings, a good network and collaboration are imperative.

The way we respond to mistakes is also crucial for motivation.



Collaborations – Patient involvement

Current cooperation of the Sjögren Europe Board Members with the scientific and research community



neces





European Reference Network

for rare or low prevalence complex diseases

Network

Connective Tissue and Musculoskeletal Diseases (ERN ReCONNET)





Conclusion

This project empowers the Sjögren's Syndrome patient community, brings hope, injects a new energy in patient advocacy and breathes motivation for collaboration to researchers, scientists and clinicians.

WORK!

Take home messages 1/3

- Promote personal initiatives
- Consider mistakes as opportunities to learn
- Help each other: inside and outside the organisation! You have more to gain than you lose

For Health Professionals and Researchers:

- Thank you for listening to patients and learning from them too
- Sjögren Europe wants to collaborate with you!



Take home messages 2/3

- 2/3
- Understand the reality of your members
- Understand the reality of the people who do the work
- Find a way to embed and conciliate those realities

Our way: flexibility, open-mindedness, trust and shared leadership

Be professional but it is the enthusiastic and supportive environment that makes the commitment to the organisation sustainable and meaningful



Take home messages 3/3

And last but not least...

Yes, we built up Sjögren Europe in less than one year, but

it doesn't matter how fast you go, as long as you don't stop



Thanks for your attention!



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