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. *

Why setting up Sjögren Europe?

- Raise awareness
- Articulate patient voices throughout Europe
- Foster patient involvement in research
- Help to address the numerous unmet needs

By patients for patients in Europe

Etc.
Landscape

Members of Sjögren Europe

National patient organisations for Sjögren’s Syndrome & rheumatic diseases

Medical Board

Clinicians, scientists, researchers

Sjögren Europe as a new partner

Other stakeholders

To increase attention, visibility and solutions for Sjögren’s Syndrome

Purpose of Sjögren Europe

Unmet needs
Key dates

April 2018 - 14\textsuperscript{th} 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

February 2019
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
Face-to-face 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

- **Background**: Numerous unmet needs
- **Aim**: Build a brighter future for patients

**Trusted connections**

**Regular and authentic communication**

**Prioritization and down-to-earth objectives**

**Shared leadership**

**Leader if needed for supervision and final decisions**

**Common mindset and spirit**

**Mistakes as opportunities to learn**

**Flexibility**

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

But as well

Adaptability

Openness

Face to face meetings

Networking: we can’t do this alone!

Compromise

Thanks Lupus Europe, FESCA, EULAR, ISN, SSF, EURORDIS, ERN-ReCONNET, etc. for the advice, the support and sharing your experiences!

Thanks to our Medical Board!
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
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.
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

• 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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