

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?



By patients for patients in Europe

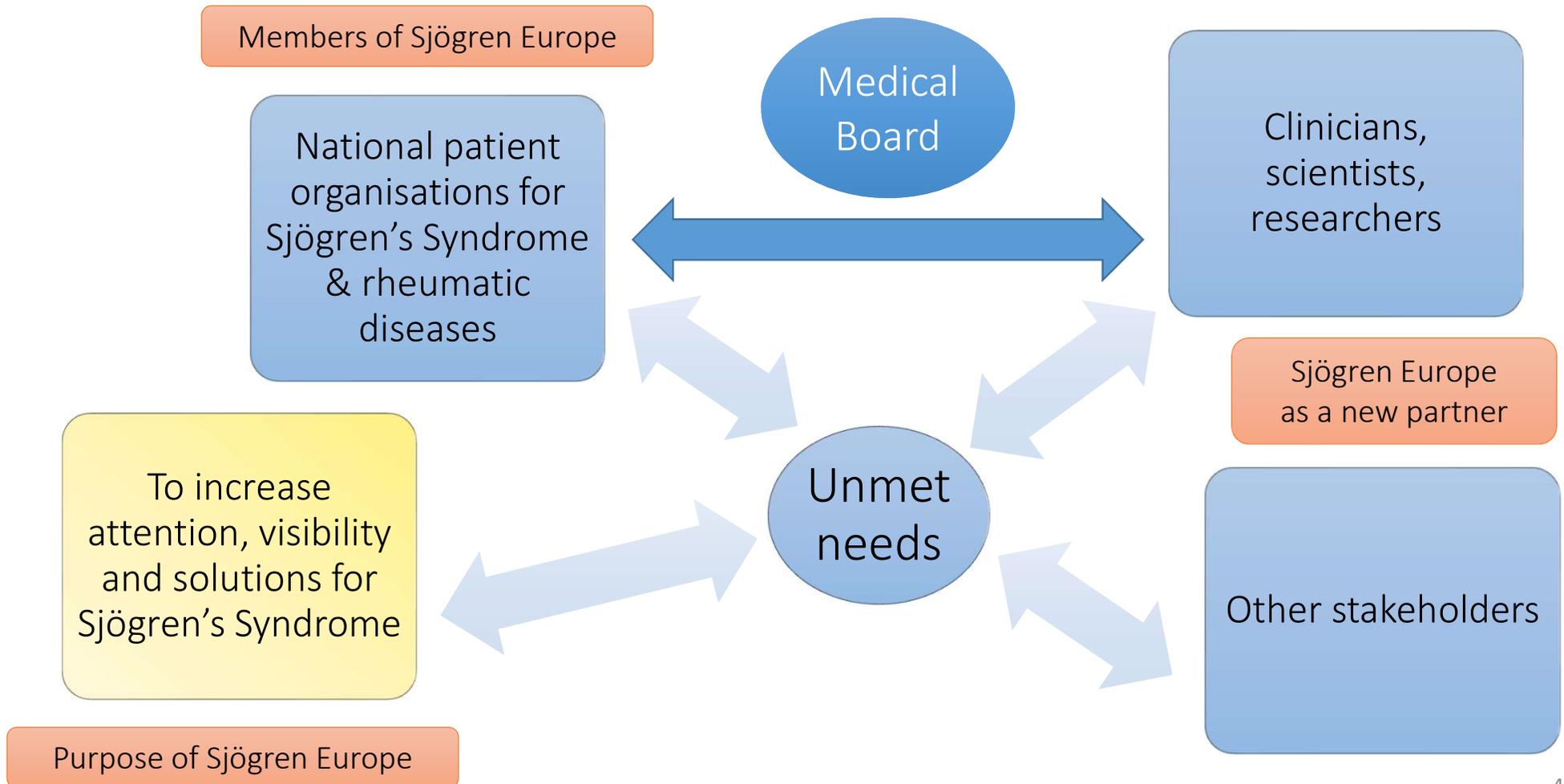
Raise awareness

Articulate patient voices throughout Europe

Foster patient involvement in research

Help to address the numerous **unmet needs**

Landscape

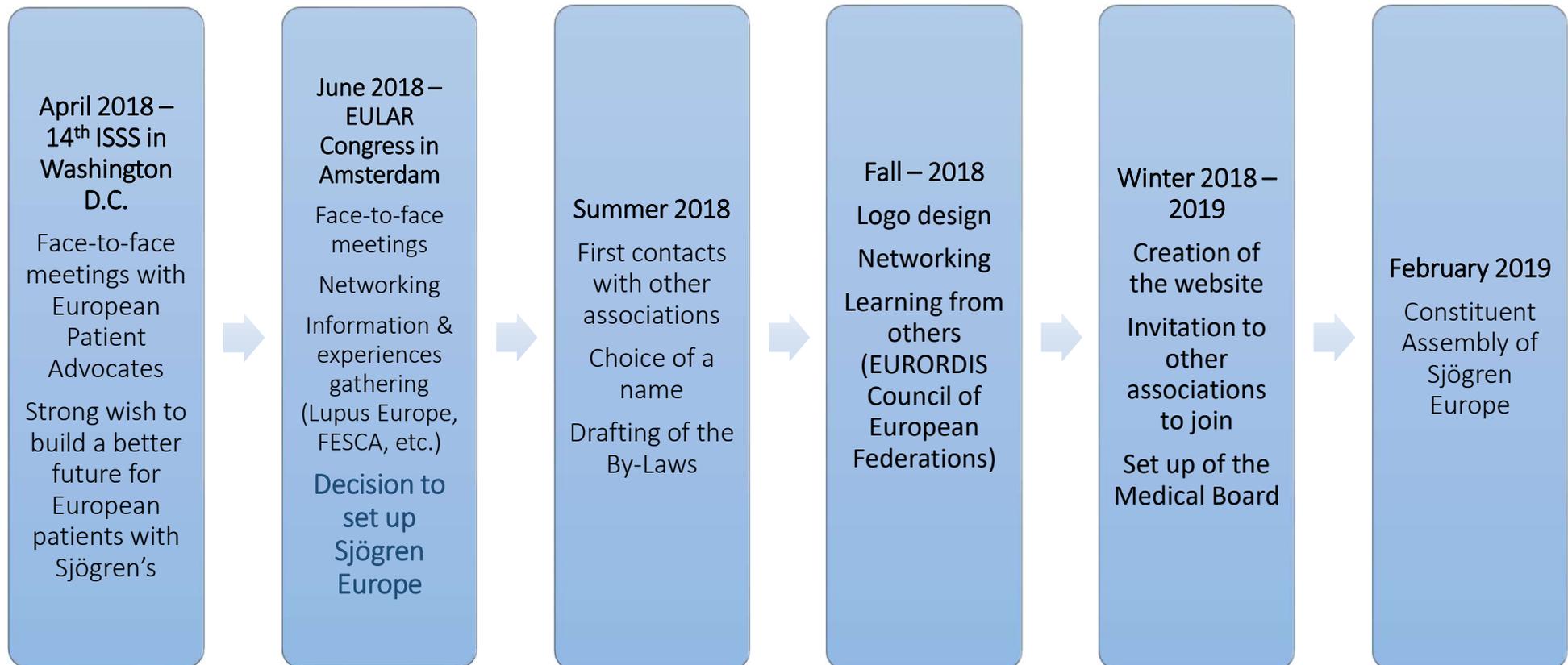




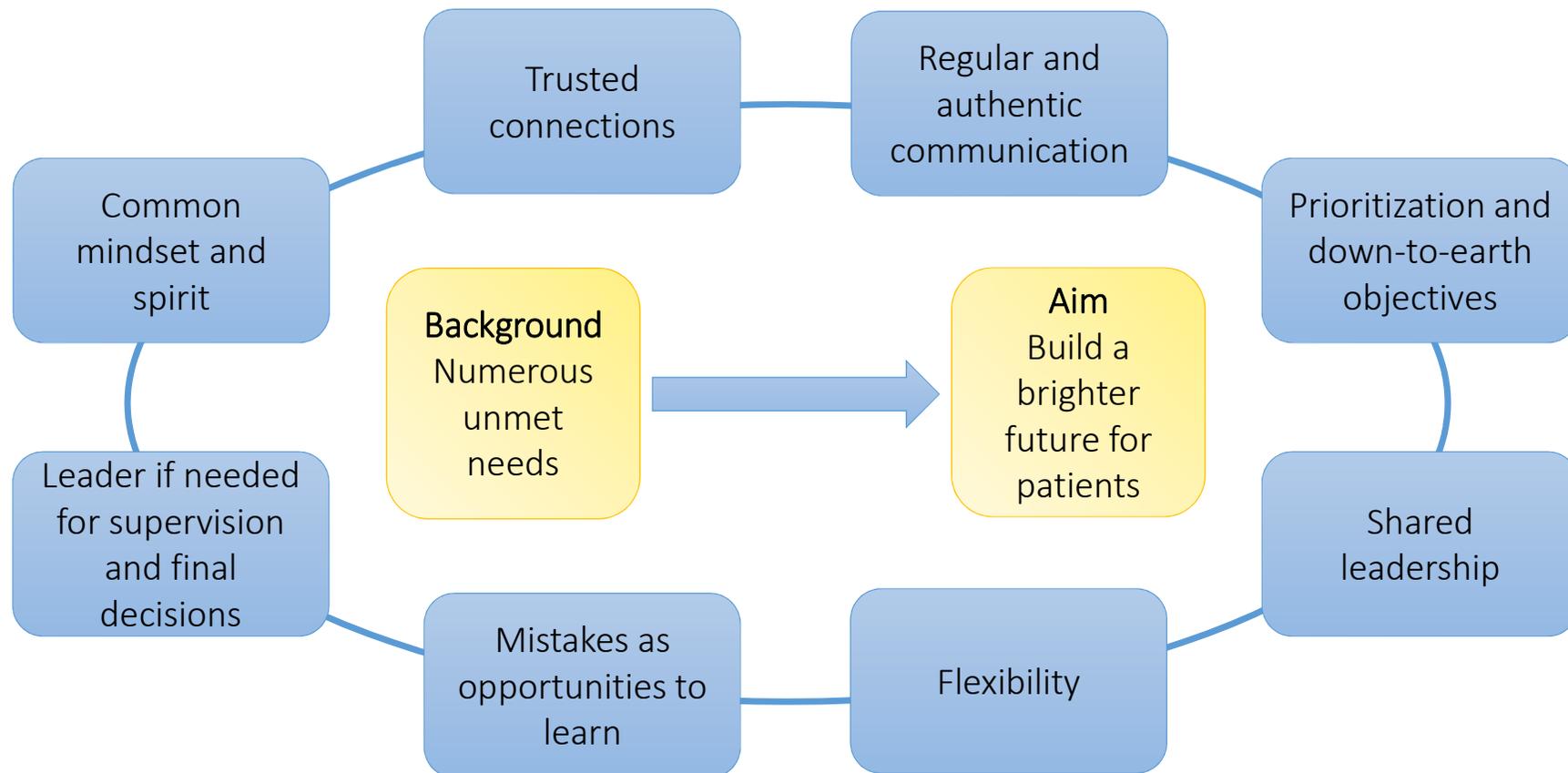
Key dates



Key milestones

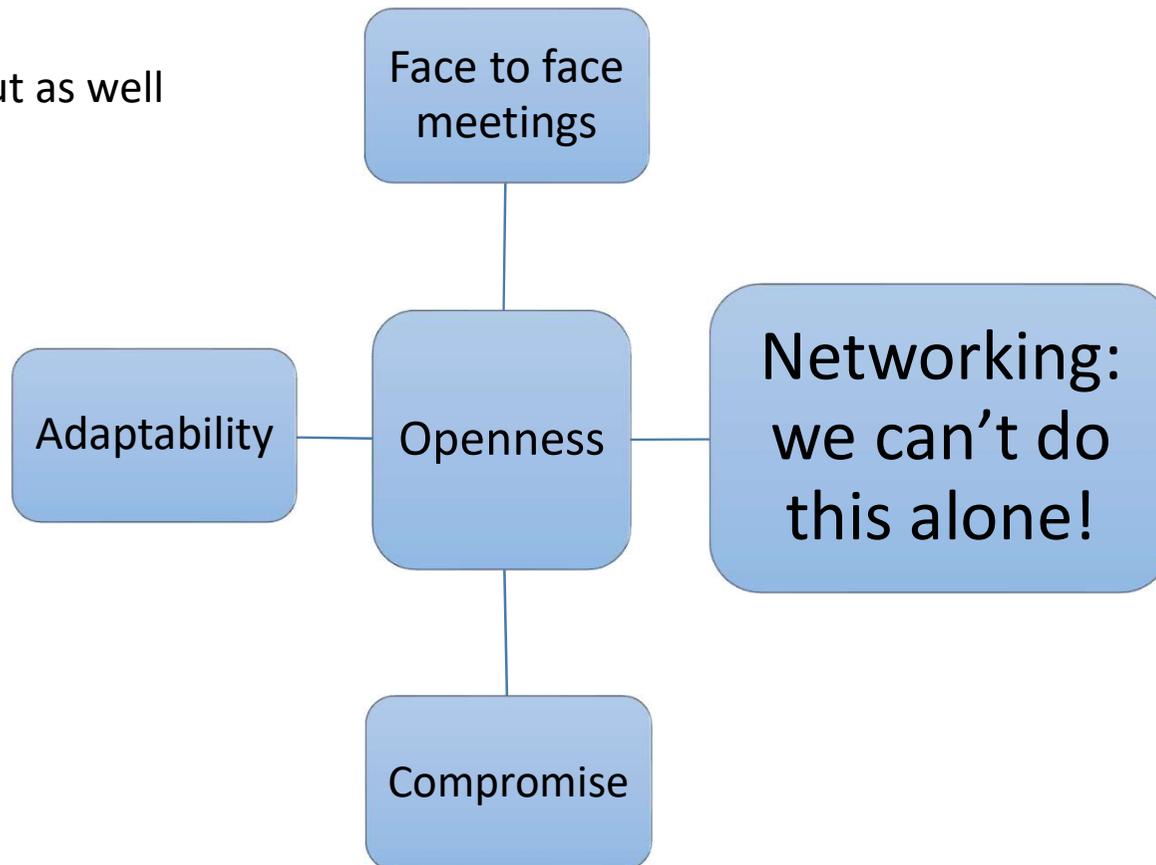


Key Ingredients for the setting up of Sjögren Europe 1/2



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

But as well



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



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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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