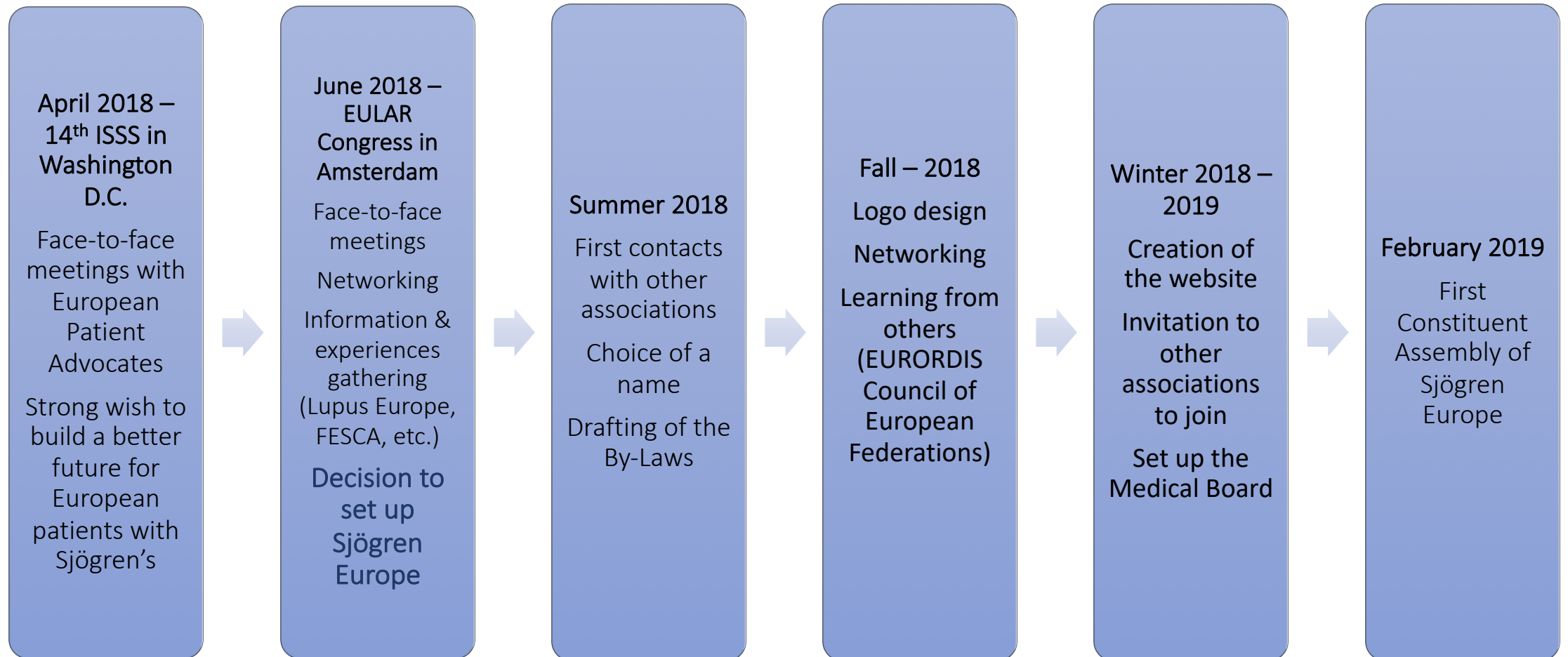




Key milestones



The Board



Why set up Sjögren Europe?



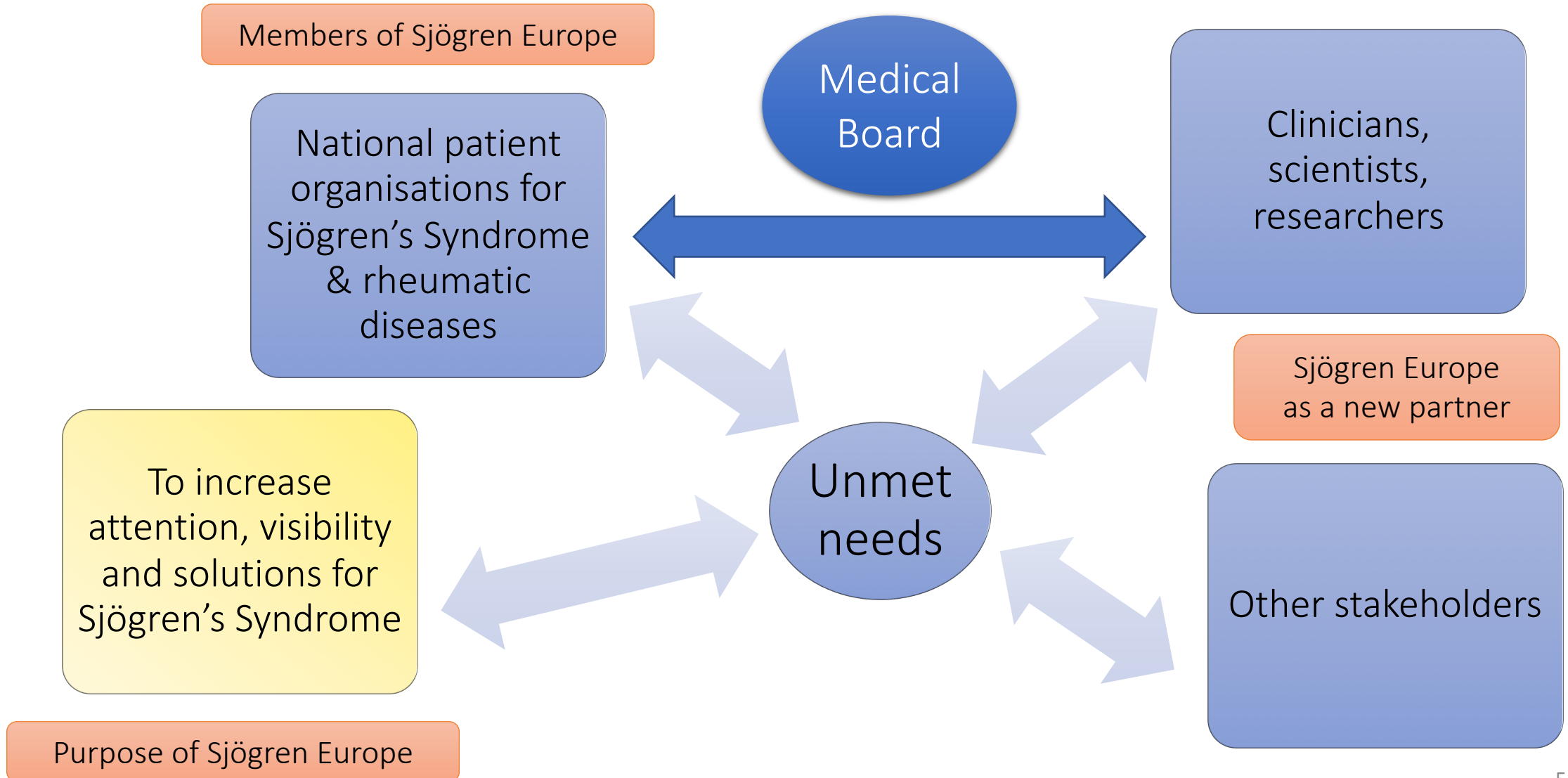
By patients for patients in Europe

Raise awareness

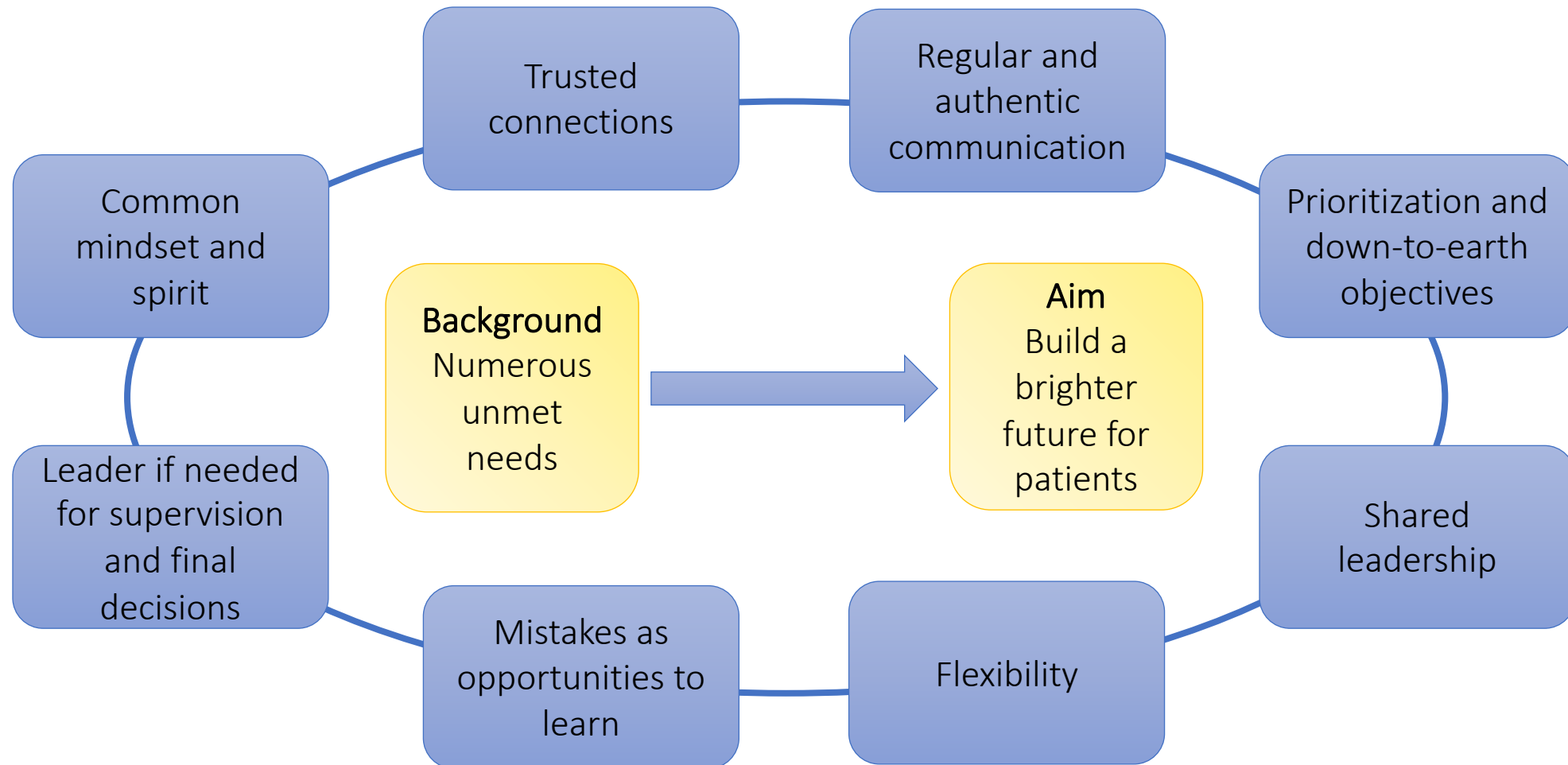
Articulate patient voices
throughout Europe

Foster patient involvement in
research

Help to address the numerous
unmet needs



Key Ingredients required to establish Sjögren Europe



Results

On the 23rd of February 2019, Sjögren Europe was formally established with 10 founder members representing 10 countries .

Six of the Board members have Sjögrens and all are unpaid volunteers

A flexible approach allows patients with extensive fatigue to work for the federation and leads to lean and efficient completion of 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.



A person's symptoms are as individual as
Their finger

A light blue fingerprint graphic with the word 'Print' written in a dark blue, typewriter-style font across its center.

Print

Our main objectives



Empower national organisations

Assist, promote and encourage the improvement of knowledge about Sjögren's Syndrome and raise awareness about the disease and all its aspects among national Sjögren's Syndrome and health-related organisations, patients, members of the health, welfare and medical professions, governmental bodies, pharmaceutical companies and the public



Work to achieve an optimal care system, medical treatment and follow-up, psychosocial support and quality of life for all the Sjögren's Syndrome patients in Europe

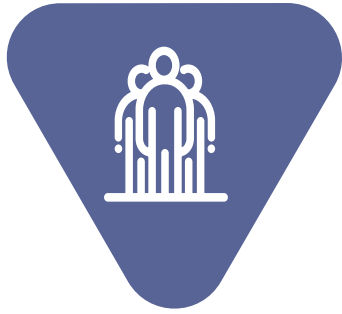


- Be involved in decisions, programs, strategies etc. which affect patients with Sjögren's Syndrome in Europe*
- Foster and/or undertake surveys and research projects related to the disease and the publication of the results of any such research*

Target groups



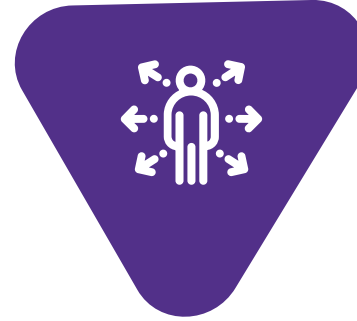
**Patients and
caregivers**



Wide public



Physicians



Authorities



Industry



Media

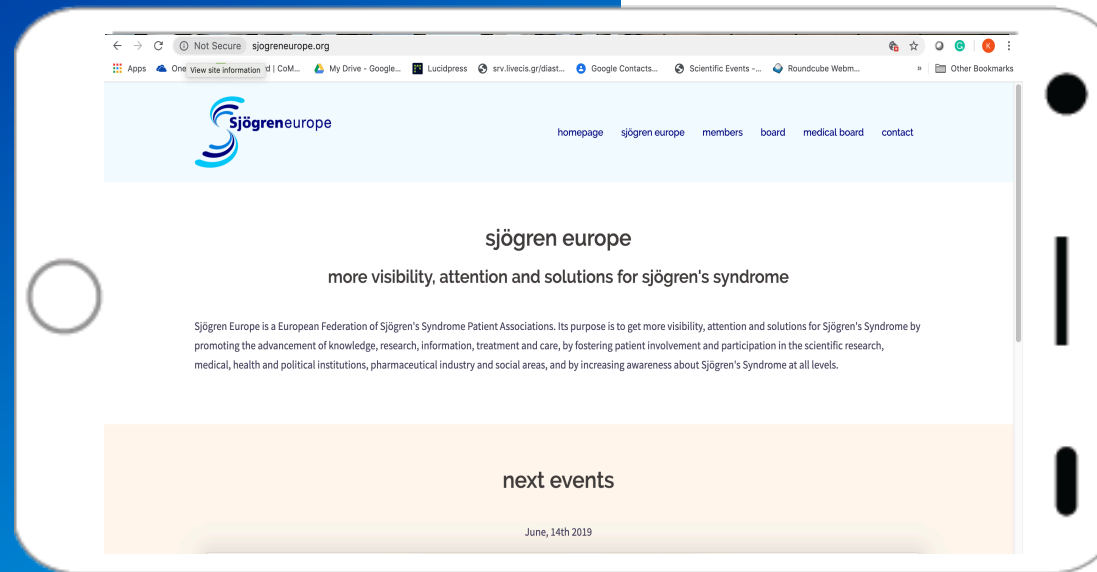
Site and Social Media Campaign



Site

Content Management of the Site in regular basis

Creation of web site traffic with SEO



Social Media Campaign

Content Management

Regular posts e.g. 2-3/week

Posts for disease awareness

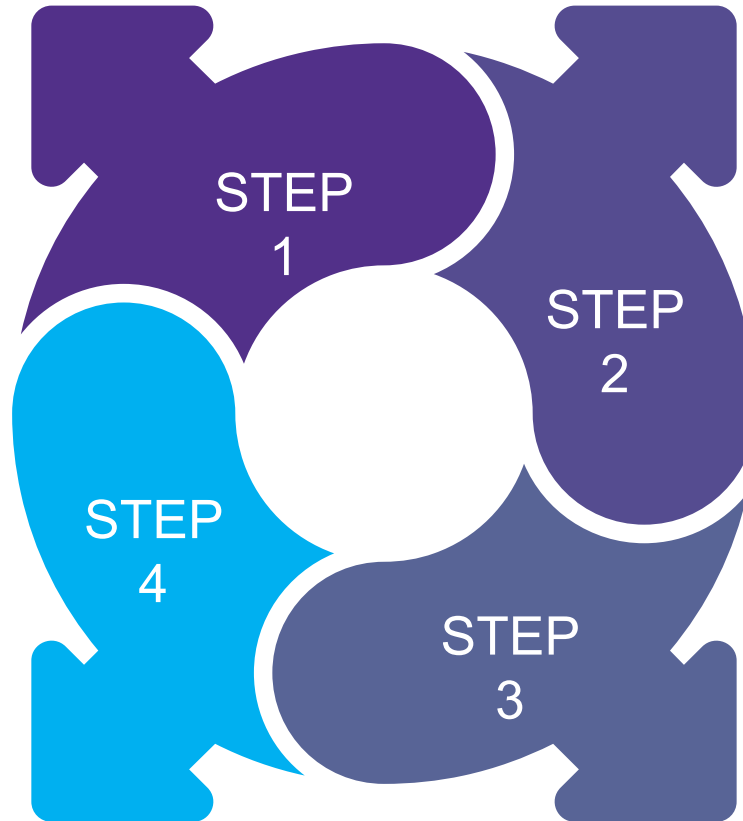
World Sjögren's Awareness Day – July 23

Social Media Campaign

Upload posts and relevant banner in social media accounts. The same posts will be adapted and posted in the local social media accounts

Info material

Create info material e.g. infographic, social media banner and cover page, a 6 page leaflet about Sjogren syndrome . All will be used and distribute via internet



Press Release

Adaptation of the central press release in local languages and distribution in local markets

Microsite for the date inside Sjogren Europe website

As Alternative one page for the Date could be included in website .



Sjögren Europe Live Webinar

Sjögren's Now

Tuesday November 3rd, 18:00-19:30 CET
(Paris, Amsterdam, Madrid time zone)

Dear friends, Colleagues and Patients,

Sjögren Europe Board is incredibly happy to invite you to our first Webinar about Sjögren's Syndrome. Given the Covid-19 pandemic, our first Patients Annual Conference has been postponed and we organised this free webinar instead. If you are a patient, a medical or just interested in the topic of Sjögren's, this webinar is just for you!

To attend, please join us by clicking the following link at the appropriate time: <https://www.eventbrite.co.uk/sjogren-europe-webinar>

PROGRAM

- | | |
|-----------|--|
| 18:00 CET | Welcome and Introduction
Alex Groppe, Sjögren Europe President |
| 18:10 CET | Therapy treatments (existing and future ones)
Prof. Basilika Kavalat, Prof. of Pharmacology and Clinical Pharmacology and Director of the Laboratory of Pharmacology and Clinical Pharmacology, Medical School, Aristotle University of Thessaloniki, Greece |
| 18:30 CET | Tackling fatigue
Prof. Wim Geenen, Prof. of Psychosomatic & Clinical Psychology, Department of Psychology, Utrecht University, Netherlands |
| 18:50 CET | Update on current research
Prof. Steve Bowman, Consultant Neurologist, Queen Elizabeth Hospital, Birmingham and University of Birmingham, United Kingdom |
| 19:10 CET | Question and answer session (Questions must be submitted in advance)
Prof. Steve Bowman and Linda Stone, Sjögren Europe Secretary.
Please, send your questions in advance to contact@sjogreneurope.org or in the chat during the webinar.
Relevant questions will be selected |
| 19:30 CET | Closing Remarks
Alex Groppe & Linda Stone |

Organised with the help of unrestricted grants from **BERNARDINI** and **NOVARTIS**.

Sjögren Europe strictly follows the EFPIA code. Sjögren Europe and the content of the webinar are totally independent from these companies.

Cooperation with pharma companies

Initiate and strengthen the contacts with pharma companies for cooperation and sponsorships.

The main goals of Sjogren Europe are to support research and

the ongoing awareness campaign for both the disease and its existence.

Collaborations – Patient involvement

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



eular



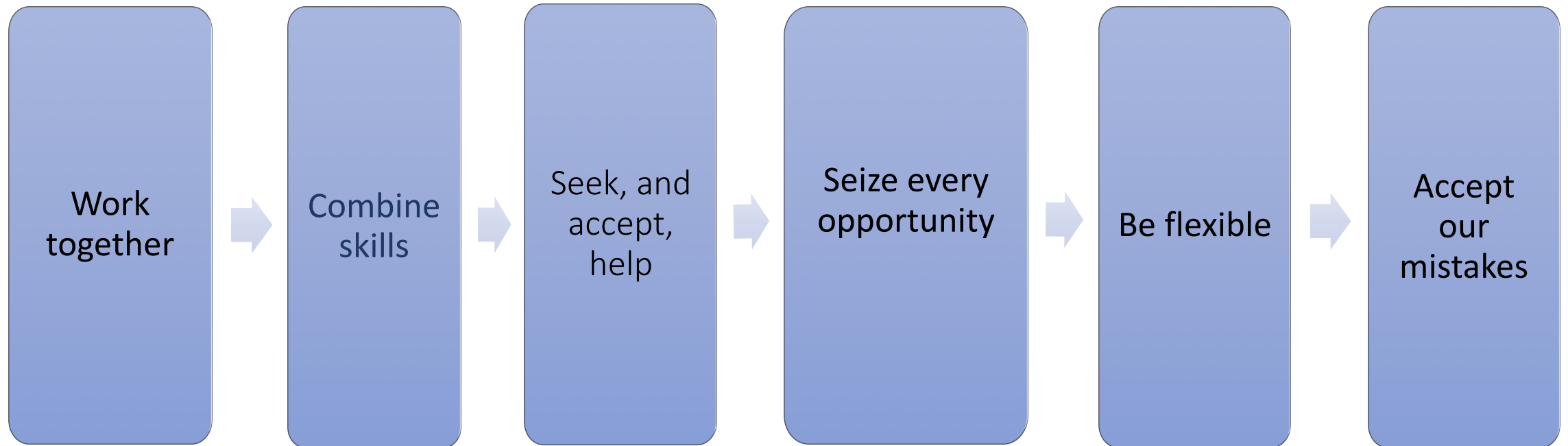
Sjögren Europe

- empowers the Sjögren's Syndrome patient community,
- brings hope,
- injects a new energy in patient advocacy and
- E
- ncourages collaboration between patients, researchers, scientists and clinicians.

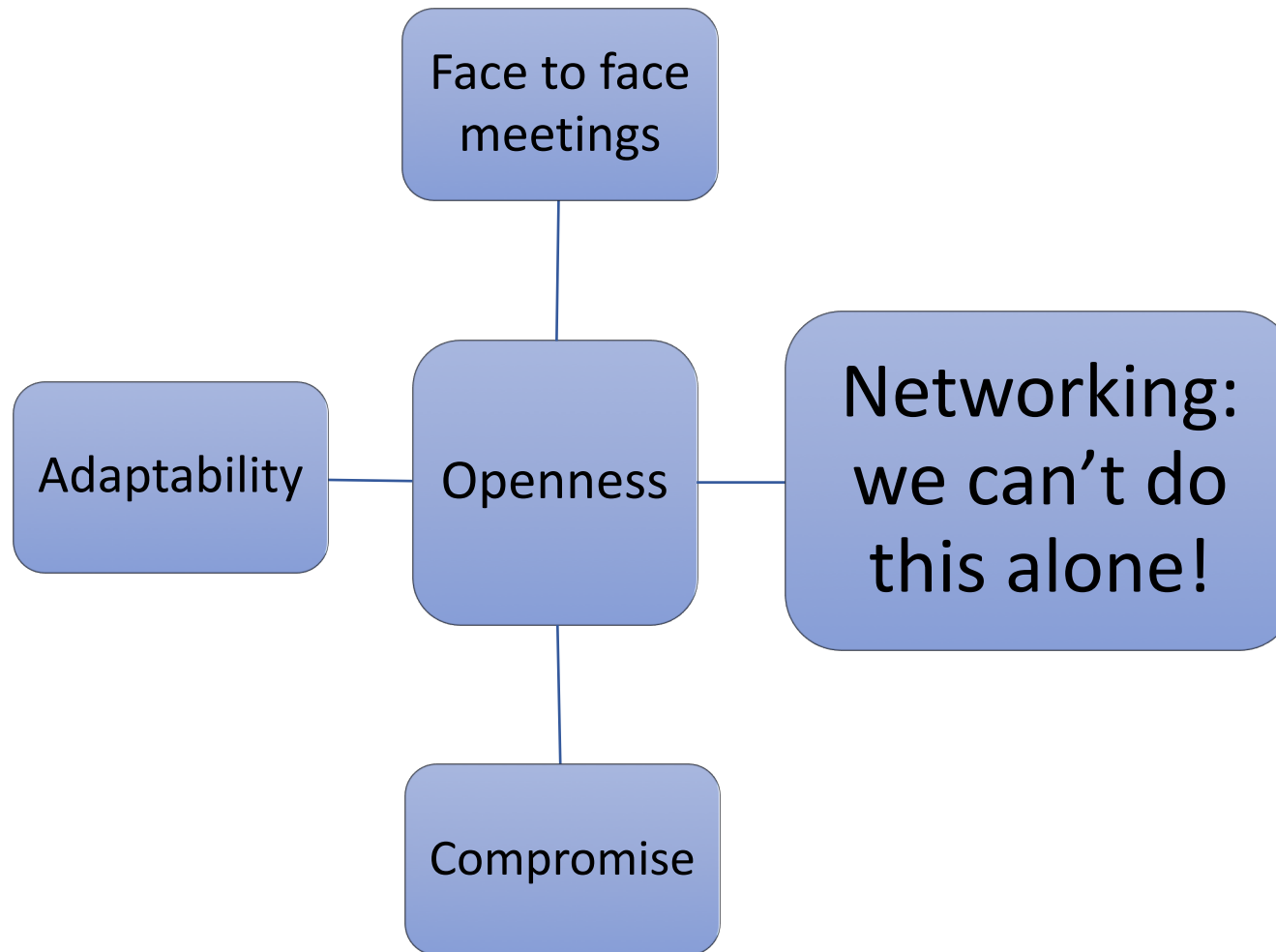
Planned activities

- Annual conference
- E-leaflets
- Webinar
- Increased interaction with EULAR PARE
- Increasing membership (currently 12 full members and 2 associate members)
- Continuing collaboration with research

How have we managed to achieve so much in less than a year and a half?



Plus



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!

Take home message

For Patient Groups

- Understand the reality of your members
- Understand the reality of the people who do the work
- Find a way to embed and accommodate these realities
- Promote personal initiatives
- Consider mistakes as an opportunity to learn
- Help each other, individually and collectively – you have more to gain than lose
- Be professional
- Maintain integrity

Take home message

For health professionals, researchers, pharma industry and regulators

- Listen to your patients – we know how we are coping, and when we are not!
- Work with us, the patient associations, to make life better, and easier
- Trust us

We are enthusiastic and committed to supporting those who suffer and those who care for them.

Please help us to achieve our goals.

Thankyou for your attention!



contact@sjogreneurope.org
www.sjogreneurope.org

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

How have we managed to achieve so much
in less than a year and a half?

Thank you for your attention!

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