

# Lupus Europe Convention - 2020

## FESCA, Federation of European Scleroderma Associations

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25 members  
21 countries in  
Europe + Israel



# Scleroderma or Systemic Sclerosis

## Outside

Skin thickness, microstomia, bowed fingers, calcinosis, digital ulcers, teleangiectasias. High impact on the self perception.

## Inside

The entire GIT is involved and also the heart, the lungs, the kidneys, the blood vessels. Fatigue.

# World Scleroderma Day

29th of June, death of Paul Klee



## Who

Each year we involve new members in the leading Team



## What

Identification of a burning topic. This year, of course, it was COVID-19 related.



## How

Each member decides the tools to spread the message. There is a budget refunded.





# World Scleroderma Congress

2022 Prague ?????



## Who

Patients, clinicians,  
industry



## What

3 days of  
discussions,  
meetings and  
roundtables



## How

In cooperation with our  
scientific partner, the  
World Scleroderma  
Foundation



# Partnership with WSF

## Consensus Statements

With multidisciplinary experts to review the research literature and find definitions for some topics (i.e. primary Heart Involvement)

## ***DETECT***

Select signs, symptoms, tests to detect an organ damage or decide which further, and maybe more invasive tests, patients should undergo.



# Partnership EULAR

## PARE

Several activities through our patients research partners, as all of you ;)

## Juvenile SSc

Few patients, few data and aggressive disease. It needs to be more investigated



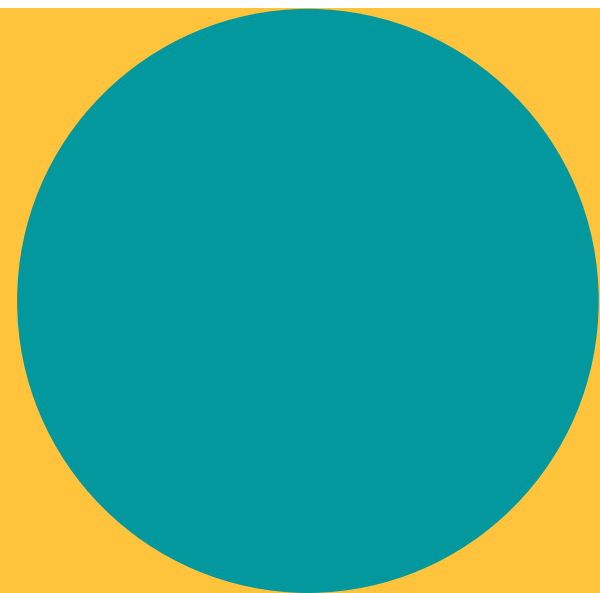
# Partnership with the ERN ReCONNET

## Towards the inside

We collect SSc patients' needs, but we also try to find transversal needs with our sister-disease to focus on.

## Towards the outside

FESCA disseminates through its members the outcomes of ReCONNET works and activities.





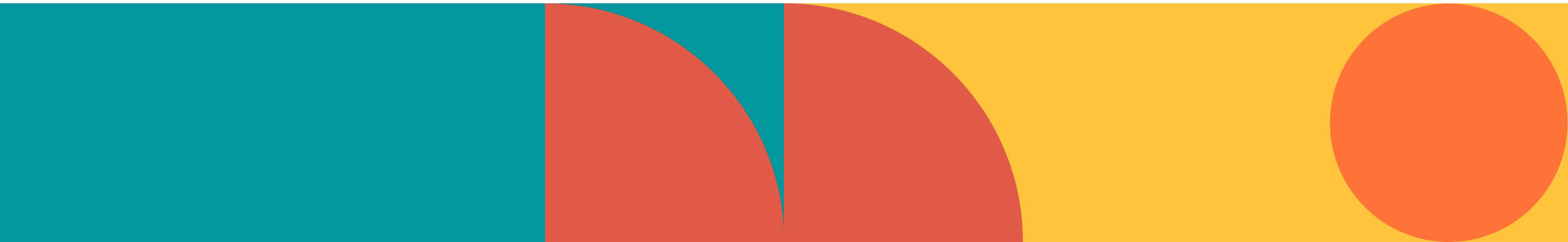
# Partnership with SPIN

## What

The mission is to work with SSc patients to identify their needs and prioritize research and to develop and disseminate accessible patient programs that improve QoL and empower patients and their loved ones.

## How

The SPIN cohort is a group of SSc patients from around the world who participate in online studies to provide info about important challenges. Some participants are also invited to test the online support programs before releasing them to the public.



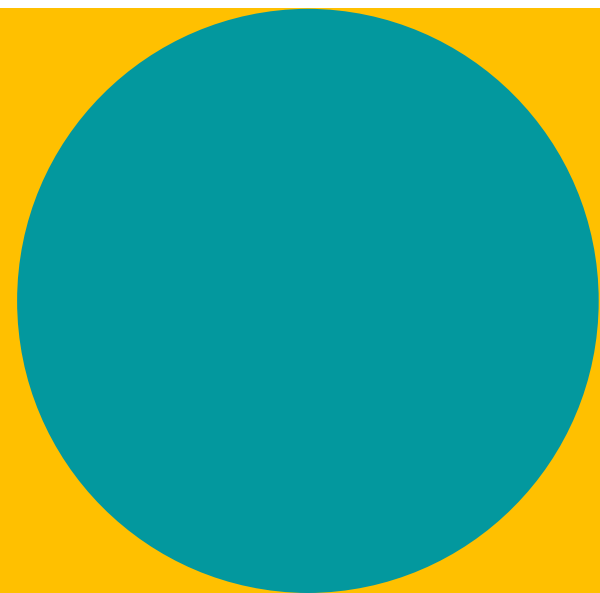
# Partnership with Pharma

## Pre-clinical Phase

Identification of clinical unmet needs relevant for SSc patients. Cooperation in the trial design with a special eye on the informed consent.

## Phase II and III

Creation of information for patients, explaining in layman language what a clinical trial is, provide hacks to cope with potential side effects of the medicine.



# Our priorities for a better future in Europe

and beyond

## Equal access to therapies

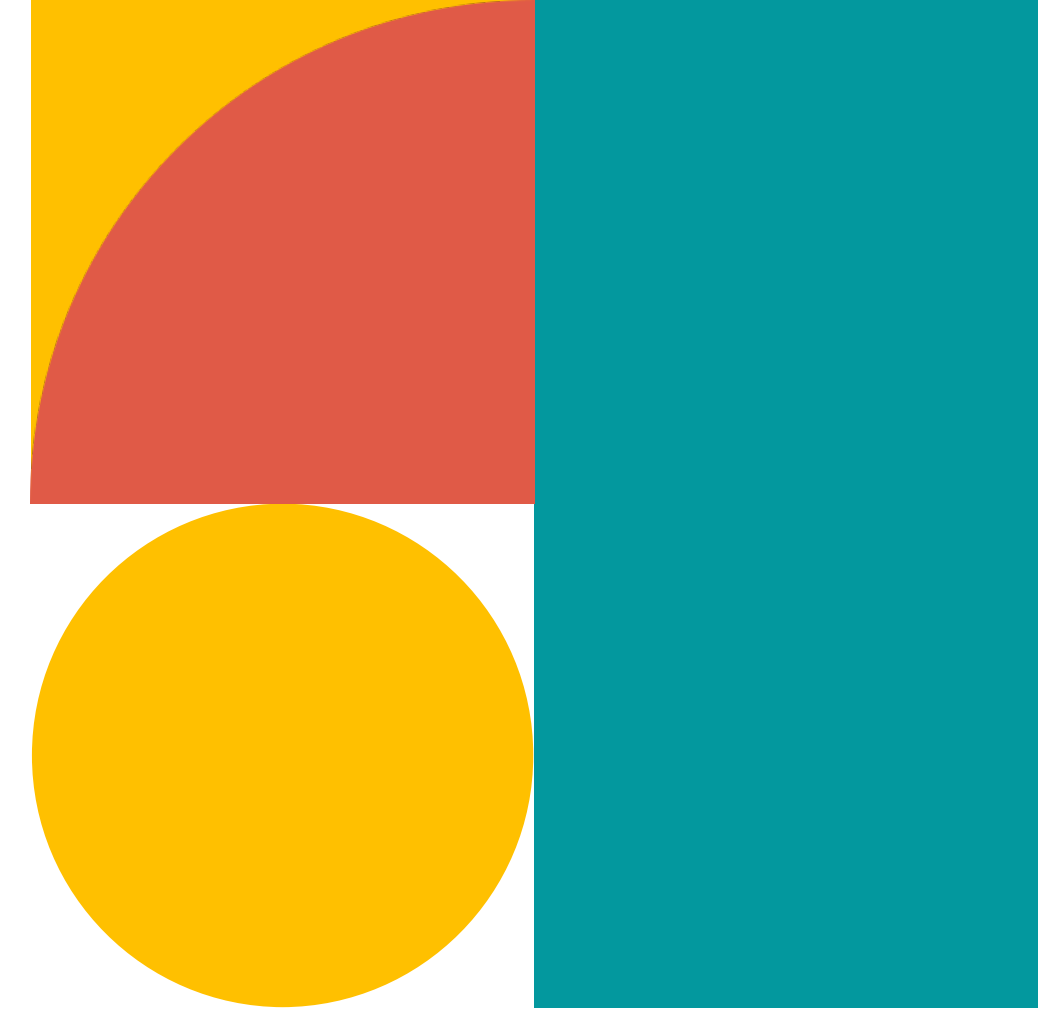
We need SSc patients all over Europe to access the best therapies. In this process ERN ReCONNECT can be really helpful.

## Foster the research as a whole

Basic and traslational research are crucial to improve the cure and the QoL of SSc patients (and caregiver). Being a rare disease it often doesn't help. WSF can be really helpful.

## Lobbing at national and European level

Fostering EU decisions and their integration into national health systems are crucial for our community. EULAR and EURORDIS, our national members and the ePAGs can play a crucial role.



Coming together is a  
beginning.

Keeping together is  
progress.

Working together is  
success.

by Henry Ford

Thank you for  
your attention

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