

# World Scleroderma Day 2021

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## WHO ARE WE?


The Federation of European Scleroderma Associations aisbl. (FESCA) is a pan-european group of national scleroderma organisations.

FESCA was founded in 2006 by patient support groups from nine EU countries. In 2021 the number of national groups have increased to 27 member associations from 21 countries, with Greece having just been approved as a new member of the "family".

Our main goal is to increase awareness of this rare and deadly disease, which is invisible to the much of the world.

## WHAT IS WORLD SCLERODERMA DAY?

Scleroderma is a rare autoimmune condition where the body's immune system becomes overactive and attacks healthy tissue. It affects around 2.5 million worldwide and is inadequately recognised or understood. Unfortunately, there is currently no cure, and the incapacitating condition can severely impact one's quality of life. Due to the lack of awareness about scleroderma, a delayed diagnosis common, and this therefore considerably influences patients' ability to manage their condition and their overall wellbeing.



FESCA endeavoured to create a day on which the disease would be recognised throughout Europe. For the first time on June 29, 2009 we celebrated for the first time the life and death of the great Swiss artist Paul Klee\* and all those who struggle with scleroderma. Then and now we campaign for a world in which equal rights, treatments and care are offered to people with scleroderma, and in which such rare diseases are not forgotten, but afforded the consideration, attention and funding of other more common diseases.

Going from a European Scleroderma Day in 2009, we developed to World Scleroderma Day in 2010, as countries outside Europe asked to join us in the campaign. During the very first Systemic Sclerosis World congress in 2010 it was agreed amongst patient associations all over the world that June 29<sup>th</sup> should be World Scleroderma Day.

\*Paul Klee died on June 29, 1940, strongly affected by scleroderma.



June 29  
International  
Scleroderma Day

## I AM MY PASSION NOT MY DISEASE

We developed a strong campaign plan with a clear aim. Our main goals for the month were to:

- Generate more knowledge and interest in scleroderma
- Promote the 29th of June as World Scleroderma Day throughout Europe
- Foster easy access to clear and reliable information about scleroderma
- Give media stage to scleroderma representatives
- Reinforce the importance of early diagnosis

We created our main graphics of a sunflower which is an international symbol for scleroderma.

We also created a main poster and planned our social media campaign with what we would post and when.



We produced two slogans which we used throughout the month which were 'I am my passion not my disease!' and 'Scleroderma and COVID-19 will not take my smile!'

This highlights our focus throughout WSD 2021, which was not on the way people with scleroderma are affected, but we wanted to draw light to the enthusiasm and love these people have for other aspects of their lives.

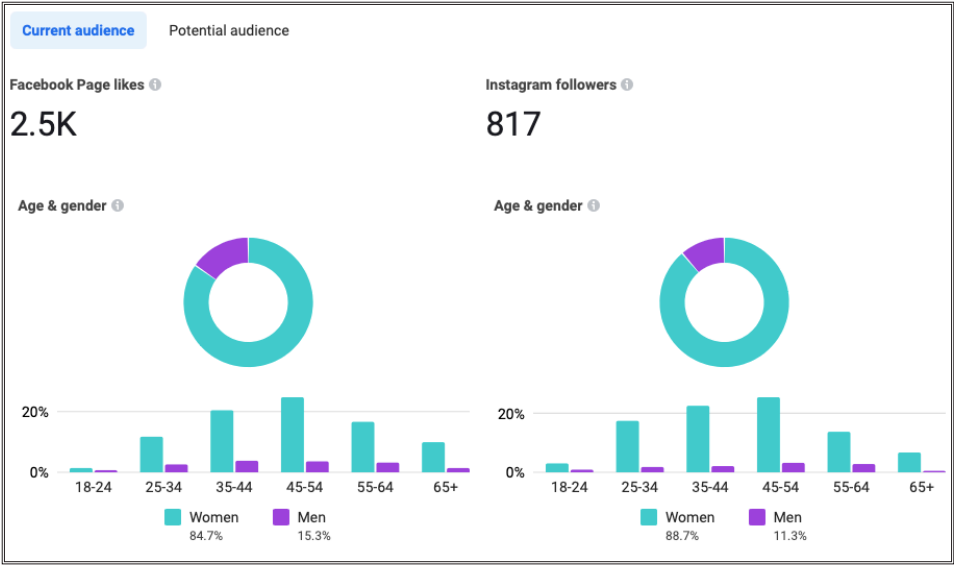
The campaign was centralized with 5 posters, rollup and 1 video. Then the materials were translated into 18 languages, so that our members could use the information on local basis along with their own awareness plans in their countries.

Watch our campaign on YouTube via the QR code below.



## THE OUTCOME

We wanted to highlight the passion that people with scleroderma have in their life. Consequently, our campaign saw us post content throughout our social media illustrating scleroderma patients' joys in life to show that living with a condition that impacts your quality of life does not define you. We asked people to share their photos of themselves doing what they love with the hashtag #sclerosmile!



Audience in total

In the whole month of June, we reached 58,500 people through Facebook and 30,000 through Instagram. Nearly 1,000 people had active sessions across all 4 of our social media channels. We posted on social media every day in June besides 3 days. Facebook is where we have most involvement with our community and 88% of these active sessions were through Facebook.



## CONCLUSION

Overall it was a successful campaign.

It is incredibly important to schedule the content for social media. Our goal was to have enough material to post on social media every day and this means planning for months before June. To have a well prepared campaign, it is important to start as early as possible.

This is as we need to:

- raise funding for the campaign
- engage affiliates (such as designers)
- engage members (translation of materials)
- make a plan for the entire campaign and schedule ahead

We also know that when using the right hashtags (#) you engage the entire world to participate and not only your member countries.

The last 5 years we have included #sclerosmile in our campaign materials, and we have experienced that the hashtag (#) has not only been used during the awareness campaign in June, but the entire year by individuals from all over the world.

## ACKNOWLEDGEMENT

Thank you to:

- our sponsors for supporting us in our campaign
- our World Scleroderma Day manager, Helena Gaspar, to lead the campaign
- the company Miligrama for the graphic support
- the members of FESCA for the support



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