

# What works to bring together your community for a disease awareness day



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(non practising)

Diagnosed with Systemic Sclerosis (Ssc, Scleroderma) and Raynaud's in 1997, aged 24

Ssc affects the vascular, immune and connective tissue systems

<http://www.eurordis.org/news/living-with-scleroderma-and-raynauds-disease>

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Expert Patient Adviser to:

- NHS England
- The European Medicines Agency (EMA)
- European Rare Diseases Organisation (EURORDIS),
- The British Society for Rheumatology (BSR)
- Sclerodermanews.com/nicola's scleroderma blog
- [www.justgiving.com/sclerodermaunit-royalfree](http://www.justgiving.com/sclerodermaunit-royalfree)
- [www.facebook.com/Raynauds-Scleroderma-Awareness-Global-Patients](https://www.facebook.com/Raynauds-Scleroderma-Awareness-Global-Patients)
- Personal blog: [www.cosmicfairy444.blogspot.co.uk](http://www.cosmicfairy444.blogspot.co.uk)

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## EURORDIS - RARE DISEASE DAY

Our objective is for the World Health Organization to recognise the last day of February as the official Rare Disease Day.

The campaign targets the general public and also seeks to raise awareness amongst policy makers, public authorities, industry representatives, researchers, health professionals and everyone with an interest in rare diseases, resulting in a great deal of media coverage.

Even though the campaign started as a European event, Rare Disease Day has progressively become a worldwide phenomenon, with the USA joining in 2009, and patient organisations in 85 countries around the world participating in 2015.

[www.sclerodermanews.com/2016/02/28/rare-disease-day-2016](http://www.sclerodermanews.com/2016/02/28/rare-disease-day-2016)

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The political momentum resulting from Rare Disease Day also serves advocacy purposes. It has notably contributed to the advancement of national plans and policies for rare diseases in a number of countries.



I had the pleasure of attending the RareDiseaseUK reception for Rare Disease Day 2016 at the House of Commons.

<http://sclerodermanews.com/2016/03/06/rarediseaseuk-reception-at-the-house-of-commons-2-3-16/>

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## WORLD SCLERODERMA DAY 2015


Advocating at the  
European Parliament in Brussels:  
'How can patient care be  
improved'

[https://www.youtube.com/watch?v=KQimB\\_F2I\\_4](https://www.youtube.com/watch?v=KQimB_F2I_4)

On a personal level, this was 11 years to the day, that I had last worn my wig and gown court robes! And a few years ago, I would never have believed that I could talk so calmly about Scleroderma!



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**WORLD SCLERODERMA DAY**  
**JUNE 29TH**

**Scleroderma** is a rare, autoimmune, connective tissue disease characterized by the thickening and hardening of the underlying connective tissues which support the skin, blood vessels, heart, lungs, and kidneys. **Scleroderma** can affect women, men and children. It is complex, debilitating, and often fatal. There are some treatments available, but there is effectively, no cure for **Scleroderma**

Many are afflicted with or affected by **Scleroderma**. Let us all do our parts to raise awareness across the world!

**SCLERODERMA CARE FOUNDATION**  
EDUCATION. SUPPORT. RESEARCH  
SCLERODERMATT.ORG

f t s

Decide on a date, check with WHO list and Rob's list

June 29<sup>th</sup> chosen for Scleroderma as this was the day that Swiss artist and Scleroderma patient, Paul Klee died.

[www.sclerodermanews.com/2016/04/11/world-scleroderma-day-june-29th-2016](http://www.sclerodermanews.com/2016/04/11/world-scleroderma-day-june-29th-2016)

[www.justgiving.com/scleroderma](http://www.justgiving.com/scleroderma)  
unit-royalfree

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- There are many different ways that you can get involved, whether you are physically able or not. Here are a few ideas:
- Teal is seen as the scleroderma awareness colour: Find your colour!
- Change your social media (twitter / facebook etc) cover photo and profile photo to an awareness photo or teal theme
- Contact your local media / radio / paper to give an interview or an awareness feature
- Take awareness leaflets to all community healthcare professionals eg. GP surgeries, pharmacies, practice nurses
- Organise an awareness raising stand in your local hospital / healthcare provider's building

[www.justgiving.com/scleroderma-unit-royalfree](http://www.justgiving.com/scleroderma-unit-royalfree)

# MEETING THE NEED OF THE RARE DISEASE PATIENT

1. Early diagnosis essential  
(increase life survival, decrease long term damage)
2. Education / Awareness  
(Holistic approach; more than just a prescription; multi disciplinary healthcare team involved, sharing of patient info)
3. Research and Development  
Better treatments with less toxic side effect profile needed with improved access to newer treatments – a CURE!  
Improved understanding of aetiology; Prevention is better than cure  
Global collaboration, sharing of data; due to rare disease patient numbers
4. EXPERT SPECIALIST CENTRES: ERN'S  
European Reference Networks - EURORDIS



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**GET INVOLVED** in any way that you can !! **PLAN AHEAD**

Join together with other rare disease patients and healthcare professionals to make a louder presence and noise on the world stage.

**Together, united globally, the rare disease community will have a stronger voice for improving rare disease patient healthcare.**