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SCLERODERMA FOUNDATION

SUPPORT • EDUCATION • RESEARCH

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A Look Back at Scleroderma Online Communities in 2013 - An Infographic

Scleroderma Online Communities

2013 Year in Review

Have you ever wondered what the most searched for terms are on the Scleroderma Foundation's website (www.scleroderma.org)? Or, maybe what are the most

discussed topics on our discussion board through Inspire?

We've put together some highlights of our online communities' activity in 2013 in an infographic for you.

Here's a peek at what we found:

- There were 3,480 discussion threads started on Inspire in 2013.
- The most viewed video on our YouTube page was viewed 3,919 times or about 39,399 minutes.
- The most popular Facebook post of the year was about World Scleroderma Day.

[Check out the full infographic >>](#)

If you'd like to learn more about scleroderma, stay up-to-date with our latest news or just connect with others who are affected by the disease, we invite you to join us on our online communities in 2014:

- [Facebook](#)
- [Inspire Discussion Community](#)
- [Twitter](#)
- [YouTube](#)
- [Pinterest](#)

Happy New Year!

Pulmonary Fibrosis Foundation Announces Care

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Center Network and Patient Registry



At the PFF Summit the [Pulmonary Fibrosis Foundation](#) (PFF) announced its plans to establish the PFF Care Center Network and the PFF Patient Registry. These

initiatives will improve the health and quality of life of patients suffering from pulmonary fibrosis and will help provide critical insights enabling the medical research community to develop more effective therapies.

The PFF Care Center Network will provide a standardized, multidisciplinary approach to patient care. This model of comprehensive patient care will help identify and establish best practices, determine the impact of specific interventions, and improve the quality of life of patients.

The PFF Patient Registry will eventually be the largest database of pulmonary fibrosis patient records with the furthest demographic reach in the country. It will provide data essential for improving the understanding of the epidemiology, incidence, prevalence, natural history, and other clinical characteristics of pulmonary fibrosis.

[Read the entire press release >>](#)

Dietary Supplement Label Database



The Dietary Supplement Label Database is a joint project of the National Institutes of Health Office of Dietary Supplements and National Library of Medicine. It contains the full label contents from a sample of dietary supplement products marketed in the U.S. and can be used to search label information from dietary supplement products that are currently on the U.S.

market and products that have been discontinued or are no longer on the U.S. market.

[Visit the Dietary Supplement Label Database website >>](#)

San Diego Chapter to Host a Special Outreach Program in February



Do you live in the Palm Springs area or do you visit during the winter months?

The Scleroderma Foundation's Greater San Diego Chapter will host its

first education and outreach program in the Palm Springs area in February. This event is open to any individuals who would like to learn more about the chapter. This is a perfect opportunity for winter "snowbirds" to learn more about the available support and education resources in the area.

Dr. Holly Hauser will also speak about important tests that people living with scleroderma are advised to have and why they should have them. Dr. Hauser is a board member and chair of the chapter's Medical Advisory Board. Additionally, event attendees are encouraged in the last hour to discuss



current and future needs for patients living in the area. Lunch will be served. There is no cost to attend.

The event will be held from 10:30 a.m. to 2:30 p.m. (Pacific) on Saturday, Feb. 8, 2014, at the Spa Resort Casino in Palm Springs, Calif. To register online, visit <https://sclerodesert2013.eventbrite.com>. You also can register by calling (619) 655-4342. For more information, contact Kelly Davidson, Executive Director, kelly.davidson@sclerosd.org or call (619) 655-4342.

[Download an informational flier for this event >>](#)



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