

Subject: Scleroderma Awareness Month Coming Soon!

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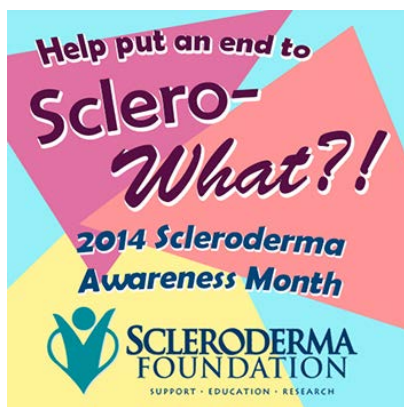


SCLERODERMA FOUNDATION

SUPPORT • EDUCATION • RESEARCH

eLetter #555 | May 16, 2014

Scleroderma Awareness Month Coming Soon!



This June, the Scleroderma Foundation wants to put an end to Sclero-What? during Scleroderma Awareness Month, and you can help!

Events, like Scleroderma Awareness Month, are crucial to the well-being of patients all over the world. Education for people who may be affected by the disease and those who are newly diagnosed is paramount so that they can access the support, resources and treatment they need as soon as

possible. Additionally, increased awareness about the disease can influence funding for much-needed research to pinpoint the cause and find a cure.

There are many ways that you can help spread awareness, from wearing teal to sharing your story with others, and a new interactive way that you can join the fight is by snapping a “selfie” for an upcoming awareness campaign to educate the public about the disease. “The people in the scleroderma community are some of the strongest, bravest and most beautiful. That’s why we’re heading straight to patients, caregivers, family members and friends, to put a face on scleroderma for others who currently are unfamiliar with it,” said the Foundation’s CEO Robert J. Riggs. “With the extreme popularity of photo sharing on social media sites, especially thanks to apps like Instagram, we want to share the beauty of the scleroderma community with people all over the world, in an effort to educate them about the truly difficult and life-altering circumstances that this disease can cause.”

Whether you’re a patient, a caregiver, a family member, friend or a health care professional, we’d like you to snap a photo of yourself and share on Facebook, Twitter or Instagram using the hashtag #sclerodermaselfie. You also can email your photo to us at mystory@scleroderma.org.

For more information about how to help during Scleroderma Awareness Month, please visit www.sclerodermaawareness.org, and stay tuned to the



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weekly eLetter to learn other ways that you can join the fight to end Sclero-What?

Remember, World Scleroderma Day is Sunday, June 29!

For National Women's Health Week, FDA Resources Help Women Make Informed Health Choices



The FDA's Office of Women's Health offers educational resources to help women at every stage of their adult lives, covering topics that range from college health to healthy aging. They develop and disseminate easy-to-read health materials and educational videos for women and connect women to these resources and other safety information on the FDA's For Women website.

Throughout this week, the Office of Women's Health conducted special health promotions to connect women to resources on how to stay healthy. Women can order a free kit of health materials on topics including mammograms, sleep problems, pregnancy, and contact-lens care. OWH is also collaborating with FDA's Office of Communications to share tips for new mothers and other resources.

[Read more at the FDA website >>](#)

Reminder! Free Webinar: Hand Surgical Options for Patients With Scleroderma



Please join the Scleroderma Foundation of Southern California in cooperation with Tri-State and Delaware Valley Chapters for our next Webinar on Hand Surgical Options for Patients with Scleroderma on **Wednesday, May 21, 2014 at 2:00pm PST.**

The presenter will be Dr. Charles Melone, Director of the Division of Hand Surgery at Beth Israel Medical Center, NY and Professor of Clinical Orthopaedic Surgery at Albert Einstein College of Medicine. Over the past 25 years in practice, Dr. Melone has gained a reputation as one of the most knowledgeable hand surgeons in the United States.

[**To join the webinar, please click here on May 21, 2014 at 2:00 pm PST and you will be taken directly to the presentation.**](#)

This is a web based presentation and you will not need to download any software to your computer. If you are accessing the presentation through a mobile device you will need to install the MegaMeeting Mobile App. It is free.

For those who will not have computer access or do not have computer speakers, **toll free audio will be available by calling 1-877-216-1555.**



Enter the passcode: 981555. For all others, follow the instructions on the screen when you click the link.

Technical questions? Please call Jerold Kappel at Scleroderma/SoCal office 310-287-0793 or email socachapter@scleroderma.org.

For other questions, contact Karen Gottesman at karen@sclerodermasocal.org.

Webinar: Understanding How to Maximize Your Independence for Everyday Living



In this webinar Stacey Moran Gausling, an occupational therapist and PAH patient based in California, discusses how to maximize living with PH. She focuses on tips and tools to modify your environment and other daily tasks to gain more independence in everyday activities. Stacey also covers how to best plan for your day with a limited amount of energy, home modification and adaptive equipment, proper breathing techniques and more to help you adapt to living with this chronic illness.

[Watch the webinar at phassociation.org >>](http://phassociation.org)

Disclaimer: The Scleroderma Foundation in no way endorses any drugs, treatments, clinical trials, or studies reported in the eLetter. Information is provided to keep the readers informed. Because the manifestations and severity of scleroderma vary among individuals, personalized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the reader's physician(s) for proper evaluation and treatment.

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