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SCLERODERMA FOUNDATION

SUPPORT • EDUCATION • RESEARCH

eLetter #546 | March 14, 2014

Make Your Voice Heard! Scleroderma Advocacy Summit on Capitol Hill, May 5 - 6, 2014



The Scleroderma Foundation's Advocacy Program provides scleroderma patients/activists from across the nation the opportunity to meet with their U.S. Senators and Representatives to educate policy makers about scleroderma and generate awareness of the "Scleroderma Research and Awareness Act" – a scleroderma-specific bill before both Houses of Congress that increases funding for scleroderma-related research at the NIH through already-appropriated spending.

Of critical importance in 2014 is our drive to have scleroderma re-listed as an approved condition that is eligible for research funding through the Department of Defense's Peer-Reviewed Medical Research Program. In spite of the scleroderma community's tremendous efforts, scleroderma was not included as an approved condition in the Department of Defense's budget for Fiscal year 2014.

If you are a person living with scleroderma, and are a good listener and speaker, have an interest in the political process, and are willing to tell your story to our lawmakers on Capitol Hill, please submit an application to join us!

[Download the summit and scholarship applications >>](#)

Only One Week Until African-American Patient Education Day in Philadelphia, PA!

There is only one week left to register for the Scleroderma Foundation's second African-American Patient

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Education Day! It will be held on Saturday, March 22, in Philadelphia, PA. Join us, along with Virginia Steen, M.D., of Georgetown University

Medical Center, and Laura K. Hummers, M.D., of Johns Hopkins University Medical Center, for the all-day learning event that will specifically look at how the African-American population is affected by the disease.

The event will be held at the Philadelphia Marriott Downtown, located at 1201 Market St., in Philadelphia. Registration starts at 9 a.m. The program begins at 10 a.m. and will conclude by 4:30 p.m. The cost to attend is \$15 per person, and includes lunch and snack.

[Click here to download the program >>](#)

There are four easy ways to register for the event:

1. [Register online >>](#)
2. Call us at (800) 722-4673 and we can process your registration and credit card payment over the phone.
3. [Download the registration form](#) and mail the completed form along with your registration fee to: Scleroderma Foundation, 300 Rosewood Drive, Suite 105, Danvers MA 01923
4. [Download the registration form](#) and fax the completed form to (978) 463-5809 (credit card only)

For those who wish to stay overnight, there is a small room block reserved for the event. Contact the hotel directly at **877-212-5752** and mention 'scleroderma.'

If you have any questions about this event, please contact Kerri Connolly, Director of Programs and Services, at (800) 722-4673 or email kconnolly@scleroderma.org.

The Extra Burdens Faced by Young People With Chronic Illness



When diagnosed with a chronic illness, young people are forced to carry several extra burdens. They are often treated as if their health issues can't be chronic, their perception of their own illness can be underestimated, and they can be dismissed as "too young to be in pain." Learn how to identify and stop behaviors that could be harmful to young people with chronic illness.

[Read the article at Psychology Today >>](#)

New Weber Thermal Wrist and Ankle Wraps

Originals by Weber have announced the availability of their new Weber Thermal Wrist and Ankle Wraps. The Weber





Thermal Wrist and Ankle Wrap is designed to relieve the pain and discomfort of cold fingers and toes caused by Raynauds Syndrome. The new Weber Wraps make use of a unique insulation material developed by NASA called Aerogel. Aerogel-infused Weber

Thermal Wrist and Ankle Wraps can make it possible to warm the blood as it circulates from the wrists and ankles into the fingers and toes.

[Read the entire release at PRweb.com >>](#)

[Learn more and order a pair at OriginalsbyWeber.org >>](#)

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