

[View this message on our website.](#)[Homepage](#) | [Forward to a Friend](#) | [Make a Donation](#)

SCLERODERMA FOUNDATION

SUPPORT • EDUCATION • RESEARCH

eLetter #558 | June 6, 2014

Help Share About Scleroderma



What if we – the Scleroderma Foundation community – could have an impact on making scleroderma more known this June? What if we were able to put our friends and family members, and their friends, and their friend's friends to work for our cause using social media? What if we were able to join forces with other scleroderma organizations to make this happen?

The three leading North American scleroderma advocacy and research organizations -- Scleroderma Foundation, Scleroderma Research Foundation and Scleroderma Society of Canada -- joined forces during June's Scleroderma Awareness Month, with a social media campaign to compel more people to learn more about the little-known and often misunderstood disease.

The campaign is named "Hard word. Harder disease." It will run across Facebook and Twitter channels using the #hardword hashtag throughout the month of June. A microsite, HardSkin.org, serves as the landing page for the pledge and general information about scleroderma with links to additional resources.

[Read more about the joint campaign here >>](#)

Take the Scleroderma Center Survey



The Scleroderma Foundation is working with The Scleroderma Foundation is working with a Lesley Ann Saketkoo, MD, MPH to gain patient insight into what is desired in a Scleroderma Center of Excellence. Healthcare workers want to know how to best provide for their patients, and it's not always so obvious



[Click Here To Visit
Our Awareness
Month Store!](#)

[Donate](#)

Quick Links

[Advocacy](#)[Contact Us](#)[Become a Member
About Scleroderma](#)[Online Chat](#)[Store](#)[Home](#)

from what's learned in medical school.

If you would like to participate in the project, please email scleroderma.patient.research@gmail.com by Tuesday June 10th at noon Eastern Standard time and a survey will be forwarded to you.

Is using a computer problematic for you? Send an email with your telephone number to scleroderma.patient.research@gmail.com and arrangements will be made to complete the survey by phone.

The collected data will be shared with the medical community and subsequently will be used to develop a guidance document so that scleroderma centers will have the opportunity to pursue patient preferences.



Bronze Conference Sponsor



Knowledge of Scleroderma May Help Dentists Treat Patients More Effectively



A survey of dentists in Massachusetts suggests that their confidence in treating patients with scleroderma may be related to their familiarity with the autoimmune disease. Dentists who reported feeling knowledgeable about scleroderma felt more prepared to provide care to patients with scleroderma, when compared to peers who did not feel as knowledgeable. Providing education to dentists may improve patient satisfaction and access to care, while simultaneously increasing dentists' knowledge and comfort.

An unpublished national survey of 350 scleroderma patients in 2011 by students and faculty at Tufts University School of Dental Medicine found that people with scleroderma have difficulty obtaining professional oral health care. Patients with scleroderma often have difficulty stretching their mouths open, making it difficult to receive care and for dentists and dental hygienists to provide care. This may contribute to the higher risk of oral diseases among dental patients who have scleroderma.

[Read more at Medical Xpress >>](#)

Watch the "Hand Surgical Options for Patients with Scleroderma" Webinar



The webinar held by the Scleroderma Foundation of Southern California in cooperation with Tri-State and Delaware Valley Chapters, titled " Hand Surgical Options for Patients with Scleroderma," is now available to view for free online for a limited time.

The webinar was presented by 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.

[Watch the webinar >>](#)

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.*

POWERED BY
blackbaud

[Unsubscribe](#) | [Visit our web site](#) | [Contact Us](#) | [Donate](#)
300 Rosewood Drive, Suite 105, Danvers, MA 01923 tel: 800-722-HOPE (4673)
© 2014 All rights reserved.