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# SCLERODERMA FOUNDATION

SUPPORT • EDUCATION • RESEARCH

eLetter #565 | August 1, 2014

## Foundation's Advocacy Team Scores Big for Scleroderma Research



We are proud to announce that the Foundation's Advocacy Team achieved its number one goal in this legislative session by getting the United States Senate to include scleroderma as an approved condition that can receive research funds through the Department of Defense Peer Review Medical Research Program (PRMRP). This opens an additional \$247.5 million in federal funding for scleroderma researchers to apply for. Scleroderma

Foundation Advocates from across the country wrote letters, sent e-mails, called, and met with their Senators or key staff. The concentrated effort and the involvement of many Foundation members throughout the country made this achievement possible.

"This just shows that our approach to advocacy works," said Foundation CEO Robert Riggs. "Our primary objective in the Foundation's advocacy work is to ensure that scleroderma gets its fair share of research funds available through Federal entities such as the National Institutes of Health and, in this case, the Department of Defense."

We congratulate and thank all of our active advocates who have continued to make the scleroderma community's voice heard on Capitol Hill!

[Click here to learn more about the Foundation's Advocacy Program >>](#)

## Thank You for An Amazing 2014 National Patient Education Conference!

From the Foundation's National Office, we'd like

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to thank everyone who attended this year's National Patient Education Conference in Anaheim, CA for such an amazing weekend. The Conference provided an incredible opportunity for the more than 500 attendees to learn more about scleroderma, and connect with others who are affected by the disease.

If you haven't done so already, [please take a moment to complete this post-conference survey](#). Your feedback helps us improve the conference experience each year. We

appreciate you taking time to offer us your thoughts!



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## Free Downloadable Booklet: Care for the Family Caregiver



EmblemHealth and the National Alliance for Caregiving are offering this free, downloadable booklet, "Care for the Family Caregiver." The booklet addresses family caregivers, those who care for relatives and loved ones. Learn more about what caregiving requires, training resources, the costs of caregiving, and so much more.

[Download the booklet from Caregiver.org >>](#)

## HEALfundr



HEALfundr, owned and operated by NeedyMeds, is a crowdfunding platform devoted to helping people in need of assistance of affording their medications and costs to health care. HEALfundr's

vision is one of secure, 100% verified campaigns where funds are paid directly to legitimate medical expenses. This implementation grants the campaigner relief from managing their medical bills and gives the donor the confidence that their donation is going to where it should.

[Learn more at the HEALfundr website >>](#)

**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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