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SCLERODERMA FOUNDATION

SUPPORT • EDUCATION • RESEARCH

eLetter #566 | August 8, 2014

Barry Sanders Scores for Michigan Chapter



When some people hear Barry Sanders' name, they think of him as the unbelievably talented running back that played at [Oklahoma State](#). Others will remember him as the third pick in the first round of the [NFL Draft](#)—going on to achieve record-breaking success with the [Detroit Lions](#).

While we certainly know Barry Sanders for his unmatched athleticism, we also know him for his big heart and continued support of the [Scleroderma Foundation](#)

[Michigan Chapter](#). Most recently, Barry announced that he has chosen to [donate half of all proceeds from his new Nike shoe](#) to the chapter.

In an email earlier this week to supporters, the chapter said, "While we certainly know Barry Sanders for his unmatched athleticism, we also know him for his big heart and continued support of the Scleroderma Foundation Michigan Chapter."

Please visit [Barry's official Facebook page](#) to thank him for his commitment to the scleroderma community.

Thank You for Helping Us Reach Our Goal

Our Advocacy Team recently achieved its No. 1 goal for this legislative session when the United States Senate chose 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 up an additional \$247.5 million in federal funding for scleroderma researchers to apply for. Thus proving, our approach works!

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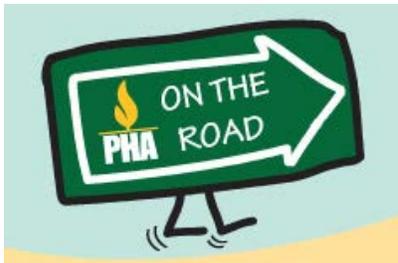
It is now very important that we express our gratitude to the Senate offices that assisted the scleroderma community with this effort. We encourage you to send a “thank you” with the Senate staffers you have engaged about this topic. We’ve made it easy for you to thank your Senate offices with a sample e-mail/phone message below. Visit www.scleroderma.org/advocacy to find your senator’s contact information.

Dear _____,

I was delighted to see that “scleroderma” is listed as a condition eligible for study through the Peer-Reviewed Medical Research program within the Committee Report accompanying the Senate’s FY 2015 Defense Appropriations Bill. I want to extend my thanks on behalf of the community of individuals affected by scleroderma for your assistance in this regard. The opportunity to participate in these research activities is incredibly meaningful to veterans, active duty military personnel, and the broader scleroderma community. Thank you again for your support and hard work.

Sincerely,

Pulmonary Hypertension Association: PHA on the Road



PHA on the Road is a free full-day regional education forum hosted by the Pulmonary Hypertension Association. PH Patients and Families Education Forum, will be visiting new cities across the country in 2014. PHA on the Road delivers much needed PH education and support to patients and families in areas close to home. The forums feature

interactive presentations, education sessions and networking opportunities with other patients, caregivers, and medical professionals.

The 2014 PHA on the Road forums will be visiting:

- Houston, Texas (Online registration closes Tuesday, Sept. 2, 2014, at 3 p.m. EST)
- San Diego, Calif. (Online registration closes Tuesday, Sept. 16, 2014, at 3 p.m. EST)

[Learn more and register at the PHA website >>](#)

Kitty Trask Holt Funding Supports Scleroderma



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Research



Kitty Trask Holt was diagnosed with scleroderma in her forties, but her positive attitude never wavered. She was approached by former Medical University of South Carolina (MUSC) President Dr. James B. Edwards about setting up a foundation for scleroderma research. Kitty's brother started raising money in 2007 and by the time Kitty died in June

2008, some 800 people had contributed. The fund in her name raised \$1.3 million, which South Carolina's SmartState Program matched.

With that money in place, the MUSC hired Dr. Carol Feghali-Bostwick as the first Kitty Trask Holt Endowed Chair in Scleroderma Research. Dr. Bostwick and her laboratory team now stand on the brink of clinical trials, which could prove to make a significant difference in fibrosis, or the thickening of connective tissue, which is characteristic of scleroderma.

[Read more about Kitty Trask Holt and Dr. Carol Feghali-Bostwick's research at the MUSC 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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