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SCLERODERMA FOUNDATION

SUPPORT • EDUCATION • RESEARCH

eLetter #540 | January 31, 2014

Scientific Peer Review of Department of Defense Medical Research Program



Scleroderma advocate and support group leader Joan Maril, of Austin, Texas, recently participated in the evaluation of research applications submitted to the Peer Reviewed Medical Research Program (PRMRP) sponsored by the Department of Defense. Ms. Maril was nominated for participation in the program by the

Scleroderma Foundation, based in Danvers, Mass. As a consumer reviewer, she was a full voting member, along with prominent scientists, during a review to help determine how the \$50 million appropriated by Congress for Fiscal Year 2013 (FY13) will be spent on future scleroderma-related research.

Consumer reviewers are asked to represent the collective view of scleroderma survivors and patients, family members and persons at risk for the disease when they prepare comments on the impact of the research on issues such as disease prevention, screening, diagnosis, treatment, and quality of life after treatment. Ms. Maril said that "Participation as a consumer reviewer was very educational, both technically and scientifically. The knowledge base of the members was most impressive. The research ideas in the pipeline were wonderful and demonstrated the need for more research funding. The process gave me hope for those of us with scleroderma that help is out there and we need to work hard to provide more monies for research."

[Read the full press release online >>](#)

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Education Day**

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There's still time to register for the Scleroderma Foundation's second African-American Patient 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.

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.

ATS Patient Information Series - Vocal Cord Dysfunction



Vocal Cord Dysfunction (VCD) refers to when your vocal cords do not act normally. With VCD, instead of your vocal cords opening when you breathe in and out, your vocal cords close. When your vocal cords close, it makes it harder to get air into or out of your lungs. VCD can be very hard to detect.

[Download the pamphlet here >>](#)



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