

Subject: Help Make 'Scleroderma' Eligible for Study by Department of Defense

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# SCLERODERMA FOUNDATION

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## Make 'Scleroderma' Eligible for Study through Department of Defense Peer-Reviewed Medical Research Program

Scleroderma has been part of Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) for several years, and, as a result, many meritorious grants have been funded, which have resulted in important medical breakthroughs for patients all over the world.



However, recently the disease was removed from the list of conditions and diseases eligible for research funding. The U.S. Congress will soon finalize the budget for the Fiscal Year 2014, and this includes the DOD's medical research program.

Please take the time to contact your elected officials and let them know how important it is to include scleroderma as an eligible condition when the House and Senate design a final FY 2014 Defense Appropriations measure.

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## Help Texas QB Case McCoy Receive Rare Disease Champion Award

Case McCoy is the starting quarterback for



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the University of Texas football team, but he also has scleroderma. He has been named a finalist in the Rare Disease Champion Award presented by Uplifting Athletes, a nonprofit organization that teams up with college football to tell stories of adversity and triumph in the rare disease community.

Case was diagnosed with morphea scleroderma when he was 4 years old. It became a regular occurrence for his family to travel from west Texas to Dallas for medical care. The side effects that the disease took on him were brutal – he lost weight, lost his hair and had to endure weekly treatments that made him violently ill. Today, Case leads the Longhorns on the football field and has become an inspirational story to people living with the rare diseases across the world.

The Rare Disease Champion Award is given to a leader in college football, individual or organization, who has realized his or her potential to make a positive and lasting impact on the rare disease community. Along with Case, this year's nominees are Jimbo Fisher, head coach, Florida State University; Chuck Priore, head coach, Stony Brook University; and Trevor Reilly, linebacker/defensive end, University of Utah. C.J. Zimmerer, fullback, University of Nebraska, is currently leading the award votes. The Rare Disease Champion trophy will be presented during the Maxwell Football Club's nationally televised Awards Gala on March 14.

Vote for Case today at [www.upliftingathletes.org/vote](http://www.upliftingathletes.org/vote). You can vote one time per day per email address. Voting ends on Friday, Jan. 31.

## Heartland Chapter Member Wins Dr. Oz's True Beauty Award Contest

Barbara Burke, a board member of the Scleroderma Foundation's Heartland Chapter, has been selected as one of three winners in the True Beauty Contest presented by TV personality, Dr. Mehmet Oz. The honor helps increase scleroderma awareness among the large following of Dr. Oz's popular daytime talk show, which discusses current health issues affecting the population, especially women. Overall, three winners were selected from thousands of entry submissions. Each winner also appeared in a video that is posted on Dr. Oz's website.



*Barb Heenan (left) with True Beauty Contest winner Barbara Burke*

Burke has localized scleroderma and has been active in helping spread scleroderma awareness through an initiative called "Paint Away Scleroderma," where she and her husband visit special events including fairs, festivals and children's parties, to face paint. They accept donations to help raise funds for scleroderma research.

"If I can help inspire one person," said Burke in the online video, "I'm living up to this contest's intention."



The Chapter's Executive Director Barb Heenan nominated Burke for the contest. In the video, she said: "I nominated Barbara because she exemplifies what true beauty is...She has embraced helping others living with scleroderma."

[See Barbara's full acceptance video on Dr. Oz's website >>](#)

## PPI Use May Cause Deficiency in Vitamin B12



Long-term use of proton-pump inhibitors (PPIs) is often necessary in people who suffer from scleroderma. However, recent data from large studies show an association of long term use of PPIs with osteoporosis (leading to fractures) and community-acquired risk of a gastrointestinal infection (*Clostridium difficile*). New data from Kaiser Permanente Health System also found an association with PPI use of vitamin B12 deficiency. Vitamin B12 is a water-soluble vitamin and its deficiency can cause fatigue, depression and long standing deficiency can lead to other neurological symptoms ([Click here to go to the NIH fact sheet for more information on Vitamin B12](#)). Patients with

scleroderma require long term PPI due to involvement of food pipe and incompetent esophageal-stomach sphincter ([Click here to view the Scleroderma Foundation medical report on digestive system involvement in scleroderma](#)).

Dr. Dinesh Khanna, a Scleroderma Foundation Medical Advisory Board Member comments, "Results from this study suggest patients should discuss annual evaluation of B12 during a blood draw with their rheumatologists and gastroenterologists and should be treated if there is deficiency. Vitamin B12 ingestion as part of multi-vitamin is recommended, though some patients can't absorb oral Vitamin B12 and they may need B12 injections."

[Click here to view the New York Times article about the study >>](#)

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300 Rosewood Drive, Suite 105, Danvers, MA 01923 tel: 800-722-HOPE (4673)  
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