



National Congressional Call-in Day Wednesday, February 8, 2012 Help Find a Cure for Scleroderma!

Why & How to Contact Your Elected Officials

WHY:

On Wednesday, February 8, 2012 the Scleroderma Foundation is asking all those whose lives have been impacted by scleroderma (whether a patient or a family member or friend of a patient) to please contact their members of Congress, both in the House of Representatives and in the Senate, and ask them to co-sponsor the Scleroderma Research and Awareness Act, In the House of Representatives the bill is H.R. 1672; in the Senate the bill is S.649

The bills will expand federal support for scleroderma research and public awareness activities at the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC). The House bill (H.R. 1672) currently has 37 bi-partisan cosponsors and was introduced by Representatives Lois Capps (D-CA) and Lee Terry (R-NE). The Senate bill (S.649) currently has 4 co-sponsors and was introduced by Senator Kirsten Gillibrand (D-NY).

HOW:

The best way to reach your elected officials in the House and in the Senate is to call the U.S. Capitol Switchboard at 202-225-3121. A Capitol operator will connect you to the office of your Representative (1) and/or Senators (2). If you do not know who your representative and/or senators are, the Capitol operator can assist you, or you can go to www.congress.org and enter your zip code. Phone numbers for all congressional offices are also listed on www.congress.org. Calling works best, but if you prefer to communicate via e-mail, you can do so through www.congress.org. You'll find a sample e-mail message below.

If you have questions about contacting your Congressional leaders, please contact the Scleroderma Foundation national office between the hours of 8:30 a.m. and 5:00 p.m., Eastern Daylight Time. A Foundation staff member can assist you.

Seven Tips for Communicating with Congressional Offices:

- 1) Identify yourself as a constituent and ask to speak with the legislator's Health Care staffer.
- 2) Tell the aide that you are a member of the Scleroderma Foundation and ask the legislator to cosponsor the Scleroderma Research and Awareness Act (H.R. 1672) or (S.649)

- 3) Briefly explain what scleroderma is. Use the following five “quick facts:”
 1. Scleroderma is a chronic, disabling, and often fatal autoimmune disease
 2. Scleroderma causes damage to one or more of the body’s organ systems, including the skin, heart, lungs, kidneys, gastrointestinal tract, and blood vessels
 3. Approximately 300,000 people in the United States suffer from scleroderma
 4. The cause of scleroderma is unknown
 5. There is no known cure
- 4) Briefly tell them your personal story about scleroderma.
- 5) Explain that H.R. 1672/S. 649 will increase scleroderma research and begin, for the first time, a public awareness campaign on scleroderma through the Centers for Disease Control and Prevention (CDC).
- 6) Give the aide your contact information and ask to be informed about the actions of the legislator this key issue.
- 7) **BE SURE TO THANK THE PERSON YOU SPEAK TO** for their time and attention!

Sample E-Mail Message:

Dear Representative / Senator NAME,

I am a constituent living in (INSERT YOUR CITY, STATE, ZIP CODE – you do not have to put your street address), and I am writing today to ask you to support the Scleroderma Research and Awareness Act (H.R. 1672) (S.649).

This bill allows for the following:

- expands federal support for research on scleroderma at the National Institutes of Health
- Increases awareness of scleroderma among the general public and healthcare providers through allocations to the Centers for Disease Control and Prevention
- Supports the training of new scleroderma researchers

Scleroderma is a chronic, disabling and often fatal autoimmune disease that causes damage to one or more the of body’s organ systems, including the skin, heart, lungs, kidneys, gastrointestinal tract and blood vessels. Approximately 300,000 people in the United States suffer from scleroderma, with approximately 80 percent of those being women, although men and children are also affected, as are all ethnicities. The cause of scleroderma is unknown, and there is no cure. The estimated total economic impact of scleroderma in the United States is \$1.5 billion annually. The direct cost of treatment for patients is more than \$460 million annually.

(INSERT A BRIEF PARAGRAPH ABOUT YOUR PERSONAL HISTORY WITH SCLERODERMA)

Thank you for reading this message. I hope I can count on your support of this important bill. Please keep me informed of your actions related to this bill.

Very truly yours,

NAME

Address

E-Mail Contact