

Dear Senator

Thank you for your leadership in the Senate on health care issues. As a constituent, I am writing to encourage you to co-sponsor S. 1545, the "*Scleroderma Research and Awareness Act*." This bipartisan bill sponsored by Senator Kirsten Gillibrand (D-NY) was introduced in the Senate on July 30, 2009.

Scleroderma is a chronic and disabling connective tissue disease resulting from an overproduction of collagen. The word "scleroderma" means hardening of the skin which is one of the most visible manifestations of the disorder. Scleroderma can affect many areas of the body including the heart, lungs, kidneys and gastrointestinal system. There is no known cause and no cure. African Americans are at higher risk of developing systemic scleroderma, and women account for 80 percent of all diagnoses. 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. Despite these burdensome figures, the federal investment in scleroderma research is only \$20 million a year.

[HERE, IN YOUR OWN WORDS, BRIEFLY DESCRIBE YOUR PERSONAL EXPERIENCE WITH SCLERODERMA]

S. 1545 would do the following:

- Direct the National Institute of Arthritis and Musculoskeletal and Skin Diseases at the National Institutes of Health to expand research related to scleroderma. The legislation authorizes \$25 million in FY10, \$30 million in FY11, and \$35 million in FY12 for this purpose. Priority areas include:
 - Development and evaluation of new treatments.
 - Research on the relationship between scleroderma and secondary conditions including: pulmonary hypertension, gastroparesis, Raynaud's phenomenon, and Sjögren's syndrome.
 - Establishment of family and "childhood-onset" patient registries.
 - Support for the training of new investigators
- Direct the Centers for Disease Control and Prevention to establish a scleroderma public awareness campaign highlighting disease symptoms, prevalence, related conditions, and the importance of early diagnosis. The legislation authorizes \$2.5 million in FY10, FY11, and FY12 for the awareness initiative.

Thank you in advance for your consideration of this request. This legislation is very important to patients and family members living with scleroderma. I would appreciate it if you would advise me of your actions regarding your co-sponsorship. I look forward to hearing from you soon.

Sincerely,

Your Name

Your Address