

PRN The Scleroderma Foundation Applauds the U.S. House of
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The Scleroderma Foundation Applauds the U.S. House of Representatives for
 Passing Legislation to Promote Research and Awareness of Scleroderma

PR Newswire

DANVERS, Mass., Sept. 30

DANVERS, Mass., Sept. 30 /PRNewswire-USNewswire/ -- The Scleroderma Foundation applauds the U.S. House of Representatives today for the passage of the Scleroderma Research and Awareness Act (H.R. 2408), introduced last March by Rep. Lois Capps (D-CA) and Rep. Vern Ehlers (R-MI). This bipartisan legislation gives hope to the estimated 300,000 Americans and their families living with this devastating disease.

Scleroderma is a chronic and disabling connective tissue disorder resulting from an overproduction of collagen. The word "scleroderma" means hardening of the skin, which is one of the most visible manifestations of the disease.

Scleroderma can affect many areas of the body including the heart, lungs, kidneys and gastrointestinal system. There is no known cause and no cure. The disease disproportionately impacts women and minorities. African Americans are at a higher risk of developing systemic scleroderma, and women account for 80% 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.

The "Scleroderma Research and Awareness Act" will :

- * Direct the National Institutes of Health to intensify and coordinate activities relating to scleroderma, including:
 - * Research on etiology and the development of new treatments.
 - * Evaluate new treatments through clinical trials.
 - * Research on the relationship between scleroderma and secondary conditions including: pulmonary hypertension, gastroparesis, Raynaud's phenomenon and Sjorgen's syndrome.
 - * 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.

Ms. Leticia Cervantes, mother of 14-year-old Cynthia Cervantes, a young scleroderma patient from Huntington Park, California who met Rep. Capps in Washington two years ago said... " I am so thankful to Congresswoman Capps for taking up our cause. When Cynthia and I met with her, we knew she would do whatever she could to help my daughter and scleroderma patients across the country. She and her colleagues in Congress have given us new hope today by passing this important legislation. She is our angel ."

"The Scleroderma Foundation is proud to be in the forefront of advocating for greater research for this devastating disease," commented Joseph P. Camerino, Ph.D., Chair of the Foundation's National Board of Directors. "With the passage of this landmark legislation, the scleroderma community has even greater hope that a cure will be found."

The Foundation encourages all patients, family, members and friends to contact their senators in Congress and ask them to support passage of this important bill. For more information, please visit
<http://www.scleroderma.org/advocacy/advohome.shtm> .

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Headquartered in Danvers, MA, with 22 chapters and 140 support groups across the United States, the Scleroderma Foundation, Inc., is an IRS-designated 501(c)(3) charitable organization. It is the nation's largest patient organization dedicated to improving the quality of life for patients with scleroderma, and funds peer-reviewed research aimed at finding better treatments, as well as the cause and cure for scleroderma and related conditions .

More information about scleroderma, systemic sclerosis, and the Scleroderma Foundation may be found at www.scleroderma.org or by calling 800-722-HOPE.

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