



## **FOR IMMEDIATE RELEASE**

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## **Hundreds Expected for 13th Annual Scleroderma Patient Education Conference *Building a “Bridge to Hope” in San Francisco July 8-10***

DANVERS, MASS. (July 5, 2011) – Nearly 600 people are anticipated to visit the heart of San Francisco Friday, July 8, through Sunday, July 10, for the Scleroderma Foundation’s 13th Annual National Patient Education Conference. Patients, family members, caregivers, doctors and other health care professionals representing 40 states, the District of Columbia, Canada and Mexico will converge at the Hilton San Francisco Union Square for this engaging and educational event that focuses on scleroderma, a rare autoimmune disease.

This year’s conference features a variety of workshops hosted by leading scleroderma researchers and medical professionals. Andreas Baxevanis, Ph.D., will give the opening keynote address on the promise of genomics and genome-based personal health care in disease management. James Lemons, Ed.D., will present the closing keynote on “Pain – The Psychology and Physiology: There is Hope.” Dr. Baxevanis is Assistant Director for Computational Bioscience, Office of Intramural Research at the National Institutes of Health (NIH), and Associate Investigator, Division of Intramural Research at the National Human Genome Research Institute in Bethesda, Md. Dr. Lemons is the director of The Lemons Center for Behavioral Pain Management in Lenexa, Kan., and a medical psychologist.

“The entire weekend is an excellent opportunity for patients to come together in a supportive, social environment to learn about scleroderma from medical professionals and their peers,” said Kerri Connolly, Director of Programs and Services. “Our conference program provides patients, their families and caregivers with excellent information on research, disease management and coping with scleroderma.”

Other conference highlights include:

- Fifty-six workshops and panel discussions for patients, family members and caregivers.
- Special sessions for children with scleroderma and their families.
- Representatives from the University of Texas Scleroderma Family Registry and DNA Repository and the University of Texas Southwestern Morphea Registry and DNA Repository will be at the conference seeking interested individuals to serve as donors and controls for scleroderma research.
- Annual Awards Banquet to honor Scleroderma Foundation members, volunteers and chapters of the Foundation for their dedication and work to advance the mission of the Scleroderma Foundation, and bring awareness to the issues facing the scleroderma patient community.

In 2011, there were 18 full scholarships and seven partial scholarships awarded to first-time conference attendees. Scholarship recipients represent 13 U.S. states, Canada and Mexico. The Scleroderma Foundation National Conference Scholarship Program is made possible by gifts from generous donors.

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## **Scleroderma Conference**

### **-Add One-**

“The volunteers and staff from the Scleroderma Foundation’s Northern California Chapter and the National Office worked diligently to assemble an exceptional program that features the country’s leading researchers, doctors and other health care professionals to share the latest information and resources about scleroderma,” said Joseph P. Camerino, Ph.D., Chair, Board of Directors. “The National Patient Education Conference offers all attendees valuable information to improve the lives of scleroderma patients and their families. It also provides a feeling of hope, friendship and understanding.”

For more information about scleroderma and the National Patient Education Conference, visit [www.scleroderma.org](http://www.scleroderma.org).

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## **About Scleroderma**

Scleroderma is a chronic, often progressive, autoimmune disease in which the immune system attacks its own body.

Scleroderma means “hard skin.” It can cause a thickening and tightening of the skin. In some cases, it causes serious damage to internal organs including the lungs, heart, kidneys, esophagus and gastrointestinal tract. As scarring, or sclerosis, of these organs and organ systems progress, they work less effectively, and can lead to organ failure and death.

Some medications and treatments can help with certain symptoms, but there is no cure for scleroderma. The disease affects about 300,000 people across the U.S. In comparison, the same number of people are affected by multiple sclerosis.

## **About the Scleroderma Foundation**

The Scleroderma Foundation is the national organization for people with scleroderma, their families and friends. It was formed Jan. 1, 1998, by a merger between the United Scleroderma Foundation and the Scleroderma Federation.

Today, the Scleroderma Foundation is headquartered in Danvers, Mass. It is a 501(c)(3) non-profit organization dedicated to serving the interests of people living with scleroderma. The Foundation has a network of 23 chapters and 145 support groups committed to carrying out the three-fold mission of support, education and research. The Scleroderma Foundation funds \$1 million in new grants each year to find the cause and cure for scleroderma.

For more information about the Scleroderma Foundation, visit [www.scleroderma.org](http://www.scleroderma.org) or call (800) 722-HOPE (4673).

**Note: The Scleroderma Foundation can arrange interviews with staff, conference attendees and speakers. Please contact Christina Relacion, Communications Manager, at (800) 722-4673, Ext. 243, or [crelacion@scleroderma.org](mailto:crelacion@scleroderma.org) for more information.**

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