



Talking Points

What is scleroderma?

- Scleroderma, or systemic sclerosis, is a chronic disease that affects a person's connective tissue. It is an autoimmune rheumatic disease.
- The word "scleroderma" comes from the words: "sclero" meaning hard, and "derma" meaning skin.
- Scleroderma affects about 300,000 people in the U.S. The number of people affected worldwide is unknown, but the disease has been reported all across the globe.
- Women are 3 to 4 times more likely to develop the disease than men.
- The disease commonly starts between the ages of 25 and 55, although there are patients of all ages.
- Scleroderma varies in symptoms and severity from patient-to-patient.
- Some scleroderma patients may have symptoms that are visible, such as tight skin. Other people may have invisible symptoms, where his/her internal organs (heart, lungs, liver, etc.) are affected.
- Hardening of the skin is one of the most visible features of scleroderma.

Scleroderma: Important Things to Know

- Lung involvement is an important predicting factor and sometimes it's the first sign someone has scleroderma. It helps predict the survival rate of people living with scleroderma. It's important to be screened with an echocardiogram and pulmonary function tests.
- Lung disease is a leading cause of scleroderma-related deaths, and is a very common serious complication of the disease.
- Often times, scleroderma can progress more rapidly and aggressively in African-Americans.
- Knowing the early symptoms of scleroderma can help prevent the chance to permanent tissue or organ damage.
- It's important to work closely with your doctors and health care team to build a supportive network to manage the disease.
- Family and friends are crucial to provide necessary emotional support and to help with a treatment program.
- In the last decade, scleroderma research has intensified in the United States and around the world.
- During the past year, there have been reports of promising research into fibrosis as well as insights into new treatment plans for the disease.

About the Scleroderma Foundation & How You Can Help

- The Scleroderma Foundation has 23 chapters and 150 support groups across the country.
- Our website is www.scleroderma.org
- We run a toll-free hotline at (800) 722- 4673. Staff members answer questions offering access to essential support services and resources.
- Take part in one of our chapter or support group-hosted "Stepping Out to Cure" walk or run events to raise awareness about the disease and help raise important funding to support our programs. Visit www.scleroderma.org/walks for more info.
- We urge people to contact his/her Congressional leaders to co-sponsor the Scleroderma Research and Awareness Act (H.R. 1429 | S. 1239) to help provide important funding for scleroderma research.