

## What is scleroderma?

1. The word scleroderma comes from the Greek words: “sclero” meaning hard, and “derma” meaning skin.
2. Scleroderma, is a complicated, chronic disease that affects a person’s connective tissues and is characterized by an overproduction of collagen. Scleroderma is categorized as an autoimmune disease. Current thinking suggests that the disease is set into motion through a combination of a genetic predisposition and an environmental trigger.
3. Scleroderma affects about 300,000 people in the United States, about one in every thousand. The number of people affected worldwide is unknown, but the disease has been reported all across the globe.
4. Scleroderma is the umbrella term for a variety of pathways which a patient may be affected. The two basic types of scleroderma are limited and diffuse (aka systemic sclerosis).
5. The exact cause or causes of scleroderma are unknown. Scientists and researchers are working hard to find the cause.
6. Women are 3 to 4 times more likely than men to develop the disease.
7. The disease commonly starts between the ages of 25 and 55, but it can occur at any age.
8. Scleroderma varies in symptoms and severity from patient-to-patient. Some patients have visible signs of the disease such as tight, skinny skin or changes in skin pigmentation. Many others deal with symptoms that are invisible to others yet are life-altering such as problems with the heart, lungs, esophagus, digestive system, blood vessels and kidneys. Some of the typical diseases that are associated with scleroderma include: Raynaud’s Phenomenon, Sjogren’s Syndrome, pulmonary fibrosis, renal crisis/failure, interstitial lung disease, GERD, irritable bowel syndrome and many more. Profound fatigue and pain lead to disability and for many, depression.
9. Currently, there is no cure for scleroderma. There are an increasing number of treatment options to ease the symptoms of the disease and make life more tolerable for the patient, but the cure remains elusive.
10. Scleroderma can be challenging to diagnose. Many people struggle for 3 – 5 years before a diagnosis is confirmed leading to higher medical costs and government spending. We suggest starting with an experienced rheumatologist; one that is familiar with and has experience treating the disease. Because many health care providers will never see a case of scleroderma, treatment centers are available to diagnose and guide the patient’s plan of care.
11. Medical and disability costs to individuals, businesses and the government for scleroderma are extremely high. The direct and indirect costs of the systemic form of scleroderma in the U.S. are estimated at \$1.5 billion. The value of lifetime earnings lost is estimated at \$300,000 per patient suffering from systemic scleroderma at the time of death. Treatment costs can be astronomical. The psychosocial impact is also significant. Scleroderma contributes to impaired quality of life, loss of employment, disruption of families dynamics, isolation, and increased incidence of depression

## Scleroderma: Important Things to Know

1. Lung disease is a very common in the systemic form of scleroderma. This very serious complication is a leading cause of scleroderma related deaths.
2. Lung involvement is an important predicting factor and it can be one of the first signs of the disease when the person is experiencing shortness of breath. Lung involvement helps predict the survival rate of people living with scleroderma. It's important to be screened with an echocardiogram and pulmonary function tests and ideally a right heart catheterization.
3. African-Americans have more severe complications from systemic sclerosis than Caucasians.
4. Early diagnosis is key to allowing the patient to live a better quality of life by limiting or slowing down the progression of permanent tissue and organ damage.
5. It's important to work closely with your doctors and health care team to build a supportive network to manage the disease.
6. Family and friends are crucial to provide necessary emotional support and to help with a treatment program.
7. In the last decade, scleroderma research has intensified in the United States and around the world.
8. During the past year, there have been reports of promising research into fibrosis as well as insights into new treatments for the disease.
9. Many resources are available from the Scleroderma Foundation – a national not-for-profit organization which can be reached by: Phone: 800-722-HOPE or on the web at: [Scleroderma.org](http://Scleroderma.org). and the Tri-State Chapter which serves Northern NJ, New York and Connecticut which can be reached by: Phone: 800-867-0885 or on the web at [SclerodermaTriState.org](http://SclerodermaTriState.org).