
National Scleroderma Awareness Month is observed in June each year to raise awareness about scleroderma and its impact on individuals and communities. The National Scleroderma Foundation promotes disease awareness and education and provides support to people with scleroderma and their families.

**What is Scleroderma?**

Scleroderma is a rare, chronic autoimmune and connective tissue disease ("What is scleroderma?", 2022). "Sclero" is the Greek word for hard and "derma" is the Latin word for skin. Scleroderma affects many parts of the body including the skin, joints, and internal organs. Scleroderma occurs when the immune system attacks healthy tissues and causes inflammation that triggers connective tissue cells to produce too much collagen, a protein found throughout the body (National Institutes of Health, 2020). Collagen provides structure and support to the skin, connective tissue, muscles, and bones. When excess collagen builds up in the skin and internal organs, it leads to the signs and symptoms of scleroderma. Cases of scleroderma can range from very mild to life threatening ("Newly diagnosed", 2022).

**Types of Scleroderma**

There are two major types of scleroderma: localized scleroderma and systemic scleroderma (National Institutes of Health, 2020):

- Localized scleroderma affects only the skin and tissues directly under the skin. It is generally mild and appears in two patterns: morphea and linear scleroderma. Morphea is patches of thick, waxy skin while linear scleroderma is lines of thick, waxy skin.
- Systemic scleroderma affects many parts of the body including the skin, tissues, blood vessels, and internal organs. It is more serious than localized scleroderma and appears in two forms: limited scleroderma and diffuse scleroderma.
    - In limited scleroderma, skin thickening appears gradually and affects the fingers, hands, face, lower arms, and lower legs. Limited scleroderma is often called CREST syndrome because of the five common features: calcinosis (calcium deposits in the connective tissue), Raynaud's phenomenon (when blood vessels narrow and restrict blood flow), esophageal dysfunction (difficulty swallowing), sclerodactyly (tight skin on the fingers), and telangiectasia (small, dilated blood vessels on the skin that appear as pink or red lines).

- In diffuse scleroderma, skin thickening appears rapidly over many parts of the body. Diffuse scleroderma causes damage to internal organs like the kidneys, lungs, heart, and digestive system.

**Causes of Scleroderma**

The causes of scleroderma are not fully understood (National Institutes of Health, 2020). Scientists believe that a combination of factors including genetics, hormones, and environmental factors play a role in the development of scleroderma. Scleroderma is not inherited, but there is a susceptibility gene that increases the likelihood of developing the disease. Researchers suspect that hormones and environmental factors, like viruses or chemicals, may trigger scleroderma.

**Symptoms of Scleroderma**

There are many signs and symptoms of scleroderma ("Symptoms of scleroderma", 2022). They are different for everyone and can range from mild to very serious. Some common symptoms include:

- Raynaud's phenomenon – occurs when blood vessels narrow and restrict blood flow, causing the fingers and toes to become white or blue and cold or numb
- Tightening and thickening of the skin
- Dry, itchy skin
- Swelling of the hands and fingers
- Calcinosis – calcium deposits in the connective tissue
- Telangiectasia – small, dilated blood vessels on the skin that appear as pink or red lines
- Skin ulcerations
- Joint pain or stiffness and loss of joint mobility
- Difficulty swallowing
- Dry eyes or mouth

**Diagnosis of Scleroderma**

Diagnosis of scleroderma may be difficult because many symptoms of scleroderma are similar to other autoimmune diseases (National Institutes of Health, 2020). There is not a specific test to determine if someone has the disease, so medical professionals use a combination of methods to diagnose scleroderma. These methods include asking about medical history, performing a physical exam, and completing laboratory tests and studies, such as a blood test, skin biopsy, CT scan, and EKG. A quick diagnosis of scleroderma can help to manage the disease and limit the risk of serious damage to internal organs ("Newly diagnosed", 2022).

**Treatment of Scleroderma**

There is no cure for scleroderma, but there are treatment options that can help to improve symptoms and prevent complications or progression of the disease ("Scleroderma", n.d.). Treatments and medications vary

depending on the severity of the disease and symptoms (National Institutes of Health, 2020). Common medications used to treat scleroderma include:

- Immunosuppressives to suppress the overactive immune system
- Vasodilators to help open constricted blood vessels
- Topical creams to treat dry, itchy, and tight skin
- Anti-inflammatory medications to help with pain and inflammation
- Corticosteroids to manage pain and inflammation

**Living with Scleroderma**

Living with scleroderma can be challenging, but there are many things that you can do to manage symptoms ("Scleroderma", n.d.). To improve your quality of life:

- Keep your body warm
- Moisturize your skin frequently
- Use humidifiers to increase moisture in the air
- Avoid harsh soaps or fragrances
- Use sunscreen before going outside to protect your skin
- Exercise regularly
- Quit or avoid smoking
- Seek support from friends, family, support groups, or mental health professionals

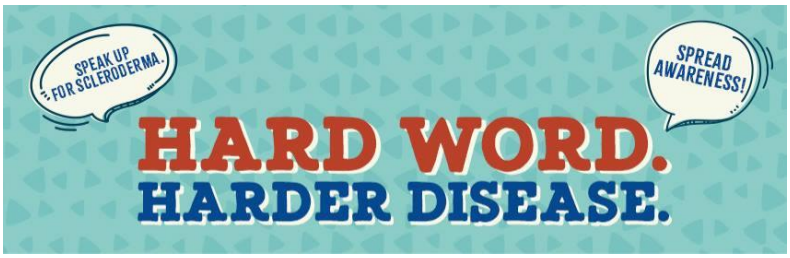
**Scleroderma Facts**

In 2022 the National Scleroderma Foundation estimated that around 300,000 Americans live with scleroderma ("Who gets scleroderma?", 2022). Factors such as age, gender, and race impact the development of scleroderma. Onset of scleroderma typically occurs between the ages of 25 and 55, but people of all ages can develop the disease. Scleroderma is more common in females than in males. Incidence of systemic sclerosis is higher in African American individuals than it is in non-African Americans. For African Americans, 23.7 people per million have systemic sclerosis while in non-African Americans 18.3 people per million have systemic sclerosis. Also, African Americans develop scleroderma earlier than others and are more likely to have lung and other internal organ involvement.

**How to Observe National Scleroderma Awareness Month**

There are many ways to raise awareness for National Scleroderma Awareness Month. Ways to get involved:

- Educate others about what scleroderma is and how it affects people.
- Participate in a Stepping Out to Cure Scleroderma walk. For more information and to find a walk near you, visit https://scleroderma.org/steppingout/
- Advocate for individuals with scleroderma. For more information about advocacy, visit https://scleroderma.org/resources/




**Additional Resources**

For more information about scleroderma, visit https://scleroderma.org/

For more information about how to observe National Scleroderma Awareness Month, visit https://scleroderma.org/get-involved/

**Sources**

National Institutes of Health. (2020, February). *Scleroderma.* National Institute of Arthritis and Musculoskeletal and Skin Diseases. https://www.niams.nih.gov/health-topics/scleroderma

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