

ISN Membership Registration

We welcome members from all countries who are interested in scleroderma or related illnesses. The ISN is a registered nonprofit **501(C)(3)** and our Federal Tax ID (EIN) is **26-0039428**.

- ☐ **ISN Annual Membership** Enclosed is \$25 or more (U.S. funds) to receive the ISN Insider newsletter by email, or \$35 to receive it by postal mail.
- ☐ **Donation - For Research Only** Enclosed is \$_____ (U.S. funds) for the ISN/SCTC Research Fund for scleroderma research.
- ☐ **Donation - Special** Please contact me, as I'd like to make a special donation or bequest.
- ☐ **Donation - Memorial** Enclosed is \$_____ in honor or in memory of: _____.
- ☐ **Other:** _____

Name: _____
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Total: \$_____ Pay by: ☐ **Check**

☐ **Visa** ☐ **Mastercard** ☐ **American Express**

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Please mail this form with payment made out to:

International Scleroderma Network

7455 France Ave So #266

Edina, MN 55435 USA

Thank You!

Systemic Scleroderma Symptoms

Please consult your doctor if you have two or more of the following symptoms, which are sometimes due to systemic sclerosis (scleroderma). Systemic scleroderma may disqualify a person for life and/or health insurance in some countries. Sometimes certain lab work or biopsy results may force an unwelcome diagnosis into the medical record.

Circulation

- ☐ Swelling of hands, feet and/or face
☐ Raynaud's: fingers and/or toes turn white or blue due to cold or stress
☐ Ulcers (sores) on fingertips or toes

Gastrointestinal

- ☐ Difficulty swallowing
☐ Heartburn (reflux)
☐ Constipation, diarrhea, irritable bowel syndrome

Heart, Lungs, Kidneys

- ☐ Shortness of breath
☐ Pulmonary (lung) fibrosis
☐ Aspiration pneumonia
☐ Pulmonary hypertension
☐ High blood pressure or kidney (renal) failure
☐ Right-sided heart failure

Muscles & Tendons

- ☐ Tendonitis, or carpal tunnel syndrome
☐ Muscle aches, weakness, joint pain

Excessive Dryness or Sjogren's Syndrome

- ☐ Excessive dryness of the mucus membranes (such as eyes, mouth, vagina), which is sometimes called Sjogren's Syndrome

Skin

- ☐ Tight skin, often on hands or face
☐ Calcinosis (calcium deposits)
☐ Telangiectasia (red dots on the hands or face)
☐ Mouth becomes smaller, lips develop deep grooves, eating and dental care become difficult

Many of these symptoms can occur by themselves or can be due to other things. Symptoms such as heartburn, high blood pressure, constipation and muscle aches are common in the general population. More unusual symptoms, such as pulmonary fibrosis or tight skin, may be more likely to lead to a diagnosis of systemic scleroderma.

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Brochure: What in the world is Scleroderma?

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What in the world is Scleroderma?

What is Scleroderma?

Scleroderma (sklare-oh-derma) means “hard skin.” This complex disease involves tightening and thickening of the skin, blood vessel damage, inflammation and immune system changes.

Around 100,000 people in the United States, mainly women ages 20-50, develop the systemic form of the illness which also involves the lungs, heart, kidney and intestinal tract.

Around 200,000 people in the United States, half of whom are children, develop localized scleroderma.

The cause of scleroderma is unknown and effective treatments are lacking. For systemic sclerosis, survival is related to how much organ damage each individual patient has. Modern medicine has made great strides in treating individual complications.

Scleroderma Research

Research is very active in many areas, including cause, the nature of the disease process, and attempts to develop treatments. Funding for research is vitally important and derives from the federal government, pharmaceutical companies, and from charitable donations.

Research has led to breakthroughs in treatment of lung and kidney problems, and survival is ever improving.

Medical science considers scleroderma to be the prototype disease of scarring or fibrosis. A breakthrough in scleroderma would lead to new understanding of other scarring diseases such as liver cirrhosis, heart and kidney failure and lung diseases.

Systemic Sclerosis

Systemic sclerosis (SSc, scleroderma, SD) begins with Raynaud’s phenomenon—poor circulation in the fingers. Some people then quickly progress to widespread tightening and thickening of their skin (**diffuse scleroderma**). In diffuse scleroderma, risk of early development of organ involvement is high. This disease impacts function, quality of life, comfort, cosmetic appearance and survival.

Around half of the people with systemic sclerosis have a slower, more benign form of the disease. In **limited scleroderma** (sometimes called CREST syndrome), skin thickening usually stays restricted to the fingers, hands and face. Organ involvement includes intestinal and lung, but is typically delayed until the second decade of disease.

Systemic sclerosis is highly variable in pace of development and severity of organ damage. Many persons have very mild disease, whereas others have rapidly progressive and overwhelming difficulties. No two people with scleroderma are alike, which makes studies of treatments difficult to interpret.

Localized Scleroderma

Localized scleroderma means that the disease is restricted to involvement of the skin only. The absence of organ involvement means that survival is normal.

The most common form of localized scleroderma is **morphea**—irregularly shaped patches of thickened skin. Localized scleroderma can also occur as **linear scleroderma** where a line of disease involves an arm, a leg or a side of the face. In children, the affected part of the body does not grow evenly so withered arms, distorted faces or shortened legs affect appearance and function.

ISN Offers Hope and Help

The nonprofit **International Scleroderma Network (ISN)** offers hope and help to those affected by scleroderma and related illnesses, as well as their caregivers and survivors.

ISN/SCTC Research Fund

The ISN supports international research efforts through the ISN/SCTC Research Fund with the Scleroderma Clinical Trials Consortium (SCTC).

ISN Support Services

- ◆ Our **sclero.org** web site offers over 800 pages of medical and support information, in 18 languages.
- ◆ Online Sclero MSN Support Group with message board and daily email list provides top-notch, well-moderated support, 24 hours a day.
- ◆ Toll Free Phone (U.S.): **1-800-564-7099**. All other: **1-952-831-3091**.
- ◆ Email support: info@sclero.org

ISN Book Series

We publish the highly acclaimed **Voices of Scleroderma book series**, with articles by world experts as well as stories from those affected by scleroderma throughout the world.

ISN Web Site Services

We also network and empower our worldwide scleroderma community. We offer to make and post free web pages for scleroderma organizations, support groups, and research studies, in all countries and languages. Join or support the ISN today!