

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.
- Voices of Scleroderma Volume 1** Enclosed is \$25 per book for ___ books.
- 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:**

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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: Voices of Scleroderma Book Series
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Voices of Scleroderma Book Series

BY THE NONPROFIT

International Scleroderma Network

EDITORS

Judith R. Thompson and Shelley L. Ensz

“Wendy was heart-set on dancing that evening even though she was connected to an oxygen machine by a fifty-foot cord. We took the machine with us and managed to ‘cut the rug,’ in spite of the difficulties.

“That was when I realized there was more life left in Wendy than in a lot of people who take their good health for granted. She had won me over.”

— *William Jordan, surviving boyfriend of Wendy Carter*

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.

Voices of Scleroderma Books

The nonprofit International Scleroderma Network publishes the Voices of Scleroderma book series, which feature articles by world experts in scleroderma as well as true stories written by those affected by scleroderma or related illnesses.

The books offer vital information and support for this largely unpredictable illness. The stories offer comfort, inspiration, humor and hope for coping with chronic illness.

Topics covered include all types of scleroderma, such as morphea, linear, en coup de sabre, juvenile, limited, diffuse, CREST, and overlap syndrome.

Also covered are many other autoimmune diseases and symptoms.

Professional Contributors

Professional contributors for Volume 1 include Dr. Joseph Korn, Gary Barg, Dr. Magdalena Dziadzio, Dr. Asim Iqbal Qureshi, and Dr. Thomas Lehman.

Dr. Korn wrote the Medical Overview of Scleroderma for Volume 1. He is the Alan S. Cohen Professor of Medicine and Rheumatology and Director of the Arthritis Center at Boston University School of Medicine in Boston, Massachusetts.

Story Contributors

Story contributors are from 16 countries, including Australia, Canada, Greece, England, India, Italy, Iran, Jordan, New Zealand, Norway, Pakistan, Peru, Poland, Puerto Rico, Romania, and the United States.

Languages

All stories in Voices of Scleroderma Volume 1 are in English, as well as ten stories in **Italian** and one story each in **Greek, Polish** and **Romanian**.

How to Purchase

You may purchase the book online at:
www.sclero.org
www.imprintbooks.com
www.amazon.com
www.ebay.com

You may order also it by phone through our numbers at right.

You may also ask your local bookstore or library to order it for you. The Voices of Scleroderma Volume 1 book ordering number is: **ISBN: 0-9724623-0-9**.

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: site-inquiries@sclero.org

ISN Book Series

The ISN publishes the highly acclaimed **Voices of Scleroderma book series**.

Voices of Scleroderma Volumes 2 and 3 are in production, with Volume 2 planned for publishing during the year 2004.

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!