

# The 2006 Scleroderma Foundation National Conference

“Because I Believe Nothing Is Impossible”

Fri., July 28 – Evening reception  
with buffet and entertainment

Sat. & Sun., July 29–30 – Conference

2006 National Conference Platinum  
Sponsor – Actelion Pharmaceuticals



Creative Science for Advanced Medicine®

This year, the Scleroderma Foundation will have its National Conference in Minneapolis, one of the midwest's best cities. By attending the National Conference you will have the opportunity to:

- Talk with top scleroderma doctors and clinicians during an educational and information-packed weekend
- Connect with people whose lives have been affected by scleroderma to share stories and support

- Learn the latest health, legal and political information, which will help improve your quality of life
- Visit the Metrodome, the largest air-supported dome in the world, and take in a baseball game
- Shop at the famous Mall of America
- Enjoy the beautiful views of some of the 1,000 lakes in greater Minneapolis

These are a few of the reasons to attend the National Conference. There are dozens of others.

The National Conference is meant to serve as a one-stop-shop in service to the mission of the Foundation. There are many opportunities to receive emotional support, become educated about scleroderma and the issues it includes, and learn about the latest in research and where it appears to be heading.

Please take a few moments to read through the workshop titles and a sample of workshop summaries, and imagine how this single weekend could be the most valuable weekend of your whole year. To view the extended summaries, please visit our website at [www.scleroderma.org](http://www.scleroderma.org).

## Conference Workshop Descriptions

*Listed in alphabetical order by workshop title*

### Advanced Directives

Advanced directives are documents signed by a competent person giving direction to health care providers about treatment choices in certain circumstances. Learn about what is involved and whether this is something you need to consider.

### Family Issues

This workshop will discuss things that need to be considered in order for family members to face chronic illness together.

### Less Well Recognized Manifestations of Scleroderma

A discussion of several clinical manifestations of the disease that are not as well recognized and are often not attributed to the diagnosis of systemic sclerosis.

### Overlap Syndromes Associated with Scleroderma

Two or more connective tissue diseases may develop at the same time in an individual diagnosed with scleroderma. This workshop will provide information

# Conference Workshop Descriptions...continued

Listed in alphabetical order by workshop title

about the features of these “overlap syndromes.”

## Scleroderma 101

For those newly diagnosed as well as those who want a better understanding, this is an overview of diagnosis, potential complications, and available treatment options.

## Scleroderma in the Media

The best awareness about scleroderma is built through relationships with your local media. This workshop will present tips, advice and ideas about how to successfully pitch stories to your local media outlets and how to develop constructive relationships with them.

## Supporting the Scleroderma Foundation

Developing a successful organization at the support group and chapter level requires resources. If you'd like to learn how to increase support locally—and learn how it happens at the national level—please don't miss this workshop.

## Alternative and Complementary Therapies

### Are Clinical Trials Right For You?

### Art of Makeup Camouflage

### Board Member Q&A

### Dental Issues

### Depression and Scleroderma

### Dietary and Nutritional Challenges

### Disability and Insurance

### Gastrointestinal Issues

### Localized Scleroderma

### Lung Involvement



Attendees from the 2005 National Conference

### Medications

### Musculoskeletal Involvement

### Occupational Therapy

### Raynaud's Phenomenon

### Sexuality in Scleroderma

### Sjögren's Syndrome

### Understanding Medicare/Medicaid

### Wound Care

### Yoga

## "Because I Believe Nothing Is Impossible"

Conference Hotel: Sheraton Bloomington Hotel, 7800 Normandale Blvd., Minneapolis, Minn. Reservations: 866-837-4278. Group rate: \$109/night. Cut-off date: July 7, 2006. Hotel check-in is 4 p.m.; checkout is 12 noon.

Important note: You must make your own hotel reservation. This is not a hotel reservation form.

Conference workshops are scheduled for Sat., July 29 and Sun., July 30, but all participants are invited to attend an evening of entertainment, including buffet dinner and dancing, on Fri., July 28 from 6:30 to 10:30 p.m.

### 1. Attendee Information (One registration form per person; please photocopy form if necessary)

First Name

Last Name

Street Address

City

State

Zip

Email Address

Telephone

**2. Conference Fees** Rates below are per person. Please note that if one person in a household is a member of the Foundation, then each household member attending can register at the discounted member rate. (Please mark one box below.)

Standard Registration (*includes all Conference activities, scheduled meal functions, and Fri. evening reception*)

- \$175 I am a Scleroderma Foundation member, with registration postmarked by July 7.
- \$225 I am a Scleroderma Foundation member, with registration postmarked after July 7.
- \$225 I am a Scleroderma Foundation non-member, with registration postmarked by July 7.
- \$275 I am a Scleroderma Foundation non-member, with registration postmarked after July 7.
- I plan to attend the Friday evening reception (included with registration fee).

#### Meal Functions Only; No Attendance at Workshops or General Sessions

- \$100 Includes Fri. night reception, Sat. night awards dinner and breakfast buffets on Sat. and Sun.

### 3. Payment Method (U.S. funds only, please)

- I am paying by check. (*Please make check payable to Scleroderma Foundation.*)
- I am paying by credit card.     Visa     MasterCard     American Express

Credit Card #: \_\_\_\_\_ Expiration Date: \_\_\_\_\_

\_\_\_\_\_  
*Name as It Appears on Credit Card*

\_\_\_\_\_  
*Signature*

\_\_\_\_\_  
*Today's Date*

### 4. Dietary Notes

I have special dietary needs as follows:  Vegetarian

Other: \_\_\_\_\_

## 5. Workshops and Meal Functions (Please mark boxes for the ones you plan to attend)

Please note that this schedule is subject to change.

### Friday, July 28

Evening reception w/buffet & entertainment – 6:30–9:30 p.m.

### Saturday, July 29

Registration 8 a.m.–5 p.m.

Exhibits 8 a.m.–5 p.m.

Welcome Session 8:30–9 a.m.

Keynote Address 9–10 a.m.

Break 10–10:15 a.m.

#### Workshops 10:15–11:15 a.m. (choose one)

- A. Scleroderma 101 – Maureen Mayes, MD, MPH
- B. Raynaud's Phenomenon – Dan Furst, MD
- C. Lung Involvement – John Varga, MD
- D. Scleroderma in the Media – Chris Underation, SF Communications Manager
- E. Overlap Syndromes – Janet Pope, MD

Break 11:15–11:30 a.m.

#### Workshops 11:30 a.m.–12:30 p.m. (choose one)

- A. Overlap Syndromes – Janet Pope, MD
- B. Sexuality – Elaine Furst, RN, BSN, MA
- C. Disability & Insurance – Mark Bronstein, JD
- D. Dental Issues – David Leader, DMD
- E. Scleroderma Lung Disease – Hyun Kim, MD

Lunch 12:30–2 p.m. (on your own)

#### Workshops 2–3 p.m. (choose one)

- A. Dietary and Nutritional Challenges – Mary Ann Nirdlinger, MD, MPH
- B. Alternative and Complimentary Therapies – Speaker TBA
- C. Wound Care – David Liedl, RN, RVT
- D. Family Issues – Roberta Diddel, PhD
- E. Scleroderma 101 – Maureen Mayes, MD, MPH

Break 3–3:15 p.m.

#### Workshops 3:15–4:15 p.m. (choose one)

- A. Medicare/Medicaid – Sara Loritz
- B. Assisted Yoga with Caregivers – Kathleen Randolph
- C. Gastrointestinal – Dinesh Khannah, MD, MSC
- D. Localized Scleroderma – Speaker TBA
- E. Hospice and End of Life Issues – Ann Jackson, MBA

Break 4:15–4:30 p.m.

### Saturday continued

#### Workshops 4:30–5:30 p.m. (choose one)

- A. Occupational and Physical Therapy – Jane Brandenstein, PT; and Janet Poole, PhD, OTR/L, FAOTA
- B. Medications – Speaker TBA
- C. Sjögren's Syndrome – Barbara Segal, MD
- D. Board Member Q & A – SF Board of Directors
- E. Plastic Surgery – Speaker TBA

Awards Dinner 6:30–9 p.m.

### Sunday, July 30

Registration 8 a.m.–2:30 p.m.

Exhibits 8 a.m.–2:30 p.m.

#### Workshops 8:30–9:30 a.m. (choose one)

- A. Dietary and Nutritional Challenges – Mary Ann Nirdlinger, MD, MPH
- B. Emotional Impact of Scleroderma – Roberta Diddel, PhD
- C. Scleroderma Lung Disease – Hyun Kim, MD
- D. Wound Care – David Liedl, RN, RVT
- E. Sexuality – Elaine Furst, RN, BSN, MA

Break 9:30–9:45 a.m.

#### Workshops 9:45 a.m.–10:45 a.m. (choose one)

- A. Gastrointestinal – Dinesh Khannah, MD, MSC
- B. Sjögren's Syndrome – Barbara Segal, MD
- C. Advanced Directives – Ann Jackson, MBA
- D. Dental Issues – David Leader, DMD
- E. Medicare/Medicaid – Sara Loritz

Break 10:45–11 a.m.

#### Workshops 11 a.m.–12 noon (choose one)

- A. Less Well Recognized Manifestations of Scleroderma – Sergio Jimenz, MD
- B. Supporting the Foundation – Frannie Waldron, SF Director of Development & Communications
- C. Lung Involvement – John Varga, MD
- D. Raynaud's Phenomenon – Dan Furst, MD
- E. Yoga for Scleroderma – Kathleen Randolph

Lunch 12–1:30 p.m. (on your own)

#### Keynote Closing: 1:30–3:00 p.m.

2006 Research Update, Daniel Furst, MD

## 6. Send Us Your Registration Form! (If this is your first Conference, please check the box below)

**This is my first time attending a Scleroderma Foundation National Conference.** Mail this registration form, one per person, to Scleroderma Foundation, 300 Rosewood Drive, Suite 105, Danvers, MA 01923. Or fax it to 1-978-463-5809. To register by credit card over the phone, call 1-800-722-HOPE (4673). **Important Note: You must make your own hotel reservation. Please see the contact information for the Conference hotel on page 3 of this Registration Form.**