



SclerOH! News

SCLERODERMA FOUNDATION
OHIO CHAPTER
SUPPORT - EDUCATION - RESEARCH

Upcoming Events

March 5 – Cincinnati / Dayton Education Day, University of Cincinnati FREE! (info - pg. 4)

June 4 - Stepping Out to Cure Scleroderma Walk, Boardman Community Park

June 25 - 1st Annual Greater Cincinnati Dog and People Walk For Research, Armco Park Lebanon

June 25 - Stepping Out to Cure Scleroderma Walk, University of Toledo Medical Center

July 29-31 - National Patient Education Conference, New Orleans, LA

August 6 - Stepping Out to Cure Scleroderma Walk, Fairborn Community Park (Greater Dayton)

August 13 - Dr. Susan K. Leone Memorial Golf Outing - Mill Creek Park Golf Course, Boardman

September 2016 - Bowl for Scleroderma, Beaver Vu Bowl, Beavercreek

September 23-25 – Ohio Patient Education Conference and Ugly Dress Gala, Columbus

*This is a very special issue of our newsletter! All three of the main articles, “When the Diagnosis is Scleroderma”, the Book Review, and the Product Review, were written by ladies who are **scleroderma patients** and members of the **Scleroderma Foundation, Ohio Chapter**. Their contributions to our newsletter are much appreciated!*

Linda’s article was even printed in the Winter 2016 issue of Women Magazine! We will publish her article in two separate editions. This issue includes Part 1. We will include Part 2 in the Spring Newsletter. The full article is available online at AWomansHealth.com.

When the Diagnosis is Scleroderma

Becoming a proactive patient is key to managing this rare autoimmune disease. By Linda Slusser

The first time my fingers grew painfully cold, turning purple, then white, and then back to a normal pink, the temperature was 60 degrees. It was April and I had been walking my dog. Over the next few weeks, any kind of cold – even an icy glass of water in my hand – triggered the same reaction in my fingers.

My primary care physician identified my symptoms as Reynaud’s phenomenon and sent me to a rheumatologist, who took a history, did an exam, and ran blood tests.

“The Reynaud’s is only one part of your condition,” he explained. “You have a rare autoimmune disease called scleroderma. It is incurable but treatable.”

What is Scleroderma

Scleroderma is a connective tissue disease where collagen is deposited in the skin and organs. Tissue thickens, causing the skin to harden and damaging internal organs. Kerri Connolly, director of programs and services at the Scleroderma Foundation, says that an estimated 300,000 people in the United States suffer from scleroderma; 75 percent of them are women. Onset usually occurs between the ages of 30 and 50.

Soumya Chatterjee, MD, MS, FRCP, director of the Scleroderma Program and associate professor in the Department of Rheumatic and Immunologic Diseases at the Cleveland Clinic, says that about 20 new cases of systemic scleroderma are diagnosed per 1 million Americans each year.

There are two main types of scleroderma: *localized scleroderma* and *systemic sclerosis*. In localized scleroderma, the mildest variety, usually only a few places on the skin are affected. Progression may stop even without treatment. Systemic sclerosis is the more serious variety, which can present in two forms: *limited* and *diffuse*.

Dr. Chatterjee says that two-thirds of patients diagnosed with systemic sclerosis will have the more benign, limited form. This form may be referred to as *CREST syndrome*, named for its common symptoms: *calcinosis* (hard, often painful calcium deposits in the skin); *Raynaud’s phenomenon*; *esophageal dysfunction*; *sclerodactyly* (tightened skin on the fingers); and *telangiectasias* (red spots on the skin). More-serious complications, such as pulmonary hypertension, can develop later.

The diffuse form of the disease is the most severe and affects one-third of the patients with systemic sclerosis, according to Dr. Chatterjee. Many of the body’s internal organs can be damaged in this form, and it can become life-threatening.



Tina Fellows
Executive Director

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Hurry! Raffle ends soon!
Buy "pigs" for
Scleroderma Foundation,
OH Chapter!

www.piggestraffle.com

Pigs Cost \$5. The plastic pigs
are dropped at the Flying Pig
Marathon. If yours hits the
target, you win!

1st PRIZE - \$10,000! (\$5k to
you & \$5k to your charity)
2nd PRIZE - lease on a Prius
3rd PRIZE - fun weekend in
Cincinnati

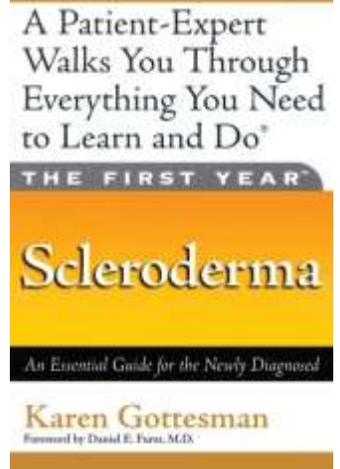
Book Review by Tiffany Masters

A series of books entitled "The First Year..." surrounding a number of diseases have been widely published by a group of expert authors in their respective fields allowing patients to virtually have their hand held through the diagnostic process. In the *First Year with Scleroderma*, a disease that prior to your diagnosis, you probably never heard mention of, Karen Gottesman, and a handful of other experts upon whom she draws information, illustrates a very manageable picture of what to expect in the next 365 days as a newly diagnosed member of our community.

First, let me say congratulations on your diagnosis. By that I mean, if you're anything like me, the first year didn't really feel like the first year at all, mostly because I spent so many years already trying to find out what was wrong with me! Statistics say most patients spend an average of five years, with five different doctors before receiving an official diagnosis. There were five doctors in four years, passing me back and forth, asking a myriad of questions, poking and prodding, x-raying and testing, until finally, in year five, they confirm it is SCLERODERMA. In all of my research, and there seemed to be a lot, (a meager attempt to help the doctors along), I had read one paragraph, about five lines long, that referred to the disease at all; hardly giving me any indication that it was *this* that was making me feel so crazy. But once the diagnosis was confirmed, this was the first book I went to for answers.

Gottesman does an excellent job of talking to us about the disease as a friend, a well-informed friend in fact, rather than a doctor who can sometimes talk over our heads, sometimes even in a condescending manner. Rather, Gottesman approaches the disease as a manageable, newly clarified part of our lives. This is not necessarily a death sentence. Rather, knowing became half the battle. But if it is truly your first year, if you are newly diagnosed, allow this book to be your guide for the next 365 days of your awakening. You'll be able to do more than just "know." In fact, my favorite part of the chronology of the text is that "it is laid out in terms of your day-to-day, week-to-week, and month-to-month questions," allowing you to take it slow, or at a pace that is comfortable to you. (p. xv) Gottesman covers areas such as, what do I talk to my doctor about? What do I expect in the coming months? And, most importantly, "how can I live WELL, with the disease." Because it is trying to cover an entire disease in a year, some of the sections are vague, but it will give you a solid jumping off point from which to move forward.

What is most important about this book is that it provides you with a voice to carry your own concerns to others, be it family and friends, or doctors and specialists, as well as an understanding that this has all been had by others before you; you are not alone. If you are a newly diagnosed patient of scleroderma, or if you've been diagnosed years ago, haven't had an in-depth conversation with your doctor in some time, allow this book to be your stepping stone. Pick it up, and don't put it down until you're done, until your voice is clear and your questions are ready to be asked. It is a quick read, but one you will go



Gottesman, Karen. *The First Year Scleroderma: A Patient-Expert Walks You Through Everything You Need to Learn and Do*. Marlow & Company Publishers: New York, 2003.

back to time and again as your year progresses and new things come to light. Because always remember, no two people with scleroderma walk the same path. And once you are through year one, take comfort in your newly found community. There is new information every day. Though we walk different paths with this disease, we all walk with the same intent: to find a path to wellness with scleroderma.

Ohio Chapter Board Members

Debbie Metz – President
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Phil Meyer – Treasurer

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Dagne Lazenby
Jolene Rodenbaugh
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Find a Scleroderma Foundation Ohio Chapter Support Group



Virtual Support Group: Meets 2nd Wednesday monthly at 7:00-8:00 pm by phone.
Next meeting – Wednesday, March 9th. Call 866-740-1260, enter code 7170191#

Akron / Canton Support Group: send email for info to info@sfohio.org

Central Ohio Support Group: Meets quarterly, Apr 3, Jun 5, Aug 7, and Oct 2 - 2:00-5:00 pm. Location: Villas at Glenealy Clubhouse, 6315 Donegan Way, Dublin 43016. Support Group Leader: Ann Barnhart, (614) 717- 6790, columbus-sg@sfohio.org.

Dayton Area Support Group: Meets on these dates for 2016: Apr 2, May 14, June 4, July 16, Sept. 10, and Oct. 8 at 10 am –12 pm at Grace Community Church, 5001 Fishburg Rd. in Huber Heights. Leader: Penny Davis (937) 554-1425, dayton-sg@sfohio.org.

Greater Cincinnati Support Group: Meets quarterly Sat.1-3 pm. Apr .2, June 18, Sept. 10, and Dec. 3 at Hyde Park Branch – Public Library of Cincinnati and Hamilton County, 2447 Erie Ave., Cincinnati. Leader: Debbie Metz, 513-232-5210; cincinnati-sg@sfohio.org.

Northeast Ohio/Greater Cleveland Support Group: Meets monthly last Thursday each month 7 pm, March – October. March meeting is contingent on weather. Location: Simon’s Restaurant, 770 Chippewa Rd., Brecksville. Support Group Leader:s Mike Hollo (330) 241-0697 and Anne Davis (440) 212-2880, neohio-sg@sfohio.org.

Toledo Area Support Group: Meets Feb.—Oct. monthly on the third Thursday of the month at 7:00 pm at St. Luke’s Hospital, Room 2, 5901 Monclova Rd., Maumee. For info, email info@sfohio.org.

Willoughby Support Group: Meets monthly, third Saturday 9:30 -11:30 am, May-September at Willoughby Public Library, 30 Public Sq., Willoughby. Support Group Leader: Larry Bodak (440) 953-2918, willoughby-sg@sfohio.org.

Youngstown Area Support Group: Meets Mar-Dec. at 5:30 on the 1st Monday of the month unless it is a holiday, then it is on the second Monday (Sept), at Davidson’s Restaurant, 3636 Canfield Rd. in Youngstown. (330) 793-0033. Come for dinner!
Support Group Leader: Leni Schulz (330) 654-2538, youngstown-sg@sfohio.org.

For updates, you can also visit www.sfohio.org.

Scleroderma Foundation Membership Dues & Donation Form

You can improve the lives of individuals with scleroderma and help in the search for a cause and cure. To join or make a donation by credit card, visit our website www.sfohio.org and click the DONATE NOW button. To pay by check or cash, complete this form today and mail to:

Scleroderma Foundation, Ohio Chapter
P.O. Box 107
Pataskala, OH 43062

NAME: _____ PHONE: _____

ADDRESS: _____ EMAIL: _____

CITY: _____ STATE/ZIP: _____

AMOUNT: _____

Please check appropriate box: \$25 Annual Membership Donation

In Honor Of: _____ In Memory Of: _____



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866-849-9030 OR INFO@SFOHIO.ORG

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SF Ohio Chapter Newsletter

Product Review



by Carmella B. Anderson

Recently I made a purchase of Ladies Converter Gloves (\$14.99) and Ladies Original Socks (\$15.99) from Heat Holders (www.heatholders.com). These items are designed to provide extra warmth. The first product that I reviewed was the gloves. They were very comfortable and easy to get on and off. When testing the gloves, I wore this product on one hand. On the other, I placed an ordinary, inexpensive glove to do a comparison. When the temperature was in the teens, the Heat Holders glove provided some warmth but still not enough to keep hands from turning a little blue. Also, I tried to put a cheap pair of gloves under them to see if that helped. It did, but not much. I would give these gloves 2.5 out of 5 stars.

My second review is for the socks. I would rate them at 1.5 out of 5 stars. They provide a little more heat than regular socks, but my feet were still ice cold. I did not try to put them over other socks which may help with a little more warmth.

Cincinnati / Dayton Education Day March 5th!

The Cincinnati and Dayton Education & Support Groups are excited to host a free education event on Saturday, March 5! Continental breakfast will be provided for you at 8:00 am. Our speakers will present from 9am until 12pm. The experts presenting are: **Surabhi Agarwal Khanna, MD**, Assistant Professor of Medicine, Division of Immunology, Allergy and Rheumatology; **Gaurav Khanna, MD**, Assistant Professor of Medicine, Division of Pulmonary and Critical Care Medicine; and **Jean Elwing, MD**, Associate Professor of Medicine, Division of Pulmonary and Critical Care Medicine, and Director, Pulmonary Hypertension Program. This forum will be held at the University of Cincinnati Medical Sciences Building at 231 Albert Sabin Way, RM 3051 (3rd Floor). Parking is available in the Eden Avenue



Garage at 3223 Eden Avenue. There is access to the Medical Sciences Building from the Garage 5th Floor. RSVP to cincinnati-sg@sfohio.org, for food count, if possible.

