



# SclerOH! News

**SCLERODERMA FOUNDATION**  
OHIO CHAPTER  
SUPPORT - EDUCATION - RESEARCH

## Upcoming Events

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

**June 12** – Haircuts for Scleroderma, Fabulous Syles & Cuts, Zanesville

**June 25** – Family Fun & Dog Walk, Armco Park Lebanon (Greater Cincinnati)

**June 25** - Stepping Out to Cure Scleroderma Walk, U of Toledo Med Center

**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

**August 27** – Hike and Family Picnic, Cuyahoga Valley National Park

**September 23-25** – State Conference & Ugly Dress Gala, Columbus

**October 1** - Bowl for Scleroderma, Beaver Vu Bowl, Beavercreek

*This article was written by Linda Slusser, who is a **scleroderma patient** and member of the **Scleroderma Foundation, Ohio Chapter**. It was printed in the Winter 2016 issue of Women Magazine! For our newsletter, this is being published in three separate editions. This issue includes Part 2. Part 1 was printed in the winter newsletter. Part 3 will be printed in the summer edition. The full article is available online at [AWomansHealth.com](http://AWomansHealth.com).*

## When the Diagnosis is Scleroderma (Part 2)

### Begin with Two Things

Feeling stunned and scared upon diagnosis of scleroderma is a natural first response, but there are steps you can take to empower yourself and move forward.

First, as tempting as it may be, do not randomly roam the Internet for information. You will encounter worst-case scenarios, as well as incorrect information. If you do search for information and find statistics or firsthand accounts that frighten you, don't panic. Scleroderma is "not automatically a death sentence," says Dr. Chatterjee. A milder form of the disease does not necessarily shorten one's normal life span. Even if you have a more severe form involving major organs, treatments can manage most symptoms.

Second, find a doctor—ideally a rheumatologist—who has expertise and experience dealing with scleroderma. It's good if the doctor practices close to your home, better if he or she is part of a group that can work with the different organs scleroderma can affect, and best if the group is associated with a research university or scleroderma center.

If your local primary care physician is less familiar with scleroderma, you can still benefit from the knowledge of an expert working in a larger research setting: patients often travel to a center where experts specialize in scleroderma to formulate a care plan and then return once or twice a year to update their treatment plan; their local physician consults the expert between visits as needed.

Dr. Chatterjee says that, at the initial visit, the expert will typically do five things:

- Confirm the scleroderma diagnosis.
- Determine the extent of the problem.
- Identify which organs are involved.
- Decide what further testing might be needed.
- Recommend a treatment plan, and, if more than one organ is affected, prioritize which one will dictate the overall management of the disease.



### Consult Reliable Resources

After you have had an initial consultation with an expert on scleroderma, spend time learning about the disease and your specific situation by consulting reliable sources. The following patient-oriented websites provide good overviews of the illness:

- American College of Rheumatology, [rheumatology.org](http://rheumatology.org)
- Cleveland Clinic, [my.clevelandclinic.org](http://my.clevelandclinic.org)
- Mayo Clinic, [mayoclinic.org](http://mayoclinic.org)
- Scleroderma Foundation, [scleroderma.org](http://scleroderma.org)

In addition, *The Scleroderma Book: A Guide for Patients and Families* (Oxford University Press, 2005) by Maureen D. Mayes, MD, offers a comprehensive discussion of how scleroderma affects the organs. Dr. Mayes devotes chapters to the skin, kidneys, gastrointestinal tract, lungs, heart, musculoskeletal system, and related conditions. In addition, she addresses patients' about sexuality and pregnancy.



**Tina Fellows**  
Executive Director

We're on the web!  
[Sfohio.org](http://Sfohio.org)

Email us at:  
[info@sfohio.org](mailto:info@sfohio.org)

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scleroderma ohio

**HAPPY 5TH ANNIVERSARY TO  
THE LILLIAN SWARTZ  
STEPPING OUT TO CURE  
SCLERODERMA 5K  
RUN/WALK**

Please join us June 25, 2016 to celebrate 5 years of walking in honor or memory of loved ones affected by scleroderma in Toledo. The fun takes place at UTM 3000 Arlington Ave. Registration is 8 a.m. - 9:00 a.m. and event starts at 9:00 a.m. There will be a 5k Run/Walk, 50/50 Raffle, Chinese Auction, DJ, and Prizes for runners. As with our other walks, you can create your own fundraising page. Register now at [www.sfohio.org](http://www.sfohio.org)!

**JOIN THE FUN IN BOARDMAN**

At the Boardman Walk, you will see old friends and make new ones. If you haven't yet experienced our walk, please join us this year. It's a 4k walk, and it will be held on Saturday, June 4, at Boardman Park, Rt. 224 in Boardman.

**There will be music, 50/50 raffle, an auction, and more! This walk has raised nearly \$400,000 to help the Scleroderma Foundation, Ohio Chapter further its mission. Register now at [www.sfohio.org](http://www.sfohio.org).**

Join us and help support the cause! Create your own fundraising page and encourage your family and friends to support your goal. We make it easy to share your fundraising page through email, Facebook and Twitter. Registration on walk day opens at 8:30 a.m. The walk starts at 9:00.

**New For All Walks This Year**



Team Captains raising more than \$100 will be entered into a raffle for a 7-day stay for up to 6 people in a condo in North Fort Myers, Florida! One raffle ticket will be awarded for each \$100 raised. We're also going to pilot an on-line auction program for great items to be auctioned at the Greater Cincinnati Walk. We will have a Scleroderma Foundation, Ohio Chapter eBay page, and will be doing a trial to see how it works in connection to walks. Watch for the link to the auction on [sfohio.org](http://sfohio.org).

**Exciting News for Ohio!**

If you have been following our progress on getting Ohio Bill 133 signed into law, then you know that this bill officially designates June as Scleroderma Awareness Month in the State Of Ohio. **I am ecstatic to report that, at the beginning of May, Governor Kasich signed the bill!** We are on the list for a ceremonial signing with Governor Kasich and Senator Beagle, the sponsor of the bill. Watch Facebook and Twitter for photos!

Thank you so much to all who have helped with this effort, especially Demeshia Trice, who initiated the battle to get the bill to the Governor's desk! Senator Beagle will be honored with an award for this accomplishment at our Ugly Dress Gala on September 24, 2016 in Columbus. You will be able to purchase tickets to the gala coming soon on [www.sfohio.org](http://www.sfohio.org).



**2016 Rosita Aguirre Scholarship  
for Scleroderma Foundation,  
Ohio Chapter State Conference**

At the Ohio Chapter State Conference, you can learn more, meet others with scleroderma, and interact with experts who are treating and researching this disease.

For 2016, we will sponsor four patients for the conference. This includes transportation, lodging, and registration fees (up to \$500). Some caregiver expenses may be eligible. Receipts will be required.

All information submitted is kept confidential. Please include: **name, phone number, address, e-mail address, reason for wanting to attend conference, medical need, financial need, and involvement in the Foundation.** Applications must be received by June 30, '16. Send them to [jrodenbaugh@zoominternet.net](mailto:jrodenbaugh@zoominternet.net) (preferable) or Scleroderma Foundation, Ohio Chapter, P.O. Box 107, Pataskala, OH 43062.

**Wonderful Opportunity!**

**We are still looking for sponsors for most of this year's events! Let us know if you or a business owner you know would like to take advantage of this great advertising opportunity!**

## Find a Scleroderma Foundation Ohio Chapter Support & Education Group

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



**Akron / Canton:** Meets 1<sup>st</sup> Thursday of each month at 6:30 pm at Cleveland Clinic Akron General Health and Wellness Center, Green, 1940 Town Park Blvd., Uniontown, OH. Leader: Trisha Gosselin, [tgosselin725@gmail.com](mailto:tgosselin725@gmail.com).

**Central Ohio / Greater Columbus:** Meets quarterly Jun 5, Aug 7, and Oct 2 - 2:00-5:00 pm. Location: Villas at Glenealy Clubhouse, 6315 Donegan Way, Dublin 43016. Leader: Ann Barnhart, (614) 717- 6790, [columbus-sg@sfohio.org](mailto:columbus-sg@sfohio.org).

**Dayton Area:** Meets on these dates for 2016: 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](mailto:dayton-sg@sfohio.org).

**Greater Cincinnati:** Meets quarterly Sat. 1-3 pm. 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](mailto:cincinnati-sg@sfohio.org).

**Northeast Ohio/Greater Cleveland:** Meets monthly last Thursday each month 7 pm, April -October. Location: Simon's Restaurant, 770 Chippewa Rd., Brecksville. Leaders: Mike Hollo (330) 241-0697 and Anne Davis (440) 212-2880, [neohio-sg@sfohio.org](mailto:neohio-sg@sfohio.org).

**Toledo Area:** Meets Mar.—Nov. monthly on the third Thursday of the month at 7:00 pm at St. Luke's Hospital, Room 1, 5901 Monclova Rd., Maumee. Leader: Jerri Sue DeTray. For info, email [info@sfohio.org](mailto:info@sfohio.org).

**Willoughby:** Meets monthly, third Saturday 9:30 -11:30 am, May-September at Willoughby Public Library, 30 Public Sq., Willoughby. Leader: Larry Bodak (440) 953-2918, [sawman269@yahoo.com](mailto:sawman269@yahoo.com)

**Youngstown Area Support Group:** Meets Mar-Dec. at 5:30 pm 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., Canfield. (330) 793-0033. Come for dinner!  
Leader: Leni Schulz (330) 654-2538, <mailto:youngstown-sg@sfohio.org>.

For updates, you can also visit [www.sfohio.org](http://www.sfohio.org).

### Ohio Chapter Board:

Debbie Metz – President; Jerry Metz – Secretary; Phil Meyer – Treasurer

Members at Large:

Dagne Lazenby, Jolene Rodenbaugh, Mariann Boyanowski

### 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](http://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: \_\_\_\_\_



MOVING? CHANGE OF NAME OR E-MAIL ADDRESS? LET US KNOW! 866-849-9030

### SCLERODERMA AWARENESS MONTH

In Australia, the sunflower has become the symbol of scleroderma awareness—because those with the disease feel better in the warmth of the sun. During the month of June, in over a dozen countries in North America and Europe, a month of awareness-building will culminate with several activities to celebrate World Scleroderma Day on June 29<sup>th</sup>. June 29 is significant because it marks the death in 1940 of the brilliant artist Paul Klee, who suffered from systemic scleroderma. Klee's work was strongly influenced by his disease. Paul Klee's legacy helped to inspire the formation of the World Scleroderma Foundation. Based in Basel, Switzerland, the WSF brings together experts in scleroderma research in an effort to support research for a cure. The WSF's lead patron is Klee's grandson, Alexander, and his family.

Not only is the search for a cure needed for the millions who suffer from the disease, but also scleroderma is the prototypical disease for other diseases. A breakthrough in understanding scleroderma would undoubtedly have a strong impact on many other diseases involving sclerosis.

Which leads us back to sunflowers. Each sunflower contains as many as 2,000 seeds, each of which, with the right conditions, becomes another sunflower. If we could find a cure for scleroderma, imagine how many other millions of people who struggle with related diseases could be helped, as well. Plant a seed to find a cure for scleroderma.



**Please share our AWARENESS messages you see on Facebook and Twitter throughout June with your loved ones!**

Resource: *Evelyn Herwitz's blog at [livingwithscleroderma.com](http://livingwithscleroderma.com).*

### FAMILY FUN & DOG WALK GREATER CINCINNATI



Please join us in the fight to cure scleroderma at our Family Fun and Dog Walk! This is an exciting new event. It will be at Armco Park 1223 N. St. Rt. 741 Lebanon, OH 45036 on Saturday, June 25, 2016. Registration will be from 9:00 - 10:00 AM with the walk beginning at 10:00 AM. Food, games, raffles and auctions will continue until 12:00 or 1:00 PM. There will be great games for children, dogs and adults!

Registration cost is \$15 per registrant (\$10 extra for t-shirt). Register at [www.sfOhio.org](http://www.sfOhio.org) or mail donations and registration information to: SFOH Dog Walk, 2675 Lebanon Rd., Lebanon, OH 45036. For more information contact Martha Merry: 513-312-4698 [merry@zoomtown.com](mailto:merry@zoomtown.com) or Debbie Metz: 513-417-5210 [debbie.metz@zoomtown.com](mailto:debbie.metz@zoomtown.com).