

Summer
2017

Fundraising Events

August 27 – Peninsula, OH
– Cuyahoga Valley National
Park - Hike & Family Picnic

September 23 –
Beavercreek, OH – Beaver-Vu
Bowl – Bowl for Scleroderma

September 28 – Canfield,
OH – Spaghetti Dinner &
Bake Sale

September 30 – Delaware,
OH – Annual Golf Outing in
Memory of Dave Ludolph

October 7 – Cleveland, OH
– Holiday Inn Cleveland
South – Gala

Please go to sfohio.org
for more information and to
register for all events



Ohio Chapter Board Members:

Officers:

Debbie Metz – President
Jolene Rodenbaugh
– Vice President
Jerry Metz – Secretary
George Kinstedt - Treasurer

Members at Large:

Mariann Boyanowski
Lucille Miller
Gabrielle Freeman
Shanelle Boyd
Kari Matsko
Patti Jordan
Josette Fyre
Amanda Ludolph

Medical Consultant:

Trisha Gosselin



SclerOH! News

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

Education Events

August 26 – Columbus, OH –
The OSU Martha Morehouse
Pavilion - with Jon Walker, MD,
Gastroenterology, The OSU
Wexner Medical Center and Ali
Ajam, MD, Rheumatology, The
OSU Wexner Medical Center.
Free Event! Food provided!

September 7 – Akron area -
Cleveland Clinic Akron General
Health and Wellness Center,
Green, OH 44685 - with Kristin
Highland, MD, Pulmonary
Medicine, Cleveland Clinic.
Event is sponsored by Gilead
Sciences.

Free event! Food provided

September 11 – Youngstown,
OH – St. John's Greek Orthodox
Church, 4955 Glenwood Ave.,
with Robert Lafyatis, MD, Visiting
Professor of Medicine, UPMC
Division of Rheumatology and
Clinical Immunology –
Free event! Food provided!

September 16 – Mentor, OH
– Mentor Public Library Main
Branch, 8215 Mentor Ave.,
Frances Cleveland Room - Topic:
Treatment of PAH Associated
with Scleroderma – Free event!

September 23 – Dayton, OH -
Grace Community Church, 5001
Fishburg Rd., Huber Heights –
Topic: Insights on Connective
Tissue Disease – Event is
sponsored by Gilead Sciences.
Free event! Food provided!

October 7 – Cleveland area –
Holiday Inn – with Cleveland
Clinic Specialists: Soumya
Chatterjee, MD, MS, FRCP, FACP,
FACR; Donald Kirby, MD, FACP,
FACN, FAGG, AGAF, CNSC, CPNS;
Joseph Parambil, MD; and Jill
Brown, MS, RD, LD, CNSC



Learning to Cope: Q & A with Tiffany Masters

Recently, an Ohio scleroderma patient, Tiffany Masters, took the time to talk to SF Ohio newsletter contributor, Hannah Wantz. She talked about some tactics that she has learned over the years to help deal with this difficult, and sometimes debilitating, disease.

HW: What type of scleroderma are you living with, and how long have you had it?

TM: I was diagnosed with limited scleroderma twelve years ago.

HW: What has been your greatest obstacle so far living with the disease?

TM: When I get tired going upstairs and have to take a break, people don't understand why that is. I

don't look sick, but I have lung involvement, and I don't have the capacity to do the things that I used to do. It's hard to explain to people because I seem to always get that eye roll. You feel guilty because you don't look sick.

HW: Do you find that people in the workplace and in social situations are more or less understanding than you would want them to be when it comes to your difficulties?

TM: I find that most people are disinterested rather than accommodating. It isn't that they don't want to be compassionate, it's just so involved, and they don't want to know. People have their own problems and don't want to listen. I find that people are indifferent, if anything.

Scleroderma Foundation Ohio Chapter Newsletter

NEW EVENT IN DELAWARE OHIO!



Do you golf or know someone who does? This event, which is raising funds for scleroderma research, will be held Saturday, September 30 at 1:30 PM (12:30 registration) at the Glen Ross Golf Club at 231 Club House Dr., Delaware, OH. The cost is \$80 per person for 18 holes, cart and dinner. A foursome can enter for \$320, and hole sponsorships are also available for \$125. Fundraising leader, Amanda Ludolph, started this event as a way to remember her father-in-law. Tickets for dinner only are available for \$30, just in case your family members or friends who don't golf would like to join you after your round! They'll have D.J. services until 9:30 PM! Please email anapier01@gmail.com to secure your spot.



Tina Fellows
Executive Director

info@sfohio.org
www.sfohio.org



[facebook.com/curesclerodermaohio](https://www.facebook.com/curesclerodermaohio)



twitter.com/ohioscleroderma



[youtube.com/sclerodermaohio](https://www.youtube.com/sclerodermaohio)

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HW: How would you personally describe what it is like living with Scleroderma to someone who has never heard of the disease?

TM: You're aware of it every single day. You have to become your own advocate by researching the disease on your own. It can take some time to get into see a doctor and by the time you do get in to see them you might not have the same issues you were having before. You need to know what it is that you are looking out for and be aware of things like, "What do I think I can eat today? Can my skin handle the sun today? Am I energetic enough to go to the store?"

HW: What sort of tools and resources do you use to cope with and manage your everyday symptoms in order to feel better and enjoy social activities, do chores, or work?

TM: Heated socks and gloves for the winter time, essential oils, argon oil, massage therapy aromatherapy, and Vitamins and supplements. I was taking 30 prescriptions a day at one point. Unless you have a Scleroderma specialist, you have to be on top of your own research so I started looking into natural alternatives. I got off of most of those prescriptions with the assistance of my doctors. I feel so much better now than I did with all of the pills. Another thing that helps is keeping a food diary. I realized early on that there were things I just couldn't put into my body anymore.

Capitol Hill Day Rescheduled for Spring 2018

Based on current legislative priorities in Washington, DC and the realities of introducing a bill into Congress in the near future, Capitol Hill Day 2017 (originally scheduled for October 25) has been rescheduled for Spring 2018.



Advocacy work to advance our cause will continue this fall and winter through grassroots efforts in congressional districts, advocacy alerts and training opportunities for current and new scleroderma advocates.

There was an outstanding workshop at the recent patient education conference focused specifically on how to utilize one's story as a powerfully effective tool to share with legislators in hopes that the elected official will co-sponsor a bill. That process is even more effective when there is a bill before Congress to co-sponsor! Training opportunities will be announced in future e-newsletters, and the date for Capitol Hill Day 2018 will be announced as soon as it is confirmed.



Spaghetti Dinner & Bake Sale Thursday, September 28, 2017 4- 7 PM

5050 Shields Road, Canfield,
Ohio 44406

Sponsored by the Masonic
Temple Argus Lodge #545
To Benefit the Scleroderma
Foundation - Ohio Chapter

\$10 per person

Ticket price includes
Spaghetti Dinner, Beverage,
& Dessert
(Take Out is Available)
\$5 Children Under 12 years old

Advanced tickets may be
purchased through Masonic or
Scleroderma Members
Gary Shane, Masonic Temple
330-719-4714
Leni Schulz, Youngstown
Support Group Leader;
Ph.: 330-654-2538



Join the Sunflower Society!

Consider joining the Sunflower Society by creating a bequest provision to the Scleroderma Foundation, Ohio Chapter in a will or trust. Whatever the size of your estate, you want your legacy to support those organizations that are important to you. It's important to realize that each estate and state is different; therefore, working with an attorney is a good idea. To find out about your planned giving options, please contact Tina Fellows, Executive Director, toll-free at 866-849-9030.

Scleroderma Foundation Ohio Chapter Newsletter

Find a Scleroderma Foundation Ohio Chapter Support & Education Group

Virtual Support Group (by phone): Meets 2nd Wednesday monthly at 7-8 pm by phone. Call toll-free 866-740-1260, enter code 7170191#.

Akron / Canton: Meets 1st Thursday of each month May - October at 6:30 pm at Cleveland Clinic Akron General Health and Wellness Center, Green, 1940 Town Park Blvd., Uniontown, OH 44685. Leader: Trisha Gosselin, akron-sg@sfohio.org. September meeting is an education day with a live speaker and food provided!

Central Ohio / Greater Columbus: Remaining meetings: August 26 at 10 am-1pm (this meeting is an education day at OSU Martha Morehouse Pavilion), and October 22 at 2-5 pm at: Villas at Glenealy Clubhouse, 6315 Donegan Way, Dublin 43016. Leader: Ann Barnhart, (614) 717- 6790, columbus-sg@sfohio.org and Assistant Leader: Barb Talicska columbus2-sg@sfohio.org.

Dayton Area: Remaining meeting dates: August 19 and September 23 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. September meeting is an education day with a live speaker and food provided!

Greater Cincinnati: Meets 2nd Saturday of the month in April, June, September and December at 1 - 3 pm. Location: 1701 Mercy Health Place, Cincinnati. Leader: Debbie Metz, 513-232-5210; cincinnati-sg@sfohio.org and Assistant Leader: Greta O'Neal.



Northeast Ohio/Greater Cleveland: Meets monthly last Thursday each month 7 pm, April -October. Location: Simon's Restaurant, 770 Chippewa Rd., Brecksville. Co-leaders: Anne Davis (440) 212-2880, neohio2-sg@sfohio.org and Cheryl Wilson, neohio-sg@sfohio.org.

Toledo Area: Meets March - November monthly on the third Thursday of the month at 7 pm at St. Luke's Hospital, ROOM 2, 5901 Monclova Rd., Maumee. Co-leaders: Jerri Sue (Sam) DeTray, toledo2-sg@sfohio.org and Lois Spratt toledo-sg@sfohio.org. Cookies and water provided!

Willoughby / Mentor: Remaining meeting date: Saturday, September 16. Time: 10:30 AM. Location: Mentor Public Library, Main Branch, Frances Cleveland Room, 8215 Mentor Ave.,

Mentor, OH 44060. Leader: Patricia Wagar. Contact willoughby-sg@sfohio.org with questions. This meeting is an education day with a live speaker on PAH.

Youngstown Area: Meets Mondays on the following remaining dates: September 11 (Education Day - location St. John's Greek Orthodox Church, 4955 Glenwood Ave, Youngstown, OH 44512 - Food provided!), October 2, November 6 and December 4. Regular meetings (all meetings except Sept. 11 meeting) held at Davidson's Restaurant, 3636 Canfield Rd. in Canfield. (330) 793-0033. Come for dinner at 5:30. 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: _____

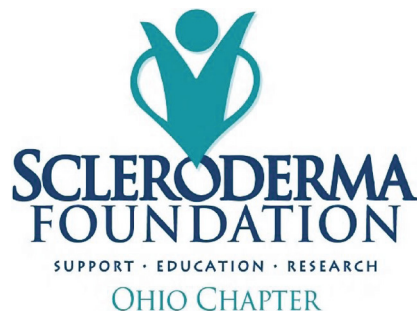
Please check appropriate box: \$25 Annual Membership Donation

In Honor Of: _____ In Memory Of: _____

This Year's Gala Has Fiesta Theme!



We're going south of the border for inspiration for this party. We will be raising funds to support the Scleroderma Foundation Ohio Chapter through auctions, raffles and more. Have dinner while you enjoy comedy entertainment and the colorful decorations! Join us for the fun. You won't want to miss this FIESTA! It will be held on October 7 after the Cleveland Clinic Education Day at the Holiday Inn in Independence, Ohio. Tickets are \$43 for the gala. Registration for the Education Day is \$5. You can register for both at a discounted price of \$45. Please go to www.sfohio.org to register.



P.O. Box 107
Pataskala, OH 43062-0107

Ohio Awarded at National Conference!

We were so honored this year to accept several awards given by the Scleroderma Foundation national office at the National Patient Education Conference in Chandler, Arizona. It was an exciting day, indeed, as we were recognized time and again throughout the ceremony! We won 4 of a possible 11 volunteer awards across the entire country.

In Ohio, we have a strong focus on patient support and are always striving to improve our groups and create more of them. Thus, we were awarded the **Patient Support Award**.

We're very lucky in Ohio to have an amazing team of assets in sisters Mariann Boyanowski and Leni Schulz. Tina Fellows nominated Mariann for **Chapter Volunteer of the Year** and the national office chose this nomination for the award. Mariann was nominated to show appreciation for her work as a board member, committee chair (several committees), fundraising leader and more. Likewise, Tina nominated Leni for the **Individual Fundraiser of the Year** and national chose this nomination for the award as well. Leni was nominated due to her work on the "Stepping Out to Cure Scleroderma" Walk in Boardman, Ohio, along with other achievements in fundraising. The national office recognized a team of two people as the **National Volunteers of the Year**. One of these people was Bob Kristof, who attends the Youngstown, Ohio Support Group (which, incidentally, Leni Schulz also leads). Bob is a professional radio and television voiceover announcer. The other was Sue Lane in Texas, who partners with Bob in working on public service announcements and getting



them aired on the radio to advertise scleroderma fundraising events being held all over the country.

Congratulations to all, and thank you for representing the Ohio Chapter in such an amazing way! Pictured left to right are Tina Fellows, Executive Director of the Ohio Chapter; Mariann Boyanowski, Board Member and Fundraising Leader of the Ohio Chapter; Leni Schulz, Support Group Leader and Fundraising Leader of the Ohio Chapter; and Bob Kristof, attendee of the Youngstown Support Group in the Ohio Chapter.