

Fall 2020

## 2020 UPCOMING EVENTS

### "Stepping Out to Cure Scleroderma"

- Cleveland's Walk for Research  
Date - September 19, 2020  
VIRTUAL WALK

Join us on Facebook LIVE for this  
virtual event on 9/19/20 at 11 AM  
Eastern!

### November Family Caregivers Awareness Month various activities

(see article enclosed)

### Winter 2020-2021 Virtual State Conference

Updates and registration info on  
sfohio.org.

These programs are made possible,  
in part, by an unrestricted grant  
from Actelion Pharmaceuticals,  
Boehringer Ingelheim.



# SclerOH! News

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

## Caregivers, the Overlooked by Lucille Miller

November is Caregiver Awareness Month and we really want to give a shout out to all of the caregivers out there! Is caregiving for your loved one easy? Probably not! Would you change how care for your loved one? Probably not!

Caregivers must ask themselves what THEY are lacking. I can't stress enough how crucial this is for you and your daily life. After all, this is a hard job!

Here are some tips that might help!

- First off, pat yourself on the back! This isn't easy and it's OK to feel your emotions too!
- Reach out to other caregivers. Remember, you are not alone! Many deal with the same feelings you do on a daily basis.
- One of the hardest things of all is this: don't forget YOUR health! After all, if you're not healthy, you won't be strong enough to help your loved one.
- Do you accept help easily? If somebody asks you to help out, are you more likely to say YES or NO? When a friend or family member asks to help out, most likely it's coming from their heart! It sincerely helps them to help you!
- Do you feel like you can talk to the doctors and communicate your feelings about what you see and feel as a caregiver? If not, this is an extremely important tool to learn. You also need to be heard!
- Caregiving is hard work. Try taking a nap or a walk to have some "you" time!
- Keep a journal. Try writing down notes, thoughts, or even changes with your loved one. Sometimes just getting it out on paper can relieve daily stress!



"There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver."

– Rosalyn Carter

"It is not how much you do, but how much love you put in the doing."

– Mother Teresa

"Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around."

– Leo Buscaglia



The Scleroderma Foundation Ohio Chapter Board of Directors is excited to share that Debbie Haussler, who has been a board member since January 2020, was just recently voted in as our Vice President. Debbie is a caregiver to her husband, Darryl, who was diagnosed with scleroderma in May 2016. She is a member of our Public Awareness Committee and brings some wonderful ideas about raising awareness. She enjoys spending time with her husband, children and grandchildren.

# Scleroderma Foundation Ohio Chapter Newsletter

## COVID-19 UPDATE

COVID-19 UPDATE: Out of an abundance of caution related to the coronavirus, the Ohio Chapter has decided to cancel all face-to-face support group meetings and education days through at least November. This fall, we will make decisions about meetings and events scheduled for December and beyond. The State Conference and Gala are cancelled for this year. Please watch our website for further updates at [www.sfohio.org](http://www.sfohio.org). We encourage patients and caregivers to stay in touch with us via the free virtual support group meetings listed on our website [www.sfohio.org](http://www.sfohio.org).



## Piggest Raffle Ever!

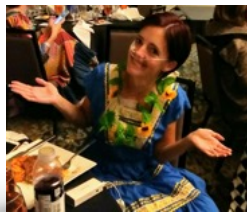
Due to the COVID-19 pandemic, the 2020 Flying Pig Marathon has been moved to the weekend of October 9-11. In light of this and to help charities raise some additional funds, they are going to continue the Piggest Raffle Ever, sponsored by Stock Yards Bank & Trust, until October as well!

You can buy your raffle tickets on [www.piggestraffle.com](http://www.piggestraffle.com) until October 10. Sunday, October 11, the Piggest Raffle Ever winners will be selected!

Remember, tickets cost \$5 each and your charity (Scleroderma Foundation Ohio Chapter) will receive 100% of the funds from those "pigs" (i.e. raffle tickets) bought on behalf of your organization (you can select us when you buy the tickets).

## Sunday Sitdowns with Lucille Miller

Consider joining us for "Sunday Sitdowns" on the last Sunday of each month at 1 PM EASTERN on our Facebook page [www.facebook.com/curesclerodermaohio](https://www.facebook.com/curesclerodermaohio) for a live discussion with a new topic each month! This is not a private support group, but it is a great way to stay connected, "chat with friends" and obtain info and entertainment! It is led by our new president, Lucille Miller, who is pictured here. Join us!



## Ohio Chapter Board Members:

### Officers:

President - Lucille Miller  
Vice President - Debbie Haussler  
Secretary - Lois Aubrecht  
Treasurer - Charlene Kiehler

### Members at Large:

Mariann Boyanowski  
Shanelle Boyd  
Patti Jordan  
Amanda Ludolph  
Demeshia Montgomery  
Alice Nagy  
Betsy Walker

### Medical Consultants:

Trisha Gosselin  
Dr. Soumya Chatterjee



## November Activities to Support Caregivers

For the first time, the Ohio Chapter is creating an initiative to recognize and support our caregivers this year during November Caregivers Awareness Month. We plan to provide them with some tools and resources throughout the month via posts on Facebook, Twitter and Instagram, hopefully help educate them about coping with the stresses of caring for a loved one with articles like the one in this newsletter, offer support from other caregivers via phone and Facebook LIVE, and one lucky winner will even receive a gift for all they do! The free phone-in caregivers-only support group meeting on Thursday, November 19th at 7 PM Eastern can be accessed by calling toll free 877-806-9883 and entering code 486576. Co-hosts of the support meeting will be caregivers, Emily Neu and Keith Miller. On November 29th, our monthly Facebook LIVE program "Sunday Sitdowns" will be co-hosted by caregivers. We hope many of you will tune in to share ideas on caregiving and what works best for you. Simply visit [facebook.com/curesclerodermaohio](https://www.facebook.com/curesclerodermaohio) at 1 PM Eastern. Lastly, patients can enter their caregiver in a prize drawing by sending their name, address, phone and email address, along with a brief write-up about what makes their caregiver so wonderful to [tfellows@scleroderma.org](mailto:tfellows@scleroderma.org) or P.O. Box 107, Pataskala, OH 43062 by October 31.

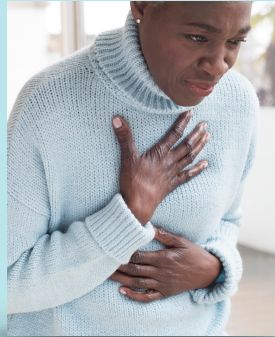


# Scleroderma Foundation Ohio Chapter Newsletter

## Look out! It's a Scleroderma Flare!

By Lucille Miller

If you read the title, you probably know what I'm talking about - the dreaded scleroderma flare! How do flares come about? Some flares occur with the change of weather, and some flares just occur for no reason at all. As you are probably aware, each of us have a different scleroderma journey, so that can bring a variety of scleroderma flare symptoms! If you have any of the most common flare-up symptoms listed below, please reach out to your doctor! Everybody is different, so it's important to be in tune with your body and how you feel. Here are just a few examples:



- Swelling in the limbs
- Difficulty swallowing
- Unusual rashes
- Changes in your breathing
- Gastrointestinal changes
- Ulcers on the hands or feet
- Heart changes (BP; pulse; pain)

Again, these are a few of the many scleroderma symptoms of a flare, but nobody knows your body better than you! If something is simply just not feeling right, reach out to your doctors. They are there for you and want to be on top of your health and progress!

## We Need You!

Have you ever thought of volunteering for the Ohio Chapter, but didn't know what types of things you could do? Contact Tina at [tfellows@scleroderma.org](mailto:tfellows@scleroderma.org) and let her know your interests. She can find a place for you to help. Currently, some of the volunteers we're looking for are: Support Group Leader - Akron / Canton Area; Support Group Co-Leader - Dayton Area; Board Members (especially members interested in sitting on the Finance and / or By-Laws Committees); Advocacy Committee Members; Social Media Committee Members to post things on Facebook for

## Scleroderma Foundation Ohio Chapter Support Groups



Due to the COVID-19 pandemic, our physical support groups are not meeting face-to-face right now. Some of them are meeting by phone or by Zoom, though! Check our website regularly for updates at [www.sfohio.org](http://www.sfohio.org)!

Please utilize our virtual option:  
Virtual Support Group: Meets

2nd Wednesday monthly at 7-8 PM either by phone or Zoom. Please check our website [www.sfohio.org](http://www.sfohio.org) for the details each month. October 14th at 7 PM Eastern, one of our lawmakers (TBD) will be giving a presentation about Ohio legislation designed to help rare disease sufferers. Call toll free 877-806-9883 and enter 486576.

Watch our website, [sfohio.org](http://sfohio.org), for details on when we plan to begin meetings in person again. This will be determined by when we think we can meet safely.

## 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: \_\_\_\_\_





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



Tina Fellows  
Executive Director

info@sfohio.org  
www.sfohio.org



facebook.com/curesclerodermaohio



twitter.com/ohioscleroderma



youtube.com/sclerodermaohio

### Cleveland's Backyard Bash for Research!

To stay safe under CDC guidelines and to keep our promise to provide life-changing support, education, and research for everyone affected by scleroderma, the Scleroderma Foundation Ohio Chapter Stepping Out walks will become exciting VIRTUAL fundraising experiences. The extraordinary circumstances that we all currently face illustrate the extreme vulnerability of individuals who have scleroderma, and why we can't miss a step! To participate, you simply register as you normally would and then walk on your own or with friends and family (at a safe



distance!) in your neighborhood, around your dining room table or wherever you choose! We'd love to see pictures of you on your walk! You can email pics to [tfellows@scleroderma.org](mailto:tfellows@scleroderma.org) or post them to our Facebook page [www.facebook.com/curesclerodermaohio](http://www.facebook.com/curesclerodermaohio)! Pictured are some shots from the Cleveland Walk in 2018.

We have one virtual walk left for 2020, which is the "Stepping Out to Cure Scleroderma - Cleveland's Backyard Bash for Research" fundraiser on September 19, 2020. For all information or to sign up / donate, go to: [WWW.SCLERODERMA.ORG/CLEVELANDWALK](http://WWW.SCLERODERMA.ORG/CLEVELANDWALK) Donations to this walk will be accepted until October 19, 2020.