

2018  
UPCOMING EVENTS

**August 18, 2018**  
Mill Creek Golf Course,  
Boardman, OH  
Dr. Susan K. Leone Memorial  
Golf Scramble for Scleroderma

**August 25, 2018**  
Cleveland, OH  
Stepping Out to Cure  
Scleroderma Walk

**September 22, 2018**  
Beaver-Vu Bowl, Beaver Creek,  
OH  
Bowl for Scleroderma -  
"Thelma's Silent Words"

**October 6, 2018**  
Delaware, OH  
Dave Ludolph Memorial Golf  
Tournament

**October 12-14, 2018**  
Embassy Suites, Columbus, OH  
State Conference and Ugly  
Dress Gala

Updates and registration info for  
events on [sfohio.org](http://sfohio.org).

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



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# SclerOH! News

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

## Your Questions about Gastrointestinal Problems Answered!

**I understand the occasional difficulties I have with swallowing, heartburn (reflux), stomach and bowel problems may be due to issues with my gastrointestinal (GI) tract. What is the GI tract, and why am I experiencing these problems?**

The GI tract includes esophagus, stomach, small bowel (intestine), large bowel (colon) and rectum. It is made up of smooth muscle, and its purpose is to move food and drink in one direction from the mouth to the rectum. We have no control over these muscles. The GI tract muscles work by reflex and keep food from backing up. In some Scleroderma patients, the smooth muscle loses its strength and wastes away. It may be replaced by fibrotic scar tissue caused by too much collagen. When this occurs, you may experience problems with your esophagus, stomach, small bowel, large bowel and or rectum.

**Are there any early signs of gastrointestinal disease?**

GI disease often begins with a decrease in appetite. This often means eating less and losing weight.

**Why do I have difficulty chewing?**

You may experience trouble chewing food because of dry membranes in the mouth. These dry membranes may be caused by Sjogren's Syndrome. Scleroderma can affect facial; skin around the mouth making it tighter than usual. This can make chewing and opening the mouth fully more difficult.

**What are some esophageal problems?**

*Difficulty swallowing:*

Difficulty swallowing food is called dysphagia. Food gets stuck somewhere in the passage between the mouth and the stomach. There isn't enough muscle power in the esophagus to move the food to the stomach. Drinking a glass of water can help wash the food down. Taking smaller bits of food and chewing food longer than usual can also help.



Normally dysphagia is not painful, but it can be uncomfortable. If it does hurt, it's possible you have developed an ulcer on the esophagus or an infection. Ulcers can occur from repeated exposure to stomach acid caused by reflux

*Reflux and Heartburn:*

Reflux is a "backwards flow" of stomach acid moving back up into the esophagus. Normally stomach acid stays in your stomach because it is blocked from going up by the lower esophageal sphincter. When a person has a reflux problem, the sphincter is too weak to hold the acid back.

Heartburn is a burning sensation in the chest that is caused by stomach acid moving backwards into the esophagus. The pain is in the left side of your chest and can move down into your left arm.

Stomach acid can also cause atypical chest pain, coughing, asthma-like wheezing due to aspiration, hoarse voice and a feeling of gagging.

**Is reflux painful?**

It can be painful and uncomfortable. The stomach's lining is strong enough to stand the stomach acid, but the esophagus is not. Over time the esophagus can be damaged by acid reflux. Simple changes in daily living and eating habits can help to prevent some of the damage. There are also medications that have been proven effective.

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# Scleroderma Foundation Ohio Chapter Newsletter

## Your Questions about Gastrointestinal Problems Answered! continued

### What can I do to limit reflux?

- Don't eat within two hours of bed time.
- Move the main meal towards midday
- Eat more frequent small meals instead of one or two large meals.
- Eat sitting up.
- Eat slowly.
- Chew food thoroughly.
- Drink sips of water between bites and make sure each mouthful is fully swallowed before taking the next bite.
- Avoid carbonated drinks. They will fill your stomach with air and push the contents up.
- Don't exercise after eating.
- Elevate the head of the bed at least four inches by placing it on wooden blocks. Just propping your head up on pillows won't work because it doesn't lift your esophagus above your stomach. Pillows should be wedged from the low back upward to avoid bending the neck or torso.
- Limit actions that increase pressure on your stomach such as bending, vigorous exercise or tight clothing.
- Try to keep your body weight within a healthy range. An overweight abdomen can put pressure on your stomach.

### Are there certain foods and/or drink that I should avoid in order to reduce my reflux and heart burn? Are there medications that can be taken to reduce reflux and heartburn?

Yes. See more information about this on <https://www.hopkinsscleroderma.org/scleroderma/frequently-asked-questions/>

### What stomach problems occur with GI disease?

Getting full with less food, nausea or indigestion (burping), erosions or ulcer formation, and telangiectasias. See more information about this on <https://www.hopkinsscleroderma.org/scleroderma/frequently-asked-questions/>

### What small and large bowel problems can occur?

Gas, cramps and bloating, constipation, diarrhea, obstruction, and bowel incontinence. See more information about this on <https://www.hopkinsscleroderma.org/scleroderma/frequently-asked-questions/>

Information extracted from [www.hopkinsscleroderma.org/scleroderma/frequently-asked-questions/](https://www.hopkinsscleroderma.org/scleroderma/frequently-asked-questions/). This is a good source for more information. Also visit [scleroderma.org](https://www.scleroderma.org) to learn more about gastrointestinal issues.

## Ohio Comes Home with an Award for the Third Year In a Row!



The 2018 Scleroderma Foundation National Patient Education Conference in Philadelphia was filled with fun, food, friends and great educational opportunities! Every year, the national office bestows individuals and chapters with awards for many different areas during the Saturday luncheon. It was thrilling to hear Debbie Metz's name called when the award for Chapter Volunteer of the Year was given. Debbie was

nominated by Executive Director, Tina Fellows, to show appreciation for her work as Board President, committee chair (several committees), support group leader and fundraising co-leader of the Cincinnati "Family Fun and Dog Walk".

Congratulations to Debbie and thank you for representing the Ohio Chapter in such an amazing way! Pictured is Debbie Metz, Board President, with her award.

## Free Education Days

We have two free education days coming up in September! Both events are open to everyone and will have food provided. We are fortunate to have wonderful speakers who are willing to share their expertise. Form new friends with scleroderma patients and families! RSVP to [info@sfohio.org](mailto:info@sfohio.org).

### September 15 at 10 AM

Dayton, OH - Grace Community Church, 5001 Fishburg Rd., Huber Heights, Ohio. Speaker: Tom Ballard, Nurse Practitioner from Knoxville, TN. Title: "Insights on PAH"

### September 18 at 6 PM

Mentor, OH - Panera Bread, 9587 Mentor Avenue, Mentor, Ohio. Speaker: Robert Schilz, DO, Pulmonary and Critical Care Medicine Physician, University Hospitals. Title: "Insights on Connective Tissue Disease"



# Scleroderma Foundation Ohio Chapter Newsletter



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

**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 for info.

**Central Ohio / Greater Columbus:** Meets every other month April - October. Remaining meetings: August 26, October 28 at 2-5 PM. Location: Villas at Glenealy Clubhouse, 6315 Donegan Way, Dublin, OH 43016. Co-Leaders: Ann Barnhart, (614) 717- 6790, columbus-sg@sfohio.org and Barb Talicska, columbus2-sg@sfohio.org.

**Dayton Area:** Meets April 7, May 5, June 2, July 14 and September 15 at 10 AM - 12 PM. Location: Grace Community Church, 5001 Fishburg Rd., Huber Heights, OH. Leader: Penny Davis (937) 554-1425, dayton-sg@sfohio.org

**Greater Cincinnati:** Meets 2nd Saturday of the month in April, June, September and December at 1:00 - 3:00 PM. Location: St. Aloysius, 4721 Reading Rd. (near Norwood Lateral), Cincinnati, OH 45237. Co-Leaders: Debbie Metz, 513-232-5210; cincinnati-sg@sfohio.org and Greta O'Neal.

**Northeast Ohio/Greater Cleveland:** Meets monthly 4th Thursday each month at 5:30 PM - dinner; 6:30 PM - meeting, April - October. Location: Michael's Place Restaurant, party room, 12841 State Rd., North Royalton, OH 44133, 440-237-2212. Co-Leaders: Anne Davis (440) 212-2880, neohio2-sg@sfohio.org , Cheryl Wilson, neohio-sg@sfohio.org , and Evett Moynihan.

**Toledo Area:** Meets March -November monthly on the third Thursday of the month at 7 PM at St. Luke's Hospital, ROOM 1, 5901 Monclova Rd., Maumee, OH. Co-Leaders: Jerri Sue (Sam) DeTray, toledo2-sg@sfohio.org and Lois Spratt Toledo-sg@sfohio.org . Cookies, coffee and water provided!

**Mentor:** Meetings on August 28 and September 18 at 6 PM. Location: Panera Bread, 9587 Mentor Ave., Mentor, OH 44060. Leader: Patricia Wagar - mentor-sg@sfohio.org

**Youngstown Area Support Group:** Remaining meetings: September 10, October 1, November 5 and December 3. Location: Davidson's Restaurant, 3636 Canfield Rd., Canfield, OH. Dinner at 5:30, meeting at 6 PM. Leader: Leni Schulz (330) 654-2538, youngstown-sg@sfohio.org

**For directions and meeting topics, contact the support group leader listed or email [info@sfohio.org](mailto:info@sfohio.org).**

### Virtual Support Group: FREE PHONE CALL!

Meets 2nd Wednesday monthly at 7 - 8 PM by phone.

Call 866-740-1260,  
enter code 7170191#.

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

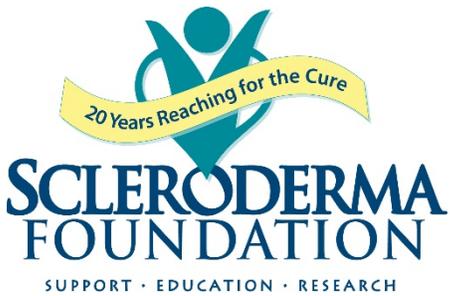
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P.O. Box 107  
Pataskala, OH 43062-0107



Tina Fellows  
Executive Director

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Ohio Attendees at the  
National Conference:

Standing L to R: Mariann  
Boyanowski, Lois Aubrecht,  
Trisha Gosselin, Kathie  
Schwartz, Greta O'Neal, Lori  
Jenkins, Tina Fellows

Seated L to R: Debbie Metz,  
Jerry Metz, Josette Frye

## Let Our Voices Be Heard

Did you know you can help with passage of our bill just by making a phone call? **Our bill, National Commission on Scleroderma and Fibrotic Diseases Act of 2017 (S. 3267), has recently been introduced in the U.S. Senate. This bill is bi-partisan and doesn't ask Congress for any money. It only requires the NIH to create a commission and a comprehensive research plan for various organization to collaborate and consider scleroderma the prototype disease.** Help us gain a co-sponsor by calling Ohio Senator, Rob Portman's, office. Simply tell the staffer the message above in bold and tell them you want Senator Portman to become a co-sponsor. That's it!



We have until the end of the year to get as many co-sponsors (Senators who support the bill) as we can.