



SclerOH! News

SCLERODERMA FOUNDATION
OHIO CHAPTER
SUPPORT - EDUCATION - RESEARCH



Ready for Bed?

By Lucille Miller

Do you feel that you are getting enough sleep at night? Studies show that a healthy person needs a minimum of 7 hours of sleep per night to fully function and feel rested. According to sleepfoundation.org, you may need 7-8 hours or 7-9 hours, depending on your age. We all know how beneficial sleep is, but many scleroderma patients declare getting enough sleep to be a huge problem in their daily life! Scleroderma affects everybody differently, so let's dive in to see what issues may be affecting you. First of all, some patients are on medications for scleroderma that prevent their bodies from relaxing enough to sleep. Others might have breathing issues which require using devices that can make getting settled difficult. Still others blame gastrointestinal issues and body pain for their tossing and turning. Are you one of the many scleroderma patients that has anxiety about the medical issues you deal with, and when you try to go to bed you just can't turn your brain off? That is also extremely common! Believe it or not, these are just a few examples of the barriers to good sleep! Unfortunately, these issues can make getting cozy in bed nearly impossible. Here are a few tips that might improve your sleep:

1) First and foremost, talk with your doctor about your concerns. They may have some suggestions pertaining to your personal scleroderma case. This is very important, but many patients don't stress the lack of sleep they're getting to their doctors. Use some of your time with your doctor to express your concerns and they may have some additional ideas to help with your personal needs.

2) If you are a napper, try to limit naps to under an hour. This might help you to feel sleepier at bedtime and create a deeper sleep.

3) Unplug! Many individuals reach for phones, computers or watch television to unwind in the evening. There is an enormous amount of time at dusk or later spent online on social media, texting, sending emails, playing games or binge-watching the newest Netflix series! However, according to CNET.com, blue light exposure (the type of light emitted by LED screens) at night can keep you awake. This happens because this type of light can slow or halt the production of melatonin, the hormone that tells our brain that it's time for bed. If you want to use a device, there are many types of blue-light filtering screens, glasses and apps that you can use!

4) Limit caffeine towards the late afternoon and early evening. This can be very hard to do, but it's necessary. Caffeine is a stimulant to help keep you awake and the later you drink it, the harder it can be to get the sleep that you deserve!

5) There are many devices that can help you relax or meditate. If you have a smartphone, there are many free applications that you can use to help you relax. You're able to play these all night long. Some have soft noises like a rain shower, sounds of ocean waves, or guided relaxation techniques. Don't underestimate the power of simple white noise! Studies have shown that the frequency of true white noise can help calm the body and induce sleep. Many use a small fan in their bedroom and find that the hum of the fan is all it takes to lull them to a peaceful slumber.

Sleep is super important to our daily lives and going without restful sleep can certainly put a strain on your body. Don't be afraid to try some new tips or revisit some you may have tried in the past. There are additional helpful ideas on the National Sleep Foundation's website, sleepfoundation.org. Remember, sleep can be some of the best medicine!

2019 Upcoming Events

Bowl for Scleroderma –
“Thelma’s Silent Words”
September 28, 2019, 2-4 PM
Beaver Vu Bowl
1238 N Fairfield Rd,
Beavercreek, OH 45432

Cleveland Education Day
October 12, 2019, 9:30 AM
Cleveland Clinic
Administrative Campus
Building 3,
AC3-LL-120/Auditorium
3050 Science Park Dr.
Beachwood, OH 44122

Dave Ludolph Memorial
Fundraising Dinner
November 15, 2019, 6:30 PM
Scioto Reserve Country Club
7383 Scioto Pkwy., Powell, OH
43065

Updates and registration info
on sfohio.org.

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

2019 Diamond National Sponsor



2019 Platinum National Sponsor



Ohio Holds 6 Successful Walks in 2019!



For the first time ever, Ohio held 6 different walks in one year. Our walks are unique, fun events and each one has its distinctive aspects in the way that they honor patients who are no longer with us, incorporate fun activities for children or pets, or just create a family-reunion type of atmosphere. The event leaders and their committees work tirelessly to make event day something that patients and their families and friends will look forward to each and every year. The Ohio Chapter is extremely proud of its walks and the awareness and funds raised at these celebrations to benefit the scleroderma community. Speaking of raising funds, these six events brought in over \$103,000! All of the thanks goes to those of you who donated, volunteered and / or participated.

Event leaders included:

Boardman walk - Leni Schulz and Mariann Boyanowski, along with their family members, Kelli Cabuno, Ron Cabuno, Brittany Holihan and Jesi Nameth
 Toledo Walk – Dawn Landrus and Robin Landrus
 Greater Cincinnati Walk – Debbie Metz
 Columbus Walk – Josette Frye
 Dayton Walk – Penny Davis
 Cleveland Walk – Lucille Miller and Trisha Gosselin.

A special note of thanks goes to Penny Davis for 8 years of leading the Dayton area walk. She has put in hundreds of hours of hard work and has decided this will be her last year for event leading. The Ohio Chapter sincerely appreciates the years of dedication and recognized her efforts at the walk on August 3. Pictured above are three board members giving Penny a token of appreciation for her leadership. Left to right in the picture are Jerry Metz, Debbie Metz, Penny Davis and Demeshia Montgomery.

As in years past, all team captains at each walk who raised over \$100 were entered into a raffle to win a 7-day stay at a condo in North Fort Myers, Florida! A ticket was awarded for every additional \$100 raised. The winner was drawn at the final walk this year, which was the Cleveland event. Lauren Papa, Team Captain of Sassy Scleroderma Steppers / The Papa Crew, was the lucky winner!

This year, a new way of recognizing those who raised money for the events was incorporated. Superstar Fundraiser buttons were given to each individual who raised \$50 or more. Some walks also gave out trophies or gift cards to the top-earning teams.

If you joined us this year – come back next season! We'd love to see you! If you've never attended one of our walks, join us next year at one of these fabulous events!

Ohio Awarded at National Conference



This year was extremely exciting for Ohioans at the national conference. We were so honored to have been named as the Chapter of the Year! The award of "Outstanding Chapter Awareness" was bestowed on us for the 2nd time in 4 years, thanks, in part, to the hard work of Demi Montgomery and the advocacy committee, as well as Lucille Miller and the Public Awareness and Social Media Committee. In addition, Jerry Metz, who just finished his term as Secretary of the Ohio Chapter Board, was named as Chapter Volunteer of the Year! It was an experience that will not be forgotten. These awards were received due to all the wonderful work of our volunteers. Thanks to all of you! Pictured L to R is Cos Mallozzi, Chair of the Scleroderma Foundation Board of Directors; Demi Montgomery, Ohio Board Member and Chair, Ohio Advocacy Committee; Tina Fellows, Executive Director and Lucille Miller, Vice President of the Ohio Board.

The Northeast Ohio / Greater Cleveland Support Group enjoyed an education day provided by United Therapeutics on July 25. The topic presented was pulmonary artery hypertension and scleroderma. Pictured L to R are Group Co-Leader, Cheryl Wilson; Tom Wilson; Vice President, Lucille Miller; Group Co-Leader, Donna Teaman; Group Co-Leader, Anne Davis; Respiratory Therapist and Speaker, Nancy Helldobler; and United Therapeutics Representative, Todd Thomas.



Find a Scleroderma Foundation Ohio Chapter Support & Education Group



**Virtual Support Group:
FREE PHONE CALL!**
Meets 2nd Wednesday monthly at
7 - 8 PM by phone.
Call 1-866-398-2885 and enter
code **395852**.

Akron / Canton: Meets 2nd Thursday of each month May – October at 6:30 PM at NEW LOCATION - Rising Sun Holistic Choices, 4216 Hills and Dales Rd., Canton 44708. Leaders: Trisha Gosselin, akron-sg@sfohio.org and Sherri Konopinski - akron2-sg@sfohio.org.

Central Ohio / Greater Columbus: Meets every other month April – October. Dates for 2019: April 28, June 30, August 24 and October 27 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: Meetings will be held at 10 AM - 12 PM on May 4, June 1, July 13, September 7, October 12. 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. Meetings held at 1 – 3 PM at St. Aloysius, 4721 Reading Rd. (near Norwood Lateral), Cincinnati, OH. Contact: Gabrielle Freeman - cincinnati-sg@sfohio.org and Greta O’Neal -cincinnati2-sfohio.org .

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 Donna Teaman.

Toledo Area: Meets April - November on the third Thursday of the month at 7 PM. NEW LOCATION is University of Toledo Medical Center, Ruppert Health Center, Office D (shared space with OB/GYN clinic). Round bldg. right next door to the Radisson hotel. Enter from South or East entrance. Leader: Lois Spratt Toledo-sg@sfohio.org.

Youngstown Area Support Group: Meets once per month on Mondays. Remaining dates for 2019: July 1, Aug. 5, Sept. 9, Oct. 7, Nov. 4, Dec. 2. Location: Davidson’s Restaurant, 3636 Canfield Rd., Canfield, OH. (330) 793-0033. Dinner at 5:30, meeting at 6 PM. Leader: Leni Schulz (330) 654-2538, youngstown-sg@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: _____



Ohio Chapter Board Members

Officers:

Debbie Metz – President
Lucille Miller – Vice President
Secretary - Open
Treasurer - Open

Members at Large:

Lois Aubrecht
Shelly Beachy
Mariann Boyanowski
Shanelle Boyd
Josette Frye
Patti Jordan
Amanda Ludolph
Jerry Metz
Demeshia Montgomery
Alice Nagy

Medical Consultant:

Trisha Gosselin



Ohioans to Visit Capitol Hill



This year, four Ohioans, along with volunteers from other states, will converge on Capitol Hill on September 17 to request support from our lawmakers for our current bill. Tina Fellows, Executive Director; Josette Frye, Board Member and Event Leader; Demeshia Montgomery, Board Member and Advocacy Committee Chair, and Carmella Anderson will visit key representatives to explain the need for this bipartisan and budget neutral bill which would establish a commission to improve coordination of National Institutes of Health (NIH)-supported research related to scleroderma and other fibrotic diseases. The goal for the journey is to gain as many co-sponsors of the bill as possible. There's an easy way to be aware of how you can help advocate for scleroderma. Please go to scleroderma.org and click on "Become an Advocate" and then click on "Sign up for alerts". You'll be notified when there is a petition you can sign on our website. Also, look for the letter to ask your own representative to co-sponsor, which you can download under the same tab. Then just sign and mail it to the address listed on the website. Pictured above L to R are Demi Montgomery, Kathie Schwartz and Josette Frye at Capitol Hill Day 2016.

Scleroderma Awareness Workshop



During Scleroderma Awareness Month this past June, the Scleroderma Foundation, the Scleroderma Research Foundation and Scleroderma Canada worked together to bring scleroderma patient stories from all walks of life to light. As a result, a whopping number of 8 million people were reached through social media posts and email blasts! People were made aware of what patients face on a daily basis. Many news media outlets picked up stories of courage and strength of patients who were holding fundraisers, telling their stories through blogs or just fighting their everyday fight. The "Know the Face of Scleroderma" campaign was extended throughout the Scleroderma Foundation National Conference in July. At the conference, Tina Fellows and Demi Montgomery facilitated an awareness workshop, where the campaign was discussed and the impact of patients who told their story was shared. Due to its success, the "Know the Face" campaign will continue through the next year.



Tina Fellows
Executive Director
info@sfohio.org
www.sfohio.org



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



[twitter.com/
ohioscleroderma](https://twitter.com/ohioscleroderma)



[Instagram.com/
ohioscleroderma](https://www.instagram.com/ohioscleroderma)