

Winter 2021

2021
UPCOMING EVENTS

**Pediatric Virtual Rare Disease
Fun Night**
February 23, 2021

**Ohio Scleroderma Virtual
Education Day**
March 20, 2021

**"Stepping Out to Cure
Scleroderma" - Boardman 4K
Virtual Funwalk**
June 5, 2021

**"Stepping Out to Cure
Scleroderma" - Columbus Virtual
Walk**
June 29, 2021

**"Stepping Out to Cure
Scleroderma" Dayton Virtual
Walk**
Date TBD

**"Stepping Out to Cure
Scleroderma" - Cleveland's Walk
for Research! Virtual Walk**
Date TBD

**Ohio Scleroderma Virtual
Conference**
October 15-16

Updates and registration info
coming soon - check 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**

It's cold outside and inside too! By Lucille Miller

You've probably heard of or have dealt with Raynaud's Phenomenon. You probably also know how challenging this disease is! We can all read tips and tricks to help out, but the question is.... Do they actually help or is there something else I haven't heard of? In honor of February being Raynaud's Awareness Month, here are a few tricks to try out that may be new to you!



• Layer up!

Put on multiple layers when going outside, multiple scarves, socks, gloves. Many patients don't want to layer up because people tend to stare. If that happens, just remember this is about YOUR health and give the curious person a smile and a kind wave! Remember - it's Ohio and the weather can be harsh! Layer! Layer! Layer!

• Prevent any cold air!

Be sure to not just bundle up, but wear a coat with snug cuffs to prevent any cold air getting through to your wrists or inside your gloves. Cold air getting to your hands can cause a Raynaud's attack.

• Staying home is OK!

Never feel guilty for saying "It's just too cold!". It's perfectly fine to do what you need to do to protect yourself from a Raynaud's attack. Only you know YOUR limits and YOUR severity of Raynaud's! The last thing you want is a Raynaud's attack causing you more problems!

• Inside prevention!

Always remember to bundle up and use multiple layers, even inside. But what if you need to get a drink? Or food? Some people wear gloves to get items out of the refrigerator or freezer. This is a great way to protect yourself indoors in cold areas!

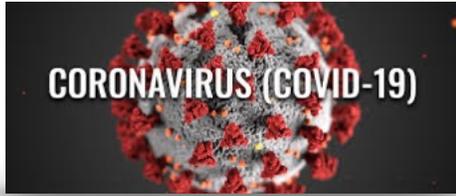
• What type of drinkware are you using?

Sometimes people don't think much about what type of cup they're using. Sounds simple, right? Well, having the correct cup or mug can be quite useful! A mug with a warm drink can feel good! But what do you use when you're drinking something cold? Try an insulated cup! They are useful for keeping drinks cold, but they are not cold on the outside! It will help protect those hands from the cold!

Scleroderma Foundation Ohio Chapter Newsletter

COVID-19 UPDATE

Out of an abundance of caution related to the COVID-19 pandemic, the Ohio Chapter will not hold in-person support group meetings or events of any kind until further notice. Please watch our website for further updates at www.sfohio.org. We encourage patients and caregivers to stay in touch with us via the free virtual support group meetings and other virtual events listed on our website www.sfohio.org.



Two decades! Can you believe that? THE OHIO CHAPTER is celebrating our 20th Anniversary! As a chapter, we have so much to be proud of! We've gone through many changes and as a chapter we are always evolving! Just to name a few,

here some highlights we've achieved: we have multiple official scleroderma treatment centers throughout the state, support groups (both video and phone-in meetings available currently), and a greatly-increased presence in social media. We have certainly made an impact! Personally, I've only been with the Ohio Chapter close to 5 years. I reflect on all that's been accomplished in this time, and it truly makes me smile! As a board, we had huge goals! Some felt so far off in the distance that we just couldn't reach them. However, because of our spectacular and dedicated team, we've surpassed our goals and we're creating new goals along with fresh new ideas! I want you to know that ALL OF YOU are a huge part of this! What this Chapter has accomplished is for all of you and would not be possible without many of you who volunteer! Know that your support of the Ohio Chapter has helped make us what we are today! I think about the future with the Scleroderma Foundation Ohio Chapter and I personally feel excited! I know that we can reach further and achieve more than we ever expected! Thank you all for everything you do!



A 20th Anniversary!

- 20 years of memories!
- 20 years of goals!
- 20 years of experiences!
- 20 years of friendship!
- 20 years of dedication!

Today we celebrate us!

Here's to many more years,
Lucille Miller, President

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 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. Join us!

Ohio Chapter Board Members:

Officers:

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

Members at Large:

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

Medical Consultants:

Dr. Vidya Sivaraman
Trisha Gosselin
Dr. Soumya Chatterjee



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!



Upcoming Support Group Meeting Dates:
2/18/21 at 7 PM - Toledo Support Group via Zoom
2/21/21 at 2 PM - Columbus Support Group via Zoom
3/1/21 at 7:30 PM - Youngstown Support Group via Zoom

Scleroderma Foundation Ohio Chapter Newsletter

Feeling the itch? By Lucille Miller



As most of us know, there are many types of scleroderma. Your specialist can identify what type you have and how severe it is. Some people that suffer with scleroderma deal with rashes or

itchiness. In Ohio during winter, that can tend to be common due to the cold and dry air! Always talk to your doctor about what you are experiencing before making changes to your care. Even though due to the pandemic it may be difficult to get an appointment or a virtual appointment may be the only option, it's still important to talk to your medical professionals first!

Below are a few things it might be helpful to AVOID to relieve itchy skin:

- Fabric softeners
- Hot baths
- Excess cold exposure
- Itchy fabrics such as wool
- Rubbing alcohol / some sanitizers
- Perfume

For some great tips on taking care of scleroderma skin, go to the American Academy of Dermatology Association website article at <https://www.aad.org/public/diseases/a-z/scleroderma-self-care> .

Ohio Virtual Scleroderma Education Day!

The Ohio Chapter is excited to bring you an Ohio Virtual Education Day on Saturday, March 20, 2021. Three experts will deliver a wealth of information to help you manage scleroderma and will be available for questions after their respective presentations. The agenda is as follows:



9 AM - Breathing for Healthy Living, Dr. Sundar Balasubramanian (Interactive breathing demonstration)

10 AM - Dealing with G.I. Complications in Scleroderma, Dr. Ali Nawras, University of Toledo Medical Center

11 AM - Scleroderma Research Update - Dr. Bashar Kahaleh, University of Toledo Medical Center

This is a free education event, but registration is necessary. Simply email your name, phone number and address to Tina Fellows, Executive Director at tfellows@scleroderma.org by 5 PM on Friday, March 19, 2021. You will be sent a link to the Zoom conference. You may join by phone or by video conference; it is not required that you join with video. Tina will be on the conference by 8:30 to help anyone link up to the Zoom and you can also call for help during that time toll-free at 866-849-9030. (Pictured above are Dr. Kahaleh and Tina Fellows as he was accepting his Ohio Chapter Special Service Award at the 2018 Ohio Ugly Dress Gala.)

Check list!

When I'm prescribed a new medication what should I ask?

- Why is the medication being prescribed?
- Do I really need the medication?
- What will it do?
- How and when do I take the medication and for how long?
- What foods, medications, or activities should I avoid while taking the medication?
- What are the possible side effects?
- What should I do if I have side effects?
- Am I able to use an alternative or generic medication that is less expensive?

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: _____



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

“
Courage doesn't always roar. Sometimes courage is the quiet voice at the end of the day saying, 'I will try again tomorrow.'
”
- Mary Anne Radmacher



Tina Fellows
Executive Director

info@sfohio.org
www.sfohio.org



facebook.com/curesclerodermaohio



twitter.com/ohioscleroderma



youtube.com/sclerodermaohio

February 23 - First-Ever Virtual Pediatric Rare Disease Fun Night!

The Ohio Chapter will host a virtual event to chase the winter pandemic blahs away! This will take place directly after the Nationwide Children's Hospital Rare Disease Day streaming webinar on Tuesday, February 23rd, which features 3 presentations. The Nationwide Children's webinar will take place at 3 - 5:30 PM and is a free event, however registration is required. To RSVP, call 614-722-4844. The Rare Disease Fun Night will begin at 5:30 and end around 7:30 PM. We'll start off with some fun icebreakers and trivia. Trivia teams can be formed with kids and parents, if needed and we'll use the honor system (which means no looking up answers on the internet!). After that, Dr. Sundar Balasubramanian is excited to lead a session teaching the young patients some simple helpful yoga poses added in with various yogic breathing exercises. Kids who wish to try more advanced poses will have a chance to do that during the last 10 minutes of his session. As part of security protocols, registration is required even though this is a free event. When an individual registers, they'll then receive the link to the event via e-mail. We hope the kiddos will add to the fun by wearing a funny hat or eye mask (think superhero or princess or whatever type they want!). Get creative! Attendees will receive a small gift afterwards as a thank-you for taking part in this new event! Download a free Eric Carle coloring page of a caterpillar or butterfly at



<https://coloringhome.com/free-eric-carle-coloring-pages>. We want the children to share their masterpieces with us at the end of the party! This event is open to any pediatric rare disease patients in the country. To participate in the Rare Disease Fun Night, just email tfellows@scleroderma.org.