

Spring 2021

2021
UPCOMING EVENTS

**"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**
August 7, 2021

**"Stepping Out to Cure
Scleroderma" - Toledo Virtual
Walk**
September 18, 2021

**"Stepping Out to Cure
Scleroderma" - Cincinnati Virtual
Walk**
October 2, 2021

**"Stepping Out to Cure
Scleroderma" - Cleveland's
Virtual Walk for Research!**
October 9, 2021

**Ohio Scleroderma Virtual
Conference**
October 16, 2021

Updates and registration info on
www.sfohio.org.

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



SclerOH! News

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

Ohio Chapter is Raising Awareness This June

TV host, musician and actress Queen Latifah revealed to PEOPLE in 2014 that her late mother, Rita Owens, suffered from scleroderma. Still, too many people in the United States know nothing about this rare, mysterious and frequently disabling condition.

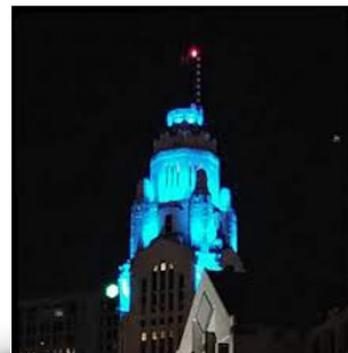
For many years, the Scleroderma Foundation and other global scleroderma organizations have recognized June as Scleroderma Awareness Month and more specifically, June 29 as World Scleroderma Awareness Day. The date of June 29 commemorates the date when gifted artist and scleroderma sufferer, Paul Klee, died.

This year, the Ohio Chapter is again taking a multi-pronged approach to increasing awareness during June, but in an even more expanded way. One of the activities the Ohio Chapter is using to increase awareness is asking local police departments, medical offices, car dealerships and other organizations to wear teal awareness ribbons throughout June. In addition, board members and their friends and loved ones will display "Honk for Scleroderma Awareness" yard signs during the month. The LeVeque Tower in Columbus, Ohio will be lit up in teal for the last full week of June (21st - 25th). There will also be a large social media presence with videos by patients and caregivers, Facebook live discussions, and posts about how people can help spread awareness. Two virtual fundraising walks, one in Boardman, Ohio and one in Columbus, Ohio will be held during June. Many press releases will be sent to radio and T.V. stations in the hopes that they will pick up the story about raising awareness in June so keep an eye and ear out for them!

Historically, the Scleroderma Foundation and its chapters has marked awareness month not only with special events and increased social media activity but also by obtaining national, state and local proclamations, and this year is no exception! We've received 9 proclamations from various Ohio cities so far thanks to a special initiative undertaken by Demeshia Montgomery, the board and the advocacy committee.

"I feel it is extremely important that the public is aware of what scleroderma is, how it affects the body and all of research being conducted to find a cure. Also, there are support groups available in Ohio to help patients and their families. I'm a scleroderma survivor and I ask that everyone step up and out to help us find a cure", says Demeshia Montgomery, an Ohio patient. She did much of the legwork to get Bill 133 introduced in the State Senate in 2015. Unsatisfied with just obtaining the annual proclamations, Demi endeavored to get a permanent bill passed in Ohio, making it the first state to pass a bill declaring June as Scleroderma Awareness Month. She worked with former State Senator Bill Beagle to accomplish this goal. This legislation was passed and signed into law by Governor Kasich in 2016. Due to this accomplishment and her work on many other advocacy projects, she won the National Advocate of the Year award in 2020.

There are many ways to spread awareness in June and all throughout the year. If you'd like to find out how or become involved with our efforts, contact Tina Fellows toll-free at 866-849-9030.



Scleroderma Foundation Ohio Chapter Newsletter

2021 Walks During June Scleroderma Awareness Month:

Stepping Out to Cure Scleroderma - Boardman Virtual 4k Fun Walk and the Columbus Virtual Walk



We've decided once again this year, in the interest of safety, to make "virtual" a reality by holding our 2021

Stepping Out to Cure Scleroderma walks in a physically distant way! Individuals who have scleroderma need us more than ever to fulfill our promise to provide support, education and research. We can't miss a step in fundraising this year!

Ohio, you can virtually do anything! Help us make this a HUGE success. Help us reach our goals for both of these walks by **June 29!** When you post pics, tag the Ohio Chapter by using @curesclerodermaohio in your Facebook post! Watch and follow us on facebook.com/curesclerodermaohio for our LIVE video for the **Boardman Walk on June 5 at 11 AM** and the LIVE video for the **Columbus Walk on June 29 at 7 PM!** Check out some amazing auction items on www.32auctions.com/2021boardmanwalk! Info & registration for the Boardman walk is at www.boardmanswalk.org. Info and registration for the Columbus walk is at www.scleroderma.org/columbuswalk

Collect donations and walk anytime, anywhere before June 29, 2021!

It's Time to Advocate!

Unlike the last several years, this year we chose not to introduce a new bill about fibrotic research into congress. The foundation instead wanted to focus efforts on an extremely important project. Over the last several months, the Ohio Chapter has played an integral part trying to ensure that Congress will continue support of the Scleroderma Peer-Reviewed Medical Research Program at the Department of Defense for fiscal year 2022.



Currently, there is a \$5 million Scleroderma Peer-Reviewed Medical Research Program at the Department of Defense. There is a strong connection between environmental exposures and the onset of autoimmune diseases, which leaves military personnel at risk for developing conditions like scleroderma. Further, scleroderma impacts military personnel because the scarring associated with the disease process has broad applications to combat injuries. Meeting with as many of the Senators who are members of the Appropriations Committee for Defense has been top priority, in addition to meeting with Ohio Senate Aides. If you'd like to help, call Senator Sherrod Brown at 1-888-896-OHIO and Senator Rob Portman at 1-800-205-OHIO and state that "We ask that Congress continue to support Scleroderma Peer-Reviewed Medical Research Program at the Department of Defense for 2022."

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!



Upcoming Meetings in June and July:

Toledo - June 17 at 7 PM
Columbus - June 20 at 2 PM
Youngstown - July 12 at 7:30 PM
Dayton - July 12 at 10 AM.

Please go to www.sfohio.org for all information and Zoom links to these meetings.

Scleroderma Foundation Ohio Chapter Newsletter

Symptoms of Sjögren's Syndrome by Lucille Miller



Sjögren's syndrome is a systemic disease, meaning that it affects all parts of the body. Many people who are affected by scleroderma, also tend to suffer from Sjögren's syndrome.

The organs primarily affected by the syndrome are the lacrimal glands which are your tear glands. And the salivary glands too! Consequently, dry mouth and dry eyes are the most common symptoms of the disease.

The dryness in the eyes may cause grittiness, stinging, burning, redness, and sensitivity to bright lights. Lack of saliva can cause extreme dryness in the mouth and may result in the patient not being able to taste foods, as well as experiencing difficulties in swallowing and speaking.

Other symptoms include swelling, stiffness, or pain in the joints and muscles, swollen salivary glands, skin rashes, dry skin and nose, persistent dry cough, and fatigue.

Be sure to talk to your doctor about this syndrome and see if it applies to you and your body!

We Can All Use a Little Help from Our Friends!

The Scleroderma Foundation Ohio Chapter is so grateful for the efforts of groups, clubs, and businesses who organize and conduct independent fundraising events. This year, four groups are doing just that, and we're so happy about it that we're sharing these events with you. If you want to donate or participate, please contact them directly.



July 24, 2021 - Poker Run at Summit Lounge in memory of Johnny H. Thomas, Jr. - All day event with many outdoor activities! - contact Vince Touart at 234-806-4144 to sign up.

August 14, 2021 - Dr. Susan K. Leone Memorial Golf Scramble - contact Ron Leone at 330-793-3561 to sign up.

Date TBD - Dave Ludolph Memorial Golf Tournament - more info coming soon

Date TBD - Bowl for Scleroderma - contact Kelley Hill to participate at 910-261-4264.

Would you be interested in a new free call-in (not Zoom) Ohio Virtual Support Group? If so, please take a 2-minute survey to let us know what days and times you'd be able to meet.

Go to: <https://www.surveymonkey.com/r/3LN5H8W> .

It's quick and easy!

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

“
*You're braver than you
believe, and stronger
than you seem, and
smarter than you think.*
”

- A.A. Mine



Tina Fellows
Executive Director

info@sfohio.org
www.sfohio.org



facebook.com/curesclerodermaohio



twitter.com/ohioscleroderma



youtube.com/sclerodermaohio

Here's a New Type of Support!



Have you heard of the BIPOC group? If not, you might find this helpful. Everyone is welcome to this support group, but it was founded to address the of Black, Indigenous and People Of Color. The next meeting will be held by ZOOM on July 11th at 4:00 PM EST! Go to www.scleroderma.org to register.

Have you had a skin biopsy? By Lucille Miller

There are various types of skin biopsies, which remove different amounts of skin. Here is some information about different skin biopsies:

- Shave biopsies remove only the top layer of the affected skin. Although bleeding may occur, the wound does not need much care.
- Incision biopsies require the affected area to be cut out, causing a larger wound. Stitches or other methods are used to close the wound, and the patient usually needs another doctor visit to make sure that the wound is healing properly and likely remove the stitches.
- Punch biopsies remove a circle of skin tissue, down to the first layer of fat beneath the skin. Though deeper than a shave biopsy, it is small and precise, and generally requires little care.

