COVID-19 UPDATE

Out of an abundance of caution related to the coronavirus, the Ohio Chapter decided to cancel all face-to-face meetings and education days for the second half of March and all of April.

This decision was made after thorough review of information from the Centers for Disease Control & Prevention and our national office’s guidelines. In mid-April, we will make decisions about meetings and events scheduled for May and beyond. Please watch our website for further updates at www.sfohio.org.

We encourage patients and caregivers to stay in touch with us via the virtual support group free phone-in meetings on the 2nd Wednesdays of each month at 7 PM.

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 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).

The Ohio April 20 Boehringer Ingelheim patient education event has been postponed. Due to the COVID-19 pandemic, the “More than Scleroderma” program that was scheduled on April 20, 2020 will be rescheduled. A new date will be advertised as soon as details become available.

Scleroderma Foundation Ohio Chapter Support Groups

Due to the COVID-19 pandemic, our physical support groups are not meeting face-to-face right now. Please utilize our virtual option: Virtual Support Group: FREE PHONE CALL! Meets 2nd Wednesday monthly at 7-8 PM by phone. Please check our website for the call-in number at www.sfohio.org soon. Beginning in May, we will have a new phone number.

Watch our website, sfohio.org, for details on when we plan to begin meetings in person again.

Also, consider joining us for “Sunday Sitdowns” on the last Sunday of each month at 1 PM 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, who is pictured above.
From the Executive Director’s desk...

Hello Members!

It was a busy quarter since our last publication! I thought I would write about a few highlights from the winter. At the end of 2019, I started a new appreciation program for our volunteers. Over the last several months, I’ve been posting a blurb and picture about each board member, fundraising event leader and support group leader and a few very special volunteers who go above and beyond on our Facebook page, each one received a gift and handwritten note, and all board members, event leaders and support group leaders were invited to regional appreciation parties (4 total parties around the state including either brunch or dinner with the others in their area). Below is a picture from our Northeast Ohio Regional Volunteer Appreciation dinner, which was a great time attended by 7 of our Ohio leaders. Our volunteers are amazing, and this is the least I could do to show my appreciation! We couldn’t carry out our mission without them!

Pictured L to R are Tom Wilson, Cheryl Wilson, Lucille Miller, Anne Davis, Tina Fellows, Lois Aubrecht and Frank Aubrecht.

It was wonderful to be an exhibitor at the Nationwide Children’s Rare Disease event again this year! On February 25th, the Ohio Chapter participated by having a booth at the conference and I gave out literature as well as teddy bears to the children. It was so nice to be able to meet some of the patients and doctors who care for them at Nationwide Children’s. They had a wonderful presentation about the genetics research and other studies they are performing in an effort to help rare disease patients. It was so inspiring to hear about what fighters these children are! It gave me increased motivation to hold a juvenile conference this fall, which will be held in conjunction with our regular state patient education conference on October 24-25, 2020 at the Holiday Inn Columbus Downtown Capitol Square.

Wishing all the best to you,
Tina Fellows

Ohio Chapter Board Members:

Officers:
President - Lucille Miller
Vice President - Open
Secretary - Lois Aubrecht
Treasurer - Charlene Kiehl

Members at Large:
Mariann Boyanowski
Shanelle Boyd
Josette Frye
Debbie Haussler
Patti Jordan
Amanda Ludolph
Demeshia Montgomery
Alice Nagy
Betsy Walker

Medical Consultants:
Trisha Gosselin
Dr. Soumya Chatterjee

Rosita Aguirre Scholarship

Rosita (little Rose) Aguirre was born in Armenia, Columbia. She came to the U.S. as a child, moved to Columbus, earned her Degree in Medical Technology, married Dr. Augusto and had 4 children. Rosita suffered from scleroderma for years before she or her husband, who was a doctor, could find out what she had. Once she was diagnosed, they reached out to the Scleroderma Foundation to say they wanted to help any way they could. Shortly after that a notice was distributed to patients in Ohio regarding an organizational meeting to start a chapter in Ohio. She stepped right up, became one of our founding members and continued serving on the Board until her death in 2008. Rosita was fortunate in her lifetime that she was able to attend national conferences; however, she knew many could not afford to go. It was her and her family’s wish that at her funeral, in lieu of flowers, monetary
New Board Members and Officers!

Betsy Walker is a new and valued board member! She is from the Cleveland area and has a close family connection to scleroderma. She has been wanting to get more involved and we couldn’t be happier! She has been volunteering with the Cleveland walk since year one!

Debbie Haussler is also a new board member! Her husband is fighting scleroderma and she felt that she wanted to join our board and help raise awareness. She is very excited about joining our public awareness committee recently, and we are so thankful to have her be a part of our board as well!

We also have some new officer positions that have been filled in the past couple of weeks. New President - Lucille Miller has been on the board for about 3.75 years. She wasted no time before jumping into many roles, including helping with the Cleveland walk, participating on the State Conference and Gala Committees, serving as assistant secretary, chairing the Public Awareness Committee and more! We are looking forward to her service in this new role. Lois is pictured above with her daughter, Trisha Gosselin.

From Page 2

donations go to the Ohio Chapter. Her family planted the seed and the Ohio Chapter helped it grow to what is now known as “The Rosita Aguirre Scholarship”. This scholarship is available to patients who want to attend a scleroderma conference to gain a better knowledge of the disease. But most of all, to know that they are not alone. The Scleroderma Foundation Ohio Chapter Patient Education Conference will be held in Columbus, Ohio on October 24-25, 2020. The 8 scholarships we are offering cover transportation expenses from anywhere within Ohio for you and a guest, hotel expenses for you and your caregiver/guest (one room), and registration fees for the conference and gala. (Meals are included at the conference and gala.) Mileage information necessary for mileage reimbursement. Please note that no child-care is provided at the conference. Cost per child over 6 years of age for the weekend (if attending all activities including gala) is $25. The Ohio Board of Directors has appointed a selection committee. Please submit a paragraph telling us a little bit about yourself and explaining why you would like to attend the conference. Please also include your name, phone number, address, e-mail address, names (and ages, if children) of those attending with you. All information submitted will be kept confidential.

Applications must be received by September 1, 2020 at 5 PM. Please send application to laubrech@ scleroderma.org (preferable) or Scleroderma Foundation, Ohio Chapter Scholarship Committee, P.O. Box 107, Pataskala, OH 43062.

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.sf ohio.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: ___________________________
It doesn’t matter where you live - YOU can participate!

Our Boardman Walk is going virtual!

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 June 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!

The Boardman Walk will still be held on June 6 as a Virtual Walk. Watch our Facebook page for a live video that day from Lucille Miller, our new president and Leni Schulz, one of the leaders of the Boardman walk. We will also hopefully have co-leader Mariann Boyanowski joining us virtually on Facebook LIVE! 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 or upload them to our Facebook page www.facebook.com/curesclerodermaohio! Pictured above is the Pat Daniels Team at the Boardman Walk.

The Cincinnati, Columbus and Toledo walks will also be held this year, but they’ll be held as one virtual event and will be called the “Stepping Out to Cure Scleroderma Buckeye Virtual Walk”! It will be held on July 25.

Please watch our Facebook page, website, upcoming newsletters or emails which will communicate the details and provide registration links to our virtual walks in the next few weeks!

New Prize offered for Team Captain Raffle

For all walks this year (physical and virtual!) the team captains will be entered into a prize drawing for an Ohio Conference Deluxe Package! Package includes: attendance for you and a guest to the Ohio Patient Education Conference, a 2-night stay at the conference hotel in Columbus, 2 tickets to the gala on Saturday night, all meal expenses Saturday and Sunday which are provided during the conference and mileage reimbursement for travel to the conference within Ohio. 1 entry for each $100 your team raises!