



2015 Events

May 16: Scleroderma Awareness Fest (family fun), Orrville. (See Page 4)

June 6: Stepping Out to Cure Scleroderma Walk, Boardman Community Park

June 20: Stepping Out to Cure Scleroderma Walk, Toledo at UTMC.

July 17-19: SF's 17th Annual National Patient Education Conference, Nashville, TN

Aug. 1: Stepping Out to Cure Scleroderma Walk & Car Show, Greater Dayton at Fairborn Community Park

Fall, 2015: Bowl for Scleroderma, Beaver Vu Bowl, Beavercreek

2015 Educational Days

Dayton – Spring

Toledo – Spring

Columbus – Summer

Cleveland with

Cleveland Clinic – Fall

Marietta – Summer

(if sufficient interest)

Visit www.sfohio.org

for more event

information & updates.

Go to page 3 for support group details.

Scleroderma Research News and Updates

Thanks to recent advances in research and treatment, scleroderma patients as a group can now expect to live longer and more productive lives—with increased hope for the future. However, a cure for scleroderma, remains an elusive goal. Research costs continue to climb. Modern laboratory staff, equipment, and supplies are expensive. Laboratories and clinical research programs must look outside their own facilities for financial support.

The Scleroderma Foundation is a leading nonprofit supporter of scleroderma research – historically budgeting an average of \$1 million annually to find the cause and cure of scleroderma.

HERE'S EXCITING NEWS!

For 2015, the Foundation recently announced it has earmarked more than \$2 million to fund research projects for the first time in its history. (See the Spring edition of the "Voice" pg. 19 for the many research projects that are being

funded by SF.)

The Foundation's Research Grant Funding Program has earned a unique place in the field of scleroderma research. It is respected by medical researchers and by government health agencies such as National Institutes of Health (NIH) and National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). The program is guided by the Foundation's Peer Research Review Committee. This committee, composed of scleroderma medical experts from around the world, helps determine which proposals will be funded each year by reading, critiquing and ranking all applications.

The Scleroderma Foundation wants to foster development of innovative, high-quality research by new and established investigators in fields related to systemic sclerosis (SSc, scleroderma).

NIAMS provides funding for the majority of scleroderma research. Although NIH grants to scleroderma researchers have increased in recent years, scleroderma funding is

still a relatively low priority.

The Scleroderma Foundation has a critically important role as catalyst - to fund and stimulate new research and new ideas. The Foundation is enlisting the support of legislators and other decision makers to establish a higher profile for scleroderma and the needs of patients.

The key to all our efforts - to ensure that productive research moves forward - is the continued generosity of our individual and corporate donors and the efforts of our legislative advocates.

The Ohio Chapter is proud to have given over \$40,000 to the Foundations research efforts in 2014.

Page 2: New Ohio Chapter Coordinator, Tina Fellows

Page 2: 2015 Scholarships For National Conference



Tina Fellows
SFOH Coordinator

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Like us  and
Share a post from our
Ohio Chapter Wall.

Ask your family &
friends to do the
same.

You will learn more
about Scleroderma
and the Ohio Chapter.

And...you'll be
helping to build
awareness!

New SFOH Coordinator

Please join us in welcoming Tina Fellows, our new Chapter Coordinator. Some of her accomplishments include being the Family Support Coordinator, Program Coordinator and Executive Assistant for the Ohio State University Medical Center. While with OSU Medical Center she coordinated a fund-raising campaign for OSU Medical Center. She also investigated real-time complaints about surgery delays, problem-solved in tense situations, and took action or referred issues to appropriate individuals for resolution. She managed office communications to staff, faculty and students. Her communication experience also included preparing press releases regarding research for the OSU marketing department. Tina says "I am excited to be affiliated with an organization that is dedicated to improving lives of patients and families through education, research and support. Helping people, especially those who are ill or impoverished, is a passion of mine. In my personal time, I volunteer for several children's organizations and am also part of a local action group seeking to improve health through better nutrition. This opportunity to work with you and this foundation is truly appreciated!"

Goodbye to Chapter Coordinator, Laurie Holden

We would like to thank Laurie Holden, our Chapter Coordinator of the past four years, who is leaving us. She has been an integral part of the major growth of our Chapter over the last few years. She has helped to grow our newsletter, including an electronic version. She also initiated and maintained the Virtual Support Group and she has provided excellent assistance to our Support Group Leaders (SGLs) and event planners. National Chapter Relations Manager, Anne Sweeney, remarked that she appreciated Laurie's professionalism and responsiveness.

In a quote from her email to SGLs, Laurie added, "I have met so many amazing people since I started in Dec. 2010. Thank you so much for your efforts on behalf of the Ohio Scleroderma community. You really do make a difference. Your continued support of our mission is truly appreciated."

We at the Ohio Chapter will miss her! We wish her well as she pursues her new professional goals.

2015 Rosita Aguirre Scholarship

The Scleroderma Foundation National Conference will be July 17-19 in Nashville, TN. SFOH offers conference scholarships to patients who otherwise cannot afford to attend.

This includes transportation, lodging, and registration fees (up to \$1500). Some caregiver expenses may be eligible. Receipts are required. To be eligible for the scholarship you cannot have received it the past 5 years. You must be a current SFOH member. To apply please explain your financial and medical need and your **involvement with the Foundation**. Also include your **name, phone number, address, e-mail address**. All submissions will be kept confidential.

Applications must be received by May 1, 2015. Scholarships will be awarded May 15, 2015. Email application to irodenbaugh@zoomintern.net (**preferable**) or mail to: SFOH Scholarship Committee, c/o Jolene Rodenbaugh, 604 Chestnut Lane, Boardman, OH 44512.

SPAGHETTI DINNER Thursday, March 26, 2015, 4-7 PM at Mason Temple, 233 Wick Avenue, Youngstown, OH 44503. Hosted and supported by the Mason Temple to benefit the Scleroderma Foundation via the Youngstown Support Group's Boardman Walk June 6th. Adults \$10; Kids \$5.

Find an SF Ohio Support Group

Virtual Support Group: Meets monthly from 7 - 8 pm by phone. Next meeting Wednesday March 18th. Speaker Dr. Nezam Altork from the University of Toledo Scleroderma Research Center. Call 866-740-1260, enter code 7170191#. Email: info@sfohio.org.

Greater Cincinnati Support Group: Meets quarterly Sat., 1-3 pm. Mar 28, Jun 13, Sept 12 and Dec 12. March 28 meeting will be at Buca Di Beppo 2635 Edmondson Road Rookwood Commons 45209. Topic "What the doctor should have told me about Scleroderma on my 1st Visit" Phil Clements on DVD. For further info contact Debbie Metz (513) 232-5210; cincinnati-sg@sfohio.org.

Central Ohio Support Group: Meets quarterly Apr 19, Jun 14, Aug 16, and Oct 18, 6:00-8:30 pm. Meeting will begin with open discussion and light dinner. Location: Villas at Glenealy Clubhouse, 6315 Donegan Way, Dublin 43016. Support Group Leader: Ann Barnhart, (614) 717- 6790, columbus-sg@sfohio.org.

Dayton Area Support Group: Meets on monthly Saturday, April-October (Apr 11, May 2, Jun 6, Jul 18, Sept 12 & Oct 3) 10 am –12 pm at Grace Community Church, 5001 Fishburg Rd. in Huber Heights. April topic: Scleroderma 101. Leader: Penny Davis (937) 554-1425, dayton-sg@sfohio.org.

Northeast Ohio/Greater Cleveland Support Group: Meets monthly last Thursday monthly 7 pm, April – October at Simon’s Restaurant, 770 Chippewa Rd., Brecksville. Support Group Leader: Mike Hollo (330) 241-0697 and Anne Davis (440) 212-2880, neohio-sg@sfohio.org.

Toledo Area Support Group: Meets on the third Thursday 7 pm at St. Luke’s Hospital, Room 2, 5901 Monclova Rd., Maumee. Support Group Leaders: Dagne Lazenby (419) 819-9605 and Anna Colnar (419) 481-4061, toledo-sg@sfohio.org.

Willoughby Support Group: Meets monthly, third Saturday 9:30 -11:30 am, May-September Willoughby Public Library, 30 Public Sq. May 16th meeting topic will be caregiving. Support Group Leader: Larry Bodak (440) 953-2918, willoughby-sg@sfohio.org.

Youngstown Area Support Group: Meets Mar-Dec. at 5:30 on the 1st Monday of the month unless it is a holiday, then it is on the second Monday (Sept), at Davidson’s Restaurant, 3636 Canfield Rd. in Youngstown. (330) 793-0033. Come for dinner. Support Group Leader: Leni Schulz (330) 654-2538, youngstown-sg@sfohio.org.

For directions and meeting topics, please check our website (www.sfohio.org).

WE APPRECIATE YOUR SUPPORT!

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 105
 Worthington, OH 43085-0105

NAME: _____ PHONE: _____

ADDRESS: _____ EMAIL: _____

CITY: _____ STATE/ZIP: _____

AMOUNT: _____

Please check appropriate box: \$25 Annual Membership Donation Both

In Honor Of: _____

In Memory Of _____

Orville Awareness Fest Night – May 16, 2015

The 2015 Scleroderma Awareness Night will be held on May 16th in Orrville, OH. The event is in honor of young Morgan Mast. It will be held from 5-8 pm at Greene Center - 875 Kidron Road. There will be a live auction, a kid's craft table, a coloring contest and a 50/50 raffle. Food can be purchased at a concession stand. Jason Alan Magic will present a comedy illusion show. He was a hit in the past and promises a bigger and better show this year. Morgan and others will speak about scleroderma, and we will show the educational video from the Foundation. A touching tradition is our balloon release. It is a visual symbol of spreading awareness about scleroderma.

We will have a "Hope for Morgan" table set up this year to sell T-shirts and ice cream as Morgan's team fundraiser. We would love to have teams for others fighting scleroderma at tables, fundraising for Ohio's Stepping Out walks. Teams may request a fundraising table by email: hope4morgan@yahoo.com. Our greatest desire for this event is to raise awareness about scleroderma and to give an evening of fun, laughter and support to those fighting this devastating disease. Please plan to come and join us.



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Tina Fellows Chapter Coordinator	