



**2015 Events**

**May 16, 2015-POSTPONED**  
Scleroderma Awareness  
Fest (family fun), Orrville

**May 21, 2015** - Toledo  
Education Day

**June 6, 2015** - Stepping Out  
to Cure Scleroderma Walk,  
Boardman Community Park

**June 20, 2015** - Stepping  
Out to Cure Scleroderma  
Walk, Toledo at UTMC

**July 17-19, 2015** - National  
Patient Education  
Conference, Nashville, TN

**Aug. 1, 2015** - Stepping Out  
to Cure Scleroderma Walk  
& Car Show, Greater  
Dayton at Fairborn  
Community Park

**September 19, 2015** - Bowl  
for Scleroderma, Beaver Vu  
Bowl, Beavercreek

**Fall 2015** - Youngstown  
Education Day

**Fall 2015** - Cleveland Clinic  
Education Day

**October 10, 2015** - Xenia  
Bike/Run

Visit [www.sfohio.org](http://www.sfohio.org)  
for **more event information  
& updates.**

**Go to page 3** for support  
group details.

**Hurry, Only a Few Days Left!**

Introducing a VERY Limited Time Opportunity to win one  
of three prizes and help the Scleroderma Foundation.  
Tell your friends and family about the

**PIGGEST RAFFLE EVER!!!!!!!!!!!!!!**

How's it Work? Easy! Adopt a \$5 PIG in the **PIGGEST  
Raffle Ever** for a chance to win on Flying Pig Marathon  
Weekend. If your adopted PIG is the first selected when  
thousands of PIGS are dropped in Downtown Cincinnati,  
**YOU win a 2-year lease on a 2015 Toyota Prius! Plus,  
every purchase helps a charity of your  
choice (Scleroderma Foundation - Ohio)!**

Raffle Details: On Flying Pig Marathon Weekend an Art's  
Rental lift will drop all of the numbered PIGS onto a  
target in Downtown Cincinnati. Come and watch as the  
pigs are dropped from the sky to see if your PIG hits the  
target and is the winner! You do not need to be present  
to win but everyone is welcome to join the Pig Drop.

Only One Chance to Win? Of Course Not... We will select  
3 PIGS as prize winners during the Pig Drop (you need  
not be present to win)! Raffle ends April 29.

- 1st Place: 2-year lease on a 2015 Toyota Prius!**
- 2nd Place: \$10,000 Cash (\$5,000 to winning ticket  
holder and \$5,000 to the charity who sold the ticket)**
- 3rd Place: Cincinnati Experience (valued at \$1,500)**

How Do I Get Started? Simple. All you have to do to  
purchase your PIGS is visit [www.piggestraffle.com](http://www.piggestraffle.com), and  
the best part is that you can choose the charity that you  
want to benefit from your purchase!



**4TH ANNUAL LILLIAN  
SWARTZ STEPPING  
OUT TO CURE  
SCLERODERMA 5K  
RUN/WALK**

Please join us June 20, 2015  
to connect with old friends,  
meet some new ones, and  
walk in honor or memory of  
loved ones affected by  
scleroderma. The fun takes  
place at UTMC 3000  
Arlington Ave. Registration  
is 8 a.m. - 9:00 a.m. and  
event starts at 9:00 a.m.

There will be a 5k  
Run/Walk, 50/50 Raffle,  
Chinese Auction, DJ,  
Refreshments, and Prizes  
for the Runners. Create  
your own fundraising page  
and encourage your family,  
friends and coworkers to  
support your goal.



**Tina Fellows**  
SFOH

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

Follow us on our NEW  
Twitter account!  
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[www.twitter.com/ohioscleroderma](http://www.twitter.com/ohioscleroderma)



Symbols for Twitter

**June is Scleroderma AWARENESS MONTH!**  
Please share our key messages on your Facebook and Twitter Pages.

## Why Are Support Groups So Great?

Why are support groups so great? I will answer that question. But first, I want to reveal a little about what they are, where they meet and how they work. A Scleroderma Support & Education Group is a wonderful resource for patients, families and friends. They are free and usually meet monthly or quarterly. Some groups meet at hospitals, some meet at churches, and others meet at restaurants, libraries, or condo clubhouses. Our groups serve many functions. These functions include providing information, teaching coping skills, and presenting a place for people to share experiences, challenges and victories. Sometimes there are special speakers, such as doctors, who talk about topics beneficial to the group. The group leaders are usually patients themselves or family members. Attendees can participate in discussion as little or as much as they like and discussions are confidential.

So, why should you attend a support group; what is so great about them? Research has shown that attending a support group can improve quality of life. There is a growing body of research about how support groups help those with all kinds of health problems and

disorders. For example, according to the American Cancer Society (cancer.org), *“Research has further shown that giving cancer patients information in a support group setting can help reduce tension, anxiety, and tiredness (fatigue), and may lower the risk of depression. A statistical combination of results ... from many previous randomized clinical trials of group psychotherapy and psychoeducation that had been completed as of 2010 concluded that although results of individual studies varied somewhat, in general these programs improved the quality of life of cancer patients/survivors and reduced their distress and anxiety.”*

Another such example is revealed in the summary of a study of diabetics as noted on psychcentral.com: *“Simmons, D. (1992).*

***Diabetes Self Help Facilitated by Local Diabetes Research: The Coventry Asian Diabetes Support Group. Diabetic Medicine 9: 866-869.***

*Researchers assessed members of a self-help group for South Asian diabetics in England ... for levels of glycated haemoglobin and knowledge about diabetes. Those who attended the group twice or more during a year had a significantly greater drop in glycated haemoglobin levels and a*

*significantly greater increase in knowledge about diabetes. Although professionals helped start the group, it continues to operate independently, emphasizing education, mutual support, information sharing, and family social activities.”*

In conclusion, I am compelled to share my own personal experience about support groups. A friend encouraged me to attend a depression group when I was going through a rough divorce some years ago. It had a profound effect on me. Discovering that someone else had the same exact feelings and thoughts literally changed my life. It is such a simple concept, yet there is no way to describe or measure how making these connections helps. It has to be experienced first-hand.

I hope that this information will remove some reservations or pre-conceived notions about support groups that are keeping you from attending a Scleroderma Support & Education Group. Realize that just as you may be helped by attending, you may also be able to help someone else by sharing experiences in a group setting.

By Tina Fellows

## Find an SF Ohio Support Group

**Virtual Support Group:** Meets monthly from 7 - 8 pm by phone. Next meeting Wednesday May 13th. Speaker Michelle Rinehart, Social Security Administration. Call 866-740-1260, enter code 7170191#. Email: [info@sfohio.org](mailto:info@sfohio.org).

**Greater Cincinnati Support Group:** Meets quarterly Sat., 1-3 pm. Jun 13<sup>th</sup>, Sept 12<sup>th</sup> and Dec 12<sup>th</sup>. June 13<sup>th</sup> meeting will be at Hyde Park Library Branch at 2747 Erie Avenue, Cincinnati, OH 45208. For further info contact Debbie Metz (513) 232-5210; [cincinnati-sg@sfohio.org](mailto:cincinnati-sg@sfohio.org).

**Central Ohio Support Group:** Meets quarterly Jun 14<sup>th</sup>, Aug 16<sup>th</sup>, and Oct 18<sup>th</sup> 6:00-8:30 pm. Meeting will begin with open discussion and light dinner. Location: Villas at Glenealy Clubhouse, 6315 Donegan Way, Dublin 43016. Topic: "Prediction of Progression & Complications in Scleroderma" Dr. Laura Hummers on DVD. Support Group Leader: Ann Barnhart, (614) 717-6790, [columbus-sg@sfohio.org](mailto:columbus-sg@sfohio.org).

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

**Northeast Ohio/Greater Cleveland Support Group:** Meets the last Thursday of the month at 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](mailto: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](mailto: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 16<sup>th</sup> meeting topic will be caregiving. Support Group Leader: Larry Bodak (440) 953-2918, [willoughby-sg@sfohio.org](mailto:willoughby-sg@sfohio.org).

**Youngstown Area Support Group:** Meets Mar-Dec. at 5:30 on the 1<sup>st</sup> 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](mailto:youngstown-sg@sfohio.org).

For directions and meeting topics, please check our website ([www.sfohio.org](http://www.sfohio.org)).

WE APPRECIATE YOUR SUPPORT



## Capitol Hill Days, April 27-29, 2015 - POSTPONED

The start of 2015 was also the start of a new Congress (114th) in Washington D.C., as well as the re-writing and re-introduction of the "Scleroderma Research and Awareness Act". Of critical importance to the scleroderma community in 2015 is not only bringing our patients' stories to the many new legislators (especially those in key congressional committees), but building on the momentum of our recent success in getting "scleroderma" relisted as an eligible condition for study through the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) in FY 15. Our plan is to reach out to Senators currently working on the FY 16 DOD to ensure that "scleroderma" remains listed.

We thank everyone who submitted a letter of interest to participate in the upcoming Scleroderma Advocacy Day on Capitol Hill in Washington, D.C. on April 28. **In spite of our best efforts to get our bill introduced into this Congress, it has not happened yet and we realize it will not happen before Congress adjourns for recess;** therefore, we are postponing Advocacy Day until a later date this year. If you have already sent in a letter of interest to participate in Advocacy Day, your application will be kept on file for consideration once the new date for Advocacy Day is finalized.

Please stay tuned for updates. Meanwhile, we thank you for your interest and your continued support to make the scleroderma community's voice heard in our nation's halls of Congress.

### Boardman Fun Walk, Have You Joined Us Yet?

We are 12 years in the making and very proud to say that, with YOUR help, our walk has raised over \$350,000 for the Scleroderma Foundation, Ohio Chapter!

Patients, caregivers and friends look forward to this REUNION. It is a time to honor their loved ones and celebrate life.

At the event, we'll have a large Chinese auction with over 75 items, 50/50 raffle, music, dancing and food! There will also be face-painting, massages and a major raffle for 2 airline tickets.

Please join us Saturday, June 6<sup>th</sup> in Boardman Park! Registration begins at 8:30 a.m. and the walk starts at 9:30 a.m. For more information, please call Leni at 330-654-2538 or go online and

look for our walk information at [www.scleroderma.org/steppingoutboardman](http://www.scleroderma.org/steppingoutboardman).

We look forward to sharing the day with you! The Youngstown Support Group and all the Walk volunteers work very hard to make this annual event a success.

If you cannot join us for the walk, but would like to donate your talents for the auction, or volunteer your time before or after the walk, please do not hesitate to call Mariann at 330-502-4491.

#### SEE YOU THERE - RAIN OR SHINE!



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