



Upcoming Education Events

Education Days are FREE to Patients and their guests

July 25, 2015 –
Columbus Patient Education Day,
Holiday Inn, 7007 N. High St.,
Worthington 43085
9 am-12 pm

Fall 2015 –
Youngstown Patient Education Day – details to come!

October 3, 2015 –
Cleveland Clinic Patient Education Day, Main Campus, 9500 Euclid Ave., Cleveland, 44195

October 3, 2015 –
Dayton Patient Education Day, 10 am-12 pm

October 20, 2015 –
Akron Education Day & New Support Grp Kick-Off, 7-9 pm

Visit sfohio.org or call 866-849-9030 for event info & updates.

Is Research Close to Finding a Cure?

We can't say for sure when a cure will be found, but research is providing better ways to treat symptoms and prevent organ damage for people with scleroderma. In the past two decades, researchers have found new clues for understanding the disease. By studying the immune system, genetics, cell biology, and molecular biology, scientists have improved treatment approaches over the years. According to the National Institute of Health's "Handout on Health – Scleroderma", (NIAMS.NIH.GOV, February 2015), advances in the understanding or treatment of this disease include the following:

"Building on research that identified a gene associated with scleroderma in Oklahoma Choctaw Native Americans, scientists are using new technology to look for other genes associated with the disease's development and severity.

The drug cyclophosphamide has been found effective in treating lung fibrosis. One study suggested that treating lung problems early with this immunosuppressive drug may help prevent further damage and increase chances of survival. Clinical trials assessing the effectiveness of other medications for lung fibrosis are ongoing.

ACE inhibitors are used increasingly for scleroderma-related kidney problems. ACE inhibitors have greatly reduced the risk of kidney failure in people with scleroderma.

Several drugs are now available to treat pulmonary hypertension. Previously, pulmonary hypertension was associated with a poor outcome, but medications have increased the quality of life and life expectancy for people with this dangerous form of lung damage.

Other studies are examining the following:

The immune system: Researchers are looking at the complex immune system trying to determine why the body creates antibodies against its own tissues. Identifying where and when the antibodies are created and how they function could lead researchers to find targets for new therapies. Researchers are already trying new therapies, including those that suppress specific parts of the immune system.

Genes: Studies continue to find the genes that predispose a person to getting scleroderma. Those genes may be targets for future therapies. Researchers are also trying to find genes (and other indicators) that could tell doctors who will develop what type of scleroderma. This could someday help doctors identify who might benefit from specific therapies.

Drug therapies: A drug that has been used to treat some cancers has been found to be effective in preventing the development of fibrosis in animal models, and investigators are trying to find out why. Other researchers are testing drugs and comparing them to existing therapies to see if they result in sustained improvement with less toxicity.

Animal models: Experiments using mice have proved valuable in past research on scleroderma. Further research using existing strains of mice continues.

Upcoming Fundraising Events

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

Aug. 15, 2015 –
Dr. Susan K. Leone Memorial Golf Outing, Boardman, OH

September 26, 2015 –
Bowl for Scleroderma, Beaver Vu Bowl, Beavercreek

October 10, 2015 –
Xenia Bike/Run

Visit sfohio.org to register, get more event information & updates.



SF Ohio Chapter Newsletter



Tina Fellows
Chapter Coordinator

- [facebook.com/
curesclerodermaohio](http://facebook.com/curesclerodermaohio)
- [twitter.com/
ohioscleroderma](http://twitter.com/ohioscleroderma)
- [youtube.com/
scleroderma ohio](http://youtube.com/scleroderma ohio)

Ohio Chapter Board Members

Debbie Metz – President
Jerry Metz – Secretary
Garry Lazenby – Vice President
Phil Meyer – Treasurer

Members at Large:
Dagne Lazenby
Jolene Rodenbaugh
Mariann Boyanowski

Is Research Close to Finding a Cure cont.

The fibrosis process: Researchers are looking into the many factors that lead to fibrosis. Some are pursuing the genetics of fibrosis. One study is looking at a small molecule, halofuginone, which seems to protect against fibrosis. Another study looks at a small molecule that apparently contributes to fibrosis. Such discoveries could be future targets for therapies.

The identification of several early immune system targets in scleroderma:

Building on this research, scientists are continuing to look for ways to treat scleroderma earlier, before it has a chance to cause irreparable damage.

Cytokines: Studies have shown that certain chemicals called cytokines, made from cells in the body, enhance the development of increased collagen. Researchers are trying to determine how cytokines contribute to the disease process."

More information on the ongoing studies being conducted is available from the following websites:

ClinicalTrials.gov

NIH.gov/health/clinicaltrials

projectreporter.nih.gov

ncbi.nlm.nih.gov/pubmed

More Answers to Come!

Although scleroderma presents challenges for both patients and their health care teams, scientists, doctors, and other health care professionals continue to find new ways to make earlier diagnoses and manage the disease better. Patient support groups also care for and educate each other to help individuals through their journey. The impact of all of this is that those with scleroderma remain active far longer than they did 20 years ago. The medical community will continue to search for more breakthroughs in scleroderma research.

New Scleroderma Clinic at OSU!

Last week, a multidisciplinary clinic opened at The Ohio State University Wexner Medical Center with pulmonary and rheumatology in a shared space. They will have a streamlined referral process to GI and vascular specialties. Drs. Ali Ajam and Brian Lamoreaux are rheumatologists who are leading the clinic along with pulmonary disorders expert, Dr. Namita Sood. For more information, go to wexnermedical.osu.edu.

Ohio Senate Bill 133 - Exciting News!

With the help of Demi Trice, Penny Davis, Debbie Metz, Jerry Metz, Ann Barnhart, Kelley Hill and many others who wrote letters or contacted their representatives, we are one step closer to having an official designation by the State Of Ohio to have June as Scleroderma Awareness Month.



On, June 24, 2015, the Ohio Senate passed legislation to designate June as Scleroderma Awareness Month. Senator Bill Beagle introduced the bill about a month ago.

Next Steps:

Bill 133 will make its way to the Ohio House of Representatives and will go through the same process there. It will be introduced and then it will have 2 hearings and then a vote. If it passes, it will go to the governor to hopefully be signed.

Please contact your Ohio house representatives to encourage them to vote for Bill 133 at www.ohiohouse.gov.

NEW GOLF FUNDRAISER COMES TO NORTHERN OHIO!

The first annual Dr. Susan K. Leone Golf Scramble will be held on August 15th at 9:00 a.m. at the Mill Creek Golf Course, One West Golf Dr., Boardman, OH 44512. The cost is \$65.00 per golfer + \$5 Skins and it includes lunch and dinner. A 50/50 raffle and Chinese auction will also be included in the festivities. A good time will be had by all so don't miss out! Sign up today at sfohio.org.



Find a Scleroderma Foundation Ohio Chapter Support Group

Virtual Support Group: Meets monthly from 7 - 8 pm by phone. Next meeting Wednesday August 12th. "Exercising with Scleroderma" – Deb Kegelmeyer, PT, DPT, MS, GCS. Call 866-740-1260, enter code 7170191#. Email: info@sfohio.org.

Greater Cincinnati Support Group: Meets quarterly Sat., 1-3 pm. Sept 12th and Dec 12th. Hyde Park Library Branch at 2747 Erie Avenue, Cincinnati, OH 45208. For further info contact Debbie Metz (513) 232-5210; cincinnati-sg@sfohio.org.

Central Ohio Support Group: Meets quarterly Aug 16th, and Oct 18th 6:00-8:30 pm. Meeting will begin with open discussion and light dinner. Topic: "Overlapping Conditions in Scleroderma" Dr. Tamiko Katsumoto (DVD from 2012 National Patent Education Conference). 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 Saturday, April-October (Sept 12th & Oct 3rd) 10 am –12 pm at Grace Community Church, 5001 Fishburg Rd. in Huber Heights. 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, 7770 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 (August 15th and September 19th) Willoughby Public Library, 30 Public Sq. 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 contact the support group leaders or info@sfohio.org.

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: _____



**MOVING? CHANGE OF NAME OR E-MAIL ADDRESS? PLEASE CALL OR
SEND US UPDATED INFO AT 866-849-9030 OR INFO@SFOHIO.ORG!**

page 4

SF Ohio Chapter Newsletter

4th Annual Dayton Step Out & Cruise-In Family Fun Run, Walk, & Car Show

Bring your family and friends on Saturday, August 1, 2015, to run, walk, or cruise-in with any year, make or model vehicle. Also enjoy a 50/50 drawing, kids activities, prize raffle, and Car Show awards to support a great cause. Food trucks will be onsite as well. At this event, Henry Williams will debut his newly restored 1991 Camaro! It showcases Scleroderma colors inside and out, and a special Scleroderma logo on the trunk. Henry's motivation for this project is his 11-year old daughter, Emily, who has Scleroderma. He wanted to spread awareness of this disease in a very unique way to help Emily and other Scleroderma patients.

**Walk Registration: 10:30am-12pm. Walk/Fun Run: 12pm.
Solid Gold Oldies featuring Brian Brenner: 12:30pm. Prize Raffle: 1:30pm. Car Show Registration: 11am-2pm. Judging: 2pm. Awards: 2:30pm. Cruise to Young's Dairy: 3pm.
Choose your walk/ run route: 3/4 mile, 1.5 mile, or 5k. A minimum \$20 donation is required to receive a T-Shirt.
Children 12 and under are free or purchase a T-Shirt for \$5.00 (Online Only).**

Event goes on Rain or Shine! Go to WWW.SFOHIO.ORG to register!



2015 National Gold Sponsor
2015 Platinum Conference Sponsor

