



SclerOH! News

SCLERODERMA FOUNDATION
OHIO CHAPTER
SUPPORT - EDUCATION - RESEARCH

2014 Events

Please join your Scleroderma Community at an event next year!

May 17: 2nd Annual Scleroderma Awareness Night, 4-8pm, Orrville

June 14: 11th Annual Walk, Boardman Pk, Boardman

June 21: 3rd Annual Walk, UTMC, Toledo

July 26-27: 16th Annual National Patient Education Conference, Anaheim, CA

Aug. 2: 3rd Annual Walk, Community Park, Fairborn

Sept.: 2nd Annual Walk, Troy

Oct. 3-5: 2014 State Conference, Embassy Suites-Columbus

October: 2nd Annual Bowl for Scleroderma, Beaver creek

“Thank you” to the Ohio Scleroderma Community

This was truly a banner year for the Ohio Chapter. We sponsored 7 events covering most of the state including our Education Day with the doctors from the Cleveland Clinic Scleroderma Clinic; we provided scholarships to 2 patients to the National Patient Education Conference in Atlanta and we made a \$40,000 voluntary contribution to the national Scleroderma Foundation’s Research

Fund. Research contributes to the quality of life of all those living with the disease and so do our support group leaders. Next are comments from a few of our leaders.

From Jan Weaver, Toledo: My favorite topic for 2013 is a speech of Dr. Kahaleh's about what I call "pure scleroderma." He talks about what it is and what you can expect and how everyone is different. It is the best explanation of this disease I have ever heard.

I have over 15 years’ experience as a support group leader and our most recent meeting provided my most memorable moment. It was a small group and we had talked everything out. (Cont’d Pg 2)



Lung Disease in Scleroderma

Diagnosing and Managing Interstitial Lung Disease in Scleroderma

By Mary Beth Scholand, M.D., Elisabeth Carr, M.D., and Tracy Frech, M.D.

Here’s an excerpt from an article in the upcoming *Voice* about how to manage interstitial lung disease in scleroderma:

Pulmonary disease is an important component of scleroderma. An estimated 80 percent of scleroderma patients have some evidence of pulmonary disease. This makes pulmonary disease second only to esophageal disease, the most commonly seen complication.

Moreover, pulmonary involvement may signify a worse prognosis for patients. The most common pulmonary manifestations of scleroderma include pulmonary hypertension (PH) and interstitial lung diseases (ILDs). The estimated mortality from pulmonary disease is 33 percent, and it is the leading cause of death among scleroderma patients.

Lung Fibrosis in Scleroderma

Like pulmonary fibrosis of

most origins, including idiopathic pulmonary fibrosis, the precise molecular events that occur in the beginning of lung fibrosis are not well understood. There is likely a complex interplay between inflammation, antibody production, oxidative stress and fibrosis occurring in the setting of blood vessel hyperreactivity. Read the rest of the article in the Winter 2013 issue of “Scleroderma Voice” magazine. For just \$25 a year, you can become a Scleroderma Foundation (Cont’d on Pg 4.)

“Thank You” - from Pg. 1

2014 Education Days

Education Days coming to Central Ohio, Cincinnati, Cleveland and Toledo in early 2014. Look for postcards in your mailbox in the New Year!



"Thank you!" Dayton Walk

expressed how they felt about themselves, the disease and what our group meant to them. I loved being the leader when the group began. I learned so much from the members. Now that I have returned as co-leader, I appreciate learning from this group. It is a very fulfilling volunteer job being the co-leader of our wonderful group.

From Ann Barnhart, Central Ohio: This year I have gotten to know 9 caregivers who are true heroes, my husband included. The dedication to their loved one with

scleroderma is overwhelming. I find myself truly blessed to be a new support group leader.

From Penny Davis, Dayton: We met many new people, renewed old acquaintances, and celebrated with our family and friends at the 2013 Greater Dayton Walk in August. Some even became new support group members. All those living with Scleroderma including myself felt honored by the support of friends and loved ones who attended. That participation along with the generosity of our sponsors fostered awareness of Scleroderma and raised

funds to support research affecting the quality of life of all those living with the disease. The Dayton Support Group sincerely appreciates your support.

December Virtual Support Group Meeting

Tuesday, Dec. 10, 7-8 p.m.
Speaker? Lori Chung, MD
Topic: "Digital Ulcers"
Dial 866-740-1260 and enter access code 7170191# to enter the meeting.

Notes from our Virtual Support Groups

Our October Virtual Support Group Meeting featured Dr. Cathy Rosenbaum, Founder & CEO of Rx Integrative Solutions, a private consulting practice in holistic medicine, who spoke on "What Your Grandmother Didn't Tell You About Dietary Supplements!" Here is some helpful information that she shared: A great reference for dietary supplements: www.mayoclinic.com. Best place to start to look for published human clinical trials about prescription medications for scleroderma: www.pubmed.com.

National Institutes of Health My Dietary Supplements site to keep track of vitamins, herbs, other products you take: <https://myds.nih.gov>.

In our November meeting we spoke about patient assistance programs with Willoughby Support Group Leader Larry Bodak who gave us these tips: www.ohiobestrx.org All Ohioans can sign up for the Ohio's Best Rx to save on their prescription medications. Use this web site to print a card, locate a pharmacy, and compare prescription drug prices. Phone: 866-923-7879.

<http://www.patientassistance.com>: Find and manage your patient assistance programs. By mail: PatientAssistance.com, Inc., 11608 Darryl Dr., Baton Rouge, LA 70815.

www.caringvoice.org: Caring Voice Coalition empowers patients who live with a life threatening chronic disease through comprehensive outreach programs and services aimed at financial, emotional and educational support. Patient Line: 888-267-1440.



"Thank you!" Troy Walk Volunteers

Virtual (phone) Support Group: 2nd Tues. each month at 7p.m. Free. Call 866-740-1260, enter code 7170191#. Interesting speakers and topics.

Find an SF Ohio Support Group

Cincinnati Support Group: Meets Sat., Dec. 14, 1-3 p.m. at Wyoming Branch Library, 500 Springfield Pike. Dr. Tamiko Katsumoto on DVD to discuss "Overlapping Conditions in Scleroderma." New patients, those interested in volunteering as group leader or with questions about quarterly meeting please contact Debbie Metz (513) 232-5210, cincinnati-sg@sfohio.org.

Central Ohio Support Group: Meets in 2014 quarterly on Saturday from 10 a.m. - 12 p.m. Dates TBD. 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 the first Saturday of the month, April-October, 10 a.m.–12 p.m. at Grace Community Church, 5001 Fishburg Rd. in Huber Heights. Support Group Leader: Penny Davis (937) 554-1425, dayton-sg@sfohio.org

Northeast Ohio/Greater Cleveland Support Group: Meets the last Thursday monthly, April – Oct., 7 p.m. at Simon’s Restaurant, 770 Chippewa Rd., Brecksville. Support Group Leaders: Susan Woodard (216) 587-5191 and Mike Hollo (330) 241-0697, neohio-sg@sfohio.org.

Toledo Area Support Group: Meets Nov. 21, 7-9 p.m. at St. Luke’s Hospital, Room 2, 5901 Monclova Rd., Maumee. Speaker: Dr. Kahaleh. Topic: Research Update. Food provided, RSVP. Support Group Leaders: Dagne Lazenby (419) 819-9605 and Jan Weaver (419) 340-9819, toledo-sg@sfohio.org. No meeting Dec.

Willoughby Support Group: Will meet in 2014. Please contact Support Group Leader: Larry Bodak (440) 953-2918, willoughby-sg@sfohio.org for more info.

Youngstown Area Support Group: Meets the first Monday monthly beginning in April, 5:30 p.m. in winter, 6 p.m. in summer 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 people with scleroderma and help identify a cause and find a 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(S): _____

Please check appropriate box(es):

\$25 Annual Membership Donation In Honor/Memory of _____

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From Pg. 1

member and receive this award-winning publication. Simply fill out the membership form on page 3, enclose your check and mail to the Ohio Chapter office, or visit www.sfohio.org to become a member online.

SAVE THE DATE!

OHIO CHAPTER
STATE CONFERENCE
OCT. 3 - 5, 2014
Embassy Suites-Columbus
2700 Corporate Exchange Dr.

VOLUNTEERS NEEDED!

Join a Board Committee! Our State Conference, Development, Public Awareness and Advocacy Committees need members. Or volunteer at an event in your area.

Contact debbie.metz@zoomtown.com.

Support our Mission with Cashmere-Feel Navy Scarf!

This logo item is brought to you by the Ohio Chapter. You can order yours for just \$22.00 per scarf, shipping & handling included! Go online at www.sfohio.org or call the Chapter Office at 866-849-9030.

