



SclerOH! News

**SCLERODERMA FOUNDATION
OHIO CHAPTER**
SUPPORT - EDUCATION - RESEARCH

2012 Calendar of Events Announced

2012 Calendar of Events

June 2: *Stepping Out for the Cure* Boardman Park in Boardman

June 24: *Stepping Out for the Cure*, Univ. of Toledo Med. Center

July 27-29: *National Conference* –Dallas, TX

Aug. 25: *Stepping Out for the Cure*, Fairborn

Oct. 6: *State Conference*, Columbus

October 7: *Stepping Out for the Cure*, Reynoldsburg (tentative)

SAVE-THE-DATE

Our Walk schedule is growing. We have added Walks in Toledo & Fairborn, building awareness in more areas of Ohio. Mark these dates on your 2012 calendar now and plan to join us.

2012 State Conference & Reynoldsburg Walk:

Beginning Friday, Oct. 5, with a welcome reception, continuing Saturday, Oct. 6, with a full-day conference at a new location, the Embassy Suites Columbus, I-270 and Cleveland Ave.

A *Stepping Out for the Cure* Walk is tentatively planned for Sun., Oct. 7 in Reynoldsburg, a nearby suburb.

More information on our events will be posted on our website and linked to our facebook page as soon as it becomes available. Please check back often and let your family and friends know.

If you haven't already, consider starting a fundraising page on firstgiving.org where you can watch your efforts build awareness and support for Scleroderma.

2012 Education Days:

We are planning Education Days in Toledo and in southwestern OH.

THANK YOU!

To all our volunteers who bring these events to life – a very BIG thank you!

To volunteer, please call our toll-free line at 866-849-9030.

We host these events to increase awareness, to support our mission and to create a community for Scleroderma patients and their families.

Name the Newsletter Contest

We hope you enjoy our inaugural issue of the *SclerOH! News*. Tara Barker's creative suggestion won our Name the Newsletter contest. Thanks, Tara!



INSIDE THIS ISSUE:

Reynoldsburg Walk	2
Boardman Walk	2
Stress Tolerance	2
Support Groups	2
Become a Member	3
Buy a Scarf	4

June Kostandaras, 1964–2011

By Mariann Boyanowski

When June Kostandaras and I met we quickly connected, sharing a rich Greek heritage and a passion to find a cure for Scleroderma. She felt strongly that one person can make a difference and shared her experiences with new patients at the Brecksville Support Group. She served on the Board of the Ohio Chapter, but then had to resign due to her

health. I know she struggled with the decision but her health had to come first. Her family shared her passion and need to make a change. June and her family started the Kostandaras Family Fundraiser in Brecksville over three years ago to build awareness and to raise money. The Fundraiser has been a huge success. Sadly, June passed away on November 11, 2011. She will be missed by so many.

June was right, one person can make a difference.



2011 Reynoldsburg Walk & Central OH Education Day



Walking for a Cure – Reynoldsburg



Thanks to all of you who joined us for our Scleroderma weekend, October 1-2. Folks attending the Education Day on Saturday were able to browse our vendors' tables and enjoy gluten-free treats while listening to our speakers, Dr. Delfin Santos & Ms. Barbara Brugler, LISW. An excerpt from Ms. Brugler's presentation on Coping with Stress & Grieving in Long-term Illness and Disability follows. See the complete notes on our website. This event was made possible through a grant from Gilead Sciences, Inc.

Sunday, Oct.2, many more steps were taken toward a cure at our *Stepping Out for the Cure* Walk in Reynoldsburg. The crowd enjoyed great prizes, tasty food and fun. Please join us in 2012.

Thank you to all who supported this event. A BIG thank you to all event volunteers and to our major sponsors AEP, ABS, Culver's, Panera and Reynoldsburg Parks & Rec.

And thank you to all the patients and caregivers who are part of the Ohio Scleroderma community. Your positive spirit is inspiration for us to fulfill our mission and build awareness in Ohio.



Thanks Supporters!



2011 Boardman Walk a Success



Walking for a Cure - Boardman

We are so proud of the Boardman Ohio Fun-Walk, it has been 8 years now and they have raised over \$300,000. What a machine! With over 40 volunteers and 10 committee Chairpersons, everyone knows what to do and you can count on each one. As they've told us, the generous sponsors

continue to provide their support year after year due to the quality of the event and the grassroots "community-based" effort. And it's very fulfilling to find at least one new family at the Walk every year that didn't know about us

previously. They leave energized and then quickly jump in to help with the next year's event, once more extending our reach and ability to Step out to Cure Scleroderma. Please join us at our next walk, June 2, 2012.

Things that influence your stress tolerance level

-Excerpted from Coping with Stress & Grieving in Long-term Illness & Disability by Barb Brugler.

• **Your support network**

A strong network of supportive friends and family members is an enormous buffer against life's stressors. On the flip side, the more lonely and isolated you are, the greater your vulnerability to stress.

• **Your sense of control**

If you have confidence in yourself and your ability to influence events and persevere through challenges, it's easier to take stress in stride. People who are vulnerable to stress tend to feel like things are out of their control.

• **Your attitude and outlook**

Stress-hardy people have an optimistic attitude. They tend to embrace challenges, have a strong sense of humor, accept that change is a part of life, and believe in a higher power or purpose.

• **Your ability to deal with your emotions**

You're extremely vulnerable to stress if you don't know how to calm and soothe yourself when you're feeling sad, angry, or afraid. The ability to bring your emotions into balance helps you bounce back from adversity.

• **Your knowledge and preparation**

The more you know about a stressful situation, including how long it will last and what to expect, the easier it is to cope. For example, if you go into surgery with a realistic picture of what to expect post-op, a painful recovery will be less traumatic than if you were expecting to bounce back immediately.

"...have a strong sense of humor, accept that change is a part of life, and believe in a higher power or purpose."



Join a Board Committee

The Ohio Chapter has formed some new committees. These committees will help the Chapter fulfill our mission. Please consider joining one of the following: 1) Development Committee 2) Promotion Committee or 3) 2012 State Conference Committee. Contact Debbie Metz (513) 232-5210 or cincinnati-sg@sfohio.org

Find an SF Ohio Support Group

Support groups, a vital part of *your* scleroderma community, offer educational discussions, shared experiences, understanding and fellowship. Meeting time and place can change because of weather or holidays. Please contact the support group leader to confirm.

Canton Area Support Group: Meets the first Saturday of the month. Please contact the support group leader for meeting information. Support Group Leader: Jaime Smith (330) 257-5857, canton-sg@sfohio.org

Cincinnati Support Group: Meets the 2nd Saturday of every month, 1–3 p.m. at Conference Center at the Mercy Hospital - Anderson M.O.B. II. Support Group Leader: Debbie Metz (513) 232-5210, cincinnati-sg@sfohio.org

Columbus Support Group: Meets the 3rd Wednesday of the month, April through October. Please call for information. Support Group Leader: Amie Black (614) 726-6514, info@sfohio.org

Dayton Support Group: Meets the 1st Saturday of the month, 10 a.m.–noon at Grace Community Church, 5001 Fishburg Road, Huber Heights. Support Group Leader: Penny Davis (937) 554-1425, dayton-sg@sfohio.org

Greater Cleveland Support Group: Meets the last Thursday of every month, 7 p.m. in the restaurant at the Richfield Days Inn & Suites (formerly the Quality Inn), 4742 Brecksville Rd., Richfield, OH. (330) 659-6151. Support Group Leaders: Susan Woodard (216) 587-5191 and Mike Hollo (330) 241-0697, neohio-sg@sfohio.org

Toledo Area Support Group: Meets the third Thursday of each month, 7–9 p.m. at St. Luke's Hospital, Room 2, 5901 Monclova Road, Maumee, OH. Support Group Leader: Jerri Sue DeTray

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, simply go online to www.scleroderma.org/development/donate.shtm or complete this form today and mail it to:

Scleroderma Foundation Ohio Chapter
P. O. Box 846
Hilliard, OH 43026-0846

NAME: _____

ADDRESS: _____

CITY: _____ STATE/ZIP: _____

EMAIL: _____

PHONE (with area code): _____

METHOD OF PAYMENT: Cash Check Amount \$ _____

Please check appropriate box: \$25 Member Dues In honor of In memory of Donation

If in memory or honor of someone, please print their name: _____

THANK YOU!



SFOH
Board Members

- Debbie Metz
President
- Garry Lazenby
Vice President
- Jerry Metz
Secretary
- Phil Meyer
Treasurer
- Mariann Boyanowski
Dagne Lazenby
-
- Laurie Holden
Chapter Coordinator

Special Scleroderma “Cashmere Feel” Navy Scarf

Stay warm this winter with our *soft* and *cozy* scarf. Net proceeds go to the Ohio Chapter to further the Foundation’s three-fold mission.
Order yours for only \$22 per scarf, shipping and handling included. For secure ordering, visit:

<http://scarf.sfohio.org>. All major credit cards accepted. Your order will be shipped in two weeks or less. Any questions regarding your order please email: maromf@aol.com or call toll-free 866-849-9030.

Thank you!



We Thank Our Sponsors

Our sincere thanks to Actelion Pharmaceuticals, United Therapeutics Laboratories, and Gilead Sciences for their continued support of SFOH’s educational programs and fundraising events.



For scleroderma questions, call **SFOH’s hotline, (866) 849-9030.**

Check us out online at **www.sfohio.org**.
Friend us on **facebook.**

RECIPIENT NAME
STREET ADDRESS
ADDRESS 2
CITY, ST ZIP CODE

