



SCLERODERMA FOUNDATION

SUPPORT • EDUCATION • RESEARCH

OHIO CHAPTER

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Calendar of Events:

June 4: *Stepping Out for the Cure*
Boardman Park,
Boardman, OH

July 8-10: *National Conference* – San Francisco, CA

July 30:
Kostandaras Family Fundraiser
Days Inn & Suites
Richfield, OH

October 2:
Stepping Out for the Cure
Reynoldsburg, OH

New President's Message

When my mother was diagnosed with scleroderma in 1976, the doctor told her to "get her affairs in order." I was diagnosed in 1989 and became a member of the Foundation to learn as much as I could to help myself. After about five years of attending support group meetings, I

decided it was time to give back and began volunteering, sometimes filling in for the leader. Eventually I became support group leader, providing a place for people to come to ease their pain and suffering, reaching out a helping hand. Then I attended a local meeting hosted by the national

by Debbie Metz

Foundation to gauge interest in beginning a chapter in Ohio. I became a founding board member in the chapter, along with long-time members Dagne Lazenby, Garry Lazenby, Jerry Metz, Phil Meyer and Amie Yaussy.

The board sets the direction of our chapter, using our mission to improve
[cont'd. pg. 2]

2010 – A Great Year for SF Ohio Chapter

This has been another exciting year for the Ohio Chapter!

In March, the Cincinnati and Dayton support groups co-sponsored an education day with Dr. Cathy Creger Rosenbaum speaking on the "Seven Balance Points to New and Better Health."

In April, the Kostandaras Family hosted another successful fundraiser at the Richfield Days Inn &

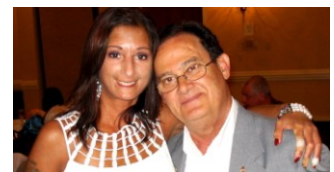
Suites.

June was a busy month for the Chapter. The first Saturday had the Boyanowski family hosting the 7th annual "Stepping Out to Cure Scleroderma" Walk in Boardman. On the third Saturday, the Toledo support group hosted an education day at the Toledo Hilton Hotel.

In October, the bi-annual Ohio State Conference took place in Columbus. This two-

day event at the Columbus Airport

[cont'd. pg. 3]



June Kostandaras and her father Nick at April 2010 family fundraiser

New President's Message (cont'd. from pg. 1)



Debbie Metz, SFOH Chapter President

"As a result of the Foundation's efforts, patients don't hear an immediate harsh medical directive as my mother did and can live longer, happier, healthier lives."

lives through support, education and research. Our mission resonated with me from the very beginning. My passion comes from my personal connection with the disease.

My mother had Scleroderma, I have it, and perhaps someone else in my family will one day be diagnosed with it. If health care professionals and patients become more educated, we can be better cared for and live a longer, happier life. I knew that I could help promote our mission to inform and support. For me, the trigger is once I see the faces and hear the voices of those with the disease, I want to help and be a support in the care of people with scleroderma.

I have seen a lot of progress in the

Foundation since I became a member 20 years ago. The *Voice* magazine and the national conference have evolved into excellent resources, our support of research continues to grow annually, and SF is now a four-star non-profit on the Charity Navigator. As a result of the Foundation's efforts, patients don't hear an immediate harsh medical directive as my mother did and can live longer, happier, healthier lives.

I have enjoyed my volunteer roles and watched our chapter grow and succeed. Through our scholarship program, we have sent patients in need to the national conference where they can learn and meet others who are coping

with the disease. I have been fortunate to be able to raise awareness and money for other organizations, and I will use this experience to keep us moving toward our common goal to raise money to support the national Foundation's research efforts.

I want to thank our board for giving me this opportunity. Mariann Boyanowski has done an extraordinary job as a volunteer and as president of our chapter for the past three years. She is an inspiration. Because of her strong organizational and leadership skills, we are in a position to move forward and to affect more lives.

I look forward to working with all of you to fulfill our mission and wish you all a happy, healthy and prosperous New Year.

SF Ohio Goes Green!

Starting with this issue, SF Ohio is going green. Instead of mailing copies to everyone, we're trying to email issues to as many of you as

possible. This not only saves paper, ink and postage, but also means quick delivery.

If you're not reading this on your computer (via email

delivery), **please send us your email address to:** info@sfohio.org

We thank you, and Mother Earth thanks you, too!



2010 – A Great Year for SF Ohio Chapter (cont'd. from pg. 1)

Embassy Suites provided a forum for six speakers to educate more than 100 participants. Copies of the six conference presentations are available at www.sfohio.org.

On the third day, participants were able to drive just a few miles east for the 8th annual Reynoldsburg Walk. This year the walk was more successful than ever!

In December, we added Janis Weaver

to the board for 2011. Debbie Metz is our new president, Garry Lazenby is vice president and Phil Meyer officially returns as our treasurer. We have hired Laurie Holden as our chapter coordinator, our first employee.

In addition, we also had eight support groups meeting throughout the state, and we have added 31 new members!

These events would not have been

possible without our passionate volunteers. Please consider volunteering with your support group or at one of our events. Speak with a support group leader at your next meeting. You can also find out what is happening in our chapter online at www.sfohio.org, on Facebook and on Twitter and through our newsletter.



Mariann & Kevin Boyanowski at 2010 Boardman Walk

**RESOLVE IN 2011
TO BE INVOLVED!**



7th Annual Reynoldsburg (Columbus/Dublin) Walk



“Walk for a Cure” Boardman Walk 2010

SFOH Board News

The board regrets to announce that June Kostandaras has resigned. We extend our heartfelt appreciation for her hard work and support and our prayers for a triumphant resolution to her health

issues. June will continue to do her successful annual fundraiser, the Kostandaras Family Fundraiser, which will take place on Saturday, July 30, at the Richfield Days Inn.

Two Notable Items...

The Department of Defense (DOD) Peer Reviewed Medical Research Program will be announcing three new scleroderma grants in the coming weeks. Consult our national website for more information.

The Tri-State Chapter (NY, NJ, CT) has recorded some of their educational seminars. These videos are available for viewing on the web at: <http://www.sclerodermavideo.com/>

Caregiver Support Info from Area Agencies on Aging

What is caregiving?

Caregiving describes any situation in which one individual helps another with essential activities of daily living. Caregiving activities may include help with dressing and bathing, grocery shopping, managing money, providing transportation, dressing wounds and administering medication.

What is the difference between “formal” and “informal” caregiving?

Care provided by an employee of an agency or organization, or a trained individual (usually for a fee), is considered “formal caregiving.” Care provided by family members and friends, most often unpaid, is considered “informal caregiving” or “family caregiving.”

Who is an informal caregiver?

Relatives and non-relatives can be informal caregivers. If you aren't currently affected by caregiving issues, chances are you will be at some point in your life. Relative caregivers are most often adult children or spouses. Fifty-seven percent of Ohio caregivers are female, 40 percent are at least 50 years old, and 62 percent are employed.

Who receives care?

Eighty percent of care receivers in Ohio are at least age 50, and 70 percent are female. Care receivers live in a variety of settings, from nursing homes to private residences.

Does informal caregiving impact communities?

Caregiving often negatively impacts the health and wellness of the caregiver as well as his or her relationships with friends and neighbors. Working caregivers often use more vacation and sick leave than non-caregiving employees. The cost of informal caregiving to U.S. businesses is estimated at \$11 to \$29 billion annually. On average, a person in Ohio may be in a caregiving role for 4.2 years. However, caregivers of parents and spouses are likely to provide care for 10 years or more. The longer a caregiving relationship exists, the higher the toll it is likely to place on the caregiver physically, emotionally and financially.

What help is available for informal caregivers in Ohio?

The **National Family Caregiver Support Program** helps individuals rise to the challenges of informal caregiving. Area Agencies on Aging and service providers help caregivers access supportive services, provide counseling, facilitate support groups and caregiver training, organize respite care (temporary relief from caregiving responsibilities) and more. Information and some supportive services are available to all caregivers.

How can I get help with caregiving?

Call toll-free, 1(866) 243-5678 to contact the Area Agency on Aging serving your community for details.

Where can I learn more about caregiver support programs?

Visit the following Ohio Department of Aging web page for more information about caregiver support.
<http://aging.ohio.gov/resources/nationalfamilycaregiversupport/>

Outgoing President's Message

by Mariann Boyanowski



Mariann Boyanowski

"Scleroderma has given me much more than it has taken away."

I was diagnosed with scleroderma in July 2000. Those of you who don't know me, I am of Greek descent, and we are a very close family. So when I received the news that I had scleroderma, it meant my whole family did, too.

My story begins with the need to find out as much about scleroderma as possible. The national conference was scheduled in Washington, DC, for that year and we were going, all of us -- me, my sister, my brother, and all of our spouses. We were off and running!

Advocacy was also a part of the conference that year, and national had done a great job of scheduling all the appointments, by state. Busloads of us arrived at Capitol Hill with one goal in mind -- to get a meeting with a member of Congress or their aide and inform them about scleroderma. The Ohio contingent met with then Congressman Strickland. He listened as we told him about the disease and asked him to support an appropriations bill for NIH funding which would support research efforts. We left there so energized and

empowered, we knew we wanted to continue to make a difference.

This is when my sister Leni and my sister-in-law Marilyn started their support group in Youngstown, and Phil Meyer asked me if I would help him run the support group in Northeast Ohio. So I did -- for the past nine years. Now, Susan Woodard and Mike Hollo are leading that group and doing a great job, too.

Phil approached me once again, in 2006, to come to a Board meeting in Columbus, and I agreed again. He is very persuasive. So, I joined the board -- for the past five years.

I accepted the presidency in 2007. It was so out of character for me to do something like this, but I felt that we had a great board that was ready and willing to move forward. They really supported all the new opportunities that lay ahead.

During my term as president, we were able to create additional awareness venues and three new support groups. We established the Ohio Conference and the Support Group Leadership Workshop.

As a board, we

supported and encouraged numerous new fundraisers of all kinds and watched them take place across the state.

Bake sales, live auctions, dinner dances, golf outings, and health fairs -- these events were all hosted by support group leaders, patients or caregivers. It was wonderful to hear their excitement after the event was over that "they could do it," too.

I want to thank the board members for all their support and for giving me the opportunity to help carry out the Foundation's mission. Had I not become a member, I would not have met my second family and my many new friends who I will cherish forever. I will continue on the board, hosting our chapter's hot-line as well as co-leading the Boardman Walk.

My very best wishes and total support go to Debbie Metz, our new Ohio Chapter President. I stand ready, along with all our board and SFOH members, to help Debbie lead us to bigger and better successes.

In closing, I just realized something. Scleroderma has given me much more than it has taken away.

Meet Our New Chapter Coordinator



Laurie Holden
Chapter Coordinator

Happy New Year to all Ohio Chapter members! I am proud to be your new chapter coordinator. It is truly amazing all that has been accomplished by this chapter through the passion of our board and volunteers.

I appreciate this opportunity and look forward to working with the board, supporting our mission and helping us grow.

I have met some of you already at support group meetings and look forward to meeting many more of you at our events and as I visit your support group.

The year 2010 was great for the Ohio Chapter. The coming year is taking shape, and I hope you will be able to participate in all that the chapter provides.

We offer a community rich in education and support. If you have yet to join us at an event, consider adding this to your list of New Year's resolutions for 2011.

Please feel free to contact me with questions or newsletter suggestions at info@sfohio.org. Best wishes for a happy, healthy and prosperous New Year!

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!

Find An SF Ohio Support Group

Support groups offer educational discussions, shared experiences, understanding and fellowship.

Canton Area Support Group: Regular meetings will resume in March 2011, weather permitting. Meets the first Thursday of the month, 6:30 p.m. at Dueber United Methodist Church, 645 Dueber Ave. SW, Canton, Oh 44706. Support Group Leader: Jaime Smith (330) 257-5857, canton-sg@sfohio.org

Carrollton Area Support Group: See you Spring 2011! Meets the first Thursday of the month, 4 p.m. at Aultman Therapy Building, Community Room, 1020 Trump Rd NW, Carrollton, OH 44615. Support Group Leader: Crystal Burgett (330) 627-7548.

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

Columbus Support Group: See you in April 2011! Meets the third Wednesday of the month, April through October. Please call for information. Support Group Leader: Amie Yaussy (614) 726-6514, info@sfohio.org

Dayton Area Support Group: See you in April 2011! Meets the first Saturday of the month, 10 a.m.–12 p.m. at Grace Community Church, 5001 Fishburg Road, Huber Heights, OH. Support Group Leader: Penny Davis (937) 554-1425, dayton-sg@sfohio.org

Northeast Ohio/Greater Cleveland Support Group: Please join us on March 31, 2011. 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: Please join us on February 17, 2011. 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 (419) 822-9693(H), (419) 822-1250 (C), toledo-sg@sfohio.org

Youngstown Area Support Group: See you in Spring 2011! Meets the first Monday of every month, 6 p.m. in summer and 5:30 p.m. in winter at Davidson's Restaurant, 3636 Canfield Rd., Youngstown, OH. (330) 793-0033. Come for dinner. Support Group Leaders: Leni Schulz (330) 654-2538 and Marilyn Panagopoulos (330) 318-6088, youngstown-sg@sfohio.org

For directions and meeting topics, please check our website at <http://groups.sfohio.org>.

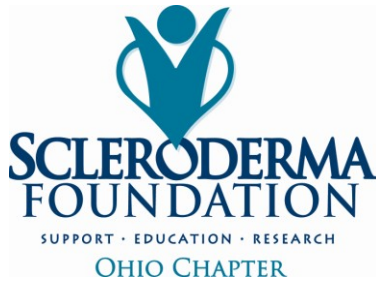
Special Scleroderma “Cashmere Feel” Navy Scarf

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.





SFOH Board Members

Debbie Metz
President

Garry Lazenby
Vice President

Jerry Metz
Secretary

Phil Meyer
Treasurer

Mariann Boyanowski
Dagne Lazenby
Janis Weaver

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Laurie Holden
Chapter Coordinator

Money for SF Through H & R Block Offer

The Scleroderma Foundation is eligible to receive \$25 for each new client referred to a participating H&R Block office when the individual pays for an original personal income tax return. A referral form must be

presented prior to completion of initial tax office interview.

To make an appointment or locate an H&R Block office call 1(800)HRBLOCK or visit www.hrblock.com.

For more information on this offer, please

visit our National SF website at http://www.scleroderma.org/medical/resources/resources_products_special-offers.shtm.

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

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.



Name It and Win \$\$\$!

Send your name suggestion for this newsletter by March 15 to Laurie Holden at info@sfohio.org

If your entry is selected, you'll win a \$100 gas card!

Reading Rack

Read any good books lately? If you have read a book that relates to an issue faced by members of the scleroderma community, consider sharing the information in a book review. Write a short summary about the book, and let others know what specifically helped you. Submit it to info@sfohio.org to be included in an upcoming newsletter.

Newly Diagnosed? Know Someone Who Has Been?

Visit the Scleroderma Foundation website and go to the "New Diagnosis" tab. You'll find very useful resources, such as a scleroderma fact sheet, lots of highly informative material to order, link to or download. A special Medical Information section shows how to get better informed and more organized about scleroderma healthcare.

There's a suggested reading list and descriptions of how to find a doctor and connect with others.

The Foundation's mission features patient support designed so no patient, caregiver or family member need ever feel alone. **Taking advantage of these resources is the key to dealing with the disease** and minimizing the feeling of isolation and despair.