



SclerOH! News

SCLERODERMA FOUNDATION
OHIO CHAPTER
SUPPORT - EDUCATION - RESEARCH

Upcoming Events

August 6 - Stepping Out to Cure Scleroderma Walk, Fairborn Community Park (Greater Dayton)

August 13 - Dr. Susan K. Leone Memorial Golf Scramble, Mill Creek Park Golf Course, Boardman

August 27 - Hike and Family Picnic, Cuyahoga Valley National Park

September 23-25 - Ohio Patient Education Conference, Columbus

September 24 - Ugly Dress Gala, Columbus

October 1 - Bowl for Scleroderma, Beaver Vu Bowl, Beavercreek

*This article was written by Linda Slusser, **scleroderma patient** and member of the **Scleroderma Foundation, Ohio Chapter**. It was printed in the Winter 2016 issue of Women Magazine! For our newsletter, this is being published in three editions. This issue includes Part 3. The full article is available online at AWomansHealth.com.*

When the Diagnosis is Scleroderma (Part 3)

Meet Again with the Expert

Armed with some basic knowledge, you are ready to schedule a follow-up appointment for a candid dialogue with the expert. This conversation is critical because with the scleroderma diagnosis you have become a “snowflake”—the word patient Mariann Boyanowski chooses to capture the unique way scleroderma appears in each patient.

“No two scleroderma patients are going to be the same,” Dr. Chatterjee explains. Scleroderma “is different from lupus or rheumatoid arthritis, which are often treated the same way through a hierarchy of medications.” With scleroderma, he says, your treatment plan will be “custom-made based on what your needs are.”

As you discuss your unique diagnosis and symptoms with the expert, you have the opportunity to become a proactive patient. Before the appointment make a list of questions; during the meeting (and all that follow, including phone conversations) take notes to record the doctor’s responses and any information you want to remember. Some patients opt to take a tape recorder or a friend or family member to help take notes and absorb the information. (If you do want to record the conversation, be sure to get permission from the doctor ahead of time.)

Be sure you get all the information you need during your visit with the expert: explore short-term and long-term expectations; ask about the possible impact on quantity and quality of life; zero in on concerns specific to you, such as the organs involved, treatment plan and potential side effects, adjustments required at home and work, and specialist referrals. When the appointment ends, be sure you know how the doctor prefers to be contacted for any follow-up questions that may arise.

Adopt Coping Strategies

Everyone with a chronic illness faces losses and accompanying grief as they try to adapt to a new reality. Nurse practitioner Megan Liddicoat, RN, BSN, tells scleroderma patients: “Acceptance is a shift that focuses on how to live—and I would put LIVE in capital letters—with the illness while not being defined by it.”²

The following are some suggestions for coping with scleroderma.

- **EAT A HEALTHY DIET.** Consulting a dietitian would be worthwhile.
- **EXERCISE.** Try walking, strength training, yoga, and chair exercise—whatever you can manage.
- **PACE YOURSELF.** Eliminate non-essential responsibilities, and rest when you need to, even for 15 minutes at a time.
- **INVESTIGATE AIDS FOR SYMPTOMS.** Mittens with finger-warming inserts for Raynaud’s provide relief.
- **TRY CREATIVE THERAPY.** Journaling, drawing, or other creative pursuits may allow you to express your feelings and relax in a healthy, productive manner.
- **PRAY OR MEDITATE.** Patient Molly Petsch’s most important coping mechanism was “depending on my lifelong habit of prayer and meditation.”
- **SEEK OUT FUN.** Participate in activities that bring you joy—either things that have always been a source of fun or, if necessary, new activities that suit your current abilities.
- **ACCEPT SUPPORT.** Family and friends are not your only bolsters. Connect with support groups, in person or online. Liddicoat says that finding even one other person to talk with on the phone could be enough: “Sometimes it helps to just have somebody else that can understand what you’re going through.” Speaking with a therapist, far from showing weakness, provides you with a neutral adviser.

(continued on Page 2)





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(continued from Page 1)

Face the Future with Hope

If you are facing a new diagnosis of scleroderma, know that though the journey ahead will present challenges, there are proactive steps you can take to live well with this condition.

- **LEARN.** “Educate yourself the best that you can,” says Dr. Chatterjee. “An educated patient does a lot better than somebody who doesn’t want to know and relies entirely on the physician.”
- **BE AWARE.** Pay attention to what is happening with your body, and see your doctor when and as necessary.
- **CONNECT.** Seek out other patients through in-person, online, or phone meetings, regional conferences, and the National Scleroderma Convention. Making these



New Hike & Family Picnic Fundraiser Comes to Northern Ohio!

Join us at the Cuyahoga Valley National Park – Virginia-Kendall Octagon Shelter for a new event to raise money and awareness for scleroderma. The hike and family picnic will be held on August 27th at 11:30 am. The event is free. You can buy lunch there for \$4 as well as t-shirts, bracelets and other cool scleroderma awareness items. We will also have an auction, games, bake sale, ½ mile hike on your own, and there are longer hikes for those interested. A good time will be had by all, so don’t miss out! Sign up today at sfohio.org or register the day of the event at 11:00 am.



Happy ANNIVERSARY, OHIO CHAPTER!

Fifteen Years Ago

By Debbie Metz, Board of Directors

As we celebrate our 15th anniversary of being a Chapter, I would like to reflect back a little. Our founding leaders like Amie Yaussy, Garry and Dagne Lazenby and Phil Meyer started us out on a great path. In Ohio we had one support group in Cincinnati and one in Toledo that were not affiliated with a Chapter. Since that time our leadership has worked to develop 8 support groups in all of Ohio’s major population centers and a virtual support group (by phone) that anyone can attend. We also have numerous education days across the state and our crowning jewel of our education efforts, our biannual conference. In addition, we are able to give \$40,000 to scleroderma research annually. So, we have been able to hire paid staff to help us execute these programs. As a Board we continue to learn and grow. Thanks to our very involved members all this is possible. Thank you, members!

connections will help you learn about the latest research and find support.

- **LAUGH.** “Rediscover humor, laughter, and play,” says Liddicoat.
- **EMBRACE POSITIVITY.** Look forward, not backward.
- **SET GOALS.** This diagnosis may alter your course, but you can set new goals and see them through. Remember that you are a person who happens to have scleroderma; the disease need not define you. Take control. Choose to live the best life you can imagine.

References

1. Merkel PA. Scleroderma. American College of Rheumatology website. Available at: <http://www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Scleroderma>. Accessed October 19, 2015.
2. Liddicoat M. Webinar #6—Grief to Hope: From Loss to Healing. Scleroderma Research Foundation website. Available at: <http://srfcure.org/for-patients/webinars>. Accessed October 19, 2015.



Rosita Aguirre Scholarship for Ohio Conference - Application Deadline Extended!

At the Ohio Conference, you can learn more, meet others with scleroderma, and interact with experts. \$500 scholarships are available for this event. All info submitted is kept confidential. Please send **name, phone number, address, e-mail, medical need, financial need, and involvement in the chapter** to jrodenbaugh@zoominternet.net or Scleroderma Foundation, OH Chapter, PO Box 107, Pataskala, OH 43062. The new deadline is Aug. 7, 2016.



Sources

- Gottesman K. *The First Year: Scleroderma: An Essential Guide for the Newly Diagnosed*. New York: Marlowe and Company; 2003.
- Mayer MD. *The Scleroderma Book: A Guide for Patients and Families*. New York: Oxford University Press; 2005.
- Patients and Newly Diagnosed. Scleroderma Foundation website. Available at: <http://www.scleroderma.org>. Accessed October 20, 2015.
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Find a Scleroderma Foundation Ohio Chapter Support & Education Group

Virtual Support Group: Meets 2nd Wednesday monthly at 7:00-8:00 pm by free phone call.
Call 866-740-1260, enter code 7170191#

Akron / Canton: Meets 1st Thursday of each month at 6:30 pm at Cleveland Clinic Akron General Health & Wellness Ctr., Green, 1940 Town Park Blvd., Uniontown, OH. Leader: Trisha Gosselin, tgosselin725@gmail.com.



Central Ohio / Greater Columbus: Meets Aug. 7, and Oct. 2 at 2-5 pm., 6315 Donegan Way, Dublin 43016. Leader: Ann Barnhart, (614) 717- 6790, columbus-sg@sfohio.org.

Dayton Area: Meets on Sept. 10, and Oct. 8 at 10 am –12 pm at Grace Community Church, 5001 Fishburg Rd. in Huber Heights. Leader: Penny Davis (937) 554-1425, dayton-sg@sfohio.org.

Greater Cincinnati: Meets Sat. 1-3 pm. Sept. 10, and Dec. 3 at Hyde Park Branch – Public Library of Cincinnati and Hamilton County, 2447 Erie Ave., Cincinnati. Leader: Debbie Metz, 513-232-5210; cincinnati-sg@sfohio.org.

Northeast Ohio/Greater Cleveland: Meets monthly last Thursday each month 7 pm, April -October. Location: Simon's Restaurant, 770 Chippewa Rd., Brecksville. Leaders: Mike Hollo (330) 241-0697 and Anne Davis (440) 212-2880, neohio-sg@sfohio.org.

Toledo Area: Meets Mar.—Nov. monthly on the third Thursday of the month at 7:00 pm at St. Luke's Hospital, Room 1, 5901 Monclova Rd., Maumee. Leader: Jerri Sue DeTray. For info, email info@sfohio.org. NO MEETING IN AUGUST.

Willoughby: Meets monthly, third Saturday 9:30 -11:30 am, May-September at Willoughby Public Library, 30 Public Sq., Willoughby. Leader: Larry Bodak (440) 953-2918, sawman269@yahoo.com

Youngstown: Meets Mar-Dec. at 5:30 pm 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., Canfield. (330) 793-0033. Come for dinner! Leader: Leni Schulz (330) 654-2538, mailto:youngstown-sg@sfohio.org.

For updates, you can also visit www.sfohio.org.

Board News!

We're growing! So far this year, we have added four new members to our board. In addition, Trisha Gosselin, RN joins us as a consultant. The new members are George Kinstedt, Lucille Miller, Gabrielle Freeman, and Shanelle Boyd. The complete list of our board of directors is as follows:

Ohio Chapter Board Officers:

Debbie Metz – President; Jerry Metz – Secretary; Phil Meyer – Treasurer

Members at Large:

Jolene Rodenbaugh, Mariann Boyanowski, George Kinstedt, Lucille Miller, Gabrielle Freeman, and Shanelle Boyd

Medical Consultant:

Trisha Gosselin

5th Annual Stepping Out to Cure Scleroderma Fun Run & Walk - Dayton, OH

Join the Dayton Support Group as we Step Out to Cure Scleroderma with a Family Fun Run & Walk. Fun for the entire family – face painting, a craft and balloon animals for the kids, a D.J., prize raffle, L & L Concessions and Cold Stone Creamery, board games, and cornhole. Team Captains raising over \$100 will be entered into a raffle for a 7-day Florida stay for up to 6 people! One raffle ticket for each \$100 raised! Registration is \$20 for Adults, \$5 for age 13-17, 12 and under are FREE! Sign up at www.sfohio.org!

When: Saturday, August 6, 2016

Where: Community Park, 691 E. Dayton-Yellow Springs Road, Fairborn, OH 45324

Registration Time: 9:30 a.m.

Event Start: 11 a.m.



Wonderful Opportunity to Help your Chapter!

We are still looking for sponsors for most of this year's events! Let us know if you or a business owner you know would like to take advantage of this great advertising opportunity!

We are also accepting donations of heirloom jewelry, gift cards, spa/ salon services, sports collectibles, tickets and other gift items to auction at our events! Call 866-849-9030 or email info@sfohio.org.

page 4

Scleroderma Foundation, Ohio Chapter Newsletter



GOLF "FORE" SCLERODERMA

The 2nd Annual Dr. Susan K. Leone Memorial Golf Scramble will be held on August 13th 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 18 holes of golf, a t-shirt, breakfast, lunch and dinner. You will have a blast as you compete in various contests such as longest putt, furthest drive and closest to the pin. Other festivities that will occur at the completion of the golf contest are a 50/50 raffle and auctions. Sign up today at www.sfohio.org.



Bowl for Scleroderma Thelma's Silent Words

Kelley Hill is the organizer of our bowling fundraiser. His mom, Thelma, passed away from scleroderma in 2004. This is a message from him regarding his mother's last day and his motivation to raise awareness and to raise funds for research.

"That morning, before I was awakened by the doctor, I was dreaming of my mother. I was sitting in her hospital room where she was up and walking around, looking out her window, and sometimes talking to me. Her words were not audible, yet I completely understood the silence. 'Everything is going to be ok. My job is complete here and it's time for me to go home.' As my mother delivered her final message to me, she turned towards the window and instantaneously, my phone rang. When I picked up the phone, I knew as the physician started talking that she was gone, but because of my mother's silent words, I knew everything was going to be ok. There is currently no cure for Scleroderma, but with enough people pulling together, there is hope. In honor of my mother, please join me for a day of not only raising money, but of raising awareness and showing support for all of the families affected by Scleroderma at Beaver Vu Bowl, Beaver Creek, OH. All contributions are tax deductible and will go directly to the Scleroderma Foundation to aid in research to find a cure." The event will be held on October 1, 2016 at 2-4 PM. Watch for registration information on sfohio.org.

