



SCLERODERMA EXCHANGE

Published by
Scleroderma Foundation Tri-State, Inc. Chapter
Binghamton, New York

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www.SclerodermaTriState.org

MISSION

To provide educational and emotional support to people with scleroderma and their families

To stimulate and support research designed to identify the cause of and cure for scleroderma as well as to improve methods of treatment

To enhance the public's awareness of this disease

2018 National Patient Education Conference

The conference was held in Philadelphia, PA, July 27-29. Attended by more than 650 patients, family members, and caregivers, it is the largest patient-focused scleroderma conference held anywhere in the world. The event featured seventy-seven presentations and workshops organized with 69 scleroderma experts, healthcare professionals, and patient presenters. During this event, the Scleroderma Foundation recognizes the outstanding achievements and contributions by individuals and chapters to the scleroderma community.



The Doctor of the Year Award was given to Lesley Ann Saketkoo, M.D., M.P.H. She holds an M.D. and a Masters of Public Health and trained in pediatrics and internal medicine at Tulane University in New Orleans, and in rheumatology at Louisiana State University.

Dr. Saketkoo is an associate professor of medicine in the Department of Medicine at Tulane University and has held faculty appointments in both pulmonary medicine and rheumatology. Her warm, friendly and deeply compassionate nature is coupled with fierce determination, boundless energy, and laser focus that is further honed by an impressive resume research and clinical leadership.



Sergio Jimenez, M.D. received the Lifetime Achievement Award. Dr. Jimenez, professor of medicine at Thomas Jefferson University in Philadelphia. Dr. Jimenez is a physician, scientist, biochemist, and molecular biologist who has devoted over four decades to the treatment of patients with scleroderma and to the study of the clinical and molecular aspects of the disease and related conditions. Dr. Jimenez is honored as an individual who has been an icon in his tireless work to advance patient care and clinical research over a 40-year career.

Once again, The Tri-State Chapter was proud to have honorees awarded for their unwavering dedication to the Scleroderma Foundation's mission; Andrew Botieri and Lee Korotzer - leaders of the ScleroMen Facebook support group received the Outstanding Patient Support Award. See our story to learn more about ScleroMen.



We gathered many of our Tri-State members together at the conference to connect. Tri-State had a great turnout as you can see by our group photo. Mark your calendar for next year! The 2019 conference will be held in Chicago, Illinois, July 19-21.



Outstanding Patient Support Award: Andrew Botieri and Lee Korotzer ScleroMen Facebook Support Group

Andrew Botieri and Lee Korotzer - leaders of the ScleroMen Facebook support group received the Outstanding Patient Support Award - presented to individuals who devote tremendous effort in providing emotional support to a select group of individuals affected by scleroderma. Because women are thought of as the primary disease population, the needs of men with this disease can sometimes be under-appreciated and overlooked. Tri-State Chapter's effort to address men's need for emotional support encountered challenges but these two awardees stepped in and took charge. ScleroMen Facebook support group allows men to share their deepest personal thoughts and feelings about the impact of the disease on their lives. Men anywhere in the world who have scleroderma can connect with each other in this safe and supportive environment. The Tri-State Chapter is proud and grateful for their commitment.



Scleroderma Foundation Tri-State, Inc. Chapter

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Helene Flapan, M.A.

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A Message from Our Executive Director

The Tri-State Chapter was founded in 1981 when Mark and Helene Flapan along with Dr Harry Spiera recognized the need to offer support to patients in Manhattan. Together they started our first support group and organized educational forums. They established our chapter as an official non-profit serving the scleroderma community.

Over the next 30 plus years Tri-State grew; in the territory, in the number of members served with patients, family, caregivers, and friends stepping forward and volunteering to lead newly formed support groups, educational events, health fairs and a host of other activities. Raising funds became necessary to financially support all these activities as well as fund the foundation's research program, again our community responded and continues to respond today through your membership, donations, and support of our many fundraising events.

Looking to the future our chapter is evolving as the world around us is rapidly changing. Technology offers us new avenues to serve our community. Today we communicate via Facebook and Twitter. We feature online videos of our educational presentations. Support groups have become virtual. In the coming months, you will see us using technology to deliver more of our services to you. We welcome your comments and feedback as we move forward. We realize change for many does not come easy, people tend to hold onto past practices they feel comfortable with.

As we enter this end of the year holiday season we are THANKFUL for all we are able to achieve in SUPPORT, EDUCATION, AWARENESS, and FUNDING of RESEARCH. We are GRATEFUL for all you contribute to making this possible. While we are evolving to better serve you, our core mission will not change.

**HAPPY HOLIDAYS and BEST WISHES
for a HEALTHY 2019!**

Bruce Cowan
Executive Director



Get to know your board

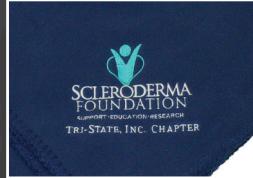


Jonathan Schorr

Jon joined the board in 2018. He serves as Chair of the Marketing Committee and resides in Hastings On Hudson, NY. He is Managing Director and Associate General Counsel in the Goldman Sachs Legal Department, focusing on litigation and regulatory affairs.

Jon's wife Adriane has been a scleroderma patient since 2003, and they and their grown children, Andrew and Allison, have been active volunteers involved in the Westchester and New Jersey walks for many years. Jon is President of his neighborhood civic association and a member of the LGBT Allies Network at work. In his free time, Jon enjoys exploring New York City restaurants with his family, rooting for the Mets and running (really, mostly walking) in the hills near his home.

**Tri-State Chapter
Scleroderma Awareness items
make great gifts.** Prices include shipping.

 36" x 36" Ladies SF Damask Pattern Scarf \$28 each	 Adult SF Shell Pattern Neck Tie \$25 each	 Adult SF Shell Pattern Self-tie Bow Tie \$25 each	 Embroidered Fleece Blanket \$25 each
 Flashlight/Rechargeable Portable Power Bank \$5 each			
 2018 Walk T-Shirt \$10 each	 Touchscreen Gloves \$8 each	 Navy Hoodie \$25 each	 Gel Hand Warmers \$5 pair

Awareness items tell the world you support finding a cure for scleroderma!

Call the Tri-State office to order: **800-867-0885**. Tell us you saw it in this newsletter & receive **10% off** or buy two more items and get **20% off** - your total when you purchase any of our awareness items!

Ask your employer about Payroll Deduction!

Some company's will allow you to donate to the Scleroderma Foundation Tri-State Chapter through your employee workplace campaign!

An ongoing contribution through payroll deduction will make a difference!

Choose the appropriate number to support our cause.

- United Way choose Scleroderma Foundation/Tri-State Chapter IRS #13-3128296
- Combined Federal Campaign choose 10089
- New Jersey Employees Charitable Campaign choose 6582
- State Employees Federated Appeal choose 999-00581
- Combined Municipal Campaign & CUNY choose 2539

FACE THE COOKIE!



WHAT'S ON YOUR PLATE FOR THE HOLIDAYS?

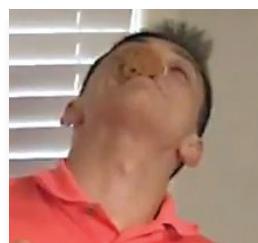
One of the best things about the upcoming holidays is spending time with family and friends – making memories, and of course, let's not forget the sweet treats!

With all of the trending “challenges” going viral around the internet, why not get on board with something that is fun and can be done with the people you like to have the most fun with? Oh, and desserts – let's not forget to involve the desserts...

#FACETHECOOKIE to the rescue!

The concept is very simple:

1. Find a chair, have a seat.
2. Place a cookie on your forehead.
3. Maneuver the cookie down to your mouth using only your face muscles (remember, no hands!).
4. Nominate two or more people to complete the challenge, or donate to www.FaceTheCookie.org
5. Provide an expiration (“*You have 24 hours to accept and complete the challenge, or make a donation to www.FaceTheCookie.org*”)
6. Share, Share, SHARE! On YouTube, Facebook, Instagram, Twitter, LinkedIn, etc.



2018 PATIENT EDUCATION FORUMS

May 19 - Now on www.sclerodermavideo.com
Columbia University Medical Center – NYC
Elana Bernstein, MD, MSC; Daniela Jodorkovsky, MD; and Stephanie Gallitano, MD

Sept. 8 - Now on www.sclerodermavideo.com
Northwell Health - Great Neck, NY
865 Northern Blvd, Suite 302, Great Neck, NY 11021
Sonali Narain, MD, MPH; Jonathan Bank, MD; and Arunabh Talwar, MD

Sept. 15 - Now on www.sclerodermavideo.com
The Bone & Joint Center - Albany, NY
1367 Washington Ave, Albany, NY 12206
Celeste Freeman, OTR/L; Michelle Morgan, MS, RDN; and Shohreh Anand, EdD

Oct. 6 - Visit www.sclerodermavideo.com
Monroe Community College - Rochester, NY
1000 East Henrietta Road, Rochester, NY 14623
Nana Duffy, MD; Christopher Palma, MD; and Theo Munson

October 26-27
2018 KGS2! - Colorado Children's Hospital
13123 E 16th Ave, Aurora, Colorado 80045
Co-Presenters: Rocky Mountain/Tri-State Chapters
Carrie Brumbaugh, RN; Kerstin Caldwell; Yvonne E. Chiu, MD; Megan Curran, MD; JoAnna Harper, PharmD; Wendi Heffner; Amy Kanallakan, MD; Kristin Kilbourn, PhD, MPH; Suzanne C. Li, MD, PhD; Luke Medolla; Katharine Moore, MD; Anne M. Stevens, MD, PhD; Vidya Sivaraman, MD; and Kathryn S. Torok, MD
Register at: 2018KGS2.SclerodermaTriState.org

November 17
Annual Research Forum - HSS - NYC
Richard L. Menschel Education Center
535 East 70th Street, New York, NY 10021
John Varga, MD; Jonathan Garlick, DDS, PhD; and Jessica K. Gordon, MD



LOOKING FOR SUPPORT?

Visit sclerodermatristate.org for additional information about our support groups.

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STATEN ISLAND, NY REGION

StatenIslandNY@SclerodermaTriState.org

THE POWER OF SUPPORT

YOU ARE NOT ALONE!

Our organization is focused on support for the patient, as well as your family and friends. Our goal is to create a large network of support, extending our reach throughout the tri-state area.

If you are not yet part of a group, try attending one! Soon meetings will become part of your daily habits toward building a healthy, balanced lifestyle. You have scleroderma, but it does not define you.

We are always looking for people who are ready to step up – assuming a leadership role. As a support group leader you'll get a sense of doing something significant – you will feel good about supporting others and in turn you'll feel good about you! We will assist you in every possible way.

For more information on current groups or to learn more about starting a group, give us a **call at 1-800-867-0885**

FACEBOOK SUPPORT GROUPS



ScleroMen provides a means for men with scleroderma to connect, share stories, seek advice and ask questions - in a caring and supportive environment. Only men with scleroderma may join this closed group by request through the leaders.

Co-Leader: Andrew Botieri - (508) 982-7523 | ScleroMen@SclerodermaTriState.org

Co-Leader: Lee Korotzer | LKorotzer@yahoo.com



Scleroderma Super Starz provides emotional and educational support to teens and young adults (13-40 years old) as well as their families and caregivers. This Facebook group focuses on sharing experiences and providing opportunities to network, post disease-related information, and share common concerns.

Leader: Amy Gietzen (716) 479-0756 | SuperStarz@SclerodermaTriState.org



Scleroderma Prime provides emotional and educational support to patients 50 years and up. This Facebook group is a safe, non-judgmental forum for its members to speak openly and share ideas for coping with the struggles faced by those with scleroderma in an environment of mutual support.

Leader: Paulette Reed (716) 400-2197 | Prime@SclerodermaTriState.org

Call 800-867-0885 - update your contact information and receive the latest Tri-State news.



How can you raise funds and awareness in 2019? Through peer-to-peer events!

Wondering what you can do?

Consider planning and hosting an event - a great way to raise funds and awareness for scleroderma. There are many third party event possibilities. Consider a golf outing, bowling night, theme party, hosting a dance or a night on the town at a local pub. Donate the proceeds from your event to the Tri-State Chapter and you'll make a difference, all while raising scleroderma awareness and having fun!

Organize an event to fit your lifestyle and schedule.

Choose an event based on your ability, energy level and time constraints. There's a third party event idea that will fit every schedule and lifestyle. Maybe you could find a sponsor that will donate one-night's ticket sales from a local performance or \$1 per score for a local team's season? You could host a Battle of the Bands or ask your company to allow a \$5 jeans day. There are so many options just remember to make it manageable and fun!

It all adds up and makes a difference!

We can assist you in developing your idea and promoting your third-party event. We'd love to hear from you!

For guidance call our Fundraising Manager Kyle at 800-867-0885. Check out this A to Z list of fundraising ideas:

Anything-A-Thon

Arts or Crafts Sale

Auction

Bake Sale

Barbecue

Barn Dance

Battle of the Bands

Bike Ride

Bingo Night

Car Wash

Clam Bake

Comedy Night

Costume Party

Dance Marathon

Darts Tournament

Dress-Down Day

Easter Egg Hunt

Egg Drop Contest

Eighties Party

Face Painting

Fifty-Fifty Raffle

Fish Fry

Football Tournament

Game Night

Garden Party

Golf Tournament

Haunted House

Holiday Card Sale

Hoe-Down

Indy Movie Showing

International Food Night

Jewelry Sale

Juggling Competition

Karaoke Night

Kite Flying

Leaf Raking

Limbo Contest

Mardi Gras Night

Masquerade Party

Mask Making Contest

Name That Tune Contest

Open House Tour

Oyster Roast

Pajama Day

Pancake Breakfast

Picnic

Pizza Party

Poker Tournament

Pool Tournament

Quiche Sale

Quiz/Trivia Night

Race

Raffle

Rummage Sale

Scavenger Hunt

Spaghetti Dinner

Square or Swing Dance

Tacky Ties day

Talent Show

Tennis Tournament

Three-Legged Race

Ugly Outfit Party

United We Stand Campaign

Variety Show

Video Game Tournament

Video Marathon

Water Park Trip

Wear Teal Day

Wheelbarrow Race

X-Mas/New Year Party

Yard Sale

Yoga Marathon

Yo-Yo competition

Zany Hat Party

Zoo trip

Zoot Suit Party/Fashion Show

"Forum Feature Film" on SclerodermaVideo.com



You may know, Tri-State films all education forum speakers and makes the videos available at SclerodermaVideo.com...

Do you wonder what's new on SclerodermaVideo? Are you looking for an engaging forum speaker? Maybe you need to refresh your knowledge on a particular topic?



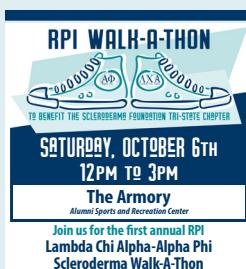
Tune in each month to our Facebook page for the **Forum Feature Film** chosen by Mary Beth Bobik-Kadylak, Tri-State's Director of Patient Education and Support. Beginning November 2018, Mary Beth will hand pick a featured film that is popular amongst our patients, a new addition to Tri-State's video library, or an oldie but goodie. She'll give you insight to what you'll hear and learn from each featured video.

Check out our Facebook page each month to hear Mary Beth's pick for our **Forum Feature Film**! You'll soon discover there is a wealth of information at SclerodermaVideo.com, available 24/7!





Check out these supporters making a difference in 2018!



On October 6th, the Fraternities and Sororities of Lambda Chi Alpha and Alpha Phi at Rensselaer Polytechnic Institute held their first "RPI Walk-A-Thon" to benefit the Scleroderma Foundation, Tri-State Chapter. The event was spearheaded by Alec Passarelli, who has close ties with a scleroderma patient in Stamford, Connecticut. After many months of planning, hard work, and collaboration with staff at the Tri-State Chapter offices; Alec, his attendees, and online supporters were able to raise over \$9,000 in donations!



On October 6th, the Fraternities and Sororities of Lambda Chi Alpha and Alpha Phi at Rensselaer Polytechnic Institute held



Supporters in Buffalo had some Halloween fun on October 27th. A group gathered at Flattery's Bar & Restaurant in West Seneca for the 1st annual "Halloween Beer Bash for Scleroderma". The event ran from 7:00 PM to 10:00 PM. Tickets included an open bar, a 43" LED HDTV door prize entry, Halloween costume contest, snacks & candy, live entertainment, 50/50 drawing, basket raffles, and much more! Organizers made tickets available on Facebook, attendees only had to search for "Halloween Beer Bash for Scleroderma"- or purchase tickets at the door.



Coming up - if you're in the Buffalo area, you can "Paint With A Purpose" to benefit the Tri-State Chapter on November 11th from 2:00 PM to 4:00 PM at the "Painting With A Twist" studios in Lancaster, NY.



Ages 18 and up are welcome. This is a BYOB event, you can bring wine, beer, snacks to enjoy during your class! Of course, no one under the age of 21 will be allowed to consume alcohol. Reserve your space at <http://www.bit.do/paintforsclero>

Both events in Buffalo were organized by our incredibly active, and generous Buffalo Support Group Leaders, Mandy Hebert, and Debbie Golinski. For more information about Support Groups, refer to page 5 of this newsletter.

amazon smile
You Shop. Amazon Gives.

Shopping on Amazon this holiday season?



Support the Tri-State Chapter while you shop!

Visit <http://smile.amazon.com/>
Search for
Scleroderma Foundation Tri-State Chapter

**When you choose
Scleroderma Foundation Tri-State Chapter
- your purchase will help aid our mission
of support, education and research -
at no cost to you!**



DONATE

Consider a Gift of Appreciated Securities

The Scleroderma Foundation funds the largest peer-reviewed research program for scleroderma in the country.

Research is key to finding a cure - we need your help!

One of the most advantageous giving strategies is a gift of appreciated securities. Appreciated securities are stocks and bonds purchased over a year ago that have a current value greater than their original cost.

This has become one of the most popular ways to give for three key reasons:

- Donations of long-term appreciated securities allow the donor to take a tax deduction for the full fair market value of the security.
- As the securities are donated rather than sold, capital gains taxes are avoided.
- If your estate will be subject to the federal estate tax, you could realize a third savings.

Gifting appreciated securities can be more advantageous for you and your donation will make a meaningful difference in our research efforts to find a cure for scleroderma.

To learn more, please consult your tax advisor, or send an email to bcowan@sclerodermatristate.org.



TRI-STATE, INC. CHAPTER

59 Front Street
Binghamton, NY 13905

Non-Profit Organization
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Permit No. 21

The Scleroderma Foundation in no way endorses any of the drugs or treatments in this newsletter; the information is provided to keep readers informed. Because the manifestations and severity of scleroderma vary, individualized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the reader's physician(s) to assure proper evaluation and treatment.

YOUR DONATION HELPS FUND OUR MISSION

Donations of **\$25 or more** include membership to the Tri-State Chapter and the national Scleroderma Foundation.

Name _____

Email (*save postage*) _____ Phone _____

Address _____

City _____ State _____ Zip _____

One-Time Amount _____ or a **Sustaining Monthly Amount** _____

Checks payable to SF Tri-State (*email required*) or **Donate online** www.SclerodermaTriState.org

Credit Card (*all information required*)

Visa Master Card American Express Discover

Card Number _____ Security Code (CVV) _____

Expiration Date _____ Zip _____ E-mail _____

Contribution is made: in honor of in memory of as a donation with membership
 to a 2018 walk participant to a 2018 walk team

Name _____

No acknowledgement needed **Send acknowledgement to:**

Name _____

Email (*saves the organization postage*) _____

Address _____

City _____ State _____ Zip _____

Mail to: Scleroderma Foundation Tri-State Chapter, 59 Front Street, Binghamton, NY 13905