



# SCLERODERMA EXCHANGE

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

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## 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

### National Patient Education Conference Tri-State Chapter receives two awards!

The 2017 National Patient Education Conference was held in Chandler AZ, July 21- 23. Attended by more than 600 patients, family members and caregivers, this is the largest patient focused scleroderma conference held anywhere in the world.

The three-day event featured 77 presentations and workshops organized with 55 scleroderma experts, healthcare professionals and patient presenters. If you have never had the opportunity to attend a conference, mark your calendar for July 27 - 29 of 2018 as the conference will be held in Philadelphia, a short drive for the Tri-State scleroderma community.

We are pleased the Tri-State Chapter was recognized for two 2016 achievements at the conference's annual awards presentation. Read on for all the details.

### Messenger of Hope – Virginia Orzel

The Messenger of Hope Award was presented to Virginia Orzel, Associate Professor and Associate Chair of Communications at The College at Brockport State University of New York.

Professor Orzel used her extensive experience in film and video production to create *"Scleroderma: The Truth"*, a documentary. It offers an overview of scleroderma and shares the journey of three Rochester, New York area patients as they cope with the challenges of scleroderma.

Motivated by her aunt's battle with scleroderma, Virginia Orzel has been an active member of the Scleroderma Foundation's Greater Rochester Support Group for 10 years. In 2015, Professor Orzel received the Provost's Post Tenure Fellowship Grant by The College at Brockport, which she used to help educate the public about scleroderma.



Her film has been screened on campus and at numerous community health agencies followed by panel discussions to educate local healthcare professionals and the general public. Several chapters of the foundation are also screening it and adopting the model of panel discussions. Virginia Orzel received

the Messenger of Hope Award in recognition of her decade-long commitment to raise awareness of scleroderma and advancing the mission of the Scleroderma Foundation. See the film using the link on our site: [SclerodermaTriState.org](http://SclerodermaTriState.org)

### 2016 Outstanding Education Program Kids Get Scleroderma 2!

In 2016, after three pediatric rheumatologists were notified that they were the winners of a multi-center grant from the Scleroderma Foundation, Mary Beth Bobik-Kadyak began a partnership with these physicians to host what would be Tri-State's first juvenile scleroderma focused event.

The physicians involved in the grant award were: Kathryn Torok, MD from the Children's Hospital of Pittsburgh, University of Pittsburgh; Anne Stevens, MD, PhD of the Seattle Children's Hospital, WA and Suzanne Li, MD, MPH from the Joseph M. Sanzari Children's Hospital at Hackensack Meridian Health. They needed to spread the word about their research – we wanted to host a family-oriented event – and the idea was born for *KGS2!* – a two-day event starting with a Halloween costume party and ending with an ice cream social!

Mary Beth, who's been with the Tri-State Chapter since 2011 as the Director of Patient Education & Support was inspired to name the event *KGS2!* - adding an element of awareness that scleroderma can occur at any age. The event wove education, support, and research into a powerful forum that also provided a generous portion of fun and social interaction for the 125 attendees. It took over a year of coordination to put this event together. Dr. Li also enlisted the support of many staff at Meridian Health to support the event with everything from IT services to program organization.

At the 2017 National Patient Conference, Mary Beth accepted the Outstanding Education Program Award for *KGS2!*. She states: *"I am very proud to have been part of this amazing event which was attended by 125 persons from 10 states! The program included sessions for everyone in the family which was an important element, as scleroderma not only impacts the child but the entire family dynamic. I want to thank all of our generous donors who came out in a big way to make this event possible. Also, I'd like to express my gratitude to the parents who took a leap of faith to bring their families from all over the country and put them into our hands for the weekend and of course to all those who did presentations and volunteered to help. The entire event was extraordinary! We are looking forward to partnering with the Colorado Chapter to host our second KGS2 in Aurora, Colorado on October 26 - 28, 2018."*



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# A Message from Our Executive Director

## *Scleroderma Research 2017*

We hope you had or will have the opportunity to attend one of our eight Patient Education Forums in 2017. The common message from our medical presenters is that more research and promising therapies are in the pipeline than ever before.

In April, Dr. Carol Feghali-Bostwick kicked off our educational program with an overview of how researchers and pharmaceutical companies are forging new collaborations. She intrigued the audience by sharing the latest method of producing drugs utilizing plant-based technology.

Additionally, greater awareness of scleroderma within the medical community is bringing about quicker diagnoses for patients, which equates to earlier and better treatment outcomes. New drugs on the market offer medical providers more tools in dealing with a patient's conditions. For example, there are multiple treatment options for Scleroderma-related lung issues, which were not available just five years ago.

Dr. Feghali-Bostwick stressed that the research community and pharmaceutical teams are also focusing on fibrosis (thickening of the skin and internal organs). Dr. Theresa Lu with the Hospital for Special Surgery in New York City is leading a group of researchers that has identified a possible mechanism behind fibrosis, which may one day lead to a treatment for scleroderma. Her research is being funded by a grant from Tri-State, which could not have happened without the generous donations and fundraising efforts made by all of you. She will be presenting an update on her project on November 19 at our annual Scleroderma Research Forum in New York City.

***If you think research is expensive, try disease!***

- Mary Lasker

Working together, everyone associated with this difficult disease is pushing research forward. There is increased hope and optimism for the near future. THANK YOU for all you do to help fund research and move the Scleroderma Foundation's mission forward.

***Happy Holidays and Best Wishes for a Healthy 2018!***



For recordings of our Patient Education Forums, visit:

***[sclerodermavideo.com](http://sclerodermavideo.com)***

Bruce Cowan

Executive Director



**Have you moved? Changed your phone number or address?  
Keep our records up-to-date by contacting us with your new  
information: [sdtristate@scleroderma.org](mailto:sdtristate@scleroderma.org) or (800) 867-0885.**

# TOGETHER WE ARE TRI-STATE!

Visit [WeAreTriState.org](http://WeAreTriState.org) and make a donation by purchasing your own piece of the Tri-State area!

The Scleroderma Foundation manages funding to support research into the cause, diagnosis, potential treatments, and ultimately a cure for scleroderma. Every year these funds are distributed to researchers and scientists through a rigorous review process that focuses on scientific distinction and translational potential.

We receive little financial support from the federal government for our research programs, so this life-saving work is only possible because of people like you. Thanks to our many generous donors, scleroderma research and awareness are progressing at a faster pace than ever before.

At the Tri-State Chapter every member is an important piece of our mission. Every patient's story provides motivation to accomplish our goals. Every Donation gives hope for a cure. For more information visit Tri-State's website: [SclerodermaTriState.org](http://SclerodermaTriState.org).

Visit [WeAreTriState.org](http://WeAreTriState.org) to choose a piece of the map or use the donation form on the back page of this newsletter if you want us to choose a piece for you.



Call our office to get a cash-donation collection form mailed to you: 800-867-0885.

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# Sclderoderma Voices: Amy Gietzen



## What was life like before you were diagnosed with Scleroderma?

I often think back to my life pre-scleroderma and the way I lived, my group of friends and how I treated other people: friends, family, and strangers. I think about how great I thought things were going and how everything I had planned was coming into existence. Amy pre-scleroderma was definitely a procrastinator! I thought I had all the time in the world to travel, finish school, spend time with my family and loved ones and have a serious job. I was an 18 year old in every sense of the word. Self-absorbed, life of the party, and carefree. Not once could I have imagined I would be the Amy that I am now, or go through so much at such a young age.

## How did your diagnosis change your life?

At first, I was in complete denial. I didn't look sick and I thought I was going to be the lucky one, the miracle patient not affected by their disease. Living with Scleroderma has changed me completely. Not just physically but mentally, emotionally, spiritually, and socially. Scleroderma makes everything a little more challenging; getting dressed, showering, and preparing meals, running errands, even brushing my teeth. Tasks once completed in seconds now take several minutes. My appearance was one of the biggest changes. My lips became smaller and thinner, my once blemish free smooth skin became bumpy, tight and tarnished with telangiectasia. Every part of my body seemed to tighten. The skin on my hands became so tight I could barely pinch myself to see if I was imagining the physical ailments. Then came the internal changes. The occasional difficulty in breathing while climbing stairs turned into major breathing problems and sometimes required oxygen at night to help me breathe. I went from gym visits three days a week to being hardly able to walk down the driveway to my car. I had to rediscover who I was in my new body. I had to embrace my disease and live the best life I could or let scleroderma consume me. As scared as I was to be stricken with limitations and the inability to do what I once could do, I was not going to let this disease run my life! I decided to regain control of my body and my life.

## What are you most passionate about?

Advocacy! To reach others living with this disease - through speaking engagements, my online support group **Scleroderma Super Starz**, educational forums and other social media outlets. Helping the scleroderma community and others affected by this disease fills a space inside me that was empty after I was diagnosed. It is an honor to come in contact with so many inspiring survivors!



## What are you surprisingly good at now?

To my surprise, I'm quite good at sewing! I started to sew about a year ago when I made a baby quilt for my godson. I wasn't sure what I was doing but with help from my aunt (a very accomplished quilter), I was amazed by what I created. I've been going to her house once a week ever since and we sew together! She teaches me and I try not to cut off what's left of my fingers in her presence, LOL.



## Where do you find support?

My support has and always will be my family. My parents have been rock stars allowing me to follow my dreams and reach goals while being my rock when times get tough. My parents were so supportive after I was diagnosed! I know it could not have been easy for them. I cannot imagine the pain and heartbreak they must have felt. Seeing their young daughter suffer knowing they couldn't take away my pain. My older sister and younger brother are amazing. They never looked at me differently and heaven help anyone else who does. My niece Samantha is so important to me, she is a secret weapon during

tough times. She is the most honest, smart, talented, and beautiful soul in the world. I have been sick since she was born, 12 years ago, this is the only Amy she knows. Without her love and support, I would not feel so confident in my own skin. My family members are truly the most important people in my life. If it were not for them I don't know what I would have done or if I would even be where I am today. They helped me stay strong and fight for my life, my freedom, my independence and my dreams.

## What are you complimented on most?

I have always had an ability to articulate, give speeches and write stories. Since my diagnosis, I have received many compliments at speaking engagements along with compliments on well-written articles! Which is so amazing. Since being diagnosed I have written over nine articles for an online publication *The Mighty*, a magazine for people living with chronic illnesses who want to voice their truth. I hoped for my work to be published and finally it's happening. I am so proud. *The Mighty* has even made me a contributor!

## Do you have any words for those newly diagnosed with Scleroderma?

I am a firm believer in staying positive and not letting this disease define me. I decided to move forward step by step and find new goals and dreams I can accomplish. My advice for newly diagnosed patients is to fight; for your life, for your dreams, and for the kind life you want to have. Also, have a great solid team of trusted doctors.

## How does your past connect you with your current endeavors?



If I wasn't diagnosed with Scleroderma at such a young age, I don't know that I would have felt so compelled to act on helping others and putting together the support group for young adults and teens. Because I was so young when I was diagnosed it definitely affected me in a major way. I had to quit my job at the young age of 24 and go on disability. I had my first major surgery at the age of 22. I had to give up my dream of becoming an RN and drop out of school at the age of 20 and

not finish my degree. I had to receive chemotherapy type drugs and because of that, I was no longer able to have children. All of this has led me down a path of helping others by telling my story, hoping others like me will realize that although it is tough and major life changes may happen it does not mean life is over. You can accomplish goals and strive for a great life. If I had my life to do over I would not change getting scleroderma. Scleroderma has brought me many hardships, pain and difficult times, but it has also brought me joy, lifelong friendships, exciting adventures, inspirational memories and a purpose - helping others fight. I am truly grateful for the opportunities I have been given.

## Who is the ideal Scleroderma Super Starz, and why should they connect?

**Scleroderma Super Starz** started for young adults or teens diagnosed with Scleroderma. I also have members in the group that are "Young at heart". I will never say "NO" to anyone who needs support or help. The group is for anyone with scleroderma looking for answers and support. **Scleroderma Super Starz** a safe haven where members speak freely about their journey with scleroderma and how it has affected their lives. The group is also open to caregivers, loved ones, close friends and spouses of the patients with Scleroderma. I incorporated a lot of fun things to keep others positive and learning. **Scleroderma Super Starz** is for people who are fighting for their lives refusing to let scleroderma win!

## Is there more you would like to share?

My overall message is that it does not make you weak to need support. Allowing people to help you, is not accepting pity. In fact, it takes a very courageous and strong person to ask for and accept help. This disease is so unpredictable and devastating on so many levels. I want others to know there is hope and there are people like you, willing to listen and fight alongside you. Sometimes young voices are not loud enough to be heard, but we have something to say and our thoughts and opinions matter. If your voice is too soft to be heard, I will be loud enough for everyone! We are the future of the disease. I am fighting for our future and opportunities to make a difference.



**"We can make a difference - it starts with us!"**



# 2017 Patient Education Forums

Special thanks to the doctors who donate their time - making our education forums outstanding events!

**August 19, 2017**

**Daemen College, Amherst, NY**  
Mary Margaret O'Neil, MD  
Jennifer Frustino, DDS, PhD

**September 16, 2017**

**The Bone & Joint Center, Albany, NY**  
Aixa Toledo-Garcia, MD  
Vivek R. Mehta, MBBS

**September 30, 2017**

**UConn Medical Center, Farmington, CT**  
Santhanam Lakshminarayanan, MD  
William E. Traverse, MD

**October 14, 2017**

**Rochester Educational Opp. Center, Rochester, NY**  
Katie Orem, MPH and Katherine Adamides, Esq  
R. James White, MD, PhD

**October 22, 2017**

**Rutgers University, New Brunswick, NJ**  
*Presented in partnership with the Delaware Valley Chapter*  
Fabian Mendoza-Ballesteros, MD and Kerri Akaya Smith, MD

**November 19, 2017**

**Annual Research Forum - HSS, New York, NY**  
Robert Kaner, MD  
Theresa Lu, MD, PhD

**December 9, 2017**

**Mt. Sinai, New York, NY**  
Margrit Wiesendanger, MD  
Ioannis Tassioulas, MD and Maria L. Padilla, MD

**Visit [sclerodermavideo.com](http://sclerodermavideo.com) for recordings from our 2017 events.**

## LOOKING FOR A SUPPORT GROUP?

Visit [sclerodermatristate.org](http://sclerodermatristate.org) for more information.

**EASTERN CONNECTICUT**  
EasternCT@scleroderma.org

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### SUPPORT VOLUNTEERS:

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These sessions provide education, support and an opportunity to listen to and ask questions of featured speakers, other attendees and the Tri-State Chapter. Visit the Tri-State website for the meeting schedule and information on how to join a Tri-State Connect support group meeting call. Leader: Jan Nitti-Gnall, MPH, MT  
email: [TSConnect@scleroderma.org](mailto:TSConnect@scleroderma.org) | call: (973) 997-5590. Check out previous meetings on YouTube: <http://youtube.com/c/sftristate>

### FACEBOOK SUPPORT GROUPS:



**SCLEROMEN**  
TOGETHER WE ARE STRONG  
SCLERODERMA FOUNDATION TRI-STATE CHAPTER

Because scleroderma manifests itself in a unique way in men, their issues and concerns are unique as well. This support system provides a means for men with scleroderma to connect with each other - share stories, seek advice and ask questions - in a caring and supportive environment. Become part of an understanding and educated group of men finding ways to deal with scleroderma and its complications. Only men with scleroderma may join by request.  
Co-Leader: Andrew Botieri (508) 982-7523 | [Scleromen@Scleroderma.org](mailto:Scleromen@Scleroderma.org)  
Co-Leader: Lee Korotzer | [LKorotzer@yahoo.com](mailto: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 & caregivers. The group focuses on sharing experiences and providing opportunities to network, to post disease-related information, and share common concerns. A safe, non-judgmental forum for members to speak openly and share ideas for coping with the struggles faced by those with scleroderma in an environment of mutual support.  
Leader: Amy Gietzen (716) 479-0756 | [SclerodermaSuperStarz@Scleroderma.org](mailto:SclerodermaSuperStarz@Scleroderma.org)

## Tri-State Scleroderma Awareness items – prices include shipping

Purchase **#UNTEALTHESACURE** awareness apparel items today! Tell the world you support finding a cure for scleroderma!

If you post a pict and tag us you'll be entered to win a prize! **#UNTEALTHESACURE**

Order online at [Scleroderma.org/sftawareness](http://Scleroderma.org/sftawareness)



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Embroidered Blanket \$25 each



Power Bank Charger \$5 each

## Raising funds and awareness through third-party events!

### Wondering what you can do to raise funds?

Consider planning and hosting a third party event - a great way to raise funds and awareness for scleroderma. There are many third party event possibilities. Consider a golf outing, bowling night, themed 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 while raising awareness and having fun!

### Organize a third-party 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 will assist you with guidance during the development of your idea and promotion of your third-party event. We'd love to hear from you! Below is an A to Z list of some fundraising ideas to get you started. For guidance call our Fundraising Manager Kyle at 800-867-0885.

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

# Giving is easier than you may think . . .

## 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
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you sign into

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your purchase will help  
aid our mission  
of support, education  
and research,  
at no cost to you!



## Consider a Gift of Appreciated Securities

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

key to the cure and 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.

Giftgiving appreciated securities is far more advantageous for you, the donor, and your donation will make a meaningful difference in our research efforts to find the cure for scleroderma.

To learn more, please consult your tax advisor, or send an email to [bcowan@sclerodermatristate.org](mailto:bcowan@sclerodermatristate.org).

No longer want to receive our newsletter? Or receive it by email only? Please call 800-867-0885 to help us Go Green!

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.

## Together We Are Tri-State! *(see page 3 for details)*

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**Checks payable to SF Tri-State** *(email required)*

**Donate online: [WeAreTriState.org](http://WeAreTriState.org) or [SclerodermaTriState.org](http://SclerodermaTriState.org) for a general donation.**

**Credit Card** *(all information required)*

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Card Number \_\_\_\_\_ Security Code (CVV) \_\_\_\_\_

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Name \_\_\_\_\_

**Send acknowledgement to:**    **No acknowledgement needed.**

Name \_\_\_\_\_

Email *(save postage)* \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Donations of \$25 or more includes membership to the Tri-State Chapter and the Scleroderma Foundation on the national level.

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