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.

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.”

Message 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
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!

Bruce Cowan
Executive Director

For recordings of our Patient Education Forums, visit: sclerodermavideo.com.

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 or (800) 867-0885.
TOGETHER WE ARE TRI-STATE!
Visit 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.

Visit 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.

Help us fund the search to cure Scleroderma.

The RxCut® Prescription Savings Card is FREE with NO enrollment, activation or expiration date. There are over 67,000 participating pharmacies across the U.S. and Puerto Rico.

Call us to get your card and start saving IMMEDIATELY! We’ll also send you cards for family and friends. Scleroderma Tri-State Chapter 800-867-0885

THIS IS NOT INSURANCE – VOID WHERE PROHIBITED BY LAW

Take control of health care expenses for the whole family, pets included!

Save up to 87% on your prescriptions.
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 telangiectasias. 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 going 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?
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 world. 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 too 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 is 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 Tassiulas, MD and Maria L. Padilla, MD

Visit sclerodermavideo.com for recordings from our 2017 events.

Looking For A Support Group?
Visit sclerodermatristate.org for more information.

Eastern Connecticut
EasternCT@scleroderma.org

Greater Enfield, CT
EnfieldCT@scleroderma.org

New Haven, CT
NewHaven@scleroderma.org

Bergen County, NJ
BergenCountyNJ@scleroderma.org

Northern NJ
NorthernNJ@scleroderma.org

Albany Capital District, NY
Albany@scleroderma.org

Greater Rochester, NY
Rochester@scleroderma.org

Long Island, NY
LongIsland@scleroderma.org

Nassau/Queens, NY
NassauQueens@scleroderma.org

New York City
NYC@scleroderma.org

Orange County, NY
OrangeCounty@scleroderma.org

Support Volunteers:

Adirondack Region, NY
Plattsburgh@scleroderma.org

Central Region, NY
CentralNY@scleroderma.org

NYC, NY Region
StatenIsland@scleroderma.org

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 Gitzen (716) 479-0756 | SclerodermaSuperStarz@scleroderma.org
Call us to purchase these Tri-State awareness items 800-867-0885

Order online at Scleroderma.org/sftsawareness

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
- 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
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.

Gifting 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.

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
• Combined Municipal Campaign & CUNY choose 2539

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

Name ____________________________________________________________

Email (save postage) __________________________________________ Phone __________________________

Address ____________________________________________________________________________________________

City __________________________ State __________________________ Zip __________________________

Amount $________ # of puzzle pieces ________ ($50 for each We Are Tri-State puzzle piece)

Checks payable to SF Tri-State (email required)

Donate online: WeAreTriState.org or SclerodermaTriState.org for a general donation.

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 Together We Are Tri-State donation

Name ____________________________________________________________

  □ Send acknowledgement to:  □ No acknowledgement needed.

Name ____________________________________________________________

Email (save postage) ______________________________________________

Address ____________________________________________________________________________________________

City __________________________ State __________________________ Zip __________________________

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

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