



SCLERODERMA EXCHANGE

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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*



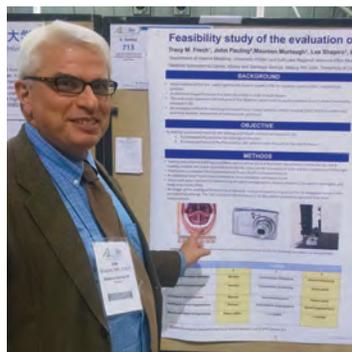
Doctor of the Year Dr. Shapiro

The Scleroderma Foundation annually presents the Doctor of the Year Award to a physician whose exemplary dedication to advancing patient care is well known to many within the

Scleroderma Foundation family. The winner of the 2016 award is Dr. Lee Shapiro of Albany, New York. Over the years, Dr. Shapiro has been an invaluable resource to the Scleroderma Foundation's leadership and has quietly but indelibly made his mark on patient care and the scleroderma community. Dr. Shapiro is director of the Steffens Scleroderma Center and is also co-director of the St. Peter's Pulmonary Hypertension Center, both in Albany. Dr. Shapiro is an active participant in the teaching program of Albany Medical College and a former Chief of Rheumatology at St. Peter's Hospital in Albany. In 2007, he received the "Distinguished Physician Lifetime Achievement Award" at the Scleroderma Foundation's national gala.

Dr. Shapiro is a graduate of Yale University and Columbia University School of Medicine. He entered the practice of rheumatology in 1982 after completing his residency and fellowship training at the University of Pittsburgh/Presbyterian-University Hospital. His practice is limited to adult rheumatology with a particular interest in the management of scleroderma. He spent a recent sabbatical at the Scleroderma Clinic of the Royal Free Hospital in London. He is the author of numerous publications in peer-reviewed journals and also has written several self-help patient guides. He is a contributor to the American College of Rheumatology (ACR) self-assessment program and is a Fellow of the American College of Physicians as well as a Fellow of the American College of Rheumatology.

A member of the Tri-State Medical Advisory Board, Dr. Shapiro is a frequent guest speaker for Chapter educational programs and at support group meetings, as well as a contributor to our "Ask the Doctor" column of the Scleroderma Exchange



newsletter. He is well respected by his patients and a great supporter of the Tri-State Chapter.

Long time patient and Chapter volunteer, June Bender sums Dr. Shapiro up best when she says he "exemplifies the title "2016 Doctor of the Year"!"

His commitment to the care of each scleroderma patient he sees and his tireless clinical research, along with his overwhelming support of our scleroderma community are making a difference in the lives of scleroderma patients and their families!"



DiDi & Gerry Kirschner

Good-Bye Friend

Gerold Kirschner, one of the earliest members of the Tri-State family, passed away on August 23. He was a member of the Board of Directors seemingly since the organization was founded in 1981 under the name

Scleroderma Society. He served until 2015 when he was awarded Board Emeritus status.

Through all those years he served diligently honoring his beloved wife DiDi who was stricken with scleroderma. After DiDi's death in 1995, Gerry stayed with the organization to faithfully raise funds and lend his business sense. His many contacts made as CEO of Glamorise Foundations and in other circles as well as his love of golf were put into play as he organized dinners and an annual golf tournament – at a golf club and later virtually – to benefit the work of Tri-State. His son Mark was an ardent supporter, making sure these events were well orchestrated.

Long time Tri-State board member, Estelle Randolph met Gerry through the Board and worked with him on many events. She notes that he was "quite a gentleman and truly devoted to DiDi. He was a smart, caring man and great conversationalist; a pleasure to talk to and work with". As we celebrate 35 years of service to the Tri-State area, we look forward with hope and fondly back remembering Gerry and the tremendous support he was to many, like his DiDi. *Shalom.*

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If we have inadvertently omitted or misspelled your name, please let us know by calling (800) 867-0885.

A Message from Our Executive Director

Forever changed

From the day I first saw the word scleroderma, like many of you, I was changed.

Learning how to say scleroderma was one thing, learning what it meant was yet another. Since then I have learned a lot, but I have never felt the pain or the profound fatigue that sets in; I have no clue the sense of loss one feels when their hands can no longer do familiar tasks; I cannot fathom looking into the mirror and seeing a reflection that is different from the one known; I don't know the stress of recounting to my doctor an illness he does not know or she cannot recognize; I have not experienced the fear that comes with realizing your body's systems are beginning to fail.

I have not suffered any of these problems, yet I have been invited to witness the disease in an intimate way, through your eyes. You have adopted me into your community. You have allowed me to witness the amazing constitution with which you deal with our disease. You have shown how to overcome overwhelming issues and have the fortitude to seek the best life possible. Your attitude and desire to choose not to give in, has made serving through my work at the Tri-State office worth every bit of effort.

As the year ends, I will be leaving the Tri-State Chapter to begin a new adventure. Like many of you have found when making life choices, caring for loved ones takes precedence. Your example makes the choice to take this step easier. Please know, you have impacted me profoundly and this disease has changed me, too.

Thank you to the staff, volunteers and many patients and caregivers that make up the Tri-State Chapter.

Blessings on each of you as you continue the fight.



Jay Peak

Executive Director



Giving is Easy with Payroll Deduction!

Can you 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 6688
- State Employees Federated Appeal choose 999-00581
- Combined Municipal Campaign & CUNY choose 2539

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.

Tri-State Voices on The Hill



Beatriz & U.S. Rep. Peter King

In September the Scleroderma Foundation organized a sojourn to Washington DC where fifty Scleroderma patients and other advocates from across the country walked the halls of Congress to tell the scleroderma story. The Tri-State contingent included patients Beatriz Nunez (Brentwood, NY) and Prasha Tuladhar (Elmhurst, NY) and her husband Dipak plus Tri-State board president Bruce Cowan. This was an opportunity to tell personal stories to help advance understanding of scleroderma and promote greater federal research funding.

David Murad, Scleroderma Foundation Director of Chapter Relations and event organizer noted that “ultimately, our goal is to get co-sponsorships of bills to ensure ongoing and additional research funding which may or may not happen with the 114th Congress. For me, the ‘success’ of the event is measured by the strength, resilience, and tenacity of the patients who faced the physical obstacles of the day (full schedule of meetings, distance between meetings, etc.) to tell their stories.”

The Scleroderma Exchange asked Beatriz and Prasha to share some of their observations about the experience as both were first timers to Capitol Hill.



Beatriz Nunez on Capitol Hill

When asked why she wanted to be involved with the Capitol Hill Day, Beatriz responded “I felt it was awesome that we can speak to our representatives and senators about the disease so many of us are fighting and how important research is.” Prasha reflected “this disease has been there for over 150 years and still there has not been any breakthrough. It is pivotal to make more funds available for research for Scleroderma...”

Neither had difficulty telling their story to different legislative

leaders. As we well know, scleroderma can have a way of taking over your life. They were able to reflect on their history with the disease relate some very personal details. Beatriz has had the disease for many years and told of her ups and downs. Prasha has a shorter history, with the disease. She has already survived life-or-death situations as well as lung transplantation and has a great appreciation of science, medicine and organ donors that have kept her alive even through a high-risk pregnancy and the birth of her daughter.



When asked about their best memory from the experience, Prasha replied, “most memorable moment was when Peter King showed interest in my medicines and how full of energy I was and how he bet I would be running a marathon next year.” Beatriz noted the many people listened and others that were so helpful all day; “they were so wonderful.”

While before the trip, neither of our Tri-State voices pictured them themselves as advocates, looking back they realize their story is powerful, and they were heard on Capitol Hill. Thanks Prasha, Dipak, Beatriz and Bruce for making your voice count!

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Shopping on Amazon this holiday season?

Support the Tri-State Chapter

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

By choosing **us**, each time you sign into **<http://smile.amazon.com>**, your purchase will help **aid our** mission of support, education and research, **at no cost to you!**



Together We Make a Difference

Thank you for all that you do. This past year has proved to be another great success for the Chapter. Together with volunteers and supporters, the Tri-State Chapter was able to produce numerous programs and events! No one has to feel like they are alone in their battle with scleroderma, because together **we are here.**

Health Fairs/Awareness Events Coordinated: 25

Educational Programs Presented: 10

Support Groups Active: 19

We are thankful for our National Gold Sponsor Actelion, and Bronze Sponsors Bayer and Reata for their generous donations that played an integral role in our educational forums this year.



We would also like to extend gratitude for the guest speakers that participated at our educational events. It was wonderful to see new faces from different organizations and schools in attendance.

We will continue to invite physicians and allied health professionals to learn more about scleroderma in order to better understand the needs of those that deal with it every day of their lives.



2016 Tri-State Accomplishments

Celebrating **35** years of service to the Tri-State area

Tools for success provided to **13** Tri-State walks



Hosted **10** educational forums -Free for patients and families

provided over **70** internet video streaming talks @ SclerodermaVideo.com



Assisted **19** support groups throughout the Tri-State area

In the past decade, Tri-State donors have helped the Scleroderma Foundation invest more than **\$11.9 million** in research



Get to know your board



Debra Signorelli

Debra was elected to the board in 1991. She hails from New York, NY and serves on the Conflict of Interest Committee and is a former board Vice President. She earned her degree from Berkley College and is the Director of Commercial

Clearance at Saatchi & Saatchi.



Marc Krieger

Marc joined the board in 2011. He is the board Vice President and is Chair for the Conflict of Interest Committee and the Fundraising Committee. Marc is also a part of the Executive Committee and is the co-leader for the Ridgefield

Park Walk. Marc is currently the Senior Vice President at Avison Young, a real estate solutions company. He founded and coached Pascack Lacrosse as well as coached for the Hillsdale Soccer Association in New Jersey, where he resides. In his spare time he likes to golf and enjoys photography.



Jeffrey Toromoreno

Jeffrey joined the board in 2016 and serves on the Fundraising Committee. Residing in Woodhaven, NY, he is a volunteer for the Manhattan walk. He is Senior Vice President for Citi Risk Management.

Jeffrey applies his networking, fundraising, financial analysis and data analytic skills to his involvement with the NYC Chapter of the National Society of Hispanic MBAs, Dean's Diversity Advisory Council at UVA Darden and as a founding member of the Latino Networks Coalition.



Mary Contadino

Mary joined the board in 2015. She serves as Chair of the Audit & Finance Committee and is part of the Executive and Human Resources Committees. Residing in Stamford, CT, she is a Coordinator for the Stamford walk. She earned her degree

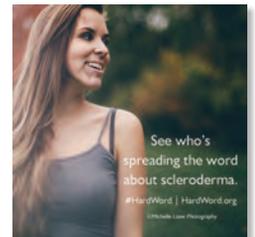
from Pace University in New York and is Director of Accounting at Newell Brands. She is also a board member for Insitute Management Accountants (IMA) Westchester Gateway Chapter and the IMA Regional Council, where she has served as past president for both along with other board positions.



“Hard Word. Harder Disease.” Part 3

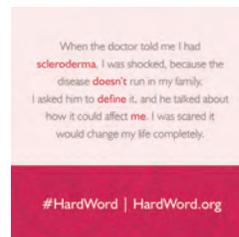
Throughout June, Scleroderma Awareness Month, the Scleroderma Research Foundation, Scleroderma Foundation, and Scleroderma Society of Canada presented the third edition of the “Hard Word. Harder Disease.” scleroderma awareness campaign. The campaign message was primarily spread through social media, particularly Facebook, Twitter, and the Mom Central blogger network which featured writers from the U.S. and Canada. The campaign’s final push was to promote World Scleroderma Day on June 29 utilizing a Thunderclap event which allowed a single message to be transmitted at 12:00 noon (EDT) on June 29 through participating follower’s Facebook and Twitter channels.

Each partner used the campaign as the central theme of its Scleroderma Awareness Month promotional efforts and augmented the effort by encouraging and mobilizing their own scleroderma community to share with social media friends. Constituents of all three organizations were encouraged to be part of the awareness generating process through simple sharing of messages with people they know. Patients and their caring circle were energized by the quality messages and international nature of the campaign. The campaign was quite successful providing an organized method of educating those, who through association with patients, have a reason to care.



The 2016 campaign achieved more than 5.71 million viewer impressions which were up almost 1.5 million from the 2015 campaign. As in the past couple of years, the scleroderma cause and greater good of serving patients was showcased. The three organizations also found common ground and used our resources to do something it would be very difficult to do alone.

There continues to be a great need to inform the public as well as the medical community about scleroderma. The ripples we have initiated over the three years have extended awareness of our disease. Plans are forming to extend that ripple even more in 2017. Approximately 100 countries around the world participated. After two successful years, a follow-up campaign slated for 2016 is being discussed. We believe that the partnership between the Scleroderma Society of Canada, the Scleroderma Research Foundation and the Scleroderma Foundation has helped hasten the pace of increased understanding of scleroderma.



KGS2!

Kids Get Scleroderma Too!



The planning began with an idea – how can we partner with local physicians to hold an event forum specifically focused on juvenile scleroderma? Our work took off soon enough as we started to build a

relationship between Tri-State and three pediatric rheumatologists who had submitted and were given a grant from the Scleroderma Foundation to do a research project focused on children.

Planning for KGS2! (Kids Get Scleroderma Too!) got started in January 2016. The plan involved organizing a program that would give specific information to a variety of people based on age. Suzanne Li, MD, MPH from the Joseph M. Sanzari Children’s Hospital at Hackensack UMC kept our momentum going with meetings, and numerous emails and phone calls. Dr. Li also recruited variety of people from Hackensack to help direct and guide us as well as to host the event at their John Theuer Cancer Center. Kathryn Torok, MD a pediatric rheumatologist from the Children’s Hospital of Pittsburgh, University of Pittsburgh.

To kick off this special event, we planned an exciting Halloween Costume Party at the Hilton Hasbrouck Heights – from the Skyball Room attendees enjoyed an awesome view of the NYC skyline. The party featured a DJ who rocked us through the night, a photobooth that was very popular especially with our young attendees; awesome food and plenty of treats for all! Mary Beth Bobik-Kadylak

played hostess that night and felt that an icebreaker was key to the event’s success – “it was a great way to break the ice, dance and be silly while getting to know the kids and their families a bit better.”

The next morning, the conference was held at Hackensack UMC and included a keynote speaker, break-out sessions based on group needs and wrapped up with door prizes, and ice cream sundae bar and the exchange of information between parents to keep the momentum going long after the day closed. The conference itself was attended by one hundred and twenty-five persons including physicians from five states and families from ten states - some from as far away as Washington and California! The conference was divided into sections for siblings, kids 5-12, teens 13-17 and adults. We hoped to provide specific programs that were meaningful to all attendees based on age - and it worked very well!

Special thanks to our sponsors who were so important to our success including: Actelion, Bayer, Reata, FibroCell, A Lasting Mark, Mr. Speaker, DEG Sound, the Marion Brucker Legacy Fund and Hackensack Meridian Health!



Patient Education is a priority for the chapter!

This year we planned and provided 10 educational opportunities for patients and families held free of charge for all!

April 24

Hospital for Special Surgery - New York, NY
Richard Burt, MD
Christy McCaffrey

May 15

Stony Brook University Hospital
Howard Blumstein, MD
Paul Strachan, MD

August 27

Geisinger Wyoming Valley Medical Center, Wilkes-Barre, Pa
Joint effort with NEPA Pulmonary Hypertension Support Group and the DVC
Robin Lucas, MD, FACP, FCCP
Carol Artlett, PhD

September 10

The Bone & Joint Center, Albany, NY
Jessica Farrell, PharmD
Mitchell Miller, PharmD Candidate
Patricia Fennell, MSW, LCSW-R

September 27

Yale University, West Campus, CT
Lenore Buckley, MD, MPH
Wassim Fares, MD
Oana Zaha, MD

October 8

Rochester Edu. Opportunity Center, Rochester, NY
Janet Pope, MD, MPH, FRCPC
Christine Jean-Jacques, PhD

October 10

Mt. Sinai Beth Israel, New York, NY
Roxana Sulica, MD
Erin Patton, MD, MPH
Charles Melone, MD

October 16

Rutgers University Student Center, New Brunswick, NJ
Joint Effort with Delaware Valley Chapter
Valentina Lyssova, DDS
Vivien Hsu, MD

October 28

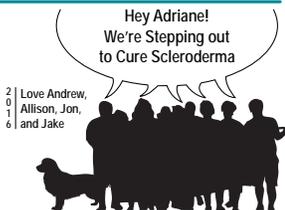
KGS2! (Kids Get Scleroderma Too!)
Hackensack University Medical Center, Hackensack, NJ
Suzanne Li, MD
Kathryn Torok, MD
Anne Stevens, MD
Theresa Lu, MD - As well as health care professionals from Hackensack UMC

November 20

Hospital for Special Surgery, New York, NY
Alan Baer, MD
Alessandra Pernis, MD
Robert Spiera, MD - Moderator

Miss a forum? Visit www.sclerodermavideo.com to view many of these sessions and a variety of recordings from prior years.

Due to an oversight, Adriane Schorr was not included as a Primary Volunteer for the Westchester walk. We are very sorry for this oversight.



Tri-State Welcomes New Staff



Mallory Evans, Fundraising Manager.

Mallory will be taking over all the fundraising efforts when Alex Matich retires. She is coming to the Foundation from the American Cancer Society where she ran Relay For Life Events. Mallory lives in the Binghamton area with her husband, 10 month old daughter, Amelia and their dog and cat. Mallory sings and plays guitar in a band called Next To Kin, who released their first CD earlier this year!

Candice Snider, Operations Specialist.

Candice functions as the bookkeeper as well as IT support for the chapter. Before joining the Tri-State staff, she was a safety manager and bookkeeper for a local trucking firm. Candice enjoys spending time with her husband, John, and camping.



Marylouise Doyle, Communications Manager.

Marylouise handles marketing communications and design related to fundraising, social media, patient support and education. She has spent her career in the creative fields including several years designing for an academic book and journal publisher as well as a major office products manufacturer. She devotes her spare time to crafts, flower gardening, DIY home projects, and spending time with Randy, her boyfriend of 26 years and her cats, Henry and Lucy.



Scleroderma Awareness Items

All prices include shipping



Zipper pull
\$2.00 each
Qty_____



Portable power bank
\$10.00 each
Qty_____



Bottle opener
\$2.00 each
Qty_____



Lapel pin
\$3.00 each
Qty_____



Knit gloves
\$5.00 each
Qty_____



Car magnet
\$3.00 each
Qty_____



Baseball cap
\$10.00 each
Qty_____

Please note:
Some Scleroderma Awareness Items are limited in quantity.

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Visa MasterCard AmEx Discover

Credit Card # _____

Exp. Date: ____/____/____ Security Code _____

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Scleroderma Foundation Tri-State Chapter 800-867-0885

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.

Make a Donation. Make a Difference.

Donation of \$25.00 or more includes membership in both Tri-State Chapter & the national Scleroderma Foundation

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Email (save postage) _____ Phone _____

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Amount _____

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

Credit Card (all information required)

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Card Number _____ Security Code (CVV) _____

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Contribution is made: In honor of In memory of Dues Donation
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No acknowledgement needed **Send acknowledgement to:**

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