



SCLERODERMA EXCHANGE

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Scleroderma Foundation Tri-State Chapter
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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

Advocacy Efforts Advance the Foundation's Education & Research Mission

Reprinted from Scleroderma Voice

Over the past few years, you've probably seen numerous articles and emails about the Scleroderma Foundation's Advocacy Program and requests for you to respond to an "Advocacy Alert." 2016 will be no exception in our efforts to make scleroderma a more recognizable disease among our nation's law makers.

"I view advocacy work as an important part of our overall mission," explained Foundation CEO Robert Riggs. "The time and energy we devote to advocacy advances education and, of course, research."

While the news is filled with stories about dysfunction and discord in Washington, we can't lose sight of the fact that the United States Government is the largest funder of medical research in the country through the National Institutes of Health (NIH) and the Department of Defense (DOD), and that includes being the largest funder of scleroderma-related research, too. "Engagement with federal officials is absolutely essential if we hope to maintain current levels of scleroderma funding let alone seek much-needed increases," said Riggs.

The voice of the scleroderma community has had tremendous impact and helped us to achieve some major milestones in 2015, including getting scleroderma listed as an "approved" condition eligible for funding through the DOD's Peer-Reviewed Medical Research Program that makes available hundreds of millions of dollars for which scleroderma researchers can apply. Additionally, the Scleroderma Foundation and its advocacy teams have joined many organizations calling for an increase in funding for the NIH, resulting in a \$2 billion increase, the first major increase in 12 years. We've also been successful in introducing the "Scleroderma and Fibrosis Research Enhancement Act" into the House of Representatives, and soon, we anticipate it being introduced into the Senate.

"Advocacy work is never done," said Riggs. "Each year, we have to roll up our sleeves and work to make our voices heard as a community. If we slack off, we will see scleroderma-related research dollars evaporate from the Federal portfolio. The old saying, 'the squeaky wheel gets the grease' is absolutely true when working with the government. If we don't fight for funding and recognition, we won't get it. We have to keep our voices heard."

To that end, the Scleroderma Foundation has identified six strategic advocacy goals for 2016:

- To ensure scleroderma remains listed as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) in Fiscal Year (FY) 2017.
- Expand the scleroderma research portfolio at the National Institutes of Health (NIH) through growth in FY 2017 appropriations and demonstrated congressional interest in this area.
- Advance House and Senate scleroderma legislation (the Scleroderma and Fibrosis Research Enhancement Act) through the legislative process and, ultimately, to enactment.
- Participate in efforts to improve access to quality, affordable healthcare and innovative therapies.
- Cultivate a national network of grassroots advocates capable of effectively engaging their elected officials to advance a legislative and public policy agenda.
- Stay current and engaged on relevant legislative and public policy issues by monitoring media outlets, participating in coalition advocacy activities, and attending events on Capitol Hill.



Scleroderma and Fibrosis Research Enhancement Act (H.R. 3666) author Congressman Peter King with a contingent of Tri-State advocates.



2015 Walk Correction

It has come to our attention that there was an error in Volume 3, 2015 of the Scleroderma Exchange. The person who raised the most money for Stepping Out to Cure Scleroderma - Hartford was Ruth Saphirstein. We are very sorry for this error.

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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

35 Years and Beyond

It is easy to get bogged down. Sometimes we get caught-up with the things in front of us and don't take the time to lift our head and project the future or consider how we got to where we are. It often takes a challenge to remind us that life is more than the narrow focus of the here and now.

The Tri-State Chapter has a long history of striving to meet its three-fold mission focused on research, education & support. In fact, the track record spans 35 years since chapter founder's Mark and Helene Flapan decided to make a difference for others and establish our non-profit organization. In the early years, they reached out to patients and generated awareness from their Manhattan apartment. Fast forward to today, where as a chapter of a national organization, we strive to meet and expand on the same objectives - with six employees working to support patients and families across three states, raising thousands of dollars each year and sharing the scleroderma story to a wide array of audiences. In other words, while the organization has grown, we have held true to the mission established 35 years ago.

Over the next year or so, you will see us celebrating the history of the Chapter as well as challenging everyone – staff, board, volunteers, patients, families, caregivers, and medical professionals – to accomplish our mission in new ways. The Tri-State board and staff have developed a strategic agenda to help guide our direction over the next three years. The agenda builds on our current programs and encourages focused attention on getting our story to a broader audience of medical professionals and the general public. More people understanding the issues and supporting research will help meet our ultimate goal: find a cure for scleroderma.

Thirty-five years of service is an enormous milestone and the development of a strategic agenda provides structure for the future. Both hold great opportunities that challenge us and ensure that we stay focused on the bigger picture while remaining diligent in pursuing our mission.

This edition of the Exchange touches on several ways you can be involved with celebrating and moving ahead. We are excited to advance together.

Jay Peak

Executive Director



Advocacy Ctd.

Each of these strategic goals has numerous initiatives associated with them. They range from work with coalition members, such as the National Organization for Rare Disorders (NORD) and the American Autoimmune Related Diseases Association (AARDA), and other strategic partnerships. There will also be trips to Capitol Hill, advocate meetings in local offices of elected officials, engagement with the U.S. Food and Drug Administration and meetings with NIH leadership.

“Most important is the engagement of our own community,” said Riggs. “The voices of patients and their families and friends are the most powerful resource we have. As we work on the strategic goals for 2016, we'll be asking for our community's help once again. For a relatively small organization and community, we've moved mountains. 2016 is no time to put down our shovels!”

For more information about the Scleroderma Foundation's Advocacy Program and to learn how you can become involved, visit www.scleroderma.org/advocacy



There are many easy, fun ways to raise money!

A question we get at the office often is “What else can I do to help raise money and defeat scleroderma?” Our first response to people is to check out our walks online and organize a team. This is a great way to raise awareness and funds for our organization. While this is more than enough for some people, many would like to do something more creative.

You are only limited by your imagination, the sky is the limit when it comes to fundraising. From a “golf fundraiser” to a “night of board games” to a “pancake breakfast” or “spaghetti dinner” to a “homemade quilt raffle” to a “battle of the bands” to a “dinner dance” the options are endless. If you so choose, you can do one-time or annual fundraisers. There are no requirements. You can hold a fundraiser to raise money for you or your team at a walk or totally independent from a walk.

During 2016 the Tri-State Chapter is celebrating its 35th Anniversary. The logo you see here will find its way onto many things, including the walk shirt and some banners this year. We suggest that if your fundraiser is independent of the walk, that you think about doing it in October 2016, if it is an inside event, or April 2017 to wrap up the year, if an outside event.

Imagine a basketball team finding a sponsor willing to donate \$1 a point scored by your team during the month or season; or maybe a Broadway theatre performance donating one-night's ticket sales; or a penny fun night at your local school with all proceeds being donated. There are countless different ways that you can help raise funds.

We can assist you but only in a limited capacity because it is **your** event. We can promote what you are doing but the work, fun and smiles are all yours. Please call Alex and he will be happy to talk with you about making your ideas become a reality.



10 Creative Fundraising Ideas

Fitness Class - Host a fitness class and charge a small fee to attend. Hold raffles after the class is over.

Dinner Dance - Host a virtual or real dinner dance and charge admission.

Restaurant Night - Many restaurants will donate a portion of their proceeds from people who come to your event.

The Golden Search - Collect donations of old, unwanted jewelry and turn it in for cash.

Birthday Pledge - In lieu of birthday gifts, ask for donations for your favorite cause.

Game Night - Host a game night and charge admission.

Comedy Night - Laugh your sides silly while raising donations.

Jeans Day - Have co-workers donate \$5 to wear jeans for a day.

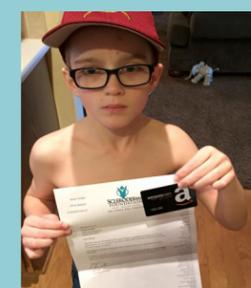
Poetry Reading - Join in with other creative writers to share their thoughts and raise money.

Wine-tasting Party - Find out if you can get wine, cheese or chocolate donated and host a wine night! Be sure to charge for admission. Raffle off leftovers!

Holiday Teal Cheer Contest

We decided to do something a little different this past holiday season and hold a Holiday Teal Cheer Contest. Supporters were asked for any and all pictures that promoted scleroderma awareness during the holidays. The pictures were then uploaded onto Facebook for voting purposes.

Voting ran for a two weeks and there were over 325 votes cast! On the day that our contest went



live, we reached over 3,000 people on Facebook! **Thanks to your creativity and support**, we were able to spread awareness during one of the busiest times of the year.

One Facebook fan sent us positive feedback on our efforts:

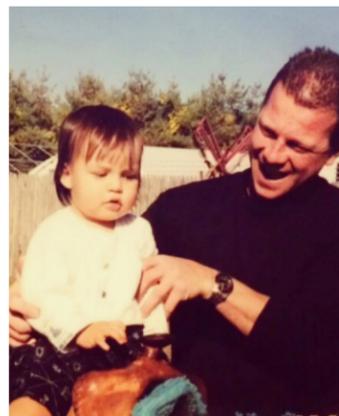
“I want to let you know I love this idea of the competition with the pictures I have friends that are sharing it and their friends are sharing it which means your great idea has helped out. This is helping us bring so much more awareness reaching people that we hadn't reached before. GREAT IDEA! Love it! Thank you!”

One part of our three-fold mission is to spread awareness of this rare disease. We were able to end the year knowing that together we made a difference and spread the word to greater audiences than we could even have hoped for! Be on the look out this year for more social media contests!



Sclderoderma Voices: Melissa

We initially started talking with Melissa when she was a college student in 2012. She first put a team together for the Stepping Out to Cure Scleroderma walk in Long Island in 2014. After a great first year at the walk, Melissa stepped into a leadership role as one of the primary walk volunteers for 2015.



In April 2014, my Father was in the ICU at North Shore Hospital, Manhasset. The more I watched my Dad suffer, it sparked my curiosity and I started to research Scleroderma and ways to support the cause. I came upon the event “Stepping Out to Cure Scleroderma” and I immediately signed up and spread the word to all of my friends and family. My Dad loved the idea and all of the support he received. I even dropped off a “Team Coppola”

shirt to my Dad at the hospital to make sure he felt included. I designed the shirt to symbolize his battle against scleroderma and how hard he continued fighting.

My dad had a feeding tube, a defibrillator placed in his heart, he was on respiratory machines, and on continuous heavy medications. My Dad was suffering his life away, every minute of it. He was diagnosed with scleroderma six years ago, it started by attacking his skin then gradually started attacking his internal organs. One organ started failing after another, he became so fragile as he was in and out of hospitals, nursing homes, and hospice care. He was a fighter, he never wanted to let go. My Dad died from scleroderma on September 23, 2014. On September 12th we were given an estimate that he had 2-3 days to live and he lasted 11 days in total.

He did not want to leave my mom, sisters, and I behind. He had worked so hard all of his life to make sure he provided and took care of all of us, only to have his life taken away by this deadly disease. Dealing with my Dad’s death has been extremely difficult, and it often makes me wonder why there isn’t a cure, and why some people have to suffer.



When someone you love dies, that part of you dies as well. Memories are the pieces in which create a unique puzzle, and when combined they form the entire picture of your life. My Dad took a piece of my puzzle with him, a piece that will never return and there’s nothing I could ever fit inside that missing space.



I am incomplete without it, without him. We shared memories that nobody else shares, which means he knew me differently than anyone else. Because of this I will never be the same. Before my Dad died, I smiled more, laughed more, and was able to light up a room. I loved coming home and telling my Dad about my day, asking for advice, or just sharing laughs. After his funeral that all changed. I lost my parent, my teacher, my rock. As a result of my Dad’s death, I learned things on my own, great things that I couldn’t have understood any other way. I learned the importance of telling people that you love them and how much you appreciate them. You should never let anyone wonder how you feel. One of the hardest things about losing a parent is the feeling that nobody understands if they have not yet gone through it as well. It is a hurtful process, it’s lonely, and there are some days where you would do almost anything to be the same as you were.



At first came bitterness, later acceptance, I realize there is no promise of tomorrow. After losing someone very important to you, you start to become grateful for the gift of life each day. You are given such a small time, and you never know when your time will run out, which is what I learned as my Dad lived a short life of 48 years. Many people do not truly appreciate

this. So treasure your life, make it worthwhile, and be thankful for it every day. Spend your life doing things that make you happy.

Because of my Dad’s death I traded innocence and fitting in for understanding and appreciation. I lost my Dad to scleroderma but gained something in return, the lesson of taking chances and appreciating the gift of life. If my Dad could see me, I would want him to know that he is still teaching me, guiding me, and that I miss him very much. My Dad taught me a huge majority of what I know now, and I will carry these teachings on for the rest of my life. I hope we find a cure for scleroderma and I pray for all those suffering from this deadly disease, and family and friends of those suffering as well. Thank you for taking the time and interest in my story and thank you to Scleroderma Tri-State for letting me be a part of a very important foundation so close to my heart.

Living with Hand Issues

Sclerodactyly is a life altering condition which can affect the hands of scleroderma patients. Over time, a person’s fingers may become semi-flexed, from skin tightening. Finger tips and joints can also become ulcerated. The condition leaves the patient with impaired function and limits their activities of daily living.

In this edition, we are sharing a list of products and supplies compiled by Raymond Scharin, O.D. Raymond has worked for many years to cope with his sclerodactyly as well as Raynaud’s and finger sores. Although we are unable to do product endorsement, we hope Ray’s list will be helpful for you.

Polly Power Grip AR 2530 - A

lightweight and easy to use plastic wrench tool for a firmer grip and more power when pulling, pushing, picking, turning, squeezing, holding etc. In my experience this is the best and most versatile product available! If you’ll only buy one product, this is the one to go with.



Eagle Creek Zipper Pulls - They allow the use of different finger surfaces to open or close zippers. Zipper pulls are especially helpful when the fingertips are painful due to ulcerations or calcinosis.

Umbrella Button Push Extender - Attach Everbilt Self Adhesive Round Vinyl Bumpers to create a protrusion to allow pushing a recessed automatic open/close umbrella button while wearing thick gloves or mittens. Unfortunately, the self-adhesive glue wears off with time, so a new self-adhesive Round Vinyl Bumper or glue has to be applied when needed.

Ablewear 754110000 Key Turner - Allows for insertion, turning and removal of keys without pressure on fingertips.

Soft Pencil Cushions - They can be fit over pencils or thin pens to allow their use with less finger compression and pain.

Loop Scissors by Mercanoids - Only gentle pressure is needed to close the scissor blades.

Good Grips / Sure Grips Button Hook

- Provides a secure, cushioned grip on hard-to-grasp buttons. It is also more durable than other buttoning tools.



Sock Aid with Black Foam Grip by Mecanoids helps pulling on sock or stockings. If it is too difficult to insert the sock or stocking onto the plastic form, another person can assist by inserting the sock or stocking onto the form. The person with sclerodactyly can then transfer the sock or stocking from the form to their own foot.

Elastic Shoelaces - Allows insertion and removal of shoes without tying and untying shoelaces.

Sammons Preston Easy Out Tube Squeezer

- The squeezer helps squeezing the contents out of tubes of ointments.



GearTies - Gear Ties are large reusable twist ties. They can be taped to zip lock bags for easier retrieval of items. Multiple colors are available so items can be color coded.

For Raynaud’s:

The North Face Himalayan Mitt - Warmest mitt I have found (Order larger to fit over glove with gauze).

Polar Feet Fleece Mitten - Intermediate weight mitten (If you have severe Raynaud’s), reasonably prized (Order larger to fit over glove with gauze).

For Bandaging Fingers:

Dynarex Gauze - Non-adherent Pads Reorder #: 3434 3” x 4”—Fold and use 3M Micropore Surgical Tape 1535-1 to make gauze pockets which can be taped to gloves with more Micropore tape. This would serve to minimize the risk of infection (change pad when needed) and to minimize pain and damage from contact to finger ulcerations and to fingers with open leaking sores (liquid calcinosis or wound fluids).

3M Micropore 1” x 10 Yard Rolls of Paper Tape - Micropore tape is excellent for repeated applications on sensitive skin. It allows for moisture evaporation and the skin to breathe and leaves minimal adhesive residue upon removal. Micropore tape is available in a dispenser pack for easier tear and convenience.

Dynarex Sterile Conforming Stretch Gauze Bandages - After application of necessary medications, fingers with ulcerations or open wounds can be wrapped with this and it can be secured with Micropore paper tape.

Thank you Raymond Scharin for sharing all this information with us!

A Free CME/CNE Activity

Doctors and nurses as well as many health care professionals are required to obtain a number of education hours every year. The Scleroderma Foundation will soon release a web activity that will be free to attend and will qualify for continuing education credits. The release for this program is planned for April 2016.

Health Fairs – Opportunities to Educate & Create Awareness

Providing health fairs at various locations throughout the Tri-State Chapter is one of the great ways to spread awareness for scleroderma. Each year, volunteers gather at health care facilities, malls, schools and businesses with information about scleroderma and overlapping illnesses. They set up the booth with items supplied by the Chapter, then talk and teach hundreds of people in a very personal way about the disease and how they too can become involved with our organization.



As part of our 35th Anniversary Celebration - we are challenging you to make a commitment to our goal - 35 health/wellness events attended! If you are looking for an opportunity to become involved – this is a great one. Contact our office and we will reach this goal together! Thank you!

Stepping Out To Cure Scleroderma 2016

Stepping Out to Cure Scleroderma offers a unique opportunity of camaraderie with people who are affected by scleroderma as they come together for a celebration of life and love. We invite all people, patients, caregivers, family, neighbors, friends, students, teachers, nurses and doctors to join us for a day of celebration. It's a chance to show in person what we so often talk about in spirit, "If you have scleroderma ...you need not feel alone."

We begin our 15th walk season with Rochester and Buffalo setting the tone on June 4, quickly followed-up by Binghamton, Long Island and Albany the next day. The following weekend there is a quartet with Hartford on June 11 and Manhattan, Syracuse and Westchester the morning of June 12. Even though Father's day is the next weekend, our volunteers are not daunted as Ridgefield Park and Stamford are celebrating with their walks on June 19. We wrap up the season with Poughkeepsie on June 25.

Stepping Out to Cure Scleroderma is our signature fundraiser and provides over half of our annual revenue. As a result of the donations secured by our supporters, our support groups, educational forums, website, SclerodermaVideo.com, and other chapter support functions are possible. In addition, we are able to contribute thousands to research each year. We sent over \$175,000 to the national office in 2015.

We need you to reach beyond the registration process. If we are to stop this disease, we need to solicit additional donations from family, friends, neighbors and coworkers, where you live, and online around the world. This extra effort makes a critical difference in the lives of thousands in the chapter, across the country and around the globe. In 2015, more than 3,000 people registered and raised about \$420,000. Your participation helped to maintain over 20 active support groups; allows us to reach people in their homes via a telephone support group;



and allows people anywhere with internet access to watch videos of many of our educational event speakers online, free-of-charge. You have helped to send almost \$2 million to the national office in the last ten years, with a large amount going straight to research. This would not be possible without you *Stepping Out to Cure Scleroderma*.

Your walks may not be until June, but fundraising starts **today**. There are three ways to register and begin to raise money. You can (1) pre-register online at <http://Walks.SclerodermaTriState.org>; or (2) pre-register via mail by completing the form on the adjacent page and mailing it to the office at least one week prior to the walk you plan to attend; or (3) register on the day of the walk at the walk (note: you save \$5 on an adult registration fee by pre-registering).

Can't attend but want to help? Register free online as a virtual walker and send out emails asking family, friends, neighbors, co-workers, and even your employer for help. Many employers match donations, take a few minutes out of your day and ask your employer. Pass this idea along to the people you are asking to donate. Whichever way you choose to register, please remember that all donations help to sustain our support for patients, family and caregivers and bring us that much closer to a cure for scleroderma.

Please make sure to register and then solicit donations today and tomorrow and tomorrow and tomorrow – up until the day of the walk. Working together we can conquer scleroderma. Take a tour of all of our walks and visit <http://Walks.SclerodermaTriState.org>.

STEPPING OUT TO CURE SCLERODERMA 2016

For more information or to register please visit <http://Walks.SclerodermaTriState.org>

THIS IS OUR PRIMARY FUNDRAISER. PLEASE COLLECT DONATIONS.

Walk day registration fee: Ages 16 and up - \$25 | Ages 5 -15 - \$5 | Ages under 5 - Free

Online \ Pre-walk mailed in registration fee: Ages 16 and up - \$20 | Ages 5-15 - \$5 | Ages under 5 - Free

Please turn in additional DONATIONS at the check-in/registration table on the day of the walk.

A signature is required for each adult (18 and over) in the waiver section below. Parents must sign for all children.

Walk Site: Albany Binghamton Buffalo Hartford Long Island Manhattan Poughkeepsie
 Ridgefield Park (NJ) Rochester Stamford Staten Island Syracuse Westchester

Last Name _____ First Name(s) _____

Address _____ Apt _____ City _____ St _____ Zip _____

Primary Phone _____ Email _____

Team Name _____

- Unable to attend my contribution \$ _____
- I am interested in volunteering for Walk 2017.
- I would like more information about scleroderma.
- I am a scleroderma patient.
- Please add me to your mailing list.

Free gift with \$250 raised (one gift per registrant/family)

Official Use Only

R C T G

I am walking in honor of _____ In memory of _____

Registration Fee(s) \$ _____ Personal donation \$ _____

Check to see if your employer has a matching gifts program. Apply for the match if possible.

List Solicited Donations Below

Return completed form(s) with check(s) or money order(s) to SF Tri-State, 59 Front St, Binghamton, NY 13905

Checks payable SF Tri-State. An acknowledgment, which serves as a tax receipt, will be mailed to each sponsor if address is provided.

	Name	Address	City	St	Zip	Donation
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						

WAIVER: Must Be Signed Checks payable: SF Tri-State Total Donations \$ _____

In consideration of being permitted to participate in Stepping Out To Cure Scleroderma, I hereby, for heirs, my personal representatives and myself assume any and all risks which might be associated with this event. I further waive, release, discharge and covenant not to sue the Scleroderma Foundation, any chapter, affiliate, support group, officer, employee, sponsor, organizer, volunteer, municipality or other representative or their successors and assigns or the park or other location, for any and all injuries or damages of any kind whatsoever suffered as a result of taking part in the event and any related activities. I agree to the use of any photo, film or video of the event for any purpose.

Adult Signature: _____ Adult Signature: _____

THIS IS OUR PRIMARY FUNDRAISER. PLEASE COLLECT DONATIONS.

Walk Locations & Dates

Date	Where	Registration	Walk
06/04/16	Seneca Park, Rochester, New York	9:00 a.m.	10:00 a.m.
06/04/16	Eastern Hills Mall, Williamsville, New York	10:00 a.m.	11:00 a.m.
06/05/16	Otsiningo Park, Binghamton, New York	9:00 a.m.	10:00 a.m.
06/05/16	Wantagh Park, Wantagh, New York (LI)	9:00 a.m.	10:30 a.m.
06/05/16	Crossgates Mall, Albany, New York	6:30 p.m.	7:30 p.m.
06/11/16	West Hartford Town Hall, West Hartford, Connecticut	9:00 a.m.	10:30 a.m.
06/12/16	Onondaga Lake Park, Liverpool, New York	9:00 a.m.	10:00 a.m.
06/12/16	Riverside Park, New York, New York	9:00 a.m.	10:15 a.m.
06/12/16	Irvington Union Free High, Irvington, New York	9:00 a.m.	10:30 a.m.
06/19/16	Overpeck Park, Ridgefield Park, New Jersey	9:00 a.m.	10:30 a.m.
06/19/16	Westhill High School, Stamford, Connecticut	9:00 a.m.	10:00 a.m.
06/25/16	Vassar College, Poughkeepsie, New York	9:00 a.m.	10:15 a.m.
???	"To Be Determined", Staten Island, New York	9:00 a.m.	10:30 a.m.





TRI-STATE, INC. CHAPTER

59 Front Street
Binghamton, NY 13905

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

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.

Did you know that many employers offer a matching gift program to their employees? Check with your employer today to see if you are eligible and fill out an application.

Make a Donation. Make a Difference.

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

Name _____

Email (save postage) _____

Address _____ City _____

State _____ Zip _____ Phone _____

Amount _____

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

Credit Card (all information required)

Visa Master Card American Express Discover

Card Number _____ Security Code _____

Expiration Date _____ E-mail _____

Contribution is made: In honor of In memory of Dues Donation (No Membership)

Name _____

Send a note to: Honoree / Family

Name _____

Address _____

City _____ State _____ Zip _____

Email (save postage) _____

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

We've updated our social media links to make it easier to follow us!

 @SclerodermaTS
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 www.SclerodermaVideo.com

 www.inspire.com

 www.youtube.com/SFTriState

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.