



SCLERODERMA EXCHANGE

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

Volume 1, 2015
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



Building Awareness – One Health Fair at a Time



Remembering Waveney

Since 1995 our organization was involved with a beautiful woman who took on and grew the scleroderma support group in NYC. This past year, we had to say good-bye to her. Today we want to be sure that you know how big of an impact one person can make when they take on a volunteer leadership role with this organization.

The group, when it was initially formed in 1995 was named the Manhattan Scleroderma Support Group. Waveney Golbourne started her leadership of the group in 2004 and remained in that role until her passing in 2014. Over those 10 years, she was an active planner, participant, and voice for patients and families alike, all while she was dealing with the affects that scleroderma was having on her own body. Waveney was a strong woman and was very committed to her support group. She was a great resource of information because of her strong business sense and her own struggles with scleroderma. Waveney became a source of comfort for many people. She was a valuable asset to other support group leaders as well and attended and participated in leadership retreats and shared her experiences in leader teleconference calls. She was looked up to and was an inspiration to many.

Continued on page 2

The old saying “many hands make light work” certainly applies to the efforts of Tri-State Support Group Leaders and volunteers! Together, with not much more than supplies from the office, we were able to increase the number of health fairs that we participated in from 14 in 2013 to 21 in 2014 – an amazing increase!

Health fairs, whether they are intended for employees, mall visitors or convention center wellness events, are just one of the ways that the word scleroderma reaches many eyes and ears throughout our region. Tri-State pays for fees associated with our presence, while volunteers set up, work the booth and pack it all away. We could not be an effective organization without all of you.

If you are interested in participating in a health fair on behalf of the organization and the people we serve, give Mary Beth Bobik-Kadylak, Director of Patient Education & Support a call, or email her at mbbkadylak@SclerodermaTriState.org. She will be happy to provide the tools that you will need to have an interesting and inviting display, and you will feel good about your efforts to spread the word about scleroderma. Thanks to all of you who have been involved and thank you in advance to all those that will become involved this year!



Stomping Out Scleroderma

July 17-19, 2015
Nashville, Tennessee

For more information and scholarship opportunities, visit:
www.scleroderma.org/conference

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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

Energy and persistence conquer all things.
-Benjamin Franklin

So often I talk with patients and hear how scleroderma saps their energy. While I definitely see the impact, and understand the difficulty, I also see your passion to not let scleroderma have the upper hand. That passion translates into the energy that fuels so much of what the Tri-State Chapter accomplishes each year.

As you read through at this issue of the Scleroderma Exchange, realize how much energy – that patients do not have – is spent accomplishing so much. That persistent energy, raises funds, advocates, raises awareness, loves one another and helps make sure medical professionals and congressional representatives know who we are.

Your energy, no matter the amount, is enough to make a tremendous impact. Thanks you!



Jay Peak
Executive Director

Waveney

The NYC support group has a long history of holding large meetings, once a month. While Waveney served as leader, only a few of those meetings were cancelled due to inclement weather that comes along with living in the north eastern part of our country, but for the most part Waveney along with her co-leaders kept plugging along. When Waveney's illness began to really take its toll, she reluctantly left her position at Columbia University, a job that she loved. She, like many scleroderma patients had to decide where to use the energy that they have each day to work for someone else, or to leave their job to spend their energies on their families, homes and their health. Waveney pushed the limits of this decision and worked hard to do both jobs well.

During the last months of her life, Waveney grew quite frail. Her co-leader, Chanell Gatewood increased her commitment by taking over meetings and helping those in need of support. Chanell then asked that Tiese Mahabir assist her with the leadership of the group. Because the group of regular attendees was so large and the fact that the number of people who live in the NYC region is so great, the group recently added Eric Goldstein as another leader to help manage the group.



We were able to see Waveney at the NYC Patient Education Forum held in April of 2014. She really looked pretty great, but you could see that she had become quite dependent, both on oxygen and on others to help her as she had increasingly quite frail. She had been battling the form of scleroderma that was much more than skin deep – systemic sclerosis. The disease had taken over interfering with her heart and lung function. Waveney passed away in August. A number of our support group leaders were able to be at her memorial service. Even with her death, Waveney was still getting the word out about the severe effects of the disease as memorial contributions were made to us in her honor. We remember this wonderful lady fondly and thank her for all that she gave of herself in service to others.

Raising Awareness and Funds Should Be FUN!

Every year dozens of people contact our office and ask what they can do to help raise funds to help scleroderma patients. Our first encouraging words are to create a team and join Stepping Out To Cure Scleroderma. But some people want to do more.

We explain that there are many ways to raise funds. From having a golf outing, regular golf or park golf (exclusive to Buffalo) to hosting a dance. The dinner dance in Hartford has been happening successfully for over twenty years and in Staten Island for seven. Bowling nights appeal to the whole family while a night on the town at a local pub works wonders for a niche group. It can be as easy as donating the fee for a missed appointment to the organization. How about holding a Cut-A-Thon, where fees are donated on a particular day.



What you can do is limited to your imagination. Keep in mind you are orchestrating these events and donating the proceeds to Tri-State. We can assist you but only in a limited capacity. We can promote what you are doing but the work, fun and smiles are all yours. It needs to be fun.

The event can be one time, annual or seasonal. What can be done is limitless and depends on your ability, energy and sometimes age. Imagine a little league team finding a sponsor that will donate \$1 a run scored for the season. Or a dance troop hosting a recital and having all of the proceeds going to charity. Imagine a Broadway Theatre performance donating one-night's ticket sales.

What you can do is limited to your imagination. Keep in mind you are orchestrating these events and

10 Fun Ways To Fundraise!

Bad Tie Day- Grab the worst tie you have! Pay to wear or collect donations to leave it at home.

Bingo- Host a bingo event- charge a fee per game.

Dance- a- thon- Break out the dancing shoes! Charge admission per couple.

Wear Teal Day- Collect donations to wear Teal in the office.

Chocolate Ban- Give up your cravings and donate what money you would have spent on it.

Game Night - Host a game night and charge admission.

Comedy Night- Laugh your sides silly while raising donations.

Pancake Breakfast- Find a diner to give back and give their breakfast sales on a specific day of the week.

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

Battle of the Bands- Gather local bands to put on a charity concert! Both musicians and guests are charged admission.

A Win For Our Advocacy Efforts



As 2014 ended, our advocacy efforts were able to claim a significant victory. Due to the strong and effective outreach of scleroderma advocates earlier in the year, "scleroderma" was once again included on the list of conditions eligible for study through

the Department of Defense Peer-Reviewed Medical Research Program.

After having been dropped from the list as a result of leadership changes within the committee responsible for developing the budget, the Scleroderma community had to

educate a new group of congressional leaders. Through many letters, phone calls and meetings, patients and those close to scleroderma made it known that the disease is one that should continue to be the focus of studies funded by the Department of Defense's medical research money.

With the passage of the fiscal year 2015 budget in December, scleroderma was officially back on the list it had benefited from for at least ten years before being dropped in 2014. Scleroderma researchers now have the opportunity to apply for part of the \$247.5 million that is included in the peer-review allocation.

While inclusion on the eligible conditions list was a victory, we cannot claim the same for the Research and Awareness bills. In the wake of the *Affordable Care Act*, Congress has

not been considering any healthcare-related legislation in a meaningful way. Popular bills, including ours with solid support from New York and Connecticut legislators, could not gain the attention they traditionally warranted.

There are plans to introduce similar bills in the 114th Congress. The new Congress appears much more favorable to health policy and in the months ahead, we need advocates to reach out to legislators and ask that re-introduced scleroderma legislation be considered as a high priority.

While at times our efforts produce disappointing results, with patience and perseverance more people understand and are willing to support our cause; take heart from the success of our campaign for inclusion in the Department of Defense program.

Scleroderma Voices: Amanda

We met Amanda at the Fall Research forum at the Hospital for Special Surgery in 2014. Her journey started early with scleroderma and has proven not to hold her back. Originally from Australia, Amanda enjoys her passion for New York City due to the many hours spent in big city hospitals. This is her story.



As a young girl, living with scleroderma presented many challenges in life. Diagnosed at age 11, with the onset appearing more than 2 years earlier, I was barely at an age to understand puberty let alone scleroderma. All sorts of strange things were going on in my body; hard, thick white patches of skin, tightening of my fingers, elbows and ankles. It felt like everything was swollen, but in fact it was just hard and thick.

Growing up in rural Australia, I was the youngest of 3 girls with loving and adoring parents. My parents struggled just as much as I did with the diagnosis, and without the knowledge of city doctors around, it felt like a see-saw of physicians – bouncing from one to the next. All sorts of creams and lotions were prescribed, and at one point I was told I was just allergic to the sun so I must stay indoors. It wasn't until we were referred to the 'Big City' in 1981 where life all changed for me, in more ways than one. A skin biopsy on my left thigh confirmed that I indeed had scleroderma.

Scleroderma initially affected me everywhere apart from my face, with my feet being the worst. My toes became deformed, and I was faced with repeated skin ulcers which took years to heal. At the age of 15, I was confronted with the first prospect of leg amputation.

Here were my friends, thinking about dates, homework and school dances – where I was wondering if I would end up as an amputee. It was lucky for me that the leg was saved at that stage, however the continual skin ulcers and repeated skin graft surgeries became too much, and here today I am a bilateral amputee.



Among the many other challenges in life for me as a teenager with scleroderma was to give up playing basketball. I could no longer catch or throw a ball, let alone run. The risk of falling and damaging my skin was too much to bare, so a revision of my passion was in order – and still today I am a massive supporter of anything basketball! (Basketball is life – the rest is just stuff!)

High School was also hard. Holding a pen with curled fingers was a difficult task, making homework more of a chore than my peers. There were many hospital visits, prolonged periods of being away from school as well as my friends. However, life in a hospital in the 'Big City' exposed me to a greater life experience where my love for big cities still continues today.

New York! There is only one real 'Big City' in the world. I first came to New York in 2004, and have returned from Australia more than 18 times, so now it just feels like home. It is a city where there is always something new to do, and you never know what could happen. I like the element of surprise! No other city is as diverse, and I have been lucky enough to meet some amazing people.

One of my favorite reasons for coming to New York is the shoe shopping. The novelty of being able to buy off the shelf shoes instead of having them custom-made is a reasonably new experience for me. The choice of shoes is great – as well as the price!



New York is also an accessible city, in the most part. To me, this is something important. In facing what we face with scleroderma, we don't need additional barriers impeding our lives. Getting to work or to our medical appointments should be as easy as getting out of bed. Accessibility doesn't just include physical barriers, it also includes attitudes and enablers in

life and I have had some great experiences to showcase that in this city.

Life with scleroderma is hard, much harder than being a bilateral amputee. Today, I am a grown woman age 44 and scleroderma has presented itself in many forms throughout my years. After a few life-changing decisions, life has come to a stable point where I am enjoying new things which were not an option for me growing up. Simple things like, shoes, skirts, dresses as well as swimming.

Scleroderma has brought about many life experiences for me but the one thing I will always say is that our tribulations would not be without our trials!

You can read more about my journey on www.accessibleaction.com



Knowledge is Power – Resources are a Keystroke / Phone Call Away.

Often times we hear that the health care providers that we rely upon to direct our care have never heard of scleroderma, or spent a ½ hour of their medical education on scleroderma, or have never seen a patient with the disease – even over the course of their career. And, that makes sense when you think about how rare the disease is but we feel that it is time to change this dynamic. Here, you will learn how to empower yourself with knowledge to make sure you enter into an intelligent conversation with those you depend on for your care and how to encourage them to learn more about scleroderma.

By using the incredible resources of the Tri-State Chapter as well as those of the national Scleroderma Foundation, you can learn so much – and from a reliable source. Searching the web can be just plain scary and can be misleading as well. Don't just search for "scleroderma". Come to our website and take advantage of all we have learned about the disease. The more you know – the better!

What makes our information reliable? We are supported by medical advisory boards (MAB) - both Tri-State and the national Scleroderma Foundation have one. These board

members are medical experts in the treatment of scleroderma. The brochures that are

provided by our organization have been developed and approved by the MAB educational committee. So, turn to us for reliable information. (See page 2 for the list of our MAB members.)

What are the available, reliable resources we offer? Scleroderma.org is the national website. At the national level you can:

- Learn about the Annual Patient Education Conference and how you can attend,
- Discover where the chapters are located throughout the country, as well as where support groups are meeting,
- Read all the brochures that the chapter makes available for educational purposes,
- Advocate for additional funds and to increase awareness for the disease,
- Find resources for everything from products to make life easier to how to participate in clinical research and,
- Use the awesome interactive tool to learn

about how scleroderma affects the body. And much more!

Adding to this resource is our Chapter's website: SclerodermaTriState.org. Here you will find:

- Chapter sponsored support groups with contact information and meeting information
- Education Forums that we provide annually with dates and location information as well as how to register,
- How and why to become a member of our organization,
- Links to current and past newsletters,
- How to join one of our 14 Stepping Out to Cure Scleroderma walks and more!

One of the rich resources of information lies in the website SclerodermaVideo.com. SclerodermaVideo.com is a collaborative effort between the Tri-State Chapter and StarLight Video Productions. Each year, we enlist the services of StarLight to record the educational programs we provide. The sessions are then edited and made available by our videographers Bill and Barbara Celnick on the website and for our lending library. You can learn a great deal about the illness in the comfort of your own home by visiting the site

and streaming the recording to your computer.

The service is available at no charge, 24/7.

Office support is another resource that is unique to our chapter compared to others around the country. We, the staff of the Tri-State Chapter are available weekdays from 9-5. Not only do we have a full-time Executive Director responsible for the overall management of the day to day operations, we employ on a full-time basis a Director of Development, Director of Patient Education and Support, and a Communications Manager. We also have a PT Bookkeeper and will soon be hiring another PT person for patient support. This model is not seen in other chapters and allows our chapter to operate in a much higher capacity than most others.

How can we take the educated patient and turn them into better healthcare advocates? Let your doctors know about us. Ask them to become members, to place our brochures in their waiting rooms and refer patients to our chapter. Encourage your providers to join

us as we fundraise for additional research efforts. If you don't have a scleroderma treatment center in your region, see what interest your provider might have to get one designated. And, don't forget, health care does not stop with your primary physician or rheumatologist. Occupational, respiratory and physical therapists, dermatology, GI and cardiology specialists can become involved as well. You are our strongest ally in spreading the word about the Scleroderma Foundation; you are our outreach to the community you live in. Join us and educate yourself and encourage your health care providers to do the same.

Useful Links

www.Scleroderma.org

www.SclerodermaTriState.org

www.SclerodermaVideo.com

Helping Health Care Professionals Learn More About Scleroderma

As you may have read in the previous article, we encourage you to tell your health care providers about the Scleroderma Foundation and the Tri-State Chapter. We offer many resources to health care providers but one of the most helpful ones for physician and nurses is the one that will allow them to gain CME (continuing medical education) or CNE (continuing nursing education) credits. Physicians and nurses each have a particular number of credits to earn each year, so why not make scleroderma part of that education! It's as easy as going to Scleroderma.org, clicking on the tab for Healthcare Professionals and scrolling down to the link for "Scleroderma and the Lung." By completing this online course, the doctor or nurse will gain more knowledge about scleroderma AND earn credit for doing so – and its free!

Let your doctors and nurses know about this amazing resource and all the other resources that we have available through the Scleroderma Foundation. If we continue to work together, we can do amazing things to increase awareness and understanding of scleroderma. Thank you!

You are our strongest ally in spreading the word about the Scleroderma Foundation and you are our outreach to the community you live in.

Stepping Out To Cure Scleroderma 2015

We begin our 14th season on May 31st with Ridgefield Park and Westchester County walks. These will be followed the next weekend by five walks ranging from Buffalo in the west to Long Island in the east, and Rochester, Binghamton and Albany in between. Hartford, Syracuse, Manhattan and Plattsburgh all take place the weekend of June 13 – 14. We wrap up with Stamford and Staten Island the weekend of June 28. Stepping Out to Cure Scleroderma is our signature fundraiser and provides about 60% of our annual revenue. Because people take the time to secure donations, our support groups, educational forums, website, SclerodermaVideo.com, and other chapter support functions are possible, and let's not forget the thousands we contribute to research each year.

We strongly encourage you to go beyond the registration process. We need you to solicit additional donations from family, friends, neighbors and coworkers. This extra effort makes a critical difference in the lives of thousands in the chapter, across the country and around the world. In 2014 more than 3,000 people registered and raised over \$400,000. Your participation helped to maintain 22 active support groups with more on the horizon in 2015. You have also helped to send over \$1.8 million to the national office in the last ten years, the majority going to research. This wouldn't be possible without you Stepping Out to Cure Scleroderma.

Our goal this year is to register 3,500 walkers and raise \$500,000. It is ambitious but together we can do it if you ask others to help.

Stepping Out to Cure Scleroderma offers a unique opportunity for solidarity as people who are affected by scleroderma come together for a great event. We invite all people, patients, caregivers, family, neighbors and 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."

Our walks are not until summer 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 us 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, coworkers, even your employer for help. 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 solicit donations today and tomorrow. Working together we can conquer scleroderma.



Where to walk | 2015

Date	Where	Registration	Walk
5/31/15	Overpeck Park, Ridgefield Park, New Jersey	9:00 a.m.	10:30 a.m.
5/31/15	To Be Determined, Westchester Cnty, New York	9:00 a.m.	10:30 a.m.
6/06/15	Seneca Park, Rochester, New York	9:00 a.m.	10:00 a.m.
6/06/15	Eastern Hills Mall, Williamsville, New York	10:00 a.m.	11:00 a.m.
6/07/15	Otsiningo Park, Binghamton, New York	9:00 a.m.	10:00 a.m.
6/07/15	Wantagh Park, Wantagh, New York (LI)	9:00 a.m.	10:30 a.m.
6/07/15	Crossgates Mall, Albany, New York	6:30 p.m.	7:30 p.m.
6/13/15	Blue Back Square, West Hartford, Connecticut	9:00 a.m.	10:30 a.m.
6/14/15	Beekmantown Town Hall Park, West Chazy, New York	9:00 a.m.	10:15 a.m.
6/14/15	Onondaga Lake Park, Liverpool, New York	9:00 a.m.	10:00 a.m.
6/14/15	Riverside Park, New York, New York	9:00 a.m.	10:15 a.m.
6/20/15	Vassar College, Poughkeepsie, New York	9:00 a.m.	10:15 a.m.
6/28/15	Westhill High School, Stamford, Connecticut	9:00 a.m.	10:00 a.m.
TBD	To Be Determined, Staten Island, New York	9:00 a.m.	10:00 a.m.

STEPPING OUT TO CURE SCLERODERMA 2015

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

Walk Registration Form

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 Plattsburgh 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 2016.
- I would like more information about scleroderma.
- I am a scleroderma patient.
- Please add me to your mailing list.

I am walking in honor of _____ In memory of _____

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

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

Official Use Only

R C T G

THIS IS OUR PRIMARY FUNDRAISER. PLEASE COLLECT DONATIONS.

List Solicited Donations Below

Return completed form(s) with check(s) or money order(s) to Scleroderma Foundation/Tri-State Chapter, 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

WAIVER: Must Be Signed

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: _____



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.

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

A new way of looking at Scleroderma.

eNOTES From hardening of skin to cardio issues, scleroderma can effect your entire body. Now offered on the Scleroderma Foundation national web page is a compelling way to see how the disease can change your body.

Under the news tab on Scleroderma.org, is an interactive body. You are able to see each body system and see what scleroderma might do. Each system gives a brief overview and the possibility for more information.

This tool is a resource for anyone looking for more information on the disease or a starting point for anyone who is interested in learning more.



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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.