



SCLERODERMA EXCHANGE

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

Volume 4, 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

In Memory of Jeff Mace

Written by Rosemary Markoff

As each of us struggles with scleroderma, we often direct our energy into trying to make a positive difference. Jeff Mace was the epitome of making a positive difference in the scleroderma community.

While maintaining his prestigious legal career as chief counsel for Lloyd's of London, he always found time for the Scleroderma Foundation Tri-State Chapter, where he served as President since 2002. He also served on the Scleroderma Foundation's National Board and on the Board of the Scleroderma Research Foundation.

Jeff was my rock when I worked as Executive Director of our Chapter. I always reached out to him for advice with any challenging situation and I came to call him "the wizard" because he always gave good, solid and caring advice. Looking back over the years, we can be thankful to Jeff for leading us to a new level of achievement. This is primarily due to the encouragement he provided in starting the *Stepping Out to Cure Scleroderma* walks. The initial walk was in 2002 in New Jersey and we now have 14 walks throughout the New York, Connecticut and Northern New Jersey area. The walks have provided an increase in contributions as well as an increase in awareness for scleroderma. While I will forever miss you, Jeff, I know that you are our angel, walking by our side as we continue to work to find the cause and cure of this disease.

Thank you, Jeff.

In Memory
Jeffrey H. Mace
1956-2015

We have lost a dear friend, board leader and valued colleague. Jeff Mace had spent over twenty years battling scleroderma. The Scleroderma Foundation Tri-State Chapter, the Scleroderma Foundation and the scleroderma community will forever be grateful for all of Jeff's efforts on our behalf.

Thank you and may you always rest in peace.



The Doctor Is In

Featuring Barry Jaffin, MD of West Side Gastroenterology, NY, NY

Why is it said that most of your immune system resides in the gut?

Ever since the beginning of time, all animals have evolved a very complex system within the gastrointestinal tract to help prevent diseases. This system is called the immune system and it is integral in keeping us disease free and it controls the inflammatory process. If not in balance, then autoimmune disorders may occur. Everyday, when we eat, our gastrointestinal tract is the first organ which comes into contact with hundreds, if not thousands of different chemical compounds. Additionally, there are contaminants such as bacteria, viruses and parasites which enter our GI tract despite taking healthy precautions.

In general, GI lymphoid tissue is involved in producing antibodies (usually IgA) and specialized cells (T-cell) to fight infection.

Gut bacteria, called the microbiota, intimately interacts with our immune system. Surprisingly, we have more foreign DNA (bacteria) than human DNA and the interactions between our immune system and hundreds of bacterial species either provoke the immune system to cause inflammation or limit the



continued on page 3

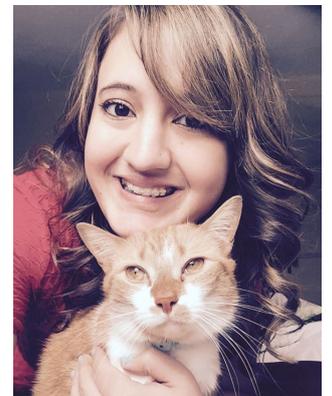
Welcome to Tri-State

You may have noticed a new name floating around the office in the past six months. Over the summer, we hired a new Communications Manager, Cassandra Conant.

Cassie began filling this role at the height of our year during walk season in June. In her new role, Cassie is responsible for overall communications, including those related to fundraising, social media, and patient support and education for the tri-state area of NY, NJ, and CT.

Cassie grew up in Norwich, NY and then moved to the Greater Binghamton area after college. She graduated from SUNY Oneonta in 2013 with a bachelor's degree in Communication Studies with minors in Computer Art and Public Relations. As an ambitious college student, she conducted a paid research study in public relations, held two internships in communications and marketing, and worked on and off campus for the entire four years. Upon graduation, she worked as a Marketing Assistant at the engineering firm McFarland Johnson for two and half years.

In her spare time, she likes to play video games, read books, exercise, and cuddle with her two cats. Welcome to Tri-State, Cassie!



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www.SclerodermaTriState.org

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

A Message from Our Executive Director

Grateful

As we begin wrapping up this year, many thoughts come to mind, but the feeling of gratitude continually comes to the top.

Again we have had the incredible opportunity to serve our scleroderma friends. Through hundreds of phone, email, Inspire.com and Facebook conversations, the staff gets to know many, many people impacted by scleroderma. The majority of these exchanges involve the struggles encountered when dealing with the disease. We also get to witness an amazing spirit that is honed by dealing with such struggles. These interactions with patients and caregivers also lead to topics addressed in our forums and support groups. We are grateful for your conversations, your openness, and your trust.

Earlier this year, our long-time Board President, Jeff Mace, succumbed to scleroderma. He was a well-respected leader and while he was very focused on helping find a cure for our disease, he also wanted to make sure that education and support were available to those impacted so that they did not have to be in the dark. Many are grateful for his mentorship.

This year we were able to add two *Stepping Out to Cure Scleroderma* walks. The walks allowed easier access to this annual gathering of the scleroderma family, more locations to promote awareness and invitations for new sponsors to help support our cause. We are grateful for the passionate volunteers that make *Stepping Out to Cure Scleroderma* a success.

Our support groups give so many a place to feel informed, encouraged and accepted. It takes caring leaders to keep the groups going and a mix of patients and caregivers – new and long-time – for a group to succeed. While we wish there was not a need, we are grateful that leaders stand ready and we can provide a place where *you are not alone*.



All the best in this season of reflection.

Jay Peak
Executive Director

Giving is Easy with Payroll Deduction

Did you know that you can donate to the Scleroderma Foundation Tri-State Chapter through your employee workplace campaign? Your ongoing contribution through payroll deduction and those of your co-workers will make a difference in the lives of many. Choose the appropriate number below and support our cause.

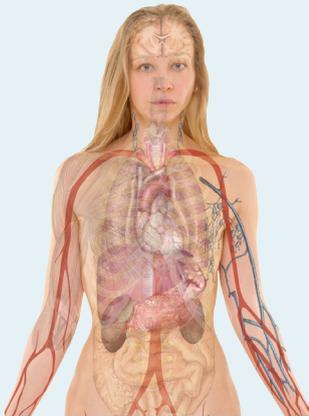
- United Way choose Scleroderma Foundation/Tri-State Chapter, IRS# 13-3128296;
- Combined Federal Campaign choose 10089
- New Jersey Employees Charitable Campaign choose 6688
- State Employees Federated Appeal choose 999-00581
- Combined Municipal Campaign & CUNY choose 2539



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.



The Doctor Is In (cont'd)

inflammatory response. Immunologists (doctors who specialize in the immune system) have categorized this system into the “innate” and “adaptive” immune system. Specialized cells (T-cells) produce chemicals such as cytokines and interleukins which can modify inflammation within the body. Some of the products of these T-cells can protect against bacteria, parasites, and lessen systemic inflammation.

Additionally, our gastrointestinal bacteria can secrete fatty acids which may help to decrease inflammation.

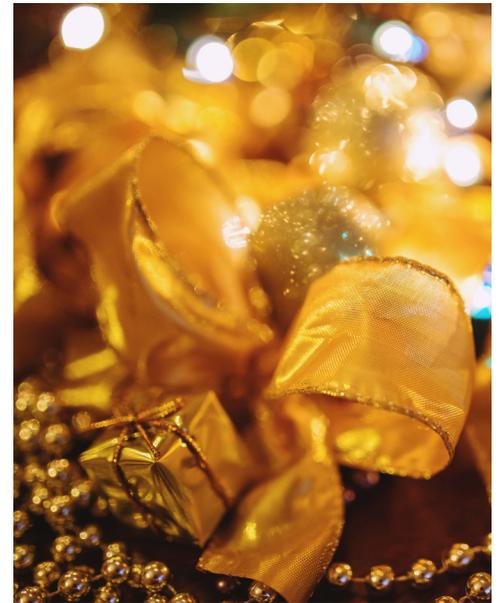
Over the last decade, researchers have shown that gut microbiota play an important role in autoimmune disorders such as inflammatory bowel disease, rheumatoid arthritis, and multiple sclerosis. In the future, it is anticipated that controlling the inflammatory response in the gut will be therapeutic to many systemic conditions, including scleroderma.

Do You Plan to Shop on Amazon? Support the Tri-State Chapter by Using Amazon Smile

Amazon Smile is a donation program run by Amazon.com that gives back to non-profits by taking a percentage of your purchase and donating it to the non-profit of your choice.

Using Amazon Smile is easy. Visit <http://smile.amazon.com/> and search for Scleroderma Foundation Tri-State Chapter. Once selected, each time you sign into http://smile.amazon.com, your purchase will help aid our mission of support, education and research.

Check items off of your holidays shopping list and give back at the same time, at no cost to you!

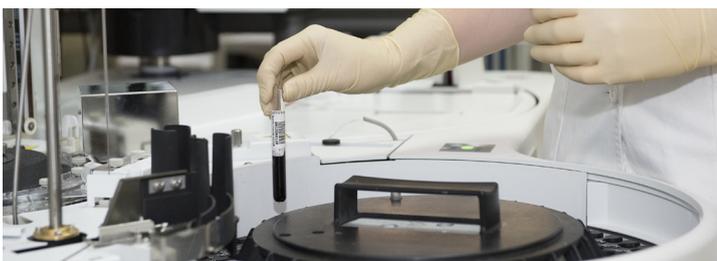


Clinical Trials Giving Hope to Scleroderma Patients

If you have been following scleroderma in the news this year, you have probably seen that scleroderma research is getting more buzz than ever! It seems like each month we hear news of a new molecule that is being studied, a new drug in development or getting put on the Fast-Track for FDA approval! The number of studies that have come to our attention (both observational and clinical trials) are continuing to grow and to recruit volunteers! Here's a sampling of some of the developments right now:

“Drugs in development or clinical trials for systemic sclerosis include: Resunab, Nilotinib, Actemra, Pomalyst, Riociguat. Research continues into the lasting effects of human stem cell transplants. RayVa and Iloprost are in trials for Raynaud's treatment. You can find information about these drugs and where clinical trials are being conducted at clinicaltrials.gov.”

If you see a trial that you are interested in, check with your doctor to get their opinion. We encourage everyone that is able and willing to participate to keep checking www.clinicaltrials.gov on a monthly basis to see if new trials have started enrollment. Because scleroderma only affects about 1 in every 1,000 people, your efforts are especially important for research. We pass along information on studies that come to our attention via Facebook on an ongoing basis – so if you are not following the Chapter page, like us at www.facebook.com/SFTriState. Your involvement will further research efforts towards a cure.



Together We Make a Difference

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

Health Fairs Coordinated: 9

Educational Programs Presented: 9

Support Groups Active: 21

We are thankful for our National Gold Sponsors Actelion and Bayer 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.



2015 Educational Events

April 26

Patient Education Forum
Hospital for Special Surgery
New York, NY
Victor Fusco, Esq.
Arnold Postlethwaite, MD

May 1-3

Support Group Leader's Retreat
Holiday Inn
Albany, NY

Presented by the Tri-State Chapter – Guest
Speakers: Barbara White (NJ Clearinghouse)
& Patricia Fennell, MSW, LCSW-R

May 16

Roundtable Discussion
Columbia University Medical Center
New York, NY
Elana Bernstein, MD
Valentina Lyssova, DDS

September 12

Patient Education Forum
The Bone & Joint Center
Albany, NY
A. Ariel Jaitovich, MD
Micheal Tadros, MD
Lee Shapiro, MD

October 7

Roundtable Discussion
Hospital for Special Surgery
New York, NY
Lindsay Lally, MD
Barry Jaffin, MD

October 10

Patient Education Forum
Rochester Academy of Medicine
Rochester, NY
Lee Shapiro, MD
Toufic Rizk, MD

October 25

Patient Education Forum
with Delaware Valley Chapter
Rutgers University
New Brunswick, NJ
Juana Hutchinson-Colas, MD
Casey Cashman

November 14

Research Forum
Hospital for Special Surgery
New York, NY
Richard Silver, MD
Romy B. Christmann, MD

December

Webinar to be Announced

Missed an event? Many of our presentations are now available to watch for free at SclerodermaVideo.com.

Facebook Photo Contest!

Submissions must be received by December 12th!

How to Participate:

Submit a photo of your teal holiday cheer to cconant@sclerodermatristate.org. Write Facebook Photo Contest in the subject line and include a 200-word or less description of how you're spreading teal cheer this holiday season. Also include your full name and phone number.

How to Vote:

Starting on December 14th, all submissions will be posted into a Scleroderma Foundation Tri-State Chapter photo album. Facebook fans of the page (<http://www.facebook.com/SFTriState>) can vote by simply "liking" a photo.

Prize:

The top three photos with the most "likes" as of January 4th at noon EST will receive a \$50 gift card to Amazon.com. You must be 18 years or older to enter.

Hardwork Pays off for Tri-State



Tri-State received the Scleroderma Foundation's Outstanding Chapter Awareness Award for our contributions in spearheading the "Hard Word. Harder Disease." campaign. Not only has the campaign increased awareness of scleroderma, according to the Scleroderma Foundation CEO, Robert Riggs, it has established a "groundbreaking alliance" that has "strengthened the messages of each organization and established a relationship of trust."

Give the Gift of Awareness



Call the Scleroderma Tri-State Office today at 800-867-0885 for more information.

Sharing the Scleroderma Story

Many scleroderma patients and their supporters know that June is Scleroderma Awareness Month. People around the world make a special effort during the month and especially on, World Scleroderma Day – June 29th in 2015 – to let others know about the disease and the obstacles patients face.

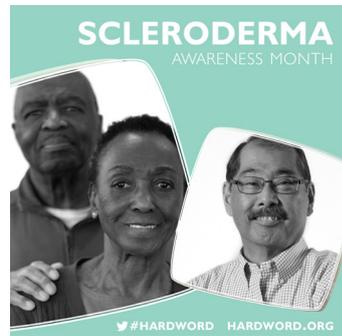
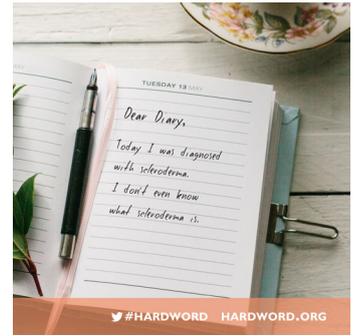
On the heels of our first-ever joint effort in 2014, the Scleroderma Foundation, the Scleroderma Research Foundation and the Scleroderma Society of Canada again joined forces to flex their U.S. and Canadian social networks and help increase understanding of scleroderma.

The second generation of the “Hard Word. Harder Disease.” campaign utilized Facebook, Twitter, Instagram and the Influence Central blogger network to help spread the word. The “Hard Word” theme acknowledges difficult obstacles we encounter when talking about the disease, such as pronunciation (hard), tissue condition (hard), and the many manifestations of the disease (harder).

Patient photos along with a variety of other images translated into compelling messages that showcased disease facts, heart-felt struggles and invitations to help educate others. Created by marketing firm, Brogan & Partners (Birmingham, MI), the messages shared with Facebook and Twitter followers proved a powerful summons to help. News releases and editorial stories sent to traditional and online media along with a team of bloggers helped to get our message out to

a new, much wider audience than was reached in 2014.

The North American partner’s mini website www.sclerodermaaware.org served as an entry point to learning more about scleroderma and allowed visitors easy access to information at any of the three partner’s main web pages. Despite the end of the campaign in late June, www.sclerodermaaware.org



Social media elements

org has continued to be a powerful tool as several hundred new users visit the site each month.

Overall, the campaign has been deemed a success. There was great impact in all of the channels as those familiar with scleroderma shared information with their friends, who in turn shared it again, opening it up to an entirely new audience. As we reflected at the end of the campaign, the effort garnered more than 3.25 million impressions. Of more importance, the blogger network became new ambassadors for scleroderma – at least for a month – and their followers learned about the disease. Likewise, many constituents of the three partners became actively engaged in sharing the scleroderma story. An added bonus is that the sharing did not stop at U.S. or Canadian borders, reports showed that people in 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.

SCLERO-DEFINED

SKLER-O-DERMA

Scleroderma is a chronic autoimmune connective tissue disease in which the body's immune system attacks its own tissue. For many, it is a life-threatening disease. Scleroderma affects women, children and men. There is still no known cause or cure.

YEAR SCLERODERMA WAS FIRST DIAGNOSED **1754**

80% of patients are women

2 types

LOCALIZED Affects the skin on the face, hands and feet.

SYSTEMIC Affects the blood vessels and internal organ systems.

90% OF SYSTEMIC PATIENTS EXPERIENCE RAYNAUD'S PHENOMENON

Raynaud's Phenomenon: A condition in which the small blood vessels of the hands and feet contract in response to cold or stress. The process makes patients extremely sensitive to cold and causes their pigmentation to turn from white to blue. As blood flow returns, the skin becomes red.

symptoms and complications

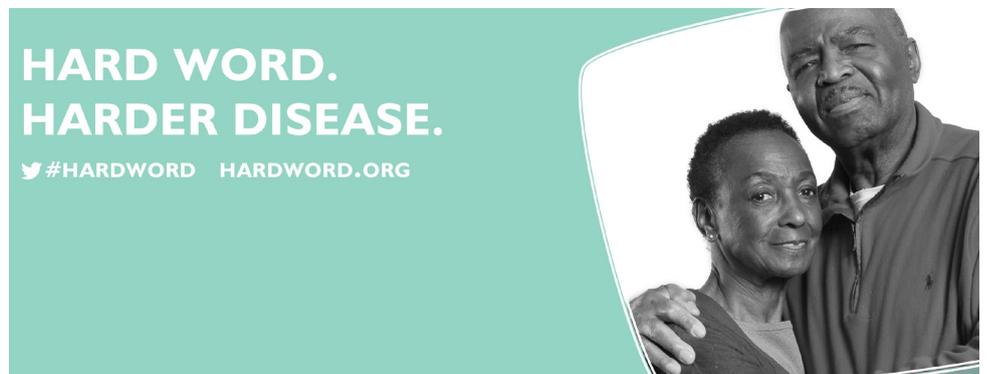
JOINT PAIN * HEARTBURN * KIDNEY DISEASE * SKIN DISCOLORATION * FATIGUE
SHORTNESS OF BREATH * PULMONARY HYPERTENSION * PULMONARY FIBROSIS
STIFFNESS * MUSCLE PAIN * SKIN THICKENING * CALCIUM DEPOSITS
LOSS OF DIGITS * SKIN ULCERATIONS * DIFFICULTY SWALLOWING

85% five-year survival rate

30-50 age when most patients are diagnosed

SOURCES
American College of Rheumatology
Scleroderma Research Foundation
Scleroderma: From Pathogenesis to Comprehensive Management

#HARDWORD
HARDWORD.ORG



Scleroderma Voices: Adriane Schorr

I have been living with the effects of Scleroderma since 2003. When I first began showing symptoms, I was a fitness instructor working 6 days/week teaching a variety of fitness classes in gyms and training clients' in their homes. I loved what I did! I was also a wife and mom to two outgoing, energetic teens- Andrew and Allison. I was, at least I thought, a healthy, active 43 year old.

The first symptom I experienced was a daily swelling of my fingers and hands upon waking-up. My fingers looked like puffy sausages and my skin was tight, making simple activities of daily living extremely difficult. I couldn't grab my toothbrush or squeeze my toothpaste. I couldn't open a jar, couldn't zip my sweater or tie my shoelaces, or even fix my hair. I initially went to my internist, who did blood work, took x-rays of my hands, and completed an overall workup. When, after several months of testing, nothing was diagnosed, I was sent to my first rheumatologist for an evaluation. This doctor determined that I had a positive ANA and diagnosed me with mixed connective tissue disease. Six months later, when my blood work showed a marker for scleroderma, I found a doctor who specialized in the disease. Ultimately it was determined that I have diffuse systemic scleroderma.

And so, my journey with scleroderma officially began. Since I loved my job in fitness, I wanted to continue working. Unfortunately the physical demands would eventually become too much for my body and I ultimately had to stop working. This was not an easy process for me to go through: initially I cut back from 6 days to 5, then to 4, then to 3 and so on until I eventually stopped completely. Simply put- I was exhausted!



Now that I am 12 years into this journey, I can say that living with an autoimmune disease such as scleroderma affects you each and every day - physically, psychologically, and emotionally. For me, it's definitely a roller coaster ride with a lot of uncertainty and unpredictability. For starters, I never know how I will feel when I wake up in the morning.... will I have any pain (a little or a lot) and how will my energy level be today? Some days, after having had 10+ hours of sleep and having eaten well the prior day, I might wake up feeling completely depleted and as if I

was run over by an 18-wheeler! Doesn't make much sense- but I've learned to tolerate this and to try and remember that there's always another day ahead of this one (hopefully a better day).

One of my biggest ongoing daily challenges has been my very severe Raynaud's Phenomenon and my inability to tolerate any cold! My Raynaud's condition began in my hands and ultimately went to my feet, ears, and nose as well. My condition is so severe that I need to use hand warmers 365 days/year and always dress in multiple layers. Even when it's 95 degrees and humid outside and most people are sweating and complaining, I've got my wool socks on, my warmers in my pockets, and am wearing a heavy sweatshirt. The slightest breeze can trigger an attack and I always need to be prepared for this. Needless to say, my numerous layers of heavy clothing (even during the dog-days of New York summer) elicit strange looks and even comments from strangers. I constantly remind myself that keeping warm and comfortable is more important than caring what others think- but, trust me, maintaining this attitude takes constant and continuous work!

Not only do the challenges of Scleroderma affect me personally, but they have a huge impact on my family as well. Fortunately, I have an incredibly wonderful and supportive family who are by my side each and every step of the way. I have been married to a terrific man, Jon, for 31 years, who is absolutely "my rock." His support NEVER wavers and he manages to ride out the high's and low's of the disease right alongside me! Additionally, when too much medical information sends me into a head-spin, he always steps up and manages the info for me. I am also extremely fortunate to have kids- now in their 20's- who are the most understanding, empathic kids one could ever hope for! When this disease puts limitations on my ability to participate in some family activity, or when we need to structure a day/meal around my medical needs, they both go along willingly and never complain. Certainly the wonderful support I receive from my family makes coping with this disease a little easier.

While scleroderma has certainly changed my life, I am a believer that everything happens for a reason. This journey has led me to become a much more patient person and I've learned to SLOW DOWN and enjoy the moment I'm in! During these past 12 years I've developed a passion for reading and gardening and have devoted more time to my loving pets. Whatever the limitations imposed by scleroderma, or any disease, I now believe you can always find joy and pleasure in life as long as you are willing to open yourself up to trying new things and going down a new, possibly different life-path. For all the challenges scleroderma has thrown my way, I've come to more fully appreciate and enjoy time spent with family and friends. What a gift!



Mar



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TRI-STATE CHAPTER

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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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State _____ Zip _____ Phone _____

Amount _____

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Visa Master Card American Express Discover

Card Number _____ Security Code _____

Expiration Date _____ Zip _____ E-mail _____

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

Name _____

No acknowledgement needed Send acknowledgement to:

Name _____

Address _____

City _____ State _____ Zip _____

Email (save postage) _____

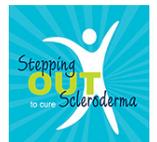
Mail to:
Scleroderma Foundation Tri-State Chapter
59 Front Street, Binghamton, NY 13905

Help Us Make 2016 the Best Walk Season Yet!

eNOTES Tri-State is currently collecting survey responses to prepare for next year's Stepping Out to Cure Scleroderma walk season.

Without your help, our walks would not be what they are today. Together we completed 14 walks in 2015. We want 2016 to be even better. In order to do that, we need feedback from all of you.

What worked? What didn't? What would you like to see improved? Do you check our social media for pictures?



If you'd like to help us out, please take the short, easy survey here:

<http://bit.ly/1RgqCWH>



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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.