



# SCLERODERMA EXCHANGE

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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

## Tri-State Chapter Honored

The Scleroderma Foundation Tri-State Chapter and four of its outstanding volunteers were honored by the Scleroderma Foundation, during the Annual Award Banquet at the 2014 National Patient Education Conference in Anaheim, California.

### Messengers of Hope in Rochester



Marilyn Sibley (left) and Rosa Johnson (far right) accept their award at our African American Health Awareness Day in Rochester, NY in October.

Rochester, NY area sisters Rosa Johnson and Marilyn Sibley joined Queen Latifah and her mother, Rita Owens in being named *Messengers of Hope* by the Scleroderma Foundation. The sisters were cited for their outstanding work in spreading a message of hope, love, and caring, along with being outstanding examples of 'sisterhood' beyond that of mere kinship.

[continued on page 3](#)

### Tri-State is Chapter of the Year



A great looking group of Tri-State Members happy to accept the award for Chapter of the Year given this year at the Scleroderma Foundation national conference.

Each year the Scleroderma Foundation honors one of its chapters for the work they do to advocate for and meet the Foundation's mission of support, education and research, over the previous calendar year. The Tri-State Chapter was named that honoree for 2013 at the July banquet. Anne Sweeney, the Scleroderma Foundation's Chapter Relations Manager noted that the Tri-State Chapter's leadership "continually works to build and maintain a network of colleagues among the Foundation's chapters and well beyond, to exchange ideas and share expertise, often leading efforts in developing effective awareness and advocacy strategies."

Of specific note, exemplary education and support programs offered to patients and caregivers throughout the Tri-State region were lauded by the Scleroderma Foundation. These educational events reach patients, in-person and online, and helped to inform educators and medical professionals about the complexities of scleroderma. Simultaneously,

the extensive network of support groups provides information, camaraderie and support to patients and caregivers throughout the region.

As a leading sponsor of the New Investigator Conference – a Scleroderma Foundation program developed to strengthen the scleroderma research infrastructure – the Tri-State Chapter nurtures the next generation of research leaders. Additionally, it works to broaden the reach of awareness messaging by establishing a media presence in New York City's Times Square; an advocacy presence on Capitol Hill; and is a leader in the Foundation's Stepping Out to Cure Scleroderma awareness and fundraising efforts.

The award was accepted on behalf of ALL those that have a stake in making the Tri-State Chapter successful including patients, volunteers, staff and donors.

### Volunteers of the Year



Suzy Ballantyne (left) and Rosemary Markoff (right) await meetings with congress members earlier this year.

Rosemary Markoff (Binghamton, NY) and Suzy Ballantyne (Clifton Park, NY) were recognized as National Volunteers of the Year, for their successful leadership of the Scleroderma Foundation's Advocacy Program.

[continued on page 3](#)

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Helene Flapan, M.A.

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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

## Humbled

From my viewpoint the Tri-State chapter has a legacy of providing quality patient support, strong educational programming and solid fundraising. Our staff and volunteers have a long, great track record of outstanding work focused on accomplishing the organization's mission.

As you see on the first page of this edition of the Exchange, the Tri-State Chapter was singled out as Chapter of the Year for its work in 2013. This surprise honor was accepted gratefully on behalf of all of those involved in our organization:

- our patients – and those close to them – who endure so much and inspire so many
- our amazing volunteers who make such an impact through events, support groups, board leadership and many, many other ways
- our donors who provide the means for all of the chapter's work
- our staff who juggles many balls and keeps a plethora of efforts moving in the right direction.

If receiving the award was not stirring enough, seeing Rosa, Marilyn, Rosemary and Suzy honored for their incredible passion and diligence made the Annual Awards Banquet one that I will long remember.

An additional note from the National Patient Education Conference...

I had the privilege of spending one day of my trip to Anaheim listening in on presentations about current research projects during the New Investigator Research Conference which was partially funded by the Tri-State Chapter. Hearing about the work of new/young investigators and witnessing the sharing of wisdom and support by senior researchers was a real treat. Feedback from participants indicates that the program is appreciated by these researchers that will continue to make a difference in the years ahead. All involved send a thank you back to our chapter for helping make the program happen.



Jay Peak  
Executive Director

## Employee Giving



You all have the opportunity to contribute to the Scleroderma Foundation/Tri-State Chapter through your fall employee workplace campaign. Choose the appropriate number and support our cause. Your ongoing contribution through payroll deduction and those of your co-workers will make a difference in the lives of many.

- United Way choose Scleroderma Foundation/Tri-State Chapter; IRS# 13-3128296;
- Combined Federal Campaign choose 38106
- 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](mailto:sdtristate@scleroderma.org) or (800) 867-0885.

## Messengers of Hope (contd)

Rochester native Rosa Johnson is extremely active as an organizer, planner and volunteer at special events serving such roles since she was 16 years old.

In 2002, Rosa was diagnosed with scleroderma. Once diagnosed, she looked inward to try to come to terms with her condition and learn as much as she could about the disease and the challenges it presented. True to her nature, it was not long before Rosa started looking beyond herself and decided that scleroderma presented her with an opportunity and calling to help others cope with their disease. She joined the Greater Rochester Scleroderma Support Group, which is part of the Scleroderma Foundation Tri-State Chapter, and has been an indispensable member of the group ever since. She has helped raise hundreds of thousands of dollars through her efforts leading the Rochester Stepping Out to Cure Scleroderma committee and is passionate about expressing her great ideas and sharing her dream of a cure. (You can read her story in the Vol. 1, 2014 edition of the *Scleroderma Exchange*)

Mary Beth Bobik-Kadylak, the Tri-State Chapter's Director of Patient Education and Support states "Rosa is a light in the darkness of a disease that has hardened her tissues, but not her heart or her soul. While scleroderma has reduced Rosa's voice to a mere whisper, she is supported by her sister, Marilyn, who ensures Rosa's voice is heard loud and clear."



**"Rosa is a light in the darkness of a disease that has hardened her tissues, but not her heart or her soul"**



Marilyn Sibley, Rosa's sister, does not have scleroderma, but lives with it every day as she helps Rosa on numerous fronts. In addition, Marilyn has taken the reins as leader of the Greater Rochester Scleroderma Support Group and is an active volunteer and compassionate advocate for others battling the disease. Earlier



this year, Marilyn became a member of the Tri-State Chapter's Board of Director which extends her impact to helping scleroderma patients, families and caregivers throughout New York, Connecticut and northern New Jersey.

Since neither Rosa nor Marilyn were able to attend the Scleroderma Foundation's Annual Banquet, the Messenger of Hope awards were presented to them, at the African-American Health Awareness Day in Rochester. The event was a testament to the hard work of these amazing ladies and allowed them to be honored in front of family, friends and dignitaries from the Rochester community.

## Volunteers (contd)

Rosemary and Suzy co-chair the National Advocacy Committee, which is one of the Scleroderma Foundation's highest-priority committees. Scleroderma Foundation CEO, Robert Riggs notes, "they have done an amazing job in pushing us down the road to success."

Suzy, a government relations professional, leveraged her influential relationships on Capitol Hill to advance scleroderma awareness in Washington. Rosemary applied her passion, creative thinking and problem-solving skills to drive the committee's initiatives forward, while inspiring other volunteers and staff to surmount bureaucratic hurdles.

Under their leadership, the National Advocacy Committee accomplished its premier goal for the legislative session: scleroderma was re-listed as an approved disease for the Department of Defense Peer-Reviewed Research Program, which provides access to millions of dollars of research funds.





# Strength in Support

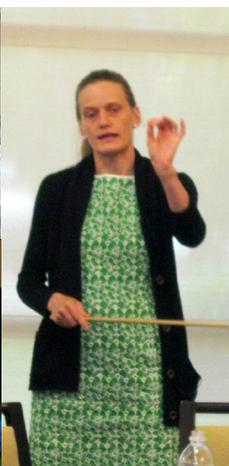
2014 was an exceptional year for the Chapter. We achieved a record number of awareness events coordinated, educational forums presented and support groups organized! We hope that each of our volunteers feels a sense of pride in all that we have been able to accomplish together!

**Health Fairs Coordinated: 21**

**Educational Programs Presented: 11**

**Support Groups Active: 22**

We also take a moment to thank Actelion and Gilead for their generosity that helped our educational programs thrive this year. Our guest speakers were amazing, we thank them for volunteering their time to educate our patients and families. We were also very excited to see many student nurses and physicians from a variety of organizations in the audience during the forums. This motivates us to continue our efforts to invite physicians and allied health professionals to learn more about scleroderma and to better understand the needs of those that deal with it every day of their lives.



## 2014 Patient Education Forums

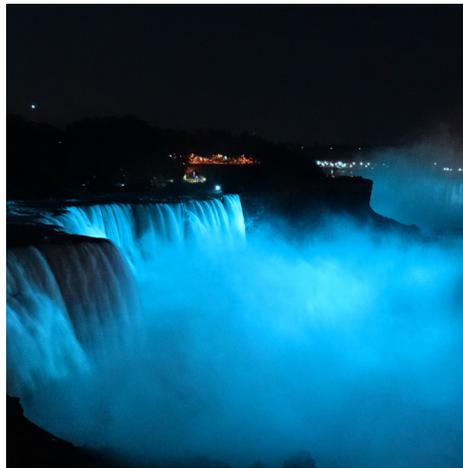
**April 12**

Hospital for Special Surgery  
New York, NY  
Mark Pettus, MD  
Sarah Taber, MD  
Seth Ginsberg



**May 4**

Stony Brook University  
Stony Brook, NY  
Howard Blumstein, MD  
Paul Stachan, MD



**June 6**

Yale University – West Campus  
Orange, CT  
Erica Herzog, MD  
Jennifer Kapo, MD

**August 9**

*with Scleroderma Society of Ontario*  
Niagara Falls Memorial Medical Center  
Niagara Falls, NY  
Janet Pope, MD  
Lee Shapiro, MD



**September 13**

The Bone & Joint Center  
Albany, NY  
Celeste Freeman, OTR/L, CHT  
Siobhan Kuhar, MD, FASM, PhD, FACS, FAAOA  
Alyssa Paulsen

**September 27**

William W. Backus Hospital  
Norwich, CT  
Harjinder Chowdhary, MD  
Thinesh Dahanayke, MD

**October 11**

Rochester Airport Marriott  
Rochester, NY  
Virginia Steen, MD  
Rev. Robin Franklin  
Tziporah Rosenberg, PhD  
Wanda Strother  
Mollie Richards  
Richard Ray, II



**October 25**

*with Delaware Valley Chapter*  
Rutgers University  
New Brunswick, NJ  
Robert Lahita, MD  
Laura Hummers, MD, ScM

**November 23**

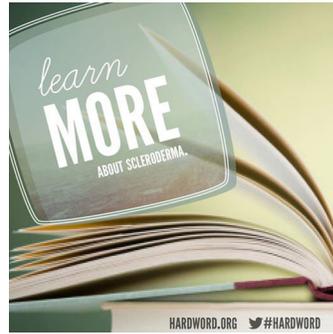
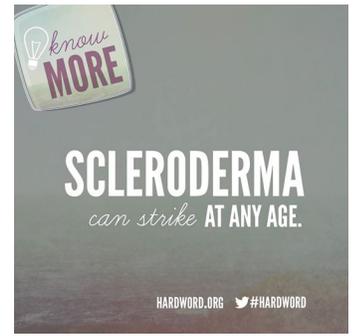
Hospital for Special Surgery  
New York, NY  
Robert Spiera, MD  
Maureen Mayes, MD, MPH  
Heidi Jacobe, MD

# Together we are stronger.

June is designated Scleroderma Awareness Month not just in our country but around the world. This year we joined forces with major North American scleroderma organizations to develop an awareness campaign that would let others know about the disease and our cause. Our first ever partnership with the Scleroderma Research Foundation and the Scleroderma Foundation enabled us to enlist the help of our members and friends to share educational messages with people near and far.

The campaign was based on the idea, “Hard Word. Harder Disease.” This theme acknowledged difficult obstacles we encounter when talking about the disease, such as pronunciation (hard), tissue condition (hard), and the many manifestations of the disease (harder). This imagery opened the door for sharing simple messages that describe what a patient deals with and who scleroderma can affect.

The campaign used several channels to get the message out. Regularly scheduled posts on Facebook and Twitter were the campaign’s backbone. These posts and tweets included information and a link to a specially created website, SclerodermaAware.org. The website asked visitors to help spread awareness and directed them to any of the three partner’s websites.



Social media elements



Additional campaign elements included a widely distributed news release which was picked up by major news outlets. Along with alerting the media, we shared the message at one of the busiest places in North America; the CBS “Super Screen” digital billboard on 42nd Street – Times Square – in New York City.

The campaign ran from June 5 through July 15. While response was slow at first, a bit of media coverage and almost daily Facebook and Twitter posts got people engaged. On June 29 -- World Scleroderma Day -- and June 30, almost 2,000 people visited SclerodermaAware.org and our Facebook messages were viewed 350,000 times.

We believe that the campaign was a success. Through the thousands of impressions gained from the digital billboard, over a million views from Facebook posts and many more from other social media outlets, the campaign met a receptive audience. And many shared it with their friends. A goal of the campaign was to use our network to extend knowledge and to invite others to learn about scleroderma. Through this campaign we found new friends both here in Canada and in many countries around the world.

Based on this success, keep an eye out for a follow-up campaign in 2015. We believe that the partnership between the Scleroderma Society of Canada, the Scleroderma Research Foundation and the Scleroderma Foundation is a positive step that makes us stronger as we seek to inform people about our “Harder Disease.”



Raising awareness in Times Square, NYC

# Scleroderma Voices: Margaret Kollitides

I'm an optimistic person. I appreciate the beauty in simple things. I believe that the glass is always half-full, not half-empty.

I live with my husband, Triphon, who is my caregiver and our adorable grey cat, Arthur. Our beloved daughter Kat is a fifth grade teacher in Florida. Kat, my sisters Nancy and Karen, and our many nieces and nephews are great about staying in touch with me. We look forward to gathering together on Thanksgiving each year.

In 2002, I was diagnosed with scleroderma, pulmonary fibrosis, and Raynaud's. In the months prior to my diagnosis, my fingers had become very red, swollen and stiff. They hurt and I could not make a fist. I went to an internist, and he recognized this symptom of scleroderma even though he'd never seen a case before. He had only read about the disease. Fortunately he made the connection between my case and the disease, and I was properly diagnosed. However, looking back I now realize I had various symptoms of scleroderma and Raynaud's years earlier that were significant and were not addressed. I even had one doctor dismiss me, stating "You don't seem that sick" although I felt very unwell.

I live with the added challenges of pulmonary hypertension, mixed connective tissue disease, fibromyalgia, and rheumatoid arthritis. I am antiphospholipid syndrome positive. I'm a bionic woman, though! Due to loss of cartilage in my joints, I now have a fabulous titanium hip and elbow.

After a thirty-year career in publishing, I retired on permanent disability in 2008. I'm expertly cared for by Dr. Jessica Gordon, Rheumatologist at the Hospital for Special Surgery and Dr. Arunabh Talwar, Pulmonologist; Dr. Uly Lyandres, Cardiologist; and Dr. Nareej Kaushik, Gastroenterologist; all at North Shore/LIJ.

I've sought from and offered support in our Nassau/Queens NY Support Group, where I am the Assistant Leader. We've been meeting for over two years. We've covered a number of topics ranging from useful, adaptive devices we use throughout the day to medical topics that include talks from a pulmonologist, gastroenterologist, physical therapist, dentist and oxygen equipment providers. Our meetings provide a confidential place to get together and share questions, successes, and challenges.

Scleroderma is a chronic disease that can be very challenging. I'm attentive to what my body is telling me. I've learned to really slow down. When I need to rest, I do. I also do not worry about what may never happen. Life is a gift and each day is meant to be lived.



Margaret Kollitides with her husband, Triphon and daughter, Kat.

## New Scleroderma Center Designations

We are pleased to share that two Tri-State area institutions have been named Scleroderma Centers by the Scleroderma Foundation. In order to receive designation from the Scleroderma Foundation, institutions must:

- Demonstrate expertise in scleroderma including clinical and/or laboratory-based research;
- Conduct clinical trials in scleroderma;
- Conduct educational activities about scleroderma, and provide information about the advances in the care and treatment of patients with scleroderma to health care professionals and the public.

All institutions designated as a center have been reviewed by the Scleroderma Foundation's Medical Advisory Board to ensure patients are provided with knowledgeable resources about diagnosis, care and research.

In September the National Medical Advisory board granted center designation to the Pediatric Rheumatology Clinic at Joseph M Sanzari Children's Hospital. Since there are very few rheumatologists that specialize in pediatric scleroderma, this new addition for children and families living in and around the Hackensack, NJ area will be a great asset.

The Scleroderma Foundation Medical Advisory board also named the Interventional Immunology Center and Winchester Chest Clinic of Yale as a Scleroderma Center. Cultivating a relationship with Yale physicians Miradu Gulati, Erica Herzog and Wassim Fares has opened a new door for patients in the New Haven area.

Our chapter is much richer with these additional centers that will help to advance our mission of research, education and support for scleroderma patients and families.

## Give the gift of awareness



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



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Amazon smile is a donation program run by Amazon.com giving 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 support our mission of support, education and research.



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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.