One of the key functions of the Tri-State Chapter is to inform people who don’t know about scleroderma. This spring, we have a chance to do that in one of the most populated areas in the world: Times Square. Through a special program that gives us the use of a digital billboard on 42nd street, we are sharing our message that “if you have scleroderma, you are not alone.”

The towering 26 feet x 20 feet (520 square foot) CBS billboard plays a 15 second video to the millions who pass through Times Square. A crowd that includes those attending some of NYC’s largest spring events such as the Tribeca Film Festival and AIDS Walk NY. The billboard is located under the CBS logo above Cold Stone Creamery at 253 W. 42nd Street. The 15 second spot is scheduled to run once an hour starting April 1 through June 30, 2013.

Our advertisement puts a face on scleroderma. It shows that the disease affects common, everyday people as well as those in the public eye such as NFL Hall of Famer Barry Sanders and actor Mark Teich. More of their stories and battles with scleroderma can be found in a 10 minute video produced last year that speaks from the patient’s perspective. The video is available on the Tri-State Chapter’s YouTube channel (sftristate). The video and the advertisement are also available to Tri-State members to share with their communities, local broadcasting stations or those close to you to raise awareness for scleroderma. Call us for details at 800-867-0885.

Our hope is that the digital spot will allow people to find the Scleroderma Foundation and take advantage of the resources and help we offer. We want those who have scleroderma, their families, and loved ones to know that they are not alone.
A Message from Our Executive Director

“Any change, even a change for the better, is always accompanied by drawbacks and discomforts.”

-Arnold Bennett

The Tri-State staff has faced a number of changes in the first months of the year. The loss of Alex Matich’s wife, then retirement of our long time office manager, Tom Knapp has given us cause to look at life and our business a bit differently. There is most certainly loss and lingering pain; some of it will pass and some will linger for a long time to come.

As we join Tom in celebrating his retirement, we also look forward to allowing the new staffers to help as we seek to accomplish the Tri-State mission. Jocelyn Bailey and Karen De Luke are quickly learning the ins and outs of our processes and will soon be adding their unique insights to our operation.

While the new realities of our office will be cause for adjustment, we look forward to serving the Tri-State patients, their families and caregivers with new voices and perhaps a little more understanding.

Tom Knapp
Executive Director

Tri-State office changes

Our Office Manager for the Tri-State Chapter, Thomas Knapp retired as of April 20. Throughout almost to ten years with the chapter, Tom saw his share of change and progress. He and his stories will be greatly missed. As he was leaving we asked him to share a few insights from his time here…

Scleroderma Exchange: What change have you seen in the Foundation since you started?

TK: When I joined the Tri-State Chapter in 2003, we were a small office with a part-time staff, located in Teaneck, NJ. We had been at this location for the better part of our 20+ years of existence. My first task was to dismantle and move the office furnishings to our new location in Binghamton, NY. Staff consisted of myself and Executive Director Rosemary Markoff. Our Chapter organized three Walks, produced one newsletter and had two Educational Forums. Now, ten years later we have four full-time, on-site staff members and one part-timer, we produce four “Scleroderma Exchange” newsletters a year, a sponsor eleven Stepping Out To Cure Scleroderma walks and one walk/5K run, and we provided ten Educational Forums in 2012. We have changed and grown substantially in the 2013 – 2013 time frame.

Scleroderma Exchange: What do you plan on doing with your retirement?

TK: Paula and I plan on traveling the USA to visit family and old friends, as well as see some areas of the country we’ve never visited – the Grand Canyon, Napa Valley and Mount Rushmore to name just a few. Maybe we’ll even take a cruise or two!!! I am an avid reader and enjoy woodworking, and I plan to do a whole lot more of both.

New faces in the office

Jocelyn Bailey joined the Scleroderma Tri-State Chapter in October of 2012 as the part-time Communications Specialist. She is now taking on many of the office’s administrative functions in addition to managing the majority of our communications in her new full-time role as Communications Manager. Her job now includes day to day office management, writing donor thank you letters, creating marketing and informational materials, as well as producing the “Scleroderma Exchange”. She will usually be the voice you will hear if you call the office. She is eager to help. Jocelyn is an avid reader and swing dancer.

Karen De Luke recently joined the Tri-State Chapter team as our part-time bookkeeper. She brings strong skills and a good understanding of our industry gained from her 13 years of experience at a New York City based non-profit called GrowNYC. In her free time, Karen enjoys cooking and watching old movies with her dad.
With your support

Stepping Out To Cure Scleroderma is here for 2013 in twelve locations on six days in June. It is not too late to register-- online, though the mail, or the day of the walk-- and raise much needed funds to help. Albany and Rochester celebrate their tenth anniversaries this year. June and Lori in Albany, and Rosa, Marilyn, Diane and Dorothy in Rochester would say that it seems like yesterday when this adventure began. But it is only through a lot of hard work from many volunteers that the twelve events across our chapter continue.

Every year brings both veterans and a new cast of walkers and corporate sponsors who together elevate the Tri-State Chapter as number one nationwide in Stepping Out To Cure Scleroderma. It is always surprising when we ask new people, especially the excited ones, where they have been in the past. Most will say they just heard about us.

Still after thirty years, it’s good to see new and eager faces join with those who have been with us from the beginning. About 25% of walk participants are new each year. That means that because our number has remained constant for the past four years, we are losing about a quarter of the previous year’s participants. If you are one of the missing past participants – PLEASE COME BACK! If there is a reason why you no longer walk please let us know. We need everyone’s support to be successful.

If you cannot attend this year but still want to help, you can register as a virtual walker (no registration fee because you will not be at the walk), personalize your solicitation page and send your link out around the world. We need your support now more than ever.

If you can attend and have not registered, please go to http://walks.SclerodermaTriState.org, check out the dates, times and locations and register today. Let’s beat the odds and make 2013 our most successful Stepping Out season ever.

We need everyone’s support to be successful.

Scan here to sign up now!

Where to Walk to Cure Scleroderma

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<th>Location</th>
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<tr>
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Tri-State is Social

Find us on Facebook and Twitter for all the latest updates on the Tri-State Chapter.
Share your story. Connect with others. Have fun!
2012 - DONATIONS MADE IN MEMORY OF

To make a donation in memory or in honor of a loved one please fill out our donation form located on the back page of this newsletter or visit www.SclerodermaTriState.org

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Don Abert
Anna Alkunbig
Martin Alox
Eugenia Maalito
Migdalia Dolly Amadio
Debra Anderson
Marjorie Anderson-Kassim
Frank Aracbasco
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Aunt Rhoda
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Dawn Barraca
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Owen Yellen
Paul Robert Zaccaria
Dr. Barbara E.
Zimmerman
Sylvia Zinzow
Viola Zinzow
Dr. Barbara F.
Owen Yellen
Marjorie Hook Welsh
Susan Wells
Joan Whelan
Marie White
Kathleen Wicnienski
Mary Williams
Sandra Williams-William
Susan Lee Wilson
Ann Debrun Arroyo
Owen Yellen
Paul Robert Zaccaria
Dr. Barbara E.
2012 - DONATIONS MADE IN HONOR OF

Because of your generosity, the Scleroderma Tri-State Chapter continues on our mission of Support, Research & Education. Your donations are appreciated.

Other Celebrations:
26 from Connecticut
Adelsberg’s 39th Anniversary
All Scleroderma patients & families
All those who suffer from Scleroderma
Charley Kopolovic’s 2nd Birthday
Durrer II / Gordon Wedding
Mooney’s 60th Birthday
Others with this illness
Samantha & Cheri Adelsberg’s Birthday
Scleroderma survivors
Shelly & Natalie’s 50th Wedding Anniversary
Yvette Strauss’s Birthday

To make a donation in memory or in honor of a loved one please fill out our donation form located on the back page of this newsletter or visit www.SclerodermaTriState.org
With the commencement of the 113th Congress in January 2013, we are happy to report that the Scleroderma Research and Awareness Act has been reintroduced in the House of Representatives through the bipartisan efforts of Representative Lois Capps (D-CA) and Representative Peter King (R-NY). The new House Bill is HR 1429. We expect that Senator Kirsten Gillibrand will be reintroducing the Senate version of the bill soon. The legislation asks for an increase in funding for scleroderma research and awareness campaigns. The bill does not seek new money, but requests that a larger allocation of money from the National Institute of Health be channeled into scleroderma research.

We encourage all of you to contact your elected officials and ask them to co-sponsor this legislation. An easy way to do this is to visit the advocacy page of the scleroderma.org website at scleroderma.org/Advocacy. By clicking the “take action now” link, you can automatically generate letters to your elected officials. If you need to find your representative or senator, search by zip code.

We are also happy to report that scleroderma has again been named as a disease eligible for the Department of Defense Peer Reviewed Research Program. Scleroderma researchers have obtained over $10 million in research funding through this program over the past several years. We look forward to researchers again securing some of the $50 million available for research during the next fiscal year.

With your help, we will continue to make progress. We encourage you to stay in touch with your elected officials to let them know how valuable their support is to you. As co-chairs of the Scleroderma Foundation Advocacy Program, we welcome any questions or comments.

Suzy Ballantyne (sballantyne1@aol.com)
Rosemary Markoff (rmarkoff@scleroderma.org)
Our guest this edition is Erica Herzog, MD. Dr. Herzog is certified in critical care and pulmonary medicine. She is an Assistant Professor of Pulmonary Medicine, Director of Translational Lung Research, Co-Director of the Yale Fibrosis Program and Assistant Director of Medical Student Research in the Department of Medicine at Yale University. Along with Robert Simms, MD, Dr. Herzog will be a guest speaker at the 2013 Scleroderma Research Forum on November 16 at the Hospital For Special Surgery, NY, NY.

Scleroderma Exchange: Can you provide a brief overview of the research you will be presenting at our Research Forum?

Dr. Herzog, MD: At this time, our research focuses on the role that inflammatory cells called fibrocytes and macrophages might play in the development and progression of scleroderma related interstitial lung disease (SSc-ILD). Our laboratory has developed several unique methods to explore this question and is at the forefront of discovery in SSc-ILD. At the Scleroderma Research Forum this November, I will share details about the research - where we were, where we are now and how our discoveries will aid those with SSc-ILD in the future.

Dr. Herzog spoke at the 2010, CT Education Forum at UConn Medical Center. Her presentation can be found at sclerodermavideo.com

Why is your membership so important?

Tri-State Chapter membership shows that you’re an active part of the scleroderma family, helping educate, create awareness and search for the cause and cure of this often devastating disease. Here are just a few things your dues help to make happen:

• **Educational and research forums:** An annual line-up of forums across the Tri-State area feature investigators and clinicians providing treatment insights and research updates. Educational programs are free of charge to members and members receive advance notice of all program events.

• **Local area support group meetings:** Our goal is to have support groups that are within an hour’s driving distance of members. Many meetings include speakers of topics of interest.

• **Scleroderma resource library:** Books, articles and DVDs on scleroderma along with our national educational forums are available free to members.

• **Excellent informational resources:** Tri-State’s newsletter, Scleroderma Exchange is published four times per year; SclerodermaTriState.org provides access to an abundance of information about scleroderma resources and chapter happenings; SclerodermaVideo.com provides streaming videos of many of the chapter’s educational forum speakers.

• **Automatic Scleroderma Foundation national membership:** You will also receive all benefits of the Scleroderma Foundation membership including a subscription to the Voice magazine, access to educational awareness programs and a discounted rate to the National Patient Education Conference.

Scleroderma study notice: Would you like to take part in a scleroderma study? If you have had a right heart catheterization in the past 2 years, you may be interested in a scleroderma study at the Hospital for Special Surgery in New York City. Dr. Elana Bernstein is looking at a new, non-invasive way to test lung function in patients with scleroderma. To learn more, call Dr. Bernstein at (212) 774-2788.

Tri-State Chapter Funds “New Investigator Conference”

An appreciation of scleroderma and related diseases depends on an increasing number of researchers committing to finding a cause and cure for this disease. To help encourage those investigators already working in the field and others who may be considering the path, the Scleroderma Foundation has put together its first ever “New Investigator Conference”.

Knowing the need to continually help talented new investigators get established so they can carry on the traditions and evolve the findings of more senior scleroderma investigators, the Tri-State Chapter became a major sponsor of the conference. Tri-State’s $25,000 donation plus contributions from corporate sponsors gives conference organizers Dr. Carol Feghali-Bostwick, Chair of the National Board’s Research Committee, and National Medical Advisory Board Chair Dr. John Varga, the latitude to plan a high quality event.

The objective of the conference will be to provide mentorship to new or younger investigators in the medical field starting off in their research job. Each new investigator is asked to prepare a 15 minute presentation on his or her scleroderma related research. After the presentation, there will be a short Q&A and later a panel discussion allowing other researchers to better understand projects and build on their understanding of work that has been accomplished. To date 16 new investigators and 11 mentors have committed to attend.

The New Investigator Conference will be Saturday, August 3, 2013 at Boston University; timing and location will allow participating investigators to also attend the International Scleroderma Workshop that begins on that same day.

Making the New Investigator Conference a reality is due in part to the hard work and dedication Tri-State’s many volunteers, patients and friends that raise money for our “cause”. You can be encouraged by this important effort which will help develop the next generation of scleroderma research leaders.

Show everyone your support and advocacy!

Visit SclerodermaTriState.org and click on get involved for more information on awareness items.
New Tri-State Resource Page

One of the latest additions to the Tri-State website is the Resources page. Find the page by going to: resources.SclerodermaTriState.org.

You will find information on support groups or help with finding a physician. You can access our recordings of our patient educational forums 24/7. If you are looking for disability information, clinical trials, how to use the DNA repository and so much more, check it out today!!

The Scleroderma Foundation in no way endorses any of the drugs or treatments in this newsletter; the information is provided to keep its 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.