June is Scleroderma Awareness Month!

June is an important month for scleroderma. For more than 20 years, the Scleroderma Foundation and its chapters have recognized June as Scleroderma Awareness Month. We celebrate it with annual awareness and fundraising events, as well as obtaining presidential, state and local proclamations. And, by working with other scleroderma organizations around the world, we now have established June 29 as World Scleroderma Awareness Day.

We’re making strides toward that day when no one will pause in conversation after the word “scleroderma.” We want it to be as well-known as any other disease. One of the best ways we can tell others about scleroderma is in our own voices. With that in mind, the theme of this year’s Scleroderma Awareness Month campaign by the Scleroderma Foundation is “I. AM. SCLERODERMA.” The hope is that this theme will inspire everyone affected by scleroderma – patient, caregiver, family, friend, and healthcare professional – to come together to share their stories. The Foundation is encouraging people to become “Scleroderma Champions.” No matter what your connection to scleroderma, you have a story to tell, and by sharing it, you can help someone who’s going through a difficult time in their own journey. Submit your story online at www.sclerodermaawareness.org or email it to mystory@scleroderma.org.

June also is the beginning of our walk fundraiser season. Of the 50 or so walks that the Scleroderma Foundation sponsors across the U.S., 12 are in the Tri-State area, including a 5k run. Not only are our walks our biggest fundraisers, but they also are a great way to raise scleroderma awareness.

This year, we’re combining two efforts – fundraising and awareness – through an innovative awareness campaign called “Walk for Cure” (walkforcure.org). The hope is that people from all over the country will upload videos that tell why they walk and how scleroderma has impacted their lives. Later this year, the videos will be bundled and sent to Congress to continue our advocacy efforts.

There are many other ways you can help during Scleroderma Awareness Month. Here are some of them: 1) Vote for the “Scleroodoodle Artwork” contest. The grand-prize winner wins a trip to the National Patient Education Conference in Dallas. 2) Download a 2012 Scleroderma Awareness Month Facebook Timeline Cover image or other icons for social networking sites. 3) Purchase special Scleroderma Awareness Month gear such as T-shirts, mugs and bags. Proceeds benefit the Scleroderma Foundation.

Now, get out there and tell a friend, neighbor or coworker about scleroderma! Visit www.sclerodermaawareness.org for more information.
A Message from Our Executive Director

Awareness – “having knowledge of”

As we boldly enter the month of June – Scleroderma Awareness Month – we are about to see the culmination of five months’ preparation and hard work for this year’s Stepping Out to Cure Scleroderma walks. Although this is my third time through the process of organizing and then carrying out Tri-State’s largest annual fund-and-awareness raiser, there is one question I continue to ask myself: “Are we making any progress towards getting more people to understand scleroderma?”

After all, there are still plenty of misconceptions; a great lack of understanding persists in those outside our immediate circle of family and friends. However, I firmly believe that it is only by joining together that our continued efforts will make an impact. Making people aware of – or, “have knowledge of” – scleroderma is the first step to understanding.

Involve yourself in a walk. Ask your friends, neighbors, and medical professionals to join you. Even if they don’t accept your invitation, I think you’ll be surprised to find an excellent opportunity to talk about the disease and to tell your story. If in-person sharing is not your comfort zone, try making a video and sharing it in our ‘Walk For Cure’ awareness campaign that is being shared via social media at walkforcure.org.

As you read in this issue’s cover story, there are several other ways we can be involved in the awareness efforts, including visiting www.scleroderaawareness.org for more ideas.

Educational Event Schedule, 2012

<table>
<thead>
<tr>
<th>Forum</th>
<th>Date</th>
<th>Place</th>
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<tr>
<td>Scleroderma Educational Forum</td>
<td>9/8</td>
<td>University of Rochester Medical Center</td>
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<td>9/15</td>
<td>Albany College of Pharmacy &amp; Health Sciences Student Center, Albany, NY</td>
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<td>Scleroderma Product Fair</td>
<td>10/13</td>
<td>Holiday Inn Hasbrouck Heights - Meadowlands</td>
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<td>10/20</td>
<td>Niagara Falls Memorial Health Center</td>
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<td>Niagara Falls, NY</td>
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<tr>
<td>Scleroderma Educational Forum</td>
<td>10/27</td>
<td>Robert Wood Johnson University Hospital</td>
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<tr>
<td>Scleroderma Research Forum</td>
<td>11/18</td>
<td>Hospital for Special Surgery</td>
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<tr>
<td>New York, NY</td>
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<td>New York, NY</td>
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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 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.

If we have inadvertently omitted or misspelled your name, please let us know by calling (800) 867-0885.
Q. I am now diagnosed with systemic sclerosis and have indicated that I am an organ donor. Can scleroderma patients be organ donors? Can my entire body be donated to scleroderma research and how can that be done?

A. I applaud the selflessness of the individual who posed the question. Organ donation could not occur without such people. Many individuals with scleroderma have been the recipients of lung or kidney transplants and, for most, their quality of life has changed dramatically for the better.

Don’t rule yourself out as a donor, but be aware that scleroderma (morphea and linear scleroderma excepted) is a SYSTEMIC disease. This is true of individuals with both limited and diffuse disease. There is the potential for the presence of vascular or fibrotic changes in internal organs, even when there is no evidence of this during life. That is, many individuals with scleroderma have “subclinical” pulmonary fibrosis when lungs are examined at autopsy, even though lung disease was never apparent during life. Similarly, clinically “silent”, previously undetected cardiac fibrosis may be present at autopsy. Individuals may have autopsy evidence of vascular disease in the kidney even when there was no history of “scleroderma renal crisis.” We know this from those generous donors who willed their bodies for post-mortem examination. That said, the organ donation community has taken the position that people should not rule themselves out as potential donors, but rather permit the appropriate donation personnel to evaluate them for suitability. Consideration is given to the health history of the individual and the status of each organ. An individual may be an appropriate donor of a cornea, pancreas, or liver, if not of a lung. Detailed information can be found at http://www.organdonor.gov.

Much that is known about organ involvement in scleroderma is derived from autopsy studies. There certainly is much that can yet be learned from autopsies. Anyone interested in donating his or her body to science is best advised to contact the closest medical school and to alert the treating rheumatologist of the donation. If that medical school happens to be a scleroderma research center, special studies may be performed. Inform your physician, but even more importantly, inform your family if you wish an autopsy performed.

Those who want to advance scleroderma research while alive can most help the cause by agreeing, if asked, to donation of blood samples and skin biopsy specimens at centers that are studying “biomarkers” of the disease. Much of this information simply can’t be derived from autopsy studies. In addition, many such “in life” studies involve following blood and tissue markers serially in an individual through the course of the disease and before and after drug interventions. It is from such studies that new treatments are most likely to arise. Over time, more and more scleroderma treatment centers are establishing such serum and tissue “banks” as part of study protocols, each of which require your written and informed consent.

Q. What is the relationship between contracting Lyme Disease and scleroderma?

A. Passions are often strong on just about any topic related to Lyme disease, because many of these issues are not yet resolved in an evidence-based fashion. Most of the readers of this newsletter live in areas in which Lyme disease is endemic and many (like this author) have no doubt had Lyme disease. However, there is as yet no evidence that infection with Borrelia burgdorferi (the bacteria that causes Lyme disease) plays any role in the development of systemic sclerosis. In Europe and Asia, but NOT in the US, high titer of antibody to B. burgdorferi have been found in patients with LOCALIZED scleroderma (morphea) and the organism itself has been found in skin biopsies from the areas of thickened skin in a small minority of those patients. So, morphea, in Europe, if not in the USA, may sometimes be a manifestation of Lyme disease.

Q. Did you know: the ratio of women to men with scleroderma is 3:1; Raynaud’s is the most common early symptom of systemic scleroderma; or that finally establishing a diagnosis of scleroderma may take place many years after symptoms first begin?

These facts and many more are just the type of information that we are eager to get out to educate others about the disease. Health Fairs are one of the ways that we achieve this educational goal. If you visit a great health fair or hear of an upcoming health fair in your community let us know about it. We need the eyes and ears of many to help us get the word out about scleroderma. And, if you are interested in volunteering to set up a table at a health fair, we will provide you all the materials you’ll need. The more people that become aware, the more voices we will have to advocate for research and education about the disease.

Thanks in advance for helping us help others. Contact Mary Beth Bobik-Kadylak, Director of Patient Education and Support at (800) 867-0885 for further information.

Health Fairs

Left to Right: Tri-State volunteers Gloria Monteverde, Venetta Pena, Myrna Carrasquillo, Beatriz Nunez, and Suzette McMillan at the 2012 Long Island Sjogren’s Walkabout at the Roosevelt Field Mall.

Our guest doctor this month is Lee Shapiro, MD

Dr. Shapiro is Director of the Steffens Scleroderma Center in Albany, NY. He is a frequent speaker for the Tri-State Chapter, a researcher and attending physician who has helped advance the treatment and understanding of scleroderma for countless individuals.

Rochester Scleroderma Support Group member Diane Reynolds (right) helps Annette Imes-Chaney (left) at the health fair in Aenon Baptist Church, Rochester, NY.
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Leo Podhorzer
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Walk Season is Here!

Every June we get a chance to raise money and awareness for scleroderma. Thousands of scleroderma survivors and their friends, family, and caregivers join together to “step out” in parks, shopping malls, and schools across the Tri-State area. We’re hoping to make this walk season the best one yet. And with new tools – social media and the online fundraising system called “FirstGiving” – we’re better equipped than ever to make that hope a reality.

It’s never too late to get involved. The doors are wide open. In a way, our walks fulfill all parts of our three-fold mission of education, research, and support. As an event that offers support, they’re like a rally for scleroderma survivors and their loved ones. As fundraisers, they generate lots of revenue to fuel our programs and research for a cure. And finally, as educational tools, what could be a better way to let more people know about scleroderma than a large gathering in a public place?

Don’t wait - get out there and get involved: http://walks.SclerodermaTriState.org

Stepping Out to Cure Scleroderma - 2012 Schedule

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<tr>
<th>Date</th>
<th>Location</th>
<th>Activity</th>
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<tr>
<td>06/02/12</td>
<td>Seneca Park</td>
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<td>Wantagh Park</td>
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<td>06/09/12</td>
<td>West Hartford Reservoir</td>
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<td>06/10/12</td>
<td>Battery Park</td>
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<td>06/10/12</td>
<td>Beckmantown Town Hall Park</td>
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<tr>
<td>06/10/12</td>
<td>Overpeck Park (walk &amp; 5k run)</td>
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<tr>
<td>06/10/12</td>
<td>Crossgates Mall</td>
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Making Our Voice Heard in Washington, DC

Your help has been appreciated with our advocacy efforts in Washington, DC and we continue to need your help as we work to seek approval of the Scleroderma Research and Awareness Act in the House (H.R. 1672) and the Senate (S 649) by the end of 2012. We still need co-sponsorships from representatives from NY, NJ and CT and also ask if you can have family and friends from other parts of the U.S. help us in this important effort.

Visit www.scleroderma.org/advocacy for information. You can also contact Suzy Ballantyne (SBallantyne1@aol.com) or Rosemary Markoff (rmarkoff@scleroderma.org), Co-Chairs of the SF National Advocacy Committee, if you have any questions.

Don’t Forget!

2012 National Patient Education Conference

The Scleroderma Foundation and the Texas Bluebonnet Chapter are pleased to announce the 2012 National Patient Education Conference will be held Friday, July 27 through Sunday, July 29, at the Gaylord Texan Hotel and Conference Center in Grapevine, Texas, about 20 minutes outside Dallas.

We are committed to helping you learn about scleroderma and how it affects you and your family. The National Conference is an event that allows you to reconnect with friends and establish new relationships with other patients and their families, researchers, and clinicians.

Find out more by visiting: www.scleroderma.org/national_conference.htm
Scleroderma Voices: Heidy

**Heidy Dornau tells her story to Scleroderma Exchange in this issue.**

In addition to being a scleroderma survivor, Heidy began leading a Tri-State Chapter support group in the Nassau-Queens area in May of 2012. You can find an extended version of our interview with Heidy by visiting www.SclerodermaTriState.org and clicking on “Personal Stories.”

**Scleroderma Exchange:** What was the process of searching for a diagnosis like for you? How did you get to where you are today?

**Heidy Dornau:** As I look back on the last 10-15 years, I realize now that I had quite a few of the symptoms of scleroderma. Unfortunately, my doctors were not that familiar with autoimmune diseases. I had pain in my joints, dry mouth, and gastro problems. The doctor said, “It happens as you get older.” I had severe gastro-related anemia with no explanation as to why. Then after several years of being treated for anemia, it got worse. I had to have part of my stomach removed to stop the bleeding. One year later, the bleeding had stopped, but now I was extremely tired and aching all over. I insisted on seeing a rheumatologist. I made the appointment and the doctor said I had either lupus or scleroderma. He did a blood workup and the results showed scleroderma (CREST). The only thing the doctor told me was that it was an autoimmune disease with no cure and medical science did not know what caused it. He told me to take Tylenol when needed for pain and we would keep an eye on my progress. No other tests were necessary, he said.

I joined the Manhattan Support Group in 2004 and made many new friends. They pulled me out of my slump and gave me answers to many of my questions. They not only gave me friendship and support but hope as well. They informed me that I needed to get a baseline and of all the tests that it would entail. Again, my doctor said it was not necessary. A few months later I was referred to Dr. Avram Goldberg, who specializes in scleroderma. Dr Goldberg confirmed what my friends at the support group said: I needed more tests performed to get a baseline. By this time I was very short of breath. He sent me to Dr. Arunabh Talwar, who is now my pulmonologist. Needless to say, for the next six months I was busy having all the necessary tests that Dr. Talwar requested. I’m on oxygen 24/7 and I now have all new doctors. All of them work together as a team. I now feel confident that they will be there for me.

**Scleroderma Exchange:** Why did you take the lead in creating a support group?

**Heidy:** I’m amazed at how many doctors are not that informed with autoimmune diseases. A lot of time was wasted before I was properly diagnosed. The public needs to be made aware of how debilitating this illness is. Dr. Talwar suggested I start a group about one year ago but, due to another medical issue, I was unable to do so at that time. On May 5th 2012, however, I am starting the Nassau-Queens Support Group. I found that the Manhattan Support Group was a blessing! They are always there for me and will always be part of my life. Unfortunately there are no support groups in Nassau or Queens where I live. It is difficult for some of the patients to get into Manhattan. I’m looking forward to this gathering. I want to help my fellow patients. A diagnosis of scleroderma is frightening. For many people it is difficult to accept and we feel at a loss. What will happen next? We don’t know. But with guidance from the Support Group and the Foundation we will make the journey together.

**Scleroderma Exchange:** What do you do to get through those really bad days?

**Heidy:** I find when I have a really bad day, the best thing for me is to call someone else up and listen to their troubles. I then say to myself, Hey, Heidy, you’re not so bad off. Things could be worse! And you know, it helps me get over my slump. Even though I will have my own support group, I will still attend the one in Manhattan as well as those in the tri-state area. I find that I always learn something new at these meetings which I can share with my group. I give thanks to the Foundation for all their guidance and especially to my family at the Manhattan Support Group!

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“Indore at www.SclerodermaTriState.org under "Personal Stories."
Scleroderma Foundation/Tri-State, Inc. Chapter
59 Front Street, Binghamton, NY 13905

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* Founder’s Circle $500 or more

Name __________________________________________________________________________
Phone __________________________________________________________________________

Print as you wish it to appear in public acknowledgements

Do not list my name in the annual report

Email __________________________________________________________________________
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All contributions of $25 or more include annual membership dues for BOTH SF Tri-State and National Scleroderma Foundation.

Please renew my membership, $25 per year
Please enroll me as a new member, $25 per year
I do not need membership benefits but I would like my contribution to help support your work
Enclosed is my/our matching gift form(s)

This contribution is made   ❑ in honor of   ❑ in memory of   ❑ is a membership gift for:

Name __________________________________________________________________________

Send a note indicating that a contribution has been made to:

Name __________________________________________________________________________
Address ________________________________________________________________________

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Please make check payable to SF Tri-State

FirstGiving is the company we use for online registrations. Go to http://walks.SclerodemaTriState.org and register for the walk most convenient to you. You’ll find you have the option to create your very own FirstGiving information and solicitation page. This page will allow you to share your fundraising goals with friends and family. It’s incredibly easy and it’s free to use – just set up your page, let your social circles know about it, and watch your funds go up and up as people donate to your cause.

Planning a Tri-State fundraiser and want to use online donations? We can help you set up a FirstGiving page.

Contact: amatich@scleroderma.org.

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Sign up for your FREE weekly email newsletter at www.scleroderma.org for up-to-date information and the latest news about research, treatments, advocacy efforts, special events and other activities to raise awareness.