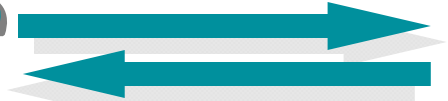




Scleroderma Exchange



Published by Scleroderma Foundation/Tri-State, Inc. Chapter, 59 Front Street, Binghamton, NY 13905

The mission of the Scleroderma Foundation Tri-State, Inc. Chapter is three fold:

To provide educational and emotional support to people with scleroderma and their families

To stimulate and support research designed to identify the cause and cure of scleroderma as well as improve methods of treatment

To enhance the public's awareness of this disease

PUT ON YOUR SHOES AND GET READY TO WALK FOR THE CURE!

WALK SEASON IS QUICKLY APPROACHING! This year our first walk is on May 23, 2010. The 2009 *Stepping Out To Cure Scleroderma* walks had 3,200 registrants that raised \$380,000. The money you raise helps support our three-fold mission of support, education and research. Since 2000, your contributions have helped fund over \$1.25 million of research within New York, New Jersey and Connecticut. Money raised also helps sustain fifteen active support groups, provide educational forums throughout the Tri-State area at no cost to participants and helps provide each issue of this newsletter to over 5,000 people.

Our goal this year is to raise **\$425,000** and register **3,500 walkers**. Please enroll sponsors today and every day until you come to the walk. Each extra sponsor you enlist brings us that much closer to finding a cure. A sponsor can be a relative, a neighbor, a co-worker or a friend. If you are a high school student, ask your teachers, your classmates and others.

(Continued on page 7)



TRI-STATE EXTENDS A WARM WELCOME TO A NEW EXECUTIVE DIRECTOR



JAY PEAK joined us at the beginning of January to fill the role of Executive Director. He is excited to step into his roll of leading the experienced Tri-State team. He is charged with energizing the organization's programs and activities, ensuring they meet the three-fold mission of providing education and emotional support; stimulating and supporting research; and enhancing the public's awareness of scleroderma.

Jay brings over 25 years experience in market development to his new leadership role. He has held management roles at a number of newspaper companies, including Gannett Co., Inc. publications in Binghamton, Utica and Rochester, New York. Most recently, Jay worked as the Market Development Director at the Central New York Newspaper Group in Binghamton, New York. He has an M.B.A. from the University of Miami and a B.A. from Western State College of Colorado. Outside of work, Jay enjoys running, spending time with his family and volunteering at church and in the community. He currently serves as Chairperson of the Board of Directors for the Children's Home of the Wyoming Conference in Binghamton, NY.

While his experience with scleroderma is limited, as a parent of two autistic children he brings an understanding of the challenges that incurable health issues can bring. He looks forward to the months ahead when he can "meet members of Tri-State, hear their stories" so that he can "make sure the services we provide meet our member's needs."

You can reach Jay by calling (800) 867-0885 or email him at jpeak@scleroderma.org.

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RESEARCH & CLINICAL TRIALS AT NORTH SHORE LONG ISLAND JEWISH HEALTH SYSTEM

The Scleroderma and Raynauds Treatment Center provides comprehensive care to patients with this rare illness. Treatment of scleroderma can be complicated. This center employs a team approach involving such specialists as rheumatologists, nurses, therapists and when needed, physicians with expertise in lung, gastrointestinal or kidney diseases. Our experience and interest in scleroderma allows for an individualized yet comprehensive plan of care for each patient.

The Scleroderma Center is part of the Division of Rheumatology and Allergy – Clinical Immunology of the North Shore Long Island Jewish Health System. The Center is staffed by full-time clinical rheumatologists, nurses, research coordinators and support staff. Interfacing with *The Program in Novel Therapeutics*, this Center is involved in therapeutic trials testing new medications. It offers cutting-edge therapy to its patients. Below is a list of trials currently available to scleroderma patients:

DISTOL: This study is being performed to determine whether an investigational drug, Treprostinil Diethanolamine, is effective in treating digital ulcers. Digital ulcers are painful, open sores on the fingertips. They are commonly seen in scleroderma patients and are difficult to treat.

MI-CP180: Med Immune has set out with the goal of developing a systemic treatment for scleroderma. The purpose of this phase one study, first study in human subjects, is to determine the safety and biologic activity of MEDI-546.

PHAROS/ DETECT: There are two ongoing observational trials for patients with scleroderma who have an elevated risk for developing pulmonary hypertension. These studies are being conducted to identify biomarkers, evaluate the progression and understand the natural history of pulmonary hypertension in scleroderma.

For more information about clinical trial opportunities, please contact Rachel Saltzman at (516) 708-2559.

RECOMMEND DOCTORS FOR OUR REFERRAL LIST

Do you know a doctor that has been a big help to you or other scleroderma patients? Recommend him or her for our referral list to help those in the Tri-State area get the medical assistance they need. We are especially seeking dentists and rheumatologists. Call (800) 867-0885 or email sdtristate@scleroderma.org with your recommendations.

2010 NATIONAL CONFERENCE

The 2010 National Patient Education Conference will take place at the Sheraton Boston Hotel at 39 Dalton Street, Boston, MA. There will be a reception with light hors d'oeuvres on July 30th from 6 to 8 pm and workshops take place July 31st and August 1st. If you wish to register by phone, please call (800) 722-4673. For more information, to register online or download a registration form, go to www.scleroderma.org.



The Doctor Is In

Q: My mother died from Scleroderma 6 years ago. Her arthritis was very bad and she looked 85 years old even though she was only 61. I am 45 and wondering what are the odds that I will get Scleroderma?

A: Scleroderma like many of our autoimmune diseases likely has a genetic component which has been increasingly explored in recent years. The familial associations, however, with scleroderma are weaker than for many of our other diseases. Although your mother succumbed to scleroderma, in general it would not be likely that you would similarly develop scleroderma, although often children or siblings of an index patient with connective tissue disorder might be more likely to show some signs of another autoimmune disorder than would a person randomly in the population without such a family history.

Q: Is there any indication that people with diffuse scleroderma are more likely to develop any forms of cancer?

A: There have been some concerns that patients with diffuse scleroderma may be more likely to develop certain cancers, in particular lung cancer. This is a complicated epidemiologic issue, as patients with scleroderma are also more likely to undergo chest CT scans which in turn would be more likely to pick up small lung cancers incidentally. Additionally, some of the treatments used for diffuse scleroderma such as cyclophosphamide may confer some increased risk for future cancers down the road (such as bladder cancer or other malignancies) which have been associated with high exposure to cyclophosphamide.

Q: Can scleroderma be cured? Is it common for the symptoms to be reversed? Does scleroderma go into remission?

A: Scleroderma can go into remission, and indeed the skin thickness seen even in patients with very diffuse scleroderma often can improve over time. This is part of the reason it is so hard to assess the efficacy of our treatments in scleroderma, since it is recognized that later in the disease course, skin that has been involved with scleroderma can often soften on its own. It would not be common however, to see areas of scarring or “fibrosis” in the lung spontaneously improve and the sense is generally once that damage is done in the lung or kidney, it is not reversible.

Q: I am a 64 year old woman who has lived with a huge variety of diagnosis and symptoms, all starting because of the presence of severe Raynauds, fatigue and rashes starting at the age of 25. Over the years my ANA has increased and the pattern has changed to centromere. I was diagnosed with Lupus at the age of 34, but that has been changed several times and now remains as

"Undifferentiated Mixed Connective Tissue Disease". Can someone explain to me exactly what this means. I have yet to get a clear answer to this question.

A: There are many overlapping features in the different connective tissue disorders, and our “criteria” as to how a specific connective tissue is defined relates to definitions that we as physicians have created to make sure we are all talking about similar types of patients particularly in the context of clinical trials. There are many patients with what we consider “undifferentiated connective tissue disorders” where they may show some features of autoimmunity such as positive autoantibodies, clinical features that can be seen in a variety of connective tissue disorders such as joint pain or inflammation, fatigue, Raynaud’s phenomena, or rashes, but do not fully meet criteria for lupus or for any other specific connective tissue disorder. In that context, we often use the term undifferentiated connective tissue disease. Mixed Connective Tissue Disease (MCTD) often is a somewhat more definable entity in which patients might have features that can be seen in lupus such as inflammatory arthritis, features of scleroderma such as Raynaud’s phenomena, or features of myositis such as muscle inflammation. Esophagus problems or even lung involvement can occur in these patients as well. They often, however, have a high titer positive RNP antibody which some clinicians feel is requisite to make the specific diagnosis of MCTD. Some patients with this syndrome evolve more into a lupus type picture although others evolve into more of a scleroderma phenotype. It is important to recognize that for all of our rheumatic diseases, even with a more specific diagnosis such as “SLE”, the individual’s particular disease manifestations are on some level unique to them and therapy and prognosis is guided by their own unique features.

Robert Spiera MD is an Associate Professor of Clinical Medicine and Director of Vasculitis and Scleroderma Programs at Hospital for Special Surgery, in New York City. Dr. Spiera is active in the care of patients with scleroderma, both as a clinician and a researcher. Dr. Spiera is the Principal Investigator in the ongoing Gleevec Trial for scleroderma patients at Hospital for Special Surgery (HSS).



About the “The Doctor Is In”

The Tri-State Chapter has a very knowledgeable Medical and Scientific Advisory Board available to answer your questions related to scleroderma. **Please send all questions to:** sdtristate@scleroderma.org with a subject line titled, “The Doctor Is In”.

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Registration Form

One free Stadium Blanket
with \$250 in sponsors (one per registrant/family)

A registration fee of \$20 for those 18 and older should accompany this form. Take a \$5 **DISCOUNT** per registrant if you register prior to the day of the walk by mailing in this registration form to the SF Tri-State office. Pre-registrants are encouraged to make copies of this form and continue to collect sponsors. Turn in additional forms and money the day of the walk. **THANK YOU!**

A signature is required for each adult in the waiver section below. Parents must sign for all children.

Walk Site: Albany Binghamton Buffalo Hartford Leonia Long Island Manhattan Plattsburgh
 Poughkeepsie Rochester Stamford Syracuse

PLEASE SIGN UP SPONSORS BELOW. THIS IS OUR MAJOR FUNDRAISER FOR THE YEAR.

Last Name _____ First Name(s) _____
 Address _____ Apt _____ City _____ St _____ Zip _____
 Home Phone _____ Work Phone _____ Ext _____ Email _____

Waiver: 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, support group, officer, employee, sponsor, organizer, volunteer 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: _____
 I am unable to attend. Please accept my contribution of \$ _____

Checks payable: SF Tri-State Mail to: Scleroderma Foundation/Tri-State, Inc. Chapter, 59 Front St, Binghamton, NY 13905

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

I am walking in honor of _____

In memory of _____

Team Name _____

- I am interested in volunteering for Walk 2011.
- I would like more information about scleroderma.
- I am a scleroderma patient.



Sponsors' Contributions

Return completed form(s) with check(s) or money order(s) to Scleroderma Foundation/Tri-State Chapter, 59 Front St, Binghamton, NY 13905
 An acknowledgment, which serves as a tax receipt, will be mailed to each sponsor if address is provided.

Put me on Mailing

	Name	Street Address	City	State	Zip	\$ Contributions	List
1							
2							
3							
4							
5							
6							
7							
8							
9							
10							
11							
12							

Please duplicate this form for additional sponsors

Total Sponsors' Contributions \$ _____

Cash - Total - Registrants - Blanket

WALK SEASON *(Continued from page 1)*

There are three ways to register for the walk. You can (1) **pre-register online for \$15** (save \$5) by going to www.scleroderma.org/steppingout/tristate.htm. By registering online you can create a free customized webpage, which tracks every sponsor you receive online and features pre-written, ready-to-send “sponsor me” and “thank you” emails. You can (2) **pre-register via mail for \$15** by completing the registration form provided in this newsletter and mailing the form and check to Scleroderma Foundation/Tri-State, Inc. Chapter, 59 Front Street, Binghamton, NY 13905 at least one week prior to the walk you plan to attend. And lastly you can (3) **register on the day of the walk** at the walk location by paying the \$20 registration fee. For additional walk, registration or corporate sponsorship information call (800) 867-0885.

Walk Dates ~ Locations ~ Time of Registration

May 23 rd	Overpeck Park, Leonia, NJ {9:00 AM}	June 13 th	Battery Park, Manhattan, NY {9:00 AM}
June 5 th	Seneca Park, Rochester, NY {9:00 AM}	June 13 th	Onondaga Lake Park, Liverpool, NY (Syracuse) {9:00 AM}
June 6 th	Wantagh Park, Wantagh, NY (Long Island) {9:00 AM}	June 13 th	Beekmantown Town Hall Park Plattsburgh, NY {9:00 AM}
June 6 th	Otsiningo Park, Binghamton, NY {9:00 AM}	June 19 th	Vassar College, Poughkeepsie, NY {9:00 AM}
June 6 th	Crossgates Mall, Albany, NY {6:30 PM}	June 27 th	Westhill High School, Stamford, CT {9:00 AM}
June 12 th	West Hartford Reservoir, Hartford, CT {9:00 AM}		
June 12 th	Island Park, Williamsville, NY (Buffalo) {10:00 AM}		

New for 2010!

5K Run

*Leonia, NJ
May 23*

MAKE A DIFFERENCE—VOLUNTEER FOR A WALK COMMITTEE!

If you have ever wondered what goes on behind the scenes to make *Stepping Out To Cure Scleroderma* work – now is the time to volunteer and solve the mystery. Every walk committee needs industrious and committed people to help. Typical committee duties include food, registration, raffles/silent auctions, giveaways (shirts and bags), set-up, clean-up and taking pictures. Most committees meet four to six times before their walks to make sure everything is organized and working smoothly. If you are interested in helping, please call (800) 867-0885 or email amatich@scleroderma.org and we can answer your questions and help you get in touch with the walk committee chair in your area. The old saying “many hands make light work” is never more evident than at *Stepping Out To Cure Scleroderma*. Without the many hands your walk could not happen!





Tri-State, Inc. Chapter
59 Front Street
Binghamton, NY 13905-4701

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The Scleroderma Foundation in no way endorses any of the drugs or treatments described herein; the information is intended merely to keep its readers informed. Because the manifestations and severity of scleroderma may 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.

If you prefer to receive this newsletter electronically and want to stay abreast of Tri-State activities, please email us at sdtristate@scleroderma.org or call (800) 867-0885.

Sign up for your FREE weekly e-mail 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.

Calendar of Events

May 2010

- 1 SW Albany, NY Support Group
- 8 Cooperstown, NY Support Group
- 8 Hackensack, NY Support Group
- 8 Rochester, NY Support Group
- 11 Northern NJ (Dover) Support Group
- 15 Long Island Support Group
- 15 Albany, NY Support Group
- 15 Hartford, CT Support Group
- 22 Orange County (Warwick, NY) Support Group
- 22 Kingston, NY Support Group
- 23 Walk - Overpeck Park, Leonia, NJ

June 2010

- 2 NYC Support Group
- 3 Binghamton, NY Support Group
- 5 Walk - Seneca Park, Rochester, NY
- 5 South West Albany, NY Support Group
- 6 Walk - Otsiningo Park, Binghamton, NY
- 6 Walk - Crossgates Mall, Albany, NY
- 6 Walk - Wantagh Park, Wantagh, NY (Long Island)
- 6 Cooperstown, NY Support Group
- 12 Walk - W. Hartford Reservoir, W. Hartford, CT
- 12 Walk - Island Park, Williamsville, NY (Buffalo)
- 12 Hackensack, NJ Support Group
- 13 Walk - Battery Park, New York, NY
- 13 Walk - Onondaga Lake Park, Liverpool, NY (Syracuse)
- 13 Walk - Beekmantown Town Hall Park, Plattsburgh, NY
- 19 Walk - Vassar College, Poughkeepsie, NY
- 19 Orange County (Warwick, NY) Support Group
- 19 Kingston, NY Support Group
- 19 Albany, NY Support Group
- 27 Walk - Westhill High School, Stamford, CT

SCLERODERMA STUDENT ESSAY CONTEST



Generating awareness and knowledge about scleroderma is possible at any age! Choosing scleroderma as a research topic helps to not only spread the word about the disease, but also helps to inform others about how they too can join the fight against scleroderma! With this in mind, the Scleroderma Foundation is proud to sponsor its first annual Scleroderma Student Essay Contest.

Who is eligible? Students in grades 4-12 are eligible to submit a written paper on scleroderma by May 3, 2010. This could be your chance to show off your work and make a difference for a worthy cause!

What must I include about scleroderma in my essay? The topic of scleroderma must make up at least 50% of the information provided in each entry to be eligible for the contest. Students will be evaluated based on creativity and originality.

What Do I Win? One winner will be selected from each of the following grade categories: 4-6, 7-9 and 10-12 by May 21, 2009 and given a special award certificate for their achievement. In addition, each winner will choose from EITHER hotel accommodations and registration for one adult and one child to the 2010 National Patient Education Conference in Boston, MA, OR a choice of a new Wii system or new iPod (based on comparable value). Winners' names and paper topics will also be featured in both the Foundation's online and print publications!

For a complete set of rules and application instructions, visit: www.scleroderma.org/studentcontest.html or call (800) 722-HOPE.