



SCLERODERMA EXCHANGE

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Scleroderma Foundation Tri-State, Inc. Chapter
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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

THE SEARCH FOR A CURE

Tri-State Chapter \$150,000 Research Grant.

Since founded in 1998, the Scleroderma Foundation has devoted significant resources to funding research in hopes of finding new treatments and ultimately, the cure for scleroderma. Over the last 19 years, the Foundation has funded \$23 million in grants, which has been possible only through the generosity of donors who share the Foundation's commitment to the search for a cure. A goal we share with our donors is to fund and stimulate new research and ideas.

The Scleroderma Foundation funds three different types of grants. *Early Career Investigator Grants* were designed for new investigators who hold faculty positions and wish to pursue careers in research related to scleroderma. This award is designed to mentor and encourage the next generation of researchers. *Established Investigator Grants* were created for promising, established investigators who wish to propose pilot studies with highly innovative themes related to the disease. *Multi-Center Collaborative Research Grants* were established to foster a more synergistic research community. This award supports two or more institutions to significantly enhance scleroderma research.



Theresa Lu, MD, PhD, associate scientist in the HSS Autoimmunity and Inflammation Program. Credit: HSS

review, critique and rank all applications based on the National Institute of Health's ranking system. Only projects of significant scientific merit are funded.

The research program is administered by the national office staff and grants are approved by the Board of Directors. The Scleroderma Foundation's Peer Review Research Committee is key to the program's success and its reputation for rigorous review. The committee is composed of highly respected scleroderma medical experts who

At this December's Peer Review Research meeting the committee ranked more grants worthy of funding than the foundation had funds available. Robert Riggs the foundation's CEO reached out to Tri-State Chapter to fund an extra grant. Our board of directors quickly convened before Christmas and voted unanimously to provide the funding for the \$150,000 two-year Established Investigator Grant. Following proper protocol, we were not advised where and to whom this grant would be provided. In January we were extremely pleased to learn this research project was for Dr. Theresa Lu at Hospital for Special Surgery in Manhattan. Her promising project titled *Leptin receptor-expressing adipose-derived stromal cells as a putative skinprotective subpopulation* could now move forward.

"Injecting ADSCs is being tried in scleroderma; the possibility of stimulating the lymphotoxin B pathway to increase the survival of these stem cells is very exciting," says lead study author Theresa T. Lu, MD, PhD. "By uncovering these mechanisms and targeting them with treatments, perhaps one day we can better treat the disease."

The 2017 research grant awards honor the efforts of those who are making significant commitments to searching for a cure. We in the Tri-State community are pleased to share this exciting news which could not have happened without the generous donors and fundraising efforts made by all of you, at so many events over the past years. Thank you!



Theresa Lu, MD, PhD



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A Message from Our Executive Director

"CHANGES"

I will start my first message to you where Jay left off in the last newsletter
"FOREVER CHANGED"

As the new Executive Director at Tri-State, my role within the chapter organization is changing. The past 14 years I have served in numerous board positions, along with volunteering at walks, speaking at patient education events and marching on Washington for our cause. Retiring from 32 years in the commercial wallcovering field to take on this new challenge is certainly a big change in my life.

Like many of you, Scleroderma has forever changed my life. In 1993 I first heard of Scleroderma when my wife the nurse became a patient. Pat fought a courageous battle for 8 years losing her struggle in June 2000.

I have spent my first evenings here in Binghamton reading through newsletters dating back to the early eighties, together we can all be proud of our accomplishments working to serve the Scleroderma communities in NY, NJ & CT. The Tri-State chapter has a rich history of "Stepping Out" to fulfill our mission of Support, Education, and Research. We have been fortunate with sound leadership from dedicated board members, a hardworking, passionate staff and YOU our army of volunteers.

We wish to publicly thank Jay for his 7 years of driving our operation, implementing many positive changes to better serve patients and their caregivers. We also want to recognize Alex Matich for his 10 years of dedication to our cause and his role in raising funds to fuel our chapter. Alex successfully organized over 100 walks, personally setting up, working and breaking down 60 plus walks over the years, February 15th Alex retired and headed south to Florida, a change in his life also.

As you read through this issue of the Exchange you will get a sense of our activities in the works for 2017, walks to raise funds and awareness, support group and patient education forums to educate and support patients and caregivers. Research; Tri-State was able to step up and fund in our own backyard. Jan's story on the success of her stem cell transplant as well as her personal narrative on being your own advocate. I met Jan in 2003 when she was first diagnosed, she like so many Scleroderma patients does not let the change to their lives brought on by this disease rule their lives.

I have had the privilege of meeting so many of you over the past 14 years as we have all worked to improve the lives of patients. I look forward to reconnecting in 2017 as well as meeting and working with new remarkable people in our community. At Tri-State, we are always seeking volunteers with talents and passion. We are currently looking for help with fundraising and spreading awareness. Please give me a call to discuss how you can be a part of the future evolution of our chapter.

Bruce Cowan
Executive Director



Scleroderma Foundation Tri-State, Inc. Chapter

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

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.

Scleroderma Voices: Jan Mitti



My journey with diffuse systemic sclerosis began fifteen years ago, at a very stressful time in my life. I had just lost my father and was working in a role requiring overseas travel for clinical trials. The first visual characteristic was Raynaud's Phenomenon. My primary care physician suggested I quit smoking and in time, the Raynaud's would probably go away. I quit smoking and waited and waited yet my hands did not change.

Results from blood work revealed I was positive for antinuclear antibodies (ANA). From working in the medical field I knew my immune system might not be working correctly. I began searching for a physician who would leave no stone unturned - a scientist. I was fortunate to find a rheumatologist who would give my condition a name. Reminding me of the absent-minded professor with a messy desk of patient charts and notes everywhere, he was a genius in disguise. In three months he diagnosed me with systemic diffuse sclerosis.

I will never forget when I received the call on a Friday, telling me that my Scl-70 was positive and the doctor wanted to see me Monday morning. I wasn't about to wait until Monday! I searched every medical website on the internet and imagined the worst, leading right down the path towards death! I was numb. I couldn't believe this could happen to me. Years of working multiple jobs to get through school to become a successful thirty-nine-year-old woman in corporate America - this news pulled the "plug"! Reality hit when I saw the doctor, hearing him say how sorry he was. What was I going to do? How was I going to tell my family? What about my career and all the hard work it took to get there? I was filled with anger, sadness, regret, loss, fear and uncertainty.

I started treatment at the Scleroderma Treatment Center in New Jersey. I was put on methotrexate immediately. My hands and arms became tight and hard within weeks. I really believe if it weren't for the immediate aggressive therapy, the first years would have been worse. Over the next few years, I tackled each symptom that arose and built a team of medical professionals around me to help become my own advocate. I prepared for each doctor visit by researching the latest therapies. Digital ulcers and Raynaud's became my biggest problems. Recurrences of infections were problematic. I pursued anything to help relieve the pain and loss of finger and hand function; joint fusions when applicable, Botox injections in my hands and medication changes to improve circulation to the extremities. I started alternative therapies producing some relief.

My battle continued but I wasn't giving up. Four years ago I went through a stressful major life event and the scleroderma became very aggressive. My skin started to harden everywhere. My hands curled more, my feet and ankles became inflamed and hard, my eyes and mouth tightened and the methotrexate wasn't working. My Raynaud's was at its worse. My scleroderma specialist tried different biologics but still no change.

I knew my stress was exacerbating the disease. The cold weather was making Raynaud's and digital ulcers worse. I picked up my bags, got in my car and moved to sunny Florida. Just like that. Escaping the stress in my life and beginning again, looking for a physician and

fortunately finding a young rheumatologist who studied under a scleroderma lung specialist. My first visit was an eye opener. During the examination, he heard cracking noises in my lungs. It was determined that I had lung fibrosis. An immunosuppressant drug, CellCept used for fibrosis and skin softening was prescribed. After three months without change, I started researching stem cell transplants. I watched videos, listened to scleroderma educational forum lectures and contacted Scleroderma Stem Cell Pioneer members on Facebook. After much prayer with family and friends and discussions with my doctors (who opposed stem cell transplant), I contacted Dr. Richard Burt's team at Northwestern Medicine in Chicago.

First I had to see if I qualified for such treatment. The team greeted me with open arms. In Chicago, I had numerous tests to see if my heart and body could handle the transplant and found out scleroderma had affected my heart. Fortunately, Dr. Burt was running a "Healthy Heart" protocol for those with heart involvement who did not qualify for the more aggressive treatment.

Once I received insurance acceptance for the stem cell transplant, family and friends helped raise money to cover expenses. I was ready. A caregiver was with me through the entire process. The support I received was overwhelming. The process started with getting my body to produce stem cells, accomplished with chemotherapy followed by an injection of medication that stimulated the bone marrow to produce millions of "stemmies". The stem cells were taken from my blood and stored for transplant. After two weeks of rest at home, my caregiver and I headed back to Chicago. I was excited and scared. I knew I was doing the right thing.

The first days of chemotherapy caused mild morning sickness and dizziness. I experienced fatigue and mood changes from high doses of prednisone but nothing made me want to stop the treatment. Friends and family flew in to support me. The day finally came for me to get my "stemmies" back. It was very emotional and exciting for all of us. A priest blessed my "stemmies" and we prayed for a new beginning, to a new healthy immune system.

The transplant was a success with no adverse reactions. Long tedious days followed while I waited for my new immune system to kick-in. I endured low energy with two blood transfusions to perk me up.

I went home and the healing began. Some days I didn't even get out of bed and others I walked in the sun. I waited patiently for my immune system to get stronger. Each week I could venture out a little more.



Jan with Dr. Richard Burt and his team

It's now been four months post-transplant. The inflammation has subsided. My legs seem to be getting softer. My friends tell me I now have wrinkles on my face - not sure if I am happy about that. My Raynaud's and digital ulcers are still prevalent and time will tell if skin softening will help. I don't regret my decision to have a transplant. Patience is a virtue and I embrace the time with open arms, looking at it as time well spent for healing.

Get to know your board



Rosemary Markoff

Rosemary has served as Board President, Secretary and Treasurer as well as Executive Director for the Chapter since her diagnosis with scleroderma over 20 years ago. She currently serves as Treasurer and is

part of the Finance and HR committees. She also is Co-Chair of the SF National Advocacy Committee and recently was invited to serve on the NIH NIAMS Advisory Council. She started and continues to serve as the Binghamton Support Group Leader and is in a leadership role for the Binghamton Walk. Rosemary is a lifetime resident of Binghamton, NY where she volunteers on a neighborhood group. She loves to spend time with her grandchildren in Maryland and Florida.



Estelle Randolph

Estelle joined Tri-State's board in 1982, the year after we incorporated, the year after her mother was diagnosed with scleroderma. Estelle's focus has always been on fundraising and awareness, mirroring her

professional pursuits as an entrepreneurial spirit as well as her roles in show business. Estelle established Tri-State's annual raffle which we still hold each fall some thirty plus year later. The chapter relies on Estelle for her historical perspective of what we have accomplished in serving the scleroderma community.



Suzy Ballantyne

Suzy joined the board in 2013. She is the National Co-Chair of the National Scleroderma Advocacy Committee. Suzy is a participant in the Albany Walk and is on the Board of the Steffens Scleroderma Foundation. She has worked for fifteen years to secure passage of the 911 Health and Compensation Act that provides for our heroes that responded to World Trade Center. Residing in Clifton Park, New York, she has three adult children and is married to Chris. Currently Suzy is Chief of Staff to the New York State Senate Conference. In her spare time, she loves skiing, hiking, kayaking, and walking on the beach.

The power of support YOU ARE NOT ALONE!

Our organization is focused on support for you, the patient, as well as your family and friends. Our goal is to create a large network of support groups, extending our reach throughout the tri-state area.

If you are not yet part of a group, try attending one! Soon meetings will become part of your daily habits toward building a healthy, balanced lifestyle. You have scleroderma, but it does not define you.

We are always looking for people who are ready to take the next step up – to assume a leadership role. Being a support group leader can give you the sense that you are doing something significant – help you feel good about supporting others. We will assist you in every possible way – just let us know when you are ready!

For more information on current groups or to learn more about starting a group, give us a call at **1-800-867-0885**



Tri-State Connect sessions provide education, support and an opportunity to listen to and ask questions of speakers, other attendees, and the Tri-State Chapter.

2017 Meetings:

February 21, April 18, June 20,

August 15; October 17, December 19

from **2:00 pm - 3:00 pm** eastern time.

Visit our website for information on how to join the call or

email: mbbkadylak@sclerodermatistate.org

View previous meetings: <http://youtube.com/c/sftristate>



SCLEROMEN TOGETHER WE ARE STRONG SCLERODERMA FOUNDATION TRI-STATE CHAPTER

ScleroMen Facebook Group

Because scleroderma manifests itself in a unique way in men, their issues and concerns are unique as well. This support system provides a means for men with scleroderma to connect with each other - share stories, seek advice and ask questions - in a caring and supportive environment.

Join **ScleroMen** and become part of an understanding and educated group of men finding ways to deal with scleroderma and its complications. The ScleroMen Facebook page is closed, only men with scleroderma may join by request.

Co-Leaders: Andrew Botieri (508) 982-7523 and Lee Korotzer
ScleroMen@scleroderma.org

2017 Tri-State Support Groups

For more information visit: sclerodermatistate.org

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Greater Enfield, CT

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Orange County, NY

Primary Contact: Jodi Lynn (845) 778-7442
OrangeCounty@scleroderma.org

Staten Island, New York

Leader: Jeanne Ryan (917) 531-6564
StatenIsland@scleroderma.org

2017 Patient Education Forums

This year we're planning many educational opportunities for patients and families - free of charge!



April 29, Saturday

Hospital for Special Surgery - New York, NY

Jessica Gordon, MD
Carol Feghali-Bostwick, PhD

August 19, Saturday

Daemen College, Amherst, NY

Mary Margaret O'Neil, MD
Additional speaker to be announced

September 16, Saturday

The Bone & Joint Center, Albany, NY

Lee Shapiro, MD
Additional speaker to be announced

October 14, Saturday

Rochester Educational Opportunity Center
Rochester, NY

Speakers to be announced

October 22, Sunday

Rutgers University, Graduate Student Lounge
New Brunswick, NY - Presented in partnership

with the Delaware Valley Chapter
Fabian Mendoza-Ballesteros, MD & Ira Merkel, MD

Date to be announced

Mt. Sinai Beth Israel, NY, NY
Speakers to be announced

Date to be announced

UCONN Medical Center, Farmington, CT
Speakers to be announced

November 19, Sunday

Annual Research Forum

Hospital for Special Surgery, New York, NY

Theresa Lu, MD, PhD

Additional speaker to be announced

Did you miss a forum?

Visit www.sclerodermavideo.com
to view many of the sessions and a variety of
recordings from prior years.



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No longer want to receive our newsletter? Or receive it by email only? Please call 800-867-0885 to help us Go Green!

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.

Make a Difference. Make a Donation.

Donations of \$25 or more includes membership to the Tri-State Chapter and the Scleroderma Foundation on a national level.

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Checks payable to SF Tri-State (email required) or Donate online www.SclerodermaTriState.org

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