Tuesday, October 1, 2013 did not go as expected. The long planned Scleroderma Foundation Capitol Hill Advocacy Day collided with U.S. government shut down, which put a well choreographed schedule into disarray. Not to worry. The Tri-State contingent of Kristen Ranieri, Julie Ranieri, Lisa Ranieri, Ruth Saphirstein, Rosemary Markoff, Jonah Peak, and Jay Peak along with 28 other scleroderma patients, caregivers, chapter leaders, and Scleroderma Foundation staff -- representing the states of CA, CO, CT, FL, GA, IL, IA, MA, MD, MI, MO, NY, TN, TX, VA, and WA -- refused to be denied the chance to advocate for scleroderma research and awareness.

Passion Overrides Shut Down

Government employees not considered “essential” were furloughed and many congressional offices were operating with skeletal staff. On the advice of our advocacy advisors – Washington, DC based Health and Medical Council of Washington (HMCW) – we visited offices of representatives and senators we were scheduled to call on, in addition to some others who were not on our list.

Not knowing how we would be received, we went to work. We faced closed or locked offices, unavailable services (e.g., wheelchairs) and long lines through security. Despite the obstacles, we told personal stories and asked lawmakers to increase awareness of scleroderma and its comorbid conditions by supporting the “Scleroderma Research and Awareness Act” (HR-1429 and S-1239), increasing funding for scleroderma related research at the National Institutes of Health, and returning “scleroderma” to the list of conditions eligible for study through the Department of Defense Peer Reviewed Medical Research Program.

Continued on page 3
A Message from Our Executive Director

Details create the big picture.
-Sanford I. Weill

A recent conversation about chapter efforts reminded me of the importance of stepping back and providing a glimpse of the bigger picture. It is easy to focus on certain activities or events and not connect the dots that show how those actions contribute to efforts the Tri-State Chapter is helping champion.

Your voice is strong; your voice is mighty

Fresh from the Capitol Hill visit to advocate for sclerodema research and awareness, it was again evident how much weight your voice carries. The calls you make, the emails you send and the letters you have signed at walks and educational forums in support of HR-1429 and S-1239 make a difference. A stack of letters delivered to the office of one representative resulted in almost immediate signing on as legislation co-sponsor. In another meeting, just a couple of letters allowed us access to an office on a day when access was limited. Keep making your voice heard and encourage your friends and family to do the same.

You make a difference for scleroderma researchers

Helping equip a new generation of researchers so they can remain focused on seeking a cure for sclerodema is important to future breakthroughs. Through your donations, Tri-State has taken a lead in the growth of this new generation by helping fund the August 3rd New Investigator Conference. The chapter’s lead sponsorship along with a grant from Actelion Pharmaceuticals enabled 16 new investigators and 10 senior investigators to have a day-long mentoring meeting. This conference was meant to begin fostering collaborative relationships between researchers and provide feedback on new investigator’s current work. The mentoring also offered new/young investigators insights on securing NIH funding, preparation for presenting scientific papers at major medical meetings, and other career advice. Feedback from the participants told us that the meeting was highly successful. Plans are being developed to continue this program in 2014.

Thank you for your continued support of our efforts and commitment to finding a cure.

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, and those of your co-workers through payroll deduction 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
Raising money in the mud

Robyn Marks called upon her friends and neighbors to support her in the mud this October. Her participation in a Tough Mudder Run in Englishtown, NJ was for a special reason; to honor the memory of her father Barry Marks who passed away from scleroderma in August 2008. With the support of her team, “The Dirty Birds”, Robyn raised over $3,000 to support the Tri-State Chapter.

Robin said she wanted to do this for her dad, and said, “He would have loved to see his little girl get ‘down and dirty’ like one of the guys.” So, with the help of Tri-State’s Hope Raiser website, Robin was able to set up a donation page, with her custom information to share with her friends and family who gave so generously in the weeks prior to her race. Robin said “I feel so lucky to have such good friends and family...my dad was amazing - so it’s easy to fund raise for him.”

If you have an idea for a fundraiser, please contact the Tri-State Chapter at 800-867-0885 so we can set up your own Hope Raiser page.

Young Binghamton Volunteer Honored

Crystal Faith Fisher, 17 of Binghamton, NY was given the Girl of Merit award during the Girls World Expo in Binghamton, NY on October 27.

Though Crystal has yet to graduate high school, she has raised over $6,800 for Stepping Out to Cure Scleroderma. Starting at the age of seven, Crystal wanted to honor a family friend who has scleroderma. Her first year in 2003 she was able to collect $111.00 and has only grown from there. Her generosity towards the Tri-State Chapter continues with her many hours of volunteer work in our offices and on the day of our Binghamton walk. She, her mother and brother are known as the t-shirt team and are responsible for distributing t-shirt to walk attendees.

Along with her work with the Tri-State chapter, Crystal is active in her local soup kitchen once a month. She also set up a book donation though a local charity winning her the Girl Scout Silver Award. She is a member of the National Honor Society, and is a avid musician, playing both the saxophone and piano.

Crystal is a true example that you can make a difference at any age. She has been an example for other young people at the walks, showing what one young person can do to help. She has continued to give of herself without looking for recognition. The Tri-State Chapter is very happy to have her supporting our mission.

Passion...

Continued from cover

One casualty of the day was the cancellation of a formal briefing for congressional representatives to be hosted by Scleroderma Research and Awareness bill (HR-1429) author Rep. Lois Capps (D-CA24). In lieu of the formal briefing, Rep. Capps received us and spent a few minutes encouraging the contingent to continue pushing. We also had the chance to meet with HR-1469 co-sponsor Rep. Peter King (D-NY2) who listened intently as our group shared stories and helped him better understand some of the care implications patients face. During these meetings, we had a chance to thank and honor the representatives for their work on behalf of scleroderma patients, families and caregivers.

After meeting with Rep. King, Rosemary Markoff, Advocacy Committee Co-Chair and Tri-State advocate, observed “We’ve clearly made an impact after all these years.” When Congressman King stated “While you may think scleroderma needs more ‘awareness’, we know the disease on Capitol Hill.” She added that “it speaks volumes to our efforts….and makes me proud to be a part of an organization that places an emphasis on advocacy.”

By the end of the day the exhausted advocates had plenty of stories to tell. While we were unable to enter some offices and attended fewer meetings than planned, we managed to access many even if it was in a hallway. There were unexpected encounters with representatives such as Richard Hanna (R-NY22) as well as Senators Diane Feinstein (D-CA) and Al Franken (D-MN). Determined perseverance paid off!

With the reopening of our government, there is growing evidence that our Capitol Hill Day efforts will pay dividends. In the days since returning, several representatives have signed on as co-sponsors of HR-1469 including Tri-State Representatives Louise Slaughter (D-NY25) and Rosa DeLauro (D-CT3). There has also been interest from both houses in helping get scleroderma back on the list of conditions eligible for Department of Defense medical research funding in the 2014 allocation.

While the day did not go as expected it was successful and will be long remembered. In the quiet halls of the congressional offices, the Scleroderma Foundation advocates definitely made some noise.

2nd African American Patient Education Day

Saturday March 22, 2013
Philadelphia Marriot Downtown
1201 Market Street
Philadelphia, PA 19107
The Tri-State Chapter works hard to organize educational programs throughout our region. This year we placed particular focus on two things: Reaching out to college students in the health care programs and bringing the latest information to our members.

With funds made available through Actelion and Gilead, along with the donations from our members, we hosted 8 programs in 2013. New forum locations included Yale University, Unity Health Systems, Rochester, NY; Doubletree by Hilton, Binghamton, NY and Rutgers University, New Brunswick, NJ. Finding new locations is always a challenge when unfamiliar with what various facilities have to offer. We relied upon the assistance and recommendations of local volunteers to help – and each program turned out to be very successful and exciting.

Efforts this year also involved reaching out to the staff members and students of local colleges to invite them to attend. This endeavor was rewarded, especially in Rochester where two professors and over 25 students attended the educational forum. Our guest speakers, Robert Dale, MD and Joy Valvano, RD provided these students with information about how scleroderma affects the body and tips on how to assist patients in both the health care and home settings. Marilyn Sibley, Rosa Johnson, Lynn and John Sindoni, Diane Reynolds and Dorothy O’Brien all played a role in the success of this Rochester event and were pleased that their efforts to reach out to students were rewarded this year. “We have tried for years to welcome medical students to our event with only limited success,” said Marilyn. “This year, we could not be more thrilled to have so many students in attendance”. To continue the momentum, the Greater Rochester Support Group extended an invitation for the professors and students who attended, to join them at their November support group meeting.

A new venture for the Tri-State Chapter was the Caring for the Caregiver forum held August 10 in Binghamton, NY – home of the Tri-State Chapter Office. With the feedback received from previous forums, we saw a need for a program that was based on the needs of the caregiver. We expect the program to become a template for a caregivers forum to be held at a different location each year. This inaugural event included four guest speakers with introductions by Mary Beth Bobik-Kadylak. These recordings are now available to borrow from our video library or by using sclerodermavideo.com. This program added a new, informative and helpful addition to our regular line-up of patient videos and we are very proud of its success.

Yale University was a new venue for us this year. Not only did we not yet have local contacts in that part of Connecticut, we
did not know as we planned the event where it would be held! Enter Mridu Gulati, MD. Dr. Gulati, a pulmonologist from Yale and Mary Beth struck up a friendship during the Yale Pulmonary Fibrosis seminar they attended in 2012. Dr. Gulati was eager about the possibility of holding a scleroderma event in her community that would serve her patients. She invited Dr. Wassim Fares to do a presentation, found a place for the event and the rest, as they say, is history! Their presentations on pulmonary hypertension and fibrosis are available online or for lending from our office.

The Joint Chapter Scleroderma Educational Forum was held November 9 at a new location—Rutgers University, and was well received. Dr. Vivien Hsu did a presentation on the new classification system for scleroderma which was rolled out this fall. We also featured a new physician to us, Robin Lucas, MD who is a pulmonologist at Robert Wood Johnson. Dr. Lucas focused on pulmonary arterial hypertension and scleroderma.

It has been a banner year for us. We increased the scope of our presentations and developed new relationships along the way. Stay tuned, 2014 program planning is already in process.
The Doctor is in

Our Guest: Harjinder S. Chowdhary, MD

Dr. Chowdhary is currently an Associate Clinical Professor at the University of Connecticut Health Center and is board certified in internal medicine and rheumatology. He recently began his own practice New England Rheumatology located in Norwich, CT.

I have Raynaud’s Phenomenon with scleroderma and was recently taken to the emergency room with shortness of breath. The staff in the emergency room were unfamiliar with scleroderma and not able to get a good reading on my oxygen level which added to the stress of the whole ordeal. Why?

Sometimes with Raynaud’s, measuring pulse oximetry may be a challenge. In finger tips with constriction of blood vessels, one may not be able to pick up oxygen saturation with accuracy. If the person is feeling alright otherwise and has no shortness of breath, then we know Raynaud’s is the cause. The measurement may be improved by waiting for Raynaud’s episode to subside. The application of vasodilating cream or placing a glove filled with warm water in the patient’s hand may be helpful. However, as an alternative, one can place the pulse oximeter on the ear lobe or forehead as newer models of pulse oximeters can pick up saturations from these locations. If the person is very short of breath and if there is a question as to whether the pulse oximeter is getting a true reading, a blood gas analysis may be the only answer, though that can also be challenging for a scleroderma patient with thickened skin and poor pulses.

I am 55 years old and have scleroderma. I’ve been hearing conflicting information about getting vaccinations. Can you tell me, do you encourage patients with autoimmune diseases like mine to get a pneumonia shot? How about flu shots? Shingles is the latest one and I had chickenpox as a child – is it safe to get a shot to prevent shingles?

Normally vaccinations are a good idea for everyone. However, if you taking drugs that decrease immunity (ie: Cellcept, cyclophosphamide, high-dose steroids) then you can’t have a “live” vaccine like the one for shingles or the nasal “vaccine” for the flu. So called “dead” vaccines are fine so we recommend the flu and pneumonia shots as much as possible.

New Scleroderma Center

We are happy to announce the designation of North Shore LIJ Health Systems in Great Neck New York as a new scleroderma center in our Chapter. To be recognized, centers must demonstrate expertise in clinical and lab-based research, conduct clinical trials and hold educational activities along with offer information about advancements in the care and treatment of scleroderma to health care professionals and the public. North Shore LIJ joins five other centers serving the Tri-State Chapter Area.

Steffens Scleroderma Center
Lee Shapiro, M.D
www.steffens-scleroderma.org

University of Connecticut Health Center
Naomi Rothfield, M.D.
Santhanam Lakshminarayanan, M.D.
http://www.uchc.edu

Hospital for Special Surgery
Robert F. Spiera, M.D.
Jessica Gordon, M.D.
Stephen DiMartino, M.D.
http://www.hss.edu

Stony Brook University Hospital
Asha Patnaik, M.D.
Julie Cherian, M.D.
http://stonybrookmedicine.edu

Rutgers - RWJ Medical School
Scleroderma Program
Vivien M. Hsu, M.D.
Suzana Morgan MD
http://njms.rutgers.edu

North Shore-LIJ Health System
Avram Goldberg, M.D.
Richard Furie, M.D.
Galina Marder, M.D.
Maria Louise Barilla-LaBarca, M.D.
Diane Horowitz, M.D.
http://www.northshorelij.com
When Elie was a little over 3 1/2 years old, I noticed what looked like a bruise down the back of her right calf. I showed a few family members and each of them were as puzzled as I was. So, I made an appointment at the pediatrician. After looking at it, he diagnosed it as eczema. I love my kids’ doctor, but, this was not eczema. I decided to pursue it with a dermatologist towards the end of 2011. It took over 2 months to get in to the dermatologist so we waited. Finally, just shy of Elie’s 4th birthday we went to see her. After careful consideration and examination, she diagnosed it as a birthmark under her skin. She said it ran in a “linear” pattern. This made much more sense to me. So satisfied, I left, happy to finally have an answer.

In May 2012, I noticed something looked different with her right foot. It looked “thicker” than her left and there was a loss of pigment on her ankle. A different doctor saw us this time and determined it was something in the “derm” of her foot, and sent me back to the dermatologist. The next available appointment was in October.

We left the office feeling helpless and scared. My husband, George, who worked in orthopedics at that time, called a foot specialist he knew. They said to bring her right over. The doctor who saw her looked, took x-rays, and looked some more. He also reassured us it was in the “derm” and her foot looked structurally fine. He said he wanted to see her in 4 weeks. We left with no diagnosis, but, feeling a little better having had the x-ray and knowing it wasn’t some kind of tumor, which of course is immediately where my mind went!

We made it our mission to find a new dermatologist that could see us before October. George started calling places out of town and came across a doctor who was a fellowship trained pediatric dermatologist! She could see us in 2 weeks. So we waited...

Even though it was only 2 weeks, the white spots were spreading like wildfire. It was like every day there were new ones and now she had a significant white spot on the top of her foot and it extended all the way up to her knee. She also had a spot brewing on her stomach. As you can imagine, we were freaking out and had no idea what to expect.

After her examination, the doctor said the words we were dying to hear. “I know what it is”. As happy as I was to hear that, I was afraid of what she was going to say next. She proceeded with, “I have only seen this twice, during my fellowship.” “Really? Twice? Oh my God!” I thought. “It is something called linear scleroderma” she said. There’s that word linear again. Although, I didn’t know exactly what it was, when I heard the word scleroderma I almost fainted.

The doctor quickly explained what it meant. That it was something very rare and that mostly children suffer from the condition. She also said “It only affects the skin and it usually burns itself out in 3-5 years.” Our prescribed treatment was steroid cream twice a day. From the beginning, that didn’t set right with me. There had to be something more than a cream to fight this. I was on a mission!

Once we arrived home, I raced to the computer and started reading. During all my research, I kept reading about Dr. Thomas Lehman at the Hospital for Special Surgery and the amazing things he was doing. We called for an appointment knowing we may not be able to see the leading physician in his field. I figured it would be months; wrong! He could see us in 1 month!

On September 11, 2012 we made the 3 hour drive to NYC to meet what I now refer to as the “Scleroderma Savior”. He confirmed what we already knew; linear scleroderma. Finally, almost a year after we began, we had a complete diagnosis. Knowing felt great, but fear of the unknown felt awful. And so our “living with scleroderma” journey began.

On the whole Elie is a trooper. Although she has scleroderma, she is no different than any other 5 year old. She loves to play games and American Girl dolls. She loves to play dress up and have her nails painted. In addition to dance, she is just finishing up her first soccer season. Her leg is significantly smaller than the other and has less muscle strength, but, she just goes and goes. She also has some major discoloration, which the doctor assures me will heal over time. She is very forthcoming about having Scleroderma and has no problem “explaining” it to people who ask. She started kindergarten in September and is joining a Daisy Troop in November.

One of our greatest blessings, since her diagnosis, was the Scleroderma Walk in June. We had planned for the 4 of us to walk, but, as we started telling people about it, they wanted to join us. First it was 10 people, then 20, then 30. We ended up with over 50 walkers. I can’t tell you how it made us feel, a huge crowd, in teal t-shirts with Elie’s name on it, supporting our little girl. Every time I think about it, I just cry. Elie won the award for the most money raised, by an individual. She received a beautiful star trophy which is proudly on display in our living room.

Although, it can be difficult, we believe everything happens for a reason. We don’t yet know what that reason is, and we may never know. For now, we try and spread the word about this disease whenever we can. I think if people can put a face to the disease, especially the face of a child, they will sit up and pay attention. If we can help other children to be diagnosed, then it is worth it.

Elie is a very happy girl, with the whole world at her fingertips. We pray her “burnout” comes quickly and leaves minimal damage in its wake. At the end of the day we are just her mom and dad trying to do our best.
The Tri-State Chapter now has the ability of help you by setting up your own fundraiser with online giving. Your fundraiser can be anything, from a run to a raffle, you now have the ability to set up an online page to support your event. This web page is now an easy way to keep track of donors, spread the news through email and social media. For more information on how to set up and take advantage of a Hope Raiser page please contact the Tri-State Chapter at 800-867-0885. With your continued support we will find a cure.

Make a Donation. Make a Difference.

Donation of $25.00 or more includes membership in both Tri-State Chapter & the national Scleroderma Foundation

Name ________________________________________________________________

Email (save postage) __________________________________________________

Address _____________________________________________________________ City ______________________

State ___________________________ Zip _______ Phone ______________________

Amount ________________________

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

Credit Card (all information required)

☐ Visa       ☐ Master Card   ☐ American Express   ☐ Discover

Card Number _________________________ Security Code __________________

Expiration Date ___________________ E-mail ___________________________

Contribution is made: ☐ In honor of   ☐ In memory of   ☐ Dues   ☐ Donation
(No Membership)

Name ________________________________________________________________

Send a note to: Honoree / Family

Name ________________________________________________________________

Address _____________________________________________________________

City ___________________________ State ________ Zip ____________

Email (save postage) __________________________________________________

Mail to:  
Scleroderma Foundation/Tri-State, Inc. Chapter
59 Front Street, Binghampton, NY 13905