



## ATS Public Advisory Roundtable

The American Thoracic Society Public Advisory Roundtable (PAR) is pleased to invite you to their annual FREE family forum. This year's theme is "Lung and Environmental Health". Patients and families will have the opportunity to meet with local experts Dr. Aryeh Fischer, National Jewish Health and Dr. Jason Kolfenbach, University of Colorado Hospital. Lunch is provided. Save the date: Saturday, May 16, 2015, 10am – 2pm in Denver. Registration will be open shortly.

## Running for Scleroderma

Andrea Prieto is running to raise awareness for scleroderma. "On March 21, 2015 I will be running my first ultra-marathon in hopes of bringing public awareness to scleroderma and the Scleroderma Foundation's fundraising efforts. The Antelope Island Buffalo Run 50k in Utah will be a grueling 32-mile trail race with 4,000+ feet of elevation gain along the way. I expect this to be the toughest challenge, both physically and mentally, I've ever faced, yet nothing compares to the ongoing struggles that those affected by scleroderma face on a daily basis" states Andrea. She is running for her mom, who has had scleroderma since Andrea was in high school. You can encourage Andrea and show your support at her Scleroderma Foundation "Hope Raising" page at <http://bit.ly/HopeRaiserAndrea>. Andrea's goal is to raise \$5,000 for scleroderma.



## 2015 "Stepping Out to Cure Scleroderma" Walks

Wow, this year will be our 11<sup>th</sup> "Stepping Out" Walk in Denver and our 5<sup>th</sup> year in Fort Collins! These events continue to grow each year as more and more walkers step out in honor or memory of their friends and loved ones with scleroderma. We do more than walk; these events include a kids' fun run, lots of food and great entertainment and live and silent auctions. Online registration will be available for the Denver Walk by mid-February and for the Northern Colorado Walk by late spring – go to [www.scleroderma.org/colorado](http://www.scleroderma.org/colorado) for more information. Keep up to date on all the news and activities of the Walks on Facebook at [www.facebook.com/steppingoutsclero](http://www.facebook.com/steppingoutsclero).



## Thank You Donors, Sponsors and Volunteers

This edition includes a special insert to recognize our 2014 donors, sponsors and volunteers. We greatly appreciate your support!

## What's Happening

- April 2015 – 9 Health Fairs located throughout Colorado.
- May 16, 2015 – ATS Public Advisory Roundtable in Denver.
- June 20, 2015 – 11<sup>th</sup> Annual Stepping Out to Cure Scleroderma Walk at Cherry Creek State Park.
- July 17-19, 2015 – National Patient Education Conference in Nashville.
- Sept. 10, 2015 – Food Fight! at Builders Appliance Center in Englewood.
- Sept 20, 2015 – 5<sup>th</sup> Annual Northern Colorado Stepping Out to Cure Scleroderma Walk at Fort Collins City Park.

For more information, go to [www.scleroderma.org/colorado](http://www.scleroderma.org/colorado) or contact us at (303) 806-6686 or [cochapter@scleroderma.org](mailto:cochapter@scleroderma.org).

*Ugly holiday sweaters at the Denver support group holiday party in December 2014.*



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## Board Update

Happy New Year!

2015 will be an exciting year with many new areas to cover. Theresa Rice, who chaired the Denver "Stepping Out" Walk committee in 2014, is back to make it even bigger and better with expanded hours, more food and great entertainment for kids and adults. The walk is scheduled for June 20, 2015.

After at least five years of trying, we have succeeded in staging Grand Rounds at hospitals. A Grand Round is where a physician from our Medical Advisory Board will talk to a group of physicians, nurses, interns and technical staff, educating them on a medical issue.

On March 10, Dr. Aryeh Fischer will present "Overview of Scleroderma" to the staff at Swedish Medical Center. On September 15, Dr. Jason Kolfenbach will present "Current Concepts in the Management of Raynaud's Disease and Skin Fibrosis" at Rose Medical Center. On July 14, Michelle MacDonald, Clinical Dietitian at National Jewish Health, will present "Nutritional Management of Small Intestinal Bacteria

Overgrowth" at Rose Medical Center. This is a huge step forward in improving awareness in the medical community.

We are planning a new event for fundraising and awareness for September 10, 2015. "Food Fight! Chefs fighting for a hard disease" will feature 12 local celebrity chefs battling to win bragging rights, while raising money and awareness for scleroderma. This will be one of the best events of the 2015 foodie scene in Denver.

The event will be held at Builders Appliance Center, 1880 W. Oxford Avenue, Englewood, CO 80110. There are fourteen cooking stations with top quality appliances. There will be four chefs preparing bite-size entrée dishes, four chefs preparing appetizers and four chefs preparing desserts. There will be four beverage stations, plus a silent and live auction. Start spreading the word to save the date.

Thanks for all your help in making 2014 such a success. I look forward to working with you in 2015.

John Niemi  
Chapter President

## Support Group News

Support groups offer a friendly forum to meet others in your area living with scleroderma. Patients, caregivers, family and friends are all welcome. For more information, visit our website at <http://bit.ly/COSupport>. Generally, all meetings will include introductions and time for open discussion on topics/questions related to scleroderma. Refreshments will be provided.

### **MILE HIGH (DENVER) SUPPORT GROUP**

February 14, 2015 – A demonstration in tai chi (Part 1) by Maria T. Lopez.

March 14, 2015 – Demonstrations in tai chi (Part 2) by Maria T. Lopez and M.E.L.T. by Juan Flores, Certified Instructor.

April 11, 2015 – Dr. Brett Fenster, Cardiologist at National Jewish Health will present on "The Heart and Scleroderma".

May 9, 2015 – To be announced.

June 13, 2015 – Picnic in the Park and Pre-Walk rally. (**NOTE: Location to be announced.**)

**Meetings are held monthly from 11:00 am - 1:00 pm at the Arthritis Foundation, 2280 S. Albion St., Denver, CO 80222.**

### **SOUTHERN COLORADO SUPPORT GROUP**

March 21, 2015 – View and discuss a video from the 2014 National Patient Education Conference (topic to be determined).

May 16, 2015 – Sharon Martin of Penrose Hospital will present (topic to be determined).

**Meetings are held in odd numbered months from 11:00 am – 1:00 pm at Penrose Cancer Center, Room CC-A, 2222 N. Nevada Ave., Colorado Springs, CO 80907.**

### **NORTHERN COLORADO SUPPORT GROUP**

February 28, 2015 – Dr. Michael Thakor, Rheumatologist with The Arthritis & Rheumatology Center of Northern Colorado, will present information on the different types of scleroderma and discuss treatment options.

April 25, 2015 – Dr. Jason Kolfenbach, Rheumatologist at University of Colorado Hospital will host a Q&A on scleroderma.

June 27, 2015 – Dr. Thomas Hecker, Podiatrist at Orthopaedic & Spine Center of the Rockies will discuss "The Foot & Scleroderma".

**Meetings are held in even numbered months from 10:00 am – 12:00 pm at the Medical Center of the Rockies, Poudre Canyon Room, 2500 Rocky Mountain Ave., Loveland, CO 80538.**

### **WESTERN SLOPE (GRAND JUNCTION) SUPPORT GROUP**

March 14, 2015 – Healing Horizons Integrated Health Solutions will give a demonstration on M.E.L.T. method, a self-treatment technique for relieving pain and stress.

May 9, 2015 – Kevin Fischer, a Cardio-Pulmonary Physician Assistant will present on interstitial lung disease.

**Meetings are held in odd numbered months from 11:00 am – 1:00 pm at Healing Horizons Integrated Health Solutions, Suite 7, 12<sup>th</sup> Street Plaza, 2139 N. 12<sup>th</sup> St., Grand Junction, CO 81501. (**NOTE: New time and location for these meetings.**)**

## *Scleroderma Has Lloyd Jones Looking to Simplify Life – Here is His Story*

Lloyd Jones was born in Little Rock, Arkansas but his family moved to Colorado for a better life when he was just four months old. Lloyd is third in line of six children with 2 older sisters, 2 younger sisters and one brother (the baby of the family). All but his oldest sister still live here.

Lloyd went to Johnson Elementary, Hamilton Junior High and graduated from George Washington High School in 1981. His oldest sister was the first to go to college and Lloyd followed in her foot steps, graduating with a degree in engineering from Colorado State University in 1986. Lloyd works for SCL Health as a software integration engineer.

Lloyd met his wife Nancy at a church function in Denver while she was visiting Colorado with her son. Lloyd later visited her in New York and they began a long distance relationship. They got married in 1997 and have raised three boys – 2 of Nancy’s and one together. The oldest is married and has a daughter. The middle son is a hard worker, holding two jobs and enjoying living in downtown Denver. The youngest is still at home and attends Smoky Hill High School where he is in the international baccalaureate program with extracurricular activities and community service required.

In 2010, Lloyd started having trouble with his skin. He saw a dermatologist and was treated for eczema. In 2011, he started having migraines which he attributed to not sleeping well because of the stress of his job and worrying about his skin issues. He also noticed some swelling in his hands. At a Broncos game, even though it was very cold, he found he could not keep his hands and feet warm. About this time he went to see his doctor and eventually was sent to a rheumatologist for blood work.

It was during this visit to the rheumatologist that Lloyd was officially diagnosed around May 2013. The appointment began with Lloyd just answering some questions for the nurses. Based on his symptoms, Dr. Jason Kolfenbach (University of Colorado Hospital-Anschutz) was brought in to see Lloyd. Just by looking at Lloyd’s hands and seeing the capillaries visible in his cuticles, Dr. Kolfenbach told him he had the classic signs of scleroderma. A follow up appointment and more tests, including an MRI and echocardiogram, confirmed Dr. Kolfenbach’s diagnosis.

Lloyd has limited systemic scleroderma with mostly skin and gastrointestinal involvement. He does not currently have any lung involvement but continues to test for it because, as an African-American, he is at a higher risk. His last 6-minute walk test and pulmonary function test results were sketchy, but the tests used a clip on his finger which, as most scleroderma patients with Raynaud’s phenomenon can attest to, will not always produce accurate results.

Because he works in the healthcare industry, Lloyd is very aware of the importance of continuity of patient care. He is working on making sure his own medical records are maintained electronically at two places including SCL Health



and University of Colorado Hospital.

Lloyd not only has tight skin related to his scleroderma but also suffers from severe itching. He currently takes the antihistamine Atarax and uses moisturizer to reduce the itching. He has developed skin nodules on his chest caused by the excess collagen production of scleroderma. He uses Clobetasol and Triamcinolone creams to treat the nodules. Lloyd tries to keep up a routine of regularly stretching his hands and fingers to maintain flexibility and has seen a hand therapist. Another skin issue that has developed is an allergic reaction to metals. Any metal on his clothes that is touching the skin, or even keys in his pocket, causes the nodules to appear.

Lloyd has been taking CellCept since January 2014. It seems to be slowing the overall progression of the disease and also has improved his skin score from in the twenties a year ago to 13 today.

With his skin issues now being managed, Lloyd is focusing on his gastrointestinal (GI) issues. He didn’t initially have GI issues, but like most people with scleroderma, he does have acid reflux. He is concerned about keeping the reflux out of his lungs so he takes Omeprazole to control it. He also takes a multivitamin to offset reduction in absorption of nutrients caused by Omeprazole. He is eating more yogurt and otherwise hasn’t had to avoid many other foods.

Lloyd regularly attends the Chapter support group meetings in Denver and describes them as a “built-in education system that is very beneficial”. Listening to others describe their symptoms makes him more aware of scleroderma issues to watch for in his own progression of the disease. Both these meetings and the Scleroderma Foundation provide him with a positive outlook in living with an autoimmune disease and encourage him not to limit how he lives.

Lloyd likes to hike but admits that scleroderma has limited this activity so instead he walks when he can, including taking the stairs to the 6<sup>th</sup> floor at work. He enjoys spending time with family and friends, likes to do home improvement projects and admits he is a computer geek! Lloyd’s goal is to simplify the “busy-ness” of life – job, family, his way of thinking – which he attributes to the stress that may have brought on his scleroderma.



## ROCKY MOUNTAIN CHAPTER

2280 S. Albion St. · Denver, CO 80222

*The Scleroderma Foundation-Rocky Mountain Chapter thanks **Rising Graphics + Printing of Evergreen** for their assistance with producing our quarterly newsletter.*

### Volunteer Opportunities

With 2015 promising to be a busy year for the Chapter, we have many opportunities for you to help advance the Foundation's mission. Get involved today!

We will be participating again this April in the 9Health Fairs. We host information tables at various locations throughout the state to spread awareness of scleroderma. Last year we attended 14 locations and would like to do those, and more, again this year. All we need is a half day of your time (6am-12pm), and we'll provide all the materials and instructions. Contact us and we'll find a 9Health Fair location close to you.

Make new friends and have some fun while helping to plan our 2015 fundraising events. Join one of our "Stepping Out" Walk committees – Denver or Fort Collins – or our new "Food Fight!" committee. A few hours a month of your time will make a huge difference to us.

#### Contact Us At...

Scleroderma Foundation  
Rocky Mountain Chapter  
2280 South Albion St.  
Denver, CO 80222  
(303) 806-6686  
[cochapter@scleroderma.org](mailto:cochapter@scleroderma.org)

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#### Or Meet Others At...

[www.inspire.com/groups/scleroderma-foundation](http://www.inspire.com/groups/scleroderma-foundation)

### How To Donate

1. Mail your check payable to the Scleroderma Foundation-Rocky Mountain Chapter to 2280 S. Albion St., Denver, CO 80222.
2. Donate on-line through the Scleroderma Foundation at [www.scleroderma.org](http://www.scleroderma.org). You can also learn on our website about donating your cars and used cell phones.
3. Check with your employer about payroll deductions for donations to the Scleroderma Foundation-Rocky Mountain Chapter (and ask them about their matching programs).
4. Create a legacy by planned giving or remembering us in your will. Get started at <http://bit.ly/SFGiftPlan>.

*The Scleroderma Foundation is a*

