

# ROCKY MOUNTAIN CHAPTER NEWS

Spring 2014



## Two Research Projects Offer Hope

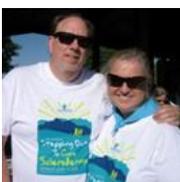
Exciting scleroderma research news was announced in April by the Northwestern Scleroderma Program and Michigan State University. Read more at <http://bit.ly/NWScleroProg> and <http://bit.ly/MSUSclero>.

## What's New For 10<sup>th</sup> Anniversary "Stepping Out"

The years have flown by since our first Stepping Out Walk in 2005! We've taken many steps and are seeing progress towards a cure. But we aren't there yet so please help us get closer by stepping out with us on June 21.



We have lots of new and exciting things planned for our 10<sup>th</sup> Anniversary Walk this year including a kids fun run, entertainment, breakfast burritos, a special treat at the finish line, guest appearances by Miss Colorado USA 2014 and Miss Colorado Teen USA 2014, new t-shirt designed by our contest winner Emiliee Reinholz and more!



You can register, start or join a team and set up a fundraising page all online at [www.scleroderma.org/steppingoutcherrycreek](http://www.scleroderma.org/steppingoutcherrycreek). Keep up on all the Walk news on Facebook at [www.facebook.com/steppingoutsclero](http://www.facebook.com/steppingoutsclero).

## Participation Program for Pulmonary Fibrosis

This new project is a program to empower people affected by pulmonary fibrosis (PF). Referred to as P<sub>3</sub>F, this study allows PF patients and their caregivers to participate in interactive forums and provides the opportunity to learn about and follow the progress of ongoing research projects. To learn more about this program or to join the study, go to [www.PFresearch.org](http://www.PFresearch.org). (Jeffrey Swigris, DO, MS at National Jewish Health is a lead member of the P<sub>3</sub>F team.)

## Chapter Receives Donation from Greeley Rotary

Kellie Tovar was just a little girl when she lost her grandmother Ellen Kegerreis to scleroderma in 1976. But the memory of her grandmother's hard skin and how she suffered from the disease has stayed with Kellie and she wanted to do something about it. That is why Kellie, Administrative Secretary for the Rotary Club of Greeley, invited the Chapter to give a presentation about scleroderma at their April meeting. We were also presented with a \$200 donation from the Rotary Club's Sharing the Caring program. Thanks Kellie and Rotary Club of Greeley for your support!

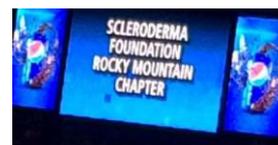


Kellie & her grandmother

## What's Happening

- **June 21** – 10<sup>th</sup> Anniversary Stepping Out to Cure Scleroderma Walk at Cherry Creek State Park. [www.scleroderma.org/steppingoutcherrycreek](http://www.scleroderma.org/steppingoutcherrycreek).
- **July 25-27** – National Patient Education Conference in Anaheim, CA. Go to [www.scleroderma.org](http://www.scleroderma.org) and click on "Attend Conference".
- **Aug. 3** – Painting For A Cause at Sipping-N-Painting, Hampden Ave. Space is limited. Register online at <http://bit.ly/SipNPaintSF>.
- **Aug. 9** – Tennis Fundraiser at Gates Tennis Center in Denver.
- **Sept. 14** – 4<sup>th</sup> Annual Northern Colorado Stepping Out to Cure Scleroderma Walk at Fort Collins City Park. (Online registration will be available by late May.)
- **Oct. 19** – Patient Education Day at National Jewish Health.

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).



Scleroderma Night at the Colorado Avalanche on March 14 raised \$580 for scleroderma!

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## Board Update

Once again we, as a Foundation, have a tremendous challenge in front of us with the United States Senate and the Senate Defense Appropriations Subcommittee. I am asking for your help to ensure that scleroderma is re-listed as a condition eligible for study through the Department of Defense Peer-reviewed Medical Research Program (PRMRP).

What does all of this mean? Let me give you some background. From 2005 to 2014, scleroderma was recognized as one of a handful of conditions eligible for study through PRMRP.

Scleroderma researches were allowed to compete for research funding because Members of Congress placed scleroderma on the eligible conditions list each year, resulting in over \$10 million of scleroderma research funding, not including three new research projects supported by the PRMRP in 2013.

In 2014, scleroderma was dropped from the eligible list due

in part that legislators weren't familiar with scleroderma. In order for scleroderma to be re-listed as a condition eligible for study in 2015, we need to educate our legislators about scleroderma and ask them to include it on the eligible conditions list.

The grassroots action plan is to write your senators asking them to work with their colleagues on the Defense Appropriations Subcommittee to see that the Committee Report accompanying the Senate's 2015 Defense Appropriations bill lists scleroderma as a condition eligible for study.

To send an electronic letter to your two senators, go to [www.scleroderma.org/advocacy](http://www.scleroderma.org/advocacy), and refer to the ACTION ALERT article. Fill in your contact information and click on send message. You can print a copy of the letter, if you'd like to. You can send as many letters as you want, so don't limit this to one letter. Thanks for your support in finding the cause and a cure.

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**

May 10 – Jinny LaRock, RN, BCIAC, owner of the Denver Biofeedback Clinic, will present on biofeedback techniques for relieving pain and stress.

June 14 – Goody bag stuffing party in preparation of our 10<sup>th</sup> anniversary Stepping Out Walk on June 21.

July 12 – Robin Hohsfield, RN, will discuss "Insights on Clinical Trials and PAH". Presented by Gilead.

August 9 – Update on the National Patient Education Conference workshops by this year's Chapter attendees.

September 13 – Maria Theresa Lopez, Attorney, will present on estate planning and end of life issues.

**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**

May 17 – To be announced.

June 21 – To be announced.

July 19 – To be announced.

August 16 - Update on the National Patient Education Conference workshops by this year's Chapter attendees.

September 20 – To be announced.

**Meetings are held monthly from 11:00 am – 1:00 pm at Penrose Cancer Center, Room A, 2222 N. Nevada Ave., Colorado Springs, CO 80907. (NOTE: New location starting with the May 17 meeting.)**

### **NORTHERN COLORADO SUPPORT GROUP**

June 28 – Sandee Maas will present on her journey with scleroderma including renal failure and a kidney transplant.

August 23 – Update on the National Patient Education Conference workshops by this year's Chapter attendees.

**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**

May 10 – A workshop video from the 2013 National Patient Education Conference will be viewed and discussed: Karen Kemper and Linda McNamara, co-authors of the book titled "If You Have to Wear an Ugly Dress, Learn to Accessorize" present on coping skills for living with a chronic illness.

July 12 – Sandee Maas will present on her journey with scleroderma including renal failure and a kidney transplant.

September 13 – Update on the National Patient Education Conference workshops by this year's Chapter attendees.

**Meetings are held in odd numbered months from 12:00 – 2:00 pm at Alpine Bank (Conference Room, 2<sup>nd</sup> Floor), 225 N. 5<sup>th</sup> St., Grand Junction, CO 81501.**

## Meet Candace Ruiz & Rena Baek

Rena Baek recently ran the Boston Marathon to raise money and awareness for rare diseases. Her patient partner was scleroderma patient Candace Ruiz. Here are their stories.

Candace Ruiz grew up in Michigan and moved to Colorado in the early 1980's to attend Colorado Mountain College. After getting her associates degree, Candace went on to raise her family. She has been married for 27 years and has two daughters: Lillian is married and lives in San Francisco; Olivia is in college in Denver studying geology. Candace eventually went back to school and completed her bachelor's degree in 2004 before going on to complete an MBA. She returned to school in January 2013 and is working on a doctorate in business administration at Walden University. Candace's husband works in hospitality. In addition to her teaching at-risk students for Corinthian Colleges, Candace also runs a part-time consulting business.

When Candace returned to school in 2001, she started experiencing acid reflux. Soon her fingers started turning blue and her skin felt tight. Candace shared her symptoms with her sister Cathie who is a scientist working at Genzyme. (Genzyme's mission is to find transformative therapies for rare diseases. To learn more about Genzyme and their research, go to [www.genzyme.com](http://www.genzyme.com).) Cathie attended a seminar at Genzyme that would eventually link Candace's peculiar symptoms to a diagnosis for her sister. The seminar was presented by a physician who treated scleroderma patients. As the physician spoke Cathie immediately knew what was wrong with her sister. After the seminar, Cathie rushed back to her office to call Candace. Cathie said "Candace, I think I know what you have." Candace, who had been doing her own research, replied "Is it scleroderma?"

Cathie asked around at Genzyme and eventually found a rheumatologist in Denver for her sister who confirmed that she had scleroderma.

Candace has CREST or limited systemic scleroderma. For Candace, the disease is mostly manageable. Her skin has loosened over the years. She thinks about the disease most when she is playing her cello because she has calcium deposits on her fingers that are painful. She also spends a lot of her work day on the computer and she likens the calcium deposits to feeling like a constant splinter in her fingers. Candace takes care of herself and regularly gets tested for her heart and lungs even though she has no internal organ involvement at this time. Candace gets easily fatigued and knows she will pay the price for several days when she over does it. The only medication she is currently on is Prevacid for acid reflux. She feels fortunate to work from home and not have to go out on cold days because of her Raynauds.

Candace recommends to someone newly diagnosed with scleroderma to learn all you can about the disease, to try to live as normal a life as possible, to have a good mental attitude and to reach out for the support you need.

It is through Cathie that Candace and Rena first met.



Candace (left) & sister Cathie



Rena at Mile 14

Rena Baek has worked at Genzyme for about 4 years. Genzyme started its "Running for Rare Diseases" team in 2009 and this year had 30 employees on their Boston Marathon team who partnered with patients of rare diseases including multiple sclerosis and scleroderma. Their goal is to raise money and awareness of rare diseases for the National Organization of Rare Disorders (NORD). For the list of all the 2014 Genzyme runners, patients and their diseases, go to <http://runningforrare diseases.org/runners-and-patients/2014-runners-and-patients/>.

Rena has always been a runner and the events at last year's Boston Marathon made her really want to be a part of it this year. Another member of the running team who works at Genzyme with Candace's sister Cathie and who knew about Candace's scleroderma suggested Rena contact Candace about becoming her patient partner. Rena and Candace got to know each other over the months of training as they chatted on Skype about Rena's progress leading up to the marathon.

Rena and Candace raised over \$3,000 and the team as a whole raised over \$100,000 for NORD through various events prior to the marathon. One fundraiser included donating money to put songs on a playlist for Rena to listen to while she was running the marathon.

Rena ran the marathon in a little over 5 hours and expressed that the encouragement from Candace, her team, the crowd along the entire route and numerous Facebook posts kept her going. Cathie and her kids were at Mile 9 cheering Rena on. Candace sent Rena a Colorado charm which Rena wore on her shoe during the marathon for good luck. Candace followed the progress of the marathon and Rena on her computer and in conversations with Cathie. Candace is convinced that she spotted Rena crossing the finish line out of all the runners!



Rena enjoys that her job as a scientist at Genzyme allows her to work directly with patients and put a face to those that their research may someday help. It gives her a real sense of purpose to her job.

Rena and Candace continue to stay in touch on Facebook. Candace is going to Boston in June to meet Rena in person for the first time. Candace will miss our 10<sup>th</sup> anniversary Stepping Out Walk this year but Rena has promised to come to Colorado and walk with her next year!



## 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.*

### **Don't Forget to Reload Your King Soopers Cards**

Don't forget to reload your King Soopers gift cards and use them to purchase your groceries and fuel. Under the King Soopers Neighborhood Rewards Program, every time you reload the card, the Chapter receives a donation of 5% of the amount. Would you like to participate? Just contact the Chapter for a pre-loaded gift card.

### **Volunteers Needed**

We are looking for the few and the proud. If you would like to get involved, we would like to interview you for a Board or Committee Leadership position. Please call Cyndy at 303-806-6686 or John at 303-947-4184. To learn more about our volunteer opportunities, go to [www.scleroderma.org/colorado](http://www.scleroderma.org/colorado) and click on "Volunteer".

#### **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)

#### **Follow Us At...**

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[www.twitter.com/SclerodermaCO](https://www.twitter.com/SclerodermaCO)

#### **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>.
5. "Step Out to Cure Scleroderma" with us on June 21! (See page 1.)

*The Scleroderma Foundation is a*

