

Fall 2013

# SCLERODERMA FOUNDATION



**SCLERODERMA  
FOUNDATION**

SUPPORT • EDUCATION • RESEARCH

**ROCKY MOUNTAIN CHAPTER**

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## *Theresa Rice Goes to Washington*

On October 1, 2013 Chapter Board member Theresa Rice traveled to Washington, D.C. to educate members of Congress about scleroderma and to ask for their help with federal research efforts and treatment development. Learn more about her experience at [bit.ly/SFCOnews](http://bit.ly/SFCOnews).

## *2013 Colorado Gives Day*

Please support Scleroderma Foundation Rocky Mountain Chapter on **December 10, 2013** for "24 hours of giving" as we participate in the 4<sup>th</sup> annual Colorado Gives Day.

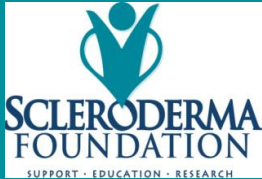
Your donation is important to help us continue our mission to educate, support, and research a cure for scleroderma. Through your donation we are able to continue to offer events such as the Patient Education Day and monthly support group meetings. Scleroderma Foundation Rocky Mountain Chapter will benefit from your donation by:

- **100% of donations made go directly to the Scleroderma Foundation**
- **Credit and debit card processing fees are waived during this day**
- **FirstBank's \$250,000 incentive fund will boost donations**
- **Increased community awareness through publicity of the event**



If you would like to help us, please visit [www.coloradogives.org](http://www.coloradogives.org). Once on the website, select donate now and search by non-profit name for Scleroderma Foundation. Starting on November 1<sup>st</sup>, you are able to pre-register for a donation ahead of December 10<sup>th</sup>, so you do not have to remember on the event day. Every donation helps us support our mission and you can donate as little as \$10.

Thank you for your continued support and for making this event a tremendous success!



This is your  
Newsletter.  
Send  
submissions to:

Cyndy Besselièvre  
Scleroderma  
Foundation  
Rocky Mtn Chapter  
2280 S. Albion St.  
Denver, CO 80222  
(303) 806-6686  
Or email them to:  
[cbesselièvre@  
scleroderma.org](mailto:cbesselièvre@scleroderma.org)

Keep up on all the latest  
news and events by  
visiting our Chapter  
website at  
[www.scleroderma.org/  
colorado](http://www.scleroderma.org/colorado).

Meet and share with  
other scleroderma  
patients on Facebook  
and Twitter. Visit our  
Chapter pages at  
[www.facebook.com/  
COScleroderma](http://www.facebook.com/COScleroderma) and  
[www.twitter.com/  
SclerodermaCO](http://www.twitter.com/SclerodermaCO).

Chat with other  
scleroderma patients at  
[www.inspire.com/  
groups/scleroderma-  
foundation](http://www.inspire.com/groups/scleroderma-foundation).

## ***NEWS FROM THE BOARD***

Dear Members and Supporters,

My, this year has gone by quickly. I guess when you are having fun, time flies.

As I near the end of my first year as your president, I am so proud of our accomplishments. Thanks to Cyndy's hard work and teamwork by many, we have accomplished quite a bit, but much more needs to be done.

I'd like to develop specific committees and I invite you to join one as a volunteer or as a volunteer leader. We need permanent committees for our Walks, volunteer coordination and training, support groups, fundraising, mailings, Patient Education Day, Colorado Gives Day and a Gala for 2014. Please consider joining the team. We will place you in your area of interest and skill. I'd like to have the groups in place prior to 2014. Contact Cyndy or me if you have questions or are interested.

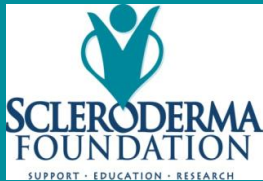
We continue to grow the Board with additions of Sandee Billen Maas, Marie Roof and Betsy Craig. Sandee is the support group leader for Denver and Marie will be treasurer in 2014. They stepped right in volunteering beyond the Board position. I'd also like to thank Kristina Meredith for being the Colorado Springs Support Group leader with Linda Conopask and getting that group up and running. My final "cheap beg" is for someone to be our volunteer coordinator. This would be someone working with Cyndy and me to develop a list of volunteer positions with job descriptions, help develop a volunteer data base and to be the source when we need volunteers.

Regards,

John Niemi  
Chapter President

### ***Chapter Board of Directors***

John Niemi, President  
Brandon Moore, Treasurer  
Theresa Rice, Secretary  
Rita Miller, Board Liaison to Support Groups  
Betsy Craig  
Phyllis Johnson  
Sandee Maas, Denver Support Group Leader  
Marie Roof



For more information or to suggest speakers or topics, contact:

**MILE HIGH (DENVER):**  
Sandee Maas  
(720) 272-7786  
[sandeejo@gmail.com](mailto:sandeejo@gmail.com)

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**FORT COLLINS:**  
Judy Laible  
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[jlaible@frii.com](mailto:jlaible@frii.com)  
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**WESTERN SLOPE:**  
Garnet Hoover  
(970) 234-1142  
[unite24u@msn.com](mailto:unite24u@msn.com)

IF WE NEED TO  
CANCEL A MEETING  
DUE TO INCLEMENT  
WEATHER, A MESSAGE  
WILL BE POSTED ON  
THE CHAPTER PHONE  
LINE AT (303) 806-  
6686 ON THE  
MORNING OF THE  
MEETING.

## 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>. We are working on scheduling our 2014 meetings so if you have ideas for topics or speakers of interest, please contact your support group leader.

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

November 9, 2013 – Brett Fenster, Cardiologist at National Jewish Health in Denver, will present on “Insights on Connective Tissue Disease in PAH”. Presented by Gilead.

December 14, 2013 – Holiday party. Join us for some fun!

January 11, 2014 - Joe Kowalchuk, owner of The Horizon Group and state certified by Connect for Health, will discuss the Affordable Health Care Act and health insurance issues.

February 8, 2014 – Julie Griffith, Registered Dietitian, will present on diet and scleroderma.

March 8, 2014 – 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.**

### **COLORADO SPRINGS SUPPORT GROUP**

November 16, 2013 – Ray Woolf, who has lived with scleroderma for many years, will share his inspirational story about hiking all 500 miles of the Colorado Trail in 2010.

December 21, 2013 – To be announced.

January 18, 2014 – To be announced.

February 15, 2014 – To be announced.

March 15, 2014 – To be announced.

**Meetings are held monthly from 11:00 am – 1:00 pm at the East Library (East Conference Room II), 5550 N. Union Blvd., Colo Springs, CO 80917**

### **FORT COLLINS SUPPORT GROUP**

December 7, 2013 – Holiday luncheon at the Moot House, 2626 S. College Ave., Fort Collins, CO 80525 at 11:15 am. Join us for some great food and conversation! **(NOTE: special date, time and location for this meeting.)**

February 22, 2014 - Dr. Kathy Thomas, a Dermatologist at the Cheyenne Skin Clinic, will discuss skin issues and scleroderma.

**Meetings are held in even numbered months from 10:00 am – 12:00 pm at the Northern Colorado Rehabilitation Hospital, 4401 Union St., Johnstown, CO 80534.**

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

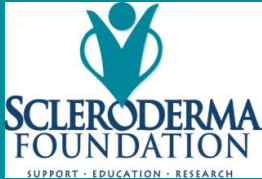
November 9, 2013 – “Coffee & Tea Time” – games and get to know each other better – at Traders Coffee & Tea Co., 666 F Road, Grand Junction, CO 81506. **(NOTE: special location for this meeting.)**

January 11, 2014 – To be announced.

March 8, 2014 – To be announced.

**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.**

*(Generally, all meetings above will include introductions and time for open discussion on topics/questions related to scleroderma. Refreshments will be provided.)*



Jackie's idea to host a tennis tournament in Crested Butte to raise money for scleroderma was sparked by an article she read in a previous Chapter newsletter suggesting to members that there are many different ways to support the cause and asking them to organize their own unique events!

*We at the Rocky Mountain Chapter who have gotten to know Jackie feel fortunate to have such a wonderful new friend and fellow supporter in the far reaches of the state. Thanks Jackie for organizing the 2013 tennis tournament. We look forward to getting to know you better in 2014!*

## MEET JACKIE BINGHAM-LEVINE

*After being diagnosed with scleroderma, Jackie feared she would never play tennis again. Today she is back on the tennis court and this fall organized a tennis tournament to raise money for scleroderma. Here is her story.*



Jackie was born and raised in Scotland on the Ayrshire Coast west of Glasgow. She attended University of Edinburgh at a specialized school for Movement Studies, Sports and Education.

For 20 years she was a Moderator and Teacher of Physical Education. She started her career in the Outer Hebrides and then spent 14 years in Aviemore teaching at Culloden Academy, Inverness in the Highlands of Scotland. In the mid-1990's Jackie traveled to Vancouver, Canada for a teacher exchange. On this trip she met her future husband Brian's brother. She returned to Scotland but the following year she came back to Vancouver and traveled down the west coast to San Diego to visit with friends whom she had met on her trip the year before. She reconnected with Brian's brother who told her Brian wanted to meet her (just from having seen her picture).

Brian lived in Denver but knowing of Jackie's love for the outdoors and an active lifestyle, he invited her to Crested Butte. Jackie's adventurous side kicked in and she flew from San Diego to Colorado Springs where Brian picked her up and they drove to Crested Butte where they spent the week together. Jackie returned to Scotland where she and Brian continued their relationship long distance for 4 ½ years. In 2000, at the age of 45, Jackie left Scotland to return to Crested Butte to marry Brian. They have lived there ever since.

Jackie teaches tennis and skiing in Crested Butte. She is a CO Tennis Association tennis clinician and is a member of the U.S. Professional Tennis Association and the U.S. Professional Tennis Registry. She is also a development coach of the Lawn Tennis Association of Great Britain. She is a Professional Ski Instructors of America Level 3 instructor.

In November of 2006, Jackie was increasing becoming fatigued. At night, her hands felt like pins and needles. She went to a doctor in January 2007 when she couldn't bend over to pick up a tennis ball and was getting tired just carrying her skis to the slopes. She knew something was wrong because she was in great physical shape. She went through a plethora of tests and was diagnosed with scleroderma in February. She didn't finish the ski season that year because of the fatigue and she could no longer hold a tennis racket. She had a very aggressive case of diffuse systemic scleroderma but was not told to watch her blood pressure.

She started teaching tennis again that summer but by mid-June she was seeing double and was very fatigued. She went to her local doctor who immediately put her in an ambulance to Denver because Jackie was in renal failure. She was in the hospital for two weeks but not immediately put on dialysis. Against her doctor's wishes, Jackie left the hospital to see if she would recover on her own. Within a week she was back in the hospital and on kidney dialysis.

Jackie had to stay in Denver for dialysis but fortunately had a friend there to stay with. Her sister came from New Zealand to be with her. During this time, scleroderma had totally taken



Jackie's advice to someone newly diagnosed with scleroderma is to keep a positive attitude. She never once believed she wouldn't get better. Jackie practiced visualization when she was very sick. She visualized and imagined herself being better, running, skiing and playing tennis again.

She also recommends doing what your doctors tell you. She felt she had a special connection with her doctors and that was very helpful.

over. Jackie had very little mobility, couldn't dress herself and had to be lifted in and out of the bath. She needed complete care.

Jackie's sister tested as a perfect match for a kidney transplant and it was set for July but her doctor did not want to proceed with a transplant at that time. Jackie returned to Crested Butte in November and remained on home dialysis until April 2008. By that time, Jackie was feeling better and wasn't retaining fluid as much. She was finally told to stop dialysis for one night and was monitored to see how she did. The dialysis ended, her kidneys had recovered but it was about 3 years until she felt that they had fully recovered. Slowly, her skin started to loosen. She exercised daily (which on some days was no more than lifting her arms over her head or standing up out of bed and walking 20 feet) and had frequent massages. Eventually she was able to start dressing herself again. During this time, Jackie couldn't eat much and never had an appetite.

As she started to get better, Jackie went into a deep depression. Why, she didn't understand. Why when she was getting better? While she was so sick, she was only able to focus on just physically getting through each day. As she got better, the depression set in because Jackie didn't know what her life would be like now. Would she ever be able to ski or play tennis again? She later learned from her doctor that her feelings during this time were normal, but she admits that it would have been helpful to have known that while she was going through the depression.

Today Jackie says she feels "brilliant, absolutely brilliant", a typical British term! She feels like she did 6 years ago and that the last 6 years were a nightmare. She is back to work full time teaching tennis and skiing. She has her confidence back and is traveling again with a trip to Scotland in October. Most of her fatigue is gone. Her Raynauds is also much better but she still wears hand warmers and good gloves when skiing.

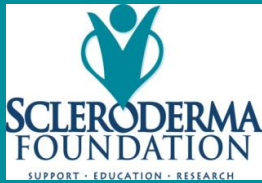
Jackie is only one of 3 people in twenty years at University of Colorado Hospital to come off dialysis. Doctors refer to her recovery as "miraculous". Because of her unique situation, she has given the doctors permission to use her blood work and tests for medical research as needed.

During her time in Denver, Jackie's friends in Crested Butte raised \$20,000 for her medical bills. Upon her return to Crested Butte she wrote an article for the local newspaper about scleroderma and to thank the local community. In 2012 she wrote another article about her journey. Then earlier this year Jackie decided she wanted to help others with scleroderma like she had been helped. That is when the idea of hosting a tennis tournament came to mind. She contacted the Chapter and got their support and encouragement to move forward. It was not until this time that she realized all that the Chapter had going on in Colorado. So over the weekend of Sept. 7th & 8th, Jackie invited the town to participate in the tournament for a fee and small donation to the Scleroderma Foundation. 28 people participated and generously donated \$1,600! Wow!

Jackie admits that looking into the future scares her so her goals are to stay healthy, fit and happy one day at a time.







## **Cyndy's Snippets**

As we approach the end of this year and the holiday season, it is a time to reflect and look ahead to next year.

This has been an amazing year with new Walks, new Board members, 4 support groups now up and running, advances in research, and much more.

I am looking ahead to next year and continuing to work with our Chapter Board, support group leaders, and volunteers to make 2014 an even better year than this year.

As I continue to meet more and more members with scleroderma, I remain as committed as ever to doing my part to find a cure for scleroderma.

## **CHAPTER NEWS**

### **RECENT ADVANCE IN SCLERODERMA RESEARCH**

On October 9, 2013, researchers at Johns Hopkins announced that using mice, lab-grown cells and clues from a related disorder has led to increased understanding of the causes of systemic sclerosis (scleroderma). The research shows that a critical culprit is the way certain cells communicate with their structural scaffolding. To read this entire article, go to <http://www.sciencedaily.com/releases/2013/10/131009133218.htm>.

### **CHAPTER MEDICAL ADVISORY BOARD**

Chapter President John Niemi has worked this year at expanding the Chapter Medical Advisory Board ("MAB"). The purpose of MAB is to present at support group meetings and the Patient Education Day, to assist the Chapter with developing relationships within the medical community, and to serve as a resource for patient inquiries. The Chapter MAB includes Aryeh Fischer, MD, Rheumatologist; Todd Bull, MD, Pulmonologist; Phil Hanna, MD, Gastroenterologist; Sue Harms, RPh, MPH, PhD, Pharmacist; Kristin Kilbourn, PhD, MPH, Psychologist; and Julia Rhiannon, MD, Rheumatologist. Thank you all for your commitment to the Chapter.

### **CHAPTER IS RECIPIENT OF SCHOMP HONDA GIVE-A-WAY**

The Chapter is the September winner of the Ralph Schomp Honda \$2,000 Community Give-A-Way! To be eligible, charities must apply through Schomp Honda's Facebook page. The charity with the most votes during the month is the winner. Chapter Board member Phyllis Johnson signed us up and posted many reminders to vote throughout the month. We had some tough competition, including Food Bank of the Rockies, yet Phyllis persevered. Thank you Phyllis and all of you that voted often!

### **NATIONAL CONFERENCE VIDEOS**

Many workshops at the 2013 National Patient Education Conference were recorded and have been posted on the Foundation's YouTube page at [www.youtube.com/user/sclerodermaus](http://www.youtube.com/user/sclerodermaus).

### **COMBINED FEDERAL CAMPAIGN**

The Combined Federal Campaign is available to federal employees only. It is an annual fundraising drive conducted by federal employees in their workplace each fall. Federal employees and military personnel raise millions of dollars each year through the CFC to benefit thousands of nonprofit charities. The Scleroderma Foundation is the recipient of funds from many CFC organizations throughout the country. To select the Scleroderma Foundation, use CFC code No. 10089.

### **PLEASE REMEMBER TO RELOAD YOUR KING SOOPERS GIFT CARDS**

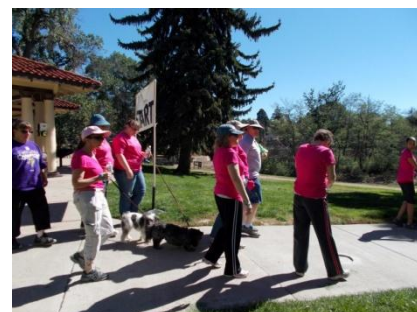
The Chapter has received \$600 in donations since we rolled out the King Soopers Gift Card Program in June. If you have one of these gift cards, please remember to continue to reload them to prepay for your groceries and fuel. Each time you reload the card, the Chapter receives a donation of 5% of that amount. The gift cards can be used at King Soopers, City Market, or any other Kroger store. If you haven't received a card and would like one, please contact the Chapter.

## RECENT EVENTS

### THREE "STEPPING OUT" WALKS THIS FALL RAISED \$29,000!

We had a busy fall with three Stepping Out to Cure Scleroderma Walks on back-to-back weekends. The 3<sup>rd</sup> Fort Collins Walk raised over \$17,000 while our first Walks in Colorado Springs and Grand Junction raised \$7,000 and \$5,000 respectively. All these Walks also helped raise awareness of scleroderma within their communities from committee members asking local businesses to sponsor the event to participants stepping out in their brightly colored t-shirts to walk for scleroderma. Each Walk had something of its own that made it such a special event.

In **Colorado Springs**, several walkers came up with some unique ways to raise funds for their team. Kristine Washburn got her employer, Bank of Colorado, to sponsor the Walk and handed out "I Gave" stickers to all her co-workers who donated to her team. Susan Janes' good friend Monika Sackuvich, a Pampered Chef Independent Consultant, hosted an "online" party and donated a portion of the sale proceeds for July and August to Susan's team. Dylan Perry organized a karaoke night in October and asked her employer, Ethos Consulting Group in Denver, to match the funds raised to donate to the Walk.



Garnet Hoover, Grand Junction support group leader asked her family to help with the **Grand Junction** Walk. Her niece, Susan Bissonnette, got her high school volunteer club involved and 20 teens helped with everything from hosting a table at the local Farmers Market to promote the Walk, to stuffing goody bags and helping at the Walk. Carol Wetherell's friend hosted a dinner party in her honor. Carol showed up with literature about scleroderma and asked the dinner guests to support her team.



From the start, the **Fort Collins** Walk committee worked hard during the months of planning to make this event a success. They hit the streets asking local businesses to support the Walk resulting in more than 30 sponsors who donated everything from cash to goody bag and auction items. With many returning volunteers at the Walk, the event itself ran like a well-oiled machine. Fort Collins Ignite's own Nick Armstrong volunteered his time to emcee. Betsy Craig volunteered her office (and staff!) for all our meetings and storing our supplies. This event was a perfect example of all we can accomplish when so many volunteer their time to help.

*We thank all our sponsors, donors, volunteers, and walkers who supported these events! To view more pictures from all our 2013 Stepping Out Walks, go to [www.bit.ly/SFCOPics](http://www.bit.ly/SFCOPics).*



### 2013 PATIENT EDUCATION DAY

More than 90 patients, caregivers, family and friends turned out to learn more about scleroderma on Sunday, Oct. 20 at the 3<sup>rd</sup> annual Patient Education Day at National Jewish Health. Thank you Dr. Aryeh Fischer, Dr. Jason Kolfenbach, Dr. Julia Rhiannon, our patient panel of June Bryant, Betsy Craig, and Margo Peter and our volunteers for being a part of this event!





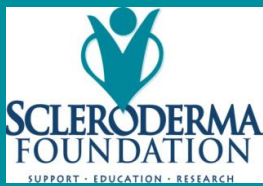
## ROCKY MOUNTAIN CHAPTER

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.*

Scleroderma Foundation

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*The Scleroderma Foundation has received the highest rating as a 4-Star Charity by the Charity Navigator for exceeding industry standards and out performing other charities in their cause.*

## ***YOUR DONATION IS IMPORTANT***

There are several options to make a donation to the Scleroderma Foundation-Rocky Mountain Chapter:

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 remembering us in your will.
5. Donate on Colorado Gives Day, December 10, 2013 (see front cover).
6. If you are a federal employee, sign up for the Combined Federal Campaign this fall (see page 6).