

Fall 2011

# SCLERODERMA FOUNDATION

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**SCLERODERMA  
FOUNDATION**

SUPPORT · EDUCATION · RESEARCH

Rocky Mountain Chapter

*COLORADO GIVES DAY  
(Tuesday, December 6, 2011)*

See page 6 for details

## *JOIN THE SCLERODERMA REGISTRY*

The Scleroderma Family Registry & DNA Repository, located at the University of Texas in Houston, needs more samples from scleroderma patients for continued research in testing the genes associated with scleroderma. For more information or to obtain an enrollment form, contact the Scleroderma Registry office at 1-800-736-6864 or [sclerodermaregistry@uth.tmc.edu](mailto:sclerodermaregistry@uth.tmc.edu). To visit their website go to <http://www.sclerodermaregistry.org>.

## *YOUR PERSONAL INVITATION!*

I would like to personally invite you to become a member of the scleroderma support group. It's a great way to connect with other people who are living with this disease. We offer valuable resources, expert guest speakers and most importantly, a safe caring place to share information and experiences. If you have been diagnosed with scleroderma or are a caregiver or family member of someone who has this disease, we encourage you to join us on the second Saturday of each month. Our support group meetings are informative, uplifting and fun!

Bonnie Schweder, Support Group Leader



This is your  
newsletter.  
Send  
submissions to:

Cyndy Besselievre  
Scleroderma Foundation  
Rocky Mountain Chapter  
2280 S. Albion St.  
Denver, CO 80222  
(303) 806-6686

Or email them to:  
[cbesselievre@  
scleroderma.org](mailto:cbesselievre@scleroderma.org)

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

Also 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/  
COScleroderma](http://www.twitter.com/COScleroderma).

## *NEWS FROM THE BOARD*

It is hard to believe we are planning for the end of this very busy year. We had our 7th annual walk at Cherry Creek State Park, added a second walk in Ft. Collins, and held our first Patient Education Day – all were very successful.

The Chapter Board has had a goal to expand for several years and in 2011 we finally achieved that goal. In August we added two new members – Belinda Krajmalnik and Tahani Rivers. This brings our total number to nine members. We are also pleased to announce that John Niemi accepted the position of Vice President.

The current Board members are:

Rita Miller, President & Chair, Fundraising Committee  
John Niemi, Vice President & Chair, Awareness Committee  
Elsie Elmore, Secretary  
Donnie Schlereth, Treasurer  
Bonnie Schweder, Support Group Leader  
Belinda Krajmalnik  
Megan Liddicoat  
Brandon Moore  
Tahani Rivers

We still welcome anyone interested in joining the Board or a Committee. The next Board meeting will be held at the Arthritis Foundation Building on Wednesday, November 30, 2011 at 3:00 p.m. Everyone is welcome to attend.

The Board would also like to say a special “THANK YOU” to Cyndy Besselievre for all her work this year. She is the reason we have accomplished so much growth.

From each of us: May your holiday season be filled with many blessings and great joy for you and your loved ones. And may 2012 be a special New Year.

Rita Miller  
Board President



Are there any topics or speakers you would like to see at a support group meeting? Let us know and we will try and work it into the schedule.

For more information about the monthly support group meetings, contact:

Bonnie Schweder  
(303)-438-7124  
[bschweder@  
scleroderma.org](mailto:bschweder@scleroderma.org)

*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

Join us at our monthly support group meetings! The first hour includes introductions and an informal discussion open to questions or topics of interest. Following a short break and refreshments, the second hour will include speakers and presentations.

Schedule for remainder of 2011:

November 12 – NEW AGENDA. Isaac Krajmalnik will speak about his life with scleroderma, having lived with the disease for more than 40 years.  
December 10 - Christmas party – join us for some holiday fun!

2012 Schedule:

January 14 - Dr Jason Kolfenbach, Division of Rheumatology, University of Colorado Denver, will discuss the skin manifestations of scleroderma including Raynauds and treatments.  
February 11 - Keith Demmon, MSPT, will discuss various exercises to assist scleroderma patients with maintaining strength and balance.  
March 10 – TBA  
April 14 – Dr. Phil Hanna, Chief-Division of Gastroenterology, National Jewish Health, will discuss the gastro-intestinal manifestations of scleroderma.  
May 12 – Afternoon Tea. Learn what foods and tea accessories you need to serve an afternoon tea. An English cream tea will be served with scones, jam and cream.  
June 9 - Walk Preparation - "goodie bag" stuffing party for our Stepping Out to Cure Scleroderma Walk on June 16, 2012.  
July 14 – TBA  
August 11 - Update on the National Conference presented by this year's Chapter attendees.  
September 8 – TBA  
October 13 – TBA  
November 10 - Joanna Goldin, PT, owner of Sport and Spine Physical Therapy, Inc., will address benefits of physical therapy for scleroderma patients.  
December 8- Christmas party.

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



What does Ray recommend to someone newly diagnosed with scleroderma?

**EDUCATE** yourself!  
Learn all you can about scleroderma so you will be able to understand doctors' diagnoses.

Join a **SUPPORT GROUP** and talk to others with the disease.

**EXERCISE**, no matter how much it hurts because it will hurt more if you don't. Ray feels he can cope with his scleroderma much better when he regularly exercises.

## MEET RAY WOOLF

*Not only does Ray have scleroderma, a rare disease that most people and lots of doctors have never heard of, he happens to have a very rare form of it. Here is his story:*

Ray was born in Edmonton, Alberta, Canada. His family moved to the United States when Ray was 6 years old for his father to complete his doctorate at

Michigan State. The family, including at the time Ray's three siblings and one foster child, moved into a 2 bedroom apartment in student housing. To escape the cramped living quarters Ray started spending lots of time outside and began to develop his love of the great outdoors.

When Ray was 13, his father accepted the position of State Director of the Board of Community Colleges in Colorado and Ray has lived here ever since. He graduated from Arapahoe High School where he played football and wrestled. He married his high school sweetheart Georgette. Ray and Georgette have 4 grown children – 2 sons and 2 daughters - and 6 grandchildren with another one on the way.

Ray went to college for one semester but when the money ran out he got a job painting. Within a few years he started his own commercial painting company which he ran for 30 years. Ray sold the business a few years ago when he could no longer keep it going due to his scleroderma.

Now that he knows what scleroderma is, Ray realizes he had symptoms since he was a teenager. His lung collapsed when he was in his twenties. He was incorrectly diagnosed with multiple sclerosis and several other diseases. He was only correctly diagnosed with scleroderma about 5 years ago.





Read Ray's daily journal about the Colorado Trail at [www.trailjournals.com/woofer](http://www.trailjournals.com/woofer).

*Interview by:  
Cindy Besselievre*

Ray has linear scleroderma with “En Coup De Sabre” and hemi-atrophy. According to his doctors this is a rare form of a rare disease. Linear scleroderma causes lesions and atrophy, usually in a linear fashion. He has lesions on his head that have entered into his brain, which started causing seizures a few years ago. He has had his right eye socket rebuilt due to atrophy that caused his eye to sink into his head leading to double vision and distortion.

Ray is quick to point out these symptoms are rare for scleroderma. While most scleroderma patients will not suffer these symptoms, Ray also has some of the more common symptoms such as Raynauds, reflux, and some lung and skin involvement.

About three years ago Ray's health went down hill fast. This was when he had to sell his business and see his family income severely decrease. On top of the seizures he was having, he also developed knee problems. He couldn't drive because of the seizures and then he couldn't even walk because of his bad knees. This sent Ray into depression. He sat around, gained weight, and gave up on life. After about a year, something clicked and Ray realized he could not keep living his life like this. So Ray did two things – he started volunteering and walking.

Through volunteering – teaching Sunday school classes, supervising youth groups and scouting trips, and becoming active with the Scleroderma Foundation-Rocky Mountain Chapter – Ray realized that there are many others much worse off than him.

Ray started walking to lose weight before his doctor would operate on his knees. Once Ray started, he didn't stop! He built up his distance each day, relying on his cane and trekking poles to help keep his balance. After 8 months of training, Ray realized a long time dream. In 2010, he walked the entire distance of the 500 mile Colorado Trail in 53 days – an amazing feat for anyone, let alone someone with scleroderma!!

Today Ray keeps busy volunteering, reading, hiking and camping with Georgette, and enjoying his grandchildren. He also works part-time test driving concept cars for a major automobile manufacturer - if this can be called “work”! He would like to some day start another business and dreams of hiking the John Muir Trail in California.



In September, the National Institute of Health granted a \$2.3 million New Innovator Award to Emmanuel Maverakis, Assistant Professor of Dermatology at the University of California Davis, to study the immune response in scleroderma and find effective therapies. The award is designed to support creative investigators with innovative ideas at an early stage of their careers. (Source: Sacramento Business Journal, September 21, 2011.)



The Scleroderma Foundation-Rocky Mountain Chapter is excited to again be a participant this year in COLORADO GIVES DAY. Colorado Gives Day is an initiative to increase philanthropy in Colorado through online giving. Presented by Community First Foundation and FirstBank, Colorado Gives Day will take place during a 24-hour period starting at 12:00 a.m. on TUESDAY, DECEMBER 6, 2011.

Why give on this particular day? Because we will benefit beyond your donation! We will receive 100% of your donation without any deduction for credit card processing fees. Additionally, the value of your donation will be increased by the FirstBank Incentive Fund. And we will also have a chance to win some cash bonuses and prizes when you give to us on Colorado Gives Day.

So mark your calendars and don't forget! To donate on December 6, 2011, go to [www.givingfirst.org/rockymntscleroderma](http://www.givingfirst.org/rockymntscleroderma).

## *OTHER WAYS TO GIVE BEFORE YEAR-END*

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/development/donate.shtm](http://www.scleroderma.org/development/donate.shtm).
3. Go to [www.scleroderma.org/development/recycle.shtm](http://www.scleroderma.org/development/recycle.shtm) to learn more about donating your car or used cell phones.
4. Federal civilian, postal and military personnel may donate through the Combined Federal Campaign by payroll deductions through December 15, 2011. The CFC Code for the Scleroderma Foundation is 10089. For more information contact your supervisor or human resources department or go to [www.opm.gov/cfc](http://www.opm.gov/cfc).



Several people attending the Patient Education Day suggested that there be some breakout time at future events to talk to other patients. While we agree this is a good idea, we give you this opportunity every month at our support group meetings. So if you haven't been to a support group meeting recently, we invite you to attend one soon. See page 3 for our support group schedule.

## *2011 – A LOOK BACK ON RECENT EVENTS...*

### *PATIENT EDUCATION DAY, SUNDAY, SEPT. 11, 2011*

At our first Patient Education Day, over 100 patients, family, caregivers, and friends gathered to learn more about scleroderma from an outstanding team of doctors. We owe the success of this event to Dr. Aryeh Fischer and National Jewish Health. We also thank all the doctors who presented at this event – Dr. Phil Hanna, Dr. Todd Bull, Dr. Jeffrey Swigris, and Dr. Kristin Kilbourn. We look forward to bringing you more of such events in the future!

### *FORT COLLINS CITY PARK SUNDAY, OCTOBER 2, 2011*



Our first walk in Ft. Collins was a huge success. We had an unexpected turnout of 150 walkers who enjoyed a very warm fall day as they completed laps around the lake to earn their lap "beads". This walk raised over \$13,000 that will go towards the Foundation goals of support, education and research.

The Ft. Collins Walk Committee all worked very hard to organize this event so we give a big THANKS to Carol Bennis, Marge Brodahl, Amanda Carroll, Betsy Craig, Jennifer Cronholm, Craig Evans, Peter Fisk, Shantel Hansen, Cori Kimball, Judy Liable, Megan Liddicoat, Ann Montera, and Jenn Thompson. Also a special thanks to all the volunteers who helped at the walk, including all the teens from Turning Point.

## *CYNDY'S SNIPPETS*

Wow, what a busy first year on the job this has been! Not only did we organize a second walk and the Patient Education Day, we also worked hard on promoting awareness of scleroderma by expanding our participation at 9Health Fairs and making our Chapter known to local doctors – some of whom already treat those with scleroderma but did not know we were here and some of whom were not familiar with the disease. We have seen this effort pay off by the increase in new members this year. We will continue these efforts in 2012 along with looking into some additional fundraising options. I am already preparing for another busy but fun year in 2012!



If you would prefer to receive the Chapter newsletters by email, contact us at [cochapter@scleroderma.org](mailto:cochapter@scleroderma.org).

### *TIPS FOR CONTROLLING FATIGUE*

People with many auto-immune diseases, including scleroderma, often suffer from fatigue which may be related to the body's reaction to the symptoms of the disease or the emotional stress of dealing with it.

With the holiday season rapidly approaching, following are some tips for coping with fatigue:

1. Rest. While this may sound obvious, listen to your body and nap or rest when it signals it needs a break.
2. Plan ahead. Schedule activities ahead of time so you can control the pace and rest when needed.
3. Prioritize. Important activities should be done first before energy becomes depleted.
4. Organize. Keep things organized and within reach to save energy.
5. Exercise. Regular exercise can reduce symptoms of chronic fatigue.

(Source: [www.arthritis.about.com/od/fatigue/a/tiredbeingtired.htm](http://www.arthritis.about.com/od/fatigue/a/tiredbeingtired.htm))



Rocky Mountain Chapter

[www.sclerodermafoundation.org](http://www.sclerodermafoundation.org)