

Fall 2012

SCLERODERMA FOUNDATION



**SCLERODERMA
FOUNDATION**

SUPPORT · EDUCATION · RESEARCH

ROCKY MOUNTAIN CHAPTER

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24 Hours to Give Where You Live!

Support the **Scleroderma Foundation-Rocky Mountain Chapter** on Colorado Gives Day! On **Tuesday, December 4, 2012**, Coloradans will come together again to raise millions of dollars for nonprofits like ours.

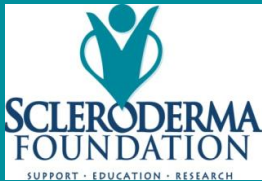
Presented by Community First Foundation and FirstBank, Colorado Gives Day is an initiative to increase philanthropy in Colorado through online giving. Donations will be accepted through **GivingFirst.org** during a 24-hour period starting at 12:00 a.m. on December 4. 100% of every donation goes to charity and the FirstBank Incentive Fund increases the value of every dollar donated.

Why is your Colorado Gives Day donation important to us? Because the Scleroderma Foundation has funded significant advances in research in the last few years as a result of individual donations such as yours. Donations to the Chapter on Colorado Gives Day will allow us to contribute to these research projects awarded at the National level and help us get closer to finding a cure for scleroderma.

So please remember us on Colorado Gives Day and make a donation at www.givingfirst.org/rockymntscleroderma.

***Scleroderma Foundation Designates National
Jewish Health & University of Colorado Anschutz
Medical Campus as Scleroderma Centers***

See page 6 for details.



This is your
Newsletter.
Send
submissions to:

Cyndy Besselievre
Scleroderma
Foundation
Rocky Mtn 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/
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

Rita Miller Reflects on Growth of Chapter During Her Presidency

Hello. This will be my last message as the Chapter President. My four years in that position ends in December. Our Chapter today looks much different than when I took this position. The Board and I had one big goal – to grow the Board with new people who could bring some fresh ideas and skills. We are well on the way to achieving this goal. We have added new people who have added much to the Board.

My other goal was to hire someone to run the Chapter. About the time we felt we were ready

I found out that the Arthritis Foundation was renting out office space. This gave us a place to keep all the things that had been taking up space in our homes & garages. This not only gave us space for the office but the use of many other things in the building.

With this in place we started to advertise for a half-time staff person. In a few days we had about 50 applications. As I was preparing to go through them we got the best news - Cyndy Besselievre said she was ready for a job change and was interested in the position. She had been the Chapter Treasurer almost since the beginning. It has been her hard work and skills that has made the Chapter grow.

We have gone from 1 Walk a year to 2 Walks. We now have 3 support groups and hope by the first of the year to have 4. We have had 2 very successful Patient Education Days.

I am sure the Chapter will continue to grow with your new President, John Niemi. He has been doing an outstanding job for the 2 years he has been on the Board. **We welcome John to the new position!**

I will still be a member of the Board. I plan to be the Board liaison with the support groups.

Thank you to everyone who has assisted me during my time as President. We have come a long way, but still have a lot to do until that day we are all waiting for – a cure for scleroderma.

With love and thanks to all,
Rita Miller



Rita (left) with family at 2012 Stepping Out Walk at Cherry Creek State Park.



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

MILE HIGH (DENVER):
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ritler55@msn.com

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jlaible@frii.com
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(303) 806-6686
cbesselievre@scleroderma.org

WESTERN SLOPE:
Garnet Hoover
(970) 234-1142
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(970) 773-7887
ladyadi@yahoo.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

After serving on the Chapter Board as President for the last 4 years, **Rita Miller** will remain on the Board and has accepted a new Board position as **Support Group Liaison**. This role will include working with each support group to plan meetings and schedule speakers, make sure Chapter and National guidelines are complied with on a timely basis, and assist with whatever is needed to continue to provide the best support possible to scleroderma patients and their caregivers and families.

Bonnie Schweder, Mile High (Denver) support group leader for the last few years, has temporarily stepped down in order to spend more time with her family and take care of her own health. She hopes to return as leader sometime next year. Bonnie has done a great job leading the Denver support group and we look forward to her return. In the meantime, **Rita Miller** and **Margo Peter** will work together to continue to lead and assist with this group.

MILE HIGH (DENVER) SUPPORT GROUP

November 10, 2012 - Joanna Goldin, PT, owner of Sport and Spine Physical Therapy, Inc., will address benefits of physical therapy for scleroderma patients.

December 8, 2012 – Holiday party. Join us for some fun and festive activities!

January 12, 2013 – Erin Rosenberg, Licensed Social Worker at The Holding Group, LLC, will discuss the importance of Advance Directives.

February 9, 2013 – Michael Varley, DDS, will present on “Dental Issues and Scleroderma”.

March 9, 2013 – 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.

FORT COLLINS SUPPORT GROUP

December 1, 2012 – Holiday party. Join us at **The Moot House, 2626 S. College Ave., Fort Collins, CO 80525** at **11:00 am** for some holiday fun and good conversation. **NOTE: Special location, date and time for this meeting!**

February 23, 2013 – Kevin Jo Dager, RN and a member of Mended Hearts, will discuss pulmonary hypertension.

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 SUPPORT GROUP

November 10, 2012 – Garnet Hoover, support group co-leader, will discuss digital ulcers – what she learned at the 2012 National Patient Education Conference and through her own research.

January 12, 2013 – To be announced.

March 9, 2013 – To be announced.

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

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



MEET CATHY & DICK WHALEN

Cathy was diagnosed with scleroderma in 2010. Since then Dick has come to refer to himself as her “Sherpa” (i.e., caregiver)! Here is their story.

Cathy and Dick were both born in upstate New York. They met while in college - in a bar on Halloween night in 1964, which Dick says explains a lot!



The Whalens have been married for 44 years, have 3 grown children and 4 grandsons. They have wintered in Florida for six years but because all their family is in Colorado, they keep coming back. During the first 4 winters in Florida they owned and lived on a sailboat, but with Cathy’s scleroderma, that became too difficult. They now have a townhouse in Palmetto, FL.

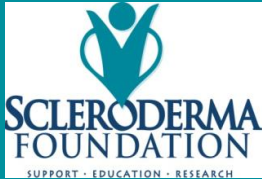
Dick’s sales job with Nabisco took them from New York to Seattle and eventually to Colorado in 1981 when Nabisco merged into RJR Nabisco. In 1988, Dick started a food service brokerage which he sold 4 years ago when he retired. Cathy worked as a middle school teacher for 29 years. She has a Masters degree in reading. She taught reading and literacy at Cherry Creek High School District before retiring.

Before Cathy was diagnosed with scleroderma, the Whalens enjoyed many outdoor activities together including scuba diving, sailing, snow skiing, and bike riding (they have biked the Ride the Rockies twice!). They also enjoyed motorcycle riding and Dick still belongs to a motorcycle club called the Cherry Hills Angels.

Cathy had chronic bronchiectasis as a child that affected her lungs. As a result, most of her left lung was removed when she was 17 years old. She had her first heart attack in 1999 at age 52, a second in 2004, and a third in 2010 soon after being diagnosed with scleroderma. She has eight stents in her heart.

While wintering in Florida in early 2010, Cathy started to notice extreme shortness of breath. They would get off the boat and she couldn’t walk to dinner. She went to the emergency room in Fort Myers where she was misdiagnosed and released without oxygen. Still short of breath, she went to see a pulmonologist who put her on oxygen. Upon returning to Colorado that spring, she had some tests and was referred to Dr. Aryeh Fischer at National Jewish Health. She met with Dr. Fischer in August. He looked at her hands and told her she had scleroderma.

Today, Cathy’s scleroderma symptoms include pulmonary hypertension, congestive heart failure, Raynaud’s (which she has had for 20 years), and a slight narrowing of her esophagus, which medication controls except she has had to give up drinking wine – a choice she would rather have not had to make! She can’t eat large amounts at one time anymore so she tends to snack throughout the day.



Cathy's advice to someone newly diagnosed with scleroderma is to learn all you can about the disease. She also advises to accept the fact that there is currently no cure and to learn how to live and function with it. You *will* learn how to cope and adapt. She recommends attending a support group. She admits that this is very difficult at first but getting to know others with scleroderma is very helpful and support group meetings can be very informative.

Cathy is on 19 medications for all her medical conditions. She takes Tracleer, Revatio, and Tyvaso (an inhaler) for the pulmonary hypertension. She is involved in a clinical study at Swedish Hospital to determine if these three medications combined can keep the pulmonary pressure in her lungs from worsening. So far it seems to be working and there is noticeable improvement.

Cathy is on oxygen 24/7 in Colorado. In Florida she uses it as needed, about 60% of the time. When she returns to Florida this fall she will have an echocardiogram and do the 6 minute walk test to determine the effect of the altitude on her condition.

The Whalens both admit that Cathy's scleroderma has had an impact on their lives and their relationship. They were always an active couple and that has changed. Cathy can't do as much as she used to and if she overdoes it one day, she will pay for it for the next few days. This is frustrating to Cathy but Dick also sometimes bears her frustration when he tries to do things for her. Having taught school for so many years, Cathy admits that the loss of "power" is tough.

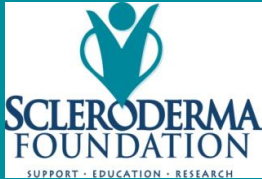
Cathy does not let scleroderma define her so she tries to do all she can at home but admits she doesn't always know when to ask for help. When Cathy was first diagnosed, Dick tried to do everything around the house. Once he started it was hard to stop but now he occasionally travels with his motorcycle club and Cathy has learned to be fine on her own.

Dick has learned to recognize when Cathy has had too much and is tiring. When it is just the two of them he will mention that maybe they should stop and go home, but he has a harder time reminding her if they are with family and friends. Instead Dick tries to remind their children that when they visit to not overextend their time even though Cathy may say otherwise. Dick admits that it is hard for the kids to accept or understand Cathy's condition because "she doesn't look sick". Cathy's scleroderma is mostly internal and not visible. Dick states that if people could see what it has done to her insides, they would understand better.

In some ways scleroderma has brought them closer together but it also has its challenges. They had to give up their sailboat which was Dick's dream. Cathy regrets this and realizes how difficult that was for Dick. They love to travel and Cathy's need for oxygen makes that complicated. The hardest thing for Dick is admitting that it is frustrating without blaming Cathy. As a caregiver, Dick finds it hard to relax and feels the pressure of always being "on call" to respond to Cathy's emergencies. Although they didn't tell their kids all about Cathy's condition initially, Dick does talk openly with their daughter who, as a midwife, understands the disease. Dick has also learned to let it "in one ear and out the other" when Cathy needs to vent her frustrations. Dick admits that being an "older" couple helps in coping with the disease because they can appreciate all they have. He feels for younger couples who are faced with this situation.

When the Whalens returned to Florida in 2010 shortly after Cathy's diagnosis in August that year, they were grateful for the social aspect that living on a boat provided them. In the close knit boating community it was impossible for them not to socialize, so they learned early on how to discuss the disease and explain the oxygen. This has helped keep them social and active today.

The Whalens' goals are to continue their lifestyle. They love to travel but are not comfortable leaving the country with Cathy on oxygen so they are making the most of their trips to and from Florida by seeing as much of the country as they can and visiting friends and family along the way.



NATIONAL CONGRESSIONAL CALL-IN DAY

The Scleroderma Foundation has organized a Congressional Call-In Day on **Wednesday, November 14, 2012** to urge U.S. Senators and Representatives to support the “Scleroderma Research and Awareness Act” (S. 649 in the Senate; H.R. 1672 in the House of Representatives).

Let your voice be heard! We encourage you to call and ask your elected officials to support this important legislation.

For more information, including tips for calling and phone numbers for your elected officials, visit our website at www.scleroderma.org/colorado.

NEWS & UPCOMING EVENTS

NATIONAL JEWISH HEALTH & UNIV. OF COLORADO ANSCHUTZ MEDICAL CAMPUS DESIGNATED AS SCLERODERMA CENTERS

The Scleroderma Foundation has designated **National Jewish Health** and **Univ. of Colorado Anschutz Medical Campus** as Scleroderma Centers of Excellence. To be recognized by the Foundation as a Scleroderma Center, institutions must (1) demonstrate expertise in scleroderma including clinical and laboratory-based research; (2) conduct clinical trials in scleroderma; and (3) conduct educational activities about scleroderma, and provide information about the advances in the care and treatment of patients with scleroderma to health care professionals and the public.

We congratulate **Dr. Aryeh Fischer** and **Dr. Jason Kolfenbach** on achieving this designation! We knew it all along and are glad to see them recognized by the National office as well.

For more information about Scleroderma Centers and clinical trials, go to <http://bit.ly/SclerodermaCenters> and click on Colorado.

NEW LOOK FOR SCLERODERMA FOUNDATION WEBSITE

Thanks to a generous gift from the Ben D. Rea Estate, the Scleroderma Foundation launched its updated website in August. It is now easier to find key information such as support groups and scleroderma treatment centers. Some other great features include Hope Raisers for setting up fundraising pages for any type of event from garage sales to karaoke contests and an updated Online Store.

If you haven't checked it out yet you can still find the website at www.scleroderma.org or go directly to our Chapter home page at www.scleroderma.org/colorado.

2013 9HEALTH FAIRS

2013 is just around the corner and we are planning for the 9Health Fairs in the spring. This year we hosted about a dozen tables at Fairs around the state. Next year we hope to do even more because these Fairs are a great opportunity to spread awareness of scleroderma. If you are interested in volunteering to host a table, please contact Rita Miller at (303) 617-0537 or ritler55@msn.com. It only takes a half a day of your time to make a difference!

2013 NATIONAL PATIENT EDUCATION CONFERENCE

It seems like we just returned from the 2012 Conference but National is already planning for next year. The 2013 Conference will be held from July 26-28 at the Hyatt Regency in Atlanta, GA. You may be eligible for a scholarship from National or our Chapter to attend the Conference. For more information, please contact the Chapter at (303) 806-6686 or cochapter@scleroderma.org.



Cyndy's Snippets

2012 has been a great year for the Chapter.

It is exciting to be a part of the growth and changes we are going through as we continue to advance the mission of the Scleroderma Foundation. I am looking forward to an even bigger and better year in 2013!

RECENT EVENTS

2012 FORT COLLINS STEPPING OUT WALK RAISES \$17,000!!

The 2nd annual Stepping Out to Cure Scleroderma Walk at Fort Collins City Park on Sunday, Sept. 30 was lots of fun and a big success. 147 walkers stepped out and raised over \$17,000!

Nadette Bonnema was the top individual fundraiser with over \$5,000 in pledges – wow! Holly Hevelone's Jazzercise of Fort Collins team showed up in force with 38 walkers! Their orange sashes were visible all along the walk course. And thanks to Dr. Michael Thakor who helped us with registration.



For more about the Fort Collins Stepping Out Walk and to view pictures, go to <http://bit.ly/COSclerodermaNews>.

2012 PATIENT EDUCATION DAY

This year's Patient Education Day on Sunday, Sept. 9 was attended by many first-timers, some who have recently been diagnosed with scleroderma and others who have had it for years but wanted to learn more about the disease.

We thank Dr. Aryeh Fischer and National Jewish Health for partnering with us to organize the event again this year. We also thank all the speakers who took time on a Sunday to share with

us their expertise of scleroderma: Aryeh Fischer, MD; Richard Nash, MD; Jason Kolfenbach, MD; Julia Rhiannon, MD; Kristin Kilbourn, PhD; Allison Costenaro, MA, LPC; Kimberly Sack, MS, PT; Chelsea Randall, MS, OT; and Martha Hansen, owner of the Youcan Toocan Store.



We Give Thanks!

This Thanksgiving we recognize the hard work of our many volunteers including Board and committee members, support group leaders, Patient Education Day and Ft. Collins Walk volunteers, and those who helped on special projects such as mailings, hosting display tables, newsletter editing, and making phone calls. Thank you Rita Miller, John Niemi, Elsie Elmore, Brandon Moore, Bonnie Schweder, Charly Littler, Tahani Rivers, Megan Liddicoat, Belinda Krajmalnik, Phyllis Johnson, Margo Peter, June Bryant, Judy Laible, Ann Montera, Garnet Hoover, Carol Wetherell, Tierra Springer, Rita Perez, Theresa Rice, Ellen Niemi, Marissa Barten, Tom Schweder, Cameron Schweder, Carol Bennis, Phil Montera, Alan Laible, Lindsay Moore, Fred Elmore, Wendy Elmore, Jean Flagg, Marianne Dinges, Dr. Michael Thakor, Betsy Craig, Rocky Craig, Jennifer Usher, James Usher, Ruth Zablow, Shantel Hansen, Cori Kimball.



ROCKY MOUNTAIN CHAPTER

2280 S. Albion St. · Denver, CO 80222

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. **“Give where you live” on Colorado Gives Day. Donate online on Tuesday, Dec. 4 at www.givingfirst.org/rockymntscleroderma.**
2. If you are a Federal employee (civilian, postal, or military), you may elect to donate to the Scleroderma Foundation from 10/1-12/15/2012 through the Combined Federal Campaign by payroll deductions. The Scleroderma Foundation’s CFC code is #10089.
3. Mail your check payable to the Scleroderma Foundation-Rocky Mountain Chapter to 2280 S. Albion St., Denver, CO 80222.
4. Donate on-line through the Scleroderma Foundation at www.scleroderma.org. You can also learn on our website about donating your cars and used cell phones.
5. Check with your employer about payroll deductions for donations to the Scleroderma Foundation-Rocky Mountain Chapter (and ask them about their matching programs).
6. Please remember us in your will or other plans.