

Winter 2012

SCLERODERMA FOUNDATION

WHAT'S INSIDE

News From the
Board.....Pg. 2

Support Group News/
Contact Info...Pg. 3

New Fort Collins
Support
Group.....Pg. 3

Meet the Chapter
Board.....Pg. 4-6

Partnering with the
Colorado
Avalanche.....Pg. 7

2012 Stepping Out
to Cure
Scleroderma...Pg. 8

Other News....Pg. 9

Make a Donation
Today.....Pg. 10



ROCKY MOUNTAIN CHAPTER

COLORADO AVALANCHE vs. ANAHEIM DUCKS

Monday, February 27, 2012
See page 7 for details

2012 STEPPING OUT TO CURE SCLERODERMA 3K/5K WALK

Saturday, June 16, 2012
See page 8 for details

9HEALTH FAIR 2012

The Chapter will again participate this year in the 9Health Fairs located throughout the metro area in early April 2012. Last year we hosted tables at a dozen locations. If there is a 9Health Fair in your neighborhood, let us know and we will look into it. The 9Health Fairs provide an opportunity to spread the word about scleroderma in a friendly and interactive environment.

To volunteer at a table to hand out literature and answer questions about scleroderma, please contact Rita Miller at rmiller@scleroderma.org or the Chapter office at (303) 806-6686. (Volunteers must generally be available from 6:00 am – noon.)



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

VOLUNTEER??? WHY NOT!!!

Volunteer...sometimes this word can be scary. Immediately we think the organization wants us to sell our soul and donate all of our time. That isn't the reality of volunteering. However, one doesn't check out the details and assumes the worst.

There is a wide range of involvement for volunteers from making phone calls to helping with mailings to being on a committee or being on the Board. And volunteers save money. If only I had more staff!!!

People don't volunteer for several "*reasons*":

1. *They don't have the time.* We are flexible and will work with your schedule.
2. *Fear of not knowing the end date.* We outline the project or Board term.
3. *People haven't been asked.* We are asking now.
4. *Indifference and apathy.* We definitely don't think our membership patients and families are this way when it comes to scleroderma.
5. *Get bored.* We can rotate responsibilities.

There are several benefits to volunteering. There is fulfillment and challenge. This creates a feeling of doing something good. You will meet interesting people. You learn as a volunteer. And it is a chance to give back.

Volunteering positively impacts the lives of those serving, as well as those being served. Volunteering feels good and it is good for you. Here are some tips to ensure you have a rewarding volunteer experience:

1. What are your motivations and goals? Do you want to make a difference in the Scleroderma Foundation-Rocky Mountain Chapter?
2. Inventory your skills. What do you enjoy the most? Do you have skills you want to improve?
3. Assess how much time you can share. Make sure you don't overpromise. Is a short-term project better than a year-long volunteer position?

To volunteer, please contact Cyndy Besselievre at cbesselievre@scleroderma.org or (303) 806-6686 or John Niemi at doodadjohn@comcast.net or (303) 947-4184.

John Niemi
Board Vice-President and
Chair-Awareness Committee



For more information about the monthly support group meetings, or to suggest speakers or topics you would like to hear about, contact:

MILE HIGH (DENVER):
Bonnie Schweder
(303)-438-7124
bschweder@scleroderma.org

FORT COLLINS:
Cyndy Besselievre
(303) 806-6686
cbesselievre@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

MILE HIGH (DENVER) SUPPORT GROUP 2012 SCHEDULE

February 11 - 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.

March 10 – Martha, owner of Youcan Toocan, will present tools/gadgets for making life easier for scleroderma patients.

April 14 – Dr. Phil Hanna, Chief-Division of Gastroenterology, National Jewish Health, will discuss the gastro-intestinal manifestations of scleroderma.

May 12 – Keith Demmon, MSPT, will discuss various exercises to assist scleroderma patients with maintaining strength and balance.

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.

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.

FORT COLLINS SUPPORT GROUP

We are very excited to announce the first support group meeting in Fort Collins! Join us on **Saturday, March 24, 2012 from 10:00 am – 12:00 pm at the Harmony Library Community Room, 4616 S. Shields St., Fort Collins, CO 80526.**

The agenda for this meeting will include introductions and getting to know one another, open discussion of questions or topics of interest related to scleroderma, and a discussion of what your expectations are and what you would like to get out of this support group. Meetings for the rest of 2012 are tentatively scheduled for May 26, July 28, September 22, and November 24. We look forward to seeing you there!



While we are excited to welcome so many new Board members over the past year, we are sad to announce that Donnie Schlereth recently was forced to resign due to her health.

Donnie has been involved with the Chapter ever since its inception more than 10 years ago and has served in numerous positions on the Board and on various committees.

We sincerely thank Donnie for all her years of service and her hard work in helping to get the Chapter where we are today. We wish all the best for Donnie.

*Rita Miller,
Board President*

MEET THE CHAPTER BOARD



From left to right—John Niemi, Brandon Moore, Bonnie Schweder, Elsie Elmore, Belinda Krajmalnik (front), Charly Littler, Rita Miller, Tahani Rivers (not pictured—Megan Liddicoat)

RITA MILLER, PRESIDENT: Like most, I did not know anything about scleroderma until my son John was diagnosed. He was first diagnosed with "mixed connective lupus" at age 21 and several years later with scleroderma. His death was unexpected, caused by a heart attack, when he was 37 years old. Several months after his death I attended my first support group meeting. I learned a lot and decided to go to more meetings. I was soon asked to be on the Board and am currently the President. My goal was to grow the Board and the Chapter. This year as President I hope to increase fundraising for the Chapter. I will stay on the Board after my presidency expires at the end of this year. In addition to being a mother, I was an Occupational Therapist and worked at Cherry Creek Schools for almost 20 years until I retired 5 years ago. Now I spend my time reading, volunteering, going to movies, and traveling.

JOHN NIEMI, VICE-PRESIDENT: My friend, Donnie Schlereth, has scleroderma. About 1 ½ years ago Donnie mentioned to me that the Board was looking for new members and she thought I would be a good fit. I met with Rita to learn about the Board and she asked me to join. I have learned much about the disease by getting to know other patients at the support group meetings and hearing what they live with. My goals for the Board in 2012 are to increase public and corporate awareness and increase fundraising for research. I am an account executive for Halo Branded Solutions. When not working, I enjoy travel, sports and volunteering.

ELSIE ELMORE, SECRETARY: I've been involved with the scleroderma support group and Board for about 6 years. My daughter was diagnosed with scleroderma, so we decided to see what the support group was all about. We learned so much from our first visit and wanted to learn more and do more, so we joined the Board. My daughter served as Secretary pro-tem, then I became Secretary later on. My reason for being on the Board is to try and get the word out to more and more people about scleroderma and



make them aware of this terrible and incurable disease. My goals for the Board for 2012 are to raise awareness about scleroderma and raise money for research. I'm employed by a small family owned business that makes hand tools for pipefitters and welders. I've been there 25 1/2 years and now work only part-time, so I am pretty much semi-retired. I've been married 50 years, and my husband and I both enjoy traveling, especially cruises, camping and fishing.

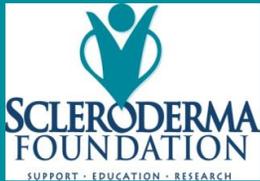
BRANDON MOORE, TREASURER: I first came to be involved with the Scleroderma Foundation through a co-worker whose family was affected by this disease. After learning more about the Rocky Mountain Chapter, I was interested in making a meaningful impact. I have been on the Board for the past year and have truly enjoyed seeing the difference the Chapter makes through the support groups, patient education day, and walks. Through my involvement with the Board it has taught me that even when you can't donate money you can make a difference in giving your time and skills to others. My goal for the 2012 year is to continue to expand our services and increase our community's knowledge about this disease while expanding the Chapters resources for future generations. My background and experience comes from my career in the banking industry. I am a Vice President at FirstBank, a local employee owned bank that is the second largest bank in Colorado. Outside of work I enjoy numerous athletic hobbies including competitive running, snow skiing, wakeboarding and golfing. I am married to my beautiful wife, Lindsay, of 5 years and we own a chocolate lab with more energy than what we know to do with.

BONNIE SCHWEDER, SUPPORT GROUP LEADER: I was diagnosed with limited systemic scleroderma in 2005. As the support group leader, being on the Board has given me the opportunity to participate in the decision-making process, be a voice for the support group, and exchange communication and feedback amongst other Board members. It has been exciting to be part of such a dynamic group of people with great ideas and then to watch these ideas become a reality. My 2012 goal for the Board is that we continue to grow and expand our ability to serve the needs of scleroderma patients and their families. I am currently a stay-at-home mom/domestic engineer. Since 1991, I have worked for Tri-County Health Department and as a contract dietitian for the American Heart Association. I enjoy traveling, reading, hiking, snowshoeing, and astronomy/star-gazing.

BELINDA KRAJMALNIK: I'm interested in the support group because my son Isaac has been afflicted with scleroderma since he was six years old, and is now 51. It's been a difficult road with many obstacles to overcome, and as difficult as it has been for us, it is nothing compared to the daily struggle he has, having to deal with pain, doctors, surgeries, secondary effects, and the emotional baggage and frustration of what he could've done with his life.

Since 2008 we have participated in the Stepping Out walks and have won the prize for the top team fundraiser for the last several years. After last year's walk, I decided that I had to get more involved and take a more active role in raising awareness about this devastating disease. I joined the Board and the Awareness Committee. By going to the monthly meetings I've had the opportunity to meet wonderful people that struggle with this disease on a daily basis. Their strength and courage is an inspiration for everybody.

Continued on Page 6



Would you like to receive the quarterly newsletters by email instead of regular mail (and help us save a tree)?

If so, please contact Cyndy Besselievre at (303) 806-6686 or cbesselievre@scleroderma.org to be added to the email distribution list for the newsletters.

CYNDY'S SNIPPETS

I thank the Board for all their hard work and the super ideas that they bring to our Chapter. I look forward to working with the Board and all the committees to make 2012 another great year for the Chapter.

MEGAN LIDDICOAT: I first learned of scleroderma years ago working with patients in the Pulmonary Hypertension Center at the University of Colorado. However, I did not really begin to fully understand the disease until I took my current position as a nurse educator and advocate with Actelion Pharmaceuticals. This position has allowed me the opportunity to work with and get to know the members of the local scleroderma support group. I have been amazed at the strength, hope and courage the patients and caregivers who deal with this disease on a daily basis have. I'm extremely proud of the progress the Board made in advancing the mission of the Chapter in 2011. I fully expect the momentum to continue in 2012.

My husband Brent is a commercial airline pilot, so we both travel a lot for work. The good thing is we both love to travel and are fortunate to be able to bring our 3 ½ year old daughter, Hayden, with us on many trips. When we are at home we enjoy exploring the many bike trails just outside our back door in the Fort Collins/Windsor area. We also keep busy with our self serve frozen yogurt shop that we opened about 2 ½ years ago.

CHARLY LITTLER: My experience with scleroderma dates back to 2007. In July that year, I went into respiratory failure. I was intubated for 17 days. During my recovery, the doctors were unable to determine the cause. A few weeks later, my fingers began to split, and I was unable to straighten them. A friend referred me to a rheumatologist. When I met him for the first time, I shook his hand and he immediately told me what the problem was. Other than Raynauds and Barrett's Esophagus, my health is now much improved. I just recently joined the Board in November 2011. I am excited to become a part of the organization, to learn more about the Chapter, bring in new ideas, and become active in fundraising. I look forward to the Stepping Out walks every year and would like to help spread the awareness and increase participation. My 2012 goals as a Board member are yet to be determined but I look forward to taking on any responsibility thrown my way. I enjoy Rugby and now that I am unable to play I love watching the games. I am 35, married (Mary) and have 2 kids (Brenton 6 and Anderson 2). I work for Staples Inc. in their Broomfield headquarters as a credit analyst. I will be graduating with my Bachelors from Colorado State University Global Campus in "Public and Non Profit Business Management".

TAHANI RIVERS: I am an environmental lawyer and moved to Denver in August 2010. I joined the Chapter soon after I learned one of my dearest loved ones was living with scleroderma. I joined the Chapter in order to become more informed about the disease and help provide better support. I have found the support group meetings so informative and have formed new friendships with members of the group. I want to try and do more to help the mission of the Chapter and thus I joined the Board in August 2011. As a new member of the Board, I hope to support the efforts to continue to bring educational and informative speakers to the support group meetings. I also hope to help raise funds for the Chapter through working on the Stepping Out walks in Denver and Fort Collins. Lastly, I hope to work on bringing another Patient Education Day to the members, as I think that education and knowledge about the disease is so important to each patient getting the best care possible.

In my down time, I love to run, do yoga, and spend time with my family and friends. I also enjoy traveling and, in particular, volunteering with organizations abroad that help children in need.



COLORADO AVALANCHE vs. ANAHEIM DUCKS

***MONDAY, FEBRUARY 27, 2012
PEPSI CENTER – 7:00 PM***

The Scleroderma Foundation-Rocky Mountain Chapter has partnered with the Colorado Avalanche for a great deal when the Av's take on the Anaheim Ducks on Monday, February 27, 2012. You get discount tickets and the Chapter gets a donation of \$5-\$8 for each ticket sold. It's a win-win situation for everyone!

To order tickets at a discounted price of \$30 in the upper level Section 372 (\$40 value), go to <http://www.pepsicenter.com/groups/avalanche/sclero0227u>.

To order tickets at a discounted price of \$55 in the lower level Section 130 (\$102 value) or in the lower level Section 254 (\$115 value), go to <http://www.pepsicenter.com/groups/avalanche/sclero0227l>.

(Seats will be held until a week prior to the game. After that time, you may still order from these links, but specific seating location is not guaranteed. For more information, contact Kristy Howell at (303) 405-6144 or khermann@pepsicenter.com.)

If we sell 50 tickets, someone from the above sections will get a chance to ride on the Zamboni! But why stop at 50? Our goal is to sell 100 tickets. The more we sell, the more we get in the form of other incentives from the Colorado Avalanche.

This is not just a fundraiser for the Chapter but is also a great way to promote awareness of scleroderma to the general public. So please help us reach our goal and buy your tickets today.

Do you know of any groups that might want to take advantage of this great deal such as local hockey clubs, co-workers, schools, health clubs, or doctors' offices? If so, please contact John Niemi at doodadjohn@comcast.net or (303) 947-4184 or Cyndy Besselievre at cbesselievre@scleroderma.org or (303) 806-6686 for flyers.



For more information about the Walk in general or to inquire about volunteer opportunities, contact:

Cyndy Besselievre
(303) 806-6686
cbesselievre@scleroderma.org

The 2nd Annual Fort Colliins Stepping Out to Cure Scleroderma Walk is tentatively scheduled for Sunday, September 30, 2012. More information about this walk will follow in the next edition of this newsletter.



CHERRY CREEK STATE PARK SATURDAY, JUNE 16, 2012

The 8th Annual 2012 Stepping Out to Cure Scleroderma 3K/5K Walk will be held at Cherry Creek State Park on Saturday, June 16, 2012. Registration begins at 8:00 a.m. and the walk takes off at 9:00 a.m.

Our walks have grown each of the past seven years so this year we are setting some lofty goals – 300 walkers and \$40,000 in pledges. But we cannot reach these goals without you. We challenge you this year to walk if you haven't before, set a personal goal for raising pledges, or organize a team and ask each team member to raise pledges along with you.

Register, form a team or create a fundraising page online at www.firstgiving.com/scleroderma-co/2012-stepping-out-to-cure-scleroderma. (On-line registration will be available on February 15, 2012.)

As in past years, we rely on the generosity of local community-oriented businesses that help us offset the costs associated with organizing the walks by their donations of cash, raffle and auction items, goodie bag items, and supplies. If you know of any businesses that may consider making a donation this year, please contact Cyndy Besselievre at cbesselievre@scleroderma.org or (303) 806-6686.

If you are unable to walk and still would like to participate in all the fun, consider volunteering. Volunteers are always needed to assist with planning throughout the year and helping out on the day of the walk.





The Rocky Mountain Chapter sadly reports the passing of two of our members in January 2012:

Nettie Radeff,
deceased January 11

Martha Youngren
deceased January 27

Our thoughts go out to their families at this time of sorrow.

2012 NATIONAL PATIENT EDUCATION CONFERENCE

The 2012 National Patient Education Conference will be held July 27-29, 2012 at the Gaylord Texan Hotel and Conference Center near Dallas, TX. For more information go to the Foundation website at http://www.scleroderma.org/national_conference_2012.htm.

The Scleroderma Foundation offers scholarships for those in need of financial assistance to help pay for the cost of the Conference. Information about the scholarships will be available on the above website in late February. The applications must be submitted by April 2012.

The Rocky Mountain Chapter also offers financial assistance for our members who would not otherwise be able to attend the Conference. However, in order to insure that all our members have a fair chance in being granted such assistance, the Chapter has set in place new policies for the 2012 Conference: (1) reimbursed expenses may not exceed \$750 per patient and \$500 per traveling companion (the Chapter will reimburse up to 3 patients and their traveling companions), (2) patients must first apply to National's scholarship program and have been rejected (patients must provide proof of National's rejection to the Chapter), (3) patients must complete the Chapter application, (4) patients must present a summary of the National Conference Workshops they attended at the Chapter support group meeting following the National Conference, and (5) if more than 3 patients apply for the Chapter reimbursement, the Board will review all applications and select the 3 finalists.

SCLERODERMA FOUNDATION INCREASES 2012 RESEARCH GRANT FUNDING

The Scleroderma Foundation has increased research funding from the budgeted \$1 million to \$1.2 million for 2012 and will fund eight grants. This accomplishment has been made possible by the thousands of supporters who share our commitment to promote and encourage research in the search for a cure for scleroderma.

The 2012 grant recipients are:

- Elena Tourkina, Ph.D., Medical University of South Carolina (Marta Marx Award)
- Ai Lam, M.D., Northwestern Feinberg School of Medicine (Mark Flapan Award)
- Flavia Castelino, M.D., Massachusetts General Hospital (Walter A. Coyle Memorial Grant by the New England Scleroderma Foundation Chapter)
- Eric Greidinger, M.D., Miller School of Medicine University of Miami
- Heidi Jacobe, M.D., University of Texas at Dallas
- Thomas Ruenger, M.D., Ph.D., Boston University School of Medicine, Department of Dermatology
- Richard Silver, M.D., Medical University of South Carolina
- Barbara Smith, B.S., M.A., Ph.D., Boston University School of Medicine

Source: Scleroderma Foundation eLetter #431 (12/16/11).



YOUR DONATION HELPS

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.
3. Donate on-line through GivingFirst at www.givingfirst.org.
4. Go to www.scleroderma.org/development/recycle.shtm to learn more about donating your car or used cell phones.
5. Check with your employer about payroll deductions for donations to the Scleroderma Foundation-Rocky Mountain Chapter.



ROCKY MOUNTAIN CHAPTER

2280 S. Albion St. · Denver, CO 80222