

Summer 2011

SCLERODERMA FOUNDATION

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Rocky Mountain Chapter

PATIENT EDUCATION DAY

You won't want to miss this event!

Sunday, September 11, 2011

9:30 a.m. – 2:00 pm

See page 6 for details

2011 FORT COLLINS STEPPING OUT TO CURE SCLERODERMA 3K/5K WALK

Register today!

Sunday, October 2, 2011

See page 7 for details



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)

WHAT'S NEW

Keep up with all that's new and chat with other scleroderma patients!

If you don't already receive the free weekly eLetter from the Scleroderma Foundation with updates on research and clinical trials, sign up today at www.scleroderma.org/e_letter_signup.shtm.

With a BIG THANKS to Betsy Craig, we are now on Facebook and Twitter! Check out these links to stay informed and chat with other scleroderma patients: www.facebook.com/COScleroderma and www.twitter.com/COScleroderma.

NEWS FROM THE BOARD

The Board thanks all who came out to the Walk on June 18 at Cherry Creek State Park. And a special thanks to all the volunteers. It was a beautiful and very successful day. See page 7 for more about the Walk.

Cyndy Besselievre, John Niemi, Bonnie Schweder, and I attended the National Leadership Conference on the Friday before the National Patient Education Conference in San Francisco. It was a chance for us to meet and interact with staff from National and other chapters around the country. The report from National is very positive in regard to funding in spite of the economic state. National is again working on getting the scleroderma funding bill through this Congress.

We also had three other members from our Chapter attend the National Patient Education Conference. All agree that the Conference is a great learning experience and enjoyed meeting so many other patients with which to share stories. The 2012 Conference is scheduled for July 27-29 in Dallas, Texas. Start to plan now for next year and remember that our Chapter provides financial assistance for patients and a traveling companion to attend the Conference.

We are looking forward to two new events this fall – our first annual Patient Education Day on Sunday, Sept. 11 and our Ft. Collins Stepping Out to Cure Scleroderma Walk on Sunday, October 2. Hope to see you at both these events.

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
Support Group Leader
(303)-438-7124
[bschweder@
scleroderma.org](mailto:bschweder@scleroderma.org)

SUPPORT GROUP NEWS

Join us at our monthly support group meetings!

The first half of the meetings will start with introductions and an informal discussion open to questions or topics of interest. Following a short break and refreshments, the second half will include speakers and presentations.

Following is the schedule for the remainder of 2011:

August 13 - Update on the National Conference presented by this year's Chapter attendees.

September 10 - NO MEETING DUE TO THE PATIENT EDUCATION DAY on SUNDAY, SEPTEMBER 11 (see page 6 for more details).

October 8 - Megan Liddicoat, RN BSN, will present "Grief to Hope", a presentation on how to cope with the stress of a chronic illness.

November 12 - Joanna Goldin, PT, owner of Sport and Spine Physical Therapy, Inc. will address benefits of physical therapy for scleroderma patients.

December 10 - Christmas party. Join us for some FUN!! We'll have great food, music, prizes, cookies, gifts and a surprise appearance by ?????!

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

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.

Looking ahead to 2012...

We have been busy putting together the schedule for 2012 – so far we have several interesting speakers and a new event scheduled for next year. There are many more ideas and possibilities that we are working on for the 2012 support group meeting schedule. Please let me know if you have any suggestions for speakers or activities – I'd love to have your input. In the meantime, keep watching for more information about the upcoming meetings...2012 is going to be a very exciting year!

Bonnie Schweder
Support Group Leader



MEET CYNDY BESSELIEVRE

Cyndy recommends that if you haven't attended a support group meeting, you should do so soon (and bring along your family and friends). Our meetings are informative and upbeat. You will learn a lot and instantly make new friends.



If you haven't met Cyndy, you will most likely be able to spot her at a Rocky Mountain Chapter-Scleroderma Foundation activity. She would be the one who is probably organizing the event, knows the answers to the questions, and is calm and in control of the situation. If that description isn't helpful enough, she has bright blue eyes, a warm smile and is a towering 5'11" tall.

It was 2001 when the first Scleroderma Chapter was formed in Colorado, and Cyndy was among the handful of founding members. Although Cyndy herself doesn't have scleroderma, her mother was diagnosed with the disease in the late 1980's. As Cyndy began to research and understand more about scleroderma, it became her passion to join the fight to find a cure. She was the Chapter treasurer for nearly 10 years before she became the first part-time, paid employee. In November, 2010 the Board of Directors made the decision to hire someone to help with the multiple tasks & details involved with growing the Chapter. To everyone's surprise, Cyndy applied for the job; she was interviewed and hired almost immediately! Her new title became "Member and Services Associate" and we all agree that she is doing an amazing job! Hiring Cyndy was the smartest move our Chapter ever made; she has put us on "the fast-track" and some of us are running after the train, barely able to keep up!



Cyndy was born in Lancaster, Pennsylvania and grew up in that area along with her parents and two sisters. Since they lived in the heart of Amish country, her father ran a tourist bus service, taking groups to the various tourist spots around the area. Cyndy and her sisters worked in the business nearly every weekend.

She attended Kutztown University of Pennsylvania, briefly majoring in Art, then changing her major to Business and Accounting. Six years after graduating from college, she became a Certified Public Accountant (CPA). She moved to Colorado in 1987, earned a Master's Degree from D.U. in Taxation and married her sweetheart, Craig, in 1990. He is "an I.T. (Information Technology) guy" and they met while employees of United Cable Television Company. With a last name like Besselievre, you might think Craig, or his family, was born somewhere exotic, like France ... but it seems he hails from Ft. Worth, Texas. *(What? Really? :-)*

The Besselievres make their home in beautiful Evergreen, Colorado. They share their living space with Zed (a very large, but friendly, Labrador Retriever), Pepper (cat 1) and Max (cat 2). Cyndy and Craig both love the great outdoors and, for fun, they like to hike, ski, bike and run. Cyndy admits to being "somewhat competitive" and has been playing league tennis for a number of years. Regular exercise has long been important to Cyndy and she makes it a priority; one of her motivators is that exercising allows her to eat chocolate and stay slim. She also loves to travel, read, draw & paint and has an interest in Civil War history. Although Cyndy avoids cooking whenever possible, she does enjoy baking, which can be a challenge at Evergreen's altitude of 7,400 feet. Some of her favorite foods are chocolate, chocolate and ... did I mention chocolate? Actually, in all fairness, Cyndy eats a very healthy, low-fat diet which she carefully and successfully balances with her chocoholic tendencies.

For the last nine months, Cyndy has been busy organizing, updating and sorting through the maze of our Chapter's paperwork. Her new position provides plenty of opportunities to use her organizational skills, but her favorite part of the job is getting to know the support group members on a more personal level and seeing the Chapter grow and move forward.

*Interview by:
Bonnie Schweder &
Margo Peter*



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.

PATIENT EDUCATION DAY

We are excited to announce the Chapter's first PATIENT EDUCATION DAY. We are partnering with Dr. Aryeh Fischer and National Jewish Health to bring you this event. We are looking forward to this event and hope you will plan on joining us!

Dr. Fischer will host the event with welcoming and closing remarks and an overview of scleroderma. Also scheduled to speak are Phil Hanna, MD on gastrointestinal manifestations of scleroderma; Todd Bull, MD on scleroderma-associated pulmonary hypertension; Jeffrey Swigris, DO on scleroderma-associated interstitial lung disease; and Kristin Kilbourn, Ph.D. on psychological aspects of scleroderma.

Date: Sunday, September 11, 2011

Time: 10:00 a.m. – 2:00 p.m. (Registration begins at 9:30 a.m.)

Location: National Jewish Health, Molly Blank Conference Center

Registration Fee: \$10.00 (includes light breakfast and box lunch)

For more information or to register, please contact Cyndy Besselievre at (303) 806-6686 or cbesselievre@scleroderma.org.

NATIONAL CONFERENCE UPDATE

More than 400 patients and family members attended this year's Conference in San Francisco. The Scleroderma Foundation's National office again did a great job with over 40 workshops featuring updates on research and clinical trials, treatments, disease management, and coping techniques. Join us at the August 13 support group meeting (see page 3) to learn about some of these workshops by our Chapter members that attended this year's Conference.

CYNDY'S SNIPPETS

It has been a busy summer with the 7th annual Walk at Cherry Creek State Park in June and the National Conference in July. Things will pick up even more as we plan for the Patient Education Day in September and the 1st annual Walk at Fort Collins City Park in October. These events are for you...don't miss out!!



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

VOLUNTEERS ARE ALWAYS NEEDED TO ASSIST WITH PLANNING THROUGHOUT THE YEAR AND HELPING OUT ON THE DAY OF THE WALK WITH REGISTRATION, WATER STATIONS, SETUP AND CLEANUP, ETC.

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

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

The Ft. Collins Stepping Out Walk will be a 3K and 5K event with laps around the lake. This Walk will also include some of the same great features as our Cherry Creek State Park Walk such as recognition of top individual and team pledge raisers, incentive gifts, a raffle, and an auction.

Registration begins at 10:00 a.m. and the Walk will start at 11:00 a.m.

Register on-line at www.firstgiving.com/scleroderma-co/2011-fort-collins-stepping-out-to-cure-scleroderma or www.scleroderma.org/chapter/colorado/walkftcollins2011.shtm.

CHERRY CREEK STATE PARK RESULTS

The 7th Annual 2011 Stepping Out Walk at Cherry Creek State Park on June 18 was our biggest and best year yet. Over 260 walkers came out and raised more than \$27,000! Thanks to all the walkers and volunteers who helped make the Walk a success.

The top individual pledge raisers were: 1st place – Belinda Krajmalnik; 2nd place – Kay Ostrom; 3rd place – Barb Gill; 4th place – June Bryant; and 5th place – Dick Whalen.

The top team pledge raisers were: 1st place – Walking for Isaac; 2nd place – Kay's Team; and 3rd place – Cheryl's Footsloggers.

As a reminder, your on-line Firstgiving pledge pages are active until Sept. 18, 2011 so it is not too late to still collect pledges to help raise more funds for scleroderma research.

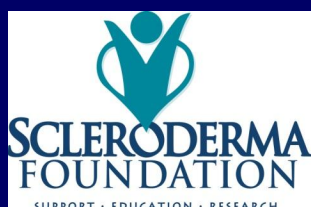


When the occasion calls for flowers, consider requesting a donation to the Scleroderma Foundation instead.

MAKE A DONATION TODAY

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.



Rocky Mountain Chapter

2280 S. Albion St., Denver, CO 80222