

Summer 2012

SCLERODERMA FOUNDATION



**SCLERODERMA
FOUNDATION**

SUPPORT · EDUCATION · RESEARCH

ROCKY MOUNTAIN CHAPTER

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NEW RESEARCH HOLDS PROMISE, BETTER OUTCOMES FOR PEOPLE LIVING WITH SCLERODERMA

A promising new research find may have a huge impact on people living with scleroderma, according to research reported earlier this summer in *Science Translational Medicine*. Dr. Carol Feghali-Bostwick, a member of the Scleroderma Foundation's Board of Directors, has led a team of researchers from the University of Pittsburgh School of Medicine who have identified a peptide that can block fibrosis in the skin and lungs.

For more information go to
http://www.scleroderma.org/media/Press_%20Releases/2012/fibrosis-news.shtm.

2012 PATIENT EDUCATION DAY

"LIVING WELL WITH SCLERODERMA"

Sunday, September 9, 2012

10:30 am – 3:00 pm

See p. 6 for details

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

Sunday, September 30, 2012 at Fort Collins City Park

Did you miss our Walk in June or do you want to walk again for scleroderma?

Then walk with us in Fort Collins!

See p. 7 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/
chapter/colorado](http://www.scleroderma.org/chapter/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

Why Should YOU Attend a Support Group Meeting?

Perhaps you already know that there are support groups available for people like us... people who have been diagnosed with scleroderma. And perhaps you have considered attending a meeting, but then decided against it. There are many reasons why we hesitate to try a support group; I should know...it took me nearly 3 years after I was diagnosed to attend my first support group meeting. Looking back, I wish I hadn't spent so much time trying to "go it alone".

For many of us, it takes some time to move past the initial shell-shock, the denial and the scary stuff we've read on the Internet. Our family and friends have never even heard the word "scleroderma" before and don't know what to say or to do for us. This is the perfect time to seek out others who have wandered through that dark tunnel and come out on the other side, those who have experience, wisdom and hope to share.

Deciding to join the Scleroderma Support Group in Denver was clearly a wise decision for me. I've learned so much about this disease (from reliable sources like researchers and physicians) and I now have a 2nd family who truly understands what I'm going through.

If you haven't yet come to one of our support group meetings, I encourage you to take the risk and check us out. I found a great article from Mayo Clinic about support groups that I hope you'll take a few minutes to read ... I've attached the link below.

<http://www.mayoclinic.com/health/support-groups/MH00002/>

I look forward to seeing you in the near future!

Bonnie Schweder
Mile-High (Denver) Support Group Leader
Board Member

Thank You Cherry Creek State Park Stepping Out to Cure Scleroderma Walk Volunteers!

The Rocky Mountain Chapter thanks all the Committee members and volunteers who helped with this year's Walk: Roger & June Bryant; Gary Bruno; Mary Coronado; Kelvis Duffie; Fred, Elsie, & Wendy Elmore; Jean Flagg; Grayson & Della Hartley; Fabian & Belinda Krajmalnik; Zig & Pamela Kukulka; Megan Liddicoat; Greyland & Grant Lightfoot; Charly, Howard, & Brenton Littler; Rita Miller; Shayna Miller; Brandon & Lindsay Moore; John Niemi; Jan Oliver; Irv Rell; Billie Richmond; Tahani Rivers; Tom, Bonnie & Cameron Schweder; Joy Shannon; Al, Theresa, Matt, & Jen Snelling; Patrick Strok; Eric Wortman.

We couldn't do it without you!



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

MILE HIGH (DENVER):

Bonnie Schweder
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bschweder@scleroderma.org

FORT COLLINS:

Cyndy Besselievre
(303) 806-6686

cbesselievre@scleroderma.org

WESTERN SLOPE:

Garnet Hoover
(970) 234-1142

unite24u@msn.com

Carol Wetherell
(970) 773-7887

ladyadj@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 - 2012

MILE HIGH (DENVER) SUPPORT GROUP

August 11 - Update on the National Patient Education Conference presented by this year's Chapter attendees.

September 8 – NO MEETING DUE TO PATIENT EDUCATION DAY on Sunday, September 9, 2012 (see p. 6 for details).

October 13 – Dr. Richard Nash of the Colorado Blood Cancer Institute will discuss stem cell therapy for scleroderma patients.

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 (location to be announced).

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

August 25 – Update on the National Patient Education Conference presented by this year's Chapter attendees.

October 27 – Hillary Beck-Gifford, ACE Certified Fitness Specialist and Yoga Instructor, will present on "Yoga for Scleroderma" including discussion of the benefits in general of exercise, yoga, and healthy lifestyle choices.

December – Christmas party (date and location to be announced).

All meetings are held from 10:00 am – 12:00 pm at Wells Fargo Bank (Board Room-2nd Floor), 401 S. College Ave., Fort Collins, 80524.

The agenda includes introductions, followed by presentations, and then informal discussion open to questions and topics of interest. Refreshments will be provided.

WESTERN SLOPE SUPPORT GROUP

September 29 – Join us at the first ever Western Slope support group meeting and meet others in your area living with scleroderma! This meeting will include introductions and a discussion of what you would like to get out of these meetings and ideas for future speakers. Refreshments will be provided.

This meeting will be held from 10:00 am – 12:00 pm at Artful Cup (Conference Room), 3090 A North 12 St., Grand Junction, CO 81506

Thank You Support Group Leaders!

Thank you support group leaders for volunteering your time and energy to organize the support group meetings. We appreciate all your hard work! Denver support group leader **Bonnie Schweder** and assistant **Margo Peter**; Fort Collins support group co-leaders **Judy Laible**, **Megan Liddicoat**, and **Ann Montera**; Western Slope support group co-leaders **Barb Donily**, **Garnet Hoover**, and **Carol Wetherell**.

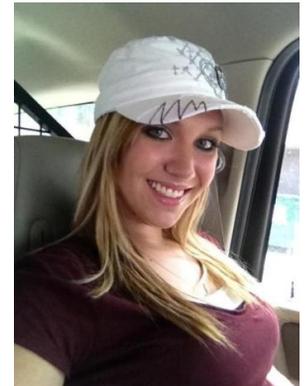


MEET CHELSEA STRANG

Diagnosed with morphea at 15 years old, Chelsea is an amazing young woman. Here is her story.

Chelsea was born in Bakersfield, CA, moved with her family to Wyoming and then Greeley, CO where she has lived since she was 3 years old.

Chelsea transferred from public school to University High School in Greeley starting in the ninth grade. The smaller school was an adjustment but allowed Chelsea to focus on her education and graduate one year early.



“Morphea” is a type of localized scleroderma consisting of patches of thickened skin usually accompanied by loss of the fatty layer under the morphea spots.

When Chelsea was a sophomore in high school, she was diagnosed with morphea. This was a very hard year for her because not only did she miss a lot of school due to treatment, doctors appointments, and pain in her back where the morphea is located but also because of the social aspect. High school kids can be very mean. At one point it went around the school that Chelsea had AIDS because of the reference to “auto-immune disease”, another time it went around the school that she couldn’t be touched because she was contagious. Being diagnosed with morphea at the age of 15 was hard enough, but she also had to put up with all the social drama and bullying because she was “different”. Chelsea was very active in sports but as the morphea got progressively worse, she had to quit playing softball, power lifting, and track in her senior year. She tried to continue power lifting but it resulted in back spasms and pain causing her to miss school and other activities. She tried not to let the disease control her life. She continued to play basketball in her senior year thanks to a coach who understood her disease. She also took a position as football manager to stay involved. High school was hard for her socially and that is partially why she wanted to graduate early. She knew what she wanted in life and was tired of putting up with the drama. Graduating early was one of the best decisions she has made.

After high school, she jumped right into CSU as a Construction Management Major. Chelsea took community college and AP classes while in high school so she started at CSU as a sophomore with 28 credits. She just recently hit the status of a junior this summer semester and also added a double major of Criminal Justice. She is not involved very much with CSU activities other than her classes because she is unable to participate in sports and because she otherwise leads a very busy life.

When not at CSU, Chelsea can be found at one of her several jobs. Her two main jobs are at Hensel Phelps Construction Company where she is employed as an estimating assistant and the Department of Revenue and State Patrol where she works in their liquor enforcement division. She also works once a month at a Bingo Hall as a bookkeeper, at her high school, and seasonally at a corn maze where her my main jobs are as courtyard manager and in concessions.



Chelsea's advise to someone newly diagnosed with scleroderma is to NOT let it control your life! Scleroderma has changed her life – she had to quit playing most sports, missed lots of school, felt like a social outcast, and went through periods of depression – but through it all she has held her head high and is determined not to let it ruin her goals and dreams. The struggle has made her more confident and aware of who she is and who she can count on. It has brought her and her family and true friends closer together.

Chelsea's first symptom of morphea was a patch of dry skin on her back. She and her family thought it might be eczema. Working as a life guard that summer, the patch started growing bigger and bigger and before long it burned whenever she went in the water and when she put on sunscreen. It was also very sensitive to touch. She was sent to three different doctors before she was properly diagnosed and treated.

In the few short years that she has had morphea, Chelsea admits that her life with scleroderma has hit some rough roads, but she makes sure to not let it control her life. Scleroderma has caused her to grow up a little quicker than everyone else. Having to quit sports was very difficult for her because it had been such a big part of her life since middle school.

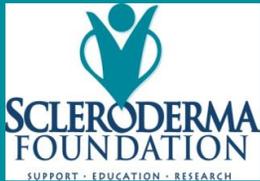
The biggest challenges to Chelsea of living with scleroderma are the “not knowing” and the social aspect of it. Every day is something new with scleroderma. You never know when it is going to stop spreading or when it is going to act up. It presents social challenges for a young person. People don't know what the disease is and they are very quick to judge. People notice how her skin is different on her back and they start asking questions or judging her. Another challenge was being on the drug Methotrexate. The doctor told her she would most likely get depressed. She tried to fight it but after a year of being on the medication she noticed she was having a lot of fights with her family, boyfriend, and friends. She was negative about everything and argued everything someone would say. She is now off Methotrexate and feels her attitude is back to normal. She is happier and is no longer fighting with her friends and family.

Chelsea has been off Methotrexate for about a year. It is about her only medication option but she prefers not to take it because of the negative impact on her attitude and personality. It also made her feel really sick 3-4 days out of the week. Her morphea is spreading and it does seem to be getting worse over time. Having lived with morphea for about three years now she is more open about it. Being put through everything that she went through in high school was tough but helped build a “backbone”. She is now proud to show her back and skin in whatever she wears and is not afraid of what people say or think. When people ask questions, she tries to answer them to the best of her knowledge to help spread awareness of this disease.

Chelsea's morphea has been a learning experience for the entire family. Her father admits that they had to learn all about the disease, the symptoms, the medications and their side effects. It took her parents awhile to realize that some of the emotional and physical aspects Chelsea was dealing with were effects of the disease and medication, not just a teenage girl growing up!

Chelsea's mother is proud that Chelsea has shown that just because she has been diagnosed with a lifelong chronic illness doesn't mean she has to quit life and give up. Chelsea continues to push herself hard at school and at work. Chelsea was a little self conscious at first but she never has tried to hide her back from others. She will always explain about the disease. For being as young as she is, she has handled having a lifelong chronic illness very well.

Chelsea's short term goal is to finish college and graduate with a double major. Down the road she hopes one day she can pass the physical aspect of being a police officer and advance into a career with the FBI. She also has a big interest in animals, especially horses, and hopes to own a ranch of her own with horses, pigs, and cows.



Aryeh Fischer, MD recently became a member of the Scleroderma Foundation's National Medical Advisory Board. Congratulations Dr. Fischer! We appreciate all that you do to advance treatment and research for scleroderma.

The Rocky Mountain Chapter sadly reports the recent passing of two of our members :

Victor DiLeo,
Deceased May 19

Donnie Schlereth,
Deceased July 25

Our thoughts are with their families at this time of sorrow.

Both Victor and Donnie asked that donations be made to the Scleroderma Foundation-Rocky Mountain Chapter in their memory.

2012 PATIENT EDUCATION DAY SUNDAY, SEPT. 9, 2012

The theme of this year's Patient Education Day is **"LIVING WELL WITH SCLERODERMA"**. Many of you commented that last year did not allow enough time for questions. We heard you! This year's presentations will be less formal and more interactive, allowing plenty of time for questions and answers.

We are excited to again be coordinating this event with Dr. Aryeh Fischer and National Jewish Health. We think you will agree that Dr. Fischer has helped us put together a great event!



The agenda is as follows:

10:30-11:00 am – Registration

11:00-11:45 am – Clinical Trials & Treatment Updates: Drs. Aryeh Fischer & Richard Nash

11:45 am-12:00 pm – Lunch Break (box lunch will be provided)

12:00 m-1:00 pm – Questions & Answers About Scleroderma: Drs. Aryeh Fischer, Jason Kolfenbach, & Julia Rhiannon

1:00-1:10 pm – Break

1:10-2:00 pm – Breakout Sessions:

- 1.) Patients – Dealing With Emotions of Living With a Chronic Disease & Relationship With Caregivers: Dr. Kristin Kilbourn
- 2.) Caregivers – Dealing With Life Style Changes & Issues of Caring For a Loved One: Allison Costenaro, MA, LPC

2:00-2:10 pm – Break

2:10-3:00 pm – Exercises for Strength, Energy, Flexibility, & Balance: Kimberly Sack, MS, PT & Chelsea Randall, MS, OT. Tools & Gadgets For Making Daily Tasks Easier: Martha Hansen.

The event will again be held at the Molly Blank Conference Center at National Jewish Health, 1400 Jackson St., Denver, 80206.

For more information or to request a registration form, please contact the Chapter at (303) 806-6686 or cbesselievre@scleroderma.org. Please register by August 24, 2012.

This program is made possible, in part, by an unrestricted grant from Actelion Pharmaceuticals, U.S.



Colorado Gives Day 2012

In the heat of summer, who wants to start thinking about the holidays? But December and the year-end giving season will be here soon enough. The Scleroderma Foundation-Rocky Mountain Chapter will again participate in the annual Colorado Gives Day on **Tuesday, December 4, 2012** (a 24-hour giving period for the benefit of Colorado non-profits). We hope you will participate in Colorado Gives Day and remember us in your year-end giving.



FORT COLLINS CITY PARK SUNDAY, SEPT. 30, 2012

The **2ND ANNUAL FORT COLLINS 2012 STEPPING OUT TO CURE SCLERODERMA 3K/5K WALK** at Fort Collins City Park is on Sunday, Sept. 30, 2012. Registration begins at 10:00 am and the Walk takes off at 11:00 am.

Join us as we complete laps around City Park Lake to raise awareness of scleroderma and money for research. Don't miss out on the fun and the chance to win some great auction items (this year will include both a silent and live auction)!

Our 2011 Fort Collins Stepping Out Walk was a huge success but we hope to top it this year with a goal of **200 WALKERS** and **\$20,000 IN PLEDGES**. Won't you help us reach our goal? Round up all your family and friends and ask them to walk with you as a team. Create an on-line fundraising page and share it by email, Facebook, and Twitter. Ask all those you share it with to also pass along the word. You may be amazed at the results if you just ask!

If you can't walk, will be out of town on Sept. 30, or have distant friends and relatives who would like to participate, register on-line for **FREE** as a **VIRTUAL WALKER** and still raise pledges to support this event. This "cyber" feature, new in 2012, allows us to spread support for this Walk outside the Fort Collins area and take this event nationwide and beyond!

Register, form a team and create your fundraising page online at www.firstgiving.com/scleroderma-co/2012-FC-SteppingOut. Or contact the Rocky Mountain Chapter for a brochure and mail-in registration form. **REGISTER BY SEPT. 14 FOR A \$5.00 DISCOUNT!**

RESULTS OF THE CHERRY CREEK STATE PARK STEPPING OUT WALK

Our 8th Annual Stepping Out to Cure Scleroderma 3K/5K Walk at Cherry Creek State Park, held on Saturday, June 16, 2012, was our biggest Walk to date. We had a record 285 walkers and raised over \$32,000 in support of scleroderma! Thanks to all our walkers, volunteers, and sponsors who helped make this event such a success. For many of you this has become an annual event for your family and friends but we also welcomed some new faces this year. We hope to see all of you again next year!

Don't forget that your on-line fundraising pages will remain active until September 15. So if someone promised you a pledge and hasn't delivered yet, let them know it is not too late!

Cyndy's Snippets

If you missed the 2012 National Patient Education Conference in Dallas in July, the Scleroderma Foundation has handouts available. Call the National office at (800) 722-4673.

Also, many workshops were videotaped. Stay tuned to National's weekly e-Letter to learn when these videos will be made available online.

Hope to see you at the 2013 National Conference in Atlanta!



ROCKY MOUNTAIN CHAPTER

2280 S. Albion St. · Denver, CO 80222



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/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 (and ask them about their matching programs).
6. Please remember us in your will or other plans.

(The Scleroderma Foundation is rated as a 4-Star Charity by the Charity Navigator. This is the highest rating awarded to charitable organizations that exceed industry standards and outperform other charities in their cause.)