

ROCKY MOUNTAIN CHAPTER NEWS

Spring 2016



12th annual "Stepping Out to Cure Scleroderma"

What's new? **New theme:** "Sole Mates"- think stepping out, soles and feet when coming up with your team names, outfits and accessories (most creative team wins a prize). **New location:** Centennial Center Park. **New kids' activities:** foot print painting, balloon twisting and face painting. **New trivia contest:** answer each question correctly and collect an item for your goody bag. **New incentive prizes:** reach levels of fundraising and receive a special gift.



Please join on us **Saturday, June 18** at **Centennial Center Park**. Sign up today at www.scleroderma.org/steppingoutdenver. Invite your friends by sharing on Facebook at www.facebook.com/steppingoutsclero. Together, we'll get one step closer to a cure for scleroderma!

Hard Word. Harder Disease.

The Scleroderma Foundation will again join forces in June with the Scleroderma Research Foundation and the Scleroderma Society of Canada to promote the scleroderma cause. Social media is the cornerstone of the campaign as we share messages about scleroderma and its impact. The website www.HardWord.org will be used as an easy place to learn about the disease and pledge to help others understand.

Throughout the month people will also be enlisted to share one last message on **World Scleroderma Day, June 29** through an effort called Thunderclap (www.thunderclap.it). One time, one message to thousands of friends and followers. The impact will be great as the message multiples through sharing.

Snooze for Scleroderma

breakfast Pot Pie, Ham Benedict III, Sammie's or Pancake of the Day – these are just a few of the yummy plates available at Snooze! To celebrate Scleroderma Awareness Month, Snooze will donate 10% of all sales to the Scleroderma Foundation on **Tuesday, June 14**. So don't sleep in too late – swing by Snooze on June 14 at 10002 Commons Street, Suite E1 in Lone Tree and order up a stack of your favorite pancakes or other breakfast treat!



Dr. Katharine Moore Joins Children's Hospital

Katharine Moore, MD has joined Children's Hospital Colorado as an Assistant Professor, Pediatrics. Dr. Moore's clinical interests include autoimmune diseases affecting children and adolescents. We welcome Dr. Moore as the newest addition to our Medical Advisory Board.

What's Happening

- June 18, 2016 – 12th annual "Stepping Out to Cure Scleroderma" Walk at Centennial Center Park.
- Sept. 7, 2016 – "Food Fight! Chefs Fighting for a Hard Disease" at BAC Appliance Center in Englewood.
- Sept. 11, 2016 – 6th annual Northern Colorado "Stepping Out to Cure Scleroderma" Walk at Fort Collins City Park.
- Oct. 16, 2016 – Patient Education Day. Location to be determined.

For more information, go to www.scleroderma.org/colorado or contact us at (303) 806-6686 or cochapter@scleroderma.org.



Tahani Rivers shares information about scleroderma at the 9Health Fair at Regis University in April. Thanks to Tahani and many other volunteers, we were able to host scleroderma information tables at more than twenty 9Health Fairs this year!

INSIDE THIS ISSUE:

Support Groups	2
Board Update – Do You Support Group?	2
Ariana's Story	3
Contact Us	4

Do You Support Group?

Web MD says “*Support groups are organizations of people who share a common disorder who meet together to discuss their experiences, share ideas, and provide emotional support for one another.*”

You may or may not have support from friends and family members. You may not think you need anything beyond what you have in place. I would just like to shed some light on how support groups can offer help that may be able to add to, or go beyond, what your inner circle is able to provide. The Scleroderma Foundation-Rocky Mountain Chapter offers support groups in Denver, Loveland, Colorado Springs, Grand Junction and has now launched a “virtual” support group that is a call-in meeting.

I was diagnosed with scleroderma in April 2011 and immediately sought out help. I found the Denver support group meeting and attended within the first few weeks of my bad news. The first thing I learned at my initial meeting was that I was safe; safe to share my anxiety, safe to cry and safe to open up. Then I filled myself with helpful information. Some of it came from printed materials, some from the presenter

that day and some invaluable information came from patients who have been there, done that! I saw people laugh, hug and smile. I was met with empathy but not pity. Truly, I was surrounded by warmth and acceptance.

Scleroderma is a disease that can manifest itself in many ways and varying degrees of severity. The one thing we all have in common is that none of us anticipated the struggles we would face each and every day. Making connections will help you feel less isolated and provide reassurance that you do not have to face the “s” word alone. The support groups have also helped my support people understand things that I may not convey well. I am blessed to have my husband, my sister, and a friend or two who may come with me to a meeting and share what they are experiencing as well.

For me, it felt like a natural transition to “give back” or “pay it forward” when I could by helping facilitate the Denver meetings. I have made so many lifelong friends through the Foundation and am very grateful. I encourage you to check out one of our support groups. If you are not in a position to come to a face-to-face meeting, the next call-in meeting is just around the corner!

Sandee Billen Maas
Board Member, Denver Support Group Leader

Support Group News

Support groups offer a friendly forum to meet others in your area living with scleroderma. Patients, caregivers, family and friends are all welcome. For more information, visit our website at <http://bit.ly/COSupport>.

“VIRTUAL” SUPPORT GROUP TELECONFERENCES

August 4, 2016 – Dr. Tracy Frech, Rheumatologist at University of Utah, will lead the call (topic to be announced).

Teleconference calls are from 7:00-8:00 pm. To participate call (712) 775-7031, enter call ID 781-611-035# when prompted.

MILE HIGH (DENVER) SUPPORT GROUP

May 14, 2016 – Heather Egermayer of Home Helpers will present on “In-Home Care or Community Care: Which is Best for You?”.

June 11, 2016 – Pre-Walk Rally and Picnic in the Park at Mamie D. Eisenhower Park, 4300 E. Dartmouth Ave., Denver, CO 80222 (corner of Colorado Blvd. and Dartmouth Ave.) **(NOTE: SPECIAL LOCATION FOR THE PICNIC.)**

July 9, 2016 – Dr. Thomas Hecker, Podiatrist, will discuss foot issues related to scleroderma.

August 13, 2016 – Mardi Gras Party and update on workshops presented at the 2016 National Patient Education Conference.

September 10, 2016 – To be announced.

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

SOUTHERN COLORADO SUPPORT GROUP

May 21, 2016 – Dr. Allison Nicklin, Physical Therapist, will present on the benefits of physical therapy.

July 16, 2016 – A presentation on the psychological challenges of scleroderma (speaker to be announced). **(NOTE: THIS MEETING WILL BE HELD IN THE VOLUNTEER CONFERENCE ROOM AT PENROSE HOSPITAL, 2222 N. NEVADA AVE., COLORADO SPRINGS, CO 80907.)**

September 17, 2016 – Update on workshops presented at the 2016 National Patient Education Conference.

Meetings are from 11:00 am-1:00 pm at Penrose Cancer Center, Room CC-A, 2222 N. Nevada Ave., Colo. Springs, CO 80907.

NORTHERN COLORADO SUPPORT GROUP

June 25, 2016 – Presentation by Bob Davidson and Aislinn Kottwitz from The Conversation Project.

August 27, 2016 – Update on workshops presented at the 2016 National Patient Education Conference.

Meetings are from 10:00 am – 12:00 pm at the Medical Center of the Rockies, Mt. Meeker and Arapahoe Peaks Rooms (lower level) 2500 Rocky Mountain Ave., Loveland, CO 80538.

WESTERN SLOPE (GRAND JUNCTION) SUPPORT GROUP

May 14, 2016 – Open discussion meeting to share your questions and concerns about scleroderma. **(LOCATION: STARVIN' ARVIN'S, 204 UTE STREET, DELTA, CO 81416.)**

July 9, 2016 – To be announced.

September 10, 2016 - Update on workshops presented at the 2016 National Patient Education Conference.

Meetings are from 11:00 am – 1:00 pm. Location to be determined.

Ariana Amoroso's Close Family Provides Her Scleroderma Support Network – Here is Her Story

Ariana comes from a large family of five children. She and a sister Cholena were born in Missouri; but the others were born in Alaska where the family moved for her parents to pursue a business opportunity when Ariana was 8 months old. Her mother, originally from Cairo, Egypt, started working for the Park Service when Ariana was in elementary school. The family eventually moved to North Dakota, then Colorado with her job. Ariana graduated from Highlands Ranch High School. She attended Metro State University where she received a degree in holistic health. Ariana worked in nursing homes and hospice starting while she was still in college. Most of her family, including her maternal grandmother and 2 uncles and their families, live in Denver. They are all very close and get together for a big family dinner at least once a week.

Ariana met her future husband Jason when she crashed a date that her sister was on with his friend. She and Jason have been married for almost 5 years and have 2 kids: 14 year old Haven whose hobbies include her iPhone, friends, shopping and playing with her younger sister; and 3 year old lyla who loves animals, family and playing with her older sister too. Jason works as a business analyst for Motorola.

Ariana's symptoms started right before her pregnancy with lyla. Her first symptom was the start of Raynaud's Phenomenon. Her hands and forearms were painful and swollen. She couldn't get her bracelets on or off. Then she found out she was pregnant and thought this was normal. But soon she realized it was something more than that when she tried to go up just 5 stairs one day and was too tired, stiff and sore with painful feet to make it to the top.

A friend suggested she see a rheumatologist because of the Raynaud's. Ariana was first diagnosed with mixed connective tissue disease and lupus. She was put on Prednisone. Because she was 20 weeks pregnant at the time, she was considered high risk which meant lots of appointments and tests. Ariana was weaned off Prednisone before lyla was born and she felt really well for the 2 months after lyla's birth. But then the swelling and flare ups returned. In February 2013, Ariana was diagnosed with scleroderma by Dr. Aryeh Fischer.

Ariana has diffuse systemic scleroderma. She has slight lung involvement so she is not on any medications at this time. Like most people with scleroderma, she has acid reflux which she treats with Omeprazole. The spring and fall are very hard on her Raynaud's but no medications seem to help so she isn't currently taking anything for it. Her fatigue is getting better. The skin on her hands and arms has improved but feels tighter on her face, chest and torso. Her symptoms come in waves; she feels fine for a year then has 2-3 months of feeling limited again.

Early on in her diagnosis, Ariana had 6 rounds of Cytoxan. However, she didn't think it was doing enough to justify the



side effects including fatigue and stomach pain. She would have 3 weeks of side effects and one good week before she would have to go back for the next round of treatment. Ariana doesn't seem to tolerate many of the treatments well so today she is only taking medication for acid reflux.

Being diagnosed with scleroderma has brought on many changes in Ariana's life. She had to quit her job. She was in and out of the car, in constantly changing temperatures and an overall stressful work environment that attributed to her pain and fatigue. She analyzed the chemicals in her house and now makes many of her own cleaning and body care products. She has become more conscious of what she eats (she tried a gluten-free diet but it didn't make much of a difference). She learned exercises from a physical therapist and an occupational therapist that she now does at home (but mostly her young girls help her to stay active and moving). The disease really impacts day to day living but she has learned to adjust. She has acquired tools to help in the kitchen and with housecleaning, many of which have filled her Christmas stocking the last few years!

Daughter Haven was 11 years old when Ariana was diagnosed. It took her a long time to sit down with Haven and talk about scleroderma because Ariana was scared of the questions she might ask. It is normal to Haven now and she really pitches in to help Ariana with opening water bottles or getting things down from the shelves.

Ariana recommends to anyone newly diagnosed to find a doctor you trust, that you can talk to who listens and who knows about scleroderma and how to treat it. Find a support network that works for you whether that is family, support groups, friends or church. She is grateful to have such a close family that supports and helps her. She also recommends going to counseling to help deal with the emotional ups and downs. Ariana spent the first year waiting for the Grim Reaper. It affected her marriage and relationships with friends. It was hard to learn how to ask for help and often she wasn't getting the help she needed. She learned to accept how some people want to help with prayers or healthy recipes as just sending good vibes her way; but she has also learned to tell people what it is she really needs from them.

Ariana hopes to have one more child, and get more involved with the Scleroderma Foundation by spreading awareness and fundraising. 2015 was her first "Stepping Out" Walk and the first time she made many friends aware of her disease. She raised over \$2,800 that was doubled by Motorola's employer matching donation! She will be walking again this year on June 18 with her extended family and friends.



ROCKY MOUNTAIN CHAPTER

2280 S. Albion St. · Denver, CO 80222

*The Scleroderma Foundation-Rocky Mountain Chapter thanks **Rising Graphics + Printing of Evergreen** for their assistance with producing our quarterly newsletter.*

Special 10% Discount on Glider Gloves

If you have Raynaud's, you know that gloves aren't just for winter. You know that a cool breeze in the summer or going to the grocery store any time of year can bring on a Raynaud's spasm. That's why you carry gloves with you year round. But it doesn't help if you have to remove those gloves to use your mobile device.



Glider Glove touch screen gloves can help. These gloves allow you to interact with a screen with your gloves on so your hands stay warm. Take advantage of a special 10% discount on Glider Gloves when you shop online at www.glidergloves.com and use the promo code **GGSF10** to receive your discount. Stay connected and protected!

(The Scleroderma Foundation in no way endorses any products, drugs, treatments, clinical trials, or studies. Information is provided for educational purposes only.)

How To Donate

1. "Step Out" and walk with us on June 18! www.scleroderma.org/steppingoutdenver
2. 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. You can also learn on our website about donating your cars and used cell phones.
3. Check with your employer about payroll deductions for donations (and ask them about their matching programs).
4. Create a legacy by planned giving or remembering us in your will. Get started at sclerodermafoundation.myplannedgift.org.

Contact Us At...

Scleroderma Foundation
Rocky Mountain Chapter
2280 South Albion St.
Denver, CO 80222
(303) 806-6686
cochapter@scleroderma.org

Follow Us At...

www.facebook.com/COScleroderma
www.twitter.com/SclerodermaCO

Or Meet Others At...

www.inspire.com/groups/scleroderma-foundation

