

ROCKY MOUNTAIN CHAPTER NEWS

Winter 2016



Rare Disease Day 2016

2016 marks the ninth year that the international rare disease community celebrates Rare Disease Day. On Feb. 29, 2016, people living with or affected by a rare disease, patient organizations, medical professionals and researchers will come together to raise awareness of rare diseases. The Rare Disease Day 2016 slogan, "Join us in making the voice of rare diseases heard", recognizes that people living with a rare disease and their families are often isolated. The wider community can help to bring them out of this isolation. Learn more and share your story about living with scleroderma and the impact on your family at www.rarediseaseday.org.



2016 National Conference Scholarships



The Scleroderma Foundation 2016 National Patient Education Conference will be held in New Orleans from July 29-31. This year's theme is "Unmask the Cure". If you haven't attended a Conference before, it is a learning experience you won't want to miss, as well as an opportunity to make many new friends. If you are in need of financial assistance to attend, you may be eligible to apply for a scholarship from the Scleroderma Foundation. The deadline to apply is March 17.

Learn more at www.scleroderma.org and click on "Attend Conference". You may also qualify for reimbursement from the Rocky Mountain Chapter. Please contact the Chapter at 303-806-6686 or cochapter@scleroderma.org for more information.

Newly Diagnosed Patient Packets

If you or someone you know has recently been diagnosed with scleroderma, we have new patient packets that may be helpful to you. The packets include information and resources about the disease and where you can find support and treatment. Please contact the Chapter at 303-806-6686 or cochapter@scleroderma.org to request a packet.

Chapter Awarded IICF Grant

Late in 2015, the Chapter received notice that we were awarded a \$10,000 grant from the Insurance Industry Charitable Foundation (IICF). The grant funds will be received this month and will be used to reach out to more patients and provide informational and educational materials to healthcare professionals in the Rocky Mountain area. This grant was by invitation only. Thank you Charles Littler, Ami Pearl and Arthur J. Gallagher & Co. for recommending the Chapter for this grant!

What's Happening

- April 2016 – 9Health Fairs located throughout the state.
- June 18, 2016 – 12th annual "Stepping Out to Cure Scleroderma" Walk at Centennial Center Park.
- Sept. 8, 2016 – "Food Fight! Chefs fighting for a hard disease" at BAC Appliance Center in Englewood.
- Sept. 11, 2016 – 6th annual "Stepping Out to Cure Scleroderma" Walk at Fort Collins City Park.

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



Spreading scleroderma awareness at the 2016 Rocky Mountain Dental Convention in January attended by 9,000 dentists, hygienists and dental students.

INSIDE THIS ISSUE:

Support Groups	2
Board Update	2
Aurora's Story	3
Contact Us	4

Chapter Board Update

I would like to introduce you to our new Chapter Manager, Andrea Ofiesh, who started in January. Andrea has event planning and non-profit experience, and will be a great asset to the Chapter. Please join me in welcoming her. She will be working alongside Cyndy Besselievre, our Executive Director.

We had our first board meeting of the year and we are on target financially. We are looking forward to a great year of fundraising in order to provide support to our members.

The dates for our fundraisers have been set, so mark your calendars! The Denver Walk is on June 18 at Centennial Center Park – the theme is “Sole Mates”. This is the 12th annual and the activities will revolve around the number 12. There is no entry fee to the Park and the layout will allow for lots of entertainment and fun for kids of all ages.

The Northern Colorado Walk will be held on September 11 at the same location – City Park in Ft. Collins. This is always a nice time in the fall! More information to follow as is available.

The “Food Fight!” chef challenge will be held on September 8

at the BAC Appliance Center. We are excited to host this event at the same fabulous location again this year. We already have chefs who want to participate and we are looking forward to a great foodie event.

We are always in need of volunteers, both on the day of these events and on the planning committees. If you would like to help, please contact Andrea at 303-806-6686 and she will let the committee chairs know you are willing to assist.

The calendar is filling up for our 2016 support group meetings! There are some great speakers lined up for the year ahead. So, come out and participate; the meetings are informative and fun. We are in search of a leader for the Southern Colorado (Colorado Springs) group. The leader for the Western Slope (Grand Junction) group needs an assistant or co-leader. Anyone in either of those areas who would like to fill this need, please contact Cyndy at 303-806-6686 to offer your services.

We appreciate this community’s support and look forward to a great year!

Deanna Ragsdale,
Chapter Board Secretary

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>.

MILE HIGH (DENVER) SUPPORT GROUP

February 13, 2016 – MELT Method presentation by certified instructor Juan Flores.

March 12, 2016 – Mona Rodriguez Merrick, a certified Holistic Health Coach and Pilates Instructor will present on “Empowerment Through Small Changes” – how to make healthy changes that are as unique as you are.

April 9, 2016 – A presentation on disability benefits and the Colorado Disability Benefits Support Program.

May 14, 2016 – To be announced.

June 11, 2016 – Pre-Walk Rally and Picnic in the Park (location 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.

SOUTHERN COLORADO SUPPORT GROUP

March 19, 2016 – Dr. Paul Menard-Katcher, Gastroenterologist at UC Hospital, will present on GI Manifestations in Scleroderma.

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

Meetings are held in odd numbered months from 11:00 am – 1:00 pm at Penrose Cancer Center, Room CC-A, 2222 N. Nevada Ave., Colorado Springs, CO 80907.

NORTHERN COLORADO SUPPORT GROUP

February 27, 2016 – Patricia Kuyper, an Occupational Therapist at UCHealth, will discuss benefits of OT for scleroderma.

April 23, 2016 – Leeann Rogowski, a Physical Therapist at Orthopedic and Spine Center of the Rockies, will present on hand therapy for scleroderma.

June 25, 2016 – Presentation by The Conversation Project (tentative).

Meetings are held in even numbered months 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

March 12, 2016 – To be announced.

May 14, 2016 – To be announced.

Meetings are held in odd numbered months from 11:00 am – 1:00 pm. Location to be determined.

Aurora's "Attitude Adjustment" Helps Her Cope With Scleroderma – Here is Her Story

Aurora was born in Denver, CO. She spent half her childhood in Conifer and the other half in Buena Vista. She lived all over Colorado before settling in Colorado Springs where she graduated from Pikes Peak Community College with a paralegal degree. Her first job in this field was in Parker in 2010 and she worked for several law firms learning different types of law before getting laid off in August 2015. After looking for work for several months, Aurora accepted a new job in early January at First American Title Insurance Company where she is a claims specialist. She helps with processing files and claims processing – a nice change from working at private law firms.

Aurora has two kids who are both into the computer game Minecraft. Alex, 12, attends the STEM School and Academy where he is studying science, technology, engineering and math (needless to say, he is a whiz at computers). Caylie turns 9 this month. She attends Summit View Elementary. She likes gymnastics, ballet and loves to dress up and dance. They all enjoy spending time together with family, watching movies, playing games and visiting the local museums.

In the spring of 2011, Aurora's fingers suddenly lost all color when she got cold. It came on very quickly; her fingers were normal one day and completely white one week later. Fortunately a doctor recognized this as Raynaud's phenomenon and immediately ordered blood tests which lead to an initial diagnosis of CREST. She was also diagnosed with celiac disease in 2011.

The next 4 ½ years were devastating for Aurora and her family as they tried to learn more about the diagnosis and confirm the type of scleroderma that she actually had. She did her own research but in 2011 there was not a lot that she could find on her own. In the fall of 2015, Aurora saw Dr. Aryeh Fischer at the University of Colorado Hospital (UCH) for the first time and was told she had systemic sclerosis but without much skin involvement. Aurora previously had lung and heart tests but didn't feel that the doctors knew what they were looking for. She is now going through all the testing again to determine a baseline for the future. Given the type of scleroderma that she has, her biggest risk is pulmonary hypertension but her tests look good for now! She will soon be seeing a pulmonologist and gastrointestinal specialist at UCH to help get her on the right track to proper treatment for her scleroderma symptoms.

Once the above tests are done, the next focus will be her celiac disease. Like most scleroderma patients, Aurora has acid reflux but the medications she has been taking for this seem to be helping. She also has difficulty swallowing so will soon have a scope and other tests to explore the problem.

To control the celiac disease, Aurora went gluten free in 2011. She has also eliminated (well, except for rare occasions) dairy and most carbohydrates. The list of what she can eat is shorter than the list of what she can't: fresh fruits and vegetables (except those with lots of



carbohydrates like potatoes and broccoli); fish and occasionally chicken or lean beef. Sticking with this diet makes her feel better, sleep better and experience less joint pain. She also exercises 3-5 days every week with cardio, strengthening and light stretching. The diet and exercise help her get up each day without feeling miserable. Otherwise she has aches, pain and swelling that leave her feeling cranky, or worse, according to the kids! Aurora is aware of the limitations on her body now. She knows she has to eat right, not stay up too late and not push too hard.

Like many people newly diagnosed with scleroderma, the first information she read on the internet was not very hopeful. This forced her into doing a lot of soul searching. She worried about how she would continue to work and raise her kids. She felt doomed. But she has made it through those first 5 years! She knows she is still at risk but feels this is her second chance to do things better. It made her realize the importance of her family and kids. She has had to depend on them which has brought them all closer together.

Over the past year, Aurora has discovered that whether it is going to be a good day or a bad day has a lot to do with her attitude. She has learned to control her stress because otherwise she gets flare ups that last a long time. The first thing she does every morning is drink a big glass of water to rehydrate, stretch, take a warm bath, read scriptures and pray to be thankful for what she has. She tries to leave the house every morning and return every evening with a smile on her face. She is taking the time to see the good when things aren't always going well.

Aurora likes to learn and would like to someday return to school to study fitness and nutrition to better help herself and others. Her dream is to earn a degree in physics from the Colorado School of Mines.

Aurora recommends to someone newly diagnosed with scleroderma to hang onto hope; know that there are people who can help you and help you help yourself; research; find the right doctors; reach out – don't do it alone and don't withdraw; build a support network of people to turn to for answers and to be there when you are feeling depressed. She also recommends attending your local Scleroderma Foundation support group meetings. The support group has helped her learn she is not struggling alone and is a source of information. It is here that she was connected to Dr. Fischer and is finally receiving the care and treatment she needs.

Although scleroderma has changed her life, Aurora feels she is back on track knowing what to research and who and what to ask to maintain her health.



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.*

Volunteers Needed For 9Health Fairs

Every spring, 9Health Fairs at locations throughout the state offer free screenings and health information to tens of thousands of Coloradans.



These health fairs are a great opportunity to spread awareness of scleroderma and you can help by hosting a scleroderma information table at a location near you. We will provide all the materials and training needed. It just takes ½ day of your time to make a difference!

Most fairs are in April with a few in late March and early May. Go to www.9healthfair.org to find a fair or contact our Chapter at 303-806-6686 or cochapter@scleroderma.org for more information.

How To Donate

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. 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 <http://bit.ly/SFGiftPlan>.

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

