



Virtual "Real Talk" Support Group Webinars

Please join us for a 4-week stress management skills training "virtual" support group. Participants will learn about how to manage stress using cognitive-behavioral strategies, relaxation and effective coping strategies. The trainings will take place on the following Thursdays from 7-8 p.m. MST: 2/7, 2/14, 2/21 and 2/28 and will be co-facilitated by Alaina Carr, MA, and Sydneyjane Roberts, MA, both Doctoral students in the UCD Clinical Psychology Program, under the supervision of Kristin Kilbourn, Ph.D, MPH. Join each session at the designated time either: 1) by computer: go to <https://join.me/coscleroderma>, enter your name and request to join or 2) by phone: (or if your computer has no audio) call 302-202-5900, enter conference ID 947-770-935.

Save the Dates for Stepping Out in 2019

Stepping Out to Cure Scleroderma Walks are the foundation's annual signature fundraising event with many walks nationwide. Each year, this event helps raise important funds to support and educate patients, raise awareness and fund research to ultimately find a cure for the disease. Last year alone, you raised over \$60,000 for the chapter and this year we're excited to raise even more. Come "be part of the cure"! Start a team to fundraise and help us reach record level donations this year.



SAVE THE DATES! Saturday, June 8 at Fort Collins City Park and Saturday, June 15 at Centennial Center Park.

Event registration is coming soon. If you would like to volunteer for either of the walks, please contact Carol Walsh at (303) 570-5820 or email cwalsh@scleroderma.org.

National Patient Education Conference

The 2019 National Patient Education Conference will be held from July 19-21 in Chicago, IL. The conference features numerous workshops covering many aspects of the disease and living with scleroderma for patients and caregivers, updates on research and treatments, and a program for just kids and teens with scleroderma.

To learn more about the conference, visit the foundation's website at scleroderma.org.



Scholarships are available to chapter members to attend the conference. For more information, go to scleroderma.org/colorado. The deadline to apply for a chapter scholarship is Friday, April 19, 2019.

What's Happening

- **June 8, 2019** – 9th Annual Northern Colorado Stepping Out to Cure Scleroderma Walk, Fort Collins City Park
- **June 15, 2019** – 15th Annual Stepping Out to Cure Scleroderma Walk, Centennial Center Park
- **July 19-21, 2019** – National Patient Education Conference, Chicago, IL
- **Sept. 18, 2019** – Food Fight! Chefs Fighting for a Hard Disease, BAC Appliance Center

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



Board member Marcy Thompson hosts the scleroderma information table at the Rocky Mountain Dental Convention in January 2019

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Board Update

As we begin 2019 our Colorado chapter Board of Directors would like to take the opportunity to share information about changes and opportunities for this year.

CHANGES

It is with great respect and sadness that we share the retirement of our Executive Director, Cyndy Besselievre. Cyndy has been leading our chapter for over eight years and in her tenure, she has brought leadership, strength, growth and persistence for success within our chapter and at the national level. Now, because of her passion for building awareness about scleroderma she will continue to support the chapter as a Board member – so she isn't going too far!

As many of you know, our chapter shares office space with a few other organizations and if you have been to our office in the last year you have noticed the new construction in the area. Therefore, we have decided to move to a new location. In March we will be moving to near Evans and Holly. We will be sending out more information as we get closer to our move.

OPPORTUNITIES

With Cyndy's departure we took the opportunity to evaluate

the operations of the chapter and we have decided to hire an additional staff person for support to our patient community and events.

With hiring an Executive Director as well as an Office Administrator, if you or someone you know would be interested in either of these positions, please go to our website for job descriptions or connect with Gloria Price, Board President at gprice@scleroderma.org.

Is this the year to connect more with our scleroderma community? If the answer is YES today or in the future, then we would be happy to talk about volunteer opportunities. We are looking for event volunteers and have a variety of opportunities with our three fundraising events as well as our fall Patient Education Day event. For information, please contact Carol Walsh at cwalsh@scleroderma.org

Thank you all for your continued support of our mission.

Gloria Jara Price
Chapter Board President

Support Group News

Patients, caregivers, family and friends are all welcome. For more information, visit our website at <http://bit.ly/COSupport>.

"REAL TALK" VIRTUAL SUPPORT GROUP

February 7, 14, 21 & 28, 2019 – 4-week stress management skills training co-facilitated by Alaina Carr, MA and Sydneyjane Roberts, MA, both Doctoral students in the UCD Clinical Psychology Program.

May 9, 2019 – Presentation on the disability process hosted by Lyndsey Ellis, Allsup.

Meetings are from 7:00-8:00 p.m. To join by computer, go to <https://join.me/coscleroderma>. To join by phone, call 302-202-5900, enter conference ID 947-770-935.

MILE HIGH (DENVER) SUPPORT GROUP

February 9, 2019 – Sarah Funk, RD, CNSC, clinical dietitian specialist at UC School of Medicine will discuss diet and scleroderma.

March 9, 2019 – Sara Palecki, a certified yoga instructor, will present on Yoga Nidra.

April 13, 2019 – To be announced.

May 11, 2019 - To be announced.

June 8, 2019 – Annual support group picnic! Details to be announced.

Meetings are from 11:00 a.m.-1:00 p.m. at the Arthritis Foundation, 2280 S. Albion St., Denver, CO 80222. (NOTE: STARTING WITH THE MARCH 9, 2019 MEETING, MEETINGS WILL BE HELD AT 5403 E. EVANS AVE., DENVER, CO 80222.)

SOUTHERN COLORADO SUPPORT GROUP

March 16, 2019 – View and discuss a video from the 2018 National Patient Education Conference titled "Taking Care of Your Hands and Face" by Janet Poole, PhD, OTR/L.

May 18, 2019 – To be announced.

Meetings are from 11:00 a.m.-1:00 p.m. at Penrose Cancer Center, Room CC-C, 2222 N. Nevada Ave., Colo. Springs, CO 80907.

NORTHERN COLORADO SUPPORT GROUP

February 16, 2019 – "Tips for Being an Empowered Patient" presented by Dr. Patricia George, Nation Jewish Health. This event is sponsored by Actelion Pharmaceuticals, lunch will be provided. **(NOTE: DIFFERENT DATE FOR THIS EVENT!)**

April 27, 2019 – Amanda Mixon, PA-C, Arthritis & Rheumatology Clinic of Northern Colorado will present on Symptoms and Treatments for Scleroderma.

June 22, 2019 – To be announced.

Meetings are from 10:00 a.m.-12:00 p.m. at the Medical Center of the Rockies, Arapahoe Peaks and Mount Meeker Rooms, 2500 Rocky Mountain Ave., Loveland, CO 80538.

WESTERN SLOPE (GRAND JUNCTION) SUPPORT GROUP

March 9, 2019 – To be announced.

May 11, 2019 - To be announced.

Meetings are from 11:00 a.m.-1:00 p.m. at Community Hospital, Legacy 1 Room, 2351 G Road, Grand Junction, CO 81505.

Scleroderma Has Brought Rena and Nate Closer Together

Rena Tullos grew up in Indianapolis, IN and moved to Colorado for her Dad's company when she was a senior in high school. She graduated from Overland High School and went on to study business at UNC Greeley. She took a business law class and loved it so much that she changed her major. She finished college at Metro State with a degree in criminal justice. She has had many jobs over the years but has worked for Otten Johnson for the last four years as the legal billing and accounts receivable administrator for 45 attorneys.

Rena met Nate at a bowling alley where she worked as a lane server. They have been together for ten years and just tied the knot in May 2018.

Rena had 28 teeth pulled for implants in 2017. A few weeks later in March 2017 the skin on her arms started hardening, turned red and became itchy. It came on so suddenly that she thought she had the flu. It all started at the vet's office where she passed out which she attributed to not eating. The next morning her right arm looked like a tree trunk. She went to Parker Adventist where they thought she was having a heart attack. The hospital did not have a rheumatologist on staff but a very alert nurse in the emergency room told the doctors what to test for.

The results were sent to UHealth where Dr. Jason Kolfenbach diagnosed Rena with scleroderma sight unseen. Rena believes that the trauma from having so many teeth pulled may have been what triggered the onset of scleroderma.



Like most people newly diagnosed with scleroderma, Rena's first reaction was "sclero-what"? She immediately went on line and found the Denver support group and support group leader Sandee Maas, who helped Rena find some answers. Whether Rena has limited or diffuse scleroderma remains up in the air. Her ANA markers are not conclusive. Her symptoms came on very fast and have since stopped. She knows that no one with scleroderma is the same and thinks that maybe her quick diagnosis and treatment has helped slow the symptoms. The most important lesson she learned is to listen to your body and to not accept "we don't know". She feels very fortunate to have found the UHealth scleroderma clinic where she is now treated by Dr. Aryeh Fischer who is well known and respected within the scleroderma community. She knows she can rely on him and trust him.

Today Rena is doing much better. She continues to bowl and works a second job in accounting besides her full time job at Otten Johnson. Her skin is much better. Her skin score has improved from a 41 in May 2017 to now an 8! She is in the Corbus Pharmaceuticals Phase III study for lenabasum. It is a

blind study so she doesn't know if she is on the placebo or the medication itself. Of course this time of year, her Raynaud's is worse but is not as severe thanks to medication. She has acid reflux and GERD. She may need her esophagus stretched. She has mild lung involvement but is not currently on any lung medication. She has a base line that Dr. Fischer is monitoring. She has small crackles in her lungs but no significant change in two years. Her energy level is better. She is not so exhausted and feels like she can get out more to do the things she enjoys (shopping!) on the weekends instead of always just resting.



Rena has always been extremely independent but scleroderma has forced her to adjust. She still struggles with asking for help but she is learning. It has strengthened her relationship with Nate. Because she has always done things for herself but now needs Nate more, he also had to learn how to be supportive, sympathetic and understanding. He is now more alert when she needs help, even if she doesn't ask for it. Before Rena was diagnosed with scleroderma, she and Nate were living together, doing their own thing and were happy. But the diagnosis forced them to step back, take a look at life and reflect on what is important. Rena told Nate that he didn't sign up for this because he is 10 years younger than her; but it has made them stronger together. They have learned to be more vulnerable with each other. Nate let Rena know he is in it for the long term which is why after ten years together, they decided to get married last year. Rena feels blessed to have Nate, his Mom, their close-knit group of friends and all those at Otten and Johnson who have been so very supportive of her over the last two years.

Rena recommends to someone newly diagnosed with scleroderma to find an excellent team of doctors, pay attention to your body and know that you are not alone. Find the best practice that works for you and don't let scleroderma define who you are. Scleroderma is a piece of who Rena now is, but she has learned to manage her life and live with it.

Rena is looking forward to 2019 including a bowling tournament with Nate in March in Las Vegas, a cruise to the Caribbean in September and the end of the Corbus clinical trial in August when the medication will become available. Last year she was planning her wedding, but this year she plans to go all out for the Denver "Stepping Out" walk in June! She will help on the planning committee and will be walking with her team by inviting her friends and coworkers to join her by sending them all her own "Save the Date" card. She continues to make others aware of scleroderma at every opportunity because knowledge is power – more knowledge, more money, more research!



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.*

Giving a Little at a Time

If making a one-time lump sum donation isn't convenient for you, there are other options that may fit better within your monthly budget.

You can make sustaining (recurring) donations securely through the Scleroderma Foundation Rocky Mountain Chapter website at scleroderma.org/colorado by clicking on the "Donate Now" button. You select the amount that is comfortable for you, whether you'd like to the donation to occur monthly or quarterly and for how long you would like the donation to recur.

Your employer may offer the opportunity to make regular payroll deductions to the Scleroderma Foundation that are automatically deducted from your paycheck. Many employers will also match all or a portion of these donations. To get started, check with your employer's HR department.

The Scleroderma Foundation accepts gifts of appreciated property. For more information contact Deb Pearce at dpearce@scleroderma.org.

Smaller recurring donations add up and make a significant difference to give hope to those affected by scleroderma. Get started today!



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 securely and safely on-line at scleroderma.org/colorado. Consider making a recurring monthly or quarterly donation.
3. Ask your employer about matching donations.
4. Create a legacy by planned giving or remembering us in your will. Get started at sclerodermafoundation.myplannedgift.org.



Contact & Follow Us...

Scleroderma Foundation
Rocky Mountain Chapter
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