



“Real Talk” Virtual Support Group

Please join us on **Thursday, November 9 from 7:00 - 8:00 p.m.** for our “Real Talk” virtual support group teleconference! This call will be open discussion. You will have the opportunity to chat with others with scleroderma and ask your questions. If you live in a remote area of Colorado or if you are too sick to travel to a meeting, this is a perfect occasion for you to meet others who can relate to what it is like to live with this disease.



To participate, call **(712) 775-7031** and enter access code **781-611-035#**.

Patient Education Day Sessions on YouTube



If you missed our recent Patient Education Day in September, or would like a refresher of the sessions presented, then be sure to check out the videos from this event on YouTube at youtube.com/COScleroderma.

Recorded sessions include an update on scleroderma research and clinical trials; management of arthritis, Raynaud’s and digital ulcers in scleroderma; a naturopathic approach to autoimmune and healing; palliative and nursing care; and a doctor/patient panel.

You Can Participate in Studies to Advance Research

Several new and ongoing lung studies are open or soon enrolling through the Scleroderma Clinic at UHealth to further research related to scleroderma associated PAH and ILD. To learn more or participate, contact Mallery Crow Adams at mallery.crowadams@ucdenver.edu. Children’s Hospital Colorado is partnering with the Childhood Arthritis & Rheumatology Research Alliance (CARRA) to study outcomes of children and adolescents with rheumatic diseases. Contact Katharine Moore, MD at Katharine.Moore@childrenscolorado.org for more information.

Please Support Scleroderma on Colorado Gives Day

Over the next month we’ll share more about Ken (see page 3) and introduce you to others in Colorado with scleroderma. Their strength and courage is amazing. By supporting the Scleroderma Foundation-Rocky Mountain Chapter on **Colorado Gives Day, Tuesday, December 5**, your donation will help us continue to provide the education and programs needed to help these and other patients thrive.



What’s Happening

• November 9, 2017 – “Real Talk” Virtual Support Group Teleconference.

• December 5, 2017 – Colorado Gives Day at coloradogives.org/rockymntscleroderma.

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

Guests enjoyed many delicious tastes and sips at the “Food Fight!” on Sept. 13 at BAC Appliance Center.



Lots of fun, in spite of the cold and rain, at the 7th annual Northern Colorado “Stepping Out to Cure Scleroderma” Walk and Fall Festival on Oct. 1 at Fort Collins City Park.



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Why Join A Non-Profit Board?

Hi, my name is Marcy Thompson. I recently joined the Rocky Mountain Chapter's board as Treasurer.

In January of 2017, Cyndy Besselievre invited me to attend a chapter board meeting. They had recently lost their Treasurer and since I was in banking, Cyndy thought I might be a good fit. Cyndy's timing couldn't have been better. I had recently served short term on other boards but currently was not involved. I began to feel like my life was missing purpose; I desired to find a way to give back to my community. I hesitantly agreed to attend one board meeting. My intent was to learn more about scleroderma primarily because my current employer often sponsored their fundraising events. I truly had no intentions of being on a non-profit board and was almost sure that I would attend one meeting and that would be the end of it.

However, the moment I entered the meeting room the exact opposite happened. I was immediately welcomed by the most caring and dedicated group of women I have ever met. The current board members educated me with their own heartfelt scleroderma stories and then conducted a professional and productive meeting. I instantly felt a connection and wanted to help. They guided me through the process and helped me evolve into my role as Treasurer.

If you have ever thought of joining a board, I want to encourage you to attend a couple of meetings. There is no upfront commitment to simply check it out.

While board positions do require some pledge of your time, the great thing about a non-profit board is that it also allows you to volunteer around your life. I found our scleroderma board very accommodating. You may also experience other life enhancements such as:

- *Enjoy an experience that enriches your resume.*
- *Meet interesting people who will add to your sphere of influence. People who join boards are a wonderful breed. You will be enriched by being in their company.*
- *Connect with your community from a much more strategic position.*
- *Be exposed to research and education about the things you're passionate about. You can learn a lot in terms of both content areas and how an organization functions.*
- *Gain different skill sets. Board service involves decision making, facilitating group process, governance, financial management, marketing and branding—all skills you can develop and apply in your professional or personal life.*
- *Leave the world a better place than when you arrived. Serving on a non-profit board is an opportunity to leave a legacy.*

One of our current board objectives is to increase our board membership. I hope that if you are seeking to do more for scleroderma, you will consider volunteering on a committee or even becoming a board member. Thank you for allowing me to serve. I am honored to be a part of this organization.

Respectfully,
Marcy Thompson

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 TELECONFERENCES

November 9, 2017 – Open discussion to address callers' issues and questions related to scleroderma.

February 8, 2018 – To be announced.

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

MILE HIGH (DENVER) SUPPORT GROUP

November 11, 2017 – This month we'll take a break from speakers to allow more time for open discussion among the group.

December 9, 2017 – Holiday party!

January 13, 2018 – Kimberly Ann Ward, LMT, CHHC, will present on "Is Leaky Gut and Stress Affecting Your Scleroderma?"

February 10, 2018 – To be announced.

March 10, 2018 – Actelion Pharmaceuticals US, Inc.'s Rizwan Quader will present on "FAQ's about PAH".

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

SOUTHERN COLORADO SUPPORT GROUP

November 18, 2017 – Holiday luncheon at Edelweiss Restaurant, 34 E. Ramona Ave., Colorado Springs, CO 80905. **NOTE:**

DIFFERENT LOCATION FOR THIS EVENT!

January 20, 2018 – To be announced.

March 17, 2018 – To be announced.

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

December 2, 2017 – Holiday luncheon at 11:00 am at The Moot House, Garden Room, 2626 S. College Ave., Fort Collins, CO 80525. **NOTE: DIFFERENT TIME AND LOCATION FOR THIS EVENT!**

February 24, 2018 – To be announced.

Meetings are from 10:00 am-12:00 pm 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

November 11, 2017 – Dana Armstrong, Massage Therapy Program Instructor at CO Northwestern Comm. College, will present on massage and pain management. Dana's students will be on hand to give free chair massages as part of this holiday event!

January 13, 2018 – To be announced.

March 10, 2018 – To be announced.

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

ALBUQUERQUE/RIO RANCHO, NM SUPPORT GROUP

This group meets on the 2nd Saturday of even numbered months from 1:00-3:00 pm at Flying Star Café, 10700 Corrales Road A, Albuquerque, NM 87114. For more information, please contact Anna Wenger at 505-974-9293 or annawenger91@gmail.com or Theresa Johnson at 520-248-2235.

Do Your Best Moving Forward Says Ken Urban – Here is His Story

Ken Urban grew up in Chicago; but not being a city person, he moved to California in his early twenties. While on a trip with buddies to Keystone Resort after a day of skiing, Ken decided that he was moving to Colorado. Five years later he met Sheila with whom he has now been married to for 11 years. Sheila works for Denver Parks and Recreation and followed her brother to Colorado after growing up in a small town in Iowa. Before the onset of scleroderma, Ken worked for a software company and he and Sheila truly loved the outdoors. They often enjoyed hiking, camping, skiing and snowboarding, backcountry skiing, and taking along their dogs whenever possible.

Ken was diagnosed with scleroderma in March 2016, just about four months after his symptoms started while on a backcountry ski trip. Ken's hands went completely numb and turned white and he was experiencing severe fatigue unlike he had ever experienced before, even as a marathon runner. He realized something was wrong and immediately



contacted his doctor who after hearing Ken's symptoms, suggested it could be scleroderma and referred him to a rheumatologist. Sheila noticed that Ken's cuticles had changed. Her research indicated that this was scleroderma and he ended up getting diagnosed a few short months later. Looking back, Ken realizes that he had a lot of fatigue the year before his diagnosis

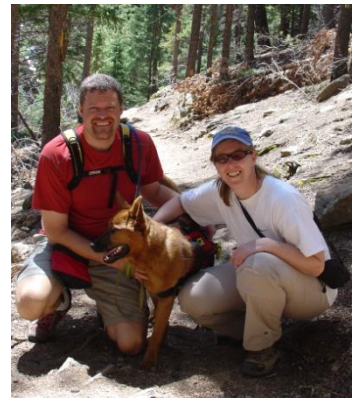
but he also has hypothyroidism so he attributed it to that.

In addition to Raynaud's, Ken had swollen and painful extremities and quickly experienced rapid mobility loss as well as tightening of his skin. Ken and Sheila found the Denver support group online and attended their first meeting in June 2016. There, Ken learned about Dr. Aryeh Fischer and the Scleroderma Clinic at UHealth, where he is now being treated. Ken's skin tightening progressed so quickly that by August 2016 his hands had curled so much that he couldn't put on gloves. The tightness spread to his face, neck, legs and chest and he was experiencing tendon rubs on all his joints. Ken also has minor damage to his heart, which is his only internal damage.

Because of his rapid skin progression, which also put him at severe risk for internal organ damage, Ken's best option to loosen the skin and slow his progression was a stem cell transplant, which he had done in December of 2016. Immediately after the transplant, Ken did experience some loosening of his skin; however, by February 2017, the tightening started again. Ken's immediate regression caused the doctors to conclude that the transplant did not work.

Ken started IVIG treatments in March of this year for 3 consecutive days each month which he is tolerating very

well without any side effects. He started taking mycophenolate, but stopped because his doctor concluded that it was not working after being on the medication for 8 months. Ken is, in addition, taking Actemra, which is a drug used primarily for rheumatoid arthritis but has shown promising results in studies for loosening skin in



scleroderma. Since Actemra takes several months to start working, he won't know for a while if it is effective. Ken also takes amlodipine and a new medication sildenafil for his Raynaud's. Ken is considering Botox injections for his Raynaud's before his digital ulcers get to the point where he risks losing his fingers. He is also on pain medications to take the edge off his chronic pain. Ken does hand therapy with an occupational therapist and works with a physical therapist to regain strength and mobility in his hands and legs.

Like some people with scleroderma, Ken's symptoms seem to come in waves. He'll have a month of noticeable progression where he can almost feel the changes daily, followed by a month or two where nothing seems to be progressing. Then the progression wave will return the next month. However, as of late, Ken does feel a little less fatigued and his skin seems to be loosening slightly; but he admits that he is waiting to see trends over time before he gets too excited!

Ken, who has run marathons, explains the fatigue with scleroderma as hitting a wall. Whether they are at a friend's house or out for dinner, when he hits the wall, he is done and has to go home and lay down. Ken's muscles would get tired running a marathon but there was always the will to go on and get through the miles. With scleroderma, the fatigue is a physical and mental state where he just can't go on and knows he must stop.

Scleroderma can put a strain on relationships as well and Ken and Sheila are no exception. Ken can't help much around the house anymore with doing the dishes, folding laundry or mowing the lawn. Ken sometimes moans at night from the pain and that makes it hard for Sheila to sleep. Sheila does her best to help Ken with daily life and although it has been tough, they are hanging in there and adapting. It's okay that the house isn't as clean as it used to be!

Other than Sheila and their dogs, scleroderma has stripped Ken of all his other passions in life. He can no longer hike, camp, ski or tinker with his car. But realizing that he must adapt, Ken is finding new hobbies such as going to car shows and, at the suggestion of his hand therapist, digging out some old models he never finished as a kid and is working on those to exercise his hands. Recently he has been able to walk the dog again and he and Sheila have started taking one-day car trips together to the mountains.

Continued on page 4



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.*

Ken's Story – Continued

Ken recommends to someone newly diagnosed to find the right rheumatologist with a specialty in scleroderma. This is a dangerous disease and you owe it to yourself to find the best of the best. Also, be ready for a fight as giving up is not an option! Get used to a new normal and get your caregivers ready and educated. Don't forget to lean on your friends, they want to help you! Ken regularly attends chapter support group meetings which has provided him with education as well as the opportunity to meet other people with scleroderma. This also gives him the chance to learn through them with what works and what doesn't as well as knowing that he isn't alone. Ken's motto is "nothing in the universe can change where you are; all you can do is your best moving forward".

NOTE: Ken documented his stem cell treatment process on Caring Bridge at <https://www.caringbridge.org/visit/kenurban>.



Contact Us...

Scleroderma Foundation
Rocky Mountain Chapter
2280 South Albion St.
Denver, CO 80222

(303) 806-6686
cochapter@scleroderma.org
scleroderma.org/colorado

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Meet Others...

inspire.com/groups/scleroderma-foundation

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.
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.
5. Join your fellow Coloradans and "give where you live" on Colorado Gives Day, Tuesday, December 5 at coloradogives.org/rockymntscleroderma.

Scleroderma changes people. It sculpts us into someone who understands more deeply, hurts more often, appreciates more quickly, cries more easily, hopes more desperately, loves more openly, and lives more passionately.