



SCLERODERMA FOUNDATION

SUPPORT · EDUCATION · RESEARCH

ROCKY MOUNTAIN CHAPTER

Connect In 2020

The Scleroderma Foundation Rocky Mountain Chapter has big plans for 2020. We are working to add a new support group and several mini-conferences to expand our reach across the Rocky Mountain region. We are teaming up with our Medical Advisory Board to educate more young medical professionals about scleroderma. Our Advocacy Team continues to seek support for the National Commission on Scleroderma and Fibrotic Diseases Act.

Check out our 2020 events and programs. They provide many opportunities for you to connect and learn from top scleroderma experts and other patients and caregivers. Scholarships are available to attend both our Patient Education Day and the Scleroderma Foundation National Conference in Bellevue, WA. Join us on June 6th and 7th at our Stepping Out to Cure Scleroderma Walks for the largest scleroderma awareness weekend in Colorado! Set up a team, tell your scleroderma story and help with our fundraising efforts.

The Chapter NEEDS YOUR HELP to grow. Do you or someone you know have some time to volunteer? There are many ways to contribute. We are all united by our connection to scleroderma. Let's work together to SUPPORT, EDUCATE and fundraise to FIND A CURE!

Advocate **Volunteer**
Attend an Event **Fundraise**
Share your Story
Learn



Contact & Follow Us

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A Note From Our President



Community. Service. Advocacy.

These are the reasons I chose to become directly involved with the Rocky Mountain Chapter of the Scleroderma Foundation almost six years ago.

Community was the most significant reason, as my dad, Shepp Parr, who passed away in October of 2019, lived with scleroderma for over 15 years. He was attending the National Conference in New Orleans when he had the opportunity to meet our chapter founder, former Executive Director and current Board Treasurer Cyndy Besselievre. Through their connection I was invited to join the Food Fight Committee as a volunteer.

After three years of service on the Food Fight Committee, I was asked to join the SFRMC Board as a member-at-large; an honor I was excited to accept. The greatest honor of all was being asked to take on the position of Board President and follow in the footsteps of past President, Gloria Jara Price. Being of service through committee and board membership has been exceptionally rewarding, as we continue to move the chapter forward in meeting our goals of support, education and research through increasingly beneficial events including Food Fight, our Stepping Out to Cure Scleroderma Walks, and Patient Education Day.

Being a member of the committee and board, has allowed me, in my daily life, to better advocate for the foundation and as such all patients, family members and caregivers. I hope you are able to contribute to the advancement of SFRMC in your own way to extend our community, be of service, and advocate for our cause. Whatever way you choose to participate will make a significant difference in increasing our reach as a chapter and serving more people as we move forward.

Andrew Parr
Board President

SUPPORT GROUPS

Patients, caregivers, family
and friends are all welcome.

For more information, visit
our website at <http://bit.ly/COSupport>.

MILE HIGH (DENVER) SUPPORT GROUP

11:00 a.m.-1:00 p.m. at 5403 E. Evans Ave.,
Denver, CO 80222

March 14, 2020 – General Discussion

April 11, 2020 – General Discussion

May 9, 2020 – General Discussion

SOUTHERN COLORADO SUPPORT GROUP

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

March 21, 2020 – General Discussion

May 16, 2020 – General Discussion

July 18, 2020 – General Discussion

NORTHERN COLORADO SUPPORT GROUP

10:00 a.m.-12:00 p.m. at the Medical
Center of the Rockies, Arapahoe Peaks
Room, 2500 Rocky Mountain Ave.,
Loveland, CO 80538

April 25, 2020 - Speaker - Betsy Craig, CEO

Menu Trinfo - Betsy will tell her personal
story of her fight with scleroderma,
including her recent stem cell transplant.

June 27, 2020 - General Discussion

WESTERN SLOPE (GRAND JUNCTION) SUPPORT GROUP

11:00 a.m.-1:00 p.m. at Community Hospital,
3rd Floor Board Room, 2351 G Road, Grand
Junction, CO 81505

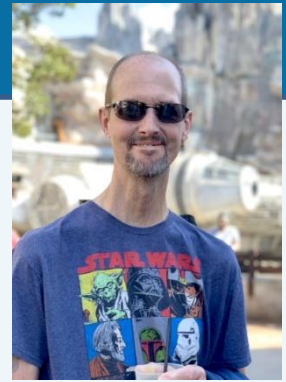
March 14, 2020 - General Discussion

April 25, 2020 – Western Slope Scleroderma Mini-
Conference – Legacy Room – 11:00- 3:00 p.m.

May 9, 2020 - General Discussion

July 11, 2020 - General Discussion

Dave's DETERMINATION



"Scleroderma isn't going to be the end of me. I just have to do things different."

Dave arrived in Denver in 1994 as a young architect. "Ten to twelve-hour workdays flew by. I love what I do." Despite his crazy work schedule, Dave found time to enjoy hockey, snowboarding, mountain biking and golf. It was on the ice at a hockey game where Dave met his wife Jen. They have been married for 16 years and have 3 children. In 2009, Dave was not happy at work. It was the height of the mortgage crisis recession and Dave decided to go into business for himself. "I am a risk taker...with Jen's support." Dave quickly built up a successful solo architect practice serving commercial retail and restaurant clients.

In 2016, Dave felt exhausted, beat up, and old. Long workdays, family obligations, volunteer work and stress were taking a toll. Dave's hands were swollen, and his fingers turned purple and white. His body was stiff, and his muscles were weakening. Dave experienced GI symptoms and began rapidly losing weight. Jen could not hold Dave's hand without causing extreme pain. He needed 2-4 Advil a day, just to get moving. Was this payback for the years of pounding from extreme sports? At Jen's urging, Dave set up an appointment for a physical, his first in 20 years.

Dave's antinuclear antibodies test came back off the charts high, however other inflammation markers were normal. He was referred to local rheumatologist Dr. Leslie Rose. She was able to rule some diseases out and noted Dave's damaged capillaries, telangiectasias and tight skin. Dave was not "getting old", he was diagnosed with diffuse scleroderma. A chest CT also found interstitial lung disease. Dave connected with experts at the scleroderma center at UC Health who introduced him to the Scleroderma Foundation.

In the years since his diagnosis, Dave has chosen to work with a naturopath and make significant lifestyle changes. Jen and Dave worked together to identify a diet (gluten free, autoimmune protocol, paleo) that halted the weight loss, helped resolve the GI symptoms, and drastically improved Dave's health. His naturopath prescribes supplements to help with circulation, balancing the body and immune system health. Dave's health gradually improved, but mentally, he was struggling.

Initially Dave hid his diagnosis from his clients. While he tried to keep up the "superhuman" appearance at work, he struggled with his role as provider for his family, and with this new vulnerability. He couldn't do things with the kids like he used to. It took time, but Dave learned how to accommodate his illness while still getting things done. "I use a leaf blower now instead of a rake."

Late in 2018, an ulcer opened on Dave's lower leg. The wound would not heal despite weekly wound care, debridement, a skin graft, a wound vacuum, fish skin, etc. Eighteen months later, 4 surgeries, numerous weeks in the hospital and in bed, Dave's leg is finally healed. It is going to be a long road back, but with the help of a personal trainer and a new found peace with his diagnosis, Dave has set a goal to get back on a snowboard this season! "Even if I am not jumping out of a helicopter snowboarding. I am still snowboarding!"



Rocky Mountain Chapter

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

UPCOMING EVENTS



March

March 19 – Kickoff Happy Hour for Food Fight, The Block Distilling Co., Denver, CO

April

April 25 – Western Slope Mini-Conference, Grand Junction, CO

May

May 3 – Patient Education Day, Aurora, CO

June

June 6 – 16th Annual Stepping Out to Cure Scleroderma Walk, Centennial Center Park, CO

June 7 – 10th Annual Northern Colorado Stepping Out to Cure Scleroderma Walk, Fort Collins City Park, CO

July

July 17-19 – National Patient and Kids Get Scleroderma Too Educational Conference, Bellevue, WA

October

October 14 – Food Fight for Scleroderma, BAC Appliance Center, Englewood, CO

Visit www.scleroderma.org/colorado