



Virtual “Real Talk” Support Group Teleconference

Join us on Thursday, August 9 from 7:00-8:00 p.m. for our quarterly virtual support group. The topic is “Stem Cell Transplants – A Patient’s Perspective”. Betsy Craig, who underwent a stem cell transplant earlier this year will discuss the process from pre-qualification testing and insurance approval to the transplant itself and how she is doing today. To participate, call 712-775-7031 and enter the call access code 781-611-035# when prompted.



Don’t Miss the Best Foodie Event Ever!



On Wednesday evening, September 12, local chefs and mixologists will bring their best bites and sips to satiate your taste buds at “Food Fight! Chefs Fighting for a Hard Disease”. Start off the evening with our special VIP experience including a red carpet arrival, hors d’oeuvres and a sparkling wine tasting featuring handpicked selections from SHERAL SCHOWE, founder of Wasatch Academy of Wine. Reggie Rivers is back as emcee and auctioneer. Raise your paddle for some great auction items including chef dinners and a “glamping trip”. Food Fight! is one of the best foodie events in Denver, so don’t miss out! Tickets are selling fast. Get yours today at cheffoodfight.com.

Kids Get Scleroderma Too

The Rocky Mountain and Tri-State Chapters are excited to co-host “Kids Get Scleroderma Too” on October 26 & 27 at Children’s Hospital Colorado. This event is for youth and teens with scleroderma, their parents and siblings. Juvenile scleroderma experts from around the country will lead educational sessions and group discussions. Friday night features a fun Halloween costume party for the whole family! Scholarships are available. Register at 2018KGS2.sclerodermatristate.org.



8th Annual Patient Education Day

Our annual Patient Education Day will be held on October 28 at UCHealth - Anschutz Medical Campus. Save the date! The Chapter’s Medical Advisory Board has once again assisted us in putting together a very informative and educational program including new sessions on nutrition, dental, sleep and renal issues and who you need on your medical team. The morning sessions will feature topics related to both adult and juvenile scleroderma. Registration will be available in August.

What’s Happening

- Aug. 9, 2018 – Virtual “Real Talk” Support Group Teleconference
- Sept. 12, 2018 – Food Fight! Chefs Fighting for a Hard Disease at BAC Appliance Center in Englewood
- Oct. 26 & 27, 2018 – Kids Get Scleroderma Too at Children’s Hospital Colorado
- Oct. 28, 2018 – Patient Education Day at UCHealth – Anschutz Medical Campus

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

Stepping Out to Cure Scleroderma Walks in June



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Board Update – Welcome New Board Members!

Hi, my name is **Christine Shephard**. I recently joined the Scleroderma Foundation Rocky Mountain Chapter's Board of Directors.

I have had scleroderma for over 21 years. I have been volunteering at the Rocky Mountain Chapter office for over a year. In that time, I have learned so much about this non-profit organization.

When Cyndy Besselievre asked if I was interested in becoming a board member, I was honored. I decided to join the board as a way to expand my understanding of the foundation and to be a part of a group who has the vision to continue the success of the chapter. Being on the board will give me another opportunity to give back to an organization impacting me personally and so many other scleroderma patients. I believe it is my next step in my volunteering journey for this amazing organization. I am looking forward to collaborating with the other board members who are generous enough to volunteer their time and talent to the chapter's mission and goals.

Hi, my name is **Barbara Frodin** and I recently joined the Rocky Mountain Chapter of the Scleroderma Foundation. When my cousin was diagnosed with scleroderma 9 years ago, I wondered exactly what it was. A year later the daughter of a really good friend was also diagnosed with scleroderma and then a friend from Austin told me his sister had scleroderma.

Anytime I would mention this disease to anyone, the comment I always heard was, "I have never heard about that disease". When Cyndy Besselievre, the Executive Director of the local chapter, asked me if I would be interested in joining the board, I really gave it a lot of thought and in the end thought here is a real opportunity to learn something new that I can share with people. I have been in sales for most of my life, and have lots of opportunity to tell people about things that I learn. Being around friends and family that are suffering from scleroderma has made me realize that they really need support, especially in the area of research. Hopefully my skills will help me share the need with groups that can help us with fundraising for research.

I have been involved with several groups as a volunteer and believe I have a new goal that will challenge me. Thank you for inviting me to become a part of this group.

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

August 9, 2018 – "Stem Cell Transplants – A Patient's Perspective" featuring Betsy Craig.

November 8, 2018 – Dr. Paul Menard-Katcher, Gastroenterologist at UCHealth, will host a Q&A on GI issues and scleroderma.

Meetings are from 7:00-8:00 p.m. Call 712-775-7031, enter access code 781-611-035# when prompted.

MILE HIGH (DENVER) SUPPORT GROUP

August 11, 2018 – Update on workshops presented at the 2018 National Patient Education Conference.

September 8, 2018 – To be announced.

October 13, 2018 – To be announced.

November 10, 2018 – To be announced.

December 8, 2018 – Holiday Party!

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

SOUTHERN COLORADO SUPPORT GROUP

September 15, 2018 – Update on workshops presented at the 2018 National Patient Education Conference.

November 17, 2018 – Holiday Luncheon! Location 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

August 25, 2018 – Update on workshops presented at the 2018 National Patient Education Conference.

October 27, 2018 – Patti Welfare, MA, Community Health Specialist, Aspen Club/Senior Services, will present on Meditation for Brain Health.

December 1, 2018 Holiday Luncheon at 11:00 a.m. at The Moot House, 2626 S. College Ave., Fort Collins, CO 80525. **(NOTE: DIFFERENT DATE, TIME AND LOCATION FOR THIS EVENT!)**

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

September 8, 2018 – A representative from Actelion Pharmaceuticals US will present on "PAH-Tips for Being an Empowered Patient" (tentative). Lunch will be provided.

November 10, 2018 – Holiday Party and update on workshops presented at the 2018 National Patient Education Conference.

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

It All Started With A Tooth Issue For Teenager Haley – Here is Her Story

Haley is sixteen years old, is learning how to drive and will be a junior in high school this fall. Her favorite class is chemistry but her passion is art. She enjoys her art classes and likes creating pottery, painting, drawing and making watercolor greeting cards. She likes to read, cook, bake and go to the Aurora Reservoir with her family. Haley lives with her parents, her younger brother Ben, a Rottweiler and a bulldog. This summer she is also bottle feeding an abandoned fawn until it is old enough to go off on its own. Her mom says Haley is an “old soul who is incredibly nurturing and is always at the center among a group of younger kids”.

When she was in 6th grade, Haley developed a spot on her chin that was thought to be unrelated to a tooth on her bottom jaw that didn't come in. Doctors dismissed it as a birthmark. Five years later, in March 2018, Haley was scheduled to have her wisdom teeth pulled but a new family dentist noticed Haley's jaw was receding. She was sent to an oral surgeon who just happened to be married to a dermatologist. He suspected something else was going on and referred her to the

dermatologist who finally diagnosed Haley with a form of localized scleroderma known as morphea. A rheumatologist confirmed linear scleroderma because of the spots on one side of Haley's chin, jaw line and down her neck. By April, Haley was on Methotrexate and Prednisone. Haley recently completed eight weeks of 24 UVA treatments to soften the spots on her chin and stop tissue build up.



Haley's pottery

Haley's parents are frustrated that it took five years for doctors to take their questions seriously and not connect the tooth issue with the spots on Haley's chin to something more serious. They feel if it had been caught and treated earlier, Haley might not need the total jaw reconstruction that they know is coming as soon as Haley stops growing.

Haley experiences fatigue and upset stomach from the side effects of the Methotrexate for usually 24-48 hours after each treatment. The immunosuppressants are causing Haley to get sick whenever she goes out so the family is hanging around home more now. Mom makes sure that Haley gets enough rest and tries to monitor Haley's energy level. Even if Haley has the energy to go out, they have to weigh the risk of exposure to a lot of people who might make Haley sick. Mom feels they are still navigating their way through this because it is all so new.

Haley missed 3 days of school every week this spring when she started her treatments; but she was able to make up all the work on her own. To stay caught up with school, she taught herself Algebra II, Spanish and AP European History and biology! Haley has talked to her friends about



Family vacation in July

scleroderma. They are supportive and help her keep up on her school work and tell her what goes on in class.

A disease like scleroderma impacts the entire family. Planning around Haley's treatments and gauging her energy level have made it harder to get out as a family. While going out to do things is harder, they view time together as a critical part of the healing process. Brother Ben has even stepped up to help with Haley's chores when she isn't feeling well. Haley's parents involve her in decisions about medical treatments as much as possible. As the parents, they know there are some things they have to decide such as what medications Haley takes; but they let Haley call the shots on when to take her treatments.

The hardest part for her parents is all the medications that Haley has to take and seeing the side effects. Seeing a teen's energy level tank and constantly getting sick is difficult. For Haley, knowing that she won't feel well for 1-2 days after treatments and knowing this will be the case for at least the next 1-2 years feels like forever to someone so young.

Because the whole family is still learning about scleroderma, they are trusting in established research for treatment options; but Haley and her parents have been discussing alternatives, including diet. Haley has been gluten-free since March and started the autoimmune Paleo diet (gluten-free, sugar-free, dairy-free) about a month ago. Haley says she hasn't noticed a difference yet but on their recent vacation, Haley had pizza and her parents could see the next day that Haley's coloring was off and that she had less energy. It's hard to balance being a sixteen year old and doing what's best for your body but Haley is really good at finding healthy recipes that the family can make together at home.

Haley is now seeing lots of specialists but her parents still feel that doctors aren't aware enough about autoimmune diseases to test for them when someone is having health issues. Haley thinks “autoimmune diseases are the new cancer” because they are so on the rise and believes if doctors had been more on the look out for it, some of her issues could have been prevented. Despite always eating a balanced diet as a family, Haley's mom feels the rise in autoimmune diseases is at least partly attributable to the chemicals in our food. Haley and her parents are committed to fighting her autoimmune disease as naturally as possible.

Haley doesn't know yet what she wants to do with her life. For now she is just looking forward to the next family vacation in Maine this fall to celebrate her birthday!



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.*

20 Years of Reaching for the Cure!

Many of you have given generously to the Scleroderma Foundation's mission of support, education, and research. You have truly made a difference in the lives of people with scleroderma; however, our ultimate goal still remains.

There is no cure for scleroderma. As deeply as we believe in the promise of medical science to one day discover a cure, we know that no one with scleroderma can afford to wait indefinitely while the disease attacks their body today. We pursue our mission with urgency born from witnessing the disfigurement and disability and death caused by scleroderma. This is why we started the *Reach for the Cure* capital campaign to fund the broad spectrum of research opportunities.



The need is great. The time is now. We sit on the threshold of the future. You can help us move quickly to capitalize on the momentum we've spent 20 years building. Let's celebrate the Scleroderma Foundation's 20th anniversary this year together by launching a new era of scientific discovery and drug development to treat and to cure scleroderma. To get there, we need increased resources to fund dramatically more research.

Will you please join us as we reach for the cure by giving as generously as you can to the scleroderma research effort? Learn more or donate at scleroderma.org/reachforthecure.

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
2280 South Albion St.
Denver, CO 80222
(303) 806-6686
cochapter@scleroderma.org
scleroderma.org/colorado
facebook.com/COScleroderma
twitter.com/SclerodermaCO
youtube.com/COScleroderma