



Stepping Out To Cure Scleroderma Walks

Join us for the 2018 Stepping Out to Cure Scleroderma Walks and help fundraise to find a cure for scleroderma. We are hosting two walks, so you have double the opportunity to join in on the fun. Both walks will feature entertainment, music, tasty goodies and fun activities for the kids. We will be honoring the top teams for their fundraising efforts with awards and prizes. Don't miss the fun! Make a difference and register today:

Fort Collins City Park
Sunday, June 10

scleroderma.org/steppingoutftcollins

Centennial Center Park
Saturday, June 16

scleroderma.org/steppingoutdenver



New Unstoppable Book Offers Hands-on Advice For Those With Scleroderma

In her new book *Unstoppable: A Recipe for Success in Life and Business*, author Betsy Craig shares a roadmap to conquer life's challenges gained through her journey with scleroderma.



Over the past 30 years, Betsy has lived by a set of ten guiding principles that are the key ingredients in her recipe for success. Filled with honest stories, humor, and practical advice, *Unstoppable* provides you the courage and inspiration to be happier and less stressed, and the tools to be able to work through situations more easily.

"When scleroderma hit me and knocked me down, I was determined to not let my disease define me," said Betsy. "The lessons I share in my book gave me the strength to get up."

(A portion of the proceeds from the sales of *Unstoppable* will be donated to the Scleroderma Foundation Rocky Mountain Chapter. *Unstoppable* is available for pre-order as an e-book and paperback on platforms such as Amazon, Kindle, Nook, and iBooks. For more information, visit betsycraig.com.)

Save The Dates For Education Coming This Fall

The Rocky Mountain and Tri-State Chapters have partnered to host "Kids Get Scleroderma Too" on October 26 & 27 at Children's Hospital Colorado. This event is for juveniles and teens with scleroderma, their parents and siblings. Our annual Patient Education Day at will be held on October 28 at UHealth Anschutz Medical Campus. Save the dates! More information is coming soon about both these educational programs.

What's Happening

- May 10, 2018 – "Real Talk" Virtual Support Group Teleconference
- May 10-12, 2018 – High Tea Party fundraiser at Carla's A Classic Design at The Streets at Southglenn
- May 20, 2018 – Colfax Marathon at Denver City Park
- June 6, 2018 – Kendra Scott Gives Back fundraiser at Park Meadows
- June 10, 2018 – 8th Annual Northern CO Stepping Out to Cure Scleroderma Walk at Fort Collins City Park
- June 16, 2018 – 14th Annual Stepping Out to Cure Scleroderma Walk at Centennial Center Park
- Sept. 12, 2018 – Food Fight! Chefs Fighting for a Hard Disease at BAC Appliance Center in Englewood

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



Anna Seaman (left) and her mother Jill meet with Congressman Scott Tipton at Capitol Hill Day in Washington, D.C. (see page 4). To learn what you can do to advocate for scleroderma, go to scleroderma.org/advocacy.

INSIDE THIS ISSUE:

Support Groups	2
Board Update	2
Why I'm Stepping Out	3
How to Donate & Contact Us	4

Board Update

Stepping Out to Cure Scleroderma Walks are the Scleroderma Foundation's signature fundraising event. Every year more than sixty walks around the country help put the face of scleroderma in front of the public.

We work hard to make our chapter walks a fun event for participants of all ages. We hope you will join our scleroderma community at one or both of our upcoming walks.

This year is the 20th anniversary of the Scleroderma Foundation and our goal is to make the walks the biggest and best yet! Why is reaching our goals important? Because it allows us to make a significant difference in funding research for scleroderma. The average grant awarded by the Scleroderma Foundation is \$150,000. Research is expensive but it is the only way we'll discover a cure. We need to continue to fund our established researchers, and bring in new investigators, or we will lose them to other fields.

So we are asking for your help. Whether on a team or walking individually, make your contribution by fundraising. Some fundraising ideas include asking family, friends, and relatives to donate; ask friends from church, your neighbors, acquaintances

where you shop, dine or bank; or ask your employer if they match donations. Your story is very powerful and can create a connection with your donors (see page 3). You can share what the Scleroderma Foundation has done for you and why it's important to fundraise and find a cure!

Did you know that 80% of individuals donate because someone asked them? Ask four friends to donate \$25 each to your fundraising efforts and boom, you've raised \$100. Now ask four more friends and you've raised \$200!

Fundraising can be fun and it's easy. Share your story through your participant center after you register, then simply email your friends and share on social media. Then watch the donations roll in on your page - you may be surprised how much support you'll get! Your story will also educate people about this disease.

For any assistance with registering, your participant center or ideas for fundraising, contact Carol Walsh at 303-570-5820 or carol@verticalmg.com.

See you at the walks!

Gloria Jara Price
Chapter 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

May 10, 2018 – Open discussion to address your issues and questions related to scleroderma.

August 9, 2018 – To be announced.

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

MILE HIGH (DENVER) SUPPORT GROUP

May 12, 2018 – Mountain States Therapy will present on therapy and exercises for scleroderma hands.

June 9, 2018 – Picnic in the Park at Mamie Doud Eisenhower Park, Picnic Site 4, 4300 E. Dartmouth Ave., Denver, CO 80222.

(NOTE: DIFFERENT LOCATION FOR THIS EVENT!)

July 14, 2018 – To be announced.

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

September 8, 2018 – 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.

SOUTHERN COLORADO SUPPORT GROUP

May 19, 2018 – **MEETING CANCELLED!**

July 21, 2018 – John Perrodin, Manager Patient Relations at Penrose-St. Francis Health Services, Centura Health, will present on patient rights and navigating the health care system.

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

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

June 23, 2018 – Carolyn Boettger, DDS, Tri-City Dental, will present on dental issues and scleroderma.

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

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

May 12, 2018 – View and discuss a video from the 2017 National Patient Education Conference titled "Evaluation and Management of Scleroderma Lung Disease" presented by Aryeh Fischer, MD.

July 14, 2018 – A representative from Actelion Pharmaceuticals US will present on "PAH-Tips for Being an Empowered Patient" (tentative). Lunch will be provided. **(NOTE: THIS MEETING WILL BE HELD FROM 1:00 P.M. – 3:00 P.M.)**

September 8, 2018 – 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.

Why I'm "Stepping Out"

Whether you are walking for yourself, to honor a friend or family member or in memory of a loved one, your participation and support of the 2018 Stepping Out to Cure Scleroderma Walks will help to raise important funds to find the cause and cure for scleroderma. Share your story.

Team O2-D2

Jessica Morrow

A year ago, and just a week shy of my 30th birthday, I received a devastating diagnosis, one that changed my life forever. I discovered that I had scleroderma and it had already caused moderate lung damage. The degree of lung damage I have incurred has resulted in my dependence on supplemental oxygen for the rest of my life.



Lung disease is currently the leading cause of death amongst scleroderma patients and it is estimated that it affects nearly 80% of the scleroderma community. Lung disease is just one of the many ways this disease can impact one's body.

This event is important because through my own experience, I have found that awareness is not only lacking amongst potential patients of this disease, but also amongst the medical professional community. We need assistance in funding to research for a cure and this starts with spreading the word.

Team Sandee Jo

Sandee Billen Maas



This is the 7th year for Team Sandee Jo. It has been 5 years since Terry gave me her "spare" kidney! Please celebrate with us on June 16th. We appreciate all of the love and blessings we have received over the past 7 years. I would not be where I am today without the love, prayers and support from my family and friends. We would love it if you would join us in celebrating all of the progress and blessings that we have had along this journey.

Team Lady

Shawna Cordova

We will be honoring our Mother, Grandmother, Great-Grandmother in this event. Our "Lady", Debra Ann Anthony.

Debra was a vibrant active grandmother and great-grandmother. She loved chaperoning school trips for her kids and then her grandkids. She could walk miles and work in her garden. Enjoying her retirement for just 2 short years, in July 2017 she started to not feel well. She started doctor visits and was treated for arthritis. Nothing helped and she started to get worse to where she couldn't walk. Thanksgiving morning she went into cardiac arrest. She never recovered. We lost our Queen on November 27, 2017. This disease took her so fast her family tried to help with research and relief but it happened too quickly.

This horrible disease took our Queen in just four months of diagnosis. We are devastated and feel some type of calling to help with the research of treatment and a CURE of this horrible disease.



Paula's Powerwalkers

Paula Christenson

I just recently created a team to raise money for research and patient education concerning scleroderma. The



outpouring of support overwhelms me and makes me happy knowing people really do care. The phenomenal thing is, the majority of donations are coming from high school buddies and long time friends! I've always said there's nothing like coming from the same backyard! It's a bond

that is stronger than time. Love you guys and appreciate the friendship.



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.*

Anna Seaman Takes on Capitol Hill!

My mom Jill has been an inspiration to both myself and my siblings since her diagnosis in 2008. She has shown continuous strength, perseverance and love through scleroderma. My entire family has witnessed my mom's fight through a stem cell transplant and the many hardships of this disease. Although my mom hasn't faltered in being an amazing mom, I have watched her struggle with scleroderma since I was five years old.

Attending the Scleroderma Foundation's Capitol Hill Day in Washington D.C. this April was my first real opportunity to make a difference. When the Scleroderma Foundation informed us that we would be going together, I was both excited and nervous because I wasn't sure how I could make a real difference as a fifteen-year old freshman in high school. While reflecting on my mom's journey, I realized that scleroderma has changed our family. Some of these changes were obvious, such as not being able to go on hikes or scratching my mom's back as her skin tightened, but the deeper changes have been an appreciation for my mom and all she has been through. She continues to amaze me on a daily basis.

While in Washington D.C., I was able to meet amazing people who were so kind and joyful in spite of this disease. Meeting these survivors helped prepare me to convince our legislators that we need to find a cure. As a team, my mother, Cyndy Besselievre and I met with the offices of two senators and four representatives from Colorado. We explained our bill and told our stories. It brought both laughter and tears at the journey my family has undertaken. I hope that through these stories, our legislators will better understand the impact scleroderma has on those fighting the disease and their families. I hope that H.R. 4638 will gain the support of the legislators we talked to and change the lives of those affected for the better.

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. Ask your employer about their matching program for your Stepping Out to Cure Scleroderma Walk fundraising efforts.
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