



## June is Scleroderma Awareness Month

 Know the Face of Scleroderma 

Scleroderma. Hard word. Harder disease. There's nothing easy about scleroderma. This autoimmune disease, which has no known cause or cure, causes hardening skin, stiff joints, digestive issues, lung scarring, kidney failure, and in the worst cases, death. But here's one of the hardest things about scleroderma: so few people are aware of the disease, researchers don't get the resources they need. That's why we need you to speak up during June, Scleroderma Awareness Month.

*Do as much as you can—  
every voice counts.*

During awareness month, you can tell a friend about scleroderma. You can share your story, or information about scleroderma on your social media. You can even start a fundraiser on [scleroderma.org/hoperaisers](http://scleroderma.org/hoperaisers). Do as much as you can—every voice counts. Before people can care, we need to make them aware.

*Speak up  
for scleroderma today.*



### What's Happening



June 8, 2019 – 9<sup>th</sup> Annual Northern Colorado Stepping Out to Cure Scleroderma Walk, Fort Collins City Park

June 8, 2019 – Denver/Mile High Support Group Family Picnic, Eisenhower – Mamie Doud Park



June 15, 2019 – 15<sup>th</sup> Annual Stepping Out to Cure Scleroderma Walk, Centennial Center Park



July 19-21, 2019 – National Patient and Kids Get Scleroderma Too Educational Conference, Chicago, IL



Sept. 18, 2019 – Food Fight! Chefs Fighting for a Hard Disease, BAC Appliance Center

### Volunteer Today!



Can you lend a hand on event days? Do you like to talk to people on the phone? Can you assist with office work? Are you a graphic designer or photographer? Are you willing to share your story to raise awareness? Can you help us raise awareness of scleroderma and lobby for scleroderma related legislation?

### Contact Us to Learn More!

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## Join the Scleroderma Advocacy Team

**We need your help** to ensure that scleroderma is included as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program during the Fiscal Year (FY) 2020 appropriations process.

Each year, the United States Senate crafts an annual Department of Defense (DOD) appropriations bill, which includes a list of conditions that are deemed “eligible for study” through the Peer-Reviewed Medical Research Program (PRMRP). For a condition to be included, Senators need to support the condition and officially ask for its inclusion. For them to support a condition-specific request, they need to be educated and asked by constituents (you) for their support. In recent years, the PRMRP funded nearly \$10 million in meritorious and meaningful scleroderma research projects.

At this critical juncture, **please reach out to the offices of your Senators and ask** that they "support the inclusion of scleroderma in the DOD PRMRP's eligible conditions list in FY 2020."

To sign up for Scleroderma Foundation Advocacy Alerts, visit:  
[scleroderma.org/advocacysignup](http://scleroderma.org/advocacysignup)

Fundraising with  
King Soopers  
Community Rewards Program



King Soopers Community Rewards makes fund-raising easy by donating to local organizations based on the shopping you do everyday. Once you link your customer card to the Scleroderma Foundation Rocky Mountain Chapter, all you have to do is shop at King Soopers and swipe your card!

Visit: [kingsoopers.com](http://kingsoopers.com) to sign up today.

## Upcoming Support Groups

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

### VIRTUAL SUPPORT GROUP

To join by computer: go to <https://join.me/coscleroderma>  
To join by phone: call 302-202-5900, enter conference ID 947-770-935

**August 8, 2019** -7-8 p.m. - Aryeh Fischer, MD, - Q and A on lungs and scleroderma

**November 7, 2019** -7-8 p.m. - Presentation on When to Apply for Social Security Disability by Lyndsey Ellis, Allsup

### MILE HIGH (DENVER) SUPPORT GROUP

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

**June 8, 2019** - Annual picnic. 11 a.m. – 1 p.m. Special Location: Mamie D. Eisenhower Park, 4300 E. Dartmouth Ave., Denver

**July 13, 2019** – General Discussion

**August 10, 2019** - Update on the workshops presented at the 2019 National Patient Education Conference.

**September 14, 2019** – General Discussion

**October 12, 2019** - General Discussion

### SOUTHERN COLORADO SUPPORT GROUP

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

**July 20, 2019** - TENTATIVE – Check our website for updates.

**September 21, 2019** -TENTATIVE – Update on the workshops presented at the 2019 National Patient Education Conference.

**November 16, 2019** - TENTATIVE – Annual Holiday Luncheon – location and time to be announced.

### NORTHERN COLORADO SUPPORT GROUP

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

**June 22, 2019** – Amanda Mixon, PA, will discuss symptoms and treatments for scleroderma.

**August 24, 2019** - Update on the workshops presented at the 2019 National Patient Education Conference.

**October 26, 2019** - Sharon Petty, PT, DPT, OCS, of UCHealth Rehabilitation Services, will discuss physical therapy and scleroderma.

**December 7, 2019** - Annual holiday luncheon at 11 a.m. at the Moot House 2626 S. College Ave., Fort Collins, CO 80525

### WESTERN SLOPE (GRAND JUNCTION) SUPPORT GROUP

11 a.m. - 1 p.m. - Community Hospital, Legacy 1 Room, 2351 G Road, Grand Junction, CO 81505

**July 13, 2019** - General Discussion

**September 14, 2019** - Update on the workshops presented at the 2019 National Patient Education Conference.

**November 9, 2019** - General Discussion

# Jessica's Journey

Jessica's scleroderma journey began on a spring morning in April of 2014 when she awoke with extreme swelling in her feet. Her primary care physician found her rheumatoid factor to be high and sent her to a rheumatologist who was mystified with Jessica's symptoms. Jessica noticed that the skin on her hands was so tight that she struggled with turning on the shower. The rheumatologist said, "it's just a little skin tightening, no big deal," she had seen people with much worse symptoms. Jessica was not satisfied with this doctor and moved onto another general rheumatologist who diagnosed her with lupus.

Over the next few years, Jessica lived her life while following her doctor's treatment plan for lupus. New symptoms emerged. Jessica's hands continued to deteriorate as she developed Raynaud's and ulcers on her fingertips. She also experienced "really bad" GERD. During one of Jessica's many doctor appointments, a very sharp physician's assistant mentioned that he really thought she had lupus, but said she had some scleroderma like symptoms as well.

"No one knows my body the way I do. This is what is wrong with me and I need you to listen to me."



In May of 2016, Jessica was hospitalized for five days with extreme fatigue and an elevated heart rate. Jessica was discharged just in time to marry the love of her life. When Jessica returned home from her wedding, she realized that even though she had missed her lupus infusions, she did not feel any different. Was lupus really her diagnosis? It was a difficult time for her. "I was always taught to not question an authority figure." An ER visit six months later would ultimately lead Jessica down the road to answers.

Jessica headed to the ER with yet another disturbing symptom, shortness of breath. The ER physician diagnosed Jessica with pneumonia and ran a CT scan. The radiologist report mentioned possible interstitial lung disease (ILD). A Google search pulled up information on the connection between ILD and autoimmune diseases.

Jessica quickly made an appointment with a pulmonologist at the ILD treatment center at National Jewish. The very next day Jessica told this pulmonologist that she thought she had scleroderma. She explained "no one knows my body the way I do. This is what is wrong with me and I need you to listen to me." Following two full days of testing, the pulmonologist agreed. He directed Jessica to a pulmonologist that specialized in ILD and scleroderma specialist, Dr. Aryeh Fischer. Three years into her journey, just shy of her 30<sup>th</sup> birthday, Jessica was diagnosed with limited cutaneous systemic sclerosis with moderate ILD and borderline pulmonary arterial hypertension.

Jessica is very appreciative of where she is in her life and thankful to be surrounded by incredibly supportive friends, family and medical team. The dynamics of her relationships have changed. "You find who is going to be there for you and who is not when you are going through a health crisis." Jessica has found it isn't easy to keep up with life between working full-time, chores, friends, family and a marriage while managing a chronic, serious health condition that causes frequent fatigue. Finger-tip ulcers can make typing or doing anything with her hands difficult. When she was first diagnosed, Jessica's Mom moved in to help, and Jessica's employer allows her to work from home four days a week. Jessica enjoys amateur photography and spending time with her friends, family and her three-year-old pit bulls named Duke and Daisy. She currently works full time as a senior analyst in the mortgage industry.



Join Jessica's team, O2-D2 for our Denver Stepping Out Walk on June 15, 2019



## Rocky Mountain Chapter

5403 E. Evans. Ave. Denver, CO 80222

### Contact & Follow Us...

Scleroderma Foundation  
cochapter@scleroderma.org  
(303) 806-6686  
[cochapter@scleroderma.org](mailto:cochapter@scleroderma.org)  
[scleroderma.org/colorado](http://scleroderma.org/colorado)  
[facebook.com/COScleroderma](https://facebook.com/COScleroderma)  
[twitter.com/SclerodermaCO](https://twitter.com/SclerodermaCO)  
[youtube.com/COScleroderma](https://youtube.com/COScleroderma)

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

Get your discounted general admission ticket throughout the month of June  
in honor of Scleroderma Awareness Month!



# FOOD FIGHT

## FOR SCLERODERMA

Join us for our fifth annual elite culinary competition featuring Denver's talented chefs and bartenders while they support and raise awareness for a hard disease — scleroderma!

For an elevated experience, join us for the Battle of the Bar, a live bartending competition in front of an esteemed panel of judges for ultimate bragging rights.

#### EVENT DETAILS:

SEPTEMBER 18, 2019

TIME: 6 - 9 P.M. VIP HOUR: 5 - 6 P.M.


BAC APPLIANCE CENTER

1880 W. OXFORD AVE. ENGLEWOOD, CO 80110

PLEASE VISIT

**FOODFIGHTDENVER.COM**  
TO GET YOUR TICKETS!



 @foodfightdenver

 @sclerodermafoodfight