

# ROCKY MOUNTAIN CHAPTER NEWS

Summer 2016



## “Virtual” Support Group Features Dr. Tracy Frech

Attend a support group meeting in the comfort of your own home? Well, that’s just what you can do with our “virtual” support group teleconference on **Thursday, August 4 from 7:00-8:00 pm!**

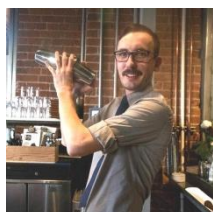
Tracy Frech, MD, MS, will discuss “Management Challenges of the Gastrointestinal Tract in Systemic Sclerosis”. Dr. Frech is Director of the Scleroderma Clinic at the University of Utah Hospital and Director of Clinical Trials for the Division of Rheumatology.



It’s easy to participate. Just call **(712) 775-7031** and enter call ID **781-611-035#** when prompted. Time will be allowed for your questions.

## Get Ready for a “Food Fight!”

What do the Scleroderma Foundation and local chefs have in common? We’re all fighting for a cure for scleroderma and local chefs and



mixologists are bringing their best to the competition! Do you remember Chef Maggie Restivo’s yummy award-winning dessert from last year? Well, she is back, as are several other returning chefs and some new challengers, on **Wednesday, Sept. 7 at BAC Appliance Center** in Englewood. New this year, local mixologists will quench your thirst with their most creative cocktails.

You get to be the judge, so get your tickets at [www.cheffoodfight.com](http://www.cheffoodfight.com). The doors open at 6:00 pm for general admission. Or upgrade to VIP and join us at 5:30 pm when accomplished New York City executive chef Vincent Tropepe will indulge you with a cooking demo and provide a signed copy of his latest book “In My Whites”.

## 6<sup>th</sup> Annual Northern Colorado “Stepping Out”

Returning sponsor Jazzercise Fort Collins will help you get your groove on and warm you up for our **“Stepping Out to Cure Scleroderma” Walk on Sunday, September 11 at Fort Collins City Park.**

As always, we’ll provide some coffee and breakfast to get you going. Hang around after you walk to bid on some great auction items including Denver Broncos’ tickets and overnight getaways. Bring the kids – we’ll keep them entertained with a kids’ fun run, balloon twisting and finger painting. Sign up today at [www.scleroderma.org/steppingoutftcollins](http://www.scleroderma.org/steppingoutftcollins). This year’s theme is “Sole Mates” so get your team excited about participating by coming up with creative team names and costumes – most creative wins a prize!



## What’s Happening

- August 4, 2016 – Virtual support group teleconference with Dr. Tracy Frech.
- Sept. 7, 2016 – “Food Fight! Chefs Fighting for a Hard Disease” at BAC Appliance Center in Englewood.
- Sept. 11, 2016 – 6<sup>th</sup> annual Northern Colorado “Stepping Out to Cure Scleroderma” Walk at Fort Collins City Park.
- Oct. 16, 2016 – Patient Education Day at UCHealth-Anschutz Campus in Aurora. (See page 4.)

For more information, go to [www.scleroderma.org/colorado](http://www.scleroderma.org/colorado) or contact us at (303) 806-6686 or [cochapter@scleroderma.org](mailto:cochapter@scleroderma.org).



400 walkers “stepped out” on June 18 at Centennial Center Park and raised \$40,000 for scleroderma. Thank you walkers, sponsors and volunteers!

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## Chapter Board Update

When talking with Cyndy Besselievre a few years ago, I heard her story of her mother's battle with scleroderma. Recognizing how much time and love she puts into this Foundation and having scleroderma affect my family as well, I chose to volunteer mostly to help out a friend. I met with Cyndy a few times, did a few things and then, I went to a support group meeting. I sat next to Ray Woolf. I enjoyed talking with him and meeting so many strong, amazing people. In time, I was asked to serve on the Board and jumped in. As a board member, I was given the opportunity to work closely with another hard working and giving person - Sandee Maas - to start the "Food Fight! Chef's Fighting For a Hard Disease" fundraiser.

My favorite part of planning the Food Fight! is getting to know all the fabulous restaurants in Denver as I look for chefs to participate. I have found that the chefs are not only extremely talented and passionate about food, but they have a passion for people as well. As you talk with them, you find that they cook because they want to make people happy and cooking wonderful food is their gift that they can share with others.

The chefs who choose to be a part of the Food Fight! do it because they want to give to our Foundation and they want to share their passion to make others smile. As you attend the Food Fight!, you will have the opportunity to meet the chefs first hand, talk with them about their career, the dish they are serving and tips and secrets to cooking great meals.

Being on the Board and working on the Food Fight! has given me a great opportunity to promote awareness of scleroderma and the Scleroderma Foundation. As I visit restaurants and other establishments in search of chefs, I have the chance to tell everyone about the Foundation, the disease, the people and the research. As in sales, you hear many "no's" before you find those who say "yes". I never count those who don't choose to participate as a loss or waste of time; I simply count it as a chance to achieve one of the goals of our Foundation – promoting awareness. And next time they hear that strange disease, they may be ready to say "yes"!

Martha Williams  
Board Member  
Food Fight! Committee Co-Chair

## Support Group News

Support groups offer a friendly forum to meet others in your area living with scleroderma. Patients, caregivers, family and friends are all welcome. For more information, visit our website at <http://bit.ly/COSupport>.

### **"VIRTUAL" SUPPORT GROUP TELECONFERENCES**

August 4, 2016 – Dr. Tracy Frech, Rheumatologist at University of Utah, will discuss "Management Challenges of the Gastrointestinal Tract in Systemic Sclerosis".

November 10, 2016 – Speaker and topic to be announced.

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

### **MILE HIGH (DENVER) SUPPORT GROUP**

August 13, 2016 – Mardi Gras party and update on workshops presented at the 2016 National Patient Education Conference.

September 10, 2016 – Dr. Jason Kolfenbach, Rheumatologist at University of Colorado Hospital, will host a Q&A to answer your questions about scleroderma.

October 8, 2016 – To be announced.

November 12, 2016 – To be announced.

December 10, 2016 – Holiday party!

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

### **SOUTHERN COLORADO SUPPORT GROUP**

September 17, 2016 – Update on workshops presented at the 2016 National Patient Education Conference.

November 19, 2016 – Holiday luncheon! (Location 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**

August 27, 2016 – Update on workshops presented at the 2016 National Patient Education Conference.

October 22, 2016 - Deanna O'Connell, Registered Dietitian, Community Health Educator, will discuss diet and scleroderma.

December 3, 2016 – Holiday luncheon at 11:00 am at The Moot House, 2626 S. College Ave., Fort Collins, CO 80525. **(PLEASE NOTE THE SPECIAL TIME AND LOCATION FOR THIS MEETING!)**

**Meetings are from 10:00 am – 12:00 pm at the Medical Center of the Rockies, Mt. Meeker and Arapahoe Peaks Rooms (lower level), 2500 Rocky Mountain Ave., Loveland, CO 80538.**

### **WESTERN SLOPE (GRAND JUNCTION) SUPPORT GROUP**

September 10, 2016 - The benefits of yoga presented by Crossroads Fitness.

November 12, 2016 – Holiday party and update on workshops presented at the 2016 National Patient Education Conference.

**Meetings are from 11:00 am – 1:00 pm at Community Hospital, Legacy 1 Room (located on first floor by cafeteria), 2351 G Road, Grand Junction, CO 81505.**

## ***Scleroderma Might Slow Her Down, But Judy Laible Still Leads an Active Life Helping Others – Here is Her Story***

Judy Laible was raised in the seaside resort of Bournemouth on the southern coast of England. She enjoyed growing up by the beach, where even on rainy days she would gather with friends under a beach hut and play cards. Judy graduated from Queen Elizabeth College of the University of London with a degree in microbiology. Being foot loose and fancy free after graduating from college, Judy took a job in the United States.

Judy was working in Grand Island, NY when she met Allen, who was in the army and getting ready to go to Vietnam. They corresponded by letters while he was gone and met up again in California when he came home. They got engaged shortly thereafter and were married in the summer of 1970. They have two daughters - Irene who lives in Colorado and has a daughter Abby, and Debbie who lives in Pennsylvania and has a daughter Olivia. Allen worked for a power plant in Wyoming for 25 years but is now retired. His early retirement is what brought them to Colorado to be closer to Irene (and Judy, being a city girl, wanted out of Wyoming!).

Judy has been working for the Larimer County Department of Health for 15 years. She thinks about retiring but she loves her job and the people with whom she works! Judy works with the Nurse Family Partnership program. It is nationwide program that started in Denver and is an evidence-based program where specially trained nurses work with lower income single mothers from pregnancy until the child is 2 years old with a focus on teaching parenting and life skills.

When not working, Judy likes to spend time with family and her granddaughters. She and Allen like to travel to Florida to visit his brother and spend time on the beach.

Judy first started experiencing aches and pains in her hands, feet and joints in the 1990's. Her doctors could not figure anything out and she received lots of different diagnoses. Initially it was attributed to a virus and Judy was given high dose aspirin to relieve the pain until her ears started ringing as a side effect. At the time she was traveling quite a bit and lost her sister to breast cancer, so it was a very stressful period in her life. After she developed Raynaud's phenomenon, had several gut tests and learned she had high ANA (anti-nuclear antibodies), she started to put 2 and 2 together. It was not until she moved to Colorado in 2003 and saw new doctors that she was diagnosed with limited systemic sclerosis.

Judy was also diagnosed with celiac disease about 6 years ago after experiencing stomach issues. This diagnosis came right before her birthday so she decided she would enjoy her birthday cake before going gluten-free! She was very frustrated with her stomach pain so was glad for the diagnosis and now she observes a strict gluten-free diet. Being gluten-free is easier today with more products and foods available. Also there is more understanding that it is not a choice for her, it is something she has to do.

Judy does not have much skin involvement. Her symptoms include gastrointestinal tract issues complicated by celiac disease, Raynaud's and dry mouth due to secondary Sjogren's syndrome. She has no lung involvement.

Her biggest concern is the fatigue associated with scleroderma. She is wiped out after a day at work. It is a different kind of fatigue than before scleroderma. A feeling comes over her whole body and she feels like she can't move. Judy admits that she is not good with managing her fatigue. She is a go-getter so often when she has a good day, she overdoes it and regrets it the next day. She tries to plan her week and errands to allow time to take it easy.

With Raynaud's, Judy needs to be cognizant to avoid putting herself in a position that brings on attacks. In winter, driving can be an issue because she has a long distance to go to work and can't do much about an attack until she can soak her hands in warm water. It is very painful when her hands turn blue and red. Even going to the grocery store, or anywhere with air conditioning, over the summer can be challenging. She takes nifedipine, a calcium channel blocker, during the winter which helps.

Judy recommends to someone newly diagnosed with scleroderma to get the appropriate medical care from doctors who are familiar with the disease. (As the Northern Colorado support group co-leader, she stresses this to new members as well as sharing tips for dealing with Raynaud's and helpful products that can make daily life with scleroderma easier.) Also, get a handle on the diagnosis and live your life; you will need to make adjustments, but learn what you can still do and enjoy it. Judy is the type that wants to know and be educated about scleroderma. She encourages other to learn about it and advocate for themselves to get the best medical care and the help they need in the medical community.

The Scleroderma Foundation has been very helpful to Judy in gaining knowledge of the disease, being informed and getting support. It has been a comfort to her to meet so many with scleroderma who inspire her and with whom she has shared experiences.

Judy is looking forward to the Northern Colorado "Stepping Out to Cure Scleroderma" Walk on Sept. 11 at Fort Collins City Park (see page 1) and is already planning the Northern Colorado 2017 support group meetings. Her goal is to build the support group and reach out to more people in her area that are impacted by scleroderma.

***(NOTE: We extend a special thanks to Judy for co-leading the Northern Colorado support group and helping to plan the Northern Colorado "Stepping Out" Walk. We greatly appreciate all that you do for those with scleroderma!)***





## 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.*

### 2016 Patient Education Day

Save the date! **Sunday, October 16** is our 6<sup>th</sup> annual **Patient Education Day**.



## UCHealth

University of Colorado Health is providing their new Conference Center on the Anschutz Campus in Aurora for this event. Topics will include Raynaud's, the skin and scleroderma, scleroderma involvement in the lungs and gastrointestinal tract, nutrition and Q&A with the experts.

We are working with the Chapter's Medical Advisory Board to finalize the agenda so look for more information by mid-August and be sure to register early to reserve your space.

Thanks to a grant from the Insurance Industry Charitable Foundation, we are able to offer scholarships this year to scleroderma patients in the Rocky Mountain Region needing to travel overnight to attend.

(This program is made possible, in part, by an unrestricted educational grant from Actelion Pharmaceuticals US, Bayer HealthCare and Reata Pharmaceuticals.)

#### Contact Us At...

Scleroderma Foundation  
Rocky Mountain Chapter  
2280 South Albion St.  
Denver, CO 80222  
(303) 806-6686  
[cochapter@scleroderma.org](mailto:cochapter@scleroderma.org)

#### Follow Us At...

[www.facebook.com/COScleroderma](https://www.facebook.com/COScleroderma)  
[www.twitter.com/SclerodermaCO](https://www.twitter.com/SclerodermaCO)

#### Or Meet Others At...

[www.inspire.com/groups/scleroderma-foundation](http://www.inspire.com/groups/scleroderma-foundation)

### How To Donate

1. "Step Out" and walk with us on Sept. 11! [www.scleroderma.org/steppingoutftcollins](http://www.scleroderma.org/steppingoutftcollins).
2. 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 [www.scleroderma.org/colorado](http://www.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](http://sclerodermafoundation.myplannedgift.org).

