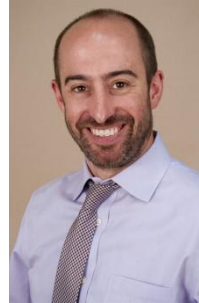




Virtual “Real Talk” Support Group Teleconference

Join us on Thursday, Nov. 8 from 7:00-8:00 p.m. for our quarterly virtual support group call. Dr. Paul Menard-Katcher, a gastroenterologist with the UHealth Digestive Health Center at Anschutz Medical Campus, will answer your questions related to scleroderma GI issues. Please email your questions in advance to cochapter@scleroderma.org. Questions received in advance will be given priority on the call. To participate, call 712-775-7031 and enter access code 781-611-035# when prompted.



Taking Charge of Systemic Sclerosis

Dr. Dinesh Khanna, Professor of Medicine and Director, University of Michigan Scleroderma Program and Janet Poole, Professor and Director of the Occupational Therapy Graduate Program in the School of Medicine at the University of New Mexico are members of a team who have designed a web based self-management program to help you learn about scleroderma, manage your symptoms and learn strategies to help you advocate for yourself. This program includes modules and resources broken down into manageable topics to guide you through the information. Get started today at selfmanagescleroderma.com.



Emergency Medical Apps

In the event of an emergency, first responders will need information from you that you may not be able to provide because you are incapacitated or unconscious. You can provide first responders with your emergency contact information, allergies, medications and more by using the emergency medical application on your iPhone or Android. By using these apps, first responders can access your critical medical information from the lock screen without needing your passcode.



With an iPhone, select the Health app, tap the Medical ID tab and select Edit to enter your medical information. To make your Medical ID available from the lock screen on your iPhone, turn on Show When Locked.

With an Android, go to the Settings app and tap Users. Tap Emergency Information to enter your medical information and emergency contact. From a locked screen, swipe up to reveal the number pad. Tapping Emergency on the number pad will access your medical information.

What’s Happening

- Nov. 8, 2018 – Virtual “Real Talk” Support Group Teleconference
- Dec. 4, 2018 – Colorado Gives Day

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

Kids had fun and got to know each other at Kids Get Scleroderma Too! in October at Children’s Hospital Colorado



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Board Update

At this time of year we often reflect and give thanks. We are grateful for all the volunteers who give so much of their time to make chapter events and programs such a success.

Our dedicated support group leaders – Sandee Maas, Lloyd Jones, Ali Davidson, Judy Laible, Barb Kinneer and Suzanne Hope – work hard throughout the year to schedule informative speakers and to stay in contact with members. They often take the time to meet one-on-one with newly diagnosed patients to ease their fears before coming to their first meeting.

The chapter Medical Advisory Board consisting of Aryeh Fischer, MD, Jason Kolfenbach, MD, Todd Bull, MD, Katharine Moore, MD, Paul Menard-Katcher, MD, Kristin Kilbourn, PhD, MPH and Michelle MacDonald, MS, RDN, CDE provides advice on research updates, assistance in planning our educational programs such as the annual Patient Education Day, presentations to support groups and training to medical professionals and students about scleroderma.

2018 Stepping Out Walks in June and the Food Fight! in September raised over \$120,000 combined! These funds support our chapter programs but also go toward funding important research at the national level. It would not be

possible to put on these events without the many volunteers who help with various tasks on the day of the event and without the committees who work all year long on the planning.

We partnered this year with the Tri-State Chapter to host Kids Get Scleroderma Too! This event featured educational sessions for parents and fun activities for teens and children with scleroderma and their siblings. Pediatric specialists with expertise in scleroderma helped us put this event together and traveled from all over the country to lead the workshops.

Christine Shephard, Suzanne Doolos and Mark Basson each lend a hand two days a week assisting with office work, projects and database management. What a help they are!

Finally, I am proud to work beside fellow chapter board members Marcy Thompson, Sandee Maas, Barb Frodin and Christine Shephard who, in addition to myself, look forward to guiding the chapter into the next year and continuing to support the scleroderma patients and community whom we serve.

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

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

February 7, 2019 – To be announced.

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

November 10, 2018 – Sara Palecki, a certified yoga instructor, will present on Yoga Nidra.

December 8, 2018 – Holiday Party!

January 12, 2019 – Open discussion – bring your questions and concerns about scleroderma to share with your peers.

February 9, 2019 – Sarah Funk, RD, CNSC, clinical dietitian specialist, will present on diet and scleroderma.

March 9, 2019 – 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

November 17, 2018 – Holiday Luncheon at Edelweiss Restaurant, 34 Ramona Ave., Colorado Springs, CO 80905. **(NOTE: DIFFERENT LOCATION FOR THIS EVENT!)**

January 19, 2019 – View and discuss a video from the 2018 National Patient Education Conference titled “Taking Care of Your Hands and Face” by Janet Poole, PhD, OTR/L.

March 16, 2019 – 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

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!)**

February 16, 2019 – Presentation on PAH by Actelion Pharmaceuticals – tentative. **(NOTE: DIFFERENT DATE 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

November 10, 2018 – Update on workshops presented at the 2018 National Patient Education Conference.

January 12, 2019 – To be announced.

March 9, 2019 – To be announced.

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

Figuring It All Out Has Been A Challenge For Christy – Here is Her Story

Christy Myers was born in Omaha, NE where she was raised in the country and rode horses. She graduated from the University of Nebraska Kearney in 1971. After marrying her husband Maurice (Moe) in 1983, the couple lived in Iowa where Moe grew up. There they farmed and both worked full time. For about 20 years, Christy commuted an hour each way everyday to her stressful job as a social services worker for the State of Nebraska. When Moe retired in 2009, they decided to move to Cheyenne, WY to enjoy riding their horses in the mountains. Christy has one sister and brother-in-law who live on a ranch in Broken Bow, NE. The sisters are very close. Before scleroderma, Christy helped work the cattle on their ranch. She also has a brother, nieces and nephews who live in Nebraska.

Although she now enjoys living in Wyoming, prior to moving to Cheyenne, Christy lost many family members which made her homesick. She was still feeling homesick when she started having symptoms of scleroderma.

Christy's Raynaud's started in the early 2000's, shortly after her father passed away. The Raynaud's came on slowly but got much worse about the time she was diagnosed with scleroderma in late 2015. Looking back, she realizes that the inflammation, circulation and GI issues she had over the

years may have been autoimmune related. She believes what may have triggered the onset of scleroderma was chronic stress due to her job and loss of family. In 2015 during a long horseback ride, her legs became



extremely swelled and she was very dehydrated. She thought at the time she may have been having kidney issues. She told her doctor about this and he ran tests to determine why she was getting inflammation. Christy tested positive for two rheumatoid factors. Her doctor sent her to Dr. Michael Thakor in Fort Collins who diagnosed Christy with limited cutaneous systemic sclerosis.

Having been diagnosed only a few years ago, Christy is still trying to determine which of her many symptoms are scleroderma related and which are not or which may be triggered by the scleroderma. Her symptoms include fatigue, weakness in her legs, tingling in her feet, osteoporosis, dehydration alternating with frequent urination, tail bone pain, poor circulation, vascular issues, muscle atrophy and nervous system issues. She has intermittent chest pain but her tests are normal. She also has gastrointestinal issues including mal-absorption, loss of motility, incontinence and duodenitis. Her acid reflux and difficulty swallowing comes and goes but scleroderma has affected her entire her GI tract.

Due to her multitude of symptoms it is hard to determine which doctor to see for what. She is still trying to build a

team of doctors who can work together to treat all her symptoms.

Christy started medication for her Raynaud's earlier this year and the vascular problems she had been having all over her body improved immediately.

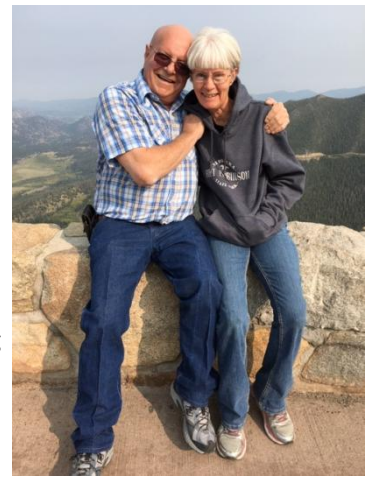
Christy has started watching her diet to see if what she eats is causing or can help her lower GI issues. She tried a gluten-free diet for 6 months but was losing too much weight. She knows that sugar and fats cause her to have GI issues. She has found that she needs to drink a lot of water everyday.

Because of her osteoporosis (and a fear of breaking something) and her scleroderma (vascular and GI problems and sensitivity to cold and extreme heat), Christy no longer can plan or go on long horseback riding trips with her husband. Scleroderma has made her more housebound because she can't plan ahead not knowing what each day will bring. Grocery store trips usually trigger a Raynaud's attack.

But Christy also sees the positive in her diagnosis of scleroderma. Since she started going to the gym in March, she is getting in better shape and her bone density has increased. She is eating better and learning how to adjust her diet to get over digestive issues more quickly. With so many symptoms, she didn't know if she should exercise or rest but now knows when to rest. She has experienced lots of anxiety over her symptoms but she is now seeing a therapist who has helped her immensely in dealing with her chronic illness.

Christy recommends to someone newly diagnosed that they join a support group as soon as possible. She was so scared of her diagnosis that she didn't reach out for over two years. When she finally did, it was the best thing she could have done for herself. She knows it is difficult for those who don't have scleroderma to fully understand so it was very helpful when she finally met others with the disease who she could talk to. Talking to others with scleroderma has helped her better understand her symptoms – which are scleroderma and which aren't. Now Christy better understands which doctor to see for a specific symptom. If someone suffers from anxiety or depression due to an autoimmune disorder, she recommends that they see a therapist who specializes in treating chronic illness.

Christy's husband Moe is battling Stage 4 cancer but is currently in remission so they spend as much time together as they can. Moe's positive attitude is contagious and gives Christy strength too. Christy loves walking and hiking with her two big dogs. Her project this winter is to work on her family's genealogy to learn more about her pioneer ancestors, including a German immigrant who started a candy company in Omaha, NE!





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.*

Reaching for the Cure on Colorado Gives Day

The Scleroderma Foundation Rocky Mountain Chapter will participate again this year in Colorado Gives Day on Tuesday, December 4. Colorado Gives Day is an annual statewide movement to celebrate and increase philanthropy in Colorado through online giving.

The Scleroderma Foundation's leadership has contributed to an impressive growth in scleroderma research activity that has helped clarify and characterize the disease, aiding in diagnosis and treatment. Innovative research has helped reduce mortality rates. Basic scientific research is developing clues to genetic components and environmental factors for scleroderma. Over the next month we'll share more in emails and on social media about how this research is helping scleroderma patients right here in Colorado.

But still there is no cure. We need your help to get there. This year you can designate your Colorado Gives Day donation specifically to research to support the Scleroderma Foundation's 20th Anniversary Reach for the Cure campaign. Please donate at coloradogives.org/rockymntscleroderma. Under Donation Details, select "Program" for where you want your donation directed, then select "Research" from the drop down list.

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.
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