

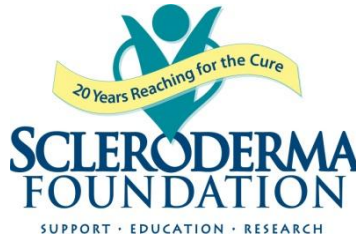
ROCKY MOUNTAIN CHAPTER NEWS

Winter 2018



Scleroderma Foundation 20th Anniversary

2018 marks the Scleroderma Foundation's 20th anniversary. As we continue to reach for the cure for scleroderma, we are committed to increasing the pace of research and increasing the pace of discovery. Look for more as the year unfolds.



"Real Talk" Virtual Support Group Webinar



Please join us on **Thursday, February 8 from 7:00 - 8:00 p.m.** for our "Real Talk" virtual support group webinar. Michelle MacDonald, RD, MS, Clinical Dietitian at National Jewish Health, will give a presentation on "Eating for Energy" including foods to eat to help combat chronic fatigue, foods to avoid and easy meals that you can prepare. To join the webinar at the designated time: 1) by computer: go to <https://join.me/coscleroderma>, enter your name and request to join or 2) by phone: (or if your computer has no audio) call 302-202-5900, enter Conference ID 947-770-935. Please place your phone and computer on mute.

Become an Advocate for Scleroderma

Tell your legislators about scleroderma and living with a chronic disease. You can make your voice heard by joining us this spring. On **Monday, March 12**, we will participate with the Chronic Care Collaborative at the Chronic Disease Awareness Day at the State Capitol in Denver. This event is an opportunity to educate our state lawmakers about chronic disease and healthcare issues in Colorado. Please register in advance at chroniccarecollaborative.org.

Members of the scleroderma community will travel to Washington, D.C. from **April 16-18** for the Scleroderma Foundation's annual Capitol Hill Day. Attendees will be trained on talking points to inform our federal lawmakers about important scleroderma legislation. Scholarships are available. For more information go to scleroderma.org/advocacy.

Running for Scleroderma

We have partnered with the 2018 Colfax Marathon as a Charity Partner. Runners can select the Scleroderma Foundation Rocky Mountain Chapter when you register as an individual runner or on a relay team. If just twenty runners select us, we get a free booth at the event to spread scleroderma awareness! So grab your running buddies and get signed up today at runcolfax.org for the 5K on **May 19** or the Marathon, Half-Marathon, Urban 10 Miler or Relay races on **May 20**.

What's Happening

- **February 8, 2018** – "Real Talk" Virtual Support Group Webinar
- **March 12, 2018** – Chronic Disease Awareness Day at State Capitol
- **April 16-18, 2018** – Scleroderma Foundation Capitol Hill Day
- **June 10, 2018** – 8th Annual Northern Colorado 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

(Registration for both Stepping Out to Cure Scleroderma Walks will be available in mid-February.)

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



Volunteer John Niemi (left) talks with Peter Vanicek, DDS about the dental issues related to scleroderma at the 2018 Rocky Mountain Dental Convention in January at the Colorado Convention Center.

INSIDE THIS ISSUE:

Support Groups	2
Board Update	2
Meet Paula Christenson	3
How to Donate & Contact Us	4

Are You In The Know?

Knowledge is power! We hear it all the time. When you have an autoimmune disease like scleroderma, knowledge can be critical. Educating yourself in today's world can be scary. There are many blogs, articles and websites that have so much information...but is it credible? Searching the Internet for medical advice can leave anyone with a bad case of information overload. The Internet can be very helpful, of course, but you have to know how to sort the reliable science from the junk.

There are many reliable sources for online information. University teaching hospitals, accredited medical schools, National Institutes of Health, Centers for Disease Control and Prevention and the Department of Health and Human Services are sites that end in .gov and can be trusted. Medical journal articles can be helpful if you can understand the technical writing! Of course the Scleroderma Foundation website has done the groundwork for you and the information is up to date and prevalent. In either case, ALWAYS discuss your findings, questions and concerns with your physician or care team.

NAVIGATING SCLERODERMA.ORG

From the home page of scleroderma.org, you will find many options. On the top of the page is a tab for "Patients and Newly Diagnosed". Here you will find a menu outlining many information sources ranging from all of the printed brochures,

upcoming patient education events, a resource page with links to other periodicals and sites. You can find a treatment center, current medical trials, local chapters and support groups. You can sign up for the E-newsletter. Under "Medical Information" you can find a link to helpful patient education videos. There is even a section for medical professionals and continuing medical education credits.

Our chapter website, scleroderma.org/colorado is tailored to meet your local needs. Our local support groups and teleconference support group dates and times are listed. You can volunteer, learn about upcoming events and find local contact information to speak to a real live human!

Don't get lost in the sea of information out there! Stay afloat and be wise when researching scleroderma. And once again, please discuss your findings and questions with your health care team.

Sandee Billen Maas
Denver Support Group Leader
Chapter Board Member
Board/Support Group Liaison



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

February 8, 2018 – Michelle MacDonald, RD, MS, Clinical Dietitian at National Jewish Health, will host a webinar on "Eating for Energy". See page 1 for details on how to join the webinar.

May 10, 2018 – To be announced.

Meetings are from 7:00-8:00 p.m.

MILE HIGH (DENVER) SUPPORT GROUP

February 10, 2018 – To be announced.

March 10, 2018 – Actelion Pharmaceuticals US, Inc.'s Rizwan Quader will present on "FAQ's about PAH".

April 14, 2018 – To be announced.

May 12, 2018 – To be announced.

June 9, 2018 – Picnic in the Park. Location 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

March 17, 2018 – To be announced.

May 19, 2018 – A representative from Actelion Pharmaceuticals US will present on "PAH-Tips for Being an Empowered Patient".

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

February 24, 2018 – Patricia Kuyper, OT, UCHealth, will present on "Hand Exercises for Scleroderma".

April 28, 2018 – A representative from the CSU Kendall Scott Nutrition Center will discuss "Nutrition and Diet for Scleroderma".

June 23, 2018 – To be announced.

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

March 10, 2018 – To be announced.

May 12, 2018 – 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.

Paula's "Unusual" Journey With Scleroderma

Paula Christenson grew up in St. Louis, MO. She lived in Springfield, MO for 20 years. About 1 ½ years ago, Paula and her husband Bud moved to Colorado because they liked it here and had no children left in Springfield. Paula and Bud's blended family includes three daughters and two sons who live all over the U.S. They have six grandchildren and one more on the way. Paula and Bud are most proud of the fact that none of their children fell through the cracks – all have good jobs and good marriages.

Paula has a masters in Educational Psychology and taught special education before she stayed home to raise the kids. She has since worked a variety of jobs including as a Mary Kay consultant, real estate agent and supporting electronic healthcare records. Bud is a peritoneal dialysis nurse who trains and supports people with home dialysis.

Paula first noticed her hands and feet swelling in June 2012. At first her doctor thought she was just getting older; but Paula didn't feel good either. Paula was a runner. She ran a half marathon in April 2012 and it was much harder than previous runs. About this time she also developed a rash on her torso. She saw a dermatologist in July 2012 who initially thought that Paula had dermatomyositis because of the rash; but also suspected some sort of autoimmune issue because of the inflammation.

The dermatologist ran blood tests but Paula had no antinuclear antibody (ANA) markers. Because of her inflammation, Paula was sent to see a rheumatologist who ran more tests. A muscle biopsy at the Washington University School of Medicine in St. Louis came back negative for dermatomyositis but positive for polymyositis, scleroderma and Raynaud's.

By this time, Paula could barely walk. She had so much inflammation that she couldn't bend to touch her feet. She was put on 60 mg of Prednisone (and Methotrexate which did not work for her). She started responding and by the end of 2012 and through most of 2013 she felt really good. She felt bad going to support group meetings because she felt so good. But what Paula didn't know and what she wasn't being treated for was a small intestinal bacterial overgrowth (SIBO). She had only some minor gastrointestinal issues – soft stool and she couldn't eat late at night.

Toward the end of 2013, Paula was throwing up at least once a week. By February 2014 her tongue was coated from a yeast infection in her esophagus and she was hospitalized for two weeks with what was believed to be bowel blockage. Paula continued to get worse. Finally her family decided that she needed better care and got her into see Dr. Fred Wigley, the Director of the Johns Hopkins Scleroderma Center in Baltimore, MD. She spent three weeks in the hospital at Johns Hopkins where doctors treated her SIBO and yeast infection and tried to "wake up" her stomach. She was down to 104 pounds. She was put on a Hickman catheter and has been on TPN (total parenteral nutrition) ever since. Paula has no peristalsis in her gastrointestinal tract. Food just

sits there because there is no muscle activity to push it through.

In October 2016, Paula's blood pressure suddenly spiked which is when doctors realized that scleroderma was impacting her kidneys too. A kidney biopsy also revealed that she had another autoimmune disease called MPGN causing too much protein in her kidneys.

Her CellCept dosage was increased to treat this. Paula believes that she had renal crisis in 2014 when she started TPN but that it did not show up until late in 2016. Paula's kidney function has been as low as 16% and is now at 33%. Her nephrologist thinks she may need a kidney transplant. She has gone through all the testing and has been turned down so far by two hospitals because she is deemed to be too high risk. She continues to look into her options for a transplant. She cannot get on a transplant list until her kidney function drops below 15%. Three of her children and a brother are all matches. Paula has had scleroderma for more than five years so it is unusual that her kidneys would be impacted now.

But Paula looks on the bright side. She has minimal lung and heart involvement. Her hands are good and she has not had a digital ulcer since 2014. Her Raynaud's is manageable. She uses an electric lap heater and stays inside when it is cold. Paula knits and sews – hobbies that she has always enjoyed – to keep her hands flexible. Even though she can't eat, she enjoys cooking which still gives her a relationship with food.

Scleroderma has changed Paula's life but she has adapted. She and Bud used to be very active, but now they enjoy bird watching. She can't run or hike much anymore (unless Bud helps push her uphill) but she does try to walk everyday and does yoga and aerobics once a week. Paula accepts that she cannot clean the entire house in one day. She has learned to be more in the moment, she can sit and be quiet and just enjoy people. She relishes the days when she feels good. She is more empathetic for people with chronic illnesses who "don't look sick" and is less judgmental. She loves going to support group meetings because she knows that she isn't all by herself and she enjoys the sharing and information. Paula has a strong faith in God and knows she isn't in this alone.

Paula recommends to anyone newly diagnosed with scleroderma to join a support group and attend the Scleroderma Foundation's annual National Patient Education Conference to educate yourself; be your own best advocate; learn and ask questions; accept that you may feel depressed but that it's also okay to get treatment for it if it's too great; enjoy life and don't feel you have to be busy every moment.

Paula is looking forward to a trip to Cancun this month and a trip to Missouri in April to help out when her newest grandbaby arrives.





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.*

Jill Seaman Assists in “Patients as Partners” Program

The Scleroderma Foundation’s “Patients as Partners” program is an opportunity for people with scleroderma to educate scientists about the challenges associated with the disease and how clinical trials can be designed to accommodate their unique needs to ensure successful outcomes.

Jill Seaman of Littleton traveled to Dallas in December to attend program meetings. Jill shared her experience. “The Bayer Corporation hosted two sessions, each with a panel of 10 scleroderma patients. The first session was patients that had participated in a clinical trial. The other involved patients that had not participated in a trial. I was part of the first session for clinical trial patients because I participated in the ASSIST trial and received an autologous stem cell transplant.

In the morning, all patients shared stories of how scleroderma affects our daily lives. In the afternoon, we discussed our experiences with our own trials – what was good, bad or could be improved upon with our own experiences.

At the end of the day Bayer shared that they are working on a compound drug for fibrotic diseases. They wanted to meet with scleroderma patients because scleroderma is a fibrotic disease that has no proven therapies or medicines. Bayer has been working on an oral medicine for 4 years. They are working on a trial that will be open to possibly 16 different countries. Bayer also said when they go into trial they will utilize the knowledge they gained from these panels to make their clinical trial protocols, procedures, equipment and paperwork easier for those with scleroderma or any other fibrotic disease. Furthermore, Bayer experts reiterated that they would keep in mind the limitations patients face on a daily basis to make this trial easier and more accessible.”

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. 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.



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