Fall 2020

SCLERODERMA FOUNDATION

SUPPORT · EDUCATION · RESEARCH

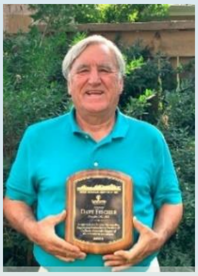
ROCKY MOUNTAIN CHAPTER

Celebrate 20 YEARS

Lew and Nettie Radeff

It was the late 90's and Nettie Radeff was traveling with her husband Lew when he noticed that she was not herself. It took one year to get a diagnosis of scleroderma. Nettie was 67 at the time and was given a very poor outlook. "Back then they just treated the symptoms and doctors didn't know much." Nettie's family banded together and set on a mission to learn as much as they could about scleroderma. Nettie's daughter Liz headed to the library and was depressed by all of the scary stuff she found. Always the fighter, Nettie was angry and figured someone had to do something since the doctors couldn't tell her what to do!

Around the same time, the Fisher family had just lost their mother Wanda Miller to scleroderma. The eldest son David remembers how the family struggled to make sense of it all. Wanda was sick for at least eight years before she died. It started out slow at first with Raynaud's. A trained nurse, Wanda took it all in stride and focused on raising her 8 children, mostly on her own. "Mom's illness progressed silently at first, but then it hit her inside and she couldn't eat and her lungs became affected. She just deteriorated." When she died, David called information to get the number for the Scleroderma Foundation (National) in Boston. The Fisher family wanted to unravel the "mystery illness" that took their mother.



David Fischer

National had received a series of calls over a few years from scleroderma patients and their families in the Denver area. Liz Radeff also reached the Scleroderma Foundation after calling information to get the phone number. National representatives explained that they did not have a chapter in Colorado and then asked, "would you like to help start one?" They started placing families and patients in touch with David Fisher. For a few years, the Denver scleroderma community met unofficially for support groups in private residences, then in the elementary school library where David Fisher served as principal. David recalled, "we grew slowly, from referrals from National and by word of mouth. My sister, Monica Williams, learned that her next-door neighbor had scleroderma and invited them to join the group. Those early meetings were so powerful. We would sometimes talk for 3 or 4 hours. Everyone's experiences were so different. My family learned and it helped us cope with our mom's death."

(Continued on page 3)

Contact & Follow Us

Scleroderma Foundation
Rocky Mountain Chapter
5403 E. Evans Ave.
Denver, CO 80222
(303) 806-6686
cochapter@scleroderma.org

scleroderma.org/colorado
facebook.com/COScleroderma
twitter.com/SclerodermaCO
youtube.com/COScleroderma

Scleroderma Treatment & Research Centers

National Jewish Health
Scleroderma Program
Main Campus
1400 Jackson St.
Denver, CO 80206
njhealth.org/scleroderma

University of Colorado
Anschutz Medical Campus
Division of Rheumatology
Anschutz Outpatient Pavilion
4th Floor
1635 Aurora Ct.
Aurora, CO 80045

INSIDE THIS ISSUE

Meet the Doctor

Dr. Melissa Griffith is the newest addition to the University of Colorado Scleroderma Clinic

Dr. Griffith was born in San Francisco, California and raised in Atlanta, Georgia. She went to college at the University of Notre Dame majoring in Biology and Spanish. Dr. Griffith attended Medical College of Georgia for medical school where she was inducted into the Alpha Omega Alpha medical honor society. She attended University of Colorado for Internal Medicine training and completed a fellowship in Rheumatology. She was attracted to Rheumatology due to her love of long-term relationships with patients and taking care of patients with medical complexity. Dr. Griffith's interest and expertise includes how to diagnose and treat autoimmune conditions that affect the lungs. Dr. Griffith was attracted to working in the scleroderma clinic due to her own family member with scleroderma lung disease. She works in the Center for Lungs and Breathing (CLB), Autoimmune Eye clinic, and Rheumatology Department at the University of Colorado. In the CLB, pulmonologists, radiologists, pathologists, and rheumatologists work very closely together in a weekly multidisciplinary conference to discuss best strategies for treatment, monitoring of disease progression, and ideas for care of the patient.

To make an appointment with Dr. Griffith contact the Center for Lungs and Breathing.
720-848-0748

SUPPORT GROUPS

All 2020 support groups will be held virtually on Zoom.

Patients, caregivers, family and friends are all welcome. For more information and Zoom meeting IDs, contact the chapter at 303-806-6686 or cochapter@scleroderma.org. http://bit.ly/COSupport

The Rocky Mountain Chapter is seeking support group leaders to help us expand into WY, MT, NM and UT. Contact Christine at cochapter@scleroderma.org if you are interested in learning more.

Support Group Dates/Times

September 12, 2020 – 11:00 a.m. MT
September 19, 2020 – 11:00 a.m. MT
October 10, 2020 – 11:00 a.m. MT
October 24, 2020 – 10:00 a.m. MT
November 14, 2020 – 11:00 a.m. MT
November 21, 2020 – 11:00 a.m. MT
December 12, 2020 – 11:00 a.m. MT
January 9, 2021 – 11:00 a.m. MT
January 16, 2021 – 11:00 a.m. MT
February 13, 2021 – 11:00 a.m. MT
February 27, 2021 – 10:00 a.m. MT
March 13, 2021 – 11:00 a.m. MT
March 20, 2021 – 11:00 a.m. MT

Rocky Mountain Chapter Beginnings

Continued from front cover:

Harriet Rutt had been diagnosed with scleroderma for over a decade before this fledgling support community was formed. Harriet and her husband Richard were very active in their community of Lancaster, PA. and created the Stroll & Roll fundraiser to benefit the Scleroderma Foundation. Their daughter Cyndy Besselievre, a Colorado resident, recalls flying across the country to rollerblade at the fundraiser. Harriet's first symptoms took several years to diagnose as scleroderma but were attributed to tightening skin: she couldn't stand the weight of even a sheet on her skin and she would say "it feels like someone is standing on my feet!" The disease attacked slowly at first with mostly skin and GI involvement; but eventually Cyndy and her sisters noticed that Harriet couldn't walk up the stairs without becoming short of breath. Harriet was diagnosed with interstitial lung disease and pulmonary arterial hypertension in 2002. Cyndy was already familiar with the Scleroderma Foundation and jumped at the chance to attend support groups and work towards the creation of a new Rocky Mountain Chapter.

2001-2021
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Madonna "Donnie" Schlereth was a force to be reckoned with. As a child and young adult, she endured 25 surgeries to repair a cleft palate and cleft lip. A successful banker and doting aunt, Donnie started to suffer from reflux and esophageal tightening, requiring several stretching procedures. Raynaud's and breathing issues came next. Donnie had done extensive research and knew she had scleroderma. Her physicians continued to dismiss her concerns. Undaunted, Donnie called National and was connected with David Fisher. Donnie's sister Marianne recalls how impactful those early support group meetings were. "That group was heaven sent for Donnie. She was finally able to learn more about scleroderma and get the names of doctors that could help her. She wasn't crazy!"

Tom and Jan Oliver connected with the support group in 2001. Tom had gone from a being "as healthy as a horse," coming up on age 50, to disabled within six months. Jan was a scientist by profession and immediately began to research. She started on the internet and found too much anecdotal and 'snake oil' stuff. Shifting gears, Jan began reaching out to top research institutions like Mayo Clinic and Johns Hopkins. It wasn't long before she was on a first name basis with top scleroderma researchers Dr. Fredrick Wiggley, Dr. Daniel Furst, and Dr. Richard Nash. Jan recalls a complement shared to her by the researchers, "Jan you know more about scleroderma than most of the doctors out there." Jan reflected, "those early support group meetings helped us all learn about scleroderma. You could compare notes with the patients about doctors and learn that cumulatively the group knew more about scleroderma than any of the individual doctors. We were all learning together."

In 2001, a representative from the National Foundation flew out and meet with the support group members to discuss setting up a chapter for the Rocky Mountain Region. After the meeting, members assembled a board of directors. David Fischer signed on as President, with Christine Skurdahl as Vice President, Monica Williams as Secretary and Cyndy Besselievre as Treasurer. The seeds of the Rocky Mountain Chapter were planted. Follow along in 2021 as we share more stories about the people that made the Rocky Mountain Chapter what it is today.

Visit our chapter webpage throughout 2021
to learn about all of our anniversary programs and events!
www.scleroderma.org/Colorado

Harriet Rutt and Cyndy Besselievre

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5403 E. Evans. Ave. Denver, CO 80222

Patient Education

SCLERODERMA FOUNDATION
VIRTUAL UNIVERSITY
· PATIENT EDUCATION ·
ROCKY MOUNTAIN SERIES

Saturday, October 3, 2020

Taking Charge of Your Lung Health

GI Manifestations of Scleroderma

Overcoming Nutrition Challenges
with Dr. Tracy Frech

Controlling Stress in an
Unpredictable World

Scleroderma 101

Skin, Muscles and Joints in Scleroderma

For more information or to register, visit www.scleroderma.org/colorado