



Scholarships for 2017 National Patient Education Conference

For first time attendees, the National Conference brings hope to those who thought they were alone in the fight against scleroderma. Lauren Higbee of Broomfield, CO attended her first National Conference last year. "Attending the National Conference last July was such a great experience. For my husband, the non-patient, he found it educational, informative, and hopeful. For myself, as the patient, it meant more than that. Each day I was surrounded by my scleroderma family; a group of women, men and children affected by the disease. A full weekend where we could all feel comfortable in our own skin, without worries of what others thought, or that others did not understand what we were going through. I look forward to attending more National Conferences in the future."



Scholarships are available for first time attendees. The deadline to apply for a scholarship is March 16. To learn more about the National Conference and scholarship opportunities, go to www.scleroderma.org and click on "Attend Conference". We hope many first timers and those who have attended before will take advantage of the proximity to Denver this year to attend the National Conference in AZ. If you are interested in carpooling, please contact our Chapter at 303-806-6686.

We Are Scleroderma!

Our Chapter goal this year is awareness. We believe there are many people with scleroderma in the Rocky Mountain region who are not aware of the support and programs that we provide for patients and their families. We want them to know we are here. We Are Scleroderma!

We are also working with our Chapter Medical Advisory Board to educate up and coming physicians. We will roll out the program this spring with a "lunch and learn" meeting between the rheumatology fellows at UHealth and several scleroderma patients.

Help Spread Awareness at a 9Health Fair

9Health Fairs are coming up again in April. Every year we try and increase the number of Fair locations where we host scleroderma information tables. But we need your help to staff the tables! We will provide you with all the information as well as talking points and instructions. It only takes a half day of your time to spread scleroderma awareness! Contact Cyndy at cochapter@scleroderma.org or 303-806-6686 to volunteer.

What's Happening

- June 17, 2017 – 13th annual "Stepping Out to Cure Scleroderma" Walk at Centennial Center Park.
- July 21-23, 2017 – National Patient Education Conference in Chandler, AZ.
- Sept. 13, 2017 – "Food Fight! Chefs Fighting for a Hard Disease" at BAC Appliance Center in Englewood.
- Oct. 1, 2017 – 7th annual "Stepping Out to Cure Scleroderma" Walk at Fort Collins City Park.

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



Ugly holiday sweaters and hats abounded at the Denver support group holiday party in December!



Meet Pam Lindquist – see Board Update on p.2

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Chapter Board Update

Happy New Year! As mentioned in the last Board Update we have been analyzing last year's successes and areas of improvement and decided on hiring a new Marketing Manager who will oversee our communication needs, be our link to the local media and aid in fundraising. We are happy to introduce to you Pam Lindquist. (Please read her remarks below).

Hello to the Rocky Mountain Chapter! I am honored and excited to be a part of such a wonderful organization. Having just started this year I am quickly learning all of the many areas that I can be a part of. The success and growth of the "Food Fight!" is fantastic and I hope to add to this growth along with the strong team at Fresh Events. The June "Stepping Out" Walk has been my main area of focus as we are busy re-doing the sponsorship packet, participant brochure and poster. With a few months before the event, we are actively looking at promotion in all areas. Meetings have already been held for the Northern Colorado "Stepping Out" Walk in October. I have already enjoyed and look forward to working to support all that Cyndy Besselievre has done so well and to hopefully take a number of these things off of her plate to ensure that she has time to focus on the important responsibilities as your Executive Director.

My background both professionally and philanthropically has been in marketing. My husband and I co-own and operate PL2, Inc. which is a consulting firm specializing in marketing and financial consulting. Some of our past professional marketing activities included managing, organizing and running WinterFest 2013 at Evergreen Lake. This event encompassed 3 sponsored sporting events in one day, employed a 225 volunteer workforce and boasted attendance exceeding 10,000 people.

PL2 has also consulted for and managed the "Special Events and Giving Back" Division known as the "Margaritas With a Mission" Program for Coyote Gold Margaritas. Supporting over 150 non-profits events with margaritas has been a very positive and rewarding experience. Possibly you had a chance to taste Coyote Gold at the Food Fight! last year.

I look forward to meeting all of you and to find out more about your thoughts and marketing goals for your Chapter. Please don't hesitate to contact me directly. I can be reached at pam.coscleroderma@gmail.com or 720-339-4687.

Thank you,
Pam Lindquist

Support Group News

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

"VIRTUAL" SUPPORT GROUP TELECONFERENCES

May 4, 2017 – Speaker and topic to be announced.

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

MILE HIGH (DENVER) SUPPORT GROUP

February 11, 2017 – To be announced.

March 11, 2017 – Presentation by Dr. Erika Enos, ND of Healing Roots Natural Medicine (tentative).

April 8, 2017 – Janet Poole, PhD, OTR/L, University of NM will discuss managing fatigue and activities of daily living.

May 13, 2017 – Mallary Crow Adams, Clinical Research Coordinator at UCHealth, will discuss the clinical research process.

June 10, 2017 – Picnic in the Park! (Location to be announced.)

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

SOUTHERN COLORADO SUPPORT GROUP

March 18, 2017 – Sandee Billen Maas will present on the Basics of Essential Oils.

May 20, 2017 – 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

February 25, 2017 – Julie Knighton, RN, MSN, Community Health Education Coordinator, will discuss programs available through UCHealth related to living with chronic conditions and pain. **(Big Thompson Canyon Room – 1st floor.)**

April 15, 2017 – Dr. Paul Menard-Katcher, Gastroenterologist at UCHealth will discuss gastroenterology problems with scleroderma. **(Longs Peak Room – lower level.) (NOTE: This meeting will be held on the 3rd Saturday in April.)**

June 24, 2017 – Kim Ferro, BSW, Aspen Club Specialist, will discuss the use of medical documents such as advanced directives and durable powers of attorney. **(Arapahoe Peaks and Mt. Meeker Rooms – lower level.)**

Meetings are from 10:00 am-12:00 pm at the Medical Center of the Rockies, 2500 Rocky Mountain Ave., Loveland, CO 80538.

WESTERN SLOPE (GRAND JUNCTION) SUPPORT GROUP

March 11, 2017 – To be announced.

May 13, 2017 – To be announced.

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

ALBUQUERQUE/RIO RANCHO, NM SUPPORT GROUP

This group meets monthly on the 2nd Saturday of each month from 1:00-3:00 pm at The Sabana Grande Recreation Center, 4110 Sabana Grande Ave. SE, Rio Rancho, NM 87124. For more information, please contact Anna Wenger at 505-974-9293 or annawenger91@gmail.com or Theresa Johnson at 520-248-2235.

Anna Gives Support to Others with Scleroderma – Here is Her Story

At age 11, Anna was a very vibrant and active little girl. Her father had gotten a new job working for an environmental waste company so her family moved from Tucson, AZ to Columbia, MO. After that her world began to change.

Right away Anna made new friends. She got into roller skating and absolutely loved it. She was pretty good. She also had a lot of other hobbies. Then all the sudden her friends and mom noticed she was slowly not able to do the things she loved and was running out of energy. She was losing weight and just did not feel good; she then knew something was wrong but did not know what.

Anna's family moved to Fargo, ND to get better health care. Anna was 12 and going into the 7th grade. Little did she know that the cold would make the conditions so much worse.

In 2004, Anna's doctor finally sent her to the Mayo Clinic in Rochester, MN. After multiple tests they found out she was positive ANA and scl-70. She was only 12; she had no idea what they were talking about. Anna was told she had diffuse systemic scleroderma. She had no idea what that meant; she just wanted to be a normal teenager.

Right after her diagnosis, it hit Anna like a ton of bricks. She had ulcers the size of dimes on both elbows and she couldn't even wear a long sleeve jacket. She was in so much pain and had no idea what to do. Her family finally decided they needed to move back to Tucson, AZ where it was warmer.

Anna was back where she grew up. Her appearance had completely changed in the two years she was gone. Her elbows finally healed but other ulcers were coming up everywhere else. She really wished she had someone to talk to back then that knew what was wrong with her and about how important and serious this disease was. She felt so alone and no one understood what was going on, not even Anna herself. If she would have met someone else that was going through all of the confusing changes she was going through, Anna thinks she would have gotten a better perspective on scleroderma and how to manage it.

Throughout the years her fingers and toes started to auto-amputate. It was the worst pain Anna ever experienced and she felt like she was all alone. The emergency room said that there was nothing they could do except to amputate. Anna learned that it was better to let it auto-amputate so that more of the finger can be saved. She can't stress enough that you are your best advocate! Anna learned that on her own.

In August 2014, Anna moved to New Mexico where her mom lives. She started to get better health care and her right hand finally healed. She lost the tips to every finger and some of her thumb on her right hand. On top of that, she found out she has PAH (pulmonary arterial hypertension) and ILD (interstitial lung disease) at the age of only 22. But she didn't let that get her down. That is when she really started doing research and being very active trying to help people online going through the same struggles she went through.

In April 2016, Anna got really sick and was rushed to the

hospital. They thought she just had pneumonia. She had never been on oxygen before. When they checked her O2 level, it was at 50%, so they put her on oxygen right away. She started to feel better and was able to eat for the first time in weeks. That was the last thing she remembers.

Anna woke up days later with a long tube down my throat, so confused. The salt from the food had made her go into heart failure and her heart filled with water. Also her ILD had worsened. She had to be on 35 liters of oxygen. The doctors thought that this was it for her. It was not! Anna survived. Slowly she was getting better and using less oxygen. After 2 weeks she could stand on her own again.

Anna had no idea that scleroderma could spread in her organs so fast. Ever since April 2016, she needs 5 liters of oxygen to walk. She doesn't want anyone to feel bad for her but she hopes to share her experiences to show how important it is to be educated about your illness.

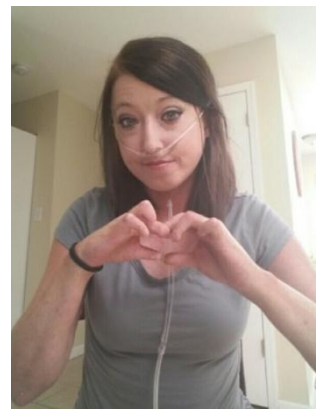
Anna now feels more empowered than ever! She has been slowly trying to get better. She thought to herself...why not start a support group? She's not going to let her hands, heart or lungs stop her! If she can help even one person then she knows she has done her part!

She is hoping to create awareness about scleroderma; also to let all her struggles be someone else's lessons. She has been living with this disease for over 12 years and dealt with so much. She just wants to be there for anyone newly diagnosed or anyone that is confused just like she was. She knows if she would have met someone like herself when she was first diagnosed things would have turned out differently.

After seeing many doctors, they finally suggested that Anna get evaluated for a lung transplant. She's not going to let this get her down. Someone suggested she put the support group on hold but she said "no way!" She is determined to make a difference, give support and help educate.

Anna recently saw the lung transplant doctors. She had 6 quick tests, met the doctor and flew home that night. She is a candidate so now she needs to do several weeks of about 25 tests to see if she is able to get it done. But first, Anna is looking into the HSCT (stem cell transplant) program at Northwestern University and hopes to be seen there as soon as possible. If she qualifies for the HSCT, she would rather do that than the lung transplant because outcome looks better.

Anna wants to show women and men that you can be beautiful no matter what! Everyone is beautiful in her eyes and any imperfections just make you look so much stronger! Anna's goal is to have a safe place to go for support for anyone impacted by scleroderma, help people feel empowered despite their disabilities and help spread awareness! She recently started a support group in Rio Rancho, NM. The group is growing and is filled with wonderful people. She has learned so much from them and hopes they are learning from her. Together we are strong!





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.*

Give to Scleroderma at No Cost to You

That right! It doesn't cost you anything to support the Scleroderma Foundation in more ways than one. Here's how:

King Soopers Neighborhood Rewards Program – Yes, we've mentioned this before! But as a reminder to those of you with the gift cards already and to those of you who would like to get involved in this program, every time you reload your card and use it to shop, King Soopers/City Market donates 5% of that amount to the Scleroderma Foundation-Rocky Mountain Chapter. You still get all your points and rewards! It's so easy to use; you can reload the card at customer service or at checkout. Get in the habit of using the card regularly and your support will help. Contact us at 303-806-6686 or cochapter@scleroderma.org for a new or replacement card.

AmazonSmile – Do you shop online at Amazon.com? Then sign up for AmazonSmile, select the Scleroderma Foundation as your charity of choice and Amazon will donate 0.5% of all your eligible purchases to the Scleroderma Foundation. To sign up, and then every time you shop online, go to www.smile.amazon.com.

Contact Us At...

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Meet Others At...

www.inspire.com/groups/scleroderma-foundation

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 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.

