



STEP STEP STEP On Up!

Fresh air, friends, laughter and loads of fun for the entire family! That's what the **13th annual "Stepping Out to Cure Scleroderma" Walk** is all about. So get ready to step out with us on **Saturday, June 17 at Centennial Center Park**.

Registration opens at 7:45 a.m. and the Walk starts at 8:30 a.m.



Comedian Sam Adams will be there to entertain. Mrs. Colorado International 2017 will make an appearance. Activities for the kids, balloons, food, music and more...don't miss this fun and important event! **Sign up today at www.scleroderma.org/steppingoutdenver**.

"Virtual" Support Group Teleconference

Back by popular demand to follow up on her discussion in November about eating healthy, **Shelley Van Pelt, RN, MSN, CNS** will join us again to host a "virtual" support group teleconference on **Thursday, May 4 from 7:00-8:00 p.m.** This time Shelley will talk about "Sugar. It's Not as Sweet as You Think" – the damage sugar does when you have an autoimmune disease.



To participate in the teleconference, call **(712) 775-7031** and enter code **781-611-035#** when prompted. Time will be allowed for your questions.

Eagle Riders Are Riding For Scleroderma



Mrs. Colorado International 2017 Birgit Daniels and the F.O.E. Eagle Riders are riding their motorcycles to raise money and awareness for scleroderma on **Sunday, May 21**. The ride starts and ends at **F.O.E. Northwest #4019 in Federal Heights**. Kick stands up at 9:00 a.m. Enjoy a scenic ride through the Colorado countryside with several fun stops along the way. Ride for free with a \$50 donation to the Scleroderma Foundation! Learn more at www.scleroderma.org/goto/pokerride.

June is Scleroderma Awareness Month

Every year in June we ramp up our efforts to spread awareness of scleroderma. Collectively we can all make a difference. Get involved this June – like and share our social media posts throughout the month of June, get some literature from us to take to your doctor's office, host a "teal" party to tell your friends about living with scleroderma, walk with us on June 17 and bring your friends, become a member of the Scleroderma Foundation. Think outside the box. What ideas do you have to spread awareness? Be sure to share with us.

What's Happening

- **May 21, 2017** – Eagle Riders Poker Run, starts and ends at F.O.E. Northwest #4019 in Federal Heights.
- **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.
- **Sept. 24, 2017** – Patient Education Day at UHealth, Anschutz Medical Campus in Aurora.
- **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.



Spreading scleroderma awareness at the 9Health Fair at UHealth, Anschutz Medical Campus in April. Thanks to our great volunteers, we were able to host scleroderma information tables at more than twenty 9Health Fair locations this year!

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Chapter Board Update

We hosted our annual Chapter meeting in February with a pizza party at Beau Jo's. Many members attended to learn more about what we do and where we are going.

2016 Accomplishments

- Stepping Out Walks raised \$65,000
- Food Fight! raised \$55,000
- Colorado Gives Day raised \$10,000
- Received \$10,000 grant from the Insurance Industry Charitable Foundation (IICF)
- Provided scholarships for members outside the Denver metro area to attend the annual Patient Education Day
- Nine Chapter members attended the National Patient Education Conference
- Expanded the Chapter Medical Advisory Board
- Provided board training and development
- Started "virtual" support group teleconferences
- Continued advocacy efforts

2017 Goals

- Raise \$70,000 at Stepping Out Walks
- Raise \$60,000 at Food Fight
- Raise \$12,000 on Colorado Gives Day
- Utilize IICF grant to develop "Lunch and Learn" program and provide education within the medical community
- Increase participation at Patient Education Day
- Grow patient outreach
- Increase participation at National Patient Education Conference in Arizona
- Increase Medical Advisory Board engagement
- Grow Chapter board of directors and volunteer base
- Increase advocacy at state and national level

We encourage you to get involved today!

Theresa Rice
Chapter President

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 – Shelley Van Pelt, RN, MSN, CNS will discuss "Sugar. It's Not as Sweet as You Think".

August 10, 2017 – 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

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

June 10, 2017 – Picnic in the Park and Ice Cream Social at Mamie D. Eisenhower Park, Picnic Site #4, 4300 E. Dartmouth Ave., Denver, CO 80222. **(NOTE: Different location for this event.)**

July 8, 2017 – Vicki Emch, Dietitian, will discuss nutrition and scleroderma.

August 12, 2017 – Update from workshops presented at the National Patient Education Conference.

September 9, 2017 – 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

May 20, 2017 – Show and tell - bring your favorite tool or gadget for daily living with scleroderma to share with the group.

July 15, 2017 – Lauren Languido, Psychology Clinic - UC-Denver, will present on chronic illness and relationships.

September 16, 2017 – Update from workshops presented at the National Patient Education Conference.

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

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.

August 26, 2017 – Update from workshops presented at the National Patient Education Conference.

Meetings are from 10:00 am-12:00 pm 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

May 13, 2017 – Jeanette Durham, MS, RD, CDE, Community Hospital, will discuss nutrition and scleroderma.

July 8, 2017 – Questions & Answers with Dr. Aryeh Fischer, Rheumatologist, Director-Systemic Scleroderma Program, University of Colorado School of Medicine (tentative).

September 9, 2017 – Update from workshops presented at the National Patient Education Conference (tentative).

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.

Mrs. Colorado International 2017 Spreads Autoimmune Awareness

Birgit Daniels is the adopted daughter of East German immigrants. She was born and raised in South Carolina. Birgit graduated from Purdue University with a degree in business management. Having spent summers in Colorado from age three until 15, she decided to move here in 1989 after graduating from college. Birgit got into the construction industry when she moved to Colorado and worked her way up the ladder to management and project management handling commercial ground-up builds and tenant finishes. She currently is a national project manager at Pacific West Construction. Birgit married Bobby in 2014 and between them they have five children.

Birgit was always healthy until about 3 ½ years ago. Her rheumatoid arthritis (RA) started with excruciating pain in her shoulders. She worked out a lot to relief the stress from work and thought she had just over exerted herself. If she rested it would get better, but the pain would come back when she resumed her workouts. Then the pain moved to her wrists, hands and knees. Eventually she had difficulty walking and getting up the scaffolding at project sites. She received a bracelet from Bobby at their wedding in 2014. They served prime rib at the reception (which Birgit now knows is a trigger food for her inflammation) and her wrist swelled so much that the bracelet was tight on her arm for the next 3 days.



Birgit speaks to legislators and patient advocates at the 10th annual Chronic Disease Awareness Day at the State Capitol in March.

The frequency and intensity of Birgit's pain and swelling increased until she was officially diagnosed with RA about four months before her wedding. Until then she thought it was probably just stress related.

Birgit knows there is no cure for RA but believes she can do things to help. She admits she is still in the denial stage because she

feels she can fix it. She has been very active all her life so the diagnosis was hard to accept.

Birgit takes methotrexate and Humira injections. RA has changed her. She suffers from fatigue from the disease and the medications. She has changed her eating habits; although she drinks more caffeine than she used to because she needs it to keep her going doing her busy work week – she hasn't listened to her doctors who have told her to slow down! Her sister is a physician's assistant so Birgit talks to her a lot about what to do and explain to her what the doctors say. (Birgit is trying to convince her sister to go into medical research and find a cure for RA!) She admits she wouldn't have made it this far without the love and support from Bobby to help her through the bad days.

Lately Birgit has had trouble sleeping. Because of the pain, she can't get comfortable at night. Then she just lies in bed

thinking which makes it worse.

Birgit feels she needs to be her own internal cheerleader. She has a high threshold of pain so she can usually deal with it. She focuses on other things that make her happy. Laughter really is the best medicine. Birgit also turns to upbeat music that makes her want to get up and move. For her, if she pays attention to the pain and gives in to it, she feels it more; but if she focuses her time and energy on being productive and interacting with people, she feels better. She has gone through bad times both mentally and physically. There have been days when she needed help bathing or honestly felt that it would feel better to cut off her arm than continue to experience the pain of RA. Her pain is more manageable today but she still pays for it later when she over does it or does something she knows she shouldn't.

Birgit recommends to anyone diagnosed with a chronic illness to get a good doctor, stay positive and stay active. Birgit keeps active enjoying her favorite outdoor activities – motorcycle riding, hiking, fishing, boating and tubing while being pulled by speed boat!

About 15 years ago, Birgit got involved in pageants on a dare. There aren't many women in the commercial construction industry to start with so it isn't typical to have many in pageants either. She won Mrs. Congeniality at her first competition! After a few pageants, Birgit realized that some are more community service based. She entered the Mrs. Colorado International 2017 competition because it is focused on giving back. This pageant has given her the opportunity to use her year-long reign to educate people about autoimmune diseases. She has always had an outgoing personality but she is amazed now how people will stop, look and listen when they see her in her sash and crown. Birgit wants to make the most of this opportunity to make a difference for those with autoimmune diseases. Her focus started with RA but she is reaching out to smaller organizations that support lesser known diseases, such as scleroderma, where she feels she can make the most impact.

Birgit will make an appearance at our "Stepping Out" Walks this year where walkers will have the opportunity to get their photo taken with her and kids will get a special gift. Birgit has also organized a motorcycle ride on Sunday, May 21 with the Fraternal Order of Eagles "Eagle Riders" to benefit the Scleroderma Foundation-Rocky Mountain Chapter (see p.1 for more information).

We are thoroughly enjoying getting to know Birgit and greatly appreciate all that she is doing to advocate for and spread awareness of scleroderma and autoimmune diseases! Birgit will compete for the International crown in August in Charleston, WV against competitors from all 50 states and other countries. We wish her the best of luck! Follow Birgit at www.facebook.com/mrscoloradointernational2017.





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.*

“Lunch & Learn” Educates Medical Professionals



UCHealth rheumatologist Dr. Jason Kolfenbach hosted a “Lunch and Learn” program on April 26 for medical residents, fellows and nurses to teach them about scleroderma. Dr. Kolfenbach discussed diagnosis and treatment and demonstrated several skin examinations. Ariana Amoroso, Ken Urban and Bobbie Jo Sanchez talked about the challenges of living with scleroderma from the patient’s perspective. Internal medicine resident Adam Berlinberg found this to be a “great experience to see scleroderma manifestations and learn from actual patients first hand”.

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.



Contact Us At...

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