

# ROCKY MOUNTAIN CHAPTER NEWS

Summer 2017



## “Real Talk” Virtual Support Group Teleconference

Please join us on **Thursday, August 10 from 7:00 - 8:00 p.m.** for our “Real Talk” virtual support group teleconference. **Linda McNamara and Karen Kemper**, authors of “If You Have to Wear an Ugly Dress, Learn to Accessorize: Guidance, Inspiration, and Hope for Women with Lupus, Scleroderma and Other Autoimmune Illnesses” will share their experiences living with serious autoimmune illnesses. They will discuss the metaphor of “The Ugly” dress which represents chronic illness and how attitudes, beliefs and behaviors can be used as “Accessories” to cope with the challenges of an Ugly Dress.



To participate, call **(712) 775-7031** and enter access code **781-611-035#**.

## Get Ready for a “Food Fight!”



It's baaaack! Satisfy your appetite and quench your thirst at the 3<sup>rd</sup> annual “**Food Fight! Chefs Fighting for a Hard Disease**” event on **Wednesday evening, September 13** at **BAC Appliance Center, 1880 W. Oxford Ave.** in Englewood. Nine of Denver’s award winning chefs and three mixologists will provide cuisine and drink for foodies from all over! Tickets won’t last long. Go to [www.cheffoodfight.com](http://www.cheffoodfight.com) for yours!

## “Step Out” to a Fall Festival

Fall Fun in Fort Collins! Step up, right up to the 7<sup>th</sup> annual **Northern Colorado Stepping Out to Cure Scleroderma Walk** on **Sunday, October 1** at **Fort Collins City Park, 1500 W. Mulberry St., Fort Collins**. This year’s Fall Festival theme offers fun activities for the entire family: 3K and 5K walk, balloon twisting, face painting, glitter tattoos, princesses, bobbing for apples, games and more! Register, set up your team and start fundraising today at [www.scleroderma.org/steppingoutftcollins](http://www.scleroderma.org/steppingoutftcollins).



## Patient Education Day is Sunday, September 24

New this year are sessions on caregivers, palliative care, naturopathy and juvenile scleroderma. This year’s annual **Patient Education Day** will be held on **Sunday, September 24** from **9:30 a.m. - 3:00 p.m.** in the **Bruce Schroffel Conference Center at UHealth – Anschutz Medical Campus** in Aurora. Registration is coming soon. Don’t miss this informative event for scleroderma patients, caregivers, family and friends!

## What’s Happening

- Aug. 8, 2017 – Kendra Gives Back at Kendra Scott Jewelry, Cherry Creek North (see p. 4).
- Aug. 10, 2017 – “Real Talk” Virtual Support Group Teleconference.
- 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 – 7<sup>th</sup> annual “Stepping Out to Cure Scleroderma” Walk and Fall Festival at Fort Collins City Park.

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



Walkers having fun at Stepping Out to Cure Scleroderma Walk at Centennial Center Park in June.

Our apologies to **Team Seaman** (tie-2<sup>nd</sup> place team with most walkers) and **Team Sandee Jo** (tie-5<sup>th</sup> place team with most walkers) whom we failed to recognize at the event. Both of these teams bring many family members and friends to support the Walk every year !

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## Chapter Board Update

Dear Scleroderma Family,

As the new board President for our chapter I wanted to take a moment to say, thank you. Thank you, to those who are supporting our organization by ways of volunteering and financial support. The dedication that you have for our mission and patients is the positive energy that is needed to continue to build awareness and help the lives of individuals who have been diagnosed with scleroderma.

I want to thank our outgoing President, Theresa Rice, for her leadership and volunteer time on the board. She will continue to be involved and we are grateful for her continued efforts to ensure success.

As I look forward to my time as President, I would like to let you know about a few of our board priorities:

- Continued efforts to build awareness within the medical community
- Communication with patients on how best to support your needs
- Internal operational evaluation

I am honored to serve with a group of incredible individuals from our board members to volunteers and of course, Cyndy.

I'm truly looking forward to getting to know many of you, don't be surprised when I call you! I have found that personal communication builds connection and will help our board gather information on how we can make strategic moves. I have been a board member for three years with the chapter and my professional career has been in the nonprofit sector as a fundraiser for nearly fifteen years.

I came to know about scleroderma twelve years ago when my oldest brother was *finally* diagnosed after several years of being misdiagnosed. In my time with the foundation, I have learned so much about scleroderma and other auto-immune diseases. I am grateful for the educational opportunities that our chapter has been able to provide for myself, my family and each one of you. The growth of the foundation over the past few years has been exciting for me to be a part of and I know that we will continue to move the chapter in the best direction for our patients and families.

Thank you again for your time and dedication!

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 TELECONFERENCES**

August 10, 2017 – Linda McNamara and Karen Kemper will discuss "If You Have to Wear an Ugly Dress, Learn to Accessorize".

November 9, 2017 – 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**

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

September 9, 2017 – Tyna O'Connor, BSN, RN, Advanced Lung Disease Clinic at UCHHealth, will discuss navigating the medical system.

October 14, 2017 – Open discussion.

November 11, 2017 – To be announced.

December 9, 2017 – Holiday party!

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

### **SOUTHERN COLORADO SUPPORT GROUP**

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

November 18, 2017 – Holiday party! **LOCATION 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**

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

October 28, 2017 – Hillary Beck-Gifford, Fitness Specialist & Yoga Teacher, will demonstrate gentle yoga including chair yoga in order to gain flexibility, strength and practice breathing techniques.

December 2, 2017 – Holiday party and luncheon at 11:00 am at The Moot House, Garden Room, 2626 S. College Ave., Fort Collins, CO 80525. **NOTE: DIFFERENT TIME AND LOCATION FOR THIS EVENT!**

**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**

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

November 11, 2017 – Dana Armstrong, Massage Therapy Program Instructor at CO Northwestern Community College, will present on massage and pain management. Dana's students will be on hand to give free chair massages to those at the meeting.

**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 on the 2<sup>nd</sup> Saturday of even numbered months from 1:00-3:00 pm at Flying Star Café, 10700 Corrales Road A, Albuquerque, NM 87114. For more information, please contact Anna Wenger at 505-974-9293 or [annawenger91@gmail.com](mailto:annawenger91@gmail.com) or Theresa Johnson at 520-248-2235.

## Princesses Get Sick Too – Deseree’s Story

Deseree Jones was born in Utah but moved to California when she was seven years old. About a year ago, she decided to move to Colorado. She has family in Colorado and was ready for something new. She chose Colorado because she has always loved it here.

Deseree is a student at the University of Northern Colorado (UNC) where she is studying elementary education. She has also run her own business for the last five years – The Party Princess. Both give Deseree a chance to pursue her passion of working with kids.

Engaged to be married in November, Anthony and Deseree met at six years old when they were ring bearer and flower girl in the same wedding! Anthony is a manager-in-training at Carrabba’s Italian Grill in Louisville.

Deseree started developing scar tissue on her hands when she was seven years old. She was losing mobility in her hands and couldn’t make a fist. She was young and it was hard to be sick when her friends were at school and having fun. She was not diagnosed until she was twelve at which time she was hospitalized for chemotherapy infusions for four days every month. She was put back on chemo twice in high school and spent her sophomore and senior years at home because she was too sick to get out of bed.

But Deseree was determined to still live her life. She got into mountain biking, dirt biking and volleyball. She played softball for 13 years. Softball helped her get mobility back in her hands but her right hand was still slow which made playing sports more difficult.



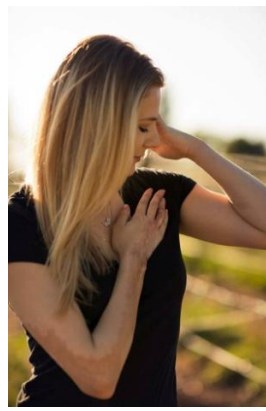
In February 2017 Deseree went back on chemo (Methotrexate) once a week every 6 weeks. It is better this time because there are now pills for maintenance.

Deseree was originally diagnosed with localized scleroderma but it is now believed to be systemic because her skin, joints and bones are affected. Scar tissue was found on her lungs earlier this year and

her kidneys are very susceptible to infection. She has burning in her stomach. Both the scleroderma and chemo caused lots of vomiting which has left scars and gashes in her stomach. Deseree eats healthier now but admits she still has the diet of a 21 year old!

Overall, Deseree is doing well today. Between her business, school, a job and planning a wedding, she doesn’t have time for flare ups. It’s not in her nature to rest, but admits she will usually be down for a few days after chemo.

Scleroderma made Deseree a more determined and motivated person at a young age and helped her find her passion. While hospitalized many times as a teenager,



Deseree realized that there wasn’t much for sick kids to do. During one hospital stay she shared a room with a 6 year old who loved princesses and, because she was sick, didn’t think she would ever get to meet one. Deseree decided then and there that when she got out of the hospital she would dress up as a princess and go back to visit the little girl. She immediately discovered a passion that led her to start her own company. The Party Princess is a business based on compassion, love and making dreams come true. Their mission is to show that princesses are more than just pretty faces. Her princesses boost children’s self-confidence and inspire them to treat everyone around them with kindness. The Party Princess hosts birthday parties and attends parades and festivals. The business also participates at many nonprofit and volunteer events focused on children. At the Denver Stepping Out Walk in June, Deseree met a little girl with scleroderma. She told her that “princesses get sick too but you can still live your dream, you are strong”. The little girl thanked Deseree and rewarded her with a big hug!

Scleroderma has taken some things away from Deseree like softball; but it can’t take away her knowledge, which is why she is studying to teach. It also taught her compassion at a very young age.

Deseree recommends to anyone newly diagnosed to never lose hope. She has beaten the odds and others can too! Live your life, don’t just survive. Use the gift given you through scleroderma to inspire others. There are limitations but you can still have dreams. After all, she is “princess with a scarred arm” and it doesn’t stop her!

Deseree didn’t live near a scleroderma support group in California so she never met anyone else with the disease. Last year she saw a poster for the Northern Colorado Stepping Out Walk on the campus at UNC. She couldn’t wait the few weeks until the Walk and the chance to meet others with scleroderma! Last year she walked for herself. This year she will be walking to help others on Sunday, October 1 at Fort Collins City Park.

Fiancé Anthony has never met anyone with such a warrior spirit as Deseree. He knows how hard it is for her and how sick she is. He is amazed that she can cry all night and still wake up with a smile. He understands when she has to cancel a date because she is fatigued and enjoys just staying home and watching a movie with Deseree. He even goes to doctor appointments with her. They are both looking forward to their upcoming wedding!





## 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.*

### **National Patient Education Conference Offers Hope**

Over 600 people attended the 2017 National Patient Education Conference in Arizona in July. Chapter member Paul Christenson found “the value of the conference is the people you meet, the resources you are introduced to, the knowledge you gain and knowing you are not the only one fighting this disease. It’s important to keep going each year because you find yourself wanting different information based on where you currently are with the disease.” Support group leader Judy Laible “met some wonderful new people and it was lovely to re-connect with so many people I had met before. This Conference gave the precious gift of hope for the future. There are so many outstanding people, volunteers and patients involved in the Scleroderma Foundation.”

### **Kendra Gives Back!**



Join us for sips, sweets, jewels and makeovers on **Tuesday, August 8, 5:00 – 7:00 p.m.** at **Kendra Scott Cherry Creek North**, 175 Fillmore St. in Denver. Kendra Scott Jewelry and Lip Bar Custom Cosmetics will both donate a portion of the proceeds from this event to the Scleroderma Foundation.

#### **Contact Us At...**

Scleroderma Foundation  
Rocky Mountain Chapter  
2280 South Albion St.  
Denver, CO 80222  
(303) 806-6686  
[cochapter@scleroderma.org](mailto:cochapter@scleroderma.org)

#### **Follow Us At...**

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[www.youtube.com/COScleroderma](http://www.youtube.com/COScleroderma)

#### **Meet Others At...**

[www.inspire.com/groups/scleroderma-foundation](http://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](http://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](http://sclerodermafoundation.myplannedgift.org).



Acceptance doesn't mean resignation.  
It means understanding that something is what it is and there's got to be a way through it.

*Michael J. Fox*