

Scleroderma

The Washington Evergreen Chapter of the Scleroderma Foundation

Increasing awareness for earlier diagnosis and greater funding toward discovering the cause and a cure

A Quarterly Newsletter

Spring 2018

Auction Recap

by *Emily Van Pelt*

Events Coordinator

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Hello everyone! Thank you so very much for all of your support before, during, and after the auction. We raised a lot of money, we had a lot of fun, and we learned a lot of things to make next year even better! Great news: every new feature introduced at the auction was a success! We increased attendance over last year through targeted Facebook marketing, we made registration and check-out a breeze by hiring a professional auction management team, and we raised a total of \$47,000!

Something we wanted to highlight this year was members of our community. We were able to showcase five community members who directly benefit from our chapter: Dacia, Chanel, Lisa, Jolie, and Amy. These wonderful women were so generous with their time to share their Scleroderma story with us. We are hoping to spotlight different community members for future events in the hopes that the people being honored will feel incentivized to bring their friends and family to share in this honor.

Thank you to everyone who participated in the post-event survey. There were 25 participants! We are using the data from the survey plus several interviews with community members and we are excited to throw an even better event next year. Our goal is to throw events that are enjoyable to all. We are here to serve you!



Upcoming Events

- **Patient Education Conference** June 16
Lynnwood, WA **FREE EVENT**
- **Scleroderma Awareness Month**
Chapter Mariners Game, June 17
- **National Conference, Philadelphia:** July 27-29
(**Register and make travel plans**)
- **Seattle Area 10K Run & 5K Walk** September 15
(**Time to register individuals and teams!**)
scleroderma.org/SteppingOutSeattle

Patient Education Conference

Saturday, June 16, 2018
10 am - 3 pm

Embassy Suites Hotels
Lynnwood, WA

Speakers include:

Edward Harris, MS *Founder/CEO of the Scleroderma Education Project* (scleroderma.info) will present his latest research on Therapeutic Plasma Exchange treatment.

Nancy Niedzielski from *End of Life Washington* will be discussing end of life expectations and care.

Shelley Van Pelt, RN MSN CNS will be discussing the latest on medical marijuana.

Nancy Clark, LMT MA will give a presentation on Bowenwork Manual Therapy.

FREE EVENT

Lunch will be provided. Taco bar with vegetarian, vegan, and gluten free options.



Day of Advocacy on Capitol Hill

by *Jeremy Harrison-Smith*
Executive Director
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In April I joined patients, family members of patients and chapter leaders from around the country in Washington DC for the 2018 Advocacy Day on Capitol Hill.

Shelley Van Pelt and I were teamed up with patients and family members from Washington and California. We spent the long day visiting the offices of 3 senators and 4 representatives.

We met with a staff member of each elected official, where we asked the representatives to cosponsor the *National Commission of Scleroderma and Fibrotic Diseases Act of 2017* (H.R. 4638). This bill would make recommendations regarding improvement to the coordination and advancement of NIH-supported research activities related to fibrosis and fibrotic diseases, and develop a long range plan for the use and organization of national resources to effectively advance research on fibrotic diseases. In days following our visit, two of the Representatives we visited signed on as cosponsors of this bill.

It was inspiring and impactful to join with patients who were able to tell their stories directly to the staff of our Senators and Representatives. I tried to be the voice for all of the patients from our state that weren't able to be there to tell their stories.



If you want to get involved in this very important advocacy work please visit:
www.scleroderma.org/action_home2

Spokane Update

by *Lisa Van Driel*
Spokane Support Group Co-leader



The 4th Annual Stepping Out to Cure Scleroderma 5k (this year in honor of Carlene Eneroth) was another success with 200 walkers, on a beautiful day out at Mirabeau Meadows in Spokane Valley. Jeremy and Marcia came to Spokane and we thank them for their work and their help in making things run smoothly. KREM 2 News even came by and did a short story that aired on the 5:00 o'clock news! May 31 through June 3 the Steam Plant once again was lit up in teal to kickoff June Scleroderma awareness month.

The Spokane Support Group meets the 3rd Monday each month in the Deaconess Education Building, Room 266. New members are always welcome. Jen Stalwick is our group's new co-leader. Welcome Jen!

Unfortunately, we are having to say goodbye to our support group leader of the past 4 years, Patty Varty. She worked tirelessly to get a walk started in Spokane back in 2015 and she and her wife, Judy Walters, will be greatly missed. They are moving to Arizona in the fall and intend to explore the Scottsdale area and spend time with family and friends.

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Patty and Judy at the auction

Fifth Annual Support Group Leader Training Retreat, April 20-22

by *Tracy Hagel*
Support Group Coordinator



Once again we held our leadership training at the beautiful Sleeping Lady Mountain Retreat in Leavenworth.

Most support group leaders were able to attend although we did have some unavoidable last minute cancellations which created the need for a great deal of last minute juggling. Fortunately the flexibility factor kicked in, and we sailed smoothly through the weekend.

Our guest presenters for the weekend were Karen Kemper MSPH, PhD, and Linda McNamara RN, MBA, authors of *If You Have to Wear an Ugly Dress, Learn to Accessorize*: They presented three sessions: Accessorizing the Ugly Dress, Grieving Your Losses, and Managing Time and Energy. These sessions provided us with practical tools for living and coping with this devastating disease. The underlying ideas can be pretty much summed up with: **Pause---Assess---Choose**.

Pause: Take time to reflect, gather strength, and regain your balance.

Assess: Learn all you can about your illness and yourself.

Choose: Define your values and use them as a compass to guide your decisions.

The session on grieving was particularly moving, noting that people with chronic illness have to grieve many losses in their lives, not just friends and family.

I led the session, *Reviewing the Support Group Leader's Role*. We examined the Support Group Leader Handbook, reviewing and updating each section. The handbooks contain important information from Inside SF for group leaders to gain a better understanding of their role in the organization. Other sections of the handbook/notebook included leadership tips, rosters, Evergreen Chapter reminders, miscellaneous handouts to copy for support group members, attendance and reimbursement forms, as well as self-addressed stamped envelopes for sending forms in a timely manner. SF brochures and other handouts were available for support group leaders to replenish their stashes.

Marcia Walker provided a well-received presentation on the governance of the Scleroderma Foundation and how it is the umbrella for our Washington Evergreen Chapter. She explained our common threefold mission, board structure, importance of compliance, and how the money we raise is distributed.

Shelley Van Pelt's illness forced her to cancel, eliminating her presentations. We contacted a local yoga instructor to come on very short notice. She led us in chair yoga and meditation techniques that we can use when we return to our support group meetings.

Following dinner on Saturday, we enjoyed a creative time of putting together our storyboards. Each leader decorated a poster board with photos, embellishments, and their individual Scleroderma Stories. Storyboards can be used as an activity with their support groups, and also can be displayed at local events.



Evaluations rated the retreat extremely successful and well received. Everyone was thrilled with the added night's stay. They felt the presentations, pace, venue, and meals, were exceptional. We will try to build in extra time to take a meditative walk around the peaceful grounds next year. The Sleeping Lady staff was extremely accommodating and attentive.



Medical Marijuana & Scleroderma

by *Shelley Van Pelt RN, MSN, CNS*



Everybody is interested in marijuana for recreational or medicinal use or both. What most people want to know is how can marijuana help me with my pain, sleep or just to make me feel better. More than 50 million Americans live with chronic or severe pain daily. Pain can disrupt everyday life by preventing you

from doing or enjoying simple tasks. Today's choices in painkillers like opioids and nonprescription medicines are tough to tolerate. Opioids have terrible side effect and can become addictive.

Legality

Currently, marijuana is legal for recreational use in 9 US states and DC, and for medical use in 20 U.S. states. In 1998 Washington State passed Initiative 692 (the Medical Use of Marijuana Act) permitting patients "with certain debilitating conditions to use medical marijuana." In 2012 Washington became the first state to legalize recreational marijuana. Classified as a Schedule I drug (along with heroine and LSD), marijuana is still illegal by Federal Law.

Uses

Marijuana has been used since 5000 BC as a medicinal herb and effective painkiller. So, is it a real possibility that marijuana can be an effective medication for you? Therapies exist, and are reasonably well-tested and safe, and should be tried. Dr. A. Bryan, University of Colorado, Boulder states, "The evidence we have thus far suggests that cannabis is moderately effective for pain relief." But many patients claim moderate to major improvement of symptoms including pain relief with marijuana.

The active ingredients of the marijuana plant include THC (Delta-9-tetrahydrocannabinol), CBD (Cannabidiol), Cannabichromene (CBC), Cannabigerol (CBG), and Cannabinol (CBN). Currently THC and CBD are used for medicinal and recreational purposes and can be purchased in state authorized "pot stores" around Washington state.

Benefits

Some of the benefits of marijuana for the treatment of scleroderma are:

Anti-inflammatory, anti-fibrotic, immune system protection, improved sleep, improved mood, anti-anxiety, improved appetite by decreasing nausea and vomiting in cancer patients, anti-seizure, and bronchodilator which eases breathing. I know from personal experience as it helped me to breathe better.

Decreased Dependence on NSAIDs and Opiates

Adding marijuana to your NSAID or opioid may, over time, decrease your need for those drugs. You may be able to use less and less and may even be able to cut them out completely. Medical marijuana can provide relief from many of your symptoms with little or no side-effects. As with all medications, supplements, or vitamins, please contact your medical doctor for advice and guidance. Never add or stop any medications without informing your healthcare provider.

Administration

There are multiple methods of administration. The most common is inhalation (smoking, vaping) and oral ingestion (edibles, gummies, capsules, sublingual tinctures). Next is topical applications (creams and essential oils). Prescription marijuana (synthetic Cannabinoids) such as Dronabinol and Nabilone come in pill form and can be very expensive and are not covered by health insurance. Therapeutic effects of each method are based on preference and experience and vary from patient to patient.

Important factors when considering each form of marijuana administration:

- bioavailability
- accuracy of dose
- time to onset the effects are felt
- duration of effect is the length of time the effects are felt
- quality and consistency of effect

Medical marijuana may provide relief from many of your symptoms and with little or no side effects. Modern research suggests that marijuana is a valuable aid in the treatment of a wide range of disease symptoms. More detailed research needs to be (and probably will be) done in the coming years.



Board of Directors:

Marcia Walker
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Vice President/Newsletter

Ken Moninski
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Tracy Hagel
Support Group Coordinator

Shelley Van Pelt
Medical/Education Outreach

Emily Van Pelt
Events Coordinator

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Jeremy Harrison-Smith

Charity Navigator

Scleroderma Foundation earned 4 out of 4 stars!

Look for the donate button on our website.

and donate with confidence.



You can easily register to have .5% of all your eligible purchases donated to the Scleroderma Foundation in Danvers, MA

Scleroderma Stories

by Dacia Bukoskey



At the age of seven, I received my official diagnoses of linear scleroderma. Imagine explaining this to a child whose main concern is who she is going to play with at recess?

Before the diagnoses was official, I went through a trial of various topical steroids to see if that would help the spots I had on my hip and the ones forming on my foot. The steroids only seemed to help soften the spots a little bit, so my doctor decided it was best to do a punch biopsy. Boy did I fight my way through that procedure; I had a nurse holding me down on each limb and my mom holding my head down. Afterward, I remember thinking that seeing that chunk of my own skin floating in the specimen jar was actually kind of cool!

Other medications then came into play. I was given daily doses of oral methotrexate and prednisone. My mom and doctor decided it was best not to tell me the side effects of the medications so that I wouldn't force any symptoms. I remember being so sick and losing so much weight. I soon realized what was happening and started to refuse medication. It was hard to be a normal kid when you felt awful all the time. I began fighting with my mom and doctors; I did not want to take that stuff! After much discussion we decided to switch to weekly shots of methotrexate. The nurse taught my mom how to give me shots and let me tell you, nothing is scarier than your mom holding a needle and being upset with you!

By the time I was twelve, my symptoms had gotten pretty bad. I couldn't open bottles by myself, I was in tons of pain and it was a struggle trying to get out of bed in the morning. Physical activity was getting harder. I went to see my doctor and he decided to try me on infusions of prednisone and methotrexate. My doctor said it was best for me to stay in the hospital for a few days to make sure I didn't have any bad reactions to the medications. Every day I was there, I woke up really early to make sure I was the first to get the game cube and TV from the nurses' station. Gaming helped pass the time more quickly! After that stay, I got one more infusion in Federal Way at the Seattle Children's Clinic there. That is where I met my first other person with scleroderma. He was a 12-year-old boy and I was so shocked; I thought I was the only person in Washington with this disease. I remember us discussing other kids making fun of us because we looked different. We were both very skinny and had tiny wrists and bigger faces.

School was hard with a disease that sometimes doesn't show that you are sick. People only saw my spots when I was in a swimsuit. Then I got lots of rude comments from other kids and even adults. I remember being told from classmates that I was a liar and not even sick. Dealing with that led to some heavy mental health issues for me that I am still dealing with now as an adult.

I am now 23 and show no signs of active disease. Yes, I still have my scars and always will, but I'm proud of them. My parents instilled in me that I should be proud of who I am and to never let anyone knock me down for looking different. I want to instill that into other kids who have scleroderma. There were no support groups for me growing up and today there still aren't many. My goal is to reach out and try to help kids who are dealing with this disease. Kids need support too. Kids who have autoimmune diseases have a 90% chance of growing up with mental health issues. I feel that if we offer greater support for these kids and really help them feel out everything and help them to make connections with other kids who are walking in their shoes that they will not feel so alone, and we can really change their lives for the better.



Nature and Mental Health

Have you heard that some doctors and mental health practitioners are actually advising patients to take walks in the woods or garden to help regulate moods and to treat depression, anxiety, and even PTSD and ADD? It's called ecotherapy, green therapy, horticultural therapy, or nature therapy.

Accessible Washington Hikes

Little Mountain Park in Mount Vernon

This gem is perfect for those with limited mobility. You can drive to the top and on a clear day you will be able to gaze out at the Skagit Valley, the San Juans, and the Olympics. They also have 10 miles of hiking and biking trails. Bring a picnic lunch.



Franklin Falls Trail near Snoqualmie Pass

This hike is 2 miles roundtrip with an elevation gain of 367 feet. You'll travel through a lush forest and walk along the river. Keep an eye out for wildlife and wildflowers. There are spots where you can cool off in the water and at the end of the trail is a spectacular waterfall. Dogs are welcome on leash.



Kubota Gardens in the Rainier Beach area of Seattle.

This spectacular Japanese garden is a public park that was designed and built 30 years ago. About one third of the garden has ADA walkways. The garden features specimen plants, granite from the Cascades, ponds, waterfalls, and walking bridges. Dogs are welcome on leash.



Hoh Rain Forest Hall of Mosses near Forks

This is a one mile path through old growth forest with only 75 feet elevation gain. Amazing views are everywhere you look. It can be busy but there are birds, wildflowers, huge trees, and MOSS hanging everywhere. I go here every time I am in the area. Sorry no dogs allowed. Picnic tables and bathrooms at the trailhead along with a ranger station/gift shop. National park fee.



Centennial Trail Snohomish to Lake McMurray in Skagit County

This paved trail is mostly flat and was created on a former railroad line. Start in Snohomish and make a pitstop at a the Snohomish Bakery or have lunch at the Trails End Pub. Start at the Machias trailhead and there are bathrooms, running water, bike repair stations and a playground for little kids. Just north of Machias you and your furry friend can cool your paws in the creek. Great dog and people watching. Views of farms, pasture, and some forest.



These examples of local hikes really only scratch the surface. Just do a search online for easy hikes or hikes with ADA trails or kid friendly hikes. Reading comments from other hikers will help you choose the hike that meets your needs. **Now get out there and commune with nature! After all, it's just what the doctor ordered.**

If you'd like to learn about how immersing yourself in nature can have health benefits please check out these articles from **The Atlantic**.

The Growing Field of Ecotherapy- The Atlantic by James Hamblin, October 2015 Issue

<https://www.theatlantic.com/magazine/archive/2015/10/the-nature-cure/403210/>

How to Harness Nature's Healing Power - The Atlantic by Julie Beck, June 23, 2017

<https://www.theatlantic.com/health/archive/2017/06/how-to-harness-natures-healing-power/531438/>

Favorite Nature Quotes

"In every walk with nature one receives far more than he seeks." John Muir

"Adopt the pace of nature: her secret is patience."
Ralph Waldo Emerson

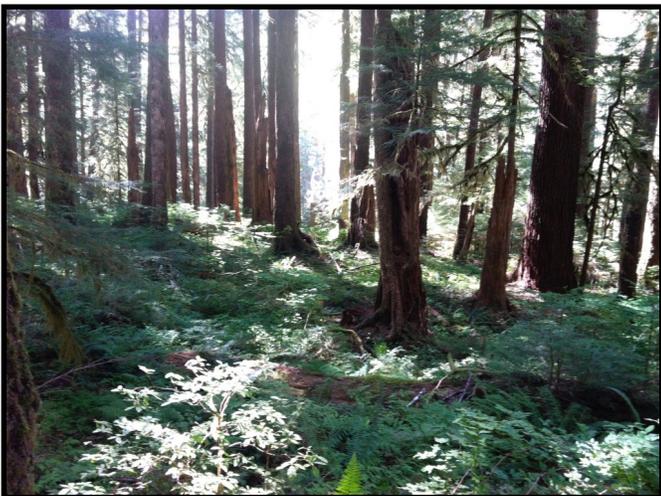
"Just living is not enough...one must have sunshine, freedom, and a little flower."
Hans Christian Andersen

"Look deep into nature, and then you will understand everything better."
Albert Einstein

"Those who contemplate the beauty of the earth find reserves of strength that will endure as long as life lasts."
Rachel Carson

"I felt my lungs inflate with the onrush of scenery - air, mountains, trees, people. I thought, 'This is what it is to be happy'."
Sylvia Plath

"Man's heart away from nature becomes hard."
Standing Bear



SFWEC Support Groups

North Sound (Mount Vernon)
Joyce Harlan and Vicki Hollmann
joyceharlan@comcast.net
vickihollman@gmail.com

South Sound Support Group (Olympia/Tacoma Area)
Shannan Roby
shannanrobby@yahoo.com

Tri-Cities Support Group
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Peninsula Support Group
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Seattle Support Group
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Caregivers' Support Group Seattle
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Spokane Support Group
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Yakima Support Group
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Scleroderma Foundation Washington Evergreen Chapter

Spring 2018

Stepping Out to Cure Scleroderma in Some Comfy New Kicks



Do you have trouble getting sneakers on and then lacing and tying them?

Tina Johnson is a scleroderma support group member in Maine who was searching for a running shoe she could put on and take off herself without having to deal with laces. She discovered that Nike had developed a zip-back sneaker to help a boy with cerebral palsy who was going off to college and needed sneakers he could put on himself.

The Nike FlyEase closure system connects a hook-and-loop strap to a wraparound zipper, letting you open or close the shoe—heel and all—in one fluid motion.

It doesn't hurt that they are really attractive, around \$60, and even come in wide and normal widths.



**The Seattle Walk/Run is September 15 at
Saint Edward State Park
in Kenmore
scleroderma.org/SteppingOutSeattle**

Some Local Employers Who Have Walk Grants or Who Match Employee Donations:

- Boeing
- Walmart
- Home Depot
- BP
- CVS
- Starbucks
- Darden Restaurants
- McDonalds
- Kroger
- Verizon
- Microsoft
- All State
- Aetna
- Real Networks
- Target
- Outerwall/Coinstar/Redbox



Check to see if *your* employer participates and maximize your donation!