

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

Summer 2018



Shelley Van Pelt is Named Outstanding National Advocate

by *Emily Van Pelt*
Events Coordinator

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The Washington-Evergreen Chapter Community's own Shelley Van Pelt, was one of two recipients of the Outstanding National Advocate Award at the Scleroderma Foundation National Patient Education Conference this year in Philadelphia and we wanted to introduce her formally to everyone and give some insight into what it takes to be an award-winning patient advocate.

Shelley, diagnosed with scleroderma in 2009, had just returned to school to complete her Master's Degree in Nursing at Seattle Pacific University when she was given the news that she had a rare autoimmune disease. Her first instinct was to find other people who had it. First, she visited the national Scleroderma Foundation website and then connected with three women, Tracy Hagel, Amy Zavala-Dean, and Vicki Hollman who subsequently played large roles in her life as a contributing member of the organization. Together, these women continued to reach out and find other patients that they could welcome into a caring community.

Shelley had been a nurse for close to thirty-three years but with her disease's level of lung-involvement, she was unable to continue working in the same capacity. She completed her master's degree and retired from nursing but still wanted to help others. She became a constant presence at support groups; offering up her medical knowledge to those who were feeling vulnerable with their new diagnosis. She naturally fell into a role within the community which she says, "is a blend between my medical knowledge with my desire to give people a sense of relief. I'm a translator. I go to doctor's appointments and I oftentimes see a newly-diagnosed patient start to become overwhelmed with new vocabulary and treatments and their eyes sort of glaze over. I can talk with both the doctor and the patient to make sure that the new information is understood and very frequently, I follow up with these patients regularly to address their questions and concerns."

Shelley is a veteran in the medical field and has worked in nearly every department—from Emergency to X-ray and Cardiology to Critical Care—her three decades of service paired with her diagnosis make her a unicorn-of-sorts in her ability to relate as both patient and caregiver. She is highly attuned to the needs of others and is energized when she is able to help someone. "My goal is to keep people out of the hospital and let people know that they can change their quality of life by giving them little life hacks that help them get over a hurdle." Whether it's diet, exercise, or relaxation, Shelley has become many people's resource for how to live well with scleroderma.

This fall, Shelley will return to school to study nutrition and functional medicine. Shelley is an advocate for a diet full of organic foods because removing processed foods from her diet greatly reduced her symptoms related to scleroderma. She hopes to assume more of a teaching role in the organization with a focus on stabilizing the human body with nutrition and using wellness techniques such as meditation and yoga to further align body and mind. With our Chapter's support, Shelley is able to provide free health and wellness clinics, connect newly-diagnosed patients to our community, lead support groups, help translate medical terminology, host webinars and support groups via video chat nationwide, travel to DC to speak about scleroderma with elected officials at both the state and federal level, advocate for patient rights, and more—she is a wonder and we are so lucky to have her. Congratulations, Shelley!



Shelley Van Pelt & Dee Burlile

SFWEC SUPPORT GROUPS

WESTERN WASHINGTON

North Sound (Mount Vernon)
 Second Friday of the month
 11 am
 Skagit Valley Hospital
 Sauk Conference Room
 Joyce Harlan
joyceharlan@comcast.net
 (360) 927-5392
 Vicki Hollmann
vickihollman@gmail.com
 (360) 731-7563

South Sound (Tacoma)
 3rd Saturday of the month
 10 am
 MultiCare Tacoma General
 Conference Room 3 (3rd floor)
 Shannan Roby
shannanroby@yahoo.com
 (360) 250-7897

Olympic Peninsula
 Tracy Hagel
herestwous@gmail.com
 (360) 268-3007

Seattle
 2nd Saturday of the month
 12 pm
 Children's Hospital
 Kris Garthe
kris@garthefamily.com
 (253)839-1539

Caregivers' Group (Seattle)
 Meets quarterly
 Children's Hospital
 Bunny Garthe
bunny@garthefamily.com

EASTERN WASHINGTON

Spokane
 3rd Monday of the month
 6 pm
 Deaconess Health & Education Center, Room 266
 Lisa Van Driel
kittykatlisa@hotmail.com
 (509) 714-1098
 Jen Stalwick
jenstalwick56@gmail.com

Yakima
 2nd Tuesday of the month
 4:30 pm
 Astria Regional Medical Center
 Victoria Harris
vharr20@gmail.com
 (509) 429-5446
 Kim Castro
kimberlyanncastro70@gmail.com

Tri-Cities (Kennewick)
 One Saturday each month
 Zintel Creek Golf Club, Kennewick
 Vicki Henry
geminiviki@aol.com
 (509) 627-5102



National Conference Recap

by Jeremy Harrison-Smith
Executive Director

jharrisonsmith@scleroderma.org

The Scleroderma Foundation celebrated its 20th anniversary this year at the National Patient Education Conference in Philadelphia. Attendance at the conference grows each year, and with a new record of 680 attendees this year was no different!

This was my third conference as our chapter’s executive director. It’s always such an informative, inspiring and intense weekend, filled with opportunities to connect and learn with other chapter leaders from around the country, hear doctors speak about the latest research and participate in excellent workshops. The Friday before the conference I attended Leadership Day along with our board members Marcia Walker and Shelley Van Pelt. Marcia was also introduced as a newly elected member of the national board of directors. Leadership Day brings together chapter staff and board members to discuss developments and improvements in how we run our chapters.

The highlight of the conference for our chapter was Shelley receiving the Outstanding National Advocate Award along with Dee Burlile from Idaho. They were honored for all the advocacy work they did this past year, which included leading webinars to teach chapter leaders how to advocate for the foundation to their elected representatives in D.C. Their advocacy work culminated with the Capital Hill Day trip to Washington D.C. in April, where they led teams of advocates that spoke to their congressional representatives about supporting scleroderma research funding and particularly the bill HR 4638.

One session at the conference that stood out was “An Introduction to Functional Medicine” by Misty Rushing. Misty is a patient and has been using Functional Medicine principals in her own treatment, and as a way to help more people learn about this she started the Facebook group Scleroderma and Functional Medicine. It was so valuable to have information about other ways to improve patient’s health and the room was packed with interested attendees.

Every year the national conference provides opportunities for patients to connect with each other, learn about the latest research and new ways to deal with this difficult disease. Our chapter sends two patients and their caregivers to the conference each year. Thanks to all of you who support us, you make these experiences possible!



National Conference Scholarship Recipients

by Shelley Van Pelt

Traveling by plane is not exactly Amy Zavala-Dean’s preferred choice of transportation. Flying makes her nervous. When she heard she won a trip to the Scleroderma National Conference in Philadelphia, Amy was not only excited, but she started planning right away!! She had been once before, but this year was different. Amy attended the 2014 Anaheim CA convention in a wheelchair and tired very easily. Some of Amy’s greatest memories from this weekend

“This time around I was more independent, no wheelchair or walking cane. I was able to participate in more workshops like Scleroderma Yoga and Musculoskeletal Manifestations of Systemic Sclerosis.”

include: Being with other scleroderma patients who understand how dealing with this disease on a daily basis can be difficult. Amy found the workshops very educational. She is planning on using the information to better help herself with healthy eating, practicing yoga for improved movement, and keeping up-to-date on new treatments and medications. She also had time to explore some of Philadelphia’s historical landmarks with her very good friend Pam Stradford. Amy and Pam spent Friday visiting Reading Market, Independence Hall and the Liberty Bell.

The best part of the trip for Amy was, “just being in the presence of these amazing people, those sicker than me that come so far to be together and participate in this great event. To see how much people with scleroderma have been through and by sharing their stories and the journey we are all on.”



Amy Zavala-Dean and Cat Davis were the 2018 recipients of the Evergreen Chapter’s scholarships to attend the Scleroderma National Patient Conference in Philadelphia.



Scleroderma Awareness Day at Safeco Field
Close to 40 chapter family & friends attended
and our name was up on the big screen!



Lynnwood Patient Education Conference
Shelley presents on the
therapeutic aspects of marijuana



The Seattle Great Wheel Was Teal
for World Scleroderma Day
Friday, June 29

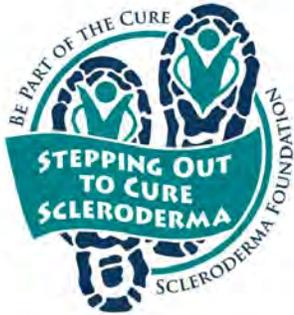
**Offering 2
Yoga for Scleroderma
Workshops
with Kathy Randolph
and Lori Pierce**

**October 12th
Holistic Health
Patient Education
Conference**
PUD building
1415 Freeway Drive
Mount Vernon, WA 98274
vanpm63@gmail.com

**October 13th
Seattle Support Group**
Kris Garthe
kris@garthefamily.com
(253)839-1539

For more info visit:
www.YogaForScleroderma.com





SATURDAY SEPTEMBER 15, 2018

Seattle Area 10K Run & 5k Walk

In honor of Gail Jaeger & Terry Warner

Historic Saint Edward State Park has lakeshore and 316 acres of land! It will be a great opportunity to connect with old friends, meet new friends and walk in honor or memory of loved ones affected by scleroderma.

Location: Saint Edward State Park, 14445 Juanita Dr. NE, Kenmore, WA

EVENT DETAILS

SATURDAY September 15, 2018

\$20 (\$25 same day) Registration fee
Saint Edward State Park
Kenmore, WA

Check-in begins at 9 a.m.
Run and Walk begin at 10 a.m.
 (Discover Pass required; day passes available)

Includes: T-shirt, raffle, music, face painting, refreshments and prizes!

(Must be present to win during raffle)

More information and to register visit our event website:

www.Scleroderma.org/SteppingOutSeattle

Or call 206-285-9822



Thank you to our sponsors:



Photos by Stan Matsui

Evergreen Chapter Vice President, Andrea Smith's Quick Pitch

Opener:

I became involved with the Scleroderma Foundation after my dear friend, Shelley, was diagnosed about 8 years ago. This was a devastating diagnosis as scleroderma is a chronic autoimmune disease that can progressively impact both quality of life and longevity.

Conversation

We work to ensure that scleroderma patients and their families are not isolated. Without the support groups and educational conferences that we put on, most patients would never meet another person with their disease. Can you imagine? Additionally, we raise money for cutting edge research that's being done to find the cause and cure.

Action for Listener

I'd love for you to come to our next event, which is our walk on September 15 or can I send you a copy of our newsletter?



Two Beautiful Ladies Who We Lost Way Too Soon.

Please join us at the walk in honor of those
who cannot be there themselves.



Terry Warner and
her husband, John



Gail Jaeger and
her husband, Chuck



Board of Directors:

Marcia Walker
President

Andrea Smith
Vice President/Newsletter

Ken Moninski
Treasurer

John Blum
Secretary

Tracy Hagel
Support Group Coordinator

Shelley Van Pelt
Medical/Education Outreach

Emily Van Pelt
Events Coordinator

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 Vicki Hollmann



My scleroderma journey began in September 1995 at the age of 39. I was in Chicago to attend our son's graduation from Navy boot camp. I got a pretty new dress and high heels to wear to the ceremony. When it came time to get ready, I could not begin to get those spiffy new shoes on due to extreme swelling in my feet. When I returned home, I began to have a lot of swelling and numbness in my hands as well. My family doctor sent me to a neurologist. He suspected I had carpal tunnel syndrome from my many years of working as a Medical Secretary. The Neurologist took one look at my hands and asked if he could see my feet. I thought, how odd, since I was there to be evaluated for carpal tunnel. When he examined my feet and saw the swelling and color changes, he said, "I'm referring you to a rheumatologist, I believe you have an autoimmune disease." I saw a rheumatologist in October 1995 and over the next few months developed all the symptoms of what was then called CREST. I received my scleroderma diagnosis in February 1996, now referred to as limited systemic scleroderma.

It has been a roller coaster of various problems over the last 22 years. My biggest challenge is with ulcers, calcinosis and scleroderma wounds. I have been dealing with debridement and calcinosis removal from my left lower leg for 6 years. The procedures are necessary, but not pleasant! I feel like my plastic surgeon is a good friend, we spend so much time together! I also face challenges with my hands, they are contracted into "claws" and I also get the calcinosis/ulcers on my fingers. I have all kinds of gadgets to help me open things and of course my hubby too!

I was able to continue work as a medical secretary for many years after my diagnosis, working until 2014 when the leg wound pain, fatigue and Raynaud's became too much. I was blessed to get Social Security disability at the age of 60, and on my first application!

During the early years of my disease, I didn't know anyone else who had scleroderma or knew what it was. I learned about a support site called Inspire. I decided to get brave and go to a national patient conference in San Francisco with someone I connected with on Inspire. That "someone" turned out to be our very own Shelley Van Pelt! Oh my what a wonderful time we had, it was just like we had always been friends! The conference was amazing, so much information to glean and friends to make. I highly recommend that everyone try to attend one if possible!

When we moved to Mount Vernon, I joined the North Sound Scleroderma Support Group. What a joy to get know these amazing folks who are so encouraging and caring. I have had the privilege of being a co-leader these past few years. I am so thankful for everyone in our group; they have become my second family!

I am so thankful for all the support I receive from my family and especially from my husband, Royce, who is my caretaker and biggest supporter. I enjoy short leisurely trips, scrapbooking, playing with our grandchildren and visits from family and friends.

Scleroderma has changed my life in many ways, but along with all my sclero-sisters and brothers, I keep fighting and hoping for a cure!





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Scleroderma Foundation Washington Evergreen Chapter

Summer 2018

Register Now For Upcoming Events!

September 15: Get Ready to Step Out!

We are fast-approaching our Seattle-area 5k/10k “Stepping Out to Cure Scleroderma” event. September 15th, 2018 at Saint Edward State Park. Registration at 9am and start at 10am. We’ve got an amazing Seahawks Package that we will be raffling off which includes game tickets, a Seahawks cooler, a Seahawks pop-up tent, and more!

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

<http://www.scleroderma.org/SteppingOutSeattle>



October 12: FREE Holistic Health Patient Conference in Mt. Vernon

This year our annual fall patient education conference is focused on holistic health. Learn all about essential oils and how they can improve emotional, mental and physical health. We will also have Kathy and Lori, the Yoga for Scleroderma gurus teaching us how we can benefit from gentle stretching, so wear your comfy clothes.

PUD building

1415 Freeway Drive

Mount Vernon, WA 98274

Contact Shelley Van Pelt to register: VanPM63@gmail.com or (360) 708-2787

