

Scleroderma

The Washington Evergreen Chapter of the Scleroderma Foundation

A Quarterly Newsletter

Winter 2018

Upcoming 2018 Events

- Yoga for Scleroderma in Spokane: March 24
- Annual Auction & Dinner: April 7
- Advocacy Day in DC: April 16
- Lynnwood Patient Workshop May
- Spokane Stepping Out Walk/Run: June 2
- National Conference, Philadelphia: July 27-29

Sneak Peek at 2018 Auction Items

- 1 Week Holland America Cruise for 2
- Bonsai & Bubbly for 12 at Pacific Bonsai Museum
- Wine Class for 20 at Total Wine & More
- 2 Nights at Anchorage Inn B&B on Whidbey Island
- 1 Week Stay in Beautiful Whistler BC
- Seaplane trip to the San Juan Islands
- Custom Pet Portrait by Disney Artist

Exciting Dinner & Auction Coming Up!

By Jeremy Harrison-Smith, Executive Director

Our biggest fundraising event of the year is coming up soon! The 2018 *Tiptoe Through the Tulips* Dinner & Auction is on Saturday, April 7 at the Rainier Golf & Country Club in Seattle.



The success of our past events has allowed us to increase the amount of money that our chapter contributes each year toward research. Because of *your* support our fundraising totals have been increasing each year, and because of this, we are now able to send two patients and their caregivers to the National Patient Education Conference each year! This past year we also added a support group in Yakima, providing more patient support in that area of our state. We have also increased the number of educational workshops we organize each year thanks to the tireless work of our Outreach Coordinator Shelley Van Pelt. To view our upcoming events, visit our chapter website: www.scleroderma.org/washington

This year's auction once again is shaping up to be a big hit. We have an excellent auction committee working hard procuring items and doing the prep work necessary for a successful event. We have everything from a 7-day cruise for two to Alaska, the Caribbean, Mexico, or Canada and New England, to an expert led tour for 12 people at the Pacific Bonsai Museum complete with champagne and pastries! Other items include: A custom portrait of your pet by Disney artist, Shelby Pothier, one summer week in Whistler Village, Golf packages, Seattle Getaways, tickets to local sporting events and more! We will also be using fun new technology this year for our silent auction called Text2Bid. You'll get to bid for items right on your phone, and you'll receive alerts if you're outbid, so you don't have to hover around your favorite item to make sure you win it. So, grab a drink and relax because your winning bid is now a finger tap away!

Please come out and enjoy a fun night with us as we raise money to support patients, offer educational workshops and fund important research. Our goal is to top last year's event record of \$56,000! Even if you can't make it to the event please consider making a donation to help us reach our goal. Thank you for your support and helping our chapter grow!

To register or donate to the auction go to: <http://scleroderma.maestroweb.com/>

Spokane Update

- **The 3rd Monday of each month
Spokane Support Group Meetings**

New members are welcome

Deaconess Education Building, Room 266
910 West 5th, Spokane

- **March 24, 2018, 11 am - 3 pm
Yoga For Scleroderma Class**

with Kathy Randolph and Lori Pierce, who are specialists in this kind of yoga. They travel all over teaching at no charge. Lori is a highly regarded motivational speaker.



We are so lucky to have them both.

Deaconess Health and Education Center, Room 266

Space is limited so please RSVP to Lisa or Patty and please help get the word out.

To learn more about Yoga for Scleroderma:

<https://www.yogaforscleroderma.com/videos/unassisted-yoga>

- **May 4-5 (pending)**

Bloomsday Trade Show



- **May 31 (pending)**

Light Up the Stacks in Teal

- **June 2, 2018, 9am - 1 pm**

Stepping Out to Cure Scleroderma Walk

at Mirabeau Meadows Park, Spokane Valley

Contact Patty if you would like to help with donations and sponsors.

Spokane's 4th annual walk is in honor of Carlene Eneroth, who lost her valiant battle with scleroderma on New Years Day.

Our thoughts and prayers go to her husband Don and her family and friends.



Lisa: kittykatlisa@hotmail.com

Patty: plvarty59@gmail.com

Dental Health Workshop

by *Shelley Van Pelt*



Dr. Patrick Bennett DDS MSD, a specialist in periodontal disease and dental implants, shared his expertise and experience with advanced periodontal disease at a dental workshop hosted by the SFWEC on February 1st in Bellingham. The key to good overall health can start in the mouth with good dental care. Highlights of the afternoon included how Scleroderma effects our teeth and gums, specialty oral hygiene care products to improve oral health and decrease incidences of advancing gum disease.

Bacteria can live in your mouth causing plaque buildup which can lead to dental problems. Dental problems can have a very negative impact on quality of life for people with scleroderma, often leading to difficulties with speech, eating and other health problems. A recent study showed patients with scleroderma have a higher incidence of missing teeth and a significant increase in periodontal disease. Typical dental problems for people with Scleroderma include:

- Limitations in opening the mouth due to collagen build-up in the skin surrounding the mouth (microstomia)
- "Purse string" appearance of the mouth
- Loss of attached gums
- Several areas of gum recession
- Dysphagia (difficulty swallowing)
- Xerostomia (dry mouth)
- Varying degrees of bone resorption
- Loss of teeth
- GERD

Brushing twice a day, using a water pick and flossing regularly along with regular dental check-ups will ensure that you have the best care. Inform your dentist about scleroderma and dental problems you are experiencing. Suggest they become familiar with scleroderma and the associated dental problems. Working with your dental care professionals to ensure that your dental care will be the best possible for your unique situation.

Thanks to Dr. Bennett for an informative afternoon and educating our group about dental problems and scleroderma.





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John Blum
Newly Elected Board Member

Charity Navigator

Scleroderma Foundation
earned 4 out of 4 stars!

*Look for the donate button
on our website.*

**and donate with
confidence.**

Bequests to SFWEC

Please consider making the
Evergreen Chapter part of
your estate planning. Your
donation goes to support
research and vital outreach
to our local scleroderma
community. For more
information contact your
financial planner
or attorney.

Scleroderma Stories

by John Blum

In the late 1990s, while rehabilitating from foot reconstruction, I found myself continuously out of breath. I thought it was due to being confined in a cast and inactive for four months. When the cough progressed to the point where I couldn't utter a sentence without coughing, even I realized it was time to seek help. After months of tests and exploratory procedures, including an open lung biopsy, I was diagnosed with progressive systemic scleroderma with lung involvement. The prognosis was rather dire: potential heart/lung transplant with an extremely low success and survival rate.

An initial treatment plan of Imuran and prednisone seemed to work, and we were all ecstatic – until the scleroderma came back, this treatment no longer worked and my condition deteriorated rapidly; I was told it was time to get my affairs in order. It wasn't until I travelled to the University of Colorado did they find something that worked and I began to respond positively—far outside the expected range. I was able to continue my career as a fish biologist and resume SCUBA diving. That was almost 20 years ago.

I became aware of the Scleroderma Foundation when friends asked me to join them at Seward Park for a Scleroderma Walk with my name on their T-shirts, a very heartwarming, yet humbling experience. I had remarkably recovered; many present that day had not. The Walk planted the seed that this Foundation might be the way for me to give back. That opportunity occurred when I was introduced to Shelley Van Pelt and Jeremy Harrison-Smith. They asked me if I would I consider joining the Board. I eagerly said yes - thank you, Board, for accepting me!

An unasked question was, why? That answer is more complex. When I was initially diagnosed, I knew no one who had this disease, nor where to turn. My family and friends, who were instrumental in my recovery, couldn't know what I was going through. Those of us challenged by this disease know what it is to feel frightened, confused, and alone. While I recovered, I wondered why I was blessed, while others were not. The answer is to assist others on this journey, and pay forward the kindness, love, and encouragement that was so selflessly provided me. And most importantly, to offer hope. We CAN beat this, and I'm committed to being here to support that effort.



**Scleroderma patients and family members please submit
your stories for future newsletters or request to be interviewed.
Contact Andrea at smithap@comcast.net**



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Scleroderma Foundation Washington Evergreen Chapter

Winter 2018

Drawing to Attend the 2018 National Patient Education Conference

Would you like to travel to Philadelphia to attend the Scleroderma Foundation National Patient Education Conference being held July 27 - 29, 2018? We can help! Our chapter will award a scholarship to one patient on *each* side of the mountains. Scholarship includes roundtrip airfare for you and a companion, conference registration, and your hotel room at the beautiful, historic **Loewes Philadelphia Hotel**. You can take anyone you'd like. Some people have brought a caregiver, spouse, parent, fellow patient, sibling - anyone you'd like to share a hotel room with and who would like to learn more. This is a fantastic opportunity to make new long-lasting friendships, learn about current therapies, build a support network and better understand how to cope with the emotional challenges of living with scleroderma. For more information on the conference visit www.scleroderma.org/conference



The drawing is March 21 so please email Jeremy and enter to win. Just let him know your name and whether you live on the west or east side of the mountains.
jharrisonsmith@scleroderma.org

Look for us online: www.scleroderma.org/washington and www.facebook.com/sfwaevergreen