

# 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

Fall 2017

### Upcoming Events

- Bellingham Dental Workshop: Feb. 1, 2018
- Seattle Patient Conference: March 2018
- **Annual Auction & Dinner: April 7, 2018**
- Spokane Stepping Out Walk/Run June 2018
- Seattle Area 10K Run & 5K Walk Sept. 2018

### Sneak Peak @ Some 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
- Heathman Lodge in Vancouver, WA
- Tacoma Rainiers tickets
- Seattle Marriott Waterfront including breakfast

For more info and to reserve your seat visit:  
<http://scleroderma.maestoweb.com/>

### Nutrition and Disease

Shelley Van Pelt RN, MSN, CNS

**Every bite you take is either fighting disease or feeding it. So, which are you doing?**



Our Bellingham Patient Workshop on October 18th was a terrific day of learning about healthcare issues specific to scleroderma. Guest speakers included pulmonologist, Dr. Brad Diestelhorst; clinical nutritionist, Karl Mincin MS; and myself. Dr. Diestelhorst spoke on the topic of pulmonary hypertension (PH), a common diagnosis with those affected with scleroderma.

Key take-aways were:

1. PH is high blood pressure in the lungs.
2. Shortness of breath is a symptom of PH even if you have normal blood pressure.
3. Yearly ECHO, EKG, chest x-ray, and PFTs can help diagnose PH
4. Early detection of PH will help with better management.
5. Follow your doctor's advice on medications, treatments, and follow-up appointments to live a better life with PH.

(cont. on pg. 4 see *Bellingham Conference*)

### Spokane Update

Our Spokane support group has had a fairly slow fall but we are gearing up for 2018.

Two recent socials were our annual Summer Extravaganza in August at the beautiful home of Scott Rollins and in November we all met at The Spaghetti Factory for our holiday get together. Both were a really great time.

As for 2018, we are planning several exciting events. Our 4th annual Stepping Out Walk at Mirabeau Meadows is in June and Lisa is working on a booth at Bloomsday again. It was a great success this year with over 40,000 people from all over the world running. It is one of the largest timed races in the US. and a great way to get our message out. She is also trying to get the Smokestacks in downtown Spokane lit up for us again in June.

When the weather is warmer, we will have a workshop in Spokane with Kathy Randolph from Reno, who specializes in Yoga for Scleroderma. We hope to involve as many support groups and people as possible. Shelley Van Pelt is helping to organize this with us. We will get all the dates for events to everyone once they are finalized.

*Here's to a great 2018.*

*-Patty and Lisa*



## Charity Navigator

has rated the Scleroderma Foundation 4 out of 4 stars!

Rated high in all categories, including **Financial** and **Accountability and Transparency**.

*Look for the donate button on our website.*  
and donate with confidence.

## Social Relationships are the Key to Health

by Emily Van Pelt, Events Coordinator

[EmilyMVanPelt@gmail.com](mailto:EmilyMVanPelt@gmail.com)

Science and research tell us that if we eat healthy, exercise regularly, get enough sleep, and practice mindful meditation our odds of increasing our lifespan go up. In studies performed around the world, people who have strong social ties within their communities have been shown to live longer and enjoy more fulfilling lives.



The Public Library of Science (PLOS.org), published an article in 2010 which included 148 studies involving 308,000 people who were tracked for close to 8 years. The studies measured how people's social lives affected their lifespans.

In an article published by LiveScience.org, Rachael Rettner interviewed Brigham Young psychologist and researcher Julianne Holt-Lunstad who said, "I think we make a compelling case that social relationships should also be taken quite seriously in terms of reducing risk of mortality,"

Regardless of age, gender, and health status, the studies continuously proved the size of a person's social network and their level of integration increases odds of survival. The key to a longer life is to make friends and create meaningful connections.

"As we encounter potentially stressful events in our lives, if we know that we've got people we can count on or that we can turn to," Holt-Lunstad continued, "we may be less likely to even perceive it as stressful, because we know we can handle it [together]."

So, this is an open invite: Please join our social network! Our shared community goals are to support each other, spread awareness, and raise funds for research.

**We are stronger together and we would love to have you!**



Bob Wallin is stepping down from the board in December. He will be missed greatly. He has served on the board for seventeen years. Bob got involved with the Evergreen chapter when his daughter, Kirsten, was diagnosed with scleroderma. He's served as both treasurer and secretary. He is looking forward to spending more time with his wife, Debbie, and his kids and grandkids. Thank you, Bob, for your many years of service.

You can still expect to see Bob and Debbie at events like the walks and auction.



**Dental Issues in Scleroderma**  
with Dr. Patrick Bennett DDS



Thursday, February 1, 2018

Saint Luke's Community Health Center  
Bellingham, WA

## *Scleroderma Stories*

*Victoria was inspired to start a much-needed support group in Yakima by her experience as the daughter of a scleroderma patient. When Victoria was only twelve her mother was diagnosed.*

*She recalls, "It was a pretty scary time for our family, as at first the doctors did not know what was going on. I remember feeling like there was no one to talk to about what Mom was going through and about what we went through as a family; there was just no support." Victoria's mother, Cheryl Deering, fought long and hard for twenty-five years.*

*"Now as an adult, I feel the need to find support to deal with what we went through and I started the Yakima group so that others can get support for themselves and for their family members. Although I do not have scleroderma myself, I have compassion for those that do and the family members who are standing by their sides."*

*Victoria now has a co-leader, Kim Castro. Kim is an LPN and has worked with hospice and private home nursing for many years.*



Yakima Support Group Leader, Victoria Harris and Family.

Victoria has been married 18 years and has 3 children.

The Yakima Group meets the second Tuesday of every month from 6 to 8 p.m.

West Valley Church, 7109 W. Nob Hill, Yakima.

Enter on the north side of the building.

You Can Reach Victoria and Kim at:

[avmaharris@msn.com](mailto:avmaharris@msn.com) and [kimberlyanncastro70@gmail.com](mailto:kimberlyanncastro70@gmail.com)

**Scleroderma patients and family members, please submit your stories for future newsletters or request to be interviewed.**

**Contact Andrea at [smithap@comcast.net](mailto:smithap@comcast.net)**

Look for us online: [www.scleroderma.org/washington](http://www.scleroderma.org/washington) and [facebook.com/sfwaevergreen](https://facebook.com/sfwaevergreen)

## Bellingham Conference

*(continued from page 1)*

Karl Mincin discussed digestive and nutritional problems commonly seen in those with scleroderma. He covered typical symptoms such as:

1. Esophageal dysfunction
2. Swallowing difficulties
3. Slow digestion problems
4. The importance of getting the right nutrition
5. The physical changes that are caused by scleroderma on our digestive systems



**Dr. Brad Diestelhorst**



**Who says there's  
no free lunch?**

I talked with the audience of patients and care-givers about holistic dietary choices and life hacks that can help make your daily life a little easier. I also discussed patient advocacy and how talking to our elected officials in Washington D.C. furthers their awareness of the autoimmune population and the necessity to fund research being done to find a cure.

We had a fun day of learning, visiting, and enjoying a tasty box lunch. I hope to see **you** at our two patient workshops in Feb and March!