Upcoming Events

- Seattle Area 5K Walk & 10K Run
  Saturday, August 12, 2017
  Saint Edward State Park, Kenmore, WA
- Bellingham Patient Conference: October 18
- Seattle Patient Conference: March 2018
- Annual Auction & Dinner: April 7, 2018

Celebrate our Chapter’s 25th Anniversary
on Saturday, August 12th
at Saint Edward State Park
Friends, fresh air, a great cause, and oh yeah, hot dogs!
sign up at www.scleroderma.org/steppingoutseattle

SFWEC and the Scleroderma Association of B.C.

SFWEC’s own Shelley Van Pelt was invited to speak at the 33rd annual General Meeting and Conference for the Scleroderma Association of B.C., Canada. With over 80 attendees, it was a terrific event with speakers on a wide range of topics including, Esophageal Disease and Scleroderma, Scleroderma and Eye Issues, and Mental Health and Chronic Illnesses. Shelley’s talk covered the benefits of holistic, healthy lifestyle choices and nutrition for those with scleroderma. These were followed by a round table group discussion on topics of interest to the attendees.

The Canada Pulmonary Hypertension Association and research students from the local universities were there to engage with patients and learn about the daily challenges and struggles they face. Research students also presented their latest research with poster boards. This gave patients and caregivers opportunities to ask questions and learn about the latest in scleroderma research in Canada.

The conference offered a wonderful buffet lunch for all attendees. This is a really great opportunity to meet people in BC and to learn from them. We are all stronger when we stand together. Please consider going to this conference next year. It is close to home and run by very welcoming folks.

Shelley is our medical/education outreach coordinator.

Spokane Update

The Spokane Scleroderma Support Group was once again busy this year. Monthly support group meetings and then adding on walk meetings, we incorporated something new this year. We had a Scleroderma Foundation booth at the Bloomsday Trade Show! Bloomsday takes place the first weekend in May and is the worlds largest timed road race with an average of 40,000 people attending!

We spoke to people from across the United States and Canada about scleroderma to help spread awareness. This year our walk took place on June 3rd, and went off without a hitch despite being only our third time putting on a walk.

Many people contributed to our success. We had volunteers who helped to set up and tear down; others helped with registration and t-shirt hand outs or manned the tables. Some helped with the awesome silent auction and raffle items and the course set up. A special thank you to Kenny Knight for once again providing the wonderful music. It was a beautiful day and we certainly appreciate all who were involved!
Support Group Leaders Training Retreat

The 4th annual training for our Washington Evergreen Chapter support group leaders was held on May 6-7th at the Sleeping Lady Mountain Retreat near Leavenworth. Tracy Hagel began the retreat by reviewing the support group leaders role and the importance of staying within the guidelines outlined by the Scleroderma Foundation. Shelley Van Pelt then presented Workshop Updates, including the prospect of starting a Virtual Support Group online.

Our guest presenter this year was Sean Burlile, PhD, who is a Rehabilitation Counselor for the U.S. Department of Veterans Affairs in Boise, Idaho.

He and his wife Dee recently started the Southern Idaho Support Group.

Dr. Sean Burlile addressed three topics over the two days. The first session, A Day in The Life of a Person With a Disability, focused on a person living with Scleroderma. Sean’s second session, titled Compassion Fatigue, demonstrated strategies to help leaders avoid burnout and the importance of having an individual self-care plan. Sean’s Sunday morning session, Legislative Advocacy, outlined his VA briefings to assist the Obama transition team when that administration took office in 2009. He also described his ongoing work with the Idaho State Rehabilitation Council and the Idaho State Independent Living Council. He provided ideas for reaching out to policymakers, for building bipartisan relationships, and understanding the importance of program branding. Support Group leaders will be able to share these ideas with their groups. Sean also offered an inspiring video called “Right Footed”, about Jessica Cox who was born without arms, who in spite of her disability, learned to drive with her feet, pilot an airplane, but more importantly she became a disability advocate.

Sean’s presentations were interspersed with other activities valuable to developing our groups. Evaluations rated the retreat as very successful and praised the speaker and the weekend’s experience. Thank you to the Evergreen Board and our sponsors for making this important event possible.
Scleroderma Stories
By Ken Moninski

As the Washington Evergreen Chapter of the Scleroderma Foundation celebrates its 25th anniversary, my thoughts turn back to my late-wife, Daina. Daina Kinderis was diagnosed with Scleroderma in the early 1980’s as a teenager. This diagnosis came after visiting multiple doctors before becoming aware of the underlying condition that was causing her hands to turn blue.

As a young woman, her symptoms became more severe and Daina sought out others like her that lived with Scleroderma. In the early 1990’s Daina developed a network that included the Arthritis Foundation and several local rheumatologists that introduced her to other Scleroderma patients in the Seattle-area. This was quite a feat given the absence of e-mail, the internet and social media. As they became known to each other, a small group of patients began to meet socially at first for coffee but soon decided to formalize their gatherings at a hospital conference room as the first “official” Scleroderma Support Group in the region.

From those first support group meetings in 1992, Daina, Alice Bradley, Patricia Lott and so many others that deserve recognition provided a compassionate forum for newly diagnosed patients and those with Scleroderma that just needed some encouragement or even a shoulder to cry upon. In addition, the mere existence of the group and their visibility at these regular meetings elevated the profile of Scleroderma among the Seattle medical community. Many doctors and related care-givers were introduced to this complex disease and the courageous women and men combating its symptoms every day.

After Daina and I were married in 1995, we moved away from Washington, living in Colorado and Connecticut. When my career brought us back to Seattle in 2003, we were both happy to witness the continuation of the Scleroderma support group and the growth of the Washington Evergreen Chapter within the Scleroderma Foundation. Beyond Daina’s original concept of support to Scleroderma patients, the Chapter was now providing educational outreach to medical professionals and raising much-needed funds to advance ground-breaking research.

Daina passed away in September 2004. It was Daina’s constant passion to improve the lives of those with Scleroderma that inspired me to continue her legacy as a donor to the Foundation and today as a Board Member with the Washington Evergreen Chapter.

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

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

Summer 2017
A Message from our Executive Director

Jeremy Harrison-Smith

We’ve had a busy and successful year so far! Our Annual Auction & Dinner was a huge success, we brought in a record amount of $56,000! It was also an honor to have the Scleroderma Foundation’s CEO Robert Riggs come and speak at the event. Many thanks to our dedicated board and awesome volunteers for making this happen!

At this year’s National Conference in Arizona our chapter was represented very well, with multiple Washington patients including conference scholarship winners Jamie Gerity and Tonda Steele. Jamie brought Joyce Harlan and Tonda brought her husband, Danny Klaver. We also had 5 out of 8 board members in attendance. The conference offered excellent workshops for patients, caregivers and family members. This year there were also workshops geared toward chapter leaders, one of which focused on Grassroots Advocacy led by our own Shelley Van Pelt and Dee Burlile, who both have experience advocating on Capitol Hill in Washington, DC.

Another advocacy workshop urged all of us to contact our representatives in D.C. and urge them to only support healthcare bills that include:

The 4 Pillars of Patient Protections

• Prohibit pre-existing condition discrimination
• Prohibit lifetime and annual caps on insurance benefits
• Allow dependents to stay on family coverage until they are 26
• Limit out-of-pocket costs for patients

For more information, please visit:
www.scleroderma.org/action_home2