

# making connections

A QUARTERLY NEWSLETTER  
SPRING 2019



Top: Auctioneer Fred Granados

Middle:  
Don't miss the Dessert Dash

Bottom:  
Attendees at last year's auction.

Photos by Zoe Pappas.

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## Tropical Dinner and Auction: Saturday, April 6th!

By *Jeremy Harrison-Smith, Executive Director* [jharrissmith@scleroderma.org](mailto:jharrissmith@scleroderma.org)

This year's annual Dinner and Auction is fast approaching, and we hope you can join us on Saturday April 6th at the Rainier Golf and Country Club in Seattle. Our theme this year is Tropical: tropical beaches, tropical vacations, tropical drinks, and tropical clothes. Come dressed in your tropical colors and be ready to have some fun!

This year we have some new and exciting aspects to the night's activities. Like last year, we'll have 100 Golden Tickets available, where the winner gets to pick out one of the live auction items (except the cruise) before the live auction starts! But NEW this year, the winner has the option to choose \$1,000 cash instead of an item! This year we will go back to the traditional bid sheets for the silent auction and include a special "teal line" on each bid sheet. If you make a bid on that line (regardless if you win the item) you'll be entered in a special drawing to win an ultimate Seahawks tailgate package.

Another new aspect to this year's event will be the Dessert Dash where every table wins a dessert! Want your table to be the first to choose one of the delicious desserts? Then bid high so your table gets first pick!

Some of the hottest items in the live auction are: a 7-day cruise to a destination of your

choice with Holland America Line, a week's stay in beautiful Whistler BC, 18 Seattle Sounders tickets to a game in a private suite, 4 nights at a beach house on Washington's coast, and a professional watercolor portrait of your pet! Plus, the energetic and talented auctioneer Fred Granados is presiding again, and he's sure to make the night fun!



To honor the life of scleroderma patient Allyson Stone who passed away in 2017, we've invited Seattle Times sports columnist Larry Stone to share the story of his friendship with Allyson at the event. We are honored to have Allyson's family also attending. We will also have the presentation of the Valerie Yarborough Award and hear from other chapter members.

We hope to see you for the big event on April 6th! 

## Board of Directors News

Did you know that your Chapter has a new board member? We are pleased to announce that **Kim Amandus** has joined our volunteer efforts. Your board of directors is hard at work behind the scenes planning the community events hosted by the Scleroderma Foundation in Washington State.

Kim is a vibrant addition to our team and her keen sense of humor is already apparent. Kim has a passion for patient relations with an emphasis on quality of life and medical care. She resides in the Seattle area and works full time as a recruiter. Kim's life has been personally impacted by Scleroderma; at the age of 17 she was diagnosed with Systemic Scleroderma. Kim wants to actively participate in finding a



cure for Scleroderma, and we are thrilled to have her creativity and experience as we move towards that common goal. Kim says, "my mission is to be an effective contributor in the drive to find a cure to help myself and others, as well as help future patients deal with this relentless disease." 

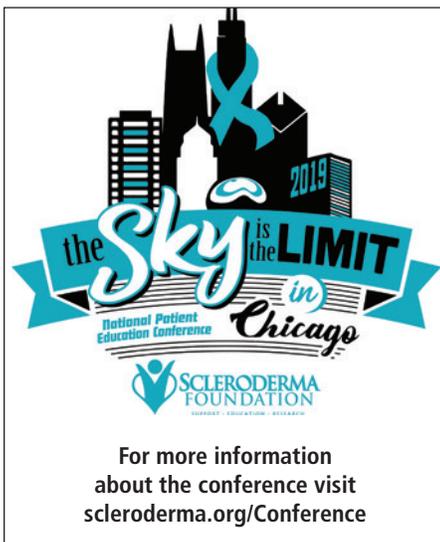


### BOARD OF DIRECTORS

- Marcia Walker, President
- Andrea Smith, Vice President
- Ken Moninski, Treasurer
- John Blum, Secretary
- Shelley Van Pelt,  
Medical/Education Outreach Coordinator
- Jamie Gerity,  
Support Group Coordinator
- Krista Chambers
- Kim Amandus
- Jeremy Harrison-Smith  
Executive Director

# Want to Attend the 2019 National Patient Education Conference? You Can Win a Trip!

This year's conference is in Chicago and takes place July 19–21st.  
Our chapter is sending two patients and their caregivers to the conference this year.  
If you'd like to be entered into the drawing send your name and contact information to Jeremy,  
Jharrisonsmith@scleroderma.org by **April 1st!**



*Last year's conference drawing winner Amy Zavala-Dean (second from left) with board members and Scleroderma Foundation CEO, Robert Riggs.*



## ADVOCACY

Make your voice heard in D.C.  
We need to advocate for research funding each year and make sure our elected officials know they need to support bills that help scleroderma patients.

To Sign up for Action Alerts to be sent to your email please visit [www.scleroderma.org/action\\_home2](http://www.scleroderma.org/action_home2) and click on "sign up for alerts".

Thank you!

## Bundling Up for Adventure

By Jamie Gerity, Support Group Coordinator  
[jgerity@scleroderma.org](mailto:jgerity@scleroderma.org)

I recently made a February trip to Kalaloch, located on the Pacific coast of Washington's beautiful but chilly Olympic Peninsula. One of my first thoughts was, "how am I going to

peel away the layers as they are no longer needed. An essential item to me is a zippered polar fleece vest. Light and easy to wear, it zips all the way to my chin, or opens for more



stay warm?" Like many other people battling Scleroderma, I have chronic chilling and Raynauds. Overcoming this challenge is critical to me; I will not allow my fear of being cold to prevent me from living.

I have gained situational experience over the past two years, being the coldest person that I know. I slowly built up my arsenal of clothing, and I feel warmer and more prepared today than when I first experienced symptoms. I am now confident to try more winter-time adventures.

My best tip for success, is to prepare for the lowest temperature, and then

ventilation. I also have a fleece neck gator to protect my neck and lower face. I am an unashamed, Raynauds ninja.

Packing for the trip, I knew that there would be a lot of hiking. Warm footwear is paramount, I shy away from breathable shoes which let in too much cold air on my sensitive feet. I packed one trusted pair of Merrel hiking boots for dry conditions, and one pair of Bogs rubber boots for wet conditions. I only wear wool socks and did not suffer cold feet on this trip. I also packed a warm pair of house slippers to stay cozy inside the cabin.

I have tried many gloves or mitten combinations, and I must share, you get what you pay for. I spent 45 dollars at REI for a "weatherproof" pair of Xtreme seamless gloves by Seirus, and they have been revolutionary in shielding me from the elements. The wind simply doesn't rush through them and they are flexible to wear. I still carry and use Hot Hands packs and have been trying a new technique of wind milling my arms in circles for increased circulation, showcasing my sweet ninja moves.

Keeping warm is a worthwhile struggle, even if it's a bulky affair. Experiencing the Washington coast in February was stunning. The empty beaches filled with pure air and crisp sunshine warmed my imagination and stirred genuine gratitude. I saw breathtaking waves zipping over a shoal, two majestic golden eagles, and cedar trees older than our country. I'm still battling the cold; however, the inconvenience is well worth the reward. 



Scleroderma Foundation  
earned 4 out of 4 stars!

Look for the donate button  
on our website and  
donate with confidence!

## Seattle Mariners Partner for Fundraiser

By Katy Koval

I've been a Mariners' fan for as long as I can remember. I grew up in the small mountain town of Roslyn, Washington. We were fortunate enough to get some of the Seattle television stations, and we spent many hours watching the games that were broadcast in the 80s and 90s. After college, I moved to Idaho for work, but was pleasantly surprised to be able to watch every Mariners' game on ROOT Sports.



Katy Koval (pictured with the Mariner Moose and Aidan Koval).

For the last three years, I have entered their Mariners Ultimate Fan contest. To my utmost delight, I was chosen as the Ultimate Fan from Idaho last summer. I was awarded a VIP trip to Seattle with my 13-year-old son for the experience of a lifetime. We had such a wonderful time touring the facility, meeting the ROOT Sports broadcast crew, and even meeting some of the players.

Through my Ultimate Fan experience, I made some connections with the ROOT Sports crew that extended beyond that special weekend. I wondered if some of those folks might be able to help make another one of my dreams come true... to have

a scleroderma awareness day with the Mariners. I emailed one of the ROOT Sports folks and asked if he knew who I might talk to at the Mariners to make this dream a reality. He didn't just pass along a random person's name; he actually did some research and kept asking within the Mariners organization until he found the right person for me to communicate with. Thanks

to his help, and later the coordination with Jeremy Harrison-Smith, this dream has come to fruition. I'm so excited and can't wait for June 22nd! While scleroderma has taken away so much from many of us, it can never take away the memories and experiences of special events like this.  Katy is the co-leader of the Idaho Support Group.

2 0 1 9 \* S E A T T L E M A R I N E R S



**SCLERODERMA FOUNDATION DAY**  
SATURDAY, JUNE 22 • 1:10 PM



**EVENT DETAILS AND PRICING**

Join us to help find a cure for scleroderma. Enjoy a day of baseball at a special price when you purchase through this offer.

- \$19 View Level Tickets
- \$36 Main Level Tickets

A portion of every ticket purchased through this special offer will benefit the Scleroderma Foundation Washington Evergreen Chapter and the Idaho Support Group.

DEADLINE TO PURCHASE: SATURDAY, JUNE 22 – 12:00 PM



To buy tickets or for more info call or visit:  
206-346-4449 \* [Mariners.com/Scleroderma](http://Mariners.com/Scleroderma)



## Upcoming Events

### SPOKANE

**BLOOMSDAY TRADE SHOW**  
May 3–4  
Spokane Convention Center

**LIGHT UP THE STACKS  
CEREMONY**  
June 2

**SCLERODERMA NIGHT  
AT THE SPOKANE INDIANS  
BASEBALL GAME**  
August 24



June 8, 2019, Mirabeau Meadows.

Create a team and register here: [www.scleroderma.org/SteppingOutSpokane](http://www.scleroderma.org/SteppingOutSpokane)

### SEATTLE

Rheumatology Research  
What's happening?

#### Juvenile Scleroderma Research

Special Guest Speaker:  
Kathryn Torok, MD

Assistant Professor of Clinical and Translational Science  
University of Pittsburgh  
Children's Hospital of Pittsburgh



Dr. Torok, along with one of her teenage patients, Jewel, during a clinic visit.

Date: Friday, March 29th  
Time: 5:00 pm – 7:00 pm  
Location: Sand Point Learning Center  
Seattle Children's Hospital  
5801 Sand Point Way NE  
Seattle, WA 98105

Appetizers will be served

Free parking on site

RSVP: NO LATER THAN March 22nd

[RheumAdmins@seattlechildrens.org](mailto:RheumAdmins@seattlechildrens.org) or call Joan at 206-987-1951

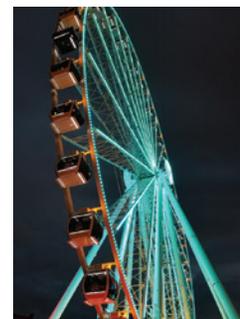


Research Institute



**SCLERODERMA  
FOUNDATION DAY  
MARINERS GAME**  
June 22nd, 1pm

Tickets on sale now at  
[Mariners.com/Scleroderma](http://Mariners.com/Scleroderma)



**LIGHT THE SEATTLE  
GREAT WHEEL IN TEAL!**

June 22nd 6–10pm

For the Scleroderma Awareness  
month of June!

**DR. KATHRYN TOROK, MD SPEAKS AT  
SEATTLE CHILDREN'S HOSPITAL**  
March 29th, 5–7pm

## Washington Support Groups

### WESTERN WASHINGTON

#### North Sound Support Group

Mount Vernon, Washington

Meets on the second Friday of the month at 11:00 a.m. (except July)

Skagit Valley Hospital  
Sauk Conference Room  
(located near the SW parking lot entrance), Mount Vernon, WA

Joyce Harlan  
360-927-5392  
joyceharlan@comcast.net and

Vicki Hollmann  
360-731-7563  
vickihollmann@gmail.com

#### South Sound Support Group

Tacoma, Washington

The South Sound Scleroderma Group meets every 3rd Saturday of the month at 10 a.m.

MultiCare Tacoma General Hospital  
315 Martin Luther King Jr. Way  
Tacoma, WA  
Conference Room MMC 3  
(3rd floor, by Atrium Gift Shop).

Shannan Roby  
shannanroby@yahoo.com  
360-250-7897

#### Penninsula Support Group

For more information, please contact Tracy Hagel

360-268-3007  
herestwous@gmail.com

#### Seattle Support Group

Seattle, Washington

Meets on the 2nd Saturday of every month from 12:00 to 2:00 p.m.

Seattle Children's Hospital  
4800 Sand Point Way NE, Seattle, WA

Kris Garthe  
253-839-1539  
kris@garthefamily.com

#### Caregivers Support Group

Meets quarterly.

Seattle Children's Hospital  
4800 Sand Point Way NE, Seattle, WA

Contact Bunny for more details: bunny@garthefamily.com

### EASTERN WASHINGTON

#### Tri-Cities Support Group

Kennewick, Washington

Meets one Saturday each month.

Zintel Creek Golf Club  
314 N. Underwood St.  
Kennewick, WA 99336.

Vicki Henry  
509-627-5102  
geminiviki@aol.com

#### Spokane Support Group

Spokane, Washington

Meets on the 3rd Monday of each month at 6:00 p.m. No meetings in July, August and December.

Deaconess Health and Education Center  
910 W. 5th Ave., , Spokane, WA  
Room #266

Lisa Van Driel  
509-714-1098  
kittykatlisa@hotmail.com

Jen Stalwick  
JenStalwick56@gmail.com

#### Yakima Support Group

Yakima, Washington

Meets on the 2nd Tuesday of each month from 4:30-6:30pm

Astria Regional Medical Center 110 South 9th Avenue  
Yakima, WA  
Board Rooms A/B  
(In cafe behind the cash registers)

Kim Castro  
KimberlyAnnCastro70@gmail.com

*2018 Support Group Leaders retreat in Leavenworth*





P.O. Box 730  
Clear Lake, WA 98235

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## Upcoming Events

**DR. KATHRYN TOROK, MD SPEAKS AT SEATTLE CHILDREN'S HOSPITAL**

March 29th, 5–7pm

**ANNUAL DINNER AND AUCTION**

April 6th, 5pm, Rainier Golf and Country Club

**SPOKANE 5K/1K WALK**

June 8th

**SCLERODERMA FOUNDATION DAY MARINERS GAME**

June 22nd, 1pm

**LIGHT THE SEATTLE GREAT WHEEL IN TEAL**

June 22nd, 6–10pm

**NATIONAL PATIENT EDUCATION CONFERENCE**

July 19th–21st, Chicago

**STEPPING OUT 10K RUN/5K WALK**

September 14th, Willis Tucker Community Park, Snohomish (New location)



Register Now at [scleroderma.maestroweb.com](http://scleroderma.maestroweb.com)