



SCLERODERMA FOUNDATION
SUPPORT • EDUCATION • RESEARCH
NORTHWEST CHAPTER

A QUARTERLY NEWSLETTER
SPRING 2020

making connections

For the Well-Being of Our Community, Chapter Moving to Online Events

By Jeremy Harrison-Smith, Executive Director jharrisonsmith@scleroderma.org

With the health and well-being of our community always our top priority, the Northwest Chapter is postponing the in-person Black, White & Teal Gala event scheduled for May 30th in Seattle.

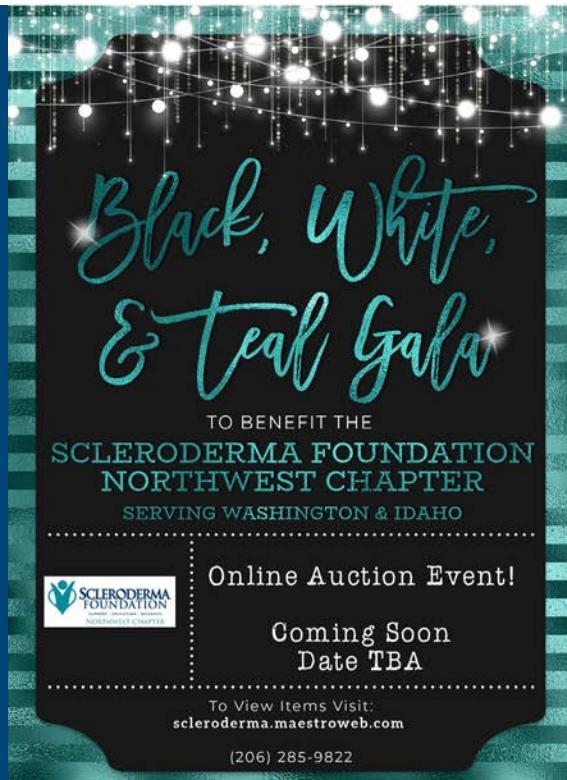
We are currently working on plans for a creative online auction fundraiser in lieu of the gala. We will also have a **Virtual Raise the Paddle Event**. Look for announcements on our website soon for more details about these online events.

As many of you know our annual dinner and auction is our biggest fundraiser of the year. As we continue in these unpredictable times we hope you will consider making a donation if possible (www.scleroderma.org/NorthwestDonate), so we can continue

supporting patients and families in our community, and maintain the forward momentum in advances in research for a cure.

The **Support Group Leaders Training Retreat** scheduled for May has been postponed until next year. We will be offering online training material and resources for support groups to meet remotely. We have also decided to change our June 6th Spokane **Stepping Out to Cure Scleroderma Walk** event to a virtual walk. Please visit www.scleroderma.org/SteppingOutSpokane to sign up or create a team!

Please visit our website for links and updated information. Please keep an eye out for future announcements from our chapter. We wish you and your family the best, and please reach out to us if we can help in anyway. C



Online
Raise the
Paddle
Event
Coming
Soon!

Photo by Zoe Pappas

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(206) 285-9822
Northwest@scleroderma.org
www.scleroderma.org/Northwest
facebook.com/sfNorthwest

Krista Chambers Moves into Board President Position

At the January Northwest Chapter board of directors meeting Marcia Walker announced she was stepping down as board president, but staying on the chapter board and the national board. Krista Chambers was voted to replace Marcia as our board president. Cyndi Whelpley was also elected as our new vice president as Andrea Smith steps down to focus on coordinating our auction event.

We want to thank Marcia for her years of leadership as our board president and her excellent guidance as our chapter has grown and improved. We greatly appreciated the experience and professionalism that Marcia brought to our chapter as president. We are happy that she is staying on the board and look forward to continue growing as a chapter with her by our side!

The following is a statement from Marcia:

It is with heartfelt gratitude to current and former board members that I leave the Presidency of the Northwest Chap-

ter of the Scleroderma Foundation. We have many successes to celebrate and so many opportunities—to support patients and their families, to increase awareness and to raise a lot more money to fund research to help find a cure for this rare disease. I plan to remain on the board and am very proud to support our new president, Krista Chambers. Congratulations and thank you to our other officers, Cyndi Whelpley, Vice President; Ken Moninski, Treasurer; John Blum, Secretary. I look forward to working with our Executive Director, Jeremy Harrison-Smith, as a different kind of volunteer! To everyone in our Scleroderma community, you continue to be my heroes.

The following is a statement from Krista:

I'm so excited and honored to be elected as President of the Northwest Chapter of the Scleroderma Foundation. This organization is very near and dear to my heart and I am looking forward to working with the most caring, committed professionals I have ever known. Thank you all so much! ☺



Marcia Walker



Krista Chambers

BOARD OF DIRECTORS

Krista Chambers, President
Cyndi Whelpley, Vice President
Ken Moninski, Treasurer
John Blum, Secretary
Shelley Van Pelt,
Medical/Education
Outreach Coordinator
Jamie Gerity,
Support Group Coordinator

Dee Burlile,
Idaho Liaison
Marcia Walker
Andrea Smith
Kim Amandus
Traci Rodgers
Jeremy Harrison-Smith
Executive Director



Scleroderma Foundation
earned 4 out of 4 stars!

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

2020 National Patient Education Conference Cancelled, Coming to Bellevue in 2022

To protect the health of individuals who have scleroderma, the Scleroderma Foundation has canceled its 2020 National Patient Education Conference scheduled to take place July 17-19 in Bellevue, Washington.

This action is deeply disappointing for our entire community; however, it is absolutely necessary. As we all know well, individuals with scleroderma, particularly those who have systemic sclerosis, are immuno-compromised and have a heightened risk for the worst-case symptoms of the coronavirus (COVID-19).

This decision was taken after thorough review of information available through public health agencies, primarily the Centers for Disease Control & Prevention and the State of Washington Public Health Department.

In lieu of the eagerly anticipated in-person educational conference and the unique and essential personal connections it provides, the Sclero-

derma Foundation is developing creative, alternative programming to be announced later.

We are pleased to announce that the conference will return to Bellevue, Washington in 2022.

The Foundation continues to be the best resource for information about scleroderma. A wealth of information can be found on scleroderma.org. Information requests can also be submitted by email, SFinfo@scleroderma.org, or by calling the Hope line, (800) 722-4673.

Video recordings of presentations by scleroderma experts at past Foundation conferences can be found at www.YouTube.com/sclerodermaUS.

The National Conference is a special experience, particularly for first-time attendees, but also for those who return every year. The Scleroderma Foundation staff and Board of Directors values each of you very highly, and we look forward to the next opportunity to share time together.

Sincerely, The national Scleroderma Foundation Team **C**



Board members and chapter members from Washington & Idaho attend the 2019 National Conference in Chicago

THE NORTHWEST CHAPTER WILL NOW HOST THE 2022 NATIONAL PATIENT EDUCATION CONFERENCE IN BELLEVUE WASHINGTON



To view updated statements from the Scleroderma Foundation Medical & Scientific Advisory Board please visit:
www.scleroderma.org/covid19_msab

Chapter Patient Education Conference a Big Success!

By Dee Burlile, Idaho Liaison DBurlile@scleroderma.org



The 2019 Northwest Chapter Patient Education Conference was held in Boise, Idaho on the weekend of November 16th, at the St. Luke's Regional

Hospital in the Anderson Convention Center. The conference included presentations by top researchers from across the scleroderma community. Booth space was provided for medical groups, pharmaceutical companies, businesses, local foundations, and various local support groups, which included: Pulmonary Fibrosis, Sjogrens, Idaho Arthritis Walk and Pulmonary Hypertension.

The presentations included: • Marcia Walker and • Dee Burlile, keynote address; • Robert Riggs via a video message, encouraging conference attendees

to grow in their self advocacy skills and congratulating the new Northwest Chapter; • Tracy Frech, MD, Emergencies in Scleroderma and Tracking Vascular Changes and Raynaud's in Systemic Sclerosis; • Lesley Saketkoo, MD, Interstitial Lung Disease/Pulmonary Fibrosis in Systemic Sclerosis; • Janet Poole, PhD, Managing Daily Life with Scleroderma: Exercises, Equipment and Techniques; • JoAnna Harper, PharmD, New Options for Pain Management: CBD and LDN.

The conference was well attended with over 90 patients and caregivers on hand. Attendees provided positive feedback and appreciated having national speakers at a local forum. They also appreciated the inclusion of other local support groups, and the silent auction. Youth volunteers from numerous Treasure Valley middle and high schools helped throughout the conference, giving them the opportunity to serve and learn.

After the conference, board members hosted conference presenters for an appreciation dinner. This gave board members and presenters the opportunity to discuss issues in the scleroderma community and provided time for board members to show appreciation for the contributions the presenters have made to the greater scleroderma community.

The Northwest Chapter has some exciting events coming up this year, including hosting the 2020 Scleroderma Foundation National Conference, and other local patient education conferences.

A special thanks to the following corporate sponsors: St. Luke's, The Grove Hotel, The Hyatt Place, Idaho Arthritis Walk, Idaho Screen Print, Knights of Columbus, Idaho Arthritis Center, Saint Alphonsus, Treasure Valley YMCA, Actelion and Boehringer Ingelheim. C



Left: Dr. Lesley Saketkoo poses with the ice sculpture!

Below left: Conference attendees listen to Dr. Tracy Frech's presentation.

Below: Conference speakers with chapter board members.





Types of Diets: Which One is Best for Me?

Shelley Van Pelt, Medical/Education Outreach Coordinator Svanpelt@scleroderma.org



We all want to live a healthier life. People diet for a variety of reasons and the options vary widely as to which diet will work for you. Finding the right diet may help improve how you feel and increase energy. The use of whole, minimally processed food is good for you. The benefits of a healthy diet (have favorable effects seen in studies) include improved blood sugar control, small improvement in cholesterol numbers, reduced inflammation and higher antioxidant levels.

NutritionED.org lists the following types of diets.

The Paleo Diet

This is a natural way of eating, one that almost abandons all intake of sugar. The only sugar in a Paleo diet comes from fruit. However, abandoning sugar is not the only stipulation. Processed foods and grains are also eliminated from the Paleo diet. The fewer number of carbohydrates in your system leads to a decreased amount of glucose. So your system will then begin to use fat as its fuel source. In a Paleo diet, dairy is also eliminated. So what can be eaten? A Paleo diet consists of fish, fowl, vegetables, fruits, nuts, oils, sweet potatoes, eggs and meat, so long as that meat is grass-fed and not grain-fed.

The Blood Type Diet

Some doctors have started to research diets that coincide with particular blood types. The premise of these diets

attempts to match people with their common dietary needs based on their blood type. For example, individuals with type O blood are recommended to eat lots of food that are high in protein. In order to lose weight, spinach, red meat, seafood and broccoli are suggested while dairy should be avoided. Those with type A blood are recommended to avoid meat and place an emphasis on turkey, tofu, and fruit while weight loss is contingent on eating a diet that consists primarily of soy, seafood and vegetables. Individuals with type B and AB blood also have their own dietary restrictions and recommendations.

The Vegan Diet

This diet is a form of a vegetarian diet as it eliminates meat and animal products. One of the primary effects of this diet is that it reduces the intake of cholesterol and saturated fat. It takes some planning, but if a vegan diet is rationed out properly, it can have many positive effects. Studies have proven that those who practice a vegan diet minimize their overall risk of coronary heart disease, obesity and high blood pressure. To compensate for a lack of meat, vegans must find a way to incorporate more sources of protein and vitamin B-12 into their diets.

The South Beach Diet

This diet was first introduced in 2003 and is based on the premise of changing one's overall eating habits by balancing out one's everyday diet. Certain carbohydrates are completely

avoided. It does not eliminate carbohydrates altogether, but aims to educate dieters on which carbs to always avoid. This often leads to developing a healthy way of eating so that it will be sustainable for the rest of people's lives. The diet includes a selection of healthy fats, lean protein, as well as good carbs.

The Mediterranean Diet

This is another kind of vegetable-heavy diet that avoids a lot of meat, but does not eliminate it altogether. This diet has been proven to help with depression, in addition to controlling blood sugar levels and helping with weight loss. The Mediterranean diet recommends the use of oil as much as possible and that means as an alternative to butter, salad dressings or marinades. It also emphasizes adding vegetables to each meal and favors fish over chicken. Whole grains, nuts and herbs are also used in larger amounts.

The Raw Food Diet

This is a diet that places a premium on eating uncooked and unprocessed foods. The diet eliminates the intake of any foods that have been pasteurized or produced with any kind of synthetics or additives. The diet is intended to create a surge in energy, a decrease in inflammation, while also lowering the number of carcinogens in one's diet. Choosing organic fresh fruits and vegetables is always best.

Resource: NutritionEd.org (2015-2020). nutritioned.org/types-of-diets.html

What is LDN?

By Michelle Moser, RPh, FACA, FAVCP Michelle@MakersPharmacy.com



That's a great question! Low Dose Naltrexone (LDN) is a prescription medication that has been around for more than 50 years but in the last 20 years scientists and physicians have found how this medication has changed the lives of many people.

Naltrexone is often used in a variety of doses, depending on the issue need-

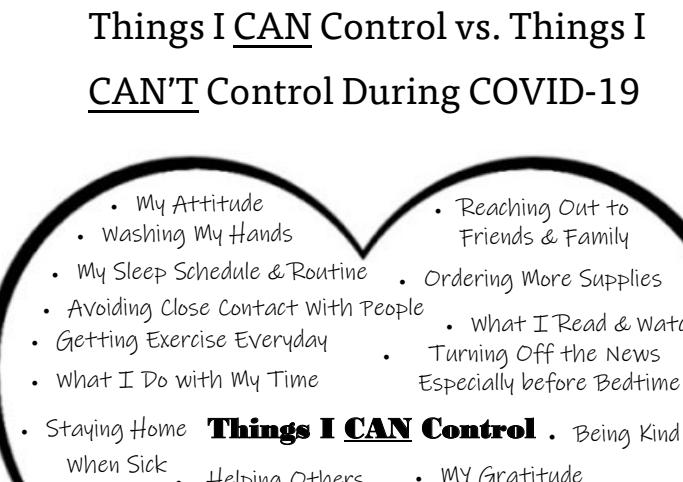
ing to be treated. When googling for information, use the terms low dose naltrexone to find the latest and greatest information. There are more than 400 published studies on LDN alone! The topics of study are varied but the principles of action of LDN are mostly the same. It's a wonder that this medication has helped so many people all over the world.

LDN has properties that function at the root of health care concerns,

where inflammation and pain starts. Because LDN blocks the four pain receptors, caution needs to be taken when administered with opiate or like pain medications, but not acetaminophen or ibuprofen-type medications. LDN also works with other receptors to modulate the immune system, at the cellular level. It also reduces a few of the pro-inflammatory chemicals in the body. It is because of these mechanisms that LDN has helped people with scleroderma, pain, and even depression.

While chronic illness is often stemmed from inflammation, many times drugs are simply a quick fix but with irritating side effects. LDN works at the root of most chronic diagnosis, allowing people to live better lives, and we have the science to prove it!

When considering low dose Naltrexone as a therapy option, consult an LDN expert pharmacist. You can find specific information at LDNresearchtrust.org. C



- Things I CAN'T Control**
- Other People's Actions
 - How Long Things will Take
 - Who will Get Sick
 - How Much Toilet Paper I can Buy
 - What scares me on the News

Created by Jamie Gerity

PLEASE DONATE IF YOU ARE ABLE
This is our second year participating in the regional giving day called Give Big. We welcome your donations to our chapter on May 6, 2020!



www.givebigwa.org/SclerodermaFoundation



Virtual Spokane Stepping Out to Cure Scleroderma Walk

Saturday June 6, 2020

To register or start a team go to:
[www.scleroderma.org/
SteppingOutSpokane](http://www.scleroderma.org/SteppingOutSpokane)

Northwest Chapter Support Groups

SOUTHERN IDAHO

Meridian, Idaho

Meets every 3rd Saturday (February-October) from 10 am-12 pm

St. Luke's Hospital
520 S. Eagle Road
Meridian, ID
Paiute Conference Room
(lower level)

Katy Koval, 208-283-2002
ikatykoval@gmail.com

Jamie McGhee,
mcjamro262@gmail.com

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

Joyce Harlan

360-927-5392

joyceharlan@comcast.net

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

Traci Rodgers

TraciRodgers33@yahoo.com

253-205-6161

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

Heidi Santana

heidi.santana927@gmail.com

Chris Slotemaker

360-908-4907

charleeslote@yahoo.com

Spokane Support Group

Spokane, Washington

Meets on the 3rd Monday of every other 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
kittylisa@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

Please contact your support group leader to learn more about upcoming virtual support group meetings



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2020 EVENTS

WEDNESDAY MAY 6TH

Give Big Day

www.GiveBigWA.org/SclerodermaFoundation

(DATE TBD)

Virtual Auction Gala

scleroderma.maestroweb.com

SATURDAY JUNE 6TH

Virtual Spokane Stepping Out to Cure Scleroderma

www.scleroderma.org/SteppingOutSpokane

SATURDAY JUNE 20TH

Mariners Game (1pm) and

Seattle Great Wheel Lighting (6–10pm)

www.Mariners.com/Scleroderma

SATURDAY AUGUST 22ND

Western WA Stepping Out Walk, Snohomish

SATURDAY OCTOBER 3RD

Boise Patient Education Conference