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MAY 2024



NEWS FROM A NEW BOARD AND COMMITTEE MEMBER

Dear friends and family of the Northwest Sarcoma Foundation. I have the pleasure of writing the opening segment/section for our May newsletter. My name is Michael Lillie I am one of 3 new board members for 2024. Myself along with Bill O'Connell, Mike Bell, and Nick Casillas are excited to share some of our ideas and experiences to help broaden the reach with NWSF this year.

Sarcoma is a rare, complex, and diverse cancer. Children and young adults are underrepresented in this disease. It consists of more than 70 different subtypes – each requiring a different treatment approach. That's why since 1996 the NWSF has been there for those in need of help and support.

My challenge to you is to help us grow, educate and support those in need in our region. I would like to throw out the "Dare to Care" campaign for the month of May. Using a grass roots technique NWSF is

asking for your voice, your friends and families voice to help carry our message on Facebook, Instagram, TikTok. I'd love to see some videos showing how you are sharing our message in the Dare to Care campaign for May. I have been in the rare disease space for over 20 years, I understand how important it is to make people aware of how we help. Sometimes I feel like I'm in back of a crowded stadium shouting about Sarcoma and my voice is muffled by the large stadium. One by one we can move that voice to the center stage and make sure that no one feels left out when it comes to Sarcoma support and education in the Pacific Northwest. Help me challenge others in our Dare to Care for May! Over the past 15 years we have touched over 1,600+ lives and gifted over 1 million dollars, help us exponentially grow these numbers. Change a life today.....

ML

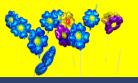


Volunteer with us!

Upcoming Committee meetings

Programs Committee 5.9. 2024 - odd months, 2nd Thursday 10 a.m. PT Events Committee 5.16.2024 2nd Thurs. ea. month 6 p.m. PT*moved to accommodate HGH PDX

<u>Marketing-Communications Committee</u> 5.1.2024 3 p.m.PT <u>Development Committee</u> 5.14.2024 2nd Tues. ea. month 6 p.m. PT



DRAGONSLAYER TRIBUTE FUND APRIL NEW TRIBUTE FUNDS











There's a saying my Uncle once said about Jesse, "If you knew him, you loved him." You see, Jesse was the kind of person who was diplomatic, generous to a fault, and positively insightful in ways that seemed impossible. To this day, whenever I encounter conflict in my life, I still see the soft smile lines form around his eyes and hear his words of comfort which always ended in mutual laughter.

Jesse England was my husband, mentor, and most importantly, my best friend. He was diagnosed with a Malignant Peripheral Nerve Sheath Tumor in 2019 at the age of 36.







In 2008 my wife and I dropped our daughter Margaret off for her first day at the University of San Diego. The day after our return I had the first of a dozen surgeries on my left knee to remove a tumor. Two years of surgery, chemo, and radiation treatment for stage-four cancer saved my leg and probably my life.

TRIBUTE FUNDS

Dragonslayer Tribute Funds are established by friends and/or families to honor the lives of specific Sarcoma patients, survivors, or loved ones lost to Sarcoma. These funds assist the Northwest Sarcoma Foundation in its mission and ensures that

No One Faces Sarcoma Alone You helping to create *thri-vors* in 2024!



5.9 - Portland @ Imperial Bottle Shop 6 - 7:30 p.m.

2024 NWSF EVENTS



Register

JANUARY

Patient Education Night

25 Topic: Chemo! Radiation! A Port! OH MY! RN Panel Discussion



Watch Video

FEBRUARY

Researcher Update Night

21 Topic: Tenosynovial giant cell tumor

Dr. Elizabeth Loggers



MARCH

O6 Dragonslayer Days
Seattle Children's Hospital

16 Knights Unite

UW Horticultural Center

Community Fun Event

Pratt Fine Arts Center

APRIL

Dragonslayer Days

Randall Children's Hospital

18 Hope Grows Here

Wonder Market - Spokane

27 Hope Grows Here Seattle Yacht Club

Sarcoma Journal Club

Dr. Kenny Gundle

MAY

Hope Grows Here

Imperial Bottle House - Portand

11 Community Fun Event UW Baseball

Patient Education Night

14 Radiation Therapy

Dragonslayer Days Drayidance Sacred Hear

Providence Sacred Heart

Community Fun Event

18 Board & Brush

JUNE

Researcher Update Night

25 Topic: PEComas and new treatments

Dr. Michael Wagner

Sarcoma Journal Club

Dr. Duncan Ramsey

JULY

Researcher Update Night

23 Topic: Chondrosarcoma and chonDragon tx Dr. Lara Davis

AUGUST

Researcher Update Night

O6 Topic: Gastrointestinal stromal tumor (GIST)
Dr. Limin Zhu

Community Fun Event

25 Hillsboro Hops

SEPTEMBER

Dragonslayer Walk

Portland

Dragonslayer Walk

Boise

Dragonslayer Walk

Spokane

Dragonslayer Walk

Seattle

OCTOBER

Patient Education Night

16 Topic: Palliative care

Dr. Elizabeth Loggers

NOVEMBER

Sarcoma Journal Club

Dr. Jeremy Sharib

Community Fun Event PDX

O9 Birdie Time Pub &

Mini-Golf

Community Fun Event SEA

O9 Pratt Fine Arts Center

DECEMBER

Patient Education Night

O3 Topic: Pathology - The hidden heroes

Dr. Chen & Dr. Kao





Casual Chats are free events, register once, the same Zoom link each time.

<u>Adult patients & survivors</u>: Second Wednesday of every month.

Next meeting, 4/10/2024 6 - 7 p.m.

Led by either Jo McNeal or Chelsea Winn

<u>Caregivers:</u> Third Tuesday of every month. Next meeting, 4/16/2024 6 - 7 p.m. Volunteer peer-led by Anita Nelson

Sarcoma Bereavement: Fourth Monday of every month.

Next meeting, 4/22/2024 6 - 7 p.m.

Volunteer peer-led by Elana Emlen

Dragonslayer Walk Registration is open

Portland 9.7.2024 @ Gabriel Park
Boise 9.14.2024 @ Ann Morrison Park
Spokane 9.15.2024 @ Mission Park
Seattle 9.21.2024 @ Magnuson Park
Volunteers needed at each location!



CONNECT WITH OTHER SARCOMA PATIENTS



Join the community

Patients and caregivers are invited to join the Sarcoma community with Smart Patients.

Individuals (18 years and older) can join the community by securely sharing their email address and setting up a free personal account. Once the account is confirmed participants will have access to information, and resources, and be able to participate in community conversations on topics of interest.

About Smart Patients:

Smart Patients is an online community where patients and their families affected by a variety of illnesses learn from each other about treatments, challenges, and how it all fits into the context of their experience. While providing patients with safe and high-quality peer support, we help the healthcare system learn from patients to serve them better.

NEW NWSF SWAG



We've added some NWSF swag! 3 designs - children & adult sizes. We've teamed up with Snarky Cancer - an organization that understands and has lived Sarcoma, to create our start of NWSF swag options. We are starting with a few choices to see what may be the most popular. Get your NWSF swag today, start shopping:

SHOP

NW SARCOMA OUT IN THE COMMUNITY

Community Fun Day at Artful Ashes







Glassblowing
Community Fun
event with glass
artists - Minhi
England!
Community Fun
events are a time
for our Sarcoma
community to
come together.





Pediatric Fun Days
are a chance for us
to connect with our
pediatric patients
pediatric patients
while they are in
treatment. We
provide a fun activity
and games. We
and games we
deliver fun packages
to those that are not
able to join us in the

Pediatric Fun Day at Randall's
Children's Hospital



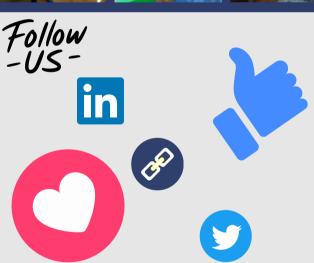




APRIL'S SOCIAL MEDIA BESTS





















My name is Dominic and in 2022 when I was 7 years old I was diagnosed with **Ewings Sarcoma of my** kidney. This journey has been very hard on me, and even though I had to lose my kidney, I have been able to get through it with a lot of help from my parents and my family, and with the help of this foundation. I know God has big plans for me and I will continue to fight!!

SARCOMA FOUNDATION

Check out all our personal stories on our website. You can help in their fight to slay the dragon.

Thank You 2024 Corporate Partners







Cancer Center







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OUR MAILING ADDRESS IS: NORTHWEST SARCOMA FOUNDATION 117 E. LOUISA STREET #443 SEATTLE, WA 98102



