



VOLUNTEER

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OCTOBER 2024

A NOTE OF THANKS FROM A PATIENT...



Upcoming Committee meetings

Development Committee 10.8.2024 2nd Tues. ea. month 6 p.m. PT Programs Committee 11.7 2024 - odd months, 2nd Thursday 10 a.m. PT Events Committee 10.10.2024 2nd Thurs. ea. month 6:30 p.m. PT Marketing-Communications Committee 10.2.2024 3:00 p.m. PT



2024 NWSF EVENTS

OCTOBER

Patient Education Night

30 Topic: Palliative care

Dr. Elizabeth Loggers

NOVEMBER

Sarcoma Journal Club

Dr. Jeremy Sharib

Community Fun Event PDX

O9 Birdie Time Pub &

Community Fun Event SEA

Pratt Fine Arts Center

DECEMBER

Patient Education Night

O3 Topic: Pathology - The hidden heroes

Dr. Chen & Dr. Kao





Casual Chat 2nd Wednesday @ 6p.m. PT









3rd Tuesday of ODD months @ 6p.m. PT

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, 10/9/2024 6 - 7 p.m.

Led by either Aaron, Couch, Jo McNeal, or Chelsea Winn

Caregivers: Third Tuesday of every ODD month.

Next meeting, 11/19/2024 6 - 7 p.m.

Volunteer peer-led by Anita Nelson

Sarcoma Bereavement: services available, learn more <u>HERE</u>.







I remember when I heard this word for the first time. It was a word and a type of cancer I had never heard of before. Pleomorphic Rhadbomyosarcoma to be exact. It was 1994. My son, Tre was 2.

The second time I heard that word regarding my son was 2014, this time it was Radiation Induced Leiomyosarcoma. Tre was 21. We knew that sarcomas were a very real threat in our lives because we had a genetic pre-disposition to cancer due to Li-Fraumeni syndrome, which is a mutation in the TP53 gene. 7 months later we would hear it again, Osteosarcoma of the jaw. He was 22. It was during this 3rd diagnosis that the social worked who at OHSU told us about the NW Sarcoma foundation and filled out the paperwork for him to a receive a \$500 grant to help with travel expenses



as we traveled from our home in Kennewick, WA to Portland OR for his treatment. 16 months later we heard it again, recurrent osteosarcoma of the jaw. He had to endure another brutal surgery.

Tre had a little bit of break from sarcomas during the next 3 ½ years. Of course there was the aftermath of treatment, subsequent surgeries, scans and biopsies. And the hard work of the physical and mental recovery from having both sides of your jaw removed and your entire life as a young adult being disrupted by cancer. He helped us start our screen printing business that raises money and spirits for all those dealing with cancer. I was lucky enough to work with him everyday. And then in 2020 at the height of covid, we heard the word again. Metastatic Vascular Leiomyosarcoma. He was diagnosed right after his 28th birthday. It was at this time that the NW Sarcoma Foundation awarded him another travel grant.

Tre fought like hell during the next 3 years. He still laughed and continued to make hugely inappropriate cancer jokes with me, much to my husband's dismay. He visited his close group of friends from here in Spokane and helped at the shop whenever he was well enough.

Treatment for sarcomas is brutal. Most of the time patients have to be admitted to the hospital for chemo treatments. And sarcomas are notoriously hard to treat with an extremely high recurrence and metastasis rate. Several of the chemotherapies used are cardio toxic, meaning they can cause heart damage.

And that's what happened to Tre. He developed the beginning stages of congestive heart failure and developed a large pericardial effusion that required surgery. It was when he stopped treatment for a 2nd surgery due to the pericardial effusion that his aggressive cancer grew to the point that nothing slowed it down.

Tre passed away on August 17, 2023 just 8 days after his 31st birthday. He didn't lose any battle. He won. He still is here in our hearts and in spirit and the cancer died with his body.

My son was a remarkable and resilient human. He never complained about cancer, he never said why me. In fact, when he would hear of someone younger than him dealing with cancer, he would wish he could take it from them too. Even after 10 years of cancering (yes we use cancer as a verb) he still felt that way. He was my favorite person and I miss him every minute of every day. He was smart, compassionate had a wicked sense of humor and was fiercely competitive. He loved his friends and family deeply. But I continue to honor him and speak his name and to do my best to make cancer suck a little less through our business and being involved with worthwhile

organizations like the NW Sarcoma Foundation.



So while you walk, remember Tre. Remember to laugh a lot and love your people. Remember to do something worthwhile. Remember to get help when you need to so you can heal, both physically and mentally. And remember that it doesn't take much to make a difference in the lives of others.

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





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.



SEPTEMBER'S SOCIAL MEDIA BESTS

















Published by Julie Perkins

September 14 at 8:21 AM · @

BOISE DRAGONSLAYERS UNITE





· September 7 at 7:46 PM · @

Amazing day! #1 team was Kaiser Permanente OR/SW WA. Way to kick us



















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