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VOLUNTEER

WEBSITE

SEPTEMBER 2023



MESSAGE FROM A BOARD MEMBER

Chappie Conrad - Board Secretary

Dear Sarcoma friends and families,

I hope that you are all doing well and were able to have an enjoyable summer without dealing with medical issues. This organization is near and dear to my heart because we started it more than twenty years ago in honor of all our Sarcoma friends and families. We are one of the oldest Sarcoma patient support groups in the US and the only Sarcoma group dedicated to supporting Sarcoma patients and families from the Pacific Northwest. We are also one of the first patient support groups to give Sarcoma patients a financial grant to pay their bills or pursue a second opinion for their care.

Adults and children dealing with Sarcomas are at a disadvantage because Sarcomas are a rare cancer that are difficult to diagnose and treat and frequently has a significant delay in getting an accurate diagnosis and treatment. Make sure you or your family or friends get a quick (4-6 week) orthopaedic or primary care/MD visit if they have a painful bone abnormality or a painless soft tissue lump, larger than a golf ball, that might represent a soft tissue Sarcoma.

September is a busy time for us because we host our most popular event, the Dragonslayer walks, with events in Portland on Sept 9th, Boise on Sept 16th, Spokane on Sept 17th, and Seattle with the addition of a fun run on Sept 23rd. These events are some of our biggest fundraisers and allow us to pay for Help's patient grants, in addition to other programs.

Please ask about our new Dragonslayer Tribute Fund program which will allow friends and family members to start a tribute fund in memory or honor of a Sarcoma patient. Contact us for additional information regarding the Dragonslayer Tribute Fund program.

Please come to say hello and support our Sarcoma patients and families at our Dragonslayer events in Portland, Boise, Spokane, and/or Seattle. We need your support to help our future Sarcoma patients.

Best Wishes
Chappie Conrad

A SARCOMA STORY



I'm Nick Casillas, I've have been an Ewing's sarcoma survivor in remission for 29-years. I was diagnosed with bone cancer in 1993 at the age of 9, after experiencing intermittent foot, ankle and joint pain on and off for the better part of a year. I still remember waking up one morning for school and being unable to bear weight on my right foot. Who could have fathomed that a seemingly benign ache and pain would result in a year plus battle for my life. As an active youth, heavily involved in year-round athletic pursuits, parallels were immediately drawn between my inability to walk and a sports-related injury of some kind. Even though there was not one specific incident myself or my family could point to. After visits to the pediatrician, resulting in rutches, mandated bouts of couch-bound inactivity, days off from school, holdouts from recess, and what seemed like endless amounts of applied rest, ice,

compression, and elevation, things did not improve. As soon as the pain subsided after being sidelined for prolonged periods of inactivity, I would be right back to where I started as soon as I was cleared to go out and run, walk, and play. Every time I was let loose to go catch, throw, and run after baseballs, footballs, and basketballs, like clockwork, I'd be again tethered to that forsaken icepack with an ace bandage wrapped around my ankle elevated on a pillow right back on the couch. Every time I'd get back on my feet, I'd soon meet my same demise, pain that would boil over to a point where I was again, unable to walk, run or play with my friends and family.

Through my Mother's persistence, I ended up in a photoshoot courtesy of the MRI's & CT technology at the time, which produced a referral from that foot and ankle specialist within 24 hours to an Oncologist and Orthopedic Surgeon. As a young child, I did not know what any of this meant, but my parents knew otherwise. It was a whirlwind to say the least, in a 24-hour period my life was flipped upside down, one minute I was an athletic, spirited 9-year-old with the world in front of me, the next minute, I was still 9 years old, but now fighting for my life. I was handed an all but certain sentence to countless rounds of chemotherapy, the near 100% chance I would lose my leg to amputation as the price I had to pay to save my life, and most importantly, the prospect of never walking quite like I had, up to that point, and running, forget about it, realistically my best days were behind me. For a kid who solely identified as an athlete first and foremost, this was like hearing there was no Christmas. I did not know a world where I wasn't running after something.

What a whirlwind and here I am today, telling a small rambling run-on sentence story hoping it helps others who are going through something similar. I have a lot to be thankful for, those doctors, nurses, support staff, counselors, teachers, and prosthetists that didn't give up on me and saved my life. My parents, siblings, and extended family supported me when I was at my lowest and advocated for me even when I couldn't for myself. I owe my life to about 50 people or so, last I counted, if not closer to 100. I have an amazing support system today my wife, 2-year-old daughter, with another girl on the way, a bunch of close friends that I've known in some cases for almost 30 years, and of course my parents, siblings, and extended family on both mine and my wife's side. The NW Sarcoma Foundation is doing great work to provide hope, education, and support to the fight against sarcoma cancers to anyone affected in the PNW. I'd like to thank them for their advocacy, they're doing great work in the community and I'm proud to volunteer for such a great cause.

Cheers to everyone fighting this ugly disease, those connected by it, and here's to finding a cure!
Thanks again for your support!

Read Nick's full story and others

[**MORE STORIES**](#)



We want your stories, not only from patients but caregivers and those whom we have lost too. Please join us in sharing more about Sarcoma from the perspective of those who have lived it. To share your story click [HERE](#)

Connecting with you in 2023!

UPCOMING PROGRAMS & EVENTS

Casual Chat



CASUAL CHAT: SURVIVORS OF SARCOMA ANGELS

Casual chat for anyone who has lost someone to Sarcoma.

Fourth Monday of every month
6 - 7:30 p.m.

Register today to receive Zoom link.

2nd Wednesday @ 6p.m. PT



CASUAL CHAT: SARCOMA CAREGIVERS

Casual chat for anyone who cares for someone with Sarcoma

Third Tuesday of every month
6:00 p.m. (Pacific Time)

Register today to receive Zoom link.

3rd Tuesday @ 6p.m. PT



CASUAL CHAT: SARCOMA BEREAVEMENT

Casual chat for anyone who has lost someone to Sarcoma.

Fourth Monday of every month
6 - 7:30 p.m.

Register today to receive Zoom link.

4th Monday @ 6p.m. PT

Casual Chats are free events:

[Adult patients & survivors](#): Second Wednesday of every month.

Next meeting, 9/13/2023

Led by either Jo McNeal or Chelsea Winn

[Caregivers](#): Third Tuesday of every month.

Next meeting, 9/19/2023

Volunteer peer-led by Anita Nelson

[Sarcoma Bereavement](#): Fourth Monday of every month.

Next meeting, 9/25/2023

Register once, the same Zoom link each time.

Volunteer peer-led by either Donna Anderson or Elana Emlen

Thank you
sponsors

DRAGONSLAYER WALKS:

JOIN US FOR OUR BIGGEST EVENTS OF THE YEAR AND HELP US FUNDRAISE FOR OUR PROGRAMS.

The Dragonslayer Walks and Seattle location's Fun Run are non-competitive, non-timed, roughly 5K walks/run to honor Sarcoma patients, survivors, and angels and raise vital funds for NWSF.

We have 4 locations again this year.
Registration is open, come join the fun!

Portland - Gabriel Park - 9.9

[PDX REGISTER](#)



SKINNYDIPPED



[VOLUNTEER](#)

Boise - Ann Morrison Park - 9.16

[BOI REGISTER](#)

Spokane - Mission Park - 9.17

[SPOK REGISTER](#)

Seattle - Magnuson Park - 9.23

[SEA REGISTER](#)



Knights Unite

a remembrance event



Saturday,
October 14
9:30 – 11 a.m.
at
U.W. Center
for
Urban Horticulture
Free event ~ register today.

[SEA REGISTER](#)

Knights Unite

a remembrance event



October 21st
at 10am
at
OHSU
Knight Cancer
Institute

Hosted in
partnership
with:



KNIGHT
CANCER
Institute

[PDX REGISTER](#)

Our inaugural Remembrance events, Knights Unite will be in October 2023. These FREE events are for those who have lost someone to Sarcoma to come together with others who understand your journey. These events will host a remembrance collage project along with memorial discussions. Please consider joining us for these inaugural events.

Seattle Location: U.W. Center for Urban Horticulture

Date: Saturday, October 14, 2023

Time: 9:30 - 11 a.m.

Tickets: FREE!

Portland Location: Knight Cancer Institute

Date: Saturday, October 21, 2023

Time: 10 - 12 p.m.

Tickets: FREE!

VOLUNTEERS

NEEDED



Volunteer with us!

Upcoming Committee meetings

Programs Committee 9.27.2023 usually 2nd Mon. ea. month 2 p.m. PT

Events Committee 9.14.2023 2nd Thurs. ea. month 6 p.m. PT

Marketing-Communications Committee 9.6.2023 1st Wed. ea. month 3 p.m. PT

Development Committee 9.12.2023 2nd Tues. ea. month 6 p.m. PT

Dragonslayer Walks - PDX 9.9.2023 | BOI 9.16.2023

SPOK 9.17.2023 | SEA 9.23.2023

AUGUST'S SOCIAL MEDIA BESTS



THANK YOU 2023 CORPORATE PARTNERS



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Cancer Center



Providence
SWEDISH



Abbisko



Seattle Children's
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