

SLAYER NEWS

FROM THE NORTHWEST SARCOMA FOUNDATION

NORTHWEST
SARCOMA
FOUNDATION

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SEPTEMBER 2024

A NOTE OF THANKS FROM A PATIENT...

I just want to thank you personally for the check & information. I cannot tell you how much it will help me & how much it means to me at this time.

7/31/2024

Best Regards,



In appreciation for all you do



Join patients like this person who sent a note of thanks, plus survivors, and those who have lost someone at the Dragonslayer Walks.

Volunteer with us!

Upcoming Committee meetings

[Development Committee](#) 8.13.2024 2nd Tues. ea. month 6 p.m. PT

[Programs Committee](#) 9.5.2024 - odd months, 2nd Thursday 10 a.m. PT

[Events Committee](#) 8.8.2024 2nd Thurs. ea. month 6 p.m. PT

[Marketing-Communications Committee](#) 8.7.2024 3:00 p.m. PT

We ♥ our
Volunteers



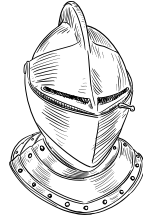
Portland, 9.7.2024 @ Gabriel Park



Boise, 9.14.2024 @ Ann Morrison Park



Spokane, 9.15.2024 @ Mission Park



Seattle, 9.21.2024 @ Magnuson Park

SLAYERS UNITE

PORTLAND 9.7.2024

BOISE 9.14.2024

SEATTLE 9.21.2024

SPOKANE 9.15.2024

NORTHWEST SARCOMA FOUNDATION
HOPE • EDUCATION • SUPPORT



GRAIL



KAISER PERMANENTE®

VOLUNTEERS NEEDED



Casual Chat



2nd Wednesday @ 6p.m. PT



CASUAL CHAT: SARCOMA CAREGIVERS
Casual chat for anyone who cares for someone with Sarcoma

Third Tuesday of every ODD month

6:00 p.m. (Pacific Time)

REGISTER TODAY TO RECEIVE ZOOM LINK!

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

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

Adult patients & survivors: Second Wednesday of every month.

Next meeting, 9/11/2024 6 - 7 p.m.

Led by either Jo McNeal or Chelsea Winn

Caregivers: Third Tuesday of every ODD month.

Next meeting, 9/17/2024 6 - 7 p.m.

Volunteer peer-led by Anita Nelson

Sarcoma Bereavement: services available, learn more [HERE](#).

UPCOMING PROGRAMS & EVENTS



Register!

2024 NWSF EVENTS

SEPTEMBER

- 07 **Dragonslayer Walk**
Portland
- 14 **Dragonslayer Walk**
Boise
- 15 **Dragonslayer Walk**
Spokane
- 21 **Dragonslayer Walk**
Seattle

OCTOBER

- Patient Education Night**
30 **Topic:** Palliative care
Dr. Elizabeth Loggers

NOVEMBER

- 06 **Sarcoma Journal Club**
Dr. Jeremy Sharib
- 09 **Community Fun Event PDX**
Birdie Time Pub &
Mini-Golf
- 09 **Community Fun Event SEA**
Pratt Fine Arts Center

DECEMBER

- Patient Education Night**
03 **Topic:** Pathology - The
hidden heroes
Dr. Chen & Dr. Kao

PEOPLE WE SERVE

John Galas has spent most of his life around soccer. At an early age, he developed a deep passion for the sport and embraced the competitive spirit inherent in it. This mindset that proved invaluable when he faced his toughest opponent yet: cancer. While playing in college he realized pursuing the sport professionally may not be an option, so he transitioned into coaching. John has now spent over 25 years leading teams through the highs of wins and lows of losses on the pitch. At an early age, he developed a deep passion for soccer and embraced the competitive spirit inherent in the sport, a mindset that proved invaluable when he faced his toughest opponent yet: cancer.

John was diagnosed with Sarcoma in October of 2023, and confronted this challenge with the same determination he displayed as both player and coach. Despite the uncertainty that loomed ahead, he remained determined to end this fight with only one outcome: a victory. Reflecting on his Sarcoma journey, John acknowledged the gravity of his diagnosis, recognizing it as one of the most difficult moments of his life. Yet, armed with unwavering support from family and friends, and a relentless fighting spirit, he embarked on a courageous battle against cancer.

"I've got one option and that's to win, however long that takes, no matter how uncomfortable it might be. I just had a mindset that I was going to win, and this was one speed bump along the way," John said. "The mentality was to fight and to stay positive, much like I coach my teams."

"Once John received his treatment plan from the medical team, we knew what we needed to put in place as he navigated chemo, radiation and surgery over the coming months," explained Anna Galas, John's wife and Critical Path Institute (C-Path) Grants Manager. "You plan and train for a competitive season with the goal of achieving the best outcome, winning, and I think we, as a family, certainly approached John's fight against cancer that way."

Through John's story you feel his passion for soccer, and his will to battle against Sarcoma. As a newfound cancer advocate, John has helped propel himself into the research world with the aim that he can help push research forward.

"You never want to be diagnosed with cancer, but there is a silver lining," John explained. "You end up galvanizing communities and helping with research. Bringing people together is the least I can do for the amount of support my family and I have received throughout this process."

Story by Claire Bassetti @ C-Path



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

ADVANCEMENT IN TREATMENT NEWS



We are thrilled to inform you that late yesterday TECELRA® (afamitresgene autoleucel) received accelerated approval from the U.S. Food and Drug Administration (FDA).

As the first new therapy option for **synovial sarcoma** in more than a decade, this approval marks a significant milestone we have achieved together. It represents years of dedicated research, development, and collaboration between our team at Adaptimmune, healthcare professionals, regulatory agencies, patients, caregivers, and advocacy groups like yours, and we are immensely grateful for your unwavering support and commitment throughout this journey.

Moving forward, we remain dedicated to ensuring that TECELRA is accessible to those who need it. We recognize the importance of patient advocacy organizations in shaping healthcare policies and practices, and we are committed to working closely with you to facilitate access, provide education, and support initiatives that will benefit patients and their families.

Thank you again for your dedication to addressing the needs and amplifying the voices of people with synovial sarcoma. We look forward to continuing this productive collaboration.

You can read the full FDA approval announcement from Adaptimmune [here](#), including information about our patient support program, AdaptimmuneAssist, or visit www.adaptimmune.com for more information.

TECELRA is a medicine used to treat synovial sarcoma when other kinds of treatments do not work.



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.

AUGUST'S SOCIAL MEDIA BESTS

Follow
-US-

Enjoying the HOPS game with the Portland area #Sarcoma community. #dragonslayersunite



Sarcoma is coming to light a little more as People Magazine shares a story of a young patient and his journey to diagnosis. Read more: <https://ow.ly/enPu50T6RN0> #nwsarcoma, #dragonslayersunite, #Sarcoma, #beyourownadvocate



Mom Warns Parents After She Says Son's Symptom for Pediatric Sarcoma Was Dismissed: 'Trust Your Intuition' (Exclusive)



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