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DECEMBER 2023

EXCITING NEWS IN THE SARCOMA WORLD

The FDA recently approved a new drug treatment for Desmoid Tumors - OGSIVEO. This is the first and only treatment for adults with Desmoid Tumors.

STAMFORD, Conn., November 27, 2023 – SpringWorks Therapeutics, Inc. (Nasdaq: SWTX), a commercial-stage biopharmaceutical company focused on severe rare diseases and cancer, announced today that the U.S. Food and Drug Administration (FDA) has approved OGSIVEO™ (nirogacestat), an oral gamma secretase inhibitor, for the treatment of adult patients with progressing desmoid tumors who require systemic treatment.¹ The FDA previously granted breakthrough therapy, fast track and orphan drug designations to nirogacestat for the treatment of desmoid tumors.

“Our team is honored to deliver the first FDA-approved therapy for patients with desmoid tumors. This community has been waiting for an effective treatment that not only shrinks their tumors but also significantly improves pain, which is the most debilitating symptom reported by people living with desmoid tumors,” said Saqib Islam, Chief Executive Officer of SpringWorks. “We are pleased with the broad label, which includes all progressing adult patients and specifically references improvement in pain, and believe OGSIVEO has the potential to become the new standard of care for people living with these devastating tumors. This is a watershed moment for the desmoid tumor community and we would like to extend our gratitude to the patients, families, investigators, and advocacy groups involved in the journey to making OGSIVEO available in the U.S.”

Congrats to our corporate partner, SpringWorks Therapeutics for this tremendous success and we are excited for the Desmoid Tumor patients who will benefit from this improved treatment.



Volunteer with us!

Upcoming Committee meetings

Programs Committee 1.15.2024 usually 2nd Mon. ea. month 1:30 p.m. PT

Events Committee 12.14.2023 2nd Thurs. ea. month 6 p.m. PT

Marketing-Communications Committee 12.6.2023 1st Wed. ea. month 3 p.m. PT

Development Committee 12.12.2023 2nd Tues. ea. month 6 p.m. PT



UPCOMING PROGRAMS & EVENTS

Casual Chat

Casual Chat
FOR ADULTS BATTLING THE SARCOMA DRAGON

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

4th Monday @ 6p.m. PT

NORTHWEST SARCOMA FOUNDATION
HOPE EDUCATION SUPPORT

Casual Chats are free events:

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

Next meeting, 12/13/2023

Led by either Jo McNeal or Chelsea Winn

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

Next meeting, 12/19/2023

Volunteer peer-led by Anita Nelson

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

Next meeting, 1/22/2024 - no meeting in Dec.

Register once, the same Zoom link each time.

Volunteer peer-led by Elana Emlen

HAPPY

Holidays



Rogelio is five-years-old and lives in Oregon. He was diagnosed with Rhabdomyosarcoma in July 2022. His tumor is inoperable but his prognosis is good after he completes chemotherapy and radiation treatments. Before his diagnosis, he was super excited to start kindergarten. He absolutely enjoys playtime, loves dinosaurs, playing with his big sister, and going to the beach to play in the ocean water.

Join us this holiday season in helping Rogelio to become a SURVIVOR!



A NEW WAY TO GIVE WHILE SHOPPING A GREAT OPTION JUST BEFORE THE HOLIDAYS!!!

We have registered with Raise Right just for you! You can purchase gift cards (eCards) through our Raise Right account and a percentage of your purchase comes back to us.

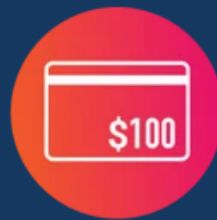
A great example is our Executive Director, Jo. She likes Starbucks as a quick and easy eating option. She can purchase a \$50.00 gift card through Raise Right, load the gift card to the Raise Right "wallet", use the Starbucks gift card donating 7% of her initial gift card purchase back to the NW Sarcoma Foundation. Jo's purchases alone for one year could add up to \$42 to NWSF. If 12 of our supporters did just Starbucks for 1 year at \$50.00 this would fund at least 1 patient grant each year.

With the holiday's right around the corner and many people giving gift cards as a gift to friends and family, YOU could make a big difference to the NW Sarcoma Foundation and a Sarcoma patient. There are over 750 stores to choose from!

Get started today! Create a free account on the RaiseRight mobile app or at RaiseRight.com. Enrollment Code: TJ4HZXHS2PA6

Gift cards that give back

See how easy it is to buy and earn online with this example.



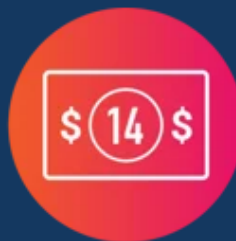
BUY A GIFT CARD

Buy a \$100 Gap eGift card from RaiseRight, with 14% earnings. Pay with your bank account or credit card.



USE IT INSTANTLY

Your \$100 eGift card is delivered to your online "Wallet" instantly, ready to use or save for later.



EARN AUTOMATICALLY

You automatically earned \$14 for your fundraising account. Way to go!



THANKS, GAP!

Your earnings come from the brand, so no extra money out of your pocket.



Have questions contact: info@nwsarcoma.org

NOVEMBER'S SOCIAL MEDIA BESTS

caregiver highlight



Mother, Wife, Friend, CAREGIVER
Movie Director, Neighbor, Author

Kate McMahon



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