

SARCOMA COALITION

We are here for you.

“Where Purpose Meets Progress in Achieving More Together”



Hoping all have been having a good summer so far!

The next **SARCOMA COALITION General Membership MEETING:**
THURSDAY, SEPTEMBER 15, 2022, at 4pm EST
A meeting zoom link to follow as the date gets closer.

Virtual Roundtable
Discussion

AGENDA:

- **Introducing Lizzy’s Walk of Faith Foundation** - New Sarcoma Coalition Member
- **Dr. Leslie Doros** – To brief the Coalition on Project Facilitate and more
- **The Golf Ball Project** - Ad Hoc Committee update
- **Future common-ground** - Coalition issues regarding sarcoma patients for collaboration
- **Presentation (10 min.) by SC member foundation regarding their signature programs** - Intro by the **Life Raft Group** - Mentoring program for patients
- **Care Oncology Protocol Information (5 min)**– Lennie to share w/ the group
- **The Message Board** - Sarcoma Coalition website - purpose / postings
- **CTOS** - SC members gathering together in November
- **Next SC General Meeting** -Planning for December

**SARCOMA COALITION MEMBERS - SAVE THE DATE:
SEPTEMBER 8, 2022, 1:00 pm – 2:30 pm EST**

**A SARCOMA COALITION SPECIAL SESSION – TO NOTE:
A FDA Special Invitation to the Sarcoma Coalition:**



Dear Colleagues:

As a member of the Sarcoma Coalition Advisory Panel in support of the Sarcoma Coalition, we would like to invite you to meet with the FDA Oncology Center of Excellence (OCE) and the Sarcoma team. This is an opportunity for us to learn more about the Sarcoma Coalition, your specific advocacy group, and discuss questions you may have for the team. We will also provide updates on recent sarcoma drug approvals. The meeting will be hosted by the FDA OCE Project Community initiative ([Project Community | FDA](#)).

Name: **A Dialogue with the Sarcoma Coalition Advocacy Community**

Oncology Center of Excellence -Food and Drug Administration

Date: September 8, 2022

Time: 1:00 PM – 2:30 PM EST

Project Manager: Christine Lincoln

We plan to dedicate the second half of the meeting to addressing topics that you identify as representatives of the sarcoma community. Questions to be addressed during this meeting will be:

****Please note that we cannot address topics or questions related to a specific drug or discuss specifics of an approval. ****

We will send out a meeting invitation with a Zoom link and additional details.

Regards,

Leslie Doros, MD, FDA Division of Oncology/office of Oncologic Disease and New Drugs

Two Questions posed by the Coalition for this meeting and for the OCE to address for the Coalition:

1. How are Clinical Trial protocols established in bringing together sarcoma subtypes for inclusion in trials?
2. How are off label drugs accessed by patients who-
 - a) do not meet the eligibility criteria for a clinical trial or
 - b) seek compassionate use through the FDA or the pharmaceutical manufacturer of the drug?

[PLEASE SEND A NOTE TO [Annie Achee](#) to confirm attendance by *September 5th* to respond back to the FDA in a timely manner) Thank you all.

A recently formed Rhabdomyosarcoma coalition of four foundations, Summer's Way, Friends of TJ, Sebastian Strong and Maddie's Promise have joined forces to advance Rhabdo data analysis. These foundations are jointly supporting the work of the Children's Oncology Group Soft Tissue Sarcoma Committee through funding of a Master Statistician. This statistician is currently working on four research projects related to rhabdomyosarcoma including

(1) rhabdomyosarcoma of the head and neck, (2) rhabdomyosarcoma of the orbit, (3) identification of biomarkers in relapsed rhabdomyosarcoma patients and (4) impact of race and ethnicity in rhabdomyosarcoma outcomes. Over 2,000 specimens will be entered into a database for analysis, with a potential to provide a targeted approach towards treatment and improve the outcomes of children with rhabdomyosarcoma.

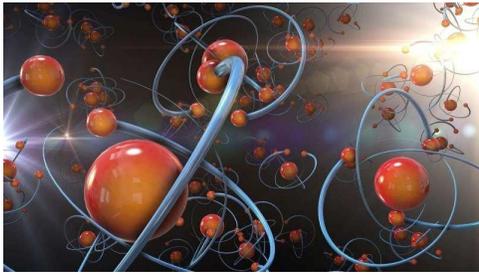


🎉 House Votes to Extend Telehealth Flexibilities Through 2024 🎉

August 2, 2022

An update to the Telehealth legislation that the Coalition members came together to sign a letter of support, representing the sarcoma patient community, to the Rare Disease Congressional Caucus and four Senators:

<https://www.asco.org/news-initiatives/policy-news-analysis/house-votes-extend-telehealth-flexibilities-through-2024>



AUGUST 8, 2022

Researchers develop a small molecule that could make immunotherapy available to all cancer patients <https://medicalxpress.com/.../2022-08-small-molecule...>

Re

searchers develop a small molecule that could make immunotherapy available to all cancer patients <https://mail.aol.com/webmail-std/en-us/PrintMessage>



New Sarcoma Coalition Advisory Panel Member

Dottie Shead, Senior Director, Patient Information Operations National Comprehensive Cancer Network (NCCN). Dottie worked with Dr. Laurence Baker and Denise Reinke in the early days of working overseeing the NCCN Clinical Practice Guidelines. Dottie is very appreciative of being asked to join the Sarcoma Coalition. Dottie has

indicated that the NCCN Guidelines are being revised for 2023 and Soft Tissue Sarcoma will be a stand alone Guideline book; Bone Sarcoma is being revised currently as well.



If Coalition member groups are aware of any other Sarcoma organizations that might be interested in knowing more about the Sarcoma Coalition, please send information by clicking this link: [Steering Committee](#) contacts.



SARCOMA COALITION FACEBOOK GROUP:

The following Facebook address is the new platform of communication among Sarcoma Coalition members - an easy way to stay connected!

<https://www.facebook.com/groups/177803061036588>

T H A N K Y O U - F R O M T H E S C S T E E R I N G C O M M I T T E E

Additional Resources:

Information to share with your patient communities to build awareness of the importance of clinical trials / the short and long terms goals to advance hopeful treatment advancements for the future:

Why would it be helpful to me to donate my tumor tissue for research?

By donating your tissue, you can help researchers find new ways to prevent and treat diseases. Learn about what's involved in making a donation. <https://www.cancer.gov/.../patient.../providing-tissue>

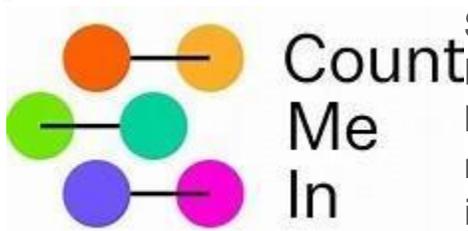
WATCH: The NCI Video of researchers and patients sending us an important message on this topic: <https://www.cancer.gov/about-nci/overview/contributing/tissue-donation-video>

**Below are organizations that also support tissue donation
(This list is not comprehensive and there may be others)**



If you have cancer, you have the power to contribute vital resources to accelerate research through pattern.org, an initiative of the Rare Cancer Research Foundation. By sharing fresh tissue from an upcoming surgery or drain, you can contribute to research at leading institutions such as the Koch Institute at MIT, MD Anderson and the Broad Institute where scientists will utilize the tissue for model generation, genomic and/or CRISPR studies. Each piece of data or model generated is a potentially transformative tool that will be shared broadly within the scientific community.

THE COUNT ME IN PROJECT:



Since late 2015, thousands of women and men living with cancer from around the United States have said "Count Me In" to partnering directly with researchers from the Broad Institute to gain new insights into how tumors develop and why they often

resist treatment. See the Count Me In Patient-Partnered Research video: <https://www.dana-farber.org/research/featured-research/count-me-in/> All cancers /sarcomas are being accepted at this time. Contact: info@lmsproject.org. to access the Project Team.



RESEARCH FOR PATIENT PARTICIPATION From CERTIS: “What’s Next?”

Certis was founded in 2016 after a patient’s family grew frustrated with the treatment options available outside the standard of care. Having a plan for your next-line treatment is critical. Certis offers an alternative—an individualized approach to determining with certainty the most effective treatment for an individual patient.

Fortunately, there are a growing number of precision oncology tools that can inform treatment decisions, including those that belong to the rapidly growing field of functional precision medicine (FPM). One emerging FPM option involves using fresh tumor tissue from a biopsy to build living models of a patient’s cancer. These personalized models function as “avatars” that can be treated with a variety of therapeutic options to determine which is most effective. Results can inform next-line treatment should a person’s cancer recur or become resistant to a previously effective therapy.

This type of testing is expensive and is not presently covered by insurance. However, Certis recently received funding that has enabled us to offer this service up to 32 patients free of charge. To qualify, individuals must undergo a biopsy of tumor tissue that has not been treated with radiation for at least 10 weeks and be willing to wait 4-6 months for results.

Unlike clinical trials that primarily benefit future patients, this type of FPM can directly benefit you.

For more information, please visit the Certis [Certis Website](#). Watch a short video series that explains the Certis personalized in vivo pharmacology testing process, from beginning to end.

“Please view a youtube video by clicking this link”

📺 Clinical Applications of Personalized In Vivo Testing: A Path to Certainty in Treatment De...

NOTE: The Sarcoma Coalition will have an opportunity to hear from **Debbie Snyder-Stanton, MBA** VICE PRESIDENT, BUSINESS DEVELOPMENT of CERTIS, for more discussion on this patient – driven research opportunity – a special session will be offered by CERTIS soon. Stay tuned for the exact date and time.