



JUNE 2024 NEWSLETTER

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SARCOMA COALITION General Meeting

Thursday, July 18, 2024 – 4 pm ET, 3 pm CT, 2 pm MT, 1 pm PT

Recurring virtual meeting / Meeting reminder will be sent 2 weeks before the scheduled meeting

A G E N D A

- **Introduction and Update on Sarcoma Research: Scott Okuno, MD**, Mayo Clinic Sarcoma Center and Medical Director for SARC – Introduction as the Coalition’s new Advisory Panel member, and what’s in the pipeline for sarcoma research
- **The Drug Repurposing Taskforce: Denise Reinke**, Coalition Advisory Panel Member and former President of SARC, and **Marco Schito, PhD**, of CURE ID/XCURES – Introduction to the CURE Drug Repurposing Collaboratory, which addresses several sarcoma subtypes
- **Briefing on Current Legislation: Veronika Panagiotou, PhD**, Coalition Advisory Panel Member and Advocacy and Program Manager of the National Coalition for Cancer Survivorship (NCCS) – Current pertinent legislation and potential action to be taken
- **The Promising Pathway Act (2.0): Jacob Cheboski**, Staff Spokesman for Senator Mike Braun (R-IN) – An introduction to Senate Bill S. 4426
- **Listen and Learn Series:** Overview of the Coalition’s online presentation series and the latest programs added
- **Sarcoma Counts / Sarcoma Awareness Month Action Item: Chandalyn Williams**, Coalition Steering Committee Member is spearheading a “Sarcoma Counts” video project; all member organizations are encouraged to participate
- **The Golf Ball Project:** Progress made to date on this project; the two organizations involved in spreading the word on “Red Flag Alerts”
 - ❖ Discussion: ideas for making contact with the medical community
 - ❖ Committee composition – new volunteers
- **New Ideas Discussion**
 - ❖ Listen and Learn Series – new topics?
 - ❖ Coalition focus – new project ideas to impact patient care and treatment
 - ❖ How are Coalition members building national awareness in communities across the country?
- **SARC Sarcoma Centers of Excellence:** Status of progress in updating the list
- **Summary of Coalition General Meetings:** Coalition action items to be addressed before the next meeting (link to the April meeting summary provided)

June – National Cancer Survivors' Month



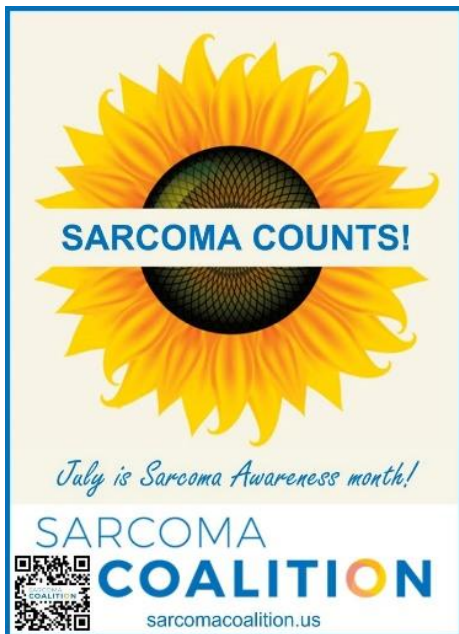
June is National Cancer Survivor Month in the United States, an observance created to honor cancer survivors living in the U.S. There is also a National Cancer Survivors Day, celebrated on June 2.

This is a time to raise awareness of cancer survivors, the issues they face throughout their lifetimes, and advocate for cancer survivorship research.

A cancer survivor is considered a survivor from the time of diagnosis until the end of life. As of 2019, there were 16.9 million cancer survivors in the United States. That number is expected to increase to 22.2 million by 2030.

July – Sarcoma Awareness Month

July is Sarcoma Awareness Month, as observed by numerous organizations, including our own. In 2021, U.S. Senator Ron Johnson (R-Wis) introduced a resolution to designate July as National Sarcoma Awareness Month. The resolution passed the Senate by unanimous consent that year and also in 2022 and 2023. We hope it will be proposed and passed again this year.



Action Item for Sarcoma Coalition Members

Chandalyn Williams, Coalition Steering Committee member, has launched a special project in connection with Sarcoma Awareness month: Sarcoma Counts. This will be a video presentation of speakers from each patient advocacy organization, plus patients sharing testimonials about their journeys. Please contact Chandalyn at info@curelms.com to coordinate your organization's participation in this important messaging – before July.

For Discussion

How are Coalition member organizations observing / celebrating/ building national awareness in communities across the country? Welcoming shared ideas during the General Meeting of the Coalition!

Scott Okuno, MD



Scott Okuno, MD, Mayo Clinic Sarcoma Center, Rochester, MN

Sarcoma Coalition Advisory Panel Member

Dr. Okuno's research objective is to allow patients to have access to new promising drugs for their cancers. The hope is that these therapies will replace present therapies and be more effective and better tolerated, both in the short and long term. By working collaboratively with other colleagues at Mayo Clinic and at other medical centers, Dr. Okuno gets to provide patients with the most effective and promising treatment options.

Professional highlights include: Medical officer, Sarcoma Alliance for Research Through Collaboration (SARC), 2011-present, founding and active member, Midwest Sarcoma Trials Partnership, 2011-present, active member, and Sarcoma Working Group, Radiation Therapy Oncology Group, 2010-present.

CURE Drug Repurposing Collaboratory's Sarcoma Initiative



At left: **Denise Reinke**, Coalition Advisory Panel Member and former President of SARC; and **Marco Schito, PhD**, of CURE ID/XCURES

The Critical Path Institute's Cure Drug Repurposing Collaboratory (CDRC) was founded to explore whether already-marketed drugs can be repurposed for diseases that are not commercially attractive. The program is designed to capture real-world clinical outcome data to advance drug repurposing and inform future clinical trials for diseases of high unmet medical need.

In brief: A very important step forward for the future of sarcoma subtype research advancement and acceleration has emerged – it is a patient's self-advocacy opportunity to contribute to this effort. Denise Reinke and Marco Schito will discuss the details of this drug repurposing initiative specifically targeting sarcomas.

CURE ID, an internet-based repository that lets the clinical community report novel uses of existing drugs, is making it possible for patients and their care partners to share their thoughts on treatments. Right now, doctors share information through a simple case report form, but the program wants to hear from patients as well! Patients sharing their personal stories can help researchers understand how well medicines work, even aspects that can't be seen in tests or pictures.

Share this message with sarcoma patients and caretakers you know:

Take the initiative to help advance research for sarcoma treatments!

You can expedite the search for safe and effective treatments by sharing your journey with [sarcoma subtype specified]. Drug repurposing is a global effort that every person living with sarcoma and taking a drug or treatment off label can contribute to.

Drug repurposing involves identifying FDA-approved drugs that may be effective for diseases they're not currently approved for. Drug repurposing includes drugs that are being used in a new way, such as to treat a different disease from the one that drug was originally studied and approved to treat; in a new dose, route, or duration; in a new combination with other drugs, or nonpharmacologic treatments, or in a new population (e.g. pregnant patient, pediatrics, neonates, etc.).

What's the impact of taking action?

With the goal to identify drugs that are proven to be safe and effective in other diseases, drug repurposing can accelerate the availability of effective treatments.

More resources:

[Sarcoma Patient One-Pager](#)

[Overview: CURE Drug Repurposing Collaboratory](#)

[Overview: Critical Path Institute](#)

Listen and Learn Series Online Presentations



Listen and Learn series presentations are offered for sarcoma patient advocacy groups to share with their respective patient and caretaker communities. They are archived on the coalition website: <https://sarcomacoalition.us/listen-learn-series/>

Nutrition and Cancer: Virtual Discussion with Alison Tierny, Oncology Dietitian

Alison Tierney, MS, RD, CD, CSO, is a board-certified oncology dietitian and cancer thriver who empowers those affected by cancer to conquer fears, take back control, and fully support their body before, during, and after cancer treatment. In this online discussion from May 22, 2024, she addresses what to eat during treatment, clinical trial participation, and more.

[Read more about Alison . . .](#)

[Watch the recorded program . . .](#)

[See the complimentary slide deck developed by the NLMSF to accompany Alison's discussion with patients . . .](#)



Making the Mouth-Body Connection in Cancer Care

Jill Meyer-Lippert, RDH, presented this topic in a January 2024 webinar produced by NCCS. She talked about oral care during cancer treatment and discussed potential oral side effects associated with various cancer treatments as well as ways to prevent, delay, or reduce these complications by focusing on prevention and patient education.

[Watch the recorded program . . .](#)



Promising Pathway Act

On May 23, Senator Mike Braun (R-IN) introduced a new and improved bipartisan **Promising Pathway Act**, designed to give patients with terminal diseases hope for new cures and treatments. The bill is intended to amend the Federal Food, Drug and Cosmetic Act to establish a time-limited conditional approval pathway for certain drugs and biological products.

Read more: [S. 4426](#)

Research Spotlight



Two Recent Research Publications on ctDNA and the Tumor Microenvironment in Soft Tissue Sarcomas

Monitoring Sarcoma Response to immune Checkpoint Inhibition and local cryotherapy with ctDNA - and the impact on Soft Tissue Sarcomas
<https://aacrjournals.org/.../Monitoring-Sarcoma-Response...>

Sarcoma microenvironment cell states and ecosystems are associated with prognosis and predict response to immunotherapy

<https://www.nature.com/articles/s43018-024-00743-y>

Other Research Publications

Sarcoma incidence worldwide: regional differences in histology and molecular subtypes –
PubMed <https://pubmed.ncbi.nlm.nih.gov/38726812/>

Prices and Trends in FDA-Approved Medications for Sarcomas:

[Cancers | Free Full-Text | Prices and Trends in FDA-Approved Medications for Sarcomas \(mdpi.com\)](#)

Best Overall Response-associated Signature to Doxorubicin in Soft Tissue Sarcomas: A Transcriptomic Analysis from ANNOUNCE

<https://pubmed.ncbi.nlm.nih.gov/38536068/>

Updated Sarcoma Centers of Excellence Resource List

The Sarcoma Alliance for Research through Collaboration (SARC) has released its updated listing of Sarcoma Centers for sarcoma care and treatment. As you will see from a disclaimer on their website, this is a work in progress, as some of the centers from the previous list are still in the process of submitting information. The SARC Sarcoma Centers Registry is a database of sarcoma institutions, centers, and practices worldwide that can be filtered by pediatric and adult care. Each center has a summary page with detailed information, including useful telephone numbers. <https://sarctrials.org/sarcoma-centers/>

The Golf Ball Project - “Addressing the Ball”



It’s time to “address the ball” (a term borrowed from golf that refers to a player’s stance in relation to the ball) in the Golf Ball Project. As you may remember, the Golf Ball Project is an initiative launched in 2020 to raise awareness of sarcomas by drawing attention to lumps and bumps of any size, especially those the size of a golf ball.

Now we’ve taken that one step further by creating a visual reminder in the form of a golf ball key chain to be given away and to spread the word about “Red Flag Alerts.” The golf balls (each ball is smaller than a real golf ball, and with an eyelet screw installed) can be made in the colors of the sarcoma advocacy organization with a ring for a key chain, including a card with a printed message on the front and the organization/logo/QR code on the back (card size: 2 ½ W by 3 ¾ L). See the wording at right for the card the NMLSF developed; you’re welcome to use our wording or develop your own.

Currently, two of our member organizations are involved in spreading the word this way: the Charlie Landers Foundation, represented by **Lisa Landers**, and the National LMS Foundation. We’ve found a wonderful resource for making these keychains and will be happy to share it with you; just contact Annie at <mailto:annieachee@aol.com>.

Once you have them on hand, prepare to share these little golf balls – and this crucial message – with friends, family, and medical providers. Stress the importance of NEVER ignoring a lump or bump. This constitutes Red Flag messaging, especially to non-sarcoma and non-oncology medical community providers, some of whom are alarmingly ill-informed about lumps and bumps.

What is it? Could it be a sarcoma?

LUMPS and BUMPS of any size, on any part of the body, and may change size over time - **Do NOT IGNORE - A Possible RED Flag!**

A lump or bump can be deep or subcutaneous and may be painful. It may change in size over time.

Be Alert -

An in-depth consultation and evaluation is necessary to eliminate the potential for possibly overlooking a form of sarcoma. Delays in treatment can be critical.

Imaging / Biopsy is the “best practice”
MRI imaging is usually best / ultrasound at a minimum initially. Biopsy / surgical intervention will reveal whether or not there is a sarcoma - Consult with a sarcoma specialist if it is.

Vanderbilt Sarcoma Study Announcement

Share this with your respective sarcoma patient communities . . . from Vanderbilt Medical Center Sarcoma Department. If you have been diagnosed with sarcoma, you are invited to join the:

**COHORT TO AUGMENT THE UNDERSTANDING OF SARCOMA
ACROSS THE LIFESPAN (CAUSAL) STUDY**

[Learn more here . . .](#)

2024 SPAGN Annual Conference



The 2024 Annual Conference of the Sarcoma Patient Advocacy Global Network (SPAGN) was held in Rome, Italy, on April 19-21.

[See videos of the key presentations . . .](#)

Stay In Touch

- Post to engage with members - on the Sarcoma Coalition FB Page: <https://www.facebook.com/groups/177803061036588>
- Share your organization's event or request for collaboration on a specific project by posting it on the Coalition website Message Board: <https://sarcomacoalition.us/research-community/message-board/>
- Contact the Coalition Steering Committee anytime: [Contact Us - Sarcomacoalition.us](https://sarcomacoalition.us/contact-us)
- [April 2024 Coalition General Meeting Minutes](#)

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