



MARCH 2024 NEWSLETTER

In This Issue

- Sarcoma Coalition General Meeting / Agenda
- Scott Okuno, MD, Joins the Advisory Panel
- SARC Introduces Podcast, "Sarcoma Talk," to the Sarcoma Coalition Membership
- The Count Me In Project
- Wendy Walk Foundation
- Sarcoma Coalition Listen & Learn Series – Clinical Trials Perspectives: A Panel Discussion
- The Golf Ball Project
- Spotlight on SPAGN (Sarcoma Patient Advocacy Global Network)
- Sarcoma Research Highlights
- FDA Special Session Held on July 28
- Planning for July: Sarcoma Awareness Month
- Reminder: Coalition Message Board and Facebook Page
- Working Together

SARCOMA COALITION General Meeting

REMINDER: Thursday, April 18, 2024, 4 pm ET, 3 pm CT, 2 pm MT, 1 pm PT

AGENDA

- **New Advisory Panel Member:** Scott Okuno, MD / SARC Talk information sharing
- **Wendy Walk Foundation profile** - Meredith Berger
- **The Charlie Landers Foundation profile** - Lisa Landers

- **The Golf Ball Project** - workgroup update
- **Listen and Learn Series** presentations - topics for the future
- **New Ideas** for Coalition collaboration for the rest of the year

Scott Okuno, MD, Joins Advisory Panel

The Sarcoma Coalition is honored to introduce Scott Okuno, MD as a new addition to the current Advisory Panel, in support the mission and purpose of the Coalition Members.

For more information about the Sarcoma Coalition Advisory Panel:

<https://sarcomacoalition.us/advisory-panel-steering-committee/>



Scott Okuno, MD

Chair, Division of Community Oncology, Dept. of Oncology

Consultant, Division of Medical Oncology, Department of Oncology

Medical Director, Oncology/Hematology,

Mayo Clinic Health System - Eau Claire, Northwest Wisconsin Region

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 other medical centers, Dr. Okuno is able to provide patients with the most effective and promising treatment options.

Professional highlights:

- Medical officer, Sarcoma Alliance for Research Through Collaboration (SARC), 2011-present
- Founding and active member, Midwest Sarcoma Trials Partnership, 2011-present
- Active member, Sarcoma Working Group, Radiation Therapy Oncology Group, 2010-present

SARC Introduces Podcast, “Sarcoma Talk,” to the Sarcoma Coalition Membership

SARC’s monthly podcast, Sarcoma Talk, explores all things related to sarcoma, including interviews with sarcoma researchers, discussions of innovative scientific initiatives in the field of sarcoma, and updates on the activities of SARC.

Subscribe and listen: [Spotify](#) | [YouTube](#) | [Apple Podcast](#)

The Count Me In Project



The Count Me In (CMI) Project at the Broad Institute of MIT and Harvard brings patients and researchers together as partners to accelerate discoveries. The project allows cancer patients anywhere in the United States or Canada to easily share their medical information, personal experience, and tumor samples for genetic analysis, propelling progress against cancer.

Count Me In aspires to empower individuals living with cancer to contribute to breakthroughs and increase the pace of biomedical research, no matter where they live. Over the next several years, Count Me In aims to enroll more than 100,000 patients living with all major cancer types, as well as rare cancers.

<https://www.dana-farber.org/research/featured/count-me-in>

Wendy Walk Foundation



Sarcoma Coalition Member Representative:
Meredith Berger
Patient Care Coordinator | Wendy Walk

Meredith Berger of [Wendy Walk](#) will introduce herself and the Foundation at the April Coalition General Meeting. Wendy Walk is an organization dedicated to the advancement of sarcoma research and funds the endeavors of top sarcoma specialists around the world who are focused on accelerating the development of innovative treatments for this rare cancer.

Wendy Walk is also committed to helping patients and their loved ones cope with the unique challenges of a sarcoma diagnosis so nobody has to experience this alone.

Since its inception in 2010, the Foundation has raised upwards of four million dollars thanks to more than ten thousand participants at 40+ walks nationwide.

To learn more, visit www.wendywalk.org.

The Charlie Landers Foundation



Sarcoma Coalition New Member Representative:
Lisa Landers
Founder | The Charlie Landers Foundation

Lisa Landers, founder of [The Charlie Landers Foundation](https://www.thecharlielandersfoundation.org/), will introduce herself to the Coalition membership as a new member of the Sarcoma Coalition and will tell us about the Foundation she established to honor the legacy of her son, Charlie Landers. Charlie passed away after a valiant two-and-a-half-year battle against Ewing's Sarcoma, a rare form of bone cancer that mainly affects children, adolescents and young adults. The Foundation's mission is to raise awareness, provide critical support to pediatric and young adult patients, and fund research to find a cure for this devastating disease.

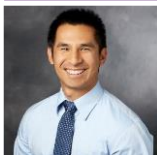
To learn more, visit <https://www.thecharlielandersfoundation.org/>.

Sarcoma Coalition Listen & Learn Series – Clinical Trials Perspectives: A Panel Discussion

A session of the Listen & Learn series was held on Feb. 20 and recorded for future access in the Resource Library of the Sarcoma Coalition website. This expert panel discussion by physician scientists from all over the country was coordinated and provided to the Sarcoma Coalition by the National Leiomyosarcoma Foundation, Coalition member, for all sarcoma patients and families.

Panel members offered key points and answered questions regarding the most important

Expert Panel Members



Nam Bui, MD
Assistant Clinical Professor,
Medicine/Oncology,
Stanford Health Care



Richard Riedel, MD
Associate Professor, Medicine
and Medical Oncology
DUKE Cancer Institute



Rashmi Chugh, MD
Clinical Professor,
Medical Oncology
University of Michigan Health



Arun Singh, MD
Assistant Professor, Dept. of Medicine
Hematology/Oncology
Ronald Reagan Medical Center
Jonsson Cancer Center



Elizabeth Davis, MD
Associate Professor of Medicine
Department of Medicine,
Division of Hematology/Oncology,
Vanderbilt Medical Center



Brittany Siontis, MD
Medical Oncologist
Mayo Clinic

considerations for patients and families, with the understanding that such research saves lives. This program can possibly be helpful to the underserved populations as well as other sarcoma subtypes that do not have patient advocacy representation.

[See the presentation on YouTube . . .](#)

Note: All Sarcoma Coalition member organizations are encouraged to offer their information sessions that would reflect a pan-sarcoma learning experience as part of the Coalition's Listen & Learn sessions in the future.

The Golf Ball Project



Ad Hoc Committee Update - Volunteers from the Coalition Membership are requested at this time to join current committee members, to continue the campaign planning for strategic messaging to the general public as well as the medical community in building awareness of the “red flags” associated with lumps and bumps of any size. Please contact current ad hoc committee members: Mitch Achee, MD, machee@comcast.net or Lisa De Young, lhdeyoung@gmail.com to volunteer.

Spotlight on Sarcoma Patient Global Advocacy Network (SPAGN)

SPAGN Annual Conference

The 14th SPAGN Annual Conference will be held Friday, April 19, 1:00pm CET to Sunday, April 21, 1:00pm CET, at the Precise House Mantegna Roma, Via Andrea Mantegna, 130, 00147 Rome, Italy.



**Sarcoma
Patient Advocacy
Global Network**

Friday:

- 15 Years of SPAEN/SPAGN
- Real-world data & evidence
- Molecular Diagnostics - an introduction
- SPAGN Annual General Meeting

Saturday

- Surgery in Sarcomas: Challenges, pitfalls, clinical trials in surgery
- Patient involvement in sarcoma clinical trials
- Working Group & Discussion Session: Clinical Trials
- Working Group & Discussion Session: Sarcoma Awareness
- Agendas for each of the following tracks: Soft Tissue Sarcoma, GIST, Bone Sarcoma, Desmoid and TGCT
- Sharing Best Practices

Sunday

- The SPAGN Market Place Sessions: Social Media, Storytelling, Fundraising, Political Lobbying, Communications Doctor-Patient, Peer-to-peer support
- Sarcoma Intelligent Specialist Networks
- Artificial Intelligence in Sarcomas
- Closing Remarks

Click here for the [Updated Conference Program](#)

EMSOS Annual Meeting

“On behalf of the EMSOS (European Musculo-Skeletal Oncology Society) Board it is our great pleasure to invite you to join the 36th EMSOS Annual Meeting combined with 24th Allied Professions Group Meeting, which will be organized in Szczecin, Poland between 12 and 14 June, 2024,” writes Daniel Kotrych, representing the Organizing Committee of EMSOS 2024.



To name just a few of the conference topics:

- Sarcoma Research: Human and Animal Cell Culture Models, Mechanism-Based Therapies in Fusion-Driven Sarcomas, Patient-Derived Cell Lines, Liquid Biopsy
- Current Diagnostic and Therapeutical Guidelines in Bone and Soft Tissue Sarcomas
- Novelties in the Systemic Treatment of Pediatric and Adult Soft Tissue and Bone Sarcomas
- The Role of Hyperthermia in the Treatment of Soft Tissue Sarcomas
- Prognostic Tools in Soft Tissue Sarcomas
- Pathology of Bone and Soft Tissue Tumors – the New Diagnostic Tools
- Current Radiotherapy Protocols in Primary and Metastatic Bone and Soft Tissue Disease
- The Approach to Metastatic Bone Disease in Children and Adults
- Principles of Limb Salvage Surgery

[Read more and register here . . .](#)

SPAGN “Voices of Sarcoma” Blog Post:

Should I Join a Clinical Trial? Six Questions Every Patient Should Ask

In SPAGN’s latest blog post, SPAGN board member Denise Reinke explores common questions that patients should consider before deciding to join a trial, including questions about patient safety and rights, and the benefits to consider before deciding whether or not this is right for you. [Read the post . . .](#)

ESGO Update

In 2023, the European Society of Gynaecological Oncology (ESGO), the EURACAN, a European Reference Network for all rare adult solid cancers, and the Gynecologic Cancer InterGroup (GCIIG), agreed to start a new joint project with the goal of developing guidelines on the complete management of patients with uterine sarcomas. The guidelines will cover low-grade endometrial stromal sarcoma, uterine leiomyosarcoma, high-grade endometrial undifferentiated stromal sarcoma, adenosarcoma of the uterus, and other rare types of uterine sarcomas.

An international development group is composed of experts from countries worldwide covering fields of gynaecologic oncology, medical oncology, radiation oncology, radiology, imaging and pathology. The article is planned for publication in the first quarter of 2024.

Don't miss out on the release of these pivotal guidelines! [Stay informed by following the ESGO page . . .](#)

Sarcoma Research Highlights

The proteomic landscape of soft tissue sarcomas

Sarcoma UK, the only cancer charity in the UK focusing on all types of sarcoma, has awarded their [Shining Star Research of the Year Award](#) for this important work, which appeared in *Nature Communications* in June 2023.

“Digging into the biology of sarcoma is vital to develop new and better treatments,” the Shining Star Award Tribute reads. “The team behind this study found that each sarcoma subtype has a unique profile, and developed a resource that can now be used by the sarcoma community to develop personalized treatments, maximize the potential of immunotherapy and improve outcomes for people with sarcoma.” [Read the scientific article on PubMed . . .](#)



“Scientists uncover the 'Rosetta Stone' of sarcoma research to personalize treatment.” (Note that not all sarcoma subtypes are included.) Read this [Institute of Cancer Research article about the study . . .](#)

Twenty-year outcome of prevalence, incidence, mortality and survival rate in patients with malignant bone tumors

This article, published in the *International Journal of Cancer* in August, 2023, reports on a study designed to update the recent epidemiologic estimates based on the Surveillance, Epidemiology and End Results database.

[Read the abstract . . .](#)

FDA Special Session Held on July 28, 2023



Dr. Leslie Doros, Medical Officer of the FDA and Sarcoma Coalition Advisory Panel member, arranged for a special information session with the FDA on July 28. The session could not be recorded, but we trust that the Coalition member groups who participated felt well-informed.

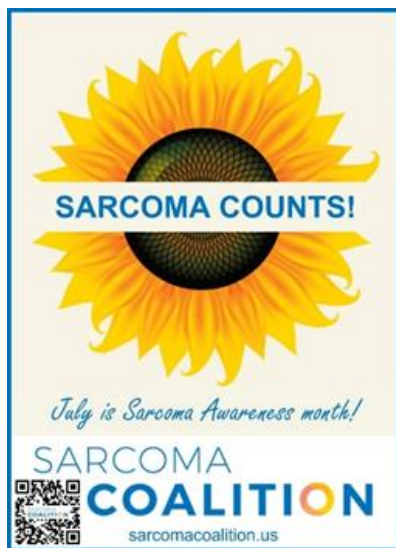
OCE Regulatory Science Online Lecture Series

In early 2022, OCE launched a new online regulatory science lecture series aimed at providing an overview of the OCE's role in oncology product development. Additional episodes are added throughout the year.

Please click on the following links and look for the white arrow at the bottom left of page to listen to each pre-recorded episode.

- Episode 1: [FDA's role in Oncology Product Development](#)
- Episode 2: [Oncology Trial Design Considerations](#)
- Episode 3: [Statistical Considerations in Designing Cancer Clinical Trials](#)
- Episode 4: [Investigational New Drug Applications](#)
- Episode 5: [Patient-Focused Drug Development and Patient-Reported Outcomes in Oncology](#)
- Episode 6: [Oncology Real-World Evidence Program](#)

Planning for July: Sarcoma Awareness Month



We are planning for the Sarcoma Coalition's observance of July as Sarcoma Awareness Month.

Chandalyn Williams, Sarcoma Coalition Steering Committee member, is coordinating a video presentation of speakers from each patient advocacy organization to participate in this year's Sarcoma Counts Campaign.

Each member organizations may offer up to two patients who are willing to volunteer to speak about their cancer journey and the support they have experienced from the patient advocacy foundation affiliation.

For more information, please contact Chandalyn at: info@curelms.com

Reminder: Message Board and Facebook Page



The [Message Board](#) of the Sarcoma Coalition website is an effective communication tool. Coalition members can post clinical trial co-funding opportunities, special events of interest or the like to highlight for Coalition members for the month. Send your Message Board posts to: Lhdeyoung@gmail.com.



Of course, posts to the Coalition's [Facebook page](#) are always welcomed. And if you haven't joined yet, please check it out!

*The Sarcoma Coalition: Working together –
through communication, collaboration,
coordination and more*



sarcomacoalition.us