



JUNE 2023 NEWSLETTER

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June Is National Cancer Survivor Month

"Survivorship" Defined: The term "survivor," when used with a disease, has evolved in recent decades. The National Coalition of Cancer Survivors (NCCS), a part of the Sarcoma Coalition

Advisory Committee, offers a thoughtful article about the definition of the term and how it's changed since the 1980s. [Read article . . .](#)

NCCS also offers a virtual presentation about cancer patient/survivor rights. In the video, NCCS Senior Policy Manager Lindsay Houff speaks about rights in the workplace, legislation action in motion, and telemedicine access - pro and con study of patient and provider perspectives. [Watch video . . .](#)

ASCO (American Society of Clinical Oncology) offers its own take on the meaning of "survivorship" and offers additional resources. [Read the article and see links at cancer.net . . .](#)

Finally, here is a source for statistics to consider during Survivorship Month: [American Cancer Society Diagnosis Statistics.](#)

SARCOMA COALITION General Meeting

REMINDER: Thursday, July 20, 2023, 4 pm ET, 3 pm CT, 2 pm MT, 1 pm PT

A G E N D A

1. **Welcome** to all participants!
2. **Golf Ball Project.** Update on the Golf Ball Project by the Coalition's Ad-Hoc Committee.
3. **Listen & Learn Series.** Review the new Listen & Learn Series presentation for comments and suggestions for future topics and dates.
4. **New NCCN (National Comprehensive Cancer Network) Guidelines.** Dottie Shead, NCCN Patient Advocacy Liaison and Sarcoma Coalition Advisory Panel Member, will say a few words about the new NCCN Guidelines for Soft Tissue Sarcoma issued June 1st.
5. **SPAGN.** A discussion with SPAGN representatives / Advisory Panel Member Denise Reinke regarding current projects the Coalition and SPAGN are collaborating on that affect sarcoma patients, and ideas/suggestions for further collaboration in 2024.
6. **JULY - SARCOMA AWARENESS MONTH.** Congressional Resolution request for 2023 submission, and Coalition Member Badges available for member foundation websites.



SARC Launches International Sarcoma Tumor Board



SARC (Sarcoma Alliance for Research Through Collaboration) is proud to announce it has launched a national, virtual multidisciplinary sarcoma tumor board.

As the care of patients with cancer, particularly uncommon cancers such as sarcoma, becomes increasingly complex and therapeutic options become more nuanced, input of multiple expert clinicians is more critical than ever for educated, optimal decision-making for the treating physicians and surgeons. This board will facilitate expert guidance on how to treat sarcomas in adults and children at any stage of the disease.

"We are excited about our SARC Multi-Disciplinary Tumor Board," said Dr. Scott Okuno, SARC's Chief Medical Officer and Professor of Oncology at Mayo Clinic, "as this allows all sarcoma providers, regardless of whether they are practicing in a small, geographically remote center or a major center, to get opinions how to treat and manage all types of bone and soft tissue sarcoma from experts in the sarcoma field."

FROM SARC: "We have received a lot of interest to receive international cases so we have decided to proceed with accepting international cases. Only physicians can submit and present cases. We meet the 2nd Friday of every month at 12:00 CST so the physician would have to be able to attend to present."

Note: **Dr. Kenneth Cardona**, a member of the Coalition's Advisory Committee, is also a member of the new SARC Tumor Board.



[Read more about the Tumor Board . . .](#)

Representing the Coalition at Professional Meetings

Sarcoma Coalition Steering Committee members represented our organization at the recent SARC meeting as well as the annual meeting of the American Society of Clinical Oncology (ASCO). Both meetings took place this month in Chicago. We passed out information handouts and the Coalition briefing card sent to member organizations earlier this year. This is a simple calling card containing key points about the Coalition, and it is for use by all members attending meetings where this information would be important to share. Feel free to download and reprint it. [Link to the briefing card . . .](#)

Save the Date: Friday, July 28 – FDA Listening Session



**A Dialogue with the Sarcoma Coalition Advocacy Committee -
Oncology Center of Excellence, Food & Drug Administration
Friday, July 28, 2:30 p.m.-4:00 p.m. ET**

Here is the notice from the FDA to the Coalition members:

Topic: This is a meeting with the Sarcoma Coalition and the FDA Oncology Center of Excellence (OCE)/ Sarcoma team. This is an opportunity for us to learn more about the Sarcoma Coalition, their specific advocacy groups, and discuss questions that they have for the team. We will also provide updates on recent sarcoma drug approvals. We plan to dedicate the second half of the meeting to addressing topics that representatives of the sarcoma community have brought to our attention.

The meeting will be hosted by the FDA OCE Project Community initiative:

<https://www.fda.gov/about-fda/oncology-center-excellence/project-community>

Vanderbilt Study Seeks Sarcoma Patients



VANDERBILT-INGRAM CANCER CENTER

The Vanderbilt-Ingram Cancer Center is looking for sarcoma patients to join the Cohort to Augment the Understanding of Sarcoma Across the Lifespan (Causal) study. Drs. Debra Friedman and Elizabeth Davis are PIs.

Anyone who has been diagnosed with sarcoma is invited to be in their research study. One of the benefits of this trial is that the patient can have blood draws and specimens collected at home via mobile lab, which is convenient and cost-saving for the patient. The Coalition can play a pivotal role in supporting patient accrual efforts, strengthening our relationship with researchers in the field.

Please tell interested patients to use the QR Code here or this link to learn more and sign up: https://redcap.link/join_causal



For more information, please contact the study team at **615-936-0638** or CAUSALstudy@vumc.org.

Articles of Interest

Real-World Data: How Can It Improve Clinical Trial Outcomes?



This article on Pharmaceutical Technology examines the ways real-world data can add value to clinical trial data, the challenges with using it, and how it may intersect with regulation. [Read article . . .](#)

Incidence and survival of soft tissue sarcoma in England between 2013 and 2017, an analysis from the National Cancer Registration and Analysis Service

"This population-based study has allowed us for the first time to define the incidence and survival rates of prevalent STS subtypes in England such as GIST, liposarcoma and leiomyosarcoma, as well as rare entities and groups with inferior outcome," reads the abstract. "This data is invaluable for service provision, benchmarking and addressing inequality." The article appears in the Dec. 2022 issue of the *International Journal of Cancer*. [Read article . . .](#)

SARCOMA COALITION Listen & Learn Series



Our inaugural Listen & Learn Series took place this spring and we are most grateful for the guest speakers who graciously shared their time to bring us the outstanding presentations made for us all.

The two presentations listed below were recorded for Coalition Patient Advocacy Members and their respective patient communities, so that all can come together to learn and ask questions. We hope that more Coalition member organizations will participate live in future Listen and Learn Series sessions.

In the meantime, Foundation members are encouraged to share these recent presentations with the patients and families they serve by sharing the video links below.

1. **March 29, 2023: ctDNA Panel Discussion with Research Clinicians from across the US**
[The Current and Future Directions of ctDNA Research for Sarcomas](#)
https://www.youtube.com/watch?v=fhsyH8bJn_I

SARCOMA ctDNA Research Panel Discussion

DERA
MODERATOR, Brian D. Crompton, MD



Dr Nam Quoc Bui
Clinical Assistant Professor of Medicine at the Stanford Cancer Institute and a specialist in the Sarcoma and Developmental Therapeutics programs, Stanford Cancer Center



Erlinda Maria Gordon, M.D
pediatric hematologist/oncologist at the Sarcoma Oncology Center, and founder of Averi Foundation Santa Monica CA. Cancer drug developer, biopharmaceutical founder and executive with a proven track record in translational biomedical research, patient care and cancer drug development.



Joanna Fryzbyl, Ph.D
Junior Scientist, RI-MUHC, Glen Site Cancer Research Program, Centre Translational Biology McGill University, Montreal, Canada
ctDNA research at Stanford and at Fryzbyl Lab



Brian D. Crompton, MD
Dana-Farber/Boston Children's Cancer and Blood Disorders Center; Research Co-Director, Solid Tumor Center; Assistant Professor in Pediatrics, Harvard Medical School B



Mathew Hemming, MD, PhD
Medical oncologist and physician scientist focused on sarcoma at Dana-Farber Cancer Institute, Massachusetts, and Harvard Medical School



David Schulman, MD
Physician Instructor in Pediatrics, Harvard Medical School Boston Children's Hospital, Dana Farber Cancer Institute



Elizabeth Davis, MD
Associate Professor of Medicine Office Address: Assistant Professor of Medicine, Division of Hematology and Oncology, Vanderbilt Cancer Center, Nashville



Elise F. Nassif, MD, Ph.D
Physician-scientist in the Department of Sarcoma Assistant Professor, Department of Sarcoma Medical Oncology, Division of Cancer Medicine, The University of Texas MD Anderson Cancer Center, Houston, TX



Jonathan Trent, MD, Ph.D
Professor Associate Director for Clinical Research Sylvester Comprehensive Cancer Center, Miami

2. **May 23, 2023: Guest Speaker Eileen Dimond, RN, MS, Cardiotoxicity Taskforce Treatment-Related Cardiotoxicity - The Impact of Cancer Treatments on the Heart, <https://youtu.be/-LtpAd1owek>**



NATIONAL CANCER INSTITUTE
Division of Cancer Prevention



2023 Patient Guidelines on Soft Tissue Sarcomas Have Arrived!



National Comprehensive Cancer Network®

The 2023 Patient Guidelines for Soft Tissue Sarcomas have arrived!

You may order up to 25 packets at no charge. Just go to <https://www.nccn.org/home/store> and scroll down until you see this navy box with wording about the pocket guidelines:



Order Free Pocket Guidelines and Guidelines for Patients

Click on that box and then scroll down on the list until you see the Soft Tissue Sarcoma booklet; type in the number you would like to order.

Or, if you'd like an electronic version, click here for the [PDF...](#)



A few complimentary copies of the printed booklet will be provided to the Coalition by the NCCN thanks to **Dottie Shead**. She is Senior Director of Patient Information / Operations within the National Comprehensive Cancer Network, and a Sarcoma Coalition Advisory Committee Member. The Coalition thanks Dottie for this gracious gesture. The Sarcoma Coalition is listed as a partner on the NCCN Guidelines booklet.

SPAGN and the SARCOMA COALITION: Working Together – Making a Difference



**Sarcoma
Patient Advocacy
Global Network**



Sarcoma Patient Advocacy Global Network (SPAGN) is the global network of national Sarcoma Patient Advocacy Organizations. Today, approximately 60 member groups from five continents gather under the umbrella of SPAGN, providing a common, international and influential patient voice for sarcoma patients around the globe.

SPAGN and the Sarcoma Coalition have a mutual goal of working together on issues that affect sarcoma communities nationally and globally. In 2022, at the Connective Tissue Oncology Society Meeting, representatives from both organizations came together to discuss the future of collaboration on important projects that will be deemed impactful for patient care and outcomes.

Click on the logos above or the links below to learn more about both groups . . .

[SPAGN - Sarcoma Patient Advocacy Global Network](#)

[SARCOMA COALITION](#)

Denise Reinke, MS, NP, MBA, principal co-founder of the Sarcoma Coalition and a current Advisory Committee Member, also serves on the SPAGN Board of Directors. Her professional position is as Research Director, Oncology, University of Michigan, Ann Arbor, MI. Denise was past president of SARC and was an investigator from its inception until approximately 2021, assuming increasing responsibilities over the years. She is uniquely positioned to be engaged in sarcoma research given her work as a sarcoma nurse practitioner, as investigator on NIH grants, and in clinical trials.



She has unique insights to assist both organizations in strengthening their collaborative relationship by working together for the greater good in common-ground projects on behalf of the sarcoma patient /family/caregiver communities being served.

JULY - Sarcoma Awareness Month

On June 6th, the Steering Committee contacted Senator Deborah Stabenow (D-MI), through her Legislative staff, to discuss the Resolution submitted for Sarcoma Awareness Month – the 7th year attempt. The discussion spotlighted a tie-in to the Cancer Moonshot and CURES Act to emphasize the importance of this request. Fingers crossed that we can succeed in Congressional recognition of Sarcoma Awareness Month officially for 2023.

New SARCOMA COALITION Membership Badge for Your Website

You are welcome to copy this Sarcoma Coalition badge for your website placement – as a proud collaborative advocacy member. This is a new design! Simply click on it, save the image as a .jpg or .png, and upload it to your website.



Stronger Together

As a Coalition member, if you are aware of other Sarcoma organizations that might be interested in knowing more about the Sarcoma Coalition, please send information to the Steering Committee.

If you have new ideas in between Coalition General Meetings, don't hesitate to contact us, as we always appreciate hearing from everyone – <https://sarcomacoalition.us/web-agency-gb-contact-us/>



Have You Joined?

SARCOMA COALITION Facebook Group



The following Facebook address is the Coalition membership platform for communication – an easy way to stay connected. Join today!

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



Happy Summer, Everyone!