SARCOMA COALITION

We are here for you.

SEPTEMBER 2026 NEWSLETTER

REMINDER: Thursday, October 15 4 pm ET - SARCOMA COALITION QUARTERLY MEETING *The last meeting in 2026*

>> Zoom link

Agenda for the meeting:

Guest Speakers:

- Dr. Thomas Lynch, PhD, Senior Researcher at Duke Cancer Institute - PRELUDE initiate in pre-cancer research
- Michael Davoli - FightCancer.org - Biomarker Test Patient Access and Barriers and how Patient Advocates can help in the Coalition setting
- NORD- Rare Cancer Day Campaign – state by state awareness Caitlyn Letourneau-Jancsy, Grassroots Advocacy Manager
- SFA collaboration on projects in 2027 - Kelley Agraves
- Sarcoma Coalition Members' patient-centered collaboration ideas for "Deliverables" for the entire Sarcoma Community in 2027

NORD'S RARE DISEASE DAY – September 23, 2026

Nord initiatives are so supportive of patient advocacy organizations: Learn more about the State Proclamations where we can all make a difference in Awareness and Action in our respective state. **Access the Toolkit**.

SARCOMA COALITION PROGRAMMING SERIES:

Friday, SEPTEMBER 25 at 1 pm ET
IMPORTANT TOPIC update presented by:

Jenica Upshaw MD, MSc
Director, Cardio-Oncology Program

Attending Physician, Advanced Heart Failure and Transplant Cardiology and Cardio-oncology, Beth Israel Deaconess Medical Center

CARDIOTOXICITY AND SARCOMA TREATMENTS usage of and - An update for patients and families / patient advocates.

Seminar Registration Link for Patient Advocates / Patients /Families – Please share this seminar information with your respective communities impacts quality of life and Survivorship.

EXPLORING THE POSSIBILITIES OF SARCOMA - THE PRELUDE Initiative

The Sarcoma Coalition is very happy to have invited the following speaker to discuss PRELUDE possibilities for application to SARCOMA during the quarterly meeting of the Coalition on October 15:

Thomas Lynch, PhD, Senior Researcher
Division of Surgical Oncology, School of Medicine
Duke University and Duke Cancer Institute

We are excited to share that we have recently brought together approximately 80 members from various departments in Duke Cancer Institute to form a working group that focuses specifically on pre-cancers - PRELUDE (Pre-cancer Research for Early Lesion Understanding, Diagnosis, and Evaluation). The group was organized in recognition that precancers are an increasingly relevant opportunity to intervene early in the cancer pathway, but much remains unknown about how and when to intercept cancer to derive the greatest benefit to patients with the least harm. The unique aspect of this group is that the members are experts from a wide range of disease sites (brain, breast, colorectal, head/neck, liver, lung, OB-GYN, pancreas, prostate, melanoma, thyroid, etc.), and research areas (epidemiology, biomarker development, biostatistics, AI, genomics, and immunology).

We aspire to facilitate and conduct cross-cutting research that enables a more targeted approach in determining the relationship between cancer hallmarks, precancer initiation, and potential interception prior to invasive disease progression. We believe this work has the potential to be both groundbreaking and practice changing for patients and families at risk for cancer.

The EASE Study for Those Living with Metastatic Cancer

Information awareness to share with patients in your respective communities that may be living in Colorado:

Are you living with metastatic cancer and feeling anxious, down, or distressed? Are you experiencing cancer-related stress or fear of cancer progression?

RMCC and the University of Colorado Boulder are offering a research study titled, The EASE Study: Randomized Trial of a Novel Approach to Addressing Fear of Progression in Advanced Cancer (IRB #25-0367), for adults with metastatic cancer that compares usual supportive care to a 6-session individual telehealth writing program. The program aims to reduce fear of progression and worries about the future and increase your ability to cope.

Participants in the study are invited to complete surveys and will be randomly assigned to either the telehealth writing program or usual supportive care. The telehealth writing program can be completed in Spanish if preferred. Las sesiones del programa de telesalud pueden realizarse en español si se prefiere.

Eligible participants can earn up to $240. You may be eligible if you:

- Are 18 years or older
- Have been diagnosed with Stage IV solid tumor cancer, Stage III recurrent ovarian cancer, extensive stage small cell lung cancer, or glioblastoma
- Feel concerned or worried about your cancer getting worse or your future with cancer
- And, are physically able to write or type for 30 minutes

Please email EASE@Colorado.edu or call/text the EASE research team at 720-897-1850 to learn more about this study and to potentially enroll. The Principal Investigator of this study is Dr. Joanna Arch.

Read Flyer about the EASE Program

More Information About EASE Program

S A R C - RESEARCH ADVOCACY COUNCIL

The SARC Research Advocacy Council had their first meeting in several months to reboot and refresh the mission and purpose of the Council. More information will be made

available to Coalition member organizations who may be interested in participating as a member of RAC. Email: annieachee@aol.com or call 303 783-0924 for more information.

SARCOMA COALITION – A CALL TO ACTION in 2027 with the framework of:

PURPOSE | ACTION | IMPACT

Elevating Our Collective Voices as a Grassroots Community of Advocates On Behalf of the Entire Sarcoma Community

Contact The Sarcoma Steering Committee