SARCOMA COALITION

We are here for you.

MARCH 2025 NEWSLETTER

CALENDAR ALERT: GENERAL QUARTERLY MEETING, APRIL 17, 4pm ET

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SARCOMA COALITION General Meeting

Thursday, April 17, 2025 – 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. Save the dates on your calendar for the next two scheduled quarterly meetings (also posted on the Coalition Facebook page and the Coalition website Message Board):

July 17, 4 pm ET *October 16, 4 pm ET*

AGENDA – APRIL 17TH MEETING

- Introducing Dr. Scott Okuno, Medical Officer of SARC and our Advisory Panel Member

  - Discussing the new SARC Sarcoma Center Directory
  - SARC Tumor Board, advocacy
  - SARC podcasts
- SPAGN – Sarcoma Awareness Day planning, – to include the Coalition. Speaker Cory Archibald, Communications Director, Sarcoma Patient Advocacy Global Network (SPAGN)
- Dr. David Liebner to discuss patient advocacy involvement in trial design and more
- The Sarcoma Coalition Advocacy Tool Kit
- The Golf Ball Project initiative – a strategy for promoting provider, public awareness – messaging in moving forward to finalize this initiative
- How do we come together to address the unmet needs of patients and caregivers? Sending patient/family perspectives to one silo for examination and evaluation to see how we can tackle the issues together. Idea: A potential Consensus Paper for Advocacy Groups to address the most important issues and implement / utilize the Advocacy Tool Kit
- Listen and Learn Series – what topics related to the unmet needs should be considered for the future?

SPAGN April 11–13 Annual Conference – In the US!

The SPAGN Annual Conference will be held in Washington, DC, April 11–13, 2025. It is **co-hosted and co-sponsored by the National Cancer Institute (NCI),** underscoring the importance of international collaboration in sarcoma advocacy. The event brings together patient advocates from around the world to discuss the latest advancements in sarcoma research, patient support and advocacy. This is the first conference SPAGN has held in the United States, marking a significant milestone for the global community. Don't miss this opportunity for us all to come together in the spirit of collaboration. Detailed information and registration here:

https://www.sarcoma-patients.org/annconf2025/

Legislation Spotlight / Updates

Provided by Nancy Goodman, Kids v Cancer Foundation, Sarcoma Coalition Member

Thursday, February 13, 2025

Kids v Cancer is thrilled to announce that yesterday, Congressman Michael McCaul re-introduced the Give Kids a Chance Act of 2025 in the House of Representatives.

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The Give Kids a Chance Act of 2025 includes four pediatric cancer bill that were cut from Congress' December funding bill:

- **The Give Kids a Chance Act –** to reauthorize the rare pediatric priority review voucher program, also known as the Creating Hope Reauthorization Act, that expired in December 2024 after yielding *65* new drugs for kids.
- **The Creating Hope Reauthorization Act** – to maximize chances scientists find cures for kids with cancer by providing for pediatric studies of *combinations* of new cancer drugs.
- **The Innovation in Pediatric Drugs Act** – to extend an enforcement mechanism for postmarket studies to pediatric study plans that are not completed.
- **The RARE Act** – to ensure the Orphan Drug Act benefits extend to the indication for which a drug is approved rather than to the designation.

The Give Kids a Chance Act is a bipartisan bill that this Congress can pass now. Last year, the Act was passed unanimously by the House of Representatives and by the Energy and Commerce Committee. The Give Kids a Chance Act was also included in Congress' end-of-year funding bill of December 2024, until the Act was suddenly dropped.

Listen & Learn Series Presentation

The latest recorded presentation in this series, posted on the Sarcoma Coalition website.

THE UNIVERSITY OF TEXAS MD Anderson Cancer Center
Making Cancer History®

B. Ashleigh Guadagnolo, MD, MPH, FASTRO, will discuss whether hypofractionated radiation should be adopted as the standard of care for extremity and truncal sarcomas.

Through case studies and clinical insights, attendees will gain a deeper understanding of the latest research and its implications for patient care.

This presentation aired on March 2, 3025. Review it here: https://youtu.be/CV17JtEHWqM.

Special Recognition

The Life Raft GROUP

Carolyn Tordella of the Life Raft Group has graciously volunteered her time as the Coalition's website administrator for two years.

Many thanks to Carolyn, who now hands the reins to another gracious volunteer, through our wonderful Steering Committee Member Erin Miller.

Erin's sister **Karen Ambrogi**, who works with the Lazarex Cancer Foundation, will now be the Coalition's new website administrator and we are most appreciative!

About the Sarcoma Coalition

The **SARCOMA COALITION** represents a strong and **united patient advocacy network** of sarcoma organizations/foundations throughout the United States and Canada, as well as with other international colleagues through the Sarcoma Patients Global Advocacy Network (SPAGN) collaborative membership.
The Coalition's purpose and mission is to:

- **Enhance collaboration**
- **Promote Sarcona Centers of Excellence**
- **Build pan-sarcoma patient awareness**
- **Lead and support special projects that impact the pan-sarcoma patient community**

- **Bridge sarcoma research community collaborations and reciprocal support**

SarcomaCoalition.us

"TOGETHER – W E C A N ! "

Next two general meetings:

July 17, 4 pm ET

October 16, 4 pm ET