SARCOMA COALITION NEWSLETTER

November 2021

The next Sarcoma Coalition General Membership meeting is scheduled for **Thursday, December 2, 2021, at 3 pm EST**. **Join the Zoom Meeting-**
https://us02web.zoom.us/j/87008016815?pwd=eEtVMVJpN0dTNm5sYzc4a01RTlNZQT09

Meeting ID: 870 0801 6815

Passcode: 463365

One tap mobile

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We are honored and privileged to present Guest Speaker-

Dr. Ishwaria Subbiah, MD, MS-MD Anderson
Assistant Professor, Palliative, Rehabilitation & Integrative Medicine; The University of Texas MD Anderson Cancer Center-

https://www.youtube.com/watch?v=QnSOji2wYbI&t=15s

Dr. Ishwaria Subbiah is a medical oncologist and palliative cancer physician at The University of Texas MD Anderson Cancer Center. She received her MS at Johns Hopkins University and her MD at St. George's University. Dr. Subbiah then went on to complete residencies at the University of Texas Health Science Center and Albany Medical Center. She completed post-graduate fellowships in developmental therapeutics, medical oncology, and palliative medicine at MD Anderson. With this robust foundation, Dr. Subbiah cultivates a clinical practice and research focus on symptom management in all patients with particular emphasis on the older adults receiving novel therapies on clinical trials.

The agenda for this meeting in addition to the named guest speaker above:

- Review electronic voting results from the Steering Committee nominations, SC governing documents, and Telehealth letter
- Discussion about the new S C Website – any edits to consider
- Collective Goals to be identified for 2022 to build the agenda for future meetings in the new year
- Growing the Sarcoma Coalition Network in 2022 / Building S C mission / purpose awareness
- Topic of discussion for the February 17, 2022, General Meeting that can have actionable/deliverables for the Patient/Family Community (see the initial list on page 6)

WE ARE PLEASED TO SHARE THE NCI MyPART MINUTE -OCTOBER NEWLETTER FEATURED THE SARCOMA COALITION: October issue of the MyPART Minute

ANNOUCING SC ADVISORY PANEL- Dr. Leslie Doros of the FDA, and Denise Reinke, APRN, BC, AOCN- join to support the Sarcoma Coalition and SC Steering Committee, as non-voting additions to the Coalition.

Dr. Leslie Doros is a Medical Officer at the U.S. Food and Drug Administration (FDA). She was a pediatric oncologist at Children's National Medical Center in DC. She received funding from the Conquer Cancer Foundation to start her research in plural pulmonary blastoma, a very rare form of lung cancer. Funding from the Foundation helped her start a clinic at the National Institute of Health for kids with chloral pulmonary blastoma. Dr. Doros received her Doctor of Medicine degree from Medical University of South Carolina:

https://www.youtube.com/watch?v=lgRBgnXcPlE

Denise Reinke, APRN, BC, AOCN, a visionary among the co-founders of the Sarcoma Coalition – to embrace the concept of the Coalition as a valuable compass for organizations to come together in support of one another in patient advocacy for impactful patient outcomes.

Denise brought her vast, extensive professional background and experience as a Nurse Practitioner, at the University of Michigan Comprehensive Cancer Center, as well as having been the CEO of the Sarcoma Alliance for Research through Collaboration (SARC) from 2007 – 2021, with Dr. Laurene Baker,

https://pubmed.ncbi.nlm.nih.gov/34289946/

The Purpose of the Advisory Panel is to:

- Aid the Sarcoma Coalition membership/Steering Committee regarding technical questions or special quests to clarify current or future research endeavors that would be helpful to the Coalition membership/Steering Committee; in discussing possible collaborations for special projects collectively agreed upon

- Provide input to the Steering Committee and the Coalition membership with technical advisory oversight to further new initiatives voted on by the membership

THE SARCOMA COALITION TELEHEALTH LEGISLATION SUPPORT - discussed at the July 15 and Sept. 16, 2021, General Membership Meetings. **If you have not already done so, please cast your electronic vote here:** https://forms.gle/V4Q1r9KMa5TzQkBD6

You can also send an email to LHDeYoung@gmail.com to request your organization be listed in support of this legislative letter, which will be going forward to the Rare Cancer Caucus members of Congress and other members of Congress as well.

Shannon von Felden – Director, Rare Disease Legislative Advocates at EveryLife Foundation for Rare Diseases
Washington DC-Baltimore

Shannon discussed current legislation with the Sarcoma Coalition during the September 2021 General Membership Meeting.

The Sarcoma Coalition membership wishes to support the current legislative bills that hold promise to protect patients to continue to receive insurance coverage for second opinion telehealth access and be able to contact a new health care provider across state lines. More than 340 organizations have sent letters to Congress in support and the Coalition will be an added voice for Rare Cancer patients, with a letter going out to Congress. Individual Coalition member organizations are encouraged to submit letters to representatives and further encourage their patient communities to do the same. For more information and instructions, please email: annieachee@aol.com or lhdeyoung@gmail.com.

EVERYLIFE FOUNDATION FOR RARE DISEASES

About the EveryLife Foundation:

EveryLife Foundation is dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments, and cures.

THE NEW SARCOMA COALITION WEBSITE IS LIVE!

The new website address for the Sarcoma Coalition is now:

https://sarcomacoalition.us/

The website has been refreshed with new and updated content, to offer helpful information for patients, as well as other sarcoma organizations that may be interested in the Sarcoma Coalition in furthering sarcoma research.

Please visit the website and offer constructive suggestions for edits or additional information to be included. This is the website of the Sarcoma Coalition – which means it is the website of member organizations, and your respective voices matter! As always, we welcome your input and suggestions to improve and strengthen the content. We look forward to your insightful input and constructive feedback for the further advancement of Coalition objectives and mission. Please send your responses regarding the new website to either: Annie Achee, annieachee@aol.com or Lisa De Young, lhdeyoung@gmail.com.

The 2022 General Membership meeting of the Coalition will be held February 17, 2022: The following topics of discussion are offered for your consideration, but your input on suggested topics is always needed and appreciated!

Potential topics for future General Membership meetings in 2022:

- ctDNA platforms currently underway for Sarcoma
- cybersecurity – and its impact on electronic patient health records

- mentoring Patients- the Life Raft Group's established program as a model
- cardiotoxicity with chemotherapy treatment- updates in care
- showcase a new Sarcoma Coalition group/organization
- other suggestions – warmly welcomed and highly encouraged!

The Sarcoma Coalition website forum is sponsored by Annie Achee and Lisa DeYoung- Legacy Steering Committee Members in honor of the Sarcoma Coalition Membership.

facebook

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

Stronger Together

SARCOMA COALITION MEMBER

Bridging collaborations through advocacy.
Coming together to work together in support of patients/families.
"Achieving More Together"