SARCOMA COALITION

We are here for you.

The Sarcoma Coalition, established in 2018, is a collaboration between 26 sarcoma advocacy organizations across the United States with a common goal: provide research support and resources for the sarcoma community. The coalition believes that establishing a synergized partnership among advocacy organizations, though each organization may have a distinct sarcoma subtype focus, builds strength in numbers and together they can "leverage our [united voice and] collective strengths to make a greater impact in helping meet the needs of the sarcoma community." Working together, the Sarcoma Coalition advocates for educational programs about sarcoma, supports research, and strives to communicate the collective voice of sarcoma advocacy organizations.

Learn more about the Sarcoma Coalition **here**. Sign up for quarterly newsletters from the Sarcoma Coalition **here**.

1. THE GOLF BALL PROJECT

Revisit the Golf Ball Project that was introduced in 2020. Collectively building awareness within the general medical community was the goal and continues to be an important focus to discuss. Adopted by Northwest Sarcoma Foundation, Rein In Sarcoma Foundation, and the National Leiomyosarcoma Foundation.

For more information/background on the Golf Ball concept video presentation by Dr. Robert Grimer (UK)
Watch--> https://www.youtube.com/watch?v=188TWJsAFlk

Is a lump a Sarcoma or a lipoma - what is the difference?
Watch--> https://www.premierhealth.com/your-health/articles/health-topics/is-this-lump-a-sarcoma-lipoma-learn-the-difference

SIZE MATTERS: https://pubmed.ncbi.nlm.nih.gov/17059708/

Evaluating Lumps and Bumps - soft tissue sarcomas
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6140092/

2. UPDATE ON TELEHEAL TH LEGISLATION AND SARCOMA AWARENESS MONTH RESOLUTION REQUEST

Sarcoma Awareness Month - S C collaborative planning – include a link to the S C website for July Sarcoma Awareness Month. Discuss ideas for a commemorative logo image in observance of the month.

The Telehealth Bills Supported by the Coalition - ***An update:*** It looks like this bill (H.R 7097) was introduced on March 16th of this year. The bill has been referred to the House Committee on Energy and Commerce. Since the bill was just introduced this week, it will be awhile before any updates are added, but you can find updates here: Congress House Bill H.R. 7097

3. THE SARCOMA COALITION RESOURCE LIBRARY

Discussion on the type of resource information to share among the Coalition members.

4. Sarcoma Patients EuroNet (SPAEN)

to come together in the spirit of collaboration to strengthen patient advocacy focus for the future. SPAEN has invited the Coalition to join in membership. Their organization is over 10 years old.

Sarcoma Patients EuroNet

5. Sarcoma Coalition Membership Directory

distributed in March to all members. Thank you Lisa De Young for preparing the Directory for all!

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6. Future Sarcoma Coalition Meeting

Dr. Leslie Doros of the FDA will discuss the FDA Oncology Center of Excellence and how patient advocacy organizations are supported by the Center.

The June Sarcoma Coalition Newsletter - a reminder to share your Foundation's special events, programs, alerts for submission and posting in the Newsletter.

Article submissions to annieachee@aol.com

Special Announcement!

SUMMER' S WAY

CANCER
TJ & FRIENDS
FOUNDATION

The **Summer's Way Foundation** in conjunction with **Friends of TJ Foundation** are pleased to announce that **Dr. Patience Obasaju** is the 2022-2023 $50,000 Young Investigator grant recipient! Dr. Obasaju is a 5th year Fellow in Pediatric Oncology while also in her 4th year in the Cellular and Molecular Medicine PhD graduate training program through the Johns Hopkins School University of Medicine.

YOUNG INVESTIGATOR GRANT RECIPIENT

CONTINUED...

Dr. Obasaju's research project under the mentorship of Dr. Christine Pratilas, will focus on cancer causing genes in rhabdomyosarcoma th (RAS family members). Inhibiting RAS has been a major challenge in the development of cancer therapies. One class of drugs Fenesil transferase inhibitors(FTIs) developed 20 years ago has been disappointing. We have now learned that a mutant HRAS does respond. Dr. Obasaju will be evaluating further what drugs can be combined with FTIs to prove therapeutic in this subset of RMS

THANK YOU ALL - Please contact any Steering Committee member for more information/questions.

WE ARE "HERE FOR YOU"

Sarcoma Coalition - Contact Us

Let' Stay Connected through the Sarcoma Coalition FB Group:
Sarcoma Coalition Facebook Page

Contact the Steering Committee anytime:
Steering Committee

S A V E THE D A T E: Thursday, May 19, 2022 4 pm EST
Sarcoma Coalition General Meeting

GUEST SPEAKER PRESENTATION - Panel Discussion

The role of IRE for Sarcomas – an expert panel discussion with the Coalition:
Topic: *The role of irreversible electroporation (IRE), also known as Nanoknife, for treatment of Sarcoma, as well as other forms of ablation.*

Background information:
Nanoknife

1) Dr. Govindarjan (Raj) Narayanan, MD
Chief of Interventional Oncology
Miami Cardiac &Vascular Institute-Baptist Health South Florida
http://miamivascular.com/physicians/raj-narayanan

2) Dr. Sean Tutton, MD, FSIR, FCIRSE
Interventional Radiologist
University of California-San Diego
https://providers.ucsd.edu/details/1326099086/radiology

3) Vinay Nagaraj
Senior Medical Science Oncology Liaison
AngioDynamics

4) Dr. Shyn is unable to attend in-person, but graciously provided a slide which will be reviewed.
Dr. Paul Shyn, MD Associate Professor, Harvard Medical School Radiology
Brigham Women's Hospital
https://physiciandirectory.brighamandwomens.org/details/180/paul-shyn-radiology-boston

Thanks to Lisa DeYoung
for the coordination of the speaker panel.