

# SARCOMA COALITION

We are here for you.

SARCOMA COALITION NEWSLETTER

January 14, 2022

HAPPY NEW YEAR TO ALL MEMBERS!



Virtual Roundtable  
Discussion

SAVE THE DATE ZOOM MEETING INVITE:

**SARCOMA COALITION GENERAL MEETING - FEBRUARY 17, 2022**

**3 pm EST, 2 pm CST, 11 pm MST, Noon PST**

<https://us02web.zoom.us/j/85083869152?pwd=d3hoSnBpTUZEdFd0Z1kyMU5WQTN6Zz09>

Meeting ID: 850 8386 9152

Passcode: 912842

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## **A G E N D A**

- 1) Follow-up update on Telemedicine Support letter sent to Congress - the voice of the Sarcoma patients heard**
- 2. Introducing the Steering Committee members in 2022:**
  - Sharon Hammond, MD
  - Lennie Woods
  - Chandalyn Williams
- 3) ctDNA recorded presentation shared with the Membership  
Dr. Brian Crompton, Dr. Mathew Hemming, and Dr. Jonathan Trent, and Dr. Neeta Somaiah - presenting updates on where the research stands on ctDNA relative to Sarcoma. Link and more information to share with everyone at the meeting.**
- 4) Interventional Radiologist Dr. Raj Narayanan- Miami, FL (formerly Chief of Interventional Radiology-University of Miami). Dr. Narayan pioneered an ablation technique for pancreatic cancer over 10 years ago.**

Dr. Narayanan has ablated more than 2 dozen EHE patients with a technology called Nanoknife (IRE) manufactured by AngioDynamics- <https://www.angiodynamics.com/>

Here is an animated video of how it works:

<https://nanoknife.com/technology/>

<https://cancertherapies.cc/nanoknife/>

Dr. Raj (as he is affectionately called by the EHE community) is now involved with **a new FDA approved clinical trial** for primary and metastatic liver tumors. The tumor must be smaller than 3cm, a maximum of 3 treated tumors total (regardless of the total number of tumors) and be a US resident. More discussion from Lisa and important links to share with everyone at the meeting. Sponsored by HistoSonics.

- 5) **What is on the Horizon in 2022?** General Membership updates on Foundations/organizations goals for the New Year in support and advocacy for their respective patient communities

Revisiting the Golf Ball Project – building the bridge of awareness for community providers, nurse practitioners and more.

- 6) **Planning for the April S C Meeting - identifying topics and speakers - gathering initial ideas to consider. A partial list below, but other ideas needed, appreciated, and welcomed!**

### **The Life Raft Group - Patient Mentoring Program**

**Cybersecurity** relative to electronic health records, Medicare fraud, and more for patients/families to be aware of.

**Cardiotoxicity / Cardio-Oncology** – discussion of the short and long terms effects of the standard drugs given to sarcoma patients and how to build awareness of self-advocacy to keep monitoring the heart after treatment is completed



## **2022 Goals for Quarterly Sarcoma Coalition ( S C ) General Meetings:**

- **Increased involvement in meetings by the S C Membership**
  - **Consistent attendance**
  - **Ideas for meeting agendas and collaborative projects for across- the board patient / family impact on quality of life and treatment outcomes.**
- **Execution of planned collaborative projects**

## **2021 SARCOMA COALITION MEETINGS in Review:**

**The December meeting** featured Dr. Ishwaria Subbiah, MD/ MS – MD Anderson Cancer Center, with a presentation on Supportive Care vs Hospice Care. The meeting also featured the new Advisory Panel members to support the Sarcoma Coalition Membership and the Steering Committee - Leslie

Doros, MD, Medical Officer of the FDA, and Denise Reinke, co-founder of the Sarcoma Coalition, and former CEO of SARC. She is now affiliated with the University of Michigan's sarcoma research program with Laurence Baker, MD.

The Steering Committee nominees introduced themselves to the Coalition for final voting of the Committee, the Telehealth Letter (a collective Coalition support letter), and the organizational guidelines of the Coalition. Suggestions for the February General Meeting were requested.

**The September meeting** featured Shannon von Felden, Director of EveryLife Foundation / Rare Disease Legislative Advocates- to discuss the telehealth legislation updates and what the Coalition can do to support this effort. Introduction of the Sarcoma Coalition website - requesting members to provide input on revisions / editing recommendations - none received / website approved. The updated Organizational Guidelines and Partnership Agreement for the Coalition operating framework- request of members to provide recommendations - none received / documents approved.

Topics for the Dec. next general meeting of the Coalition requested of members: The Lift Raft Group, suggested and offered a presentation on their Patient Mentoring Program. Other topics for consideration in future meetings: Cybersecurity (electronic health records impact, Medicare fraud, and what patients/families need to be aware of); Chemo-induced cardiotoxicity – what should patients know to build awareness and promote self-advocacy prior to chemotherapy treatment.

The **May meeting** featured Dr. Jason Hornick, Pathologist, MD, PhD, Pathology at Brigham and Young Women's Hospital, Boston, MA. Dr. Hornick discussed sarcoma pathology and research updates. Q & A for the members. Discussion on future topics and ideas for collaborative projects. Revisiting the Golf Ball Project.

The **July meeting**, featured Dr. Mihaela Druta, Research oncologist at Moffitt Cancer Center, Tampa, FL. Dr. Druta discussed the provider perspectives of telemedicine in the care and treatment of sarcoma patients, and the impediments that detract from quality care. She urged the Coalition to address needed action to help the patient community.



The Sarcoma Coalition belongs to ALL MEMBERS - and its progress towards cumulative successes throughout the year, depends on all of us. We are all in this together! And we all appreciate each other's contributions toward the Coalition motto:

*“Where Purpose Meets Progress in Achieving More Together”*

**The Sarcoma Coalition website:** [sarcomacoalition.us](http://sarcomacoalition.us)



**SARCOMA COALITION FACEBOOK GROUP:**

**The following Facebook address is the new platform of communication among Sarcoma Coalition members - an easy way to stay connected!**

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

**As always, the Sarcoma Coalition Steering Committee is available to our membership welcoming your constructive comments and values your input!**