

SARCOMA COALITION

We are here for you.

December 2022 Newsletter



HOLIDAY MESSAGE FROM THE STEERING COMMITTEE

The Sarcoma Coalition Steering Committee extends warmest wishes to all member foundations within the Coalition – a beautiful holiday season with family and friends, and a prosperous new year.

Your membership and active participation within the Coalition makes the difference in serving the Sarcoma Community – the stakeholders, patients and their families with a collective voice. Special projects that can deliver a positive impact to the future of their care and treatment is the ever present focus of the Coalition as we move forward into the new year.

May 2023 be a wonderful year for all!

GENERAL MEETING AGENDA

Thursday, January 19, 2023 4:00 pm EST

Reminder Calendar Invite with Zoom link to follow in January

- Review of Membership Survey results (Sent to membership separately)
 - Golf Ball Project Update
- Focus planning for 2023 with Advisory Panel Guidance

Survey: You should have received a survey monkey on 12/16/22 with a few brief questions. Check your spam if you did not receive it. This survey will help us bring the news and resources that you look forward to and that will support your organization's mission.



A new schedule for the future Sarcoma Coalition General Meetings are provided as follows: The Third Thursday of January, April, July and October at 4 pm EST.

Sarcoma Coalition Newsletters will be forthcoming in March, June, September, and December. All member organizations are encouraged and welcome to submit articles of interest to the entire Coalition membership to:

<https://sarcomacoalition.us/web-agency-gb-contact-us/>



CONNECTIVE TISSUE ONCOLOGY SOCIETY MEETING (CTOS) November 16 –19 (Vancouver, BC)

Jeff Kramer: This was the first time I ever attended a medical oncology meeting and was overwhelmed with access to Sarcoma Experts from all over the world. I had the opportunity to have a dialogue with clinical researchers, leaders and experts. I learned a lot about their experiences and perspectives about research, clinical trials and treatment and had candid conversations about Chondrosarcoma and how patient advocacy groups need to be at the table to include the views of patients and caregivers. In the opening ceremony, William Tap, President of CTOS; shared a slide on the large screen with the logos of about 50 sarcoma patient advocacy groups and the title of the slide was Partnerships and Collaborations. I also saw posters around the convention center with the same title and logos. We were honored to have our logo included on that slide and poster. However, the content of the conference was all medical. My hope is that future CTOS conferences include presentations, panelists with members from our organizations to include the views of patients and caregivers who struggle with sarcoma and share our views on how to improve clinical trials and treatment.

National Leiomyosarcoma Foundation (NLMSF): The opportunity to take the voice of the patient community to meetings and discussions with the researchers was and has always been a special and important goal for the NLMSF. The foundation has taken the voice of the Sarcoma Coalition as well, not only to CTOS but also the European Medical Society of Oncology (ESMO) in Milan in 2020 at the invitation of the Sarcoma EuroNet, now renamed to: Sarcoma Patients Advocacy Global Network – now in collaboration with the Sarcoma Coalition. Global impact for impacting patient outcomes in care and treatment is an important reason to all come together for the greater good.

Clear Cell Sarcoma Foundation: We are always inspired at CTOS, the meeting full of medical professionals eager to make the lives of Sarcoma patients better. The annual ultra rare sarcoma meeting is most important to us because CCS falls in the group of 56 ultra rare STS subtypes. This gathering of sarcoma experts published an ultra rare consensus paper in 2021 born from one of these meetings. Now they are focused on designing a retrospective study of Ultra rare sarcoma treatments used at sarcoma centers and those outcomes in hopes to gather useful data that will translate to choosing better treatments sooner. Hearing how these experts are having hard conversations and really trying to navigate difficult institutional and geographic hurdles inspires hope for all sarcoma families. Patient Advocacy was also a big highlight of the meeting and we felt so welcome to be part of the conversations. CCSF handed out a flier of early survey results from our patient survey and the feedback from researchers was positive. Several have reached out to work with us and we are so grateful. The SPAGN advocates room was really nice to have for us to gather. It was so great to see many members at CTOS!



If any Sarcoma Coalition members are attending sarcoma meetings in the future, efforts to connect at the meetings will be a hopeful goal. Having the opportunity for in person Sarcoma Coalition membership meet and greet would be a valuable opportunity for us all.

 **Congratulations** to Philip Leider for becoming the new board president of the [@SarcomaAlliance](#). A lawyer, he is the brother of the nonprofit's founder, Suzanne Leider, who died 20 years ago. He served on the board before.

 **Congratulations** to Dr. Okuno on being appointed to [@SARCtrials](#) Chief Medical Officer, working with SARC's leadership to set strategies for SARC's clinical programs. Dr. Okuno is a Professor of Oncology and Research Clinician at Mayo Clinic in Rochester, MN. He is also Executive Committee Chair of the National LMS Foundation - Sarcoma Patient Advocacy Global Network International Research Roundtable for Leiomyosarcoma. He is also an important member of Rein In Sarcoma.

Welcome New Sarcoma Coalition Members



The Founder Matthew R. DiCaprio, MD of Sarcoma Strong is an organization founded by, Matthew R. DiCaprio, MD, a practicing Musculoskeletal Oncologist who wanted to do more for his local sarcoma family.

Our goals are simple." We want to be able to support our sarcoma families at every step of their journey with sarcoma." Sarcoma Strong - dedicated to raising awareness of Sarcoma, supporting our Sarcoma warriors & families, and raising funds to fuel research!!



<http://www.sarcomastrong.com/>.

(518) 489-2666. sarcomastrong@gmail.com.

WELCOME NEW

SARCOMA COALITION ADVISORY PANEL MEMBERS

We are grateful for the Advisory Panel Members and the wealth of experience they bring

<https://sarcomacoalition.us/advisory-panel-steering-committee/>



Richard Davidson (he/him), Chief Executive

richard.davidson@sarcoma.org.uk | sarcoma.org.uk

Richard has been working in the third sector for more than two decades. Since July 2018 he has been Chief Executive of the bone and soft tissue cancer charity, Sarcoma UK.

Before joining Sarcoma UK he was Director of Engagement for the UK's blood cancer charity, Anthony Nolan where he was responsible for overseeing communications, advocacy, fundraising and marketing. Prior to that he spent 11 years as the Director of Policy and Public Affairs at Cancer Research UK, the world's largest cancer charity. Richard is Chairman of Game of Throne's actress Emilia Clarke's charity, SameYou, which is dedicated to increasing access to rehabilitation services after brain injury and stroke for young people and he is a trustee of the Devon Air Ambulance charity in the South West of England.



The National Coalition for Cancer Survivorship (NCCS): Information about the NCCS, a wonderful resource for empowering patient advocates: <https://canceradvocacy.org/>



Veronika Panagiotou, PhD

Advocacy and Program Manager – National Coalition for Cancer

Veronika Panagiotou, PhD, serves as the Advocacy and Program Manager for the NCCS Coalition of Cancer Survivors. Her responsibilities include managing the [Cancer Policy and Advocacy Team \(CPAT\)](#), [Survivorship Champions](#) and various advocacy initiatives.

Dr. Panagiotou's passion for working in survivorship and advocacy emerged after being diagnosed with Non-Hodgkin's Lymphoma when she was 25 years old. As a young adult cancer survivor, she has witnessed firsthand the need for recognition of the financial toxicity of treatment, the creation of more supportive services, and the availability of survivorship care. Before joining NCCS as a staff member, Veronika was an active CPAT member. She has met with her representatives to share her story and to advocate for policies such as the

Affordable Care Act that saved her life by giving her access to cancer treatment.

To learn more about CPAT: [Cancer Policy and Advocacy Team \(CPAT\)](#), [Survivorship Champions](#)

A recap of the supportive resource assistance of the Sarcoma Coalition Advisory Panel:

- Support the Sarcoma Coalition membership/Steering Committee regarding technical questions or special requests to clarify current or future research endeavors that would be helpful to the Coalition membership/Steering Committee; in discussing possible collaborations for special initiatives / 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.



RESEARCH Publication Highlight

Global Patient Involvement in Sarcoma Care—A Collaborative Initiative of the Connective Tissue Oncology Society (CTOS) & Sarcoma Patients EuroNet (SPAEN) renamed recently to: Sarcoma Global Patient Network (SPAGN)

<https://pubmed.ncbi.nlm.nih.gov/35205602/>



If a Coalition member organization is aware of any other Sarcoma organizations that might be interested in knowing more about the Sarcoma Coalition, please send information to the Steering Committee contacts at: <https://sarcomacoalition.us/web-agency-gb-contact-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![Sarcoma Coalition Group | Facebook](#)