

SARCOMA COALITION

We are here for you.

SARCOMA COALITION (S C) NEWSLETTER
JUNE , 2022

SAVE THE DATE: Thursday, JULY 21, 2022 4 pm EST
Sarcoma Coalition General Meeting

MEETING AGENDA

- **Dr. Leslie Doros, Medical Officer - FDA – to provide a briefing on the Oncology Center of Excellence and - the Rare Diseases Cure Accelerator and Analytics Platform**
- **Sarcoma Coalition Roundtable Discussion on what areas we see as “common ground” issues that patients and families across sarcoma subtypes have experience – and where we can make a difference.**
- **Adopting the Golf Ball Project to build awareness within the community Providers – general oncologists, nurse practitioners, P.A.’s etc.**
- **Sarcoma Coalition Membership – plan the next Fall General Meeting (The Life Raft Group has offered to present on their Mentoring Program)**
- **SAVE THE DATE: August 18 1 – 3 pm -THE FDA offers a special session for the Sarcoma Coalition - to discuss the Oncology Center Of Excellence and what it means for patient advocacy groups and more.**

Special session on Thursday, August 18, 2022. Time to be announced.
This is a separate session from the General Meeting of the Coalition.

- **New Advisory Panel Members of the Sarcoma Coalition**



THE SARCOMA COALITION VIRTUAL ROUNDTABLE DISCUSSIONS ON:

- **Common ground issues that affect patients across sarcoma subtypes**
- **Identify areas of collaboration for the future**
- **Follow up on the IRE treatment presentation – information for patients/families along with insurance guidance for coverage**
- **Review the Golf Ball Project – to continue the initiative**
- **Plan for the Fall General Meeting of the Coalition**
- **Discuss getting together in person at CTOS with SPAEN – who will be spearheading a patient advocacy meeting at CTOS in November.**
- **Sarcoma Coalition Member Organization Events – FB posts**
<https://www.facebook.com/groups/177803061036588>



The GOLF BALL PROJECT

<https://docs.google.com/document/d/172ZuGj1OybCE1qip-QXuUINxDexCReUS/edit?usp=sharing&oid=115625543641746161210&rtpof=true&sd=true>

<https://www.youtube.com/watch?v=188TWJsAFIk> – Dr. Robert Grimer-UK



MESSAGE from the Osteosarcoma Institute.

“For the Golf Ball Project, we have several ideas but plan to start small with an article about it on our blog/newsletter and social media. We’re meeting with our marketing team tomorrow on a variety of different projects and plan to bring this up at that time. Ideally, for the article, we would like to find the right person(s) to interview about the Golf Ball Project to share the story in OSI’s voice.”

Vanessa Peterson – Development Manager

Osteosarcoma Institute

vpeterson@osinst.org



Dr. Leslie Doros, FDA Medical Officer and Advisor to the Sarcoma Coalition, will provide a briefing on the Oncology Center of Excellence: <https://www.fda.gov/about-fda/oncology-center-excellence/who-we-are-oncology-center-excellence> and the Rare Diseases Accelerator & Analytics Platform: <https://www.fda.gov/drugs/regulatory-science-research-and-education/rare-disease-cures-accelerator>



SAVE THE DATE: THURSDAY, AUGUST 18, 2022 1 – 3 pm EST

THE F D A has offered a special session for the Sarcoma Coalition - to present information on the topics below and explain how these initiatives will be supportive of our respective patient advocacy initiatives in a collaborative way with the FDA:

- the FDA presentation on the Oncology Center of Excellence introduction to members
- the Rare Diseases Cure Accelerator and Analytics Platform

INTRODUCING THE NEW ADVISORY PANEL MEMBERS OF THE SARCOMA COALITION:



George D. Demetri, MD is director of the Sarcoma Center at Dana-Farber, director of the Ludwig Center at Dana-Farber/Harvard Cancer Center, and executive director for Clinical and Translational Research at the Ludwig Institute for Cancer Research.

EDUCATIONAL TITLES Professor, Medicine, Harvard Medical School Director, Center for Sarcoma and Bone Oncology, Dana-Farber Cancer Institute Quick Family Chair, Medical Oncology, Dana-Farber Cancer Institute **DF/HCC PROGRAM AFFILIATION** Developmental Therapeutics Center at Dana-Farber/Harvard Cancer Center, and executive director for Clinical and Translational Research at the Ludwig Institute for Cancer Research.

- Director, Sarcoma Center
- Senior Vice President for Experimental Therapeutics
- Institute Physician
- Quick Family Chair in Medical Oncology
- Professor of Medicine, Harvard Medical School

Clinical Interests

- Bone sarcomas
- Developmental therapeutics
- Gastrointestinal stromal tumors (GIST)
- Soft tissue sarcoma

My academic career has been devoted to applying novel insights from fundamental molecular biological and biochemical research to the problems of human cancer to develop rationally targeted anti-cancer therapeutics in an academic environment.



Alessandro Gronchi, MD

Fondazione IRCCS Istituto Nazionale dei Tumori (National Cancer Institute)
Milan, Italy

The fields of study he is best known for:

- Cancer
- Internal medicine
- Surgery

He mainly investigates Sarcoma, Surgery, Internal medicine, Soft tissue sarcoma and Oncology. The study incorporates disciplines such as Radiation therapy, Radiology, Soft tissue and Cancer in addition to Sarcoma. His work carried out in the field of Surgery brings together such families of science as GiST and Disease.

He serves as chair of the soft tissue sarcoma committee of the Italian Sarcoma Group (ISG), past-chair of the EORTC Soft Tissue and Bone Sarcoma Group, past president of the Connective Tissue Oncology Society (CTOS) 2017, President Elect of the Italian Society of Surgical Oncology (SICO), member of the Sarcoma Disease Site Working Group of the Society of Surgical Oncology (SSO) 2018-2021; he is a member of the European Society for Medical Oncology (ESMO), the European Society of Surgical Oncology (ESSO), the European Surgical Association (ESA) the American Society of Clinical Oncology (ASCO) and is honorary member of the Polish Society of Surgical Oncology (PSSO). He is one of the initiators of a Trans-Atlantic collaborative effort on retroperitoneal sarcoma (Trans-Atlantic RetroPeritoneal Sarcoma Working Group, TARPSWG), which involves over 50 institutions worldwide

Dr. Gronchi has authored more than 320 scientific publications, serves as Associate Editor of the Sarcoma Journal, Clinical Sarcoma Research, Tumori Journal, Journal of Surgical Oncology and Annals of Surgical Oncology.



THANK YOU ALL for the COLLABORATIVE SPIRIT that brings us all together, as the strong Patient Advocacy Network that we are and want to continue to be!

**SARCOMA COALITION
STEERING COMMITTEE**

Contact us any time with your ideas, perspectives, recommendations, and just to connect with one of us or all of us!

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

“We Are Here For You!”