SARCOMA COALITION

We are here for you.

SEPTEMBER 2024 NEWSLETTER

NOTE: GENERAL MEETING Oct. 17, 2024

In This Issue

- Oct. 17 – Sarcoma Coalition General Meeting / Agenda
- Remembering Dr. Christopher Fletcher
- FDA News and Sept. 20 Listening Session
- Listen and Learn Series Presentations
- Notice from the NCCN
- New Survey! Global Sarcoma Diagnosis Pathway Survey for Patients and Caregivers
- Oct. 5-6 – Annual Sarcoma Exchange Meeting
- Nov. 13-16 – CTOS (Connective Tissue Oncology Society) Meeting and CTOS Connect Alert for November 14!
- ASCO 2024 Palliative Care Guidelines and Article Update
- NIH/National Cancer Institute News Updates
- Sarcoma Research Spotlight – pan-sarcoma research articles of interest
- Address the Ball Updates and Call for Subcommittee Volunteers
- Sarcoma Coalition Call for Voting (for new Steering Committee)
- About the Sarcoma Coalition

SARCOMA COALITION General Meeting

Thursday, October 17, 2024 – 4 pm ET, 3 pm CT, 2 pm MT, 1 pm PT

Recurring virtual meeting / Meeting reminder will be sent 2 weeks before the scheduled meeting

AGENDA

- **Announcing the Sarcoma Coalition Steering Committee 2025 Voting Ballot** Time-sensitive ACTION ITEM for the Coalition Membership. YOUR Voice / YOUR Vote Needed! **PLEASE VOTE BY MONDAY, SEPT. 30.** **CLICK HERE FOR ONLINE VOTING!**
- **Dr. Leslie Doros, FDA Medical Officer** – Our guest speaker will address FDA highlights and talk about the FDA listening session scheduled for Friday, Sept. 20. Details below.
- **Legislative Updates by Veronica Panagiotou** – National Coalition for Cancer Survivors (NCCS)
- **Listen and Learn Series Session:** Heather Stone of NCATS / CURE ID will share her perspectives on the Repurposing Drug initiative for rare cancers (more info below).
- **Recorded Listen and Learn Series Sessions** held on Aug 23rd and Sept 4th – see below
- **Kathrin Schuster, Executive Director of SPAGN**, will address the Global Sarcoma Diagnosis Pathway Survey for Patients and Caregivers
- Call for Volunteers for the "Address the Ball" Coalition Campaign to save lives
- **GETTING TOGETHER AT CTOS** – to be together in person! Nov. 14th in San Diego!

Remembering Dr. Christopher Fletcher

Dr. Christopher Fletcher, one of the world's foremost surgical pathologists, passed away on July 28, 2024, at the age of 66.

For those of you who may have known Dr. Fletcher or heard him speak, or who were present at his special CTOS (Connective Tissue Oncology Society) tribute, which highlighted his amazing impact through his work, dedication, and commitment in the field of pathology . . . we all will remember him for this as well as his wonderful wit!

Dr. Christopher Fletcher leaves behind a legacy of excellence and compassion that will endure long after his passing. He will be greatly missed by all who had the privilege of knowing him, and his contributions to the field

of pathology will not be forgotten. Our thoughts are with his family and friends during this difficult time.

In Memoriam: Dr. Christopher Fletcher | Brigham and Women's Hospital

FDA News and September 20 Listening Session

Our guest speaker for the October 17 General Meeting, Dr. Leslie Doros, Medical Officer of the FDA and Sarcoma Coalition Advisory Committee Member, will address the following topics:

FDA News: Rare Disease Innovation Hub to Enhance, Advance Outcomes for Patients

The FDA has announced it will establish a Rare Disease Innovation Hub. "The Hub will work across rare diseases but will especially focus on products intended for smaller populations or for diseases where the natural history is variable and not fully understood, as we recognize that development of therapies for these conditions can be particularly challenging." Read more . . .

2024 FDA CBER Patient and Care Partner Listening Meeting

The FDA's Center for Biologics Evaluation and Research (CBER) is excited to host a patient and care partner listening meeting: **Patient and Care Partner Perspectives on Safety Considerations for Approved Gene Therapy Treatments for Rare Diseases** on **Friday, Sept. 20** , **11:00 a.m.–4:30 p.m. ET.**

The objectives of this listening meeting are to hear from patients and care partners on their perspectives on short-term and long-term risks of approved gene therapy products, to learn what types of information patients would find helpful in their decision-making when considering gene therapy, to learn about their considerations and experience of participating in post-market long-term follow up studies, and to help inform a patient-centered protocols for long-term follow up of gene therapy products.

The meeting will be divided into two sessions and patients, advocates, and caregivers are encouraged to request to speak during the registration process. The deadline to request to speak is **Friday, August 30, 2024 at 11:59 p.m. ET**.
Please join us for this patient-focused event:

- **Date:** Friday, September 20
- **Time:** 11:00 a.m.–4:30 p.m. ET
- **Location:** This free virtual listening meeting will be hosted on Zoom.

Registration: Registration is required: 2024 CBER Patient and Care Partner Listening Meetings | FDA

Listen & Learn Series Presentations

Upcoming Presentation: On October 17, during the Sarcoma Coalition's Annual Meeting!

CURE ID, with speaker Heather Stone of NCATS (NIH's National Center for Advancing Translational Science)

Heather Stone, Health Science Policy Analyst in FDA's Office of Medical Policy, shares her perspectives on the Repurposing Drugs initiative for rare cancer sarcoma.

"We need to learn from the experiences of clinicians and patients through platforms like #CUREID (cure.NCATS.io) and collaborate through public-private partnerships like the CURE Drug Repurposing Collaboratory or #CDRC (c-path.org/CDRC)," she says. "Join the movement to make the most of the drugs we already have, especially for patients with rare diseases!"

Two Past Presentations Offered by the National LMS Foundation to the Sarcoma Coalition

These important updates for sarcoma treatment and care are available for viewing now and will be posted on the Coalition's website under the Listen & Learn Series.

Immunotherapies in Sarcoma – Current Data and Promising Strategies

Listen & Learn Series Presentation: August 23, 2024

Dr. Christian Meyer, Johns Hopkins Cancer Institute - a recorded presentation from August 23, 2024, discussing the following research publication update: Immunotherapy in Sarcoma: Current Data and Promising Strategies | American Society of Clinical Oncology Educational Book (ascopubs.org)

Recorded Presentation Link: Immunotherapy in Sarcoma: Current Data/Promising Strategies

The Sarculator – Nomogram

Listen & Learn Series Presentation: Sept. 4, 2024

Dr. Nam Bui, physician scientist at Stanford Cancer Institute, discusses the many aspects of the Sarculator-Nomogram used throughout the sarcoma oncology community. : The following publication and more about the Sarculator are linked below in the Research Spotlight section of this newsletter.

Sarculator is a Good Model to Predict Survival in Resected Extremity and Trunk Sarcomas in US Patients | Annals of Surgical Oncology (springer.com)

Recorded Presentation Link: The Sarculator – Nomogram

Notice from the NCCN

Here's a recent communication from the National Comprehensive Cancer Network®:

Hope you are doing well and enjoying what is left of summer! We are beginning our fundraising efforts for our 2025 planned projects. We have 2 books that will be updating in 2025 that you may have interest in:
NCCN Guidelines for Patients: Bone Cancer and **NCCN Guidelines for Patients: Soft Tissue Sarcoma**.

Below are the benefits of our various collaboration options:

Collaboration Options & Benefits:

Sponsorship – For your financial support of $10,000 for NCCN Patient Guidelines Library

- Organization's name, logo and collaboration language is on the supporter page of the patient guidelines book
- Opportunity to offer patient quotes for consideration for use in the patient guidelines book
- Review final draft of the patient guidelines book before posting
- Should NCCN issue a press release, option of a coordinated press release from your organization
- Your organization's name, mission statement and website link will be included on NCCN's Patient & Caregiver Resources tab on nccn.org
- Direct link from your website to NCCN Patient Resources landing page www.nccn.org/patientresources

Resource - Share your belief in the importance of NCCN Guidelines for Patients – **no charge**

- Organization Name and website will be listed on the "Resource" page of the patient guidelines book
- Your Organization's name, mission statement and website link will be included on NCCN's Patient & Caregiver Resources tab on nccn.org
- Direct link from your website to NCCN Patient Resources landing page www.nccn.org/patientresources

Please let me know if you have any questions or concerns. I look forward to hearing from you!

Kind regards,
Mary Ellen

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Project Coordinator
NCCN Foundation

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NCCN.org – For Clinicians | NCCN.org/patients – For Patients

For access to the NCCN Cancer Guidelines:

https://www.nccn.org/guidelines/category_1

New Survey! The Global Sarcoma Diagnosis Pathway Survey for Patients and Caregivers

Sarcoma Patient Advocacy Global Network

The Global Sarcoma Diagnosis Pathway Survey is now online!

💡 Sarcoma patients face significant challenges in diagnosis, often experiencing delays and misdiagnoses, with serious consequences on treatment decisions, prognosis and survival. While data highlighting these issues exist, the sarcoma community lacks comprehensive, internationally collated information about the sarcoma diagnosis pathway.

🌍 **To address this, the survey aims to gather valuable data directly from sarcoma patients and caregivers worldwide. SPAGN wants to better understand the patient experience in receiving a timely and correct diagnosis.**

📣 **Dear patients, dear caregivers: Please make sure your experiences are heard and counted and fill out the survey here: https://awareness.sarcoma-patients.org/survey/**
The survey will take approx. 12-15 minutes to fill out.

About SPAGN

The Sarcoma Patient Advocacy Global Network (SPAGN) is the global network of national sarcoma patient advocacy organizations. Uniting more than 65 member groups from five continents, SPAGN is the voice for sarcoma patients around the globe.
SPAGN is working to improve the treatment and care of sarcoma patients through information and advocacy, supporting its national members by increasing the visibility of sarcomas with policymakers and the public.

Kathrin Schuster
Executive Director, SPAGN

Kathrin Schuster will be present at our Oct. 17 meeting to discuss this initiative!

SARCOMA COALITION
We are here for you.

This is a wonderful supportive opportunity for SPAGN and the SARCOMA COALITION to join together for the greater good of the Sarcoma Community on a global scale.
The Global Sarcoma Diagnosis Pathway Survey for patients and caregivers is online! Please participate!

And a New SPAGN Publication

Setting the international research agenda for sarcomas with patients and carers: Results of phase II of the Sarcoma Patient Advocacy Global Network (SPAGN) priority setting partnership - PubMed (nih.gov)

Oct. 5-6 – Annual Sarcoma Exchange Meeting

The annual Sarcoma Exchange is October 5th & 6th. Information and registration details below. It is a free and virtual event.

The Sarcoma Exchange is an educational virtual conference produced by the Sarcoma Alliance and dedicated to sarcoma patients and the people who support them.

The event is for Sarcoma patients, survivors, co-survivors, caregivers, patient advocates, and medical experts. It is designed to help attendees connect with one another and exchange information about current therapies and available resources.

Read more and register . . .

Nov. 13-16 – CTOS (Connective Tissue Oncology Society) Meeting and CTOS Connect Alert for Nov. 14!

ctos | Bringing together the world's sarcoma specialists

Save the Dates: November 13-16, 2024

The Connective Tissue Oncology Society (CTOS) annual meeting of Researchers and Patient Advocates for 2024 will be held **in San Diego, CA at the Manchester Grand Hyatt.**
The Connective Tissue Oncology Society is a non-profit professional medical organization whose members are a multi-disciplinary group of specialized physicians, medical professionals, and scientists.

Sarcoma Coalition Membership: "CTOS CONNECT" Alert for November 14!

Please respond by September 31, 2024!

A special tradition began a few years ago with a gathering of the Sarcoma Coalition members in attendance at the annual CTOS meeting. We've had a wonderful opportunity to get to know one another on a personal level and in person!

This year we are gathering to share a meal on **Thursday, November 14, at 6:30 p.m.** The Seaport Village is behind the hotel and there are several restaurants within walking distance. We'll discuss this when we meet for the General Meeting on Oct 17th. In the meantime, if you're planning to attend CTOS this year and are able to join us, please email annieachee@aol.com.

Let's all come together to be together – in person!

ASCO 2024 Palliative Care Guidelines and Article Update

ASCO Guidelines: Update on Palliative Care, 2024

In 2012, the American Society of Clinical Oncology released a provisional clinical opinion on the timing and use of palliative care services for people with cancer. The report recommended that palliative care be combined with standard oncologic practice early in the disease course in order to improve quality of life for cancer survivors. There is quite a bit of data to back up this recommendation. For example, among gynecologic oncology patients, collaboration with palliative care services has been shown to decrease the symptom burden by half within one day of consultation.

Clinical Practice Guidelines: Palliative Care for Patients With Cancer: ASCO Guideline Update | Journal of Clinical Oncology (ascopubs.org)

NIH/National Cancer Institute News Updates

NIH NATIONAL CANCER INSTITUTE www.cancer.gov

MyPART Minute - August 2024

The MyPART Minute - August 2024 (govdelivery.com)

MyPART Minute - July 2024 - Article about the Sarcoma Coalition in observance of July – Sarcoma Awareness Month:

https://content.govdelivery.com/accounts/USNIHNCI/bulletins/3a522a8

Sarcoma Research Spotlight – pan-sarcoma research articles of interest

The Sarcolator / Nomograms as Predictive Tools for Sarcoma Treatment

Sarculator is a Good Model to Predict Survival in Resected Extremity and Trunk Sarcomas in US Patients | Annals of Surgical Oncology (springer.com)

More information: http://www.sarculator.com/

The sarculator stratified prognosis of patients with high-risk soft tissue sarcomas (STS) of extremities and trunk wall treated with perioperative chemotherapy in a randomised controlled trial (RCT)

Online nomogram is an important clinical tool for surgeons and oncologists in the prognostic evaluation of patients with sarcomas

Other Topics

Immunotherapy in Sarcoma: Current Data and Promising Strategies
An ASCO (American Society of Clinical Oncology) Educational book. From the abstract: "Here, we review the current evidence for immunotherapy use in bone sarcomas (BS) and soft tissue sarcomas (STS), with immune checkpoint inhibitors (ICI) and adoptive cellular therapies including engineered T-cell therapies, chimeric antigen receptor (CAR) T-cell therapies, tumour infiltrating lymphocytes (TILs) and cancer vaccines and biomarkers of response." Read online book . . .

Proteomic profiling improves prognostic risk stratification of the Sarculator nomogram in soft tissue sarcomas of the extremities and trunk wall
A DNA replication protein signature-Sarcoma Proteomic Module 6 (SPM6) was evaluated for association with clinicopathological factors and risk groups. SPM6 was added as a covariate together with Sarculator in a multivariable Cox model to assess improvement in prognostic risk stratification. Read article . . .

Progress in histology-specific treatments in soft tissue sarcoma
The research behind this article explored the current treatment landscape for localized and metastatic STS, focusing on the combined use of radiotherapy and chemotherapy for both extremity and retroperitoneal tumors, and with a particular emphasis on the most innovative histopathology driven therapeutic approaches. Read article . . .

Every cancer has a unique metabolic profile that describes the tumor's ability to grow and proliferate. This page describes some of those profiles. Read more . . .

The Van Tine lab focuses its research on studying cancer metabolism to develop novel therapeutic strategies for soft tissue and bone sarcomas.
Research | Van Tine Laboratory | Washington University in St. Louis (wustl.edu)

Received 07 May 2024, Accepted 22 Jul 2024, Published online: 05 Aug 2024
Full article: Progress in histology specific treatments in soft tissue sarcoma (tandfonline.com)

Address the Ball Updates, Call for Subcommittee Volunteers

The Sarcoma Coalition is not the only organization to promote the Golf Ball Project and "Address The Ball."

Here we are in Perth, Australia with the same awareness-building message:

Sarcoma Smart
@SarcomaSmart

Promoting awareness of sarcoma symptoms and research. Get all odd lumps, bumps, aches or pains checked by a GP - it may save your life.

Perth, Western Australiajoin.worldcommunitygrid.org/?recruiterId=1...Joined October 2018

As you well know, sarcomas sometimes present as a lump or bump. If all Coalition sarcoma subtypes will come together and help spread the word, we can have a big impact in our patient communities. Patients can share the messaging with friends, family, medical teams in their community (e.g., dermatologists, orthopedists, primary care physicians, PA's, nurse navigators, and many more) . . . we can do this and we can do this TOGETHER!

As an example, The Charlie Landers Foundation and the National Leiomyosarcoma Foundation have done just that. We worked together and made it happen. Are there more of you who would be willing to help? If so, please contact annieachee@aol.com to learn more about what we are doing for messaging.

Call for Subcommittee Volunteers for the Golf Ball Project's "Address the Ball" Campaign

This subcommittee consists of volunteers from the Coalition Membership coming together to review successful efforts from member organizations and discuss ideas on how best to promote the Golf Ball campaign.

Periodic meetings are held to discuss ways to reach out to the medical community and the public – on the importance of following up medically if lumps and bumps of any size/ the size of a golf ball are found on one's body - awareness strategies to save lives. A very worthy "deliverable" to communities across the nation and abroad!

Please contact Mitch Achee, MD to volunteer: machee@comcast.com

Sarcoma Coalition Call for Voting (for new Steering Committee)

It is time for the current five-member Sarcoma Coalition Steering Committee to pass the baton to a new group of volunteers. Five Coalition members have volunteered to be voted in to serve

– a very rewarding way to serve within the Coalition. The New Steering Committee members are to begin their terms in January of 2025.

Click here to read about the proposed slate, including a short profile of each volunteer, and to cast your vote: ONLINE VOTING HERE.

COALITION MEMBERS, PLEASE VOTE no later than Sept. 30th.

OFFICIAL ANNOUNCEMENT at the October 17th Sarcoma Coalition Meeting!

Again, CLICK HERE FOR ELECTRONIC VOTING.

The Role of the Coalition Steering Committee:

The Sarcoma Coalition Steering Committee champions Coalition member organizations coming together in unity, as a patient advocacy network, sharing patient experiences and strategies for roundtable discussion; focusing on patients' access to care and credible treatment through Sarcoma Centers of Excellence.

The collective goals of this patient advocacy network are to enhance and improve delivery of care/treatment from diagnosis to end-of-treatment and long-term Survivorship. Guest speakers for General Meetings are invited to address patient advocacy areas of interest.

About the Sarcoma Coalition

The **SARCOMA COALITION** represents a strong and **united patient advocacy network** of sarcoma organizations/foundations throughout the United States and Canada, as well as with other international colleagues through the Sarcoma Patients Global Advocacy Network (SPAGN) collaborative membership.
The Coalition's purpose and mission is to:

- **Enhance collaboration**
- **Promote Sarcona Centers of Excellence**
- **Build pan-sarcoma patient awareness**
- **Lead and support special projects that impact the pan-sarcoma patient community**
- **Bridge sarcoma research community collaborations and reciprocal support**

SarcomaCoalition.us

"TOGETHER – W E C A N !"

Next general meeting: January 16, 2025