

SFA Spotlight - March 2017

Welcome to our newsletter! Please be on the lookout for this newsletter every month as a way to keep you more involved and engaged with information important to the SFA community.

Please be sure to include sfainfo@curesarcoma.org in your address book. If you do not wish to receive this email on a monthly basis, please <u>contact us</u>.



Bert's Blog

This post was written by Bert E. Thomas IV, PhD, MBA, CEO of the Sarcoma Foundation of America.

Each year, the Sarcoma Foundation of America holds its annual gala, "A Celebration of Life," in New York City to raise money to support our sarcoma research efforts. This evening serves as an opportunity to

generate the funds needed to invest in the kind of innovative and novel research that brings us closer to new treatments and, ultimately, to the cure for sarcoma.

But "A Celebration of Life" goes well beyond simply being a fundraising event.

The SFA sees "A Celebration of Life" as an evening to honor the heroes in the sarcoma community whose actions move us towards better patient outcomes and whose stories inspire the hope necessary for all sarcoma patients to fight their cancer. These heroes come in all forms; they are patients, survivors, caregivers, healthcare providers, researchers, and those whose work is dedicated to creating new therapies and treatments.

Read more...

Sarcoma Advocates Take Part in Rare Disease Week on Capitol Hill

Sarcoma patients, survivors, and their loved



ones from around the United States traveled to Washington, DC, to make their voices heard during Rare Disease Week. Taking their message to Capitol Hill, these advocates urged legislators and their staff to make the needs of the rare disease community a priority.

Traditionally, the rare disease community had united on the last day of February each year to celebrate Rare Disease Day. What

began as a one-day focus on rare diseases has now turned into a week of events and programming designed to draw attention to the special needs of those who are dealing with rare diseases like sarcoma.

While the Sarcoma Foundation of America works tirelessly every day to raise awareness, Rare Disease Week serves as a wonderful opportunity to further educate the public, legislators, and government regulators about the challenges faced by those with sarcoma.

You are Invited to the 2017 "A Celebration of Life"

Join us for our annual celebration featuring a silent auction, dining and dancing!

The evening will honor the achievements of those who have made a difference in the sarcoma community. Funds raised at "A Celebration of Life" support the SFA's mission of funding research, educating patients and caregivers, and increasing disease awareness.



NOBILITY IN SCIENCE AWARD

Gary K. Schwartz, MD

Chief of Hematology and Oncology
Columbia University School of Medicine/New York Presbyterian Hospital
Professor of Medicine
Deputy Director
Herbert Irving Comprehensive Cancer Center

PUBLIC SERVICE AWARD

Richard A. Moscicki, MD

Deputy Center Director for Science Operations U.S. Food and Drug Administration

VISION OF HOPE AWARD

Lilly Oncology

COURAGE AWARD RECIPIENTS

Suthakar Iyer
Tom Peroulas

COMPASSIONATE CARE AWARD Yelena Ustoyev, AGPCNP-BC

THURSDAY, APRIL 20, 2017

6:00 pm - 10:00 pm

GUASTAVINO'S

409 E 59th Street New York City, NY

Please visit http://www.curesarcoma.org/nyccelebration/ for more information on how to become a sponsor, purchase tickets or journal ads, or to <a href="mailto:ma

Wingad Walks for the Cure

Keith Wingad is hitting the Appalachian Trail in April!

Keith is walking the entire 2,181 miles of the Appalachian trail to honor the memory of his friend Sig Kohl who died last year from sarcoma. He is raising money for the Sarcoma Foundation of America as a part of his journey to help find the cure for sarcoma. His trek is expected to take about six months to complete and we are excited to follow his journey!



You can track his progress and support his fight by donating; http://support.curesarcoma.org/goto/wingadwalk.

For every \$20 raised on Keith's page by April 24, SFA's Event Manager will walk a mile with Keith!

Race Season is Just Four Months Away!



The 2017 Race to Cure Sarcoma[™] season officially kicks off this July with the inaugural Race to Cure Sarcoma[™] Milwaukee. The race will be held on July 16 in Downtown Oconomowoc, WI.

Grab your friends, family and neighbors and get registered: http://support.curesarcoma.org/milwaukee. You won't want to miss out on the fun!

Check out the list of other cities we will be hitting this year:

Pittsburgh Cure Sarcoma

Saturday, July 8

http://support.curesarcoma.org/Pittsburghhttp://support.curesarcoma.org/Milwaukee

Race to CureSarcoma™ Milwaukee Sunday, July 16 Race to Cure Sarcoma™ Philadelphia Sunday, September 10 http://support.curesarcoma.org/Philly

Race to Cure Sarcoma™ Denver
Saturday, September 16
http://support.curesarcoma.org/Denver

Race to Cure Sarcoma™ Chicago

Saturday, October 28 http://support.curesarcoma.org/Chicago

Registration for the remaining 2017 races will open in the near future.

St. Louis, MO: October 8
Richmond, VA: October 14
Nashville, TN: November 4
Miami, FL: November (date TBA)
New Jersey:(date TBA)

For more information on registration, fundraising, and sponsorship opportunities, visit www.racetocuresarcoma.org. Be sure to follow the SFA on Facebook and Twitter for the latest information as it becomes available.

Questions about the Race to Cure Sarcoma[™] series or interest in serving as a volunteer? Contact us at race@curesarcoma.org.



SFA Supports the Angiosarcoma Project

The Sarcoma Founation of America is proud to be a supporter of the Angiosarcoma Project. This program, coordinated by the Broad Institute and the Dana-Farber Cancer Institute, aims to study Angiosarcoma by partnering directly with patients. It is the SFA's hope that the success of this project will lead to better treatments for Angiosarcoma patients.

From the Angiosarcoma Project website: "Help transform our understanding of Angiosarcoma. If you have been diagnosed with angiosarcoma, join a nationwide movement of patients, doctors, and scientists by sharing your tumor samples, your medical information, and your voice. Together, we can develop a comprehensive resource that will drive discoveries about this orphan cancer."

For more information on how to get involved with the Angiosarcoma Project, please visit https://ascproject.org/home.

Consider a Tribute Gift

Tribute gifts are a good way to honor someone who has been impacted by sarcoma. Through your tribute gift, you honor their humanity and their hopes for a cure, just as you honor their life.

After your gift, the Sarcoma Foundation of America will send



a note to the individual(s) or family you designate. We will let them know of your thoughtful and generous gift. The amount will not be disclosed. You will also receive an acknowledgement and tax receipt for your records.

In the coming months, please look for our new area on our website for tributes.

To learn more about tribute giving, please contact Michele Levy in our office at 301-253-8687 ext 102 or mlevy@curesarcoma.org.

Survey Opportunity for Soft Tissue Sarcoma Patients

Analysis Group, Inc. (AG) is surveying individuals with soft tissue sarcoma to understand their preferences for treatment of soft tissue sarcoma. Your participation will help to advance knowledge in this field.



The Study: AG is seeking individuals with soft tissue sarcoma to share their views

and preferences for treatments of soft tissue sarcoma in an online survey lasting approximately 15-20 minutes.

To Participate: You will be eligible to participate if you meet all of the eligibility criteria described below. Your participation is voluntary. You will not be asked to provide personal identifying information in this survey. Your responses to the survey and additional information will be kept confidential per Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations, and will be reported and published only in summary form (e.g., averages or percentages among respondents). This study has been reviewed by the Western Institutional Review Board (WIRB).

Fore more information and to access the online survey, visit http://www.curesarcoma.org/survey-opportunity-for-people-with-soft-tissue-sarcoma-2/.

This information is being provided as a service from the Sarcoma Foundation of America. The SFA is not involved in this study and will not have access to any patient information.

Get Involved!

Interested in hosting an event in your area? Contact us at events@curesarcoma.org.

Looking for volunteer opportunities or other ways to get involved? Contact us at getinvolved@curesarcoma.org.





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STAY CONNECTED:









