



Raising Awareness ... about Breast Sarcomas



With pink everywhere — even the wives of the presidential nominees showed up in hot pink for the second debate — it's hard to forget that October is Breast Cancer Awareness Month. But awareness for

carcinomas, with no mention of sarcomas, can confuse those of us with these rare diseases. Sarcoma patients and their loved ones often ask why they aren't getting the same treatment as someone they know with cancer in the same location.

At the Sarcoma Alliance, volunteers are building resources in plain English. When we don't have something on our website, we refer people elsewhere. For example, the Sidney Kimmel Comprehensive Cancer Center offers a good explanation of breast sarcomas. www.hopkinsmedicine.org/

If you wear a pink ribbon this month, feel free to add a yellow one to it for sarcoma.

... about Childhood Sarcomas

Last month was Childhood Cancer Awareness Month. In addition to our other resources, we're working on a page that questions how statistics on rhabdomyosarcoma and other sarcomas are presented. sarcomaalliance.org/what-you-need-to-know/how-rare-is-sarcoma-really This page continues a story we put out on the Internet last year about the way childhood sarcomas are counted. www.prweb.com/releases/

... about Gyn Sarcomas

Last month was also Gynecologic Cancer Awareness Month. Earlier, our blog had featured advances in gyn sarcoma, including upcoming international clinical trials. sarcomaalliance.blogspot.com

We're still trying to get Congress to name July as Sarcoma Awareness Month. The Tampa Tribune ran a piece on its editorial page, explaining why we're having such difficulty passing a simple resolution. www2.tbo.com/news/ If you'd like to help, go to sarcomaalliance.org/news/sarcoma-awareness-month/

Read about the winning Ocean of Hope athletes (including Steve Shlens, below) on our blog. sarcomaalliance.blogspot.com/



YOU ARE NOT ALONE

Sarcoma Stories



Josephine Schiavo

After her Aunt Jo was diagnosed with sarcoma, Christina Moore did a beautiful thing.

As Miss Brooklyn 2011, Christina raised more than \$15,000 for the Sarcoma Alliance to honor Josephine Schiavo. As Miss Verrazano 2012, Christina estimates she raised almost \$13,000 for sarcoma nonprofits last week with Casper's Cure, a dinner-dance. "We had family, friends and community members all gathered in one room for a beautiful cause," she says.

"Aunt Jo is my No. 1 inspiration. She's so full of life," she says. Josephine returns the compliment: "She's growing into such an amazing woman. I'm in awe of her."

[Read the complete story](#)

Alliance members will go to Prague

The Connective Tissue Oncology Society [\[www.ctos.org\]](http://www.ctos.org) is an international multidisciplinary organization for those who treat and/or research sarcomas. Its annual meeting will be Nov. 14-17 in Prague, capital of the Czech Republic.

As part of the conference, the Sarcoma Alliance for Research through Collaboration will present findings from its clinical trials Nov. 15. SARC [\[www.sarctrials.org\]](http://www.sarctrials.org) (sometimes confused with the Sarcoma Alliance) is a nonprofit composed of sarcoma physicians who cooperate with their counterparts at different institutions to conduct clinical trials.

The Alliance is sending Arthur Beckert, our executive director, to these meetings. Four board members also plan to attend. We want to hear the latest research, inform doctors about ways we can help their patients, and strengthen relationships with them and other advocates.



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