

Executive Director's Corner **WE ARE LUCKY THERE ARE SO MANY GREAT PEOPLE** by Arthur Beckert



People often ask why I like working for the Sarcoma Alliance; it can be summed up in one word the "people." I'll begin with the Sarcoma Alliance Board of Directors. When I started, they were a group of nine committed individuals from northern or southern California. Most had been on the board since its early days and were family or friends of our founders, Suzanne Leider and Wendy Sommers. Since then the board has grown to 15 people from all over the U.S. — Washington to New York, Florida to Ohio, back to Texas, Nebraska and, of course, California. They set policies and priorities for the organization but also help in so many ways — client services, graphic and web design, fundraising and anything else to assure a dynamic, successful future. I should add that many past board members stay involved, helping us in numerous ways.

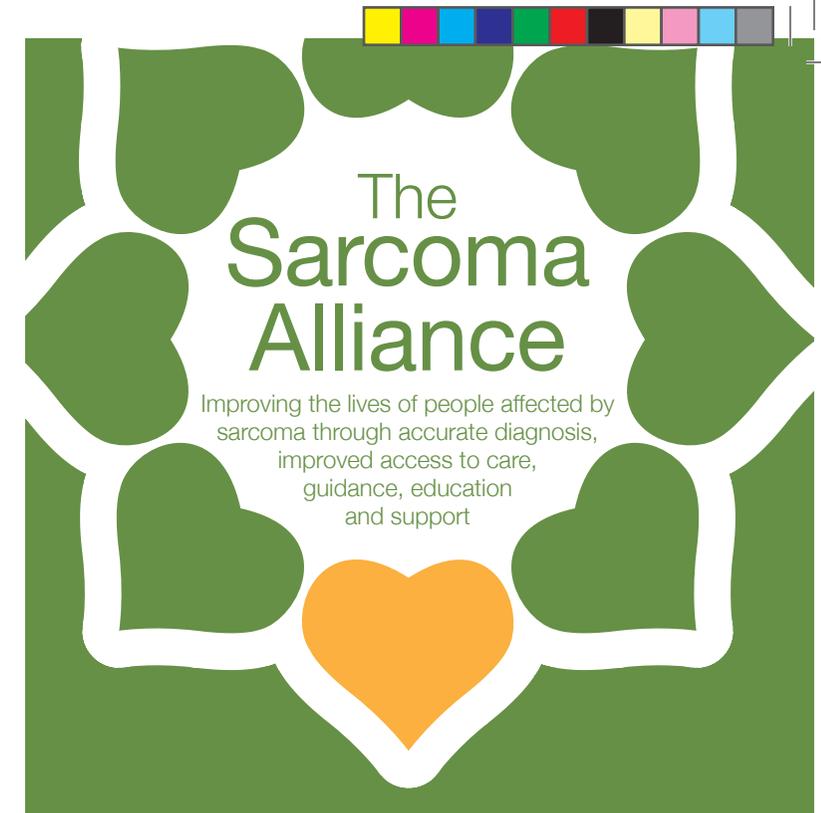
Next are the incredible, brilliant physicians who dedicate their lives to providing the best possible patient care, to investigating promising new treatments and therapies, and to sharing their vast knowledge and experience so we can do a better job meeting the needs of those affected by sarcoma. There is also a wonderful world of sarcoma patient advocates who raise money for research, provide love and support to anyone who needs it, gives everyone hope for the future.

Next, we have a very special group of volunteers who help us year after year, some who have been impacted by sarcoma, all who greatly believe in our mission. These include Aimee Spector and Fred Sardisco, the team captains of our Ocean of Hope campaign and all the wonderful team members;

Jenny Bolsky, who has done our taxes for years; Charlie Lustman, who has put together a moving, uplifting operetta about his experience with osteosarcoma; Warren Bailey, Jennifer Nellany, the Ferretti family, Christina Moore and her special aunt Josephine Schiavo; and the family and friends of Erin Pott, who give to us in so many ways, from fundraising to inspiration; and Christina Witt at Brush Dance Greeting Cards, who each year sells holiday cards for our benefit. There is also an army of unnamed people who come to our events and help in any way they can.

We will work hard to help you any way we can, to find the information you need and give you hope for the future.

Last, but certainly not least, is the sarcoma community. I never know who will be on the other end of a phone call, who will be seeking information or advice in an email, or popping up on any one of our web-based services — the discussion board, chat, blog or Facebook. It might be a newly diagnosed patient, a family member or friend of someone with sarcoma, or a person who knows someone who could use our help. We will work hard to help you any way we can, to find the information you need and give you hope for the future. You make me laugh and cry. You inspire me to be there, to work hard, and to do everything I can so that you do not ever feel you are alone and no one understands what you are going through. Thank you to everyone for all your help, support and just for being who you are. ☺



DEAR FRIEND OF THE SARCOMA ALLIANCE,

Every day in this country, about 40 people hear the word "sarcoma" for the first time. Sarcoma. It doesn't even sound like a cancer, does it? But it is one of the most difficult to diagnose, difficult to treat and difficult to cure. It strikes young and old alike, suddenly and seemingly randomly. When my daughter was diagnosed, I had never heard of sarcoma, I knew no other child (or adult) with it, and I had no idea where to turn for information. It was truly terrifying to feel we were fighting a dangerous enemy alone.

Continued >>

SARCOMA ALLIANCE BY THE NUMBERS: Our Assistance Fund has given over 375 grants totaling nearly \$190,000 to individuals for life-saving second opinions. Our Peer-to-Peer program has over 1,000 individuals from all 50 states and 12 countries. Our Chat Room meets Wednesday at 8 p.m. and on Sunday at 9 (Eastern). Our Facebook page has over 1,500 members. Our Discussion Board has over 2,000 members. WE HELP EVERYONE, AFFECTED BY ANY TYPE OF SARCOMA, ALWAYS FREE OF CHARGE.



775 East Blithedale, #334 • Mill Valley, CA 94941-1564 • Telephone (415) 381-7236 • Fax (415) 381-7235 • email info@sarcomaalliance.org • www.sarcomaalliance.org

The Sarcoma Alliance Officers and Directors:

Joan Darling, President
Jeff Bradbury, Vice President

Ade Lawal, Treasurer
Denise Lapins, Secretary
Claude Alexander
Kellie Flynn

Deborah Gates
Jim Johnston
Philip Leider
David Murphy
Ali Olig

Jennifer Pavelka
Kevin Plottner
Suzie Siegel
Marites Tullius

Medical Advisory Board:

Laurence Baker, D.O.
George Demetri, M.D.
Burton Eisenberg, M.D.
Charles Forscher, M.D.
Robert Goldsby, M.D.

Linda Granowetter, M.D.
Richard O'Donnell, M.D.
Brian O'Sullivan, M.D.
Raphael Pollock, M.D., Ph.D., F.A.C.S.
Sharon Weiss, M.D.

Sarcoma Alliance Staff:

Arthur Beckert, Executive Director
Pamela Cresta, Office Manager

That's why the Sarcoma Alliance came into being 12 years ago. And that's why wonderful people like Christina Moore donate their time and talent to sustaining the Alliance. There was and there continues to be a need to provide people affected by sarcoma with the information and support they need to obtain optimal treatment, to find hope from others who understand their fears, to know that they are not alone.

In the past dozen years, the Sarcoma Alliance has helped thousands of people throughout the U.S. and the world, by giving grants for second opinions from experts; by connecting us to our peers; by supporting us through a chat room, discussion board, Facebook page, and live events; and by providing authoritative and educational information.

As the only national organization whose sole mission is information, guidance and support for people affected by sarcoma, we continue to be deluged with requests for assistance. Please help us fulfill our mission by giving generously from your heart. Your donation directly helps people affected by sarcoma receive the education, support and guidance they desperately need.

On behalf of those we serve, many thanks for your continued support, and our best wishes to you and your family for a happy, healthy and prosperous 2012.

Joan Darling
President, Board of Directors

BEAUTIFUL INSIDE AND OUT

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

As Miss Brooklyn 2011, Christina raised over \$16,000 for the Sarcoma Alliance to honor her aunt, Josephine Schiavo, who has survived an aggressive sarcoma. Neither had heard of sarcoma before Josephine was diagnosed. Now more than a thousand people have learned about sarcoma through the pageant, fundraisers, newspaper articles, a blog, YouTube, dance clinics and plain old word-of-mouth.

"Aunt Jo is my No. 1 inspiration. She's so full of life," says Christina, 21. Josephine, 45, returns the compliment: "She's growing into such an amazing woman. I'm in awe of her."

The two women are bound by love, not blood. Christina is the daughter of Josephine's best friend. Josephine has two sons, 16 and 20, and the Brooklyn families have been close for years. Josephine's illness brought them closer.

In April 2007, she hit her head but the bump she felt didn't go away. An X-ray in May showed a mass, and in July she had surgery. She was diagnosed with malignant fibrous histiocytoma (MFH), which was later updated to undifferentiated pleomorphic sarcoma (UPS). Both the old and the new terms refer to soft-tissue sarcomas that can't be classified otherwise. The head is an unusual place for sarcoma to start.

By November, CT scans showed many small spots in her lungs and liver. A lung biopsy confirmed that the sarcoma had spread. The day after Christmas 2007, she started a chemo cocktail called AIM for Adriamycin (doxorubicin), Ifex (ifosfamide) and mesna.

"I got chemotherapy for eight months, and I was in and out of the hospital quite a number of times." Josephine stopped chemo, and by July 2008, scans showed some metastases gone and others stable. The mets have stayed stable. Her doctor said she was the first patient he had treated with UPS that responded so well to chemotherapy.

Josephine found little information on sarcoma until she came across the Sarcoma Alliance website and its chat room. "It was my go-to site for sarcoma information."

Meanwhile, someone suggested Christina enter the Miss Brooklyn Scholarship Pageant after seeing her dance. When she discovered that she could benefit a worthy cause, she turned to Josephine, who suggested the Sarcoma Alliance.

"I received a phone call that she came in fourth but with a spirit not diminished. She still hoped to help us in the future," says Arthur Beckert, executive director of the Alliance. "This year, she entered the contest again, and I received an excited call that she had won!"

Christina was crowned Oct. 9, 2010. By Feb. 12, 2011, she had organized the Valentine's fundraiser called Cupid's Cure.

"The event in Brooklyn, one of the boroughs of New York City, brought together more than 200 people to honor Josephine and support the Sarcoma Alliance," wrote Arthur, who flew from his home in California to attend. Balloons and sunflowers decorated the tables. There was dinner, dancing and a raffle.

"Aunt Jo and I knew that if we were going to coordinate a fundraiser, it wasn't going to be your typical 'fundraiser,' but instead a true celebration of life," Christina wrote on her blog. "We were there not to be saddened by Josephine's struggle, but rather empowered and inspired by her tremendous fight. Her positive attitude and outlook on life is one to be admired by all, for it is the reason she is with us today. Her zest for life, loud voice and contagious personality is unbelievable and I wanted that to be able to shine the most the night of the event!"

"What I've been doing this year is take two things I love and fused them together: Aunt Jo and dance."

Christina has danced for 18 years, with a special love for jazz dance. She is a senior at Wagner College in Staten Island, where she is getting a bachelor's degree in arts administration, with a minor in dance. Five years ago, she returned to Brooklyn's Christa McAuliffe I.S. 187, which has kindergarten through 8th grade, to be the drama club choreographer.

As Miss Brooklyn, she adopted the platform: "Performers with a Purpose: Bringing Sarcoma Awareness Center Stage." She traveled to McAuliffe and two other Brooklyn public schools once a week to teach dance clinics — and the idea that the arts can be used to help others. One sixth-grade boy told her: "I'm doing this because a year ago my Grandpa died of sarcoma, and I want to get the word out."

"When one person opens up, others feel free to tell their story, too," Christina said.

On May 7, 500 dancers from the community performed, including Christina's students, of course.



Christina hosted another fundraiser June 4 at Adventurer's Park Family Entertainment Center in Brooklyn. The Sarcoma Alliance got a portion of ticket sales, and she and her crew sold baskets, held a raffle and put on a variety show in which she and her students performed. "It turned out to be a really nice family fun day."

2011 has been stressful, she acknowledged. "But hands down it was the best year of my life. I wouldn't trade it for anything. It brought my friends and family together in so many ways." She hopes to compete in another pageant, and she and Josephine plan to do Cupid's Cure next year.

"Life is too short to sit back and let things happen," Christina says. "You have to take charge and MAKE things happen." 🌻

POWER OF THE OCEAN **BENEFIT FOR THE ASSISTANCE FUND**
To raise money for the Assistance Fund, our Ocean of Hope team is organizing the Power of the Ocean, which will be 5–9 p.m. January 21 at Saint Rocke in Hermosa Beach, Calif. The event will celebrate nonprofit organizations that use the ocean as a means of outreach, therapy, rehabilitation and hope.

Our partner in this event is the P.S. I Love You Foundation for its Day at the Beach program. Expect great food and drinks, a silent auction and great local bands; plus you can stay after the event and listen to more great music at Saint Rocke without paying a cover — on a Saturday night — unheard of! Buy tickets at www.poweroftheocean.eventbrite.com.