

you are not alone

Improving the lives of people affected by sarcoma through accurate diagnosis, improved access to care, guidance, education and support



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The Sarcoma Alliance News

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International Sarcoma Patient Advocate Network (iSPAN)

iSPAN met for the fourth time on November 4, 2009 in conjunction with the annual meeting of the Connective Tissue Oncology Society (CTOS). Almost 30 individuals representing advocacy groups, pharmaceutical companies, professional associations and universities met to hear updates of activities of common interest and to explore how we can better work together. iSPAN's mission statement:

iSPAN is comprised of international individuals and organizations that desire to work together to improve communication, share information and address legislative and regulatory matters affecting sarcoma patients, medical professionals and researchers. iSPAN members complement and benefit each other through shared communication and networking. In return, iSPAN serves as a common voice for sarcoma advocacy utilizing its strengths and diversity.

During the past year iSPAN has been an increasingly effective voice for sarcoma advocacy organizations. Among the activities during the past year and at CTOS are:

1. Increased funding for rare diseases at the National Institute of Health
2. Working to include sarcoma in the National Cancer Institute's cancer genome project
3. Working to assure that the clinical trial process can support advances for rare diseases
4. Supporting patient registry projects of the Sarcoma Foundation of America and the Life Raft Group (GIST)
5. Working to establish and support collaborative tissue banks
6. Keeping informed on important clinical trials such as ARIAD's Ridaforolimus Clinical Trial (http://www.ariad.com/wt/tertiarypage/succeed_trial) and Ziopharm's PICASSO trial (http://www.ziopharm.com/patients/PICASSO_Main.html)
7. Exploring ways to increase effective collaboration of the many issues of importance to all sarcoma groups

The Sarcoma Alliance is one of the original members of this group and is excited that so many groups have come together for the benefit of the sarcoma community. 



A Decade of Guidance, Support and Education

Arthur Beckert

When Wendy Sommers and Suzanne Leider started the Sarcoma Alliance, guidance, education and support was the guiding principle. The Alliance's mission was to help everyone — newly diagnosed, long term survivors, family members, caregivers and friends, women and men, young and old, and every sarcoma subtype — in short everyone affected by sarcoma. This mission, this focus created an organization that never existed before.

This single mindedness served us and those affected by sarcoma well during the past decade. In 2009 the Alliance proudly celebrated its tenth anniversary. What started out as an organization with a simple discussion board and phone line has grown to an organization that is able to meet the diverse needs of the sarcoma community. Here is some of what we do.

- **Sarcomaalliance.org** – Our website has grown and changed to meet the evolving needs of the sarcoma community. We have and will continue to do so expand information on pediatric and adolescent / young adult sarcoma. We are now on Facebook and You Tube; we blog regularly, and are looking at other ways to make ourselves more accessible and user friendly.
- **Discussion Board** – The board now has multiple forums that provides an active, vibrant place where individuals can seek support, advice and feedback from others who have had similar experiences.
- **Chat** – Our chat room is moderated on Wednesday and Sunday evenings by Dave Murphy, a long time member of the Alliance Board of Directors.

- **Peer to Peer Program** – For one on one support our peer to peer program will match individuals together based on their own expressed preferences.

- **Financial Assistance** – The Hand in Hand, Financial Assistance Program provides grants to individuals for expenses associated with getting a second opinion from a sarcoma specialist.

- **Other initiatives** – This year we will begin to regularly send out information using our eNewsletter. We have begun to conduct surveys of our community to we can get objective information on what we are doing well and areas where we need to change and expand.

We have also developed wonderful relationships with many other sarcoma advocacy and professional organizations. Over the years received financial support from Ariad, Autodesk, Chapman and Associates, Genentech, Novartis, and Pfizer. We are very proud of this as it demonstrates a belief in what we do and has allowed us to grow and expand.

Finally, our relationships with the sarcoma community is what keeps us going, keeps our focus and inspires us to work harder. During my five years at the Alliance I have the privilege of meeting, talking on the phone, and exchanging emails with sarcoma survivors, family members and friends. I hear stories that make me laugh and others that make me cry. Thank you all for your support and belief in our mission; we couldn't do it without you. 🌻



ARIAD

Autodesk

Ariad and Autodesk Award Grant's to the Alliance

Once again Ariad has supported the Peer to Peer Program with a \$10,000 grant. Ariad has supported this important program since it began over 4 years ago. Since that time over 700 people has signed up from 47 states and from 20 countries outside the U.S. We continue to receive feedback on how valuable this program and thank Ariad for its generosity.

Autodesk awards the Alliance a grant for programming support

Autodesk has awarded the Alliance a \$2,000 grant to support website and programming projects. This grant will help us to improve our website and the programs it supports. This is the third grant we have received from Autodesk in support of our technology needs. A big thank you to Autodesk. 🌀

SPECIAL THANKS

During the past year the Sarcoma Alliance has benefited from the time and energy of people all over the United States.

SUE BO'S RUN was held August 22, 2009 in Vandalia, Ohio in memory of Susan Bohardt by her husband, Bob, and his family.

BOB FERRETTI WALK/RUN was held in New Jersey in September 2009 for the fourth time. This event is organized by the Ferretti family and friends in memory

of Bob. 2009 was another successful and exciting day.

PUTTS FOR PED, held in October 2009 also in New Jersey, was the third annual golf tournament in memory of Michael Pedrick. Jennifer Nellany, his wife, and her friends have devoted many hours to assure a fun-filled day of lunch and golf.

ERIN POTTS INVITATIONAL VOLLEYBALL TOURNAMENT was put on by many friends of Erin -Katie Frisbie, Sue Rejdukowski, Angela Franklin

and Tina Pryor. Erin, who lost her battle with Ewing's sarcoma in December 2009, loved volleyball and continued to support her team even after extensive surgery on her leg prevented her from playing.

Together these events raised over \$40,000 for the Alliance and have made a tremendous difference for us during a difficult financial time for everyone. These events, along with many individual donations, assured that we could continue with all our programs and activities. Thank you.

Ocean of Hope

It started out as a gesture of support, one friend to another, a paddleboarder to the founder of the Sarcoma Alliance, Keith Munemitsu to Suzanne Leider. Keith told Suzanne: I will dedicate my race in the Catalina Classic to raising money and awareness for sarcoma and the Alliance. The Ocean of Hope was born.

The Catalina Classic is a 32-mile paddleboard race from Catalina Island to Manhattan Beach in southern California. It's a test of conditioning, commitment and willpower across the open ocean.

The Ocean of Hope, like the Sarcoma Alliance, grew and changed over the next 10 years. What started as a single race evolved into a series of paddleboard and outrigger races throughout California and Hawaii.

After Keith stepped down, Mark Schulein became team captain, leading and inspiring in words and by example an ever-larger group of paddleboarders. Eventually, Mark stepped aside, too. Even paddleboarders have to grow up a little. With a wife, child and successful, growing business, he didn't have time to lead the team, which had added a group of talented and hardworking women who paddle outrigger canoes. Fortunately, there was no vacuum in leadership. Fred Sardisco volunteered to lead the paddleboarders while Aimee Spector headed the outrigger team.

2009 was an inspiring year, as the Ocean of Hope celebrated its 10th anniversary. The Catalina Classic was one of those rare years with calm winds and smooth seas. It made for fast times, where exhaustion was due to the athletic effort and not to battling the elements. It raised \$53,537, compared with the \$18,285 in 1999.

The outrigger team remained one of the top ones, competing in races throughout California and Hawaii.

Joe Bark, the No. 1 paddleboard-maker, has provided boards to the Alliance for a very successful series of fundraising raffles. Almost every competitor uses his boards, works of art that epitomize form following function.

Finally, there is the sarcoma community. You inspire the paddlers, the outrigger team, the Sarcoma Alliance staff, board and volunteers. You are why the Sarcoma Alliance exists and why, year after year, the Ocean of Hope is so successful. Thank you, one and all. ☀



Ocean of Hope 2010 Gets off to a Great Start

On March 7 the Cold Hands Paddle at Cabrillo Beach in San Pedro, CA kicked off our Ocean of Hope (O2H) campaign for 2010. This awesome (some say not even cold!) 4 mile course from Cabrillo Beach, was open to paddleboards, stand up paddleboards and new this year outrigger canoes. Fred Sardisco and Aimee Spector are this year's O2H team captains and have done a tremendous job of organizing the team.

One of the highlights of the day was a raffle for two Joe Bark paddleboards. Steve Reidy, of Westlake Village, won the stand up board. He was very stoked! Aimee's seven year old son Slade won the traditional 14 ft paddleboard. (No, the raffle wasn't rigged! His ticket was picked fair and square!). Slade generously decided to put the board back into the raffle for August, so we'll raffle off two boards at the Catalina Classic After Party on August 29. Thank you Joe Bark and thank you Slade. The raffle raised over \$1,000 getting our 2010 season off to a great start.

If you reside in California and would like to buy raffle tickets to support the Ocean of Hope, you can send checks made out to the Sarcoma Alliance to: Aimee Spector c/o Ocean of Hope 1714 Havemeyer Lane, Redondo Beach, CA 90278 Tickets are \$3, two for \$5, four for \$10... and fifty for \$100. No reason not to get at least one! Thanks for sending a self-addressed stamped envelope. There are only 2000 tickets being sold, so the more you buy, the better your chances of winning!

PADDLEBOARDERS

Nick Alford
Peter de'Avila
Jason Howerton
Fred Sardisco
John Simich
Brad Thomas



OUTRIGGER TEAM

Katy Arnold
Jeane Barrett
Leah Beebe
Shannon Crystal
Jean Geddes
Lise Fernow
Alice Haas
Dani Hart
Jessie Kennedy
Kim Lanie
Tanya Muhle

Kellie Lancaster

Laurie Parker
Agnes Regezkey
Jill Schooler
Aimee Spector
Shienlu Stokesbary
Heather Suskin
Lorie Vos
Suzanne White
Lisa Wilson

BEACH TEAM

Arthur Beckert
Jeff Bradbury
Joan Darling
Disney Voluntears
Betsy Haas-Beckert
Ade Lawal
Philip Leider
Brenda Mooney
Joan Mousseay

Dave Murphy

Ali Olig
Janine Padia
Fred Sardisco
Ellen Silver
Aimee Spector
Tracey Talley
Marites Tullius

AND THANK YOU

Barney Tong,
Fuji Film, and
Samy's Camera
for another great
year of pictures.



Letter from the President **Joan Darling**

When the Sarcoma Alliance began over ten years ago, it was very much a California-based organization. But people affected by sarcoma live everywhere, and in recent years the Alliance has truly become a national, even international organization.

When I first joined the Board of Directors, only two of us (from Nebraska and Illinois) were from outside California. Since then, we have added Board members who reside in Texas, Mississippi, Florida, and Indiana. Our newest Board of Directors members continue that trend. Within the last year, we are pleased that Deborah Gates from Poulsbo, WA;

James Johnston from Mount Kisco, NY; and Jennifer Pavelka from Cincinnati, OH, have joined the board. We are extremely happy to have such a well qualified and geographically diverse group help in providing our unique and essential services.

The Sarcoma Alliance has awarded Assistance Fund grants to people in almost every state in the US, and our Discussion Board has over 1,200 members from around the world. If you know anyone anywhere in the world who has been affected by sarcoma and needs assistance, support, or information, send them our way; the Sarcoma Alliance is here for them. 🌟

A Note from Amy Blythe

I found a decent-sized lump in the right side of my groin back in June of 2009. I ignored it, until it became larger, painful and the whole area was swollen (this was at the end of September 2009). I saw my gynecologist, thinking it might be that sort of a problem. She did an ultrasound and couldn't figure out what the lump was. She then referred me to an oncologist. The oncologist thought I had a cyst and a hernia. So, he sent me to a general surgeon to have the cyst removed and the hernia repaired.

I had my first surgery at the end of October 2009 to have the "cyst" removed. Once it was sent to pathology, I got news that it wasn't a cyst. I was diagnosed with myxofibrosarcoma, five days before my 26th birthday. The "cyst" was actually a burrito-sized tumor. I was then sent to the H. Lee Moffitt Cancer Center in Tampa, FL. They have a Sarcoma Clinic there, so I already felt hopeful. After another CT scan and some more testing, it was decided that I would have a second surgery. My second surgery was scheduled three days before Christmas of 2009. They rebuilt my abdominal wall, took out more tissue and lymph nodes, removed scar

tissue from the first surgery, and replaced the mesh that was put in place for the hernia during the first surgery. Thankfully and miraculously, I was able to leave the hospital on Christmas Eve.

On January 4, 2010, I got the pathology results from my second surgery — they got it all! No signs of cancer in everything they removed. I'll be getting CT scans every three months, but for now I am in the clear. For anyone going through any type of sarcoma, keep your head held high, stay positive (even though it's REALLY HARD), and keep the faith. 🌟



ANNOUNCEMENTS

Sarcoma support groups meet regularly in Los Angeles, CA; Portland, OR; Greenville, SC; Houston, TX; and central Wisconsin. Visit our website for meeting times and other details.

The Sarcoma Alliance offers a live chat room at www.sarcomaalliance.org under Support. Open 24 hours a day. Drop by any time you need support, encouragement, or just want to talk to others. We also offer these regularly scheduled chats: Sunday, 8–10 p.m. EST and Wednesday, 9–11 p.m. EST with Dave Murphy, Sarcoma Alliance board member.