



# Letter from the President

My messages are usually ones that draw upon your emotions and remind you why the Sarcoma Alliance is such a needed organization in the lives of people affected by this dreaded disease! This message will have a different focus — it's our way of letting you know that we are creating other methods to reach out to you so that you know, "You Are Not Alone". In addition to the Discussion Board we have on our website, we've also created a Facebook ([www.facebook.com](http://www.facebook.com)) page for everyone to link into. This is a way to reach out to different people of different ages who might be more comfortable with those technologies and social networking systems. OK, you guessed it. I'm talking about people way younger than myself! But, since sarcoma is a common pediatric cancer and indeed 'teens' and young adults are a large population who are confronted with this cancer — we need a way to reach them. So check out our pages and become our friend! We also feel that we could better

utilize email as a way of communicating with you more often and to keep you up to date with what's happening in the sarcoma community. Therefore send us your email address. Write to [info@sarcomaalliance.org](mailto:info@sarcomaalliance.org)

Did you know that July is Sarcoma Awareness Month? On Sunday, July 27th we are going to have a nationwide Sarcoma SHOUT OUT! At 6PM EDT, 5PM CDT, 4PM MDT, and 3PM PDT — put on your best sarcoma gear and step outside. Shout out — any phrase related to sarcoma! Just as the Peter Finch character did in the 1977 released movie, Network, when he shouted, "I'm sick and tired and I'm not going to take it any more." Then take a photo of yourself, your family, your friends and POST them on our MySpace or Facebook pages.

We'll send you a reminder — we just need your email!

*Ellen Silver*

## sarcoma alliance

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### 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](http://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.*

- **July 2008** Sarcoma Awareness Month
- **July 27, 2008** Sarcoma Shout Out (see President's Message)
- **August 24, 2008** Ocean of Hope Celebration, Manhattan Beach, CA

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

2008 Volume 7 No. 1

## Gynecological Oncologists Welcome Sarcoma Advocacy

by Suzie Siegel

Gynecologic oncologists welcomed the Sarcoma Alliance to their 39th Annual Meeting in March in Tampa. For the first time, the Sarcoma Alliance had a table in the exhibit hall, and our organization and its mission were listed in material distributed by the Society of Gynecologic Oncologists ([www.sgo.org](http://www.sgo.org)).

During the conference I was able to talk with many physicians about sarcoma and the advocacy community. A prominent gyn oncologist thought uterine leiomyosarcoma (ULMS) was completely different from LMS outside of the gynecologic area. He had never heard of sarcoma departments at cancer centers, nor did he know about SARC (Sarcoma Alliance for Research through Collaboration at [www.sarcrtials.org](http://www.sarcrtials.org).) He saw no point in a gyn onc talking to a medical oncologist in a sarcoma department. Another gyn onc who doesn't do chemotherapy had never heard of the c-kit mutation or Gleevec. One doctor was reluctant to take a pamphlet, saying there's little that can be done for ULMS. A few others expressed sadness, and perhaps futility.

But many others take an aggressive approach to sarcoma, and welcomed pamphlets, pins, pens and wristbands. A few put on ribbons or wristbands right then. A common comment was: "I've got a patient who will be really interested in this!" A Brooklyn doctor loaded up on merchandise, saying LMS is so prevalent in the New York City area that someone should do a study. A doctor from West Virginia said the same. I assured doctors from outside the United States that their patients could use our services if they read English and have access to the internet.

Coding for insurance reimbursement continues to be an issue. Some health-care professionals code sarcoma by the site of origin, instead of using codes for "soft-tissue sarcoma." This can result in the denial of treatment. Another issue is aromatase inhibitors for LMS patients. Some doctors prescribe these drugs, while others await further study.

Some of the gyn oncs research sarcoma. Although the meeting's agenda listed no discussions of sarcoma, at least 14 posters mentioned it. Following is a summary of these studies.

*(Continued on page 11)*

# International Sarcoma Patient Advocate Network

by Matt Alsante, Arthur Beckert, & Melissa Hill

## Mission Statement - March 2008

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 our strengths and diversity.

## Introduction

The International Sarcoma Patient Advocate Network (iSPAN) held its second meeting on October 31, 2007 prior to the annual meeting of the Connective Tissue Oncology Society annual meeting in Seattle, Washington. iSPAN is open to all patient advocacy organizations and committed individuals with the goal of fostering communication and collaboration to improve the lives of those diagnosed with sarcoma. iSPAN serves as a common voice to support sarcoma patient advocacy, legislation and research. This year over 20 individuals met representing over a dozen organizations. Additionally, the meeting was generously supported by CTOS and by Novartis Pharmaceuticals, Inc.

The meeting began with a brief presentation from Arthur Beckert summarizing the history of iSPAN and the goals the meeting. One tangible outcome of the first meeting of iSPAN was the first comprehensive directory of sarcoma organizations. He hoped that advocacy groups would agree that many issues could be better addressed if sarcoma advocacy groups would work together. These include raising awareness, assuring that all sarcoma patients receive the best care in the most appropriate setting, increased funding for research, giving more flexibility for drug research and approval for rare diseases, tissue banking, and patient registry.

## Welcome

Chappie Conrad, MD an orthopaedic surgeon at the Seattle Cancer Care Alliance and founder of the Northwest Sarcoma Foundation welcomed the group.

He complemented everyone's efforts and believes that it is very important for the provider community to support and work closely with patient advocates. Although there have been improvements in sarcoma care, he believes that the grading system needs to improve and there needs to be new and better drugs.

## Raising Sarcoma Awareness

The group next talked about raising awareness about sarcoma in general and about the unique needs of sarcoma patients. Currently there are a number of sarcoma awareness events in the US, mostly in June and July. One step in raising awareness would be for the sarcoma community to agree on a common time for awareness events. Bruce Shriver of the Liddy Shriver Sarcoma Initiative gave a presentation about Team Sarcoma in July and the incredible growth this has had during the past few years.

The group agreed that designating July as Sarcoma Awareness Month would give everyone a long period of time to put together events to bring attention to sarcoma. Everyone agreed that there was no pressure or need for any organization to modify their existing calendar. However it is hoped that organizations would organize events and activities that would generate local, regional or national press coverage. These events could be coordinated with existing activities such as Team Sarcoma or could be held on their own. Events could include walks, runs, picnics, educational session at hospitals, and even include governmental proclamations of July of Sarcoma Awareness Month.

## ARIAD – Upcoming Phase III Trial of Deforlimus

Camille Bedrosian, MD of ARIAD next gave a presentation on the upcoming Phase III trials of Deforolimus (formally AP23573). The trial will be open to those with metastatic soft tissue and bone sarcomas. Deforolimus is an mTOR inhibitor that affects cell growth, division, metabolism and angiogenesis. By blocking mTOR the cancer cells will starve and die. ARIAD recently received FDA approval for the Phase III study design and is starting to centers through out the world to conduct the clinical trial. They hope to enroll 650 patients at 125 sites. More information can be found at [www.succeedtrial.com](http://www.succeedtrial.com).



The group agreed that designating July as Sarcoma Awareness Month would give everyone a long period of time to put together events to bring attention to sarcoma.

### Advocacy Initiatives

Mark Thornton, MD next gave an overview of the Sarcoma Foundation of America and its efforts to improve the FDA's drug approval process for rare diseases. SFA along with the Alliance Against Alveolar Soft Part Sarcoma has petitioned the FDA to modify its drug approval process for rare diseases. This "Citizen's Petition" can be approved through an administrative process and does not need changes in current regulations or law. Briefly this petition outlines a streamlined process for testing and approval for new agents for rare cancers. (Please contact the Sarcoma Alliance if you would like more information about this initiative)

Estelle Lecointe, AFPS, Ensemble contre le GIST gave a presentation on activities of the GIST community in France. The most important is their support of two studies.

### What's Next?

Everyone agreed that it is important that the advocacy community work together on the many issues of common interest. It is equally important that iSPAN serves as a vehicle of support for the sarcoma community so that every organization can continue to grow and prosper, retain their independence and stay true to their mission. ✨

# Grants

During the past six months, the Sarcoma Alliance has been the recipient of three generous grants. We are truly thankful for the support of these organizations and their belief in our mission and work.



For the second time Ariad has awarded a \$20,000 grant in support of the Alliance's Peer to Peer Program. This program launched in 2005 now serves over 400 individuals from over 40 states and a dozen countries. This grant will allow us to increase outreach activities and make ongoing program changes to improve the administration of this important program.



In January Genentech awarded a \$30,000 grant in support of additional upgrades to the Sarcoma Alliance website and increased focus on pediatric issues. One of the first results of this grant is the Guidelines for Pediatric Care that has been approved by the Sarcoma Alliance Board of Directors and is now on our website. Look forward to many exciting changes during the coming year.



Novartis awarded a \$5,000 grant in support of a sarcoma advocacy group meeting held in conjunction with the Annual Meeting of the Connective Tissue Oncology Society. (see story on page 4). Novartis first supported this activity in 2005. A major result of this support has been the establishment of the International Sarcoma Patient Advocate Network and a comprehensive directory of sarcoma organizations throughout the world. A copy of this directory can be emailed. Send your request to [abeckert@sarcomaalliance.org](mailto:abeckert@sarcomaalliance.org).



### Meet our new board members

#### ADE LAWAL

Ade Lawal is a Director of Service at GE Healthcare. He resides in the greater Los Angeles area and is responsible for taking care of diagnostic imaging equipment such as CTs, MRIs and X-Ray machines for many hospitals and outpatient imaging centers. Prior to joining the Sarcoma Alliance, Ade has been involved with several non-profit boards particularly those that serve families and children going through life's challenges. Ade has a Bachelor's of Science in Commerce from the University of Virginia and an MBA from Harvard Business School. He enjoys running, cooking and performing arts. Although he once performed in a Broadway style show, he generally sticks to his day job.

#### SUZIE SEIGEL

Suzie Siegel spent more than 18 years as a full-time newspaper reporter and editor at newspapers in Little Rock, New Orleans and Tampa. She has a bachelor's of journalism degree from the University of Missouri and a master's in women's studies from the University of South Florida. She's in remission from metastatic leiomyosarcoma and spends much time volunteering on behalf of sarcoma patients. Last year, the Alliance named her consumer of the year. She participates in peer-to-peer programs for the Alliance as well as the M.D. Anderson Network. She volunteers for the H. Lee Moffitt Cancer Center in Tampa, where she lives. As a sarcoma advocate, she has attended three meetings of the Connective Tissue Oncology Society and two meetings of the Society of Gynecologic Oncologists. She has written about those meetings and other subjects for the Alliance, Leiomyosarcoma Direct Research, and the Liddy Shriver Sarcoma Initiative. Her personal experience with sarcoma can be found at [www.sarcomaalliance.org/Stories/stories25.html](http://www.sarcomaalliance.org/Stories/stories25.html) 🌟

### The Alliance Thrives

This past year the Alliance worked hard to provide better services to those who face a diagnosis of sarcoma. And this was accomplished through hard work and generosity of so many wonderful people.

Our newly launched website makes navigation easier for users and allows the site to maintain current with relevant and timely information for the sarcoma community.

Our Peer to Peer network continued to grow, and Hand in Hand: the Suzanne R.Leider Memorial Assistance Fund awarded a record number of grants to individuals to seek second opinions from sarcoma specialists. The growth of these two programs demonstrates that the Alliance is reaching those in need and providing valuable services.

Our accomplishments are due to a committed Board of Directors, staff, volunteers, and scores of generous donors who provide the financial means for us to thrive. This issue of *The Sarcoma Alliance News* is dedicated to those who believe in our mission and support us with generous donations. We value every donation and work to assure that every dollar is spent wisely helping those in the sarcoma community from the newly diagnosed to long term survivors, to their families, caregivers and friends.

From the bottom of our hearts, thank you! 🌟



### Ocean of Hope – Attention All Los Angeles Area Boaters

The Catalina Classic, a 32 mile paddleboard race from Catalina Island to Manhattan Beach, will be held on August 24th. This is the Alliance's biggest fundraiser and one of the most fun ways to contribute to the sarcoma community. For those of you who would rather be on the water than hanging out on the beach, we have a fantastic opportunity for you. All paddlers must have an escort boat accompany them throughout the race. In past years some paddlers have had to withdraw from the race because they could not secure an escort boat. In 2008 we don't want this to happen. If you have a boat and would like to stay at Catalina Island the night of August 23rd, spend the day on the ocean escorting a paddler on August 24th, and are interested (or even think you might be), please contact Arthur Beckert at the Alliance office or by email at [abeckert@sarcomaalliance.org](mailto:abeckert@sarcomaalliance.org). 🌟

#### SUCCEED CLINICAL TRIAL ANNOUNCEMENT for people diagnosed with metastatic sarcoma

ARIAD Pharmaceuticals has launched an international Phase 3 clinical trial of deforolimus, a novel mTOR inhibitor, in patients with metastatic soft-tissue and bone sarcomas. Patients who are currently receiving chemotherapy for the treatment of their sarcoma may wish to discuss the SUCCEED trial with their doctors to see if it may be right for them. For more information about the trial or to find a trial site nearby, you can visit [www.succeedtrial.com](http://www.succeedtrial.com) or call toll-free 1-877-621-2302 or internationally 1-617-621-2302 or email at [ClinicalTrials@ARIAD.com](mailto:ClinicalTrials@ARIAD.com)

# First Annual Putts for Ped Charity Golf Outing

by Jennifer Nellany



Friday, October 5, 2007, started off as a misty morning, with a more unforgiving rain storm looming. Of course, when you have worked so hard to plan an event, you realize that you can control everything but the weather, and all you can do to affect the weather is pray. Friends and family of Michael Pedrick gathered early to set up and finalize all the last minute details of the First Annual *Putts for Ped* golf outing, proceeds to benefit the Sarcoma Alliance. I and my fellow organizers Rick Brown, Mikey Mitchell, and Brian Weyman, friends of Michael's, scrambled around to get everything in place for golf. Michael's mother, sisters and nieces did their part in organizing the items to be auctioned after the outing. For this group, anything less than perfection was unacceptable!

As the golfers arrived, the rain let up, and the mist was replaced with a sense of unity and bonding among the group, almost all of whom had known Michael, some only as an acquaintance, others as a brother, uncle, or life-long friend. Michael was initially diagnosed with synovial cell sarcoma in September 1999, and after radiation and chemotherapy, his cancer had been defeated. From the time of his diagnosis, the Sarcoma Alliance, which at the time was basically an email chain, was a valuable source of information and support. The only downside was that I felt guilty when people I became close with lost their own battle to sarcoma, because Michael was doing so well.

Michael and I met in our senior year of high school and were together since then. We finally got married in February 2005 and we thought we were on top of the world. Shortly after we returned from our honeymoon, Michael mentioned he was having trouble breathing, so he got a CT scan which showed that his cancer had returned. This time, the round was awarded to cancer, and he lost his battle on July 25, 2006. Since that day, there has been a huge empty hole in the world, and every person at the golf outing has been doing their part to fill that hole with memories of Michael. This golf outing was a way for us to all be together so that maybe, for one day, the hole didn't seem so big.

The remainder of the day brought a lot of laughter and some very bad golf while people remembered Michael and his fondness for participating in golf outings just like the one being held in his memory. The consensus of the attendees was that they played the worst golf of their lives, but they had the most fun they have ever had at a golf outing. The group of organizers agrees that this constitutes a raving success! The success was made even sweeter by the fact that we raised almost \$7,000 for the Sarcoma Alliance. We look forward to the Second Annual *Putts for Ped* golf outing and to raising even more money for the Sarcoma Alliance in 2008! ☀

## Sarcoma Alliance News to go Electronic

To bring you the latest from the Sarcoma Alliance in a more timely and efficient manner, we will start to distribute our newsletter electronically. Please send your email address to [info@sarcomaalliance.org](mailto:info@sarcomaalliance.org); in the subject line put newsletter and in the body of the email put the mailing name and the city where the newsletter is sent. The Alliance treats all our information as highly confidential and will never make any personal information available to anyone.

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## Gynecological Oncologists

(Continued from cover)

### Radiographic Studies

Doctors at Columbia University Medical Center in New York concluded that the cost of CT scans didn't justify their use before surgery for uterine cancers, except in high-risk cases such as sarcomas. Doctors who saw a CT before surgery were more likely to handle a patient differently if she had a uterine sarcoma. An issue for patients is that doctors may not know a tumor is a sarcoma before surgery.



Korean doctors at the Asan Medical Center in Seoul studied uterine sarcoma. "PET or PET/CT was highly effective in discriminating true recurrence in patients with suspected recurrence and was highly sensitive in detecting recurrence in asymptomatic patients."

### Predicting Outcomes

A University of Miami study found ethnicity has little value in predicting stage, grade, histology, recurrence or survival of women with uterine sarcoma.

Doctors at Stanford and the UCSF, and UC-Irvine analyzed 831 cases of endometrial stromal sarcoma. Removing or preserving ovaries did not affect survival, nor did adjuvant radiation therapy. The poster also noted: "The excellent survival in patients with grade 1 and 2 disease of all stages supports the concept that these tumors are significantly different from grade 3 tumors."

At Baylor College of Medicine and the M.D. Anderson Cancer Center, both in Houston, doctors examined uterine smooth-muscle tumors of uncertain malignant potential, called STUMP. They found that recurrence was more likely in younger women, and they urged more research on menopause status and the use of hormones.

Another Baylor study found that removing ovaries did not affect the survival of young women with stage 1 ULMS. It suggested surgeons leave ovaries alone if they look normal.

A ULMS study at Stanford and UCSF found metastases in the lymph nodes of 6.6 percent of the patients who had their lymph nodes removed, and those patients didn't live as long. Removing ovaries didn't appear to affect patients' survival.

UC-Irvine did a 20-year review of ULMS patients and found that they were less likely to have a pelvic recurrence if they had radiation after surgery. Patients who got radiation also were a little more likely to make it to the 5-year mark, but overall, they didn't live any longer than women who didn't get radiation. Patients who got

Gemzar plus Taxotere lived longer than those who got other forms of chemo.

This last poster underscores the need to update the uterine sarcoma pages on the Women's Cancer Network ([www.wcn.org/](http://www.wcn.org/)), which were last updated in the fall of 2006. They still mention only two chemo drugs for LMS: Adriamycin and Temodar. The site was created by the Gynecologic Cancer Foundation ([www.thegcf.org](http://www.thegcf.org/)), which is affiliated with the SGO. The GCF also published the 2007 State of the State of Gynecologic Cancers. The report is geared toward initial treatment. Reading the report, a patient might not realize she needs routine imaging to check for recurrences, and if the disease does recur, she might benefit from chemo or more surgery.

As is true for many cancer publications, "cancer" often refers only to carcinoma in the GCF report. A woman like me, with a gyn cancer in a site other than the uterus, might be confused by the list of causes, treatments, etc.

For more information on gyn sarcomas, please see my 2006 articles at:

[www.sarcomaalliance.org/News/news3a3.html](http://www.sarcomaalliance.org/News/news3a3.html)

[www.liddyshiversarcomainitiative.org/Newsletters/V03N03/nccn.htm](http://www.liddyshiversarcomainitiative.org/Newsletters/V03N03/nccn.htm) ✨

## OTHER NEWS

### Charlie Lustman



Singer/songwriter/producer and cancer survivor, Charlie Lustman, has recently completed the first pop record about a cancer experience. Charlie's battle with osteosarcoma in his jaw bone didn't stop him from creating his inspiring collection of uplifting and emotional pop songs. The album entitled, *MADE ME NUCLEAR*, will be available this summer 2008 at [MadeMeNuclear.Com](http://MadeMeNuclear.Com). He will be performing his songs at many venues this summer raising awareness about sarcoma and the Sarcoma Alliance. Information will be posted on our website.

### Charitable Auto Resources, Inc.



The Sarcoma Alliance is pleased to announce a new way to support us. The Alliance is partnering with Charitable Auto Resources, Inc. (CARS) to receive donations of automobiles. With a simple phone call to 877-537-5227 or email [donations@charitableautoreources.com](mailto:donations@charitableautoreources.com), you can arrange to have a car picked up and sold. You will get a tax deduction, and the Sarcoma Alliance will receive the proceeds of the sale.