

THE SARCOMA ALLIANCE NEWS

2006 Volume 5 No. 3

Ocean, Land – Two Worlds, One Purpose

Pictures by Barney Tong courtesy of Fuji Film

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6:00 AM

It is still dark when the gun goes off and over 90 paddlers slide into the Pacific, into the glassy, smooth harbor. Conditions are perfect for a long glide. This is going to be great. (The paddlers actually woke up at 4:40 AM, but that is too early to start this story). Within ten minutes there is a stiff breeze and a chaotic chop. The glide is gone. Each paddler must dig hard, using powerful arm strokes to propel their paddleboards across the surface of the water and fight to get through every foot of the next 32 miles. This is going to be a long, hard day.

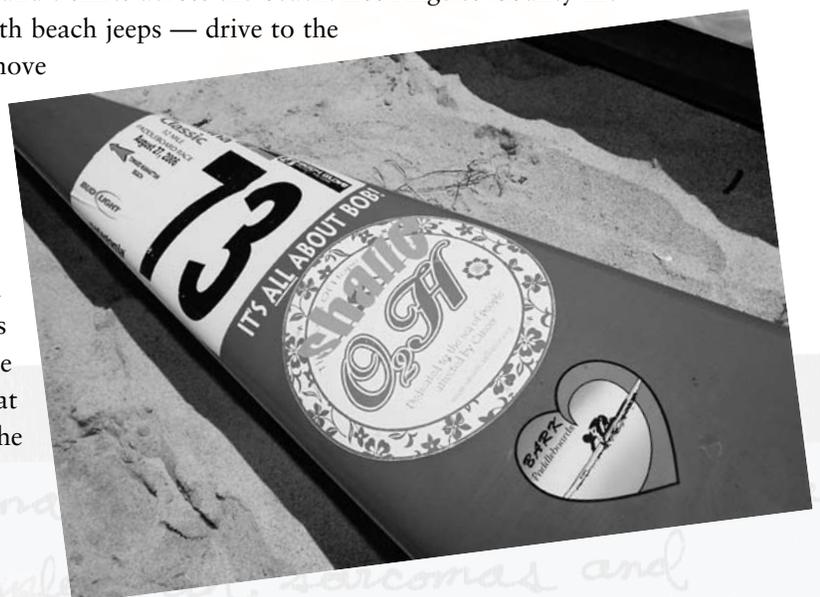
Most everyone on the land is snuggled in bed or maybe having a cup of warm coffee, reading the paper. Ah, this is the life.

8:30 AM

Two and a half hours later with a relentless breeze, whitecaps and an ugly sea offering no rest, the paddlers are muttering to themselves, "this is a very hard and very long day."

The Sarcoma Alliance beach crew members arrive with packed cars and begin to carry tents, drinks, foods and t-shirts across the beach. Los Angeles County life-guards — angels with beach jeeps — drive to the parking lot and move most of the heavy items. Many have helped out in past years and know the drill. The tents go up, tables arranged and food and towels are readied for the pod of paddlers that will arrive later in the morning.

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Beyond Face Value By Terry Healey

AT 20 YEARS OLD, LIFE WAS SMOOTH SAILING. I was a junior at the University of California at Berkeley, a confident, athletic, successful student. Some even considered me handsome. I was living life on “easy street.”

But that year, several people began to ask if something was wrong with my nose. My right nostril appeared to be flared out. I eventually took notice of a bump pushing against my right nostril, and when it didn't go away, I made an appointment with a doctor. After telling me it was probably a pimple, when it didn't disappear three weeks later, he finally suggested a biopsy.

It turned out that I had a tumor, a rare fibrosarcoma. I would later discover how lucky I was that I got the right diagnosis, given how few of these tumors pathologists see. The bulk of the tumor was removed during the biopsy, but I underwent surgery to excise any remaining tumor cells. Fortunately the procedure was minor, and with only a few sutures, I returned to classes looking like I had been in a fight with someone, not something.

But six months later, I discovered a new lump in the same nostril. Then my cheek began tingling. Numerous specialists confirmed that my previous, supposedly unthreatening tumor had procreated a horrific, life-threatening malignancy. Prescribing more surgery, my doctor warned that I might lose part of my nose, but his main concern was saving my life. I suppose I was too young to contemplate dying, but the notion of disfigurement was devastating.

I awoke from surgery to find that half of my nose had indeed been removed, along with half of my upper lip, muscle and bone from my right cheek, the shelf of my eye, six teeth and part of my hard palate. My doctor promised to make me ‘streetable’ before I left the hospital. What I didn't realize then was that this was his way of preparing me for a life of disfigurement.

As I re-entered the real world, I noticed adults staring and children pointing — and sometimes laughing — at me. My hospital room had protected me; outside of it, I was vulnerable and exposed. Of course I cared what other people thought of me; I relished the admiring looks the old Terry had received. Now I was petrified of potential reactions to the new Terry.

During the following months, I encountered many friends whose occasional and inadvertently negative reactions left an indelible mark on me. Even worse, radiation treatments were shrinking my facial tissue, magnifying my deformity. My self-esteem sank increasingly lower, and I constantly sought reassurance from others: “Do my looks bother you?” “How could you like me?”

Five years and 20 reconstructive surgeries later, I was still plagued with insecurity. During my last procedure, I met a woman receiving treatment at my hospital. We began dating, but after hearing me ask — for the umpteenth time — how she felt about my looks, she ripped into me. The bulk of my problem, she informed me, was not my physical appearance, but my emotional insecurity. Her honesty helped me realize that my mental and emotional scars were far more disfiguring than my physical ones. Once I got over the devastation that she was no longer interested in me, I began to realize how lucky I was that she had highlighted my greatest weakness. With a fresh perspective, I realized that surgery wasn't something I could control. What I could control was focusing on rebuilding what was inside.

I began examining myself from the inside out and used prayer and support from loved ones to boost my spirit and self-esteem. I volunteered at The Wellness Community, a cancer support organization, and discovered that helping others is great therapy: I felt progressively better as I offered inspiration and hope to those coping with cancer. With time, my emotional pain subsided.

Altruism seemed to be the greatest form of therapy. I began to feel better about myself as I realized that I could bring tremendous inspiration and hope to those coping with cancer. Over time, the pain I felt from being an outcast subsided.

We all wrestle with insecurity. For me, it took something devastating to recognize that battle scars make people interesting and wise; trauma helps us appreciate life and prepares us for its inevitable adversities. Today I am thankful for who I am — a much stronger and wiser person than the old Terry. I am grateful for my experience because I appreciate every day of my life, and I am more forgiving and tolerant than ever before.



What I learned I hope to teach others.

- Each of us has the ability to take control of our lives. We have to learn to focus on what we can control, and stop worrying about what we cannot control.
- We owe it to ourselves to surround ourselves with people we trust. Without trusting my family, friends, and medical team, I wouldn't have had the positive attitude necessary to carry on.
- We can all face our challenges, but we need to focus on the most pressing issues so we don't get overwhelmed with all that we want to improve about ourselves.
- And finally, we need to be aware, alert, attentive and more accepting of one another, because we never know in life who or what will impact our lives and inspire us to achieve things we never thought possible.



I remain cancer-free 20 years after treatment. I published a book about my triumph in February 2006, called *At Face Value*. I am also a motivational speaker, and though my primary business is consulting, speaking has proven to be the most therapeutic part of my recovery. I learned a lot at a very young age and am grateful for those gifts and lessons that I hope I can communicate

to people faced with challenges and adversity in their own lives.

*Terry Healey is a technology marketing strategy consultant. He is also an author and a motivational speaker. You can contact him via email at terry@terryhealey.com. For more information about his speaking and his recently released book, *At Face Value: My Triumph Over A Disfiguring Cancer*, please visit his website www.terryhealy.com.* 🌻

Executive Director's Corner

Earlier this year a major milestone in the fight against cancer was reached — for the first time, the number of American lives lost to cancer declined. This is a remarkable accomplishment, particularly in light of our aging and growing population.

Cancer survival has doubled in the past 20 years — today, more than 10 million Americans are alive after facing a cancer diagnosis. More than 75% of children with cancer are alive at least five years after their diagnosis.

After years of strong national commitment to biomedical research, and a doubling of the National Institutes of Health budget between 1998 and 2003, national research funding has taken a sudden dismal turn.

The budget being proposed by President Bush, NIH funding will remain roughly flat at \$28.6 billion for fiscal year 2007. In reality, the NIH budget will drop nearly 4 percent when adjusted for inflation. The proposed budget of the National Cancer Institute alone will suffer at least \$40 million in cuts.

Unfortunately, discoveries in these areas require expensive advanced technology. Fewer of the most promising grant proposals are being funded, and grants that are being awarded are much smaller.

If President Bush's proposed budget passes, opportunities for treating, preventing and eliminating cancer will, at best, hold stagnant. At worst, cancer deaths will begin to rise again. This could have particularly dire consequences for sarcoma research since it already gets such a small piece of the pie. We can't let that happen. Yet, it will happen unless we reaffirm our commitment to support

biomedical research. Please support increased funding for NIH and the National Cancer Institute by contacting your local Representative and Senator.

P.S. In the last issue I recognized and thanked individuals who made extraordinary contributions to the Alliance in 2006. I have to add Rachel Sherman, a sarcoma survivor who is an inspiration and leader for everyone around her. Following is her story, provided to us by Mort Sherman, her proud Dad. Thank you, Rachel.

Rachel had an angiosarcoma removed from her left breast in June, 2004, when she was 20 years old. Reconstruction took place at the same time. She returned to Muhlenberg College for her senior year and made Dean's list both semesters.

During the spring of her senior year, the Cherry Hill, NJ, community paid her tribute through a program called "Rising Stars" in which graduates of the Cherry Hill community performed as part of a fundraiser for ovarian cancer and for The Sarcoma Alliance.

Following her graduation, Rachel went to Portland, Oregon, for training by a company called Game Face. Immediately following that training, she was hired as part of the front office administration by the Brockton Rox, an independent minor league baseball team. She has been recognized as the top salesperson this year.

Volvo International awarded Rachel one of 50 worldwide honorary mentions during its annual Volvo Heroes recognition.

She lives in Brookline, MA, and is beautiful, smart, fun to be around, and a full of joy. She continues to be our center and our inspiration. 🌻

The Role of the Pathologist and Tertiary Care in the Diagnosis and Treatment of Sarcomas

by Andrew Horvai, M.D. Ph.D.

For patients with sarcomas it is important to be seen by physicians who are expert in the diagnosis and treatment of sarcomas. These physicians include medical oncologists, surgeons, radiologists and pathologists. Because sarcomas are rare and often difficult to diagnose, the role of the pathologist in assuring optimal outcome is extremely important.

The therapy for any sarcoma should involve the timely delivery of appropriate treatment in a caring and supportive environment. The following article highlights the importance of the tertiary care center in the treatment of both bone and soft tissue sarcomas. As a Pathologist with a special interest in sarcomas, I will particularly emphasize the difficulties posed in the diagnosis of these rare tumors.

In health care, *tertiary care* refers to centers, often affiliated with major university hospitals or research institutes, that have personnel and facilities for very specialized diagnosis and treatment. In contrast, *primary care* focuses on general health care and prevention that, in turn, may refer patients to *secondary care* specialists.

The treatment of sarcoma, whether from bone or soft tissue, foremost requires accurate diagnosis. The details of treatment modalities are beyond the scope of this article, but in general, treatment options range from observation (in the case of a purely benign lesion) to aggressive surgery, chemotherapy and/or radiation therapy. An accurate diagnosis, in turn, requires a collaborative effort between the clinician who is most familiar with the patient, the radiologist who interprets imaging findings (X-rays and other studies) and the pathologist who

examines tumors both with the naked eye and under a microscope. Based on the appearance of the tumor, combined with the clinical and radiology findings, the pathologist renders a diagnosis that will ultimately guide treatment.

Sarcomas pose a particular challenge to diagnosis for a variety of reasons, but most notably because of their rarity: sarcomas represent less than 1% of all cancers.¹ The basic principles learned during a pathologist's training to distinguish benign from malignant are derived largely from the vastly more common cancers such as lung, colon and breast. Unfortunately, some of these principles do not directly translate to the sarcomas. More specifically, several entities that may appear malignant microscopically follow an entirely benign course: the so-called *pseudo-sarcomas*. One such example is *nodular fasciitis* (pronounced *fah-shi-eye-tis*) a prototypical pseudosarcoma that is occasionally misdiagnosed as a malignancy because of microscopic appearance. Conversely, some types of tumors that appear relatively harmless under the microscope and are thus misdiagnosed as benign, actually follow a malignant course with potential for metastasis.

Furthermore, sarcomas currently include a vast number of distinct entities, with classification that is in constant flux as new molecular techniques become available. The current World Health Organization (WHO) classification of soft tissue and bone tumors recognizes some 130 different diagnoses² and even this does not include some rather large categories of tumors.

Today, the diagnosis of some sarcomas requires special studies to demonstrate specific abnormalities within the chromosomes of the tumor cells. Synovial sarcoma is an

example of one such cancer. While its appearance under the microscope can be confused with other sarcomas, synovial sarcoma usually has a very specific genetic abnormality involving the X chromosome and chromosome 18 that help the pathologist arrive at the diagnosis. The genetic change (X;18 translocation) in synovial sarcoma is known as a “somatic” mutation. This means that it is not passed on from parent to child, but rather acquired sometime during the development of the child. The mutation is only present in the cells of the sarcoma, but not in other cells in the body, including the eggs and sperm. Therefore, a person with synovial sarcoma cannot pass the mutation on to their offspring, nor could they have acquired it from their parents. There is evidence that the risk of developing some types of sarcomas (e.g. osteosarcoma) can be inherited from parents to offspring, but synovial sarcoma does not appear to be one of these. Of course, the techniques to detect chromosomal abnormalities have to be at the pathologist’s disposal to obtain this information.

Sarcomas of bone pose a further challenge because in no other area of pathology is the correlation between the microscopic appearance and the X-rays of a tumor more critical. In fact, pathologists specializing in diseases of bone often maintain that most diagnoses cannot be made with the microscope alone but require interpretation of the corresponding X-rays. Bone sarcomas are even rarer than their soft tissue counterparts¹ so that a dedicated association of pathologist and radiologist, both experienced in the tumors of the skeleton, is obligatory.

Fortunately, tertiary centers, such as the Comprehensive Cancer Center at UCSF, Mayo Clinic, M.D. Anderson Cancer Center and others exist specifically to meet the above challenges. Proficiency in diagnosis requires the practical knowledge gained by caring for a large number of patients with sarcoma on a regular basis. However, even a busy center with a multidisciplinary team specializing in sarcoma probably does not encounter every possible diagnosis daily. Therefore, specialists in such centers maintain rigorous investigative and teaching components to their practice. These aspects allow familiarity with the latest scientific literature, publication of new diagnostic guidelines, development of therapeutic trials, and

organization of conferences to educate primary and secondary care providers. In summary, the expertise and skills to implement the latest advances in the diagnosis and treatment of sarcomas should be sought out at centers that specialize on these rare cancers. 🌞

Andrew Horvai, M.D. Ph.D.
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10:00 AM

Now everyone knows it's a harrowing day on the water. Usually by this time the lead paddlers are well on their way, starting to head north up the coast to Manhattan Beach and the finish. This year the leaders are still a couple of miles away from the coast and the turn to head up north. Each paddler asks him/herself, "Why do I do this?" They look down on their boards and see the names: Tracey, Shoshana, Michael, Shane, Bob, Tim, Suzanne, Wendy and Susan. Some of these individuals fought sarcoma with bravery and dignity and have died but are always remembered. Others, who carry on, help those around them and remind everyone that you can live with, and sometimes even beat, a diagnosis of sarcoma. All of these names, emblazoned on the paddleboards, provide a reminder to the paddlers as to why they are doing this. Their spirits provide inspiration and courage for the paddlers to push on.

Our volunteers have set out a splendid spread of food and drink in anticipation of many hungry paddlers, spectators, and volunteers. The day is perfect. Warm but not too hot thanks to a steady ocean breeze. Now is the time to enjoy each other's company, renew old friendships, and make new connections. It is a time for Sarcoma Alliance board members and staff, survivors, caregivers, families, and friends to find comfort in each other. It is a time to learn, to feel inspired, and to share a glorious day away from the hospital, the doctor's office, or the workplace. It is a time to just let out your breath and to appreciate the wonder of being alive.

Catalina Classic 2006

Classified	Time	Classified	Time	Classified	Time
1. Kyle Daniels	5:34:07	33. Dasha/Reilly	7:18:11	51. Brian Reynolds	6:18:11
2. Jamie Mitchell	5:39:47	34. Steve Adams	7:18:11	52. Brian Reynolds	6:18:11
3. Sean Schuchman	5:54:30	35. Sam Wagner	7:18:11	53. Michael Galt	6:18:11
4. Justin Mitchell	6:02:49	36. Robyn Sauer	7:18:11	54. Robyn Sauer	6:18:11
5. Eric March	6:04:22	37. Paul Sauer	7:18:11	55. Robyn Sauer	6:18:11
6. George Piaz	6:04:22	38. Robyn Sauer	7:18:11	56. Robyn Sauer	6:18:11
7. Eric March	6:04:22	39. Robyn Sauer	7:18:11	57. Robyn Sauer	6:18:11
8. George Piaz	6:04:22	40. Robyn Sauer	7:18:11	58. Robyn Sauer	6:18:11
9. Eric March	6:04:22	41. Robyn Sauer	7:18:11	59. Robyn Sauer	6:18:11
10. George Piaz	6:04:22	42. Robyn Sauer	7:18:11	60. Robyn Sauer	6:18:11
11. Eric March	6:04:22	43. Robyn Sauer	7:18:11	61. Robyn Sauer	6:18:11
12. George Piaz	6:04:22	44. Robyn Sauer	7:18:11	62. Robyn Sauer	6:18:11
13. Eric March	6:04:22	45. Robyn Sauer	7:18:11	63. Robyn Sauer	6:18:11
14. George Piaz	6:04:22	46. Robyn Sauer	7:18:11	64. Robyn Sauer	6:18:11
15. Eric March	6:04:22	47. Robyn Sauer	7:18:11	65. Robyn Sauer	6:18:11
16. George Piaz	6:04:22	48. Robyn Sauer	7:18:11	66. Robyn Sauer	6:18:11
17. Eric March	6:04:22	49. Robyn Sauer	7:18:11	67. Robyn Sauer	6:18:11
18. George Piaz	6:04:22	50. Robyn Sauer	7:18:11	68. Robyn Sauer	6:18:11
19. Eric March	6:04:22	51. Robyn Sauer	7:18:11	69. Robyn Sauer	6:18:11
20. George Piaz	6:04:22	52. Robyn Sauer	7:18:11	70. Robyn Sauer	6:18:11
21. Eric March	6:04:22	53. Robyn Sauer	7:18:11	71. Robyn Sauer	6:18:11
22. George Piaz	6:04:22	54. Robyn Sauer	7:18:11	72. Robyn Sauer	6:18:11
23. Eric March	6:04:22	55. Robyn Sauer	7:18:11	73. Robyn Sauer	6:18:11
24. George Piaz	6:04:22	56. Robyn Sauer	7:18:11	74. Robyn Sauer	6:18:11
25. Eric March	6:04:22	57. Robyn Sauer	7:18:11	75. Robyn Sauer	6:18:11
26. George Piaz	6:04:22	58. Robyn Sauer	7:18:11	76. Robyn Sauer	6:18:11
27. Eric March	6:04:22	59. Robyn Sauer	7:18:11	77. Robyn Sauer	6:18:11
28. George Piaz	6:04:22	60. Robyn Sauer	7:18:11	78. Robyn Sauer	6:18:11
29. Eric March	6:04:22	61. Robyn Sauer	7:18:11	79. Robyn Sauer	6:18:11
30. George Piaz	6:04:22	62. Robyn Sauer	7:18:11	80. Robyn Sauer	6:18:11

11:30 AM

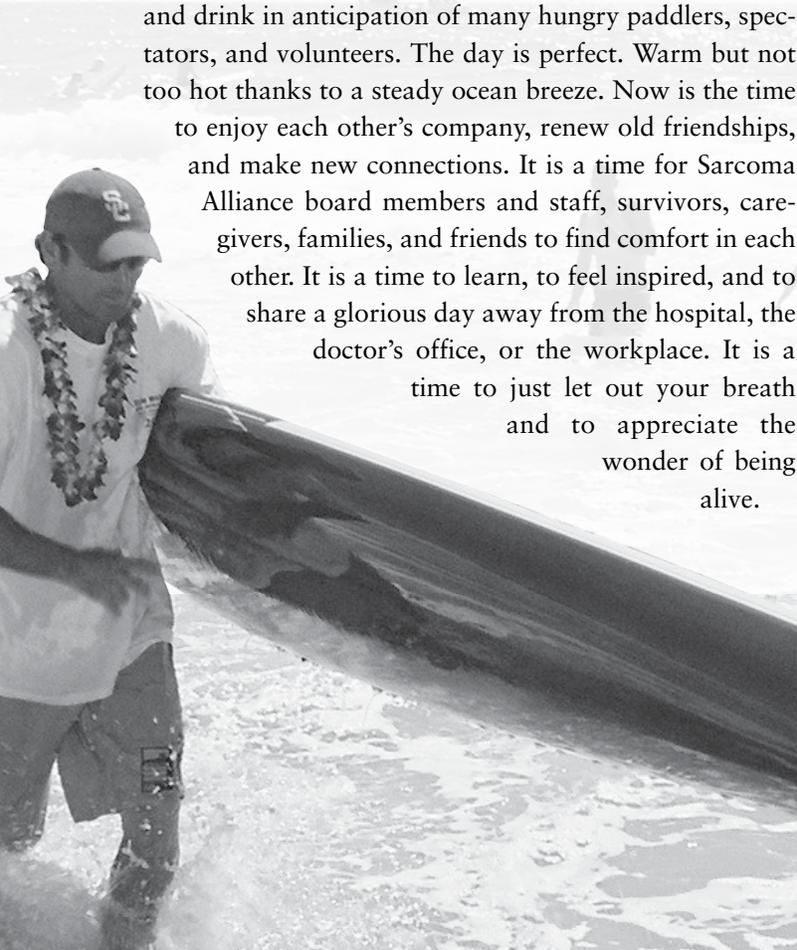
Almost there. The finish is in sight for the lead group. Shoulders hurt, eyes sting from the salt, and the rash guards have only partially done their job.

Excitement on the beach builds as the Catalina Classic announcer reports that the first paddler is due in shortly.

High Noon and Beyond

The ocean and land merge. Paddlers continue to arrive at the beach right up to the cutoff time of 3:30. All are happy and proud for they have survived a grueling race and created a bond among themselves that only those who made the journey can truly understand. Every paddler on the Ocean of Hope team who started the race finished. Smiles are everywhere. This is what the Ocean of Hope is about — inspiration, hope, love, happiness, and reflection.

The Sarcoma Alliance congratulates every paddler, volunteer, donor, sponsor and everyone who made this day such a fantastic success. A special thank you goes to Mark Schulein, Ocean of Hope team captain and leader extraordinaire, whose commitment and enthusiasm is the reason that this event is so successful each year. The final tally is not in, however to date O2H 2006 has raised over \$70,000. This is a new all time high. Since 2000, when the Ocean of Hope campaign began, this annual event has raised over \$250,000 to support the Sarcoma Alliance.



Mark Schulein



Hand in Hand: The Suzanne R. Leider Memorial Assistance Fund

The Ocean Team

Nick Alford, Joe Arancio, Mark Belanger, Jeff Bradbury, Kelly Brown, James Buckman, Jane Cairns, Jeff Cutler, Jack Hamilton, Michael Igloi, Scott Lincoln, Jim Netzer, Miles Pritzkat, Tim Ritter, Ron Roebuck, Mark Schulein, Brad Thomas, Gene Boyer



The Land Team

Arthur Beckert, Robert Chambliss, Reyna and Chris Cruz, Cathie English, Jared Holmes, Laura Kanamori, Brian and Kendra Krause, Susan Johnson, Mary Juno, Jeff Leider, Philip Leider, Susan Leider, Susan Lowenbraun, Kathy and Danielle Moncure, Dave Murphy, Michael Neumeyer, Aileen Oliver, Reggie Olivar, Florante, Linda and Albert Ortaliza, Kevin, Elisabeth and Emily Plattner, Krista Pollock, Ellen and Shoshana Silver, Liz Steinfield, Tracey Talley, Barney Tong, Christine Tope, Marites, Michael and Will Tullius, Daphne Yousem.

The Pie Team Extraordinaire

Christine Tope who kept the bellies of the entire beach full of delicious homemade pies

Bob Chambliss who much to everyone's amazement brought ice cream ☀

Our Sponsors and Donors

Anvil Steel, Dare Devil, Fuji Film, Pfizer Pharmaceuticals, the 100's of individuals who donated from their hearts in amounts ranging from \$5-\$3,500.00

Guests of Honor

- ☀ Charles Forscher, M.D.
- ☀ Sharon Leider
- ☀ Shane Lincoln

Mark Your Calendars

The Roadster Rumble returns April 21, 2007 at Joe's Garage in Tustin, CA. This exciting and magical evening benefits the Assistance Fund which provides grants to individuals seeking second opinions. We hope you will be able to join us for dinner, entertainment and auctions of a fantastic array of gifts, dinners and week-end getaways.



Follow-up

Dan Ng, President and Theresa Chu of the SF Bay Area New Century Lions present Arthur Beckert with a \$400 check for the Assistance Fund. A bowling event held in June was reported in the last newsletter.



Letter from the President

Not Just Four Words

As you log onto our website and type www.sarcomaalliance.org you are greeted by four words... *You Are Not Alone*. That is our welcoming message. Many organizations use this tagline as their clarion call to embrace their constituents. They include several cancer organizations, rape and crisis intervention programs and groups that work with people suffering from chronic headaches — to name just a few. *You Are Not Alone* means so much to so many. I watched the meaning of these four words come to life at our Ocean of Hope campaign this summer on the shores of Manhattan Beach. We came together as a sarcoma community reaching out to each other offering support, education and guidance. People active in our Peer to Peer Network met face to face for the very first time; while participants from our Redondo Beach support group met new friends and had the opportunity to mingle with sarcoma expert, Dr. Charles Forscher. On this day, people with sarcoma and their caregivers came together and proved *You Are Not Alone*. I also watched our paddlers under the leadership of team captain Mark Schulein come together to support their own community when a loved one, Shane Lincoln, was in a serious accident. The paddling community united to help and support the Lincoln family throughout weeks and months of recovery. The friends and family of The Sarcoma Alliance don't just use the words *You Are Not Alone* — they live it. We all have much to be proud of as we come together to love, help and support each other.

Ellen Silver

sarcoma alliance

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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.

■ *April 21, 2007 Roaster Rumble, Tustin, CA — A magical evening benefit for Hand in Hand: the Suzanne R. Leider Memorial Assistance Fund*