

THE SARCOMA ALLIANCE

NEWS

2007 Volume 6 No. 2

Extreme Makeover — Website Edition

Contributing Writers and Editors:

Arthur Beckert
Kim Fine
Sharon Leider
Liz Steinfeld
Ellen Silver
Russ Silvestri
Aimee Spector
Sally Thierer

The Sarcoma Alliance Officers and Directors:

Ellen Silver, President
Tracey Talley, Vice President
Jared Holmes, Treasurer
Joan Darling, Secretary
Jeff Bradbury
Denise Lapins
Philip Leider
Susan Lowenbraun
David Murphy
Kevin Plottner
Marites Tullius
Jean-Laurent Vilon
Daphne Yousem

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

The Sarcoma Alliance Staff:

Arthur Beckert, Executive Director
Pamela Cresta, Office Manager

The Sarcoma Alliance is excited to announce a new, improved website — same address but with a great new look and feel. Jean-Laurent Vilon, a member of the Alliance's Board of Directors was instrumental in taking the vision of so many people who have come to rely on its content to make it have greater appeal to both the first time visitor and long time users of the information and services the site provides.

Jean-Laurent said, "Interactive experiences happen by design, not by happy accident. They occur when creative thinking is combined with analytical discussions about the target for which the web site is designed. Here I started to focus on sarcoma patients. What do they want? Which help are they looking for? Are they looking for hope or just information or maybe both?"

The goal is a site where the information is the main focus and not the design interface itself. The easy access to information was the main concern. The result is a simple web site that has an elegant interface.

We began by looking at what information we had, how it was organized, and how users actually used the site. From this came a totally redesigned home page where users can easily find the information they need about the Sarcoma Alliance's programs and services as well as information about the diagnosis and treatment of sarcoma. Right from the home page are links to the discussion board, chat room, Peer to Peer Program and our assistance fund services. Information on sarcoma centers are more prominently displayed.

Most importantly, we wanted to put a human face on sarcoma and tell stories that connect with the audience that shows they are not alone. That's what the goal of this web site is all about.

During the coming year we will be focusing on the site content. We will be updating information where needed and adding additional content so that it is more useful to everyone affected by sarcoma. If there is information or topics you would like included please let us know. The site is yours, and we will continue to work hard so that everyone in the sarcoma community can get the information he or she needs. ☀

Ocean of Hope 2007 — Bigger Than Ever

Who Said Paddleboarding Isn't a Team Sport?

August 26, 6 AM, the paddleboarders take the first of many strokes that will take them from Catalina Island to Manhattan Beach. Some are lying on their stomachs, some are kneeling. All know that 32 miles of open ocean are ahead of them; hopefully the seas will be calm and the winds kind, but the day it is not starting out that way. Usually, the early morning brings little wind and light seas. Today, the wind is stiff and the seas are choppy. Many are thinking that this will be another challenging day on the ocean, a repeat of 2006. The strokes continue bringing them closer to the finish line; they must navigate the next six to nine hours alone with only an occasional shout of support from their escort boat. Alone, a long day lies ahead.

But they are not alone. They are members of the Ocean of Hope team. The biggest team ever. Many are racing today, some are on escort boats, some on the beach; everyone is dedicated to supporting the Sarcoma Alliance and what it represents. At the start they all can see a huge bright yellow flag emblazoned with Ocean of Hope and the Sarcoma Alliance sunflower. They all are wearing yellow rash guards, have O2H decals on their paddleboards, and many are riding with the names of loved ones who died from sarcoma or others who carry on with life. All are inspirational!



Mark Schulein and Bob Chambliss

So they are not just racing for themselves. They are racing for others on the team; they are racing for the Sarcoma Alliance; they are racing for everyone affected by sarcoma — survivors, family members, caregivers, and friends. Every team members knows a friend with sarcoma, team member Bob Chambliss who was battling sarcoma, some also have family members or friends who have battled the disease. They all know how important the Sarcoma Alliance's services and programs are for everyone in the sarcoma community.

Who are these fantastic, generous individuals? Kyle Daniels defending race champion and eventual repeat race winner; a real estate appraiser, hardware store owner, geologist, one from the steel industry, one from high tech; from all walks of life. They love the sea and are connected by a cause — to help everyone affected by sarcoma. This team of record size raised a record sum for the Sarcoma Alliance. At last count the \$80,000 barrier was passed for the first time!

A great team is not successful by itself. There is support. The most important on race day is the escort boat and crew that helps with navigation; provides food and drink and shouts of encouragement. There is also a beach team. A team who starts planning months before the event and arrives the day of the race in the early morning. Tents go up, banners are hung, and tables are set up with a bounteous spread of food and drink so that all the competitors can refuel after a day of great caloric output.

THE TEAM

Nick Alford	Jeff Cutler	Tim Ritter
Matt Belanger	Kyle Daniels	Ron Roebuck
Gene Boyer	Jack Hamilton	Fred Sardisco
Jeff Bradbury	Mike Igloi	Mark Schulein
Kelly Brown	Scott Lincoln	Richard Snyder
James Buckman	Scott Loos	Brian Spear
Jane Cairns	Jay Miller	Brad Thomas
Evan Cassaday	Jim Netzer	
Bob Chambliss	Miles Pritzkat	

ON THE BEACH

Arthur Beckert
 Matt Belanger
 Kelly Brown
 Jeff Green, Whole Foods
 Susan Johnston
 Laura Kanamori
 Kendra and Brian Krause
 Jeff Leider
 Philip Leider
 Dave Murphy
 Albert Ortaliza

Kevin Plottner

Krista Pollock
 Mark Schulein
 Ellen Silver
 Liz Steinfield
 Tracey Talley
 Christine Tope et al-
 they were awesome!
 Marites Tullius
 Michael Tullius
 Daphne Yousem
 Manhattan Beach
 Life Guards

OUR SPONSORS

Albertsons,
 Marina del Rey
 Coolies
 Christine's Pies
 Hennessey's Taverns
 Kinesys Performance
 Sunscreen
 O'Neill Clothing
 Quicksilver
 Whole Foods,
 Santa Monica

Once again, this year, the spread included homemade pies and ice cream. Whole Foods donated all the ingredients! Can you believe it — pie a la mode on the beach?! All kinds of pies — apple, strawberry-rhubarb, kick sarcoma in the butt pies. The pie comes from another team; Christine and her pie making super team — Kathryn Chambliss, Tracy Gossett, Kate Hoffman, Kristin Killey, Ellie Light, Natalie Light, Meredith McCarthy, Larissa Supplitt, Dana Wright — who made fantastic crusts the first time she ever made them, and of course Jeff Light, who took out the trash and did other manly things.

The beach team is joined by their friends and family, those of the racers. The day is electric; it is fun, exciting and relaxing. The day is a time for everyone to get together and enjoy each others company and be part of a team with a purpose.

Attention Los Angeles Area Boaters — We are always on the look out for someone with a boat who would like to be an important part of the Ocean of Hope. If you would like to be an escort boat for one of our fantastic paddles, please contact the Alliance for details. ☀

Lanakila Outrigger Canoe Club

Aimee Spector

Outrigger paddling is an ancient sport, rooted in tradition and is centuries old. Paddling has a rich history that, alongside surfing and paddleboarding, forms the holy triad for watermen. Most of the original paddlers in Hawaii, and the first paddlers in California, were true waterman and waterwomen, with the outrigger canoe just another extension of their connection to the ocean.

The Sarcoma Alliance is excited and honored to welcome the Lanakila Outrigger Canoe Club’s top women’s team to the Ocean of Hope. Based in Redondo Beach, Lanakila is the first outrigger club to join the cause — supporting everyone affected by sarcoma. With help from the Alliance and from sponsors like Patagonia, Kialoa Paddles, and Kinesys, the team raced in some of the most contested and competitive outrigger races in California and Hawaii. They trained hard together as a team under a watchful eye of their coach, Jill Schooler

They competethroughout the year, with the bulk of its races beginning in May and culminating in the Moloka’i Channel Crossing in September.



This race is considered the Superbowl of outrigger racing — 42 miles of often treacherous open ocean paddling with a team of 10 women against over a hundred other teams from every part of the world. They consistently placed in the top 2% of their races.

In their first year they raised over \$4,000. Traveling to races outside of California gave them a chance to spread the message about this deadly cancer and to help elevate the consciousness of those who want to support the cause. The Alliance looks forward to a long relationship with this fantastic group of women. And next year when the team returns to Hawaii, the Alliance’s Executive Director is happy to volunteer to carry their paddles to the beach. ☀



- THE TEAM**
 Jeane Barrett
 Jill Schooler
 Aimee Spector
 Nicki Brodowy
 Lorie Vos
 Kellie Lancaster
 Shien Lu Stokesbary
 Laurie Parker
 Celeste Wise
 Alice Haas
 Suzanna White

Executive Director's Corner



We Couldn't Do It Without You

Each year I like to recognize and thank individuals who gave their expertise and precious time to the Alliance and its programs. Once again Sharon Lieder has been the leader in raising funds for the Assistance Fund, Mark Schulein was the team captain for our Ocean of Hope fundraising campaign, and Jenny Bolsky kept us honest with the IRS by doing our taxes. During the past year we have been extremely lucky to have help from some new faces.

Liz Arnold

This year for the first time the Sarcoma Alliance was named as a beneficiary in someone's estate. Liz Arnold an estate planning attorney in Mill Valley, CA generously spent some time educating and advising the Alliance on both the process and timing of wills and estates. In her free time, Liz tutors high school students, volunteers with Habitat for Humanity, and travels to Guatemala each year as a Spanish interpreter for a medical mission. She can be frequently found hiking in the hills of Marin County.

Rachael Beckert

After the Sarcoma Alliance implemented a new database to manage our mailings and to track donations, there were a number of projects that required manual clean up. Rachael spent part of her summer in the Sarcoma Alliance office helping out with that project. She also came up with the idea for our wonderful "You are not Alone" bracelets and donates her time and the materials for the benefit of the Alliance. Rachael recently graduated from Cornell University with a major in nutrition and is at the University of California, San Francisco in a dietetic internship program.

Gene Boyer

Last year Gene called the Alliance and asked if we needed any boats to escort a paddler during the race. Of course we replied. Not only did Gene escort one of the Ocean of Hope team members but did an unbelievable job of fundraising. He competed in this year's race. His boat flew an Ocean of Hope flag to inspire the competitors.

Suzie Siegel

Suzie gets our consumer of the year award as she makes sure that everyone around her has Sarcoma Alliance t-shirts, wears a "You are not Alone" bracelets or one of our sunflower pins. She also contributes to our newsletter

and website and educates everyone around her about sarcoma and the Sarcoma Alliance. An LMS survivor herself, she is very active in the sarcoma community willing to talk with everybody about their disease and offering suggestions about what they should do. She spends a lot of time with sarcoma patients at Moffitt Medical Center in Tampa, FL.

Barney Tong

Barney has been our ever faithful photographer for the Ocean of Hope. He provides his valuable time, film, camera and printing. He spends the entire day at the beach photographing all the activities of the Ocean of Hope including paddlers as they emerged from their epic race to the award ceremony. He provides photos for our newsletter, website and to everyone who sponsors one of the racers.

Michael Tullius

Mike has helped with the Alliance since its founding. He originally helped Suzanne by creating a program to manage a database for mailings and to track donations. He then helped make many, many fixes to our first website. He has tirelessly worked to make and maintain the functionality of the bulletin board as well as to serve as the administrator of the website, resolving problems for the site in general and for users.

These are just a few of the wonderful people who make the Alliance what it is. Many others help throughout the year and every event takes a small army to make it successful. Others have put together their own events benefiting the Alliance. This issue of The Sarcoma Alliance News reports on many of these events. Thank you to all; we couldn't do it without you. 🌻

Corrections

In our last newsletter we listed all those who made donations to the Sarcoma Alliance in 2006. We also listed individuals who had donations made in their honor or memory. Following are corrections to this list. We apologize for these errors.

Donations

Friends of the Alliance
Stan Weintraub

*Donations made in memory
of the following individual*
Lucille Popolo

Educational Programs

The Sarcoma Alliance and the Northwest Sarcoma Foundation were proud to partner with **Patient Power** on a series of programs in late June. This five part series of one hour programs addressed the diagnosis and treatment of sarcoma. Both medical experts and sarcoma survivors participated in each program. The programs can be found on the web at: <http://www.patientpower.info/listenhealthtopiclist.asp?Topic=Sarcoma>



The Sarcoma Alliance is pleased to partner with **CancerCare** to offer a free, one hour telephone education workshop entitled: Treatment Update on Sarcoma. It will be presented on January 23rd from 1:30 to 2:30 pm Eastern Time. Dr. George Demetri, a world renowned sarcoma expert and member of the Alliance's Medical Advisory Board, will be the featured speaker for this program. To learn about this free program and to register visit: http://www.cancercare.org/get_help/tew_details.php?tew=sarcoma_012308&ret=%2Fget_help%2Ftew_calendar.php

CancerCare is a national nonprofit organization that provides free, professional support services to anyone affected by cancer: people living with cancer, caregivers, children, loved ones and the bereaved. CancerCare programs — including counseling, education, financial assistance and practical help — are provided by trained oncology social workers and are completely free of charge. Founded in 1944, **CancerCare** now provides individual help to more than 91,000 people and receives 1.6 million online visits each year. For more information, call 1-800-813-HOPE (4673) or visit www.cancercare.org. ☀

Patient Power began in February 2005 and is a weekly show hosted by Andrew Schorr, eleven-year leukemia survivor, patient educator and patient advocate. The show features renowned medical experts on topics that include cancer, pain, diabetes, and heart issues, as well as comment from experts in clinical trials and top pharmacists. The show serves to bring patients together in a radio and Internet community to help navigate an often inhospitable health care system. Patient Power takes questions from callers and Internet listeners on topics such as how to find the right doctor, how to advocate effectively, when to get a second opinion from a specialist and how to evaluate one treatment option over another. ☀

Amanda Thierer Memorial Car Cruise

Dale and Sally Thierer

September 1, 2007 dawned as one of those perfect late summer days — clear blue skies, sunny with no humidity. It was a perfect day for a car show. Dale and Sally Thierer thought their daughter, Amanda, who passed away on June 5, 2007, after a ten month battle with synovial sarcoma, would have approved. Perhaps she had a hand in the beautiful weather.

The First Annual *Amanda Thierer Memorial Car Cruise* was a tremendous hit here in the little northeastern Pennsylvania town of Lehighton. While the Thierers would like to take credit for the idea, it was masterminded and orchestrated by a good friend, Dave, his girlfriend Jody and her family. Besides about 50 hot rods

and street rods, there was the Hemi Hunter Nostalgia Top Fuel Dragster, vintage motorcycles, tractors, and just about anything old with an engine! Food, a Chinese Auction, a bake sale, and a live band added to the festivities and a good time was had by all. A highlight was when the Hemi Hunter was fired and run for a few minutes — a 3,000 horsepower nitro-methane burning Chevy motor can sure get a crowd's attention! Local TV and newspapers covered the event and the big question at the end of the day was, "are you going to do this again next year?" You betcha.

In all they raised over \$2,300.00 to benefit the Sarcoma Alliance and make people aware of this awful

disease. Not a bad first effort. As Sally was told by a good friend of Amanda's, "it's one thing to pick up the paper and read about someone you don't know dying from some rare disease. It's another thing when it happens to someone you know and love." How true. Amanda's death devastated her little community in Schuylkill County, PA. She was well known and well loved by so many people. The Thierers hope by making this an annual event to not only keep Amanda's memory alive, but to someday save other parents from the nightmare of watching sarcoma steal their child away from them. Amanda definitely would have approved. ☀



American Association for Cancer Research (AACR)

Annual Meeting – April 14- 18, 2007, LA, CA.
Survivor – Scientist Program

Arthur Beckert

This past spring I participated in AACR's Scientist - Survivor Program (SSP). AACR is the oldest and largest scientific organization in the world focused on the causes, diagnosis, treatment and prevention of cancer. This fantastic program, held in conjunction with their annual meeting, brings cancer survivors, advocates and leading researchers together to share information and to learn from each other. In this 9th year of the program there were representatives from many different types of cancer including bladder, breast, brain, prostate, lung and thyroid who traveled from all over the United States and from foreign countries such as South Africa, Uganda and Estonia.

The program began with presentations from AACR staff outlining the program's history and goals. One of its primary purposes is to bring together leading cancer researchers with survivors and advocates to provide an understanding of fundamental scientific concepts and important topics in all aspects of cancer research. This is accomplished with special presentations to the group and informal meetings at meals and throughout the day.

This year participants were divided into seven work groups with three to four mentors per group. The mentors for my group were Stephen M. Hahn, M.D., Chairman and Professor of the Department of Radiation Oncology at the University of Pennsylvania, Lilie Lin,

M.D., Assistant Professor of Radiation Oncology also at the University of Pennsylvania, Jane Permmutter, Ph.D. an independent advocate and breast cancer survivor, and Danny R. Welch, Ph.D., a professor at the University of Alabama. They were all generous with their time and patiently answered all our questions. By understanding the concepts behind the research, we all gained a greater comprehension of the meaning of advances in cancer care. They were all genuinely interested in each of our organizations and what we do to help patients navigate the health care system and carry on with their daily lives.

Throughout the week, the group was provided with special presentations from leading cancer researchers. These presentations were designed to present cutting edge, complex issues in a manner that could be readily understood by a non-scientifically trained audience. There were lots of opportunities for questions. Topics included Phase I Clinical Trials, Ethics and Clinical Trials, and Angiogenesis. I was also able to attend conference presentations on funding challenges facing the National Cancer Institute and New Approaches to Imaging, Diagnosis and Treatment of Sarcomas.

Diagnosis and treatments of cancer are in a period of tremendous change and promise. Relatively recently it was believed that various types of cancer would respond the same to treatments. It is now known that for a single



tumor type there are genetic differences meaning that treatments will often be effective for only a tumor with a specific genetic makeup. Genes control the production of proteins which are a key for cell growth and reproduction. If one can interfere with protein formation then cell reproduction will stop and it (and the tumor it comprises) will die. Scientists are learning, however, that there are many different pathways of protein formation and these pathways vary depending on the tumor type. The big challenge facing scientists today is to translate this knowledge of genetic variation and protein formation pathways into meaningful, effective treatments.

Perhaps, even more exciting is the treatment and prevention of cancer using vaccines. You have all probably heard of the approval of a vaccine against human papilloma virus (HPV) one of the most common causes of cervical cancer. Additionally, the Federal Drug Administration recently approved a vaccine for the treatment of prostate cancer. More are on the horizon.

One of the most important benefits of the AACR's Scientist - Survivor Program was the opportunity was to

talk informally with other advocates and researchers. We were able to learn about everyone's background and the challenges faced by patients with different types of cancer. We were also able to learn about other cancer advocacy organizations and how they go about accomplishing their mission. The challenges facing all organizations are similar. How do we ensure all cancer patients receive the best possible care? How do we ensure that the medical community is aware of the latest advances in diagnosis and treatment and that patients are referred in a timely manner to the providers with the greatest expertise and experience in treating specific types of cancer?

At the conclusion of the program I left with many new friends with whom I will be able to rely upon for information and advice and a greater understanding of ongoing advances in cancer research. The staff at AACR were fantastic in helping us through the maze of this huge conference and making the logistics of attending such a conference go without a hitch. As a result of participating in the Scientist-Survivor Program, I will be better prepared to help those who contact the Sarcoma Alliance. 🌟



Spirit of Survival 2007

SOS EAST

Not just another day in the park...

What spirit. What joy. What dedication. They came together to support their 'sarcoma' experience. Twenty five strangers became a family of one as they met in Central Park on June 24th to participate in the 2nd Annual Spirit of Survival East. They walked around the reservoir, sharing stories and memories about themselves and those they loved. Some people came from great distance, others happened upon us quite coincidentally. The Davis' (Ruth and Marty) came from Vermont, Marty having just recouped from surgery and treatment. The Grossman Family came from New Jersey, and Sharon and Mark were strolling in the park with their dog, found us by mistake and found camaraderie by sharing their story of the impact of sarcoma on their lives. In a city as busy as New York, a group of strangers spent a few leisurely hours walking in the sunshine gaining strength from each other.

"The day was beautiful" says Susan Herzog, co-coordinator of the event. "Everyone who came to the event was thrilled to meet someone else who had experienced this disease". There were those who were newly diagnosed and those with 8 to 15 years of survivorship

SOS WEST

A wet day couldn't dampen the spirits...

A wet, cool week brought soggy conditions to San Francisco's Golden Gate Park the site of the third annual Spirit of Survival West on October 14th. However the spirits of the 40 plus participants could not be dampened. The course, designed by Sarcoma Alliance Board member Jeff Bradbury brought the group through some of the prettiest sections of the park including tree shrouded trails, breath taking views of the Pacific Ocean and a small herd of buffalo. Yes, there are buffalo in Golden Gate Park!!

The day included a 5K walk or run and for the ambitious few and twice the fun a double loop for a 10K reward. Leading the charge on the double loop was the Sarcoma Alliance's own Medical Advisory Board member, Richard



under their belt. People shared stories of diagnosis, treatment and survivorship. Others ran in honor of those not able such as Stacy Pilson who ran for her mom who was just diagnosed and awaiting authorization to start treatment.

Susan and her daughter Lauren organized the morning's stroll around the reservoir again this year and were thrilled with the turn out! A special shout out to Amy Shilling who volunteered, manned the booth, talked with people passing by about sarcoma and who without the day would not have gone so smoothly! Thank you to all those who turned out and see you next year! The Spirit of Survival East is proof that You Are Not Alone when you can rely on the Sarcoma Alliance for support, education and guidance. ☀



O'Donnell. Doctor O'Donnell, an orthopaedic surgeon at UCSF Medical Center returning for the second year wore a smile on his face as he completed the first loop and carried it another 3 miles to the finish. Returning for a Spirit of Survival three-peat was Alicia Parlette and friends. Alicia under treatment for aveolar soft part sarcoma walked to the spectacular Pacific and returned to keep everyone entertained with stories about the trials and tribulations of living with sarcoma. Her spirit and positive attitude is an inspiration for everyone. We had participants from all over northern California and from far away as Texas.

Every event includes a fantastic group of hard working volunteers and sponsors to make it all happen. Odwalla provided a bounteous amount of energy bars keeping everyone well nourished before and after the event. Thank you to Rachael Beckert, Rialena Bradbury, Pam Cresta, Emily Cresta, Emilyn Lugtu, Alyssa Lagtu, Nick Lugtu and Luke Tapsall. We couldn't have done it without you. See you in 2008. ☀

Greetings from an Ironman — What one person can do

Russ Silvestri

On March 3, 2007, Russ completed the New Zealand Ironman in 11 hours, 10 minutes and 45 seconds.

Russ is incredibly grateful to everyone for supporting him and the fight against sarcoma cancer. Together, they raised more than \$20,000 in honor of Pat Corliss, his mother in law. Everyone's support and generosity were overwhelming. Russ, his wife Beth, daughters Allie, Diana, Catherine, and the Corliss Family are forever grateful.

The satisfaction of achieving a goal, overcoming the challenges, applying the discipline to the training regimen coupled with the opportunity to share it with the family created a memorable experience. One of the fortunate things with the training and trip to New Zealand was it involved the entire family from Catherine being able to visit her birth country, to raising money for Sarcoma and Pat. Read on to see what happened.

Prolog

The Ironman Race started for Russ on March 15, 2006, when he registered for the race. Training was constant throughout 2006. The last two months, the training volume picked up dramatically averaging 18 to 20 hours a week with two sessions a day. Balancing the training with family and work were a challenge; the training sessions often started at 4:30 AM and ended at 9 PM.

Race day started at 4:10 AM with a 1200 calorie carbohydrate laden breakfast. During the race he burned a total of 12,870 calories. The nutritional challenge of the Ironman claims more victims than anything else.

The Swim

The swim start is a deep water mass start. All 1003 competitors are boxed into 400 square meters; all pushing the starting line. Just position yourself and go -- too close to the front, you



get mauled by faster swimmers — too far back you get blocked by slower swimmers. Prior to the start, a canoe of Maori warriors provided a nice local touch along with another group on the beach doing a traditional “Haka”, while helicopters circled overhead. The race started with the shot of a canon; the thrashing began. Russ got stuck behind slower swimmers and piled on from behind. Eventually, the swim sorted itself out; he finished in 1 hour and three minutes.

The Bike

Heading out of the transition area and onto the road through town, Russ was moved by the cheering crowds. He realized how fortunate he was to be competing and to have family, friends, and colleagues that are so supportive. It hit him that he was actually doing the race that had been on his calendar for nearly a year.

He was mentally prepared for the hills and kept thinking pace don't race, focus on the heart rate. Tempting as it was to hammer the early hills and pass people, he stayed seated, spinning a low gear which would pay dividends later in the day. The bike was out 28 miles and return, twice. The course was a rough road, relatively flat but with a few hills and a building wind kept it interesting. Five hours and 32 minutes later he was off the bike and transitioning to the run. He changed his clothes but failed to change socks, which hurt him in the second half of the marathon as two large blisters on his feet would prove.

The Run

The run, a 26.2 mile marathon, started by going up a ramp over the

main road and back through town. After five and a half hours of cycling, running was extremely difficult as his legs felt like two stumps. The sun was now out in full force, with the temperature in the 80's. The two lap out and back course provided more opportunities to see his family. The first time through was the last time he smiled, according to Beth. What really struck him was how fast the other runners were going. He knew it was going to be a while before he would see the finish line.

The first five miles went pretty well but things changed quickly as he faced the first significant hill. The hill seemed to get steeper and the temperature warmer, until he reached the top. He kept thinking — do not stop, the next aid station is coming. Mentally he broke the run into short little pieces — run until the next intersection, the next aid station, and the spectator in the red shirt; these are the landmarks he focused on. For the remainder of the race, he walked the hills and ran the flats,

Rounding the last turn before the finish, with 200 meters to go, the goal was in reach. At last he really was almost there. The earlier spectator cheers of keep it going, you're almost there had felt empty and misleading as he was plodding along. Until you have the finish line in your sights you are not almost there. Starting down the runway, Russ saw his family and was surprised, as all three kids ran onto the course escorting him through to the finish line. Diana nearly tackled him. Visions of going down in front of the crowd and not being able to get up went through his mind. They were able to get it together and proceed to the finish line when Russ heard across the loudspeaker “Russ Silvestri of San Francisco, you are an Ironman”.

Will he do it again? Right now Russ does not feel the need, but as each day goes by the race seems easier. Beth says that it sounds like childbirth.

A few days after Russ completed his Ironman, Pat Corliss passed away at home surrounded by her husband Paul and many members of her family. Until she died she continued to enjoy life to the fullest and inspired many. 🌻

Roadster Rumble

The Roadster Rumble Returns Remembering Suzanne Leider and Helping Others in her Name

For the second time the “Roadster Rumble” was held at Joe’s Garage in Tustin, CA to support our program: *Hand In Hand, the Suzanne Renee Leider Memorial Assistance Fund of the Sarcoma Alliance*. In April 2007 over 200 dedicated supporters gathered to help raise funds to provide grants for second opinions from sarcoma specialists to those diagnosed with sarcoma. Dressed in vintage ‘50’s threads, guests enjoyed wonderful food and wine and danced to the music of Phil Shane. They also participated in fun filled and competitive live and silent auctions.

The evening was dedicated to the memory of Dr. Richard Gandin who was eloquently remembered by his wife, Marsha, his children Jennifer, Rachel and Matthew, as well as family, friends and colleagues from across the country.

Two time grant recipient, Victoria Westermark, put a face on the importance of how the Hand in Hand awards allowed her to pursue second opinions from physicians specializing in the diagnosis and treatment of sarcoma as she carried a personal message for those in the audience who live with this rare disease.

Major supporters included Michael Madden of Salient Consulting, Tracey Talley, Lawrence and Sherrie Nagin, Paul Heckler of Yosemite Capital, Steve Williams of HMWC, Jack and Sharon Leider, Marsha Gandin, Jason Vaughn and Kelly Flynn. Special thanks to Darcy Lewis and her Pacific Mutual volunteers who kept the evening going so smoothly, to Fiesta Florists for providing the beautiful centerpieces and to Tony Salas for his sensitive and insightful video work. Hugs to the steering committee, you know who you are! We could not have done this without all of you. You are the best!!!

The evening raised over \$45,000 which goes directly to Hand In Hand for financial support to sarcoma patients for second opinions. 🌟

THE STEERING COMMITTEE

Sue & Neil Bershad
Jennifer & David Burlison
Molly & John Calder
Stella & Nick Cretikos
Kellie Flynn
Marsha Gandin
Karen & Bruce Harris
Hillary & Jerry Hyman
Carole & Mike Kamper
Denise Lapins
Sue & Dennis Leibel

Sharon & Jack Leider
Stephanie Leider
Dorothy & Zane Leshner
Ruth & Ira Lott
Linda & Frank Meyskens
Edie Mintz
Keith & Kim Munemitsu
Tracy Barbara & Herb Stern
& Mike Parks
Myra & John Stillman
Carrie & Rob Young
Suzanne & Al Yesk



Long Time Friends Raise Money for the Assistance Fund

Kim Fine

September 30th, classmates of Newport Harbor High School (NHHS) class of '85 celebrated their 40th birthdays together at *Phil's California Bar & Grill* in Fountain Valley. The class thought a birthday party would be a way to raise money in memory of Suzy Leider and Terry Denigan. They lost both these classmates to different forms of cancer and Terry's family believes supporting Suzy's Hand in Hand — The Assistance Fund is a way to honor Terry as well.

In 2005 the class split the proceeds from their 20 year reunion to the Assistance Fund and The St. Vincent de Paul Society, Center for the Homeless in LA. Terry's family believed more could be done if the class did not split donations, so they decided that all profits from NHHS '85 events will be given to Assistance Fund. The Denigan's want to help others in need, as a way to honor their son, and have been extremely generous in supporting NHHS '85 events, as have Jack and Sharon Leider.

Since many classmates still live in Newport Beach, they used their 40th birthday as reason to get together and raise money in memory of Terry and Suzy. One classmate, Philip Carter, was extremely generous allowing them to use his restaurant. About 30 people turned out to celebrate and a dozen others who could not attend, mailed in donations to support the cause. To date, over \$1,200 has been raised.

Suzy and Terry fought with courage and grace. Many of their high school friends have been friends since kindergarten and memories of their smiles and laughter go way back. Their lives were too short, yet had an impact beyond measure — the classmates are more compassionate, more aware of their connectedness and are more willing to support causes beyond their own. They hope donations will keep rolling in and look forward to making future events. 🌻



Debs's Special Connections Raises Money for the Alliance

Deb's Special Connections will be donating a portion of their sales to the Sarcoma Alliance and has provided a direct link to the Alliance website. Deb has gifts, collectibles, home, garden and seasonal decor. Browse through their listings and discover the awesome selection of new products. They have something for everyone on your shopping list, him, her, or the one who has it all. Wholesale prices every day!!! Quality products, great prices and gift cards! Open your FREE account today! www.DebsSpecialConnections.com

Deb's dad found out he had liposarcoma in 1994. Sadly in 1994, there was no help or any information to be found. He had two surgeries and radiation during this time and had no growth or problems until November 2006. That is when Deb found the Sarcoma Alliance and started doing some research. She found out about Yondelis and questioned her Dad's doctors. He has been on Yondelis now for about eight months and is doing great!!! 🌻



Letter from the President

My Promise

I became Bob's "other mother" quite by happenstance. It was one of those unplanned treats that would come to mean so much and brighten my life. We met during the early morning preparation for the 2004 Ocean of Hope. He volunteered and we appreciated this big strapping gentleman who helped lift, carry and schlep. After the set up was complete and I went to thank him for all of his help, we started a dialogue that would continue throughout our friendship. It was a story of sarcoma (myxoid liposarcoma to be specific) and how it had impacted his life. Bob approached sarcoma intellectually, researching details, understanding medical options and always in charge of the course of choices he would make over the next few years. He used the programs and resources offered by the Sarcoma Alliance, engaging in exchange of information with many on the bulletin board. Bob was on the beach that year but he made a promise to himself that he'd be a paddler the year after. In 2005, Bob joined the Ocean of Hope team and jumped into the Pacific Ocean with dreams of crossing the channel. Each stroke of his arms caused excruciating pain (my interpretation, never a sentiment he'd ever admit to). He made it to the mid point when he was pulled out of the choppy waters. It wasn't for lack

of ability; it was due to a huge mass on his shoulder that had sprung up over the past few weeks and which was all too familiar. For the next two years, Bob faced everything sarcoma could have thrown at him. Distant recurrences, post operative infections, spinal and lung mets, radiofrequency ablation, chemotherapy, radiation, and finally palliative care. Each sarcoma recurrence, each medical complication, each failed clinical trial was met with Bob's realistic optimism and with his dream to go the distance at the next Ocean of Hope.

A few days before my Bob died, he had a dream. He dreamt that he was my daughter, Shoshana. While no expert in dream interpretation, it seemed obvious to me what he wanted, what he longed for, what he hoped for. That he, like Shoshana, would be cancer free — with sarcoma no longer a part of his daily life. The last time I saw Bob, as I sat close, stroking his hand, kissing his face, I gave him my promise — that she, my Shoshana, would carry for him, my Bob, the 'hope' that he and everyone with sarcoma has — to be free of this disease. My promise is that we at the Sarcoma Alliance will keep on fighting the fight, linking peers to peers and "other mothers" to gentle sons so that they are never alone and that they always have hope. Sarcoma is daunting, but you don't have to go it alone.

As I say goodbye to my Bob, there's one more promise I want to make to him — that at the Ocean of Hope in 2008 we will make sure that your spirit is taken the distance — from start, to midchannel to the finish line. Your team, your friends, your "other mother" will make certain of that!

Ellen Silver

sarcoma alliance

775 East Blithedale, #334
Mill Valley, CA 94941-1564

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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 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.

■ *January 23, 2008 Treatment Update on Sarcoma, 1:30–2:30PM Eastern Time; Presented by CancerCare, co-sponsored by the Sarcoma Alliance a free telephone education workshop for everyone affected by sarcoma. For information visit www.cancercare.org or call 1-800-813-HOPE (4673)*