



# Letter from the President

## Going Forward — Looking Back

On January 1st 2006, the Sarcoma Alliance took a huge step in going forward with its desire for continued growth by installing a new Executive Committee signaling a shift from its founding leadership. I am joined by Tracey Talley (Vice-President), Jared Holmes (Treasurer) and Michael Ostland (Secretary) as the 2006 Officers of the Board of Directors. With this come new responsibilities and a promise to keep the Sarcoma Alliance on a path for success with each new step building upon the strong programs and services already in place. It's impossible to go forward without acknowledging the past and thanking those who gave so much.

I became involved with the Sarcoma Alliance at the 2002 Ocean of Hope. Never before had I met so many people whose lives were touched by sarcoma or who in the face of personal loss were so gracious and optimistic. I was in awe of Sharon Leider, a mother who had just lost her daughter, who was on the beach smiling, energetic and eager to support those with similar experiences. She gave with her heart at a time when hers was breaking. Since then I have had the privilege of getting to know Sharon, walking along side her at the Spirit of Survival and dancing with her at the Hand in Hand: Roadster Rumble. Sharon is the 'mother' of this organization and it's her strength that has challenged all involved to strive for excellence.

Philip Leider has served as President for the past two years. His dedication and commitment to the Sarcoma Alliance has been a mission of love. Philip has been an extraordinary leader having taken this small organization, growing its presence within the sarcoma community and creating a foundation of fiscal solvency that will guide its future. Philip's words are to be treasured and he leads with strength, grace and wisdom. He has given so much at a time when it would have been so easy to walk away. Philip's selfless vision is an inspiration to us all.

A quiet strength describes outgoing Vice President, Marites Tullius. She has been the perfect 'second' in command with shoulders so strong she has buoyed the Sarcoma Alliance to new heights. Morning, noon or night you can find Marites working on client services issues, attending oncology meetings, organizing activities for the Ocean of Hope or a host of other services needed to keep the organization going. Marites has taught us all so much about leadership. She works hard, delivers on her promise and always keeps the Sarcoma Alliance in the forefront of her mind.

Our past has been strong and serves as mentor for the hard work that must continue. My promise and that of the new Executive Committee is to continue to strive for excellence on behalf of the Sarcoma Alliance. We welcome all of your support and assistance as we go forward.

*Ellen Silver*

### sarcoma alliance

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#### announcements



*Sarcoma support groups meet regularly in the San Francisco Bay Area, Los Angeles, Houston 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.*

- June 11-17, 2006 *Sarcoma Awareness Week*
- June 18, 2006 *Spirit of Survival East, New York City – see website for details*
- August 27, 2006 *Ocean of Hope Celebration in Manhattan Beach, CA*
- October 2006 *Spirit of Survival West, San Francisco Bay Area — see website for details*

# THE SARCOMA ALLIANCE NEWS

2006 Volume 5 No. 1

## Peer to Peer Network Up and Running

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**YOU ARE NOT ALONE.** This simple statement has been the driving force of the Sarcoma Alliance since it was founded in 1999. With each new program developed we strive to fulfill our mission to support, educate and guide all sarcoma patients and their caregivers. For years, we provided support by sharing information on our website, through conversations with members using our bulletin board, in support groups, and by providing personalized information packets. However nothing can substitute for that personal, one-on-one connection. Therefore, the Sarcoma Alliance is proud to launch the Peer to Peer (P2P) network — the ultimate support. It's the best way to know that you are not alone.

P2P seeks to create personal relationships between people affected by sarcoma. A young woman in the Midwest with uterine leiomyosarcoma wants to talk with someone who has experienced similar side effects or perhaps a newly diagnosed teenager who is scared and confused wants to meet another teen who has dealt with the same concerns. We hope over time to develop a large network of participants so we can match people based on needs. A newly diagnosed patient with a 5 year survivor, a mother to a mother or a synovial cell sarcoma patient with another synovial cell sarcoma patient. Individuals will request how they want to be connected (age, gender, sarcoma sub-type, patient or caregiver).

Creating this ultimate support has been a long time vision of the Sarcoma Alliance. The vision was kept in the forefront for all these years by Philip Leider and this December, P2P became a reality as a result of the tremendous efforts of Michael Ostland, Secretary of the Board of Directors. His dedication, hard work and commitment enabled us to implement this program. A special thanks to Michael Ward for lending us his expertise in programming and database development.



*Continued on page 2*

## Here's a brief overview of the Peer to Peer network.

### *Who can participate?*

Anyone who is affected by sarcoma is welcome to participate and can volunteer to act as a guide for someone in need. This includes patients, family members, and caregivers. You can join the Peer to Peer network if you are looking for guidance or if you can listen and provide support.

### *What is the Peer to Peer network?*

A one-on-one personal connection that allows patients and caregivers to communicate confidentially with each other, share experiences and knowledge, and find emotional support. These discussions will take place by email, on the phone, or in person. A person will be matched with another participant based on each individual's needs and what is important to him or her; this may be the specific sarcoma subtype, disease location, age, sex or other personal preferences.

### *How will it work?*

People with sarcoma, those who have long survived, caregivers and others will fill out an application to participate in the program. It is preferable to complete an application directly on the Sarcoma Alliance website — [www.sarcomaalliance.org](http://www.sarcomaalliance.org). The form can also be downloaded from the web, or one may request that an application be mailed. Each participant must sign a confidentiality agreement and adhere to a code of ethics.

Once the application is received, the information will be added to the peer-to-peer database. Participants will be matched through an automated computer process, which will generate 5-10 potential matches for each person. A final match will be made by the Sarcoma Alliance staff. Finally, only after each person has been contacted by a representative of the P2P network, information about the potential peer shared with them will contact information be sent to both parties.

### *What if I previously filled out an application?*

We respectfully request that you complete another application because our updated form captures more information than the original one. Those who have previously applied will be contacted to determine whether they are still interested; if so, they will be asked to fill out a new application. All applicants should visit our website and complete a new application. If need be, a hard copy of the application will be mailed to you.

### *What if I don't feel comfortable with my match?*

The Sarcoma Alliance recognizes that not all matches will work. It is also possible that the needs of either or both people may change over time. Anyone, for any reason, may notify the Sarcoma Alliance that he or she would like to be matched with someone else or no longer wants to participate in the program. It is critical to the program's success that each participant feels comfortable and fulfilled by his or her experience. Just as a patient must feel comfortable and have confidence with a health care provider, everyone in the P2P network must feel it is beneficial. We anticipate this will happen from time to time and therefore no one should feel awkward or offended if a change is requested.

### *Want more information?*

Please contact the Sarcoma Alliance office and speak with Arthur or Judith, our fine staff. They will provide you with any information you need. We look forward to welcoming you to the Peer-to-Peer network!! As a member You are Not Alone! 

# Coping with The Hospital Stay by John Link

INPATIENT CHEMOTHERAPY CAN BE EXTREMELY HARD on cancer patients. Under some sarcoma chemotherapy protocols, patients may find themselves in the hospital for five or six days a week for one year, or even longer. In order to cope with these stays, patients and their caregivers must find ways to occupy their time.

There are many ways to survive the rigors of lengthy hospital stays. In 1997 when I was 17, I was diagnosed with osteosarcoma. I spent more time in the hospital than in my own home, so much so that I called my parents' home my second home. I would sleep for days at a time, and when I was awake, I didn't feel like doing anything. However, I soon realized that I had to keep my mind and body active and focus on something other than the cancer; it was in my body, but it was not going to take over my life.

Some simple ways to pass the time are by playing games, reading, listening to music and watching television and movies. I would be lying if I said I didn't do my fair share of these, as they are distracting and easy to share with family members or hospital staff. I would listen to CD's over and over and find myself dissecting the lyrics and trying to relate my experiences and emotions to the music. To this day, when I hear certain songs, I am reminded of my days on the pediatric ward.

Another great way to stay active in the hospital is by doing art therapy. I am not much of an artist, but sculpting was a great escape and gave me a chance to explore my creative side. Writing in a journal about feelings, thoughts and daily life is valuable and will give you something to contemplate in the years ahead. It is a wonderful way to express yourself if you don't want to talk.

Getting out of bed is by far the most important way to cope with hospital stays. Walking around will help you maintain your leg and arm muscles. For sarcoma patients who have difficulty walking, get out of bed and get someone to push you around in a wheel chair! Moving around will get your blood flowing and will help make you stronger and rehabilitate more quickly.

When I became restless, I would grab a magazine or book and my portable CD player and walk the halls. I usually ended up in the same place: the end of the hallway in front of a window with a beautiful view. I would sit by the windowsill and watch the people outside. I would think about what I was going through, about my family, my friends, my school and about the music. I was magically transported outside and could feel the cool air on my face and the blades of grass under my feet. That window took me out of the hospital and kept my mind, body and spirit active. I used my imagination and creativity, plus I gained hope in becoming healthy.

Finally, the most essential element to survive lengthy hospital stays and maintain physical and mental health is support. I was lucky that my hospital was near my home and my school. The nurses would joke that my room had

a revolving door. My friends kept coming and entertaining me; they kept me up to date and made me feel that I was still a part of their lives.

However, some people are not so lucky. Sometimes the hospital is just too far away. But with technology and online support groups and chat rooms, people can talk

about their life or their cancer, or just have a laugh, meet new people and share advice and tips. At the time of my treatment I knew only one or two other people with the same type of cancer as me, but now with the internet and online support groups I have met hundreds.

Cancer can be dreadful and powerful disease. It can make you sick and cause destruction, but it does not have to take over your body. To beat cancer, you need to stay as mentally and physically active as possible. Cancer can be part of your life, but it shouldn't be your life.

*John Link has written a book about all aspects of his treatment for Osteosarcoma. Visit [www.linktobeat.com](http://www.linktobeat.com) to find out how to order his book: The Link to Beating Cancer.* 

**I soon realized that I had to keep my mind and body active and focus on something other than the cancer; it was in my body, but it was not going to take over my life.**

# Wisconsin Walk by Richard Nesbitt

RICH NESBITT, A SURVIVOR OF SARCOMA, malignant fibrous histiocytoma, organized the 3rd Walk-for-Sarcoma Relay Event on June 11, 2005 in central Wisconsin. People volunteered to form a relay team to walk a 45-mile trek from Marshfield to Wausau. Volunteers also helped as support staff for the walkers. The relay began from the Hope Lodge in Marshfield at 5 AM. and completed their walk at Marathon Park at 5:45 PM. after walking for 12 hours and 45 minutes, faster than the last walk.

There was one main rest stop at Hanna's Henhouse in Edgar, WI. Tom Schuh, the owner, held a karaoke night and the donated prizes that were received for the

competition were raffled off. A total of \$905 was raised by this event. The money raised was donated to Sarcoma Alliance and Sarcoma Foundation of America.

Rich used Automatic Position Reporting System (APRS) to track the progress of the relay team on the route. People could follow the progress of the walk on their home computer at [www.findu.com](http://www.findu.com). Local amateur radio operators hosted an on-the-air special event and made contact with operators across the nation to promote sarcoma awareness. Watch for news about 2006 event at Rich's sarcoma web page: [www.sarcomasupport.com](http://www.sarcomasupport.com). 

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## iSPAN: the International Sarcoma Patient Advocate Network by Sharon Anderson

ON NOVEMBER 19TH, THE SARCOMA ALLIANCE HOSTED A SUMMIT of 27 leaders from 14 sarcoma advocate organizations. This meeting was convened in Boca Raton, Florida prior to the 11th Annual Connective Tissue Oncology Society (CTOS) Meeting and was made possible due to a generous grant from Novartis Oncology. Representing the Sarcoma Alliance were board members Ellen Silver and Dave Murphy, and Executive Director Arthur Beckert. The group launched the International Sarcoma Patient Advocate Network (iSPAN) which will communicate regularly and meet once a year.

### A Beginning

Over the past five years, numerous groups and foundations have been founded to serve various segments of the sarcoma community. This meeting, therefore, was called to ascertain ways to support and strengthen their efforts and effectiveness. The initial goals were to learn about each organization's unique role, efforts and contributions; to establish a communication process among the groups; to discuss the most current developments, issues and needs for advocacy; and to define future goals and collaborative strategies.

### Building a Network

A pre-meeting survey and phone interviews solicited opinions and suggestions from both those who could and could not attend. Participants expressed unanimous support for networking and ongoing communication.

### Issues for Collaboration

The pre-meeting survey generated a detailed list of needs and issues for possible collaborative work. This list served as a catalyst for discussion and decision-making. Three main categories emerged:

- Research: increasing studies/clinical trials
- Patient education, support and outreach
- Standards of care for all sarcoma treatment

### Outcomes

A directory of 50 sarcoma advocate organizations and foundations was developed and distributed among these groups. The directory identifies each organization's services and directs patients to get the specific help they need. Another outcome of the meeting was the creation of two iSPAN Task Forces each of which created goals with concrete action plans for the next six months: The Funding Research/Legislative Affairs Task Force will educate others and prioritize legislative initiatives. The Patient Education, Support and Outreach Task Force will develop patient support materials and work toward raising awareness of the issues and unique needs of the sarcoma community.

*Sharon Anderson, an LMS survivor, did a wonderful job of helping to plan and facilitating the meeting. The sarcoma community owes her a big thank you.* 

# Spirit of Survival



**MAY 28, 2005**  
**5-10K WALK/RUN**

## An inspiring day at the Marin Headlands

ON MAY 28TH MORE THAN 100 SUPPORTERS OF THE SARCOMA ALLIANCE enjoyed a magnificent morning in Marin County's scenic Tennessee Valley for the Spirit of Survival 5k/10k walk/run. This event would not have been possible without the hard work and commitment of Jeff Bradbury, a long time friend of this organization and Ellen Silver, our own board member. In 2001 Jeff first lent his athletic prowess to the Sarcoma Alliance in a seven-day, 150 mile race through the desert in Morocco.

Many sarcoma survivors, family members, friends and caregivers attended this event.

Others came in tribute to those who lost their battle to this terrible disease and to show support for everyone impacted by sarcoma. Among the attendees was Alicia Parlette, who came with a large contingent of family and friends. She was the team captain of Running for Miracles and raised \$2,100. Congratulations and thank you!!! Alicia has been documenting her battle with alveolar soft part sarcoma in a series of heart felt stories in the *San Francisco Chronicle*. You can read Alicia's Story or order it in book form on the web at <http://www.sfgate.com/alicia/>

After checking in and listening to welcoming remarks from Arthur Beckert, the group was treated to a splendid rendition of the Star Spangled Banner by



Shoshana Silver, a synovial sarcoma survivor and Ellen's daughter. Chad Crittenden, another synovial sarcoma survivor, who had gained national prominence on CBS' *Survivor Vanuatu*, gave some moving remarks of how helpful the Sarcoma Alliance had been to him when he was first diagnosed with the disease. (To read more about Chad's experiences see our last newsletter: 2004 Volume 4, No. 1.)

Seventy-five participants enjoyed the 5k journey out to the Tennessee Valley Beach and back. Andrew McWhorter was first to cross the finish line in 24:24; Robin Reynolds was the first woman in 29:51. Thirty-five brave souls tackled the 10k event with a 1200 foot climb to the top of the ridge above the valley. All

who followed this route

were rewarded with fantastic views of the valley to the south and all the way to Mt Tam and Point Reyes to the north. Rob Spinosa was first on this very difficult course in a time of 51:29; Penny DeMoss was the first woman, narrowly missing a sub one hour run, with a time of 1:00:12.

The real winners of the morning were all those who participated in supporting each other and the Sarcoma Alliance. Thank you to everyone who was able to come out and to everyone else who supported

this event by sponsoring participants and sending donations. A final thank you to all who volunteered, making the morning a memorable one for all. The event raised more than \$20,000, which will allow the Sarcoma Alliance to continue to grow and expand, and support sarcoma patients everywhere. ☀



Photos by Penni Gladstone, San Francisco Chronicle

# Leadership Donations — 2005

The Sarcoma Alliance was honored and touched with the number of donations we received in 2005. Every donation, no matter the amount, is appreciated and is vital to the ongoing efforts to provide guidance, education and support to everyone impacted by sarcoma. The following individuals and organizations made leadership gifts to the Sarcoma Alliance's in 2005.

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Lexani Wheel Corp  
Rella Lutzky  
Michael Madden %Salient  
Consulting Group  
Marriott Hotel  
McCormick & Schmick's  
Margie Gutierrez Moline  
Bonnie Monahan/  
Nancy Morrison  
Napa River Inn  
Newport Hills Drugs  
Novecento  
Pinot Provence  
Plums Café  
Richard Ruhe  
Russo's Pet Experience  
Carol & Alexander Sachal  
Sage Restaurant  
The Spa  
Barbara Stern  
Wendy Stillman  
Trader Joe's  
Summerhill Home Collection  
Target  
Urban Gardener  
Carlos Vasquez  
Custom Bodies  
Visages by Sonia  
Vogue Salon  
Ellie Weinstein  
Westin S. Co Plaza  
Robin Williams  
Michael Wirtanen  
William Yates  
Sol & Bunny Zechter  
Zov's

## GRANTS

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Autodesk, Inc  
Novartis Oncology  
Philadelphia Foundation  
(Rachael Sherman –  
Rising Stars)

## PRODUCT DONATIONS

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Ann Callison, Mojowear  
Tracey Talley

# April in Paris

## ***C'est Une Histoire* Exhibition Honors Photographer Laetitia Vilon And Raises Euros For The Sarcoma Alliance**



Laetitia Vilon



IT WAS A TALE OF TWO SISTERS. Laetitia Vilon and Suzanne Leider lived thousands of miles apart and never knew each other. But their memory brought together their brothers — and an international cast of art lovers, philanthropists and sarcoma advocates — this past April for the *C'est Une Histoire* photo exhibition in Paris, France.

In the summer of 2002, photographer and artist Laetitia Vilon had decided to work on a project with her brother, Jean-Laurent Vilon. Together they designed and developed an art exhibition on the Internet. It was conceived as the first step of a long art venture. The second step was to organize an art event in Paris around the *C'est Une Histoire* theme. Unfortunately life decided otherwise. Laetitia died of synovial sarcoma on November 19, 2002.

Jean-Laurent was left to carry Laetitia's story forward. He assembled her hauntingly beautiful photographs, meticulously prepared them for exhibition, and arranged to exhibit them in Paris. But he wanted to do something more to honor Laetitia and her story.

Jean-Laurent knew that the event would be important for two reasons. First, to help Laetitia continue to live among us through her work, to let her work and her story see the light of day and become better known, to answer her desire to cultivate differences, to foster acceptance of those differences, to work through memory, and to show what lives on. Second, to help those who suffer from the same illness as Laetitia, sarcoma, whose lives have been impoverished, who have explored all possibilities, and are left in anguish after having exhausted the knowledge of the medical experts.

That's when Jean-Laurent found the Sarcoma Alliance. He wanted to partner with a sarcoma support organization, and he turned to the Internet to see what was out there. He visited the Alliance's web page, read the life story of Suzanne Leider, the founder of the Sarcoma Alliance who had also succumbed to synovial sarcoma, and immediately knew that this was the organization that should benefit from Laetitia's legacy. Jean-Laurent e-mailed Suzanne's brother, Philip Leider, then President of the Board of Directors of the Sarcoma Alliance. The rest is history.

Jean-Laurent and Philip recognized right away that they shared a unique bond and became instant friends. They swapped stories about their sisters, brainstormed about the *C'est Une Histoire* exhibition, and set the wheels in motion.

Many people worked tirelessly on two continents to help make the event a reality. Jean-Laurent's business, Safran, LLC, organized the entire event, spearheaded communications, and designed a stunning website showcasing Laetitia's work for the exhibition. Vilon family friend Annie Cénac of the Cénac Foundation offered gallery space for the exhibit near the Champs Elysées. Photography teacher Pierre Barbo of ETPA in Toulouse reproduced all of Laetitia's photos for the event, and Jean-Laurent's parents, Bernard and Annie Vilon, covered all of the printing costs. Park Hyatt Paris served as the Official Hotel sponsor of the event, and *Arts Actualités* Magazine and Jacques Mounier ran a full-page article heralding the event.



Philip Leider, Sharon Leider, Annie Vilon and Jean-Laurent Vilon

Suzanne Leider

Laetitia Vilon

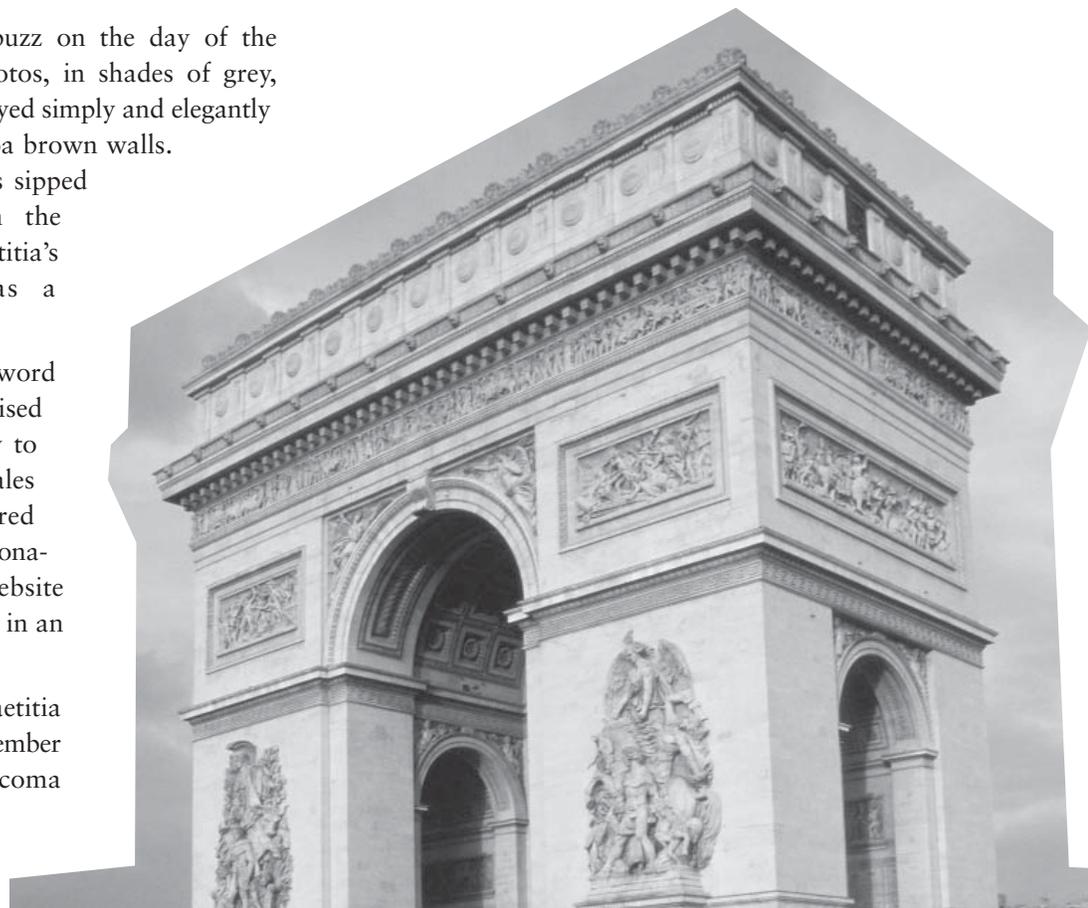
Jennifer Henerlau of the Sarcoma Alliance worked to promote the event in America and coordinated all arrangements with Jean-Laurent and his team. Philip Leider, his mother Sharon, his partner Tony Buckman, and Tony's mother Julie Thompson flew to Paris for the event and shared a wonderful welcome dinner with Jean-Laurent, his girlfriend Charlotte, and Annie Cénac. It was a sparkling prelude to a luminous exhibition.

The Galérie Marceau was abuzz on the day of the opening. Laetitia's abstract photos, in shades of grey, white and light blue, were displayed simply and elegantly without frames against the cocoa brown walls. The international mix of guests sipped champagne as they took in the profundity and simplicity of Laetitia's images and words. It was a magical opening.

In addition to spreading the word about sarcoma, the event also raised a substantial amount of money to benefit the Sarcoma Alliance. Sales of Laetitia's photos garnered \$15,620 during the event, and donations through the official website ([www.unehistoire.com](http://www.unehistoire.com)) brought in an additional \$3,000.

When we read the story of Laetitia and see her photographs, we remember that the struggle against sarcoma

continues. We remember that we are all brothers and sisters in this fight. The stories of those who have battled sarcoma — Laetitia, Suzanne and so many others with stories of courage and generosity — inspire us to reach out, around the world, and make a difference. ☀️



# A Recipe for Success:

# The Ingredients of the Ocean of



IT TAKES MORE THAN JUST WATER to make a great paddleboarding event like the Ocean of Hope campaign succeed.

This summer, raising almost \$50,000 to benefit the sarcoma community, we showed what it takes to assemble the finest fundraiser in the west:

**It takes dedication...** On August 28th in the dark of the morning before the sun came up, Team O2H 2005 entered the chilly waters of the Pacific Ocean. As they started their 6-8 hour journey, each paddler used nothing more than the strength of their arms, sheer will and determination to coax them onward in the 32-mile journey from Catalina to Manhattan Beach. Paddleboarding is not a sport for the weak or light-hearted. It takes great physical strength and mental fortitude to face the elements of an uncertain ocean. It takes months of preparation and practice. For Team O2H, it takes a commitment to the sport and to the mission of the Ocean of Hope campaign.

**It takes leadership...** The Ocean of Hope is the premier event for the Sarcoma Alliance, and its success rides on the strong shoulders of its Team Captain, Mark Schulein. The details of putting on a successful race are numerous and skillfully coordinated by 'Shu'. Mark actively recruits paddlers all year long; looking for dedicated volunteers who will not only brave the channel-crossing but will assist the Sarcoma Alliance in raising money for its programs and services and awareness to the general public. Every year Team O2H grows in numbers and gains the support of the paddling community. This year, Team O2H was 14 members strong — 13 men and 1 woman — thanks to Mark's tireless efforts on behalf of the Sarcoma Alliance and the community the Alliance serves.

**It takes motivation...** For some it's the physical challenge, for others it's to honor those they love who have battled cancer. Kelly Brown raced for the first time this year. Kelly is himself a cancer survivor, having contracted melanoma 13 years ago. Jane Cairns, a strong competitor who again finished first among the women with an outstanding race time, dedicated her race in loving memory of her dad who passed away earlier this year. As the conditions on the ocean became more and more grueling, she focused on her father and the strength he demonstrated during his lifetime. Nick Alford and James Buckman raced to honor loved ones battling cancer. Matt Belanger supported O2H and



dedicated his paddle to the memory of his dad who passed away earlier this year. Veteran O2H team member Scott Lincoln suited up again this year and braved the waves of the Pacific to support the Sarcoma Alliance (in memory of his mother who passed away from breast cancer). First-time paddlers Jim Netzer and Bob Chambliss were propelled across the ocean to highlight the efforts of the Sarcoma Alliance.

Front Row: James Buckman, Mark Schulein, Jane Cairns, Scott Lincoln, Tim Ritter and Miles Pritzkat.

Back Row: Matt Belanger and Keith Munemitsu.



# Hope ("O2H")

For Bob Chambliss, the motivation was personal. As he tells his own story: "I am one of the people who came home from the doctor one day, and had to Google 'sarcoma'. That was a bleak moment, to be sure. In the Sarcoma Alliance, though, I found a wealth of information, lucidity, and hope...and for that I'll always be grateful". Last year, Bob volunteered and helped on the beach. This year he trained and entered his first Catalina Classic. By jumping on to his paddleboard, Bob raised more money than any paddler in the history of the Ocean of Hope.

**It takes good friends...** Since 1982, Joe Bark ([www.joebarkpaddleboards.com](http://www.joebarkpaddleboards.com)) has been hand crafting custom paddle boards, each made to the specifications of the paddler. As the racers come ashore, the BARK logo adorns most of the boards competing in the Catalina Classic. This year, Joe donated a 14-foot paddleboard to the Ocean of Hope. The board became the object of desire during an exciting raffle coordinated by Team O2H paddler Ron Roebuck. During post Classic festivities, Joe drew the winning raffle ticket. The winner was Jeff Bujer, who will put the board to good use to further the efforts of the Ocean of Hope.

**It takes staff...** The Sarcoma Alliance is lucky to have dedicated and caring staff who showed their mettle in their diligent efforts throughout the O2H season. Many thanks to Arthur Beckert, Jennifer Hennerlau and Judith Jaslow.

**It takes volunteers...** Helping Mark coordinate the event are Sarcoma Alliance Board members Marites Tullius and Ellen Silver. For them, the Ocean of Hope is an opportunity to support the sarcoma community, to fulfill the mission of the organization and to make certain that no one with sarcoma feels isolated or alone. Many people rolled up their sleeves and pitched in to help including other SA Board members, Dave Murphy, Tracey Talley, Jared Holmes, Kim Baltzell, Denise Scrivner and Philip Leider. Other volunteers who worked tirelessly throughout the

day were: Michael Newmyer, Krista Pollock, Susan Johnston, Kendra and Brian Krause, Liz Steinfield, Sharon Leider, Mike Tullius, Judi Hyman, Laura and Sean Kanamori, Albert Ortaliza, Reyna Ortaliza and Chris Cruz.

**It takes generosity...** Each year, people donate \$3,000.00 to sponsor a paddleboard to honor or memorialize a loved one with sarcoma. Paddleboards crossed the Pacific in 2005 bearing the names of heroes Suzanne, Tracey, Jason, Sam and Shoshana. The Ocean of Hope campaign garnered almost \$50,000.00 in donations, with leadership gifts from the following: Anvil Steel, Wawanesa Insurance (Toni Messerer), Barry Sopinski, Bob Curtis, Barraday Inc. (Sue Nugent), Jack and Sharon Leider, and HG Ash Foundation (Suzanne Kurtz).

Leading the fundraising effort in dollars garnered by paddlers were: Bob Chambliss, Nick Alford, Mark Schulein, Scott Lincoln and James Buckman. Many thanks are due to the organizers of the Catalina Classic and the beach festivities (Gibby Gibson, Buddy Bohn and Kyle Daniels). This year the beachgoers were treated to delicious edibles supported in part by Ralph's and Costco.

**It takes a team...** Paddling for Team O2H this year were our heroes: Nick Alford, Matt Belanger, Kelly Brown, James Buckman, Jane Cairns, Bob Chambliss, Jack Hamilton, Mike Igloi, Scott Lincoln, Keith Munemitsu, Jim Netzer, Miles Pritzkat, Ron Roebuck, Tim Ritter and Mark Schulein.

**It takes a community...** The Sarcoma Alliance would like to thank *everyone* who supported another successful year of the Ocean of Hope. Our ability to provide much needed services is dependent upon your generosity. We are truly grateful for these gifts. If you missed the opportunity to give, please visit us at [www.sarcomaalliance.org](http://www.sarcomaalliance.org) or call our office. Donations are always welcome. Mahalo and see you next year! 🌻

# “Roadster Rumble”

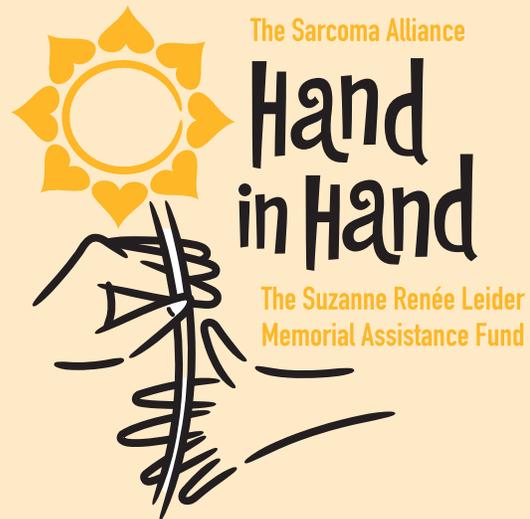
## And Raises \$40,000 For Sarcoma Support

THE “ROADSTER RUMBLE” ROARED INTO HIGH GEAR at the Joe MacPherson Automotive Museum in Tustin, California on October 1, 2005. It was the second annual fundraiser for *Hand in Hand: The Suzanne Renée Leider Memorial Assistance Fund*, which provides grants to sarcoma patients so that they can obtain crucial second medical opinions from sarcoma specialists. Guests enjoyed a roarin’ good time as they raised nearly \$40,000 to support this critical program.

The evening featured a delicious dinner served by 25 Carrots, a live and silent auction boasting many desirable items, and Elvis stand-in Phil Shane’s rock-n’-roll revival. Two hundred guests, decked out in their best 50’s and



60’s wear, rocked the night away. Sharon Leider chaired the event. She was assisted by a dynamic volunteer steering committee including Kim Baltzell, Sue & Neil Bershad, Jennifer & David Burlison, Suzanne Butnik & Albert Yesk, Stella & Nick Cretikos, Kellie Flynn, Marsha Gandin, Hillary & Jerry Hyman, Carole & Mike Kamper, Sue & Dennis Leibel, Stephanie Leider, Dorothy & Zane Leshner, Ruth & Ira Lott, Linda & Sandy Lyle, Edie & Jerry Mintz, Barbara & Herb Stern, and John and Myra Stillman. Jen Nelly Linton, Jen Hartfield and Tanya Pustelnik of Fiesta Florist provided beautiful floral arrangements. An extra special thank you goes to Marsha Gandin who not only chaired the auction committee but underwrote the cost of Joe’s Museum and to Jack Leider another generous underwriter.



The evening’s festivities opened with a cocktail reception and silent auction amid the vintage car and motorcycle collections. Over 100 items were donated for the silent and live auctions and included box seats at the Hollywood Bowl, a wine country package, hotel stays, artwork, clothing and wonderful meals donated by local restaurants. Charmian Carr, who played Liesl in the screen version of *The Sound of Music*, graced the evening with her beauty and donated signed copies of memorabilia from the film. A three-month-old shipoo puppy stole the show, charming everyone around the room before heading home with the highest bidders.

When the guests were seated for dinner, event chair Sharon Leider warmly thanked everyone for attending and told everyone: “Our daughter Suzanne saw a need, had a vision and began a journey of discovery and asked that we continue her work as her legacy. It has been a great honor to work with the community she inspired



during her short but meaningful life. Suzanne care about people, and they felt her love and responded by becoming a significant part of her commitment to live a conscious, purposeful

# Rocks Joe's Garage



life and not let cancer define who she was. My family and I are honored and humbled by the dedication of people in the community who have turned their love and admiration for her into a living memorial.”

Board President Philip Leider next thanked everyone for their support and highlighted some of the many programs the Sarcoma Alliance offers to support the sarcoma community. Philip then introduced Arthur Beckert, Executive Director of the Alliance, who explained why second medical opinions are so important and how the *Assistance Fund* provides hope and reassurance for sarcoma patients and their families, friends and caregivers.

The highlight of the evening came from Mary Ann Vaughn and Kellie Flynn, who have personally benefited from the Assistance Fund and other services and programs provided by the Sarcoma Alliance.

Mary Ann began by telling the group that her daughter, Meagan Johnson, who had received an assistance grant from the Alliance, was too ill to attend. However, both Mary Ann and Meagan felt it was an honor and

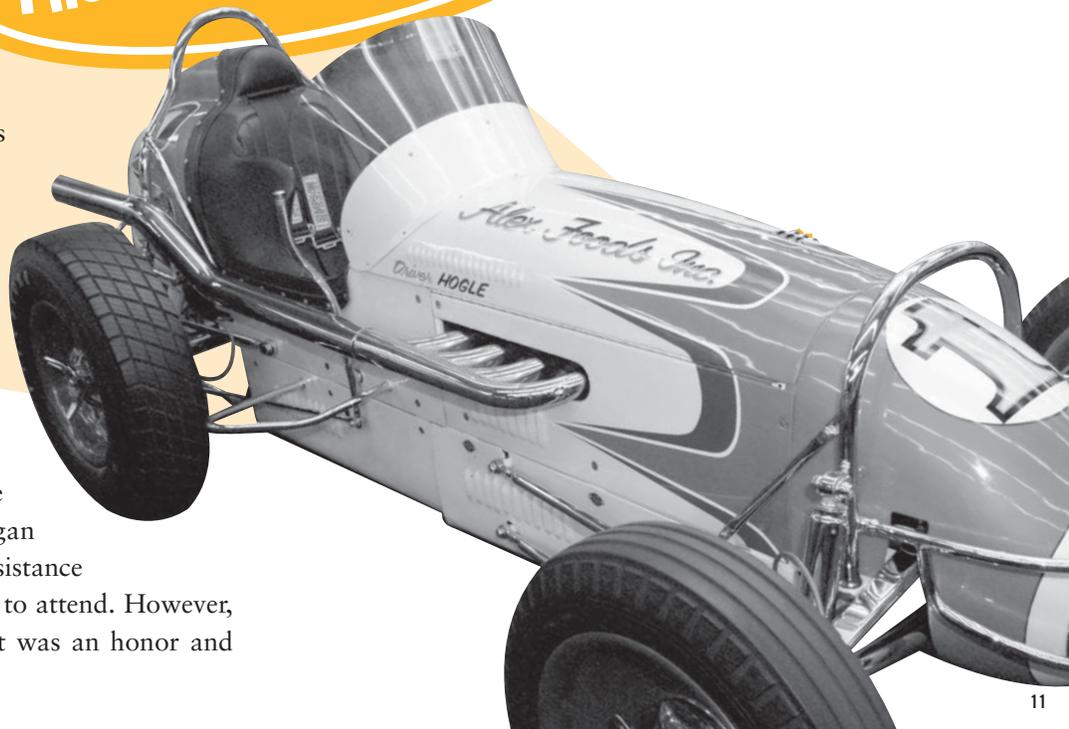
duty to share Meagan's story and convey how important the financial support from the Alliance was to them. Mary Ann explained that sarcoma is a terrible and frightening diagnosis. Because it is so rare, most physicians have very little, if any, experience with sarcoma diagnosis and treatment. The Assistance Fund removes a barrier to receiving the best care and provides tremendous comfort to sarcoma patients and their loved ones.

Kellie Flynn echoed the moving comments of Mary Ann and emphasized how the Sarcoma Alliance was the one place where she was able to receive information and support during her battle with sarcoma. Since that battle, Kellie has directed her energy to working as a key volunteer to the Alliance and the sarcoma community it serves.

The Roadster Rumble was the second fundraiser in what we hope will be a long line of gala events supporting the sarcoma community. For more information about the Assistance Fund or to join us as a volunteer, please visit our website at

[www.sarcomaalliance.org](http://www.sarcomaalliance.org)  
or call the office at 415-381-7236. 🌻

The Roadster Rumble



## New Board Members

### **Jeff Bradbury**

Jeff grew up with the Leider family and has been a long time friend of the Sarcoma Alliance. In 2001 he raised money for the Alliance by running in the Marathon des Sables, a 150 mile race across the Sahara in Morocco. In 2005 he was the moving force behind the successful Spirit of Survival walk/run in California. He is currently a product manager in the semiconductor industry.

### **Joan Darling, Ph.D.**

Joan's daughter was diagnosed with alveolar rhabdomyosarcoma, a pediatric sarcoma, in 1996 at the age of 13. She successfully underwent a year of treatment that included twelve rounds of chemotherapy, 28 doses of radiation, and five operations at Omaha Children's Hospital and at Mayo Clinic in Rochester. Joan is a biologist and works as an environmental consultant in Nebraska. Since 2001 she has volunteered as a Patient Advocate with the Children's Oncology Group (COG), the cooperative group that designs and implements clinical trials for childhood cancers, and she is a member of the Soft Tissue Sarcoma and Late Effects Committees as well as Long-Term Follow-Up Guidelines taskforces. In addition to her work with the COG, she volunteers in a variety of other patient advocacy roles, including co-managing the ACOR Rhabdo-Kids mailing list; serving on the board of Lincoln Candlelighters and facilitating the adult support group; attending the Sarcoma Advocate Summit in 2005; and contributing articles to ESUN (Electronic Sarcoma Update Newsletter). She hopes to contribute to the sarcoma community by representing pediatric sarcoma patients, who make up roughly 1,500 of the 10,000 sarcoma patients diagnosed each year in this country.

### **Jean-Laurent Vilon**

Jean-Laurent established Safran, LLC in Chicago with a goal of providing high end branding consulting for corporate businesses and the fashion industry and has worked with fortune 100 companies and major Hollywood studios.

Jean-Laurent found the Sarcoma Alliance after Laetitia, his sister, died of synovial sarcoma in 2002. He was putting together an exhibit of her photographs and wanted to do something to honor her and her story. The Paris exhibit was the culmination of his efforts and was a wonderful tribute to his sister and resulted in generous donations to the Alliance. Jean-Laurent brings skills in graphics, web design, marketing and branding to the Alliance.

# New Sarcoma Alliance Officers

## Ellen Silver — President

As Executive Director of PAC/LAC, a non-profit maternal and child health organization, Ellen has focused her efforts on assisting professionals and health care systems create comprehensive and seamless services to improve pregnancy and birth outcomes. To have a healthy pregnancy; multiple approaches and numerous services must be delivered and those efforts must be coordinated. Ellen teaches professionals and consumers strategies to advocate for enhanced services. Her role as an advocate was never as great as when her daughter, Shoshana was diagnosed with synovial sarcoma. Navigating the complex medical system of both services (surgical oncology, medical oncology and radiation oncology) and working within the guidelines of a health maintenance organization, Ellen used all of her professional skills to create a coordinated and seamless treatment plan for her daughter. Ellen has been active in all aspects of the Alliance with particular emphasis on grants and fund raising.

## Tracey Talley — Vice President

Currently serving as Chief Financial Officer of Valley Presbyterian Hospital, Tracey is known for his dollars and sense attitude in the Southern California health care industry. As a former Regional Vice President of Finance for Tenet Health Care in Los Angeles, Tracey managed a capital budget of \$60 million for 12 hospitals. Particularly close to Tracey's heart is his connection with the Sarcoma Alliance. A cancer survivor himself, he has worked diligently to spread the word about the importance of cancer research. Thankfully, Tracey's treatment was successful, and he continues to talk to other survivors about cancer and tells them to make sure to explore all options, just as he did. During the past year, Tracey has led the Alliance in the development of a strategic plan.

## Jared Holmes — Treasurer

Jared a synovial sarcoma survivor joined the board in 2005. After working for a full service financial corporation, Jared moved to sales in the window industry. He brings a strong financial background to the Alliance and as Treasurer will be valuable leader in the management of the Alliance's precious financial resources.

## Michael Ostland — Secretary

Michael is a Senior Statistical Scientist at South San Francisco biotechnology company Genentech, where he currently supports clinical trials in non-small cell lung cancer and ovarian cancer. Michael has seen the importance of support and education for cancer patients. He joined the Sarcoma Alliance to contribute to this under-served community and was the guiding force behind the successful launch of the Peer to Peer Program. Michael received a B.A. in mathematics from University of California, San Diego, and a Ph.D. in statistics from University of California, Berkeley.

# New Staff

## Arthur Beckert — Executive Director

Arthur joined the Alliance in the spring of 2005. He brings experience from 6 years in the nonprofit world and over 20 years in healthcare. Arthur spent over 10 years with the California Medical Association followed by San Francisco General Hospital and Blue Shield of California. He spent six years with Kids in Distressed Situations, a non profit based in New York. He is excited to combine his health background with nonprofit experience to give the Sarcoma Alliance greater visibility and to serve the sarcoma community.

## Judith Jaslow — Office Manager

Judith joined the Alliance last summer and brings 20 years of well-rounded experience in marketing communications, ranging from medical education, account and convention management, to market research. Her extensive background in healthcare includes the National Oncology Alliance (NOA), a group purchasing organization for oncology clinics, the International Mobile Health Association, Cubist Pharmaceuticals of Cambridge, Massachusetts, and FCB HealthCare/San Francisco.

She earned a BA from New York University and master's degree in Public Health from Yale University. Besides her love of travel, in which she indulged by serving as assistant director of a French cruise ship and leading tours in France, she tutors in French and exercises a flair for drama by performing her original monologues in Bay Area regional theaters. Judith resides in San Anselmo, California.