

you are
not alone

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



**Contributing Writers
and Editors:**

Arthur Beckert
Joan Darling
Suzie Siegel
Aimee Spector

**The Sarcoma Alliance
Officers and Directors:**

Joan Darling, President
Jeff Bradbury, Vice President
Ade Lawal, Treasurer
Denise Lapins, Secretary
Claude Alexander
Kathy Chambliss
Jared Holmes
Philip Leider
David Murphy
Kevin Plottner
Suzie Siegel
Ellen Silver
Tracy Snell
Marites Tullius
Jean-Laurent Vilon

Medical Advisory Board:

Laurence Baker, D.O.
George Demetri, M.D.
Burton Eisenberg, M.D.
Charles Forscher, M.D.
Robert Goldsby, M.D.
Linda Granowetter, M.D.
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 News

Summer 2009 • Volume 8, No. 1

Adjuvant Chemotherapy

Suzie Siegel

Suzie recently attended the annual meeting of the American Society for Clinical Oncology (ASCO) in Orlando, FL. Following is her report of one of the sessions. This report is also on the Sarcoma Alliance blog and includes helpful links.



Medical oncologists in sarcoma still disagree over the value of adjuvant chemotherapy (therapy in addition to treatment, e.g. surgery) for many subtypes, and that was apparent in a discussion at ASCO last month. The ASCO Daily News reported on it, but I'll add in some of my own notes.

Dr. George Demetri of the Dana-Farber Cancer Institute in Boston talked specifically about GIST. The other two doctors in the session talked about chemo in general for other subtypes. Session Chair Ian Robert Judson, MD, of the Royal Marsden Hospital, United Kingdom, noted that questions arise about the appropriateness of adjuvant therapies because of several factors. Soft tissue sarcomas are rare diseases, he explained, and there are conflicting data on the efficacy of chemotherapy as well as variations in clinical practice regarding the standard treatment for these diseases.

“We know that there are variations in response to these treatments among individuals, and unless we learn more about how to identify who is likely to benefit, we run the risk of administering a lot of unnecessary treatments with accompanying toxicity,” said Dr. Judson in an interview with ASCO Daily News. He noted that the physician must take into account the individual patient's level of risk tolerance, along with the best available evidence regarding the likelihood of benefit when deciding whether to initiate adjuvant therapy for these malignancies.

Robert S. Benjamin, MD, of M. D. Anderson Cancer Center, reviewed recent literature regarding adjuvant chemotherapy for soft tissue sarcomas. He noted that the Sarcoma Meta-analysis Collaboration in 1997 found that doxorubicin-based chemotherapy improved time to local and distant recurrence and overall recurrence-free survival; however, there was not a significant improvement in overall survival. After the 1997 study, ifosfamide was added to doxorubicin, and

(Continued on page 3)

Executive Director's Corner



This newsletter includes the names of those who generously supported us in 2008. We are so grateful that year after year so many show their belief in our mission and our programs that strive to help everyone affected by sarcoma. This past year was an exciting one. After changing the look and feel of our website in 2007, we have updated much of the site and added many new sections. These include:

- New pediatric section
- New section for adolescents and young adults
- A Peer to Peer program that has grown to over 500 people from 47 states and 16 countries outside the United States
- A greatly enhanced discussion board with eleven different forums
- An expanded financial assistance section. In 2008 our Assistance Fund program gave grants to almost 90 individuals seeking second opinions from sarcoma specialists, almost double from the previous year.

We are also working with many other sarcoma organizations and individual advocates to increase funding

from the National Cancer Institute for sarcoma research and clinical trials. Additionally, we are working to make sure that the needs of those who suffer from rare cancers such as sarcoma are part of any health care reform legislation.

So far in 2009 we have attended conferences of oncology social workers, oncology nurses and oncology physicians. We also met with representatives from the pharmaceutical industry to learn about the latest clinical trials. These conferences help to make sure that health care professionals are aware of our programs and services and keep us informed about the latest in sarcoma diagnoses and treatment.

This year is proving to be a challenging one for the Sarcoma Alliance, and we hope that you will continue to support us. Please inform everyone about the unique needs of sarcoma patients, families and caregivers and how the Alliance meets those needs. I hope 2009 is a year of great hope, promise and health. We always enjoy hearing from you about the job we are doing and what we can do to better meet the needs of everyone affected by sarcoma. Thank you. ☀

OTHER NEWS

Ocean of Hope



Our largest fundraising campaign of the year has begun. We hope you will consider a donation to the Sarcoma Alliance this year. If you will be in Southern California on August 30, please come to Manhattan Beach to volunteer or just to spend a wonderful day with other sarcoma survivors, families and friends and to meet the Sarcoma Alliance board.

eNewsletter

In order to bring news more quickly and efficiently we will be primarily sending out our newsletter by email. If you have received your copy in the mail it means we do not have your email address. To stay abreast of the latest Alliance activities, send your email address to info@sarcomaalliance.org.

ProSolutions Software Partners with the Sarcoma Alliance



The Sarcoma Alliance is proud to report that ProSolutions Software has designated the Sarcoma Alliance as its charity of choice. ProSolutions is the leading software provider for the management of spas and salons and will be donating up to 15% of the cost of software purchases to the Alliance. On behalf of everyone we help, the Sarcoma Alliance thanks ProSolutions for this wonderful partnership.

10-10-10

After answering if a newborn child is a boy or a girl, the proud parent usually smiles and says "and 10 fingers and 10 toes!" What would it be worth to you for you, your child or a loved one to keep those 10 digits? It could be as little as \$10!

As we celebrate 10 years of serving the sarcoma community, we are launching our 10-10-10 campaign — our most ambitious to date! Sarcoma is a rare form of cancer with a very high mortality rate — the most noticeable form affects patients in their arms and legs. As so little is known about the disease, quite often the recommended course of action is amputation. But that does not need to be the case. The Sarcoma Alliance provides direct support to those affected by this disease. But this can only be accomplished with your help.

To help thousands who are trying to keep their 10 fingers and 10 toes, simply go to www.sarcomaalliance.org.

We hope you'll join our cause and help make a difference!

Ocean of Hope Campaign begins with the Catalina Relay

By Aimee Spector



The 2009 Ocean of Hope campaign seems to begin earlier and earlier each year thanks to a wonderful group of paddleboarders and members of the Lanakila Outrigger Team. This year Aimee Spector is leading the charge with races dedicated to the Sarcoma Alliance and a fantastic raffle featuring a stand up paddle board from Joe Bark. The raffle was a tremendous success raising over \$4,000. Alicia Gaut was the very happy and excited winner. Thank you, Aimee for the great beginning to 2009.

Following is report of Aimee's latest adventures...

"I raced with my Lanakila teammate Shien Lu who is really awesome at pulling out the stops on race day. We both had an excellent race and were fired up the whole way. Jane Cairns, paddleboarder extraordinaire and Ocean of Hope team member, was our escort boat driver, so, come on, how could we go wrong?"

We left Catalina on Sunday to begin the race with grey overcast skies, a side wind and not much bump. In short, conditions pretty much stunk.

There were about 50 teams racing, a total of 110 paddlers, with three teams in our division. That doesn't sound like much I know, but this is 40 miles of grueling racing, so it comes down to the elite (or crazy, or both). My partner and I battled it out with another team the whole way

across, pretty much trading places until around mile 25. Then our rival team got a 3-minute lead, and we thought maybe all was lost. But Shien Lu and I are pretty phenomenal racers, so we decided we should just close that gap, and in less than 5 miles, we had. Then it was a dog fight to the finish. I would like to say we won, because that is an awesome ending, but we didn't. We finished a boat length behind, about 20 seconds. But honestly, it was one of the best races I have ever had. I couldn't have asked for a better partner, escort boat driver, or finish (well, unless we had won).

I had Tina Owens' name on my canoe across the channel (she died of sarcoma last year a few months after the Catalina Classic where Matt Belanger had her name on his paddleboard), and her husband Bill and daughter Sarah were at the finish to greet me. Slade and Kelly were also on the beach in full 02H regalia; I was proud to be racing as member of Ocean of Hope. I think it gave me that extra push when conditions were terrible, or when a change went wrong, or when Jane told me we weren't even 1/2 way there yet.

On a side note, the third place team came in about 45 minutes behind us. So a boat length isn't too bad at all!"

Talk to you soon,
Aimee 🌀

(Adjuvant Chemotherapy continued from cover)

that improved survival a little, he noted. Since then, other drugs have been developed or tried with sarcoma. He criticized a 2007 study by the EORTC, saying it was not representative of a global, random population.

He recommends neoadjuvant chemotherapy (therapy before other treatment, e.g. surgery), if possible, because it lets the oncologist judge whether the tumor is reacting to the chemo. In regard to adjuvant chemo, he would like to see doctors give more of it for a longer period of time. "I don't put much stock in the argument that chemotherapy doesn't work," he said. "We know that, yes, it works and no, it doesn't work nearly well enough. So we need to give more of it, not less. Stage III sarcomas are such a bad group of tumors that, even though we

know the treatment is going to be awful for the patient, not treating them is ethically unacceptable."

Dr. Benjamin suggested that clinicians should not approach adjuvant therapy for soft tissue sarcomas using the same rules for breast cancer therapies because of broad differences between the diseases.

He noted that breast cancer is more common and more homogeneous than sarcoma and therefore results in larger studies and more numerous therapies, whereas there are limited options for sarcoma. An abstract from the French Sarcoma Group, presented at last month's ASCO, found little benefit for grade 2 patients, but improved survival for those with grade 3. 🌀

Donors

sarcoma alliance 2008

Diamond Sunflower \$1000+

Aptium Oncology
Parveen Azam
David Bass
Valerie and Eugene Max Boyer
Scott Burke
Kathy Chambliss
Richard Cohn
Gina D'Amato
Maurice Duca
Rita Ferretti
Fleetwood Athletic Assoc.
Leah Funt
Marsha Gandin*
Genentech Foundation
David J. Goss
Bob Gray
Brad Green
Murray Halpern
Hotel Monaco
Harold Hyman
Lanco Corporation
Jack and Sharon Leider*
Philip Leider*
Christine Loeb
Nathan Lustman
Stuart Matsuda
John Oskin
Katherine Estes Rogers
Foundation
Jennifer Rowland
Jeff Schulein*
"Skadden, Arps,
Slate Law Firm"
Spin Master Ltd.
Stone Miller
James & Alice Storey
Robert & Kathy Sutton
Tracey Talley
Carolyn Tonkin
Chris Trent
Wells Fargo Foundation
Zolla Family Foundation

Platinum Sunflower \$500 - \$999

Anastasi Construction Co.
Harvey & Ruth Anderson
Rick & Ann Anderson
David Ayers
Michael Beach
Dr. Mark Bell
Mark & Monica Bottino
Bottino's Supermarkets

Mary Bradbury*
William David Caldwell
R. Flake Chambliss
Eric Choi
Brian & Jane Coffin
Patti Culpepper
Christopher DeRosa
Fritz Duda Company
Robert Dunklau
Bruce Giantonio
Lyndon Golin
H. Max Chuck & Kay Harrison
Erin Heimbinder & David
Yacubian
James Hormel
Host Connections International
Marilyn Jones & Mitchell
Kaplan
Stephanie Leider*
Dorothy Leshner*
Carol Lewnau
Michael & Susan Liebowitz
Chuck & Phoebe Loos
Joel Lucich
Glen & Marty Mcilvaine
Lessie Miller
Michael Mitchell
Michael Newmyer
Olukai 'Ohana (Family)
Philadelphia Door & Lock Co.
Scott Poulton
Wallace Reynolds
Gary Robertson
Saint Rocke/Fundraiser for
O2H
Larry Schneider
Suzie Siegel
Ellen R. Silver
Suzanne(Bovone) &
Timothy Smith
Mark Stout
Michael Streefland
Barry & Sharon Taylor
Michael Taylor
Stephen & Carole Taylor
Marites Tullius*
Chris Turner
Dave Walker
Michael Walker
Sandy Waterman
Sue Woodham

Golden Sunflower \$250 - \$499

Arnold's Safe & Lock Co.
Tony Audino
Kim Baltzell*

Bank of America
Matching Gifts
Arthur Beckert*
Belshire Environmental
Sue & Neil Bershad*
Susan Bielecki
James Bierig*
Norman & Donene Bird
Robert Booker
Rani Braun
Buck Construction
Jack Buckman
Tony Buckman
David Caskey
Sophia Chasabenis
Charles & Sherry Clark
Jane & Leroy Collins
Craig Cook
Nick & Stella Cretikos*
Bill & Josh Cunningham-Corso
Joan Darling
Lisa & Zack Davis
Michael Davis
George & Christina Derby
Sandra Doe
Troy Donoviel
Amy S. Doppelt*
Sandy Fainbarg
Carl Famiglietti
Kerry Flynn
Angie Frick
Kevin Garnier
Eleanor Gordon*
Green Contractors
Stephen Haley
Janet Holmes
Michael & Carole Kamper*
Mary Hoffman Keady
Ryan Kelly
Barbara Klein*
Brian Kleven
Susan Koenig
Francesca Kostrencich
Bryan Krupin
Leon & Tensel Leach
Chulbom Charles Lee
Susan Leibel*
John Leonardi
Ira Lott*
Mazen Madani
Michelle Maryott
James Matthews
Andrew Mazur
Tom & Anne McDermott
Lorna Meyer & Dennis Calas
Dr. & Mrs. Frank Meyskens*
Dave & Terrie Mileski
Janette Miller

Timothy Moore
Narvaez Law Firm, P. A.
Dennis Nellany
Jim Netzer
Tom & Candice Nguyen
David Oshinsky
Bill & Tina Owens
Billy Owens
Wendy Owens
Trevin & Kari Panaia
Frank & Donna Pedrick
Pivot Architecture
Steven Plenge
Gail & Steve Rinaldi
Rick & Dustin Robertson
Fred Sardisco
Sara & John Schifino
Kevin Scott
Denise Scrivner*
Matt Sherring
Wesley Sierk
Byron Snider
Barry Sopinsky
Ramona & Rod Spector
Rich & Pat St.Claire
Liz Steinfield
John Stillman*
Blake Stringer
Ronald Tamkin*
United Way of the Bay Area
US Mortgage Bankers
Jean-Laurent Vilon
Dr. Irwin Wedner*
Brian Weyman
Bill Worthington

Friends of the Alliance

Thomas Abaldo
Heidi Adler
Helaine Adler
Adobe Matching Gift Program
David Agler
Robert Albrecht
Victoria Alexander
Susan & Nelson Algaze
All-Sport Driving School
Craig Ames
Charles & Kay Anders
Lisa Anderson
Christine Anderson
Kay & John Anderson
Dave Andrews
Greg Andrews
Matthew Anhut
Applera Corporation
Bryan Arguello
James & Dorothy Arnold
Katy Arnold
Mike Arnone
Fred Armst
Mark Arranaga
Jackie Atkins
Julie Ayer
Kelly Ayer
David J. & Eleanor Ayers
Stephen & Marsha Backer
Jen Backus Davis
Chelsea Baier
Michael Bakos
Joan Bakst
Kathleen & William Balch
Louis & Mary Barba
Mike & Leslie Barber
Randy & Liz Barber
Denise Barma
John Barry
Joan & Raymond Bartell
Ann Batman
William Bauer
Ann Beals
Lois Beamesderfer
Siobhan Beebe
Kathy Ann Beezer
Dianne Belanger
Matt Belanger
Kate Beley
Tiffany Benkert
Aubree Benner
Hinda Beral
Robert Beranek
Jim Bergner
Guillaume Bernard
Ruth Bernstein
Sima & Milt Bernstein
Rita Bettino
Megan Bialas-Potts
Kasey Bielecki
Jen Bilik
Lori Bilker & Gregory Kong
Sylvia Binley
Frank Bird
Cory Bird
Jordyn Black
Brian Bloodgood
Debbie Bodan
Maureen & David Bodo
Body in Balance
Carol Boice
Abigail Bomba
Damon Paul Booth*
Brian Bosse
Stacey & Sean Bowe
Annelisa Bowers
Linda Boyer
Wendy Boyer & Amy Jensen
Charles & Michele Bramley
Charlie & Helen Brand
Ellen Breger
John Brennan
Chris Brennan
Andrea Brewer
Jim & Robyn Bridges
Dick & Kathy Brigance
Kimberley & David Brisbin
Theresa Brisbin
Joseph & Angela Broderick
Dorothy Brookins
Brooks Enterprises
Constance & Richard Brown
Robin Brown
Slade Brown
Amy Brown
Harry Brown
Phyllis Brown
Fran Brown
Robert Brown
Erica Brown
Carl & Esther Browning
Scott Brownsberger
Whitney Bruice
Betty Bryan
Harry & Alyce Buckman
Timothy Buckman
Kerry Buckman
Kent Buesking & Carol Tom
Michele Burk
Janice Burns
Mary Burns
Sandy Bursten*
Bernard Burzinski
Mark Buscher
Jeff Busey
Lucy Bush

Cliff Butcher	Jeanne Cunningham	Curtis Farrell	Nick Grungo	Innovative Media & Marketing
LuEllen & Michael Buzzinotti	Jennifer Cusano	Nico Fasano	Julie Guthrie	Innovative Silicon
Cadence Design Systems	Paula Cushing	Kristin & Michael Fay	Gena Haddox*	William Ireland
Margie Cambra	Ronald Damore D.D.S.	David Fazio	Michael Haley	Barbara Isaacs
James Cammarata	Jon & Briana Danielson	Joe Feeney	Susan Haley	Kristine Iwakoshi
Karen Joy & Ronald Campbell	Priscilla Dann	Chad Feiler	Liz Hall	Maria & Hiraku Iwano
Robert Campbell	Carrie Darling	Monika & David Feinberg	Karen Halstead	Brian Iwano
Allison Capaldi	Tim & Karen Dasey	Louise Feinberg	Jonathon Ham	Craig Iwano
Capitol Hill Mansion, Inc.	Pierre Daublain	Gaylene Feldbush	Phil Hamburg	Judith & Grant Jackson
David Capka	Zack Davis	Jay Feldman	Chris Hamilton	Bette Jean Janicke
Jennifer Capo	Bill & Debbie Davis	Larry Felix	Pauline Hammack	Trisha Jenks
Joyce Carey	Jennifer Davis	Meg Fender	LeeAnn Hancock	Beverly Johnson
Ann Marie Carinalli	Stevee Davis	Regina Fennewald	Christine Hansen	Celeste Johnson
Leonard Carlin D.D.S.*	Patricia Davis	Max Fennewald	Betsy Hanson	David Johnson
Marie Carr	Martin & Ruth Davis	Julie Ferguson	George & Rosemary Hardy	Mike Johnson
Brenda Carter	Dazzy O's Bar & Grill	Gina Fermil	Cheryl Harkenrider	Elizabeth Johnston
Joseph Cartlidge	Claudia De Fries	Mary Ann & Michael Ferretti	Tavia Jane Harpending	Rachelle C. Jones
Tisa Casas	Edward De'Avila	Robert F. Ferretti	Judy & Jim Harrington	Trudy & Ronald Jones
"Castle Marne, LLC"	Maria & Miquel De'Avila	Steven Ferretti	Karen Z. Harris*	Charles Jordan
Theresa Castro*	Virginia De'Avila	Virginia Fickes	Dani Hart	Georgine Jorgensen
Lori Cavagnaro	Victoria DeGoff	Arlene & Steven Fienberg*	Tami Hart	JP Morgan Chase Foundation
Frank Cavallaro	Elisa Delapena	Arleen Figaro	Tom Harvey	Dana Julian
Jeffrey & Debra Cease	Robert Delgado	Amanda Fisher	Dina Hataishi	Sarah Kailath
Jarretta Chaffin	Keith Deloach	Clint & Yvonne Fisher	Pamela Hauptert	Susan Kamberos*
Hilary Chambers	Spero Demoleas	Christine Fitzpatrick	Terry Healey	Louis Kamberos
Brian & Katey Chamblin	David Deutsch	Michael Fleischauer	Don Healey	Bill & Peggy Kantaros
Maria Chan	Marlyne Diamond*	Jason Flick	Brian Healey	Roger Kaplan*
Susan Chandler & Dave Borgmann	Jess DiFrancetsco	Kellie & John Flynn*	Melba & Herbert Heck	Christine & Kiley Kasian
Carol Charnay	Larry Divney	Pat Foley	Jennifer Hedayat	Sho and Yoko Katsuyama
Tom Chiarine	DKD Property Management	Glenn Fout	Hans & Linda Heinsen	Sharon Katz
Leslie Chinchin	Bradley Dock	Bill Fox	Linnea Hemenez	Sherri & Fred Katz
Peter & Lisa Cicione	Docs Auto Wholesale	Rosemarie Franklin	Jennifer Henerlau	Mary Elizabeth Keady
Lisa Clapper	Stacey Doe	Martin Fuchsmann	Tracy & Steve Henneberry	Loni & Tim Keane
Jamie Clark	Charles & Kathryn Doerr	Robert Fugimoto	Doug Herich	Alice Kelly
Geralin Clark	Etty Dolin	Phil & Nancy Fullerton	Holly Hering	George & Stacey Kendall
Kelly Clark	David Dolotta	Richard Funnell	Vickie & Josh Herron & Family	Patrick Kennedy
Richard Clark	Phyllis Domm	Jillian Gaffney	Denise Hertle	Emily & John Kennedy
Jodi Clark	Mike Donaghy	Nora Gallick	Donald Hesselbach	Tim & Robin Kennedy
Ralph & Carol Clayman*	Cynthia Donald	Darlene Galvin	Kathleen Hetzel	Lauren Klein
Melissa Clemens	Tara Donnelly	Cara Gamberdella	Constance Cooper Heytink	Larry Kleman
Mark Clement	Lisa Donovan	Gary Ganz	Janice Hickey	Larry & Seta Kleven
Jim Clements	Jean Doub	Bruce & Linda Garbett*	Jessica Hicks	Cheryl Klishch
Rhonda & David Clinkscale	Carole & Raymond Dougherty	Stacey Garmshausen	Charlotte High	Jason Knee
Sterling Coberly	Linda & Daniel Dougherty	Nina Gaston	Mike & Faye Hill	Eunice Koch
Ashleigh Cole	Tom Dowd	Mark & Amber Gatej	Shari Hinish	Mary Kocinski
Iris Collazo Beauchamp	Brigid Dowd	Angie Gee	Teiva Hirshon	Stephen Koffler*
Maura Collins	Dr. & Mrs. Allen Drapkin	Dan Geiser	William Hoanzl	Jason Komes
Beverly Collins	Laurel Dubb	Glenda Gelster	Andrea Hoberman	David Konigsberg
Jeff Collins	Denise Duclos	Sandra & Richard Gerber	Charles Hochstedler	Kerry Konrady
Bunny Comitale-Cowgill	Carol & Normand Duclos	Robin Gerhard	Rolf & Joan Hoerauf	Michelle Korrell
Lawrence Conley	Barbara Dugal	Elizabeth Gershon	Robert & Julie Hoffman	James Kostoryz
Margaret Conley	Joyce Dunigan	Bob Giandonato	Amy & David Hoffman	Frank and Karen Kostrencich
William Conn	Kevin Dunlap	Keith Gibbons	William P. Hogle Jr.	Robert Kraft*
Amy & Nick Conti	Marjorie Durante	Keith & Jen Gibbs	Ron & Barbara Hohenstein	Arthur Krause
Judy & Bob Cook	Linda & Douglas Dusseau	Kyle & Diane Gillis	Terry & Liz Hoiland	Larry Kravet
Christopher Cook	Richard Duvall	Timothy Gilmore*	Richard Holdaway	Gary & Catherine Krewer
Jamie Cook	Bradley Dycus	Howard Gitlin*	Manuel Holguin Jr.	Michael and Sharon Kronenberg
Erin Corbett	Benjamin Dyett	Bob Gleason	Judi Holmes	Robert & Sophie Kubichek
Kevin and Angela Corcoran	Ian Eastman	Joshua Glenn	Barb Holyoke	Matt Kucinski
Kathleen Corcoran	Bob & Alice Eckles	Richard & Jolee Godino	Home Source	Martin Kudo
Matt Cordeiro	Don & Kellie Eckles	Miriam & Lawrence Goldberg	Jeff Honea	Bill Kuhn
Ann Corin	Josh & Terri Edwards	Norton Goldman	Karen Hooper	Robert and Karen Kushell*
Erica Corner	Shirley & Ken Elkington	Daniel Gomez	Paula Hoppe	Annie LaBarge
John Cotugno	Denise Elliott	Ambrose Gondola	Tom Horton	Charles LaFlamme
Thomas Coughlin	Ed & Ruby Elsner	Sol Gonzalvo	Kathryn Hospodar	Marion Lam
Susan Coulbourne	Gary & Pamela Elster	Victoria Gooch	Louise Howard	John & Alice Lamalfa
Marilyn Covey	Bob Endt	Mark & Sandy Graboyes	Peter & Lynn Hubble	Margaret Lambe
Tim Cowherd	April England	Janet Grant	Charles Hudes	Abbe Land
Lisa Cowley	Paula Erickson	Daniel Greulich	Linda & Bob Hughes	Julia & Fredrick Land
Steve Coyne	John & June Ernst	Sheila & Charles Griffin	Mary Hunt	Gregory Lash
Emilie Cresp	Elodie Espeset	Griffin Ace Hardware	Andy Huntington	Rich and Debbie Laskowski
Renee Croce	Terry Everett	Ray Griffith	Marilyn Hurst	Birthe Lauchengco
Rich Cronin	Stephen & Susan Faessel	Rose Griffith	Robertta Hutchins	Gregory & Coleen Laurent
Cynthia Cruse	Michael Fairchild	Michael Grimes	Amy & Michael Hyatt	Neil & Lois Layden
Carlos & Henedina Cruz	John & Susan Fansmith	Matthew Grosinger	Heather Ijams	Laura Y Lee
Joseph Cserepes*	Edward & Susan Fargo	Grossman Family	Leah Ilan	Michael Lee
Culture & Heritage Museums	Jeff Farrell	Leann Grover	Lois Anne Indorf*	Gary & Vickie Lee

Lavonda Lee	Stephanie McNamara	Marla Osinski	Robert M. Resnick*	Leni Sequitin
Sarah Belle Lee	Elise McVeigh	Aspen Padilla	Jamie Reyes	Laura Setteducate
Carole Leff	Margaret Mead	Cristina Pajo	Carrie Reynolds	Therese & S. Scott Shafer
Jamie Leff	Ida Melucci	Janet Palaniuk	CAtherine Rhodes	Mike Shaffer
Esther Leider*	Mary Lou Menley	Eleanor Palk*	Francis & Joan Riffel	Rachel & Michael Shaffer
Jeff Leider*	Bree Mercer	Kenneth Palley	Karen & Kent Riley	Mickie Shapiro*
Amy Leifer	Robin Meyen	Elisa & Christopher Palm	Jay & Sally Robert	Jill Shea
Frances Leonard	Kristi Meyer	George & Kathleen Palmer	Kesler Roberts	Nancy Sheehan
Jay Leonetti	Edward & Diane Meyers	Tasha Pappas	Ann Roberts	Shellback Tavern
James Leonetti	Edward Meyers M.D.	Paradigm Winery	Chris Robertson	Samantha Shenkle
Christine Lepold	Microsoft Matching	Parke Bank	Ronna Robertson	Mort & Debbie Sherman
Marissa Levinson	Gifts Program	Vince Parretta	Jenna Robinson	Joan Shetter
Nicole Lewon	Esther & John Middlemass	Juli & Kenneth Parrott	Shauna & Henry Robinson	Audrey Shoji
Irwin and Eleanor Light	Robert & Edna Miklos	Dipte Patel	Doral Robinson	Dana Shrader
Thomas & Joan Lindsey	Mohammed Milhem	Jerrilyn & Frank Patrick	Diana Rodriguez	William & Mildred Sievers
William & Paula Linge	Terri Millard	Valerie Patscheck	Karen Rodriguez	Sign Depot
Guy & Aretta Lingo	Joan Miller	Jared & Amanda Patterson	Ron Roebuck	Hugh & Carolyn Silver
Mark & Kumi Lipe	Christine Miller	Jennifer Pavelka	Joseph Rogers	Nancy Silver
M. John Lippman*	Gretchen Miller	Mark & Barbara Pedrick	Joel Rogers	Michael & Ethel Silverman
John & Ailene Littrel	Dolores Miller	Frank & Dolores Pedrick	Michael Rogerson*	Steven Silverstein
Karen Conrad Livingston*	Carol Miller	Amy Pedrick	Patricia Romine	Robert Simon*
Sean Loftus	Lillian Modzeleski	Mary Pedrick	Laura Rose	Alexandra Simoncini
Scott Lohman	Carolyn & Leland Moede	Mantha Peeler	Betty Rossi	Leora Singer
Dana F. Longo	Debbie Mogil*	Tim Pelle	Francis Rossi	Donnie & Karla Sladek
Sara Loos	Ricky & Shelley Montgomery	Joanne Pena	Raymond Rossi	Kathleen Slane
Helaine Lopes	Melissa Monti	Tim Penczar	Joseph A. Rossi	Linda Small
Kelly Loux	Susan Moon	Ira Perlman	Kara Rossi	Joan & David Smedley
Ray Lovell	Kelly Moore	Mark & Kristen Perlmutter	William Rouse	Bruce & Maureen Smith
Heidi Lovette	Gina More	Dan Peterson	Harold W. Rudolph	Amy & Tim Smith
Andrew Loyst	Meg Moreta	Marilyn & George Peterson	Robert Ruggeri	Andrew Smith
Sanford & Linda Lyle	Dan Moriarty	Kevin Peterson	Jaime & Sharon Ruiz	Cay Smith
Kelly Lynch	Robyn Morningstar	Ronnie Pezeshk	John & Marion Rundle	Suzanne Smith
Beth & Bruce MacDonald	Linda Morris	Kelly Pierce	Scott Rush	Bradley Smith
James Mackay	Margaret Morris	Susan Pierce	Richard Russell	Laurie Ann Smith
Charity Mackey*	Ted Morris	Anne Pilat	Virginia & Harold Rutherford	Douglas Smith
Carolyn & David Macy	Mary Morrissey	Dominick Pisano	David Rutt	Don Smith Jr.
Marianne & Roy Madden	Louis Mosconi	Darren Pitzele	Stacey & David Ryan	Kirby & Angie Snider
Michael Magilton	Janice Moseley	Maria Planas	Leslie B Ryan	Steve Snook
Sheryl Main	Sam Moser	Terry Plawker	Stephanie Saito	Richard & Dolores Snyder
Laura Maki	Micaela Moskos	Kevin Plottner	Vince Salem	Marcela Sobie & Mary Paul
Bernice Malkin	Jen Mullen	Larry Poindexter	Jovita Salinas	Andrew Sohn
Kathleen Malosh	Mullen & Reagan	Marni Poll	Lisa Salter	Virginia Solari
Jon Maltz	Mungo Marketing	Muriel & William Porter	Samson, Wahl & Associates	Lois Song
Daniel Mangel	KellyAnn Murphy	Rachel Posner	Michelle Samuelson*	South Bay Jr. Athletic Group
David Marcum	Ron & Liz Musolino	Abraham Pottish	David Sandor*	Cathi & Jim Spear
Marina Rel Rey Canoe Club	Lynn & Nicholas Musulin	Ingrid Poulin	Jeanne Sandor	Scott & Debbie Spear
Susan Mariner	Matt Naborak	David Powers	Katie Sanford	Sandor & Elaine Spector
Julie Marino-Garret	Ken Nagdev	Dianne Powers	Sabri Sansoy	Jennifer Spegal
Mark Markland	Star Nagdev	Jimmy, Page, Cooper &	Joseph & Robyn Saracco	Ellen Speyer*
Brian Marks	Lori Nakama	Hudson Powers	Maxine Sassano	Karen Spillane
Lee & George Marks	Sharin Nakayama	Sarah Pretti	Stuart Sato	Heidi Springer
Susan Marron	Janet Neary	Charlotte Price	Tim Scanlon	Dana Staggs
Ashley Martin	Jayne & Bruce Neary	Jennifer Prince	Gina Schaefer	Mary Stanfield
Nira Maslin	Heather & Matthew Neborak	Carrie Pritchett	Linda & Robert Schafer	Kendall Starnes
Michelle Massie	Forrest Nelson	Danielle Puteri	Steve Scheinfeld	Kirsten Starsiak
Helen Masterson	Dr. Ed Nevin*	Steve & Melinda Putnam	David Schlaeger	Robert & Carol Staszewski
Materials Research & Design	Tom & Jane Newman	Matthew Putney	Amy Schlemo	Doug & Courtney Stefano
Clark Matson	Noreen Neyrinck	Charlie Quaid	Carol Schlesinger	Mike Stefanskiewicz
Marsha Maus	Louise & Herb Niekerk	Tony Quesada	Schmid Family	Harley Stegman
Alice McCarthy	Alan Nishio	Scott Quick Jr.	Rick Schoch	Frank Steinfield
Jim McCaverty	Nicholas Noonan	Rabbi Arnold Rachlis*	Kenneth Schorr	Joe Steinfield
Patrick McClain	Karen Noppe	Mark & Sharon Raivetz	Dawn Schroeder	Adela Steinman
Martha McClarty	Gertrude Noskin	Kristine Rajczyk	Gordon Schroyer	William Steinmetz
Regan McCurdy	Alison Novak	Reenie Ramirez	Mark Schulein*	Cory Stepanek*
Kevin McDonald	Josephine O'Con	William Raskin*	Bill Schultz	Mark Stephenson
Shirley McDonald	Lois Odabash	Kristin Rasmussen	Tracey Schwartz	Herb Stern*
Jack & Patricia McDowell	Mearl O'Dell	Allen Rasor	Eric Schweiker	Kyna Sternlight
Mike McElroy	Richard O'Donnell, MD*	Mikii Rathmann	Phyllis Scirrotto	Patricia Stevens
Tim McElroy	Brian & Mary O'Donnell	Tom & Kathy Rawdon	Bill Scola	Debra Stiles
Mark & Laurie McEvoy	Jennifer & Patrick O'Donnell	Linda & Charles Ray	Stephanie & Richard Scott*	Wendy & Michael Stillman
Kristan McFadden	Sue Okoroski	Scott Recknor	Dolores T. Scott	Raymond & Evangelyn Stokes
Tom & Chris McGivern	Anne Oliphant	Claire & Edward Reda	Annie Seawright	Linda J. Stoll
Judith & Thomas McGunnigle	Nellie Olsen	Derek Redfield	Dale Seay	Steen Strand
Greg & Mollie McLvaine	Darby O'Neill	Scott Reed	Eric See	Seth Streeter
Dan & Suzy McInerney	Linda Onisko	Stewart Reid	Barbara Segal*	Angela Stringer
David & Jamie McLain	Original Pancake House- Poway	Ronald Reilly	Scott & Jan Sell	Theresa Stronski
Donna McMahan	Mike Osinske	Robin Reiner	Paul Selluck	Evan Studer

Barry Stultz
 Barry Sturner
 Melanie & Karl Sublett
 Gerald Sufrin
 JB Sugar
 Elaine Sulzer
 Jeanette Sunderland
 Dawn Suskin
 Heather Suskin
 Diane Suskin
 Shirley Swanson
 Hillary Sweeney
 Rick & Patricia Sweeney
 Daniel Sweeney
 Gin Takahashi
 Carol Tanner
 Lillian Tarring
 Scott & Tricia Taylor
 Linda Teague
 Shelah Teeters
 Dorothy Terman*
 Debbie Terman
 Art Thayer
 Linda & Ward Thayer
 Kim & Steve Theiss
 Carol & Raymond Theriault
 Michelle Theriault
 Jaala Thibault
 Nancy Thistle
 Helen Thole
 Rhonda Thomas
 Duncan Thomas
 Joanne Thomas
 Karly Thomas
 Patti Thomas
 Christopher Thompson
 Ann Thompson
 Hal Thomsen
 John & Sarah Thomson
 Greg Thorne
 Marisela & Erik Thorson
 Matthew Till
 Raymond & Margaret Tirado
 TLG Medical Products
 "TM Ventures, LLC."
 Doris Tobias
 Laura Tomsco
 Pamela & Paul Tomsco
 Cindy Torbert
 Tom Torpey
 Stephan Tow
 Kathleen & Steven
 Trachtenberg
 Kellen Trachy
 Joan & Donald Treat
 Nick Trotta
 Anne Marie Troyano
 Dennis Tschacher
 Todd Tucker
 Joyce Turkovich
 Tyra Turner
 Twin Rivers Plumbing, Inc
 Nicole Urso
 Greg Van Dyke
 Erich Van Stralin
 Guy Vandenbrink
 Anne Vandercook
 Michael & Gina Varra
 Linda Vaz
 Todd Villeneuve
 Claudia Villicana
 Julie Vilon
 Valerie Vivian
 Dustin & Jen Voag
 Kathleen Voelz
 Catherine Von Euw
 Robin & Kenneth Wagner
 Gary Waldron*

Greg Walker
 Rich Walker
 John & Lynn Wallace
 Shelley & Peter Wallace
 Ralph & Karen Wallem
 Stewart Walsh
 Diane Walstrom
 Ryan Wand
 Mike Wang
 Tena Ware
 Kelly Webb
 David Wechter
 Mort Wedner
 Shell Weinberg
 Gerry Weinstein*
 Emily Weiss
 Victoria Wells
 Clark Welton
 Pauline Wen
 Pearl Werber
 Rich Wessel
 Susan West
 Kelly & Glen West
 Robert & Lisa Weyman
 Laura Whisenant
 Vicki Whitacre
 Alycia Whitmore
 Louis Wiener*
 Brett Williams
 Debra Williams
 Brent Willman
 Maureen Wilmot
 Laura Wilson
 James Wineland
 Kenneth & Barbara Wineland
 Irvin & Rosalie Winesuff
 Andy & Angie Wood
 Dr. Marvin Worcell*
 Bill Wygal
 Bob Wyler
 Sam Wyman
 Margo Wyman
 Richard Yacenda
 Suzanne & Al Yesk
 Ken Yonkers
 Michelle Yrisarri*
 Chris Zalewski
 Marc Zalinsky
 Brain Zatonni
 Stuart Zimmerman
 Ann Zopatti
 Helen Zoppie
 Norman Zuckerman*
 Joseph & Teresa Zuhoski

Donations were made in honor of the following individuals

Nick Alford
 Matt Belanger
 Gene Boyer
 Jeff Bradbury
 Kelly Brown
 Slade Brown
 James Buckman
 Tony Buckman
 Jeff Bujer
 Jane Cairn
 Jennifer Capo
 Mary Ann Cashman
 Lori Cavagnaro
 Jason Clapper
 Chad Crittenden
 Kyle Daniels

John Dasey
 Peter De'Avila
 Carolyn Faeth
 Bob Ferretti
 Mark & Sandy Graboyes
 Tiffany Graley
 Terry Healey
 Jared Holmes
 Bob Horn
 Russell Jones
 Doreen Kossove
 Kendra Krause
 Philip Leider
 Suzanne Leider
 Scott Loos
 Charlie Lustman
 Made Me Nuclear
 Kelly Magee
 Daniel Mariner
 Jay Miller
 CJ Morgan
 Jim Netzer
 Tina Owens
 Michael Pedrick
 Matthew & Alethia Pettine
 Kevin Plotner
 Christina Powers
 Seth Raivetz
 Ashley Robertson
 Ron Roebuck
 Jennifer Rowland
 Fred Sardisco
 Mark Schulein
 Ellen R. Silver
 Hugh & Carolyn Silver
 Shoshana Silver
 Chad Smith
 Brian Spear
 Dave Stringer
 Heather Suskin
 Tracey Talley
 Brad Thomas
 Ashley Thompson
 Jason & Micheline Villeneuve
 James Whitman
 Brett Williams
 Women's Team Lanakila

Donations were made in memory of the following individuals

Nana Allen
 Bryan Ayer
 Marisa Baker
 Fred Barma
 Lewis Belanger
 Eli Benjamini
 Susan Bohardt
 Richard Bovone
 Michelle Brides
 Quillion Brwon
 Michael Burress
 Sarah Burstein
 Will Bush
 Allison Cappabianco
 Robert Chambliss
 Kevin Cheda
 Erin Ching
 Teddy Collar
 Pat Croliss
 Patrick Dugal
 Bob Ferretti
 Lloyd Figaro
 Jacob Frick

Richard Gandin D.D.S.
 Mary Gleason
 Steve Grant
 Laurie Greener
 Russell Grimes
 Margaret Hagen
 Rose Hand
 Daniel Holyoke
 Lin-Chia Hsu
 James Jones
 Miranda Keane-Moore
 Cammy Krank
 Paul Michael Krewer
 Michael Francis Laviola
 Suzanne Leider
 Jeff Lewnau
 Sam Loeb
 Carol Lucking
 Jeanne McClain
 Jack McClarty
 Rita McClean
 Ward Glen McConnell
 Joe McKenna
 Gary McNamara
 Daniel Meaney
 Scotty Mendoz
 Dennis Mergo
 Albert Meyer
 Linda Middaugh
 Frederick Kevin Miller
 Shelly Mills
 Heather Montaganoo
 Andrw Nolt

Charles Oskin
 Tina Owens
 Michael Pedrick
 Margie G. Pisani
 Kim Pohlman
 John Warren Potthoff
 Carlos Ray
 Connie Reynolds
 Brent Ritchey
 April Kinchloe Roberts
 Ashley Robertson
 Sue Rogers
 Jon Rowland
 Kelly Ann Russell
 Ed Shelley
 James Shoji
 Ron C. Smith
 Wendy Sommers
 Andrew Staszewski
 David Steelman
 Cal Thomason
 Ron Tonkin
 Charles Travelsted
 Jamie Turkovich
 Luis Vazquez
 Michael Steven Weiss
 Edwin Werber
 Arnold Wermes
 James Westerlund
 David (Willie) Williams
 Jim Wilson
 Amalie Wolf
 Pae Yeung

Special thanks to our volunteers

Jenny Bolsky – For doing our taxes

Jennifer Capo - For the *Give It, Get It* fundraiser in Los Angeles

Lori Cavagnaro – For *Date of the Decade* fundraiser in Colorado

Ferretti Family – For the *Bob Ferretti Walk* in memory of Bob

Sharon Leider – For *Assistance Fund Program* fundraising

Jennifer Nellany – For *Putts for Ped*, an afternoon at the golf course in memory of her husband

Mark Schulein – For leadership of the *Ocean of Hope* Team

Aimee Spector – For leadership of the *Outrigger* Team

Barney Tong – For taking wonderful *Ocean of Hope* pictures

Guidance, Education & Support
 Since 1999





Letter from the President **Joan Darling**

In 1996 my life took the terrible detour that comes when one first hears the word sarcoma. In my case, it was my 13-year-old daughter who was diagnosed with rhabdomyosarcoma, one of the three types of sarcoma that is more likely to affect children than adults. Fortunately, she was among the lucky 50 percent of kids with her type and stage of rhabdo who survived. In the intervening years, I've tried to make the best of that unexpected turn of events by volunteering my time with a variety of sarcoma and pediatric cancer organizations. Three years ago, I was honored to be asked to join the board of the Sarcoma Alliance, and more recently even more honored to be asked to be Board President.

Why do I volunteer for the Sarcoma Alliance? Because it is unique among organizations. It is the only national non-profit that is focused exclusively on support, education and guidance of people affected by sarcoma. Some might wonder why we don't raise funds for research, but that isn't our mission. Our mission is to help the person who has just been diagnosed with a type of cancer they've never heard of before; who is searching for the best possible treatment option; who is in the midst of a difficult and scary treatment; who has upcoming scans and is worried about relapse; who is a survivor concerned about long-term effects of chemo or radiation; or who is a

caregiver and feels no one else understands their life right now. Those are the people who need a useful suggestion, a friendly word, a helping hand; who need to know that they are not alone. Those are the people who need the Sarcoma Alliance.

The year 2009 is an historic one for the Sarcoma Alliance as we are celebrating our 10th anniversary. Many Board members and other volunteers worked hard during that first decade to make the Sarcoma Alliance what it is today, and although I'd like to thank them all by name, the newsletter editors would have a fit! Let me just mention the efforts of the previous board officers: Ellen Silver, who made the position of President of the Board seem so easy; Tracey Talley, who as Vice President always focused on the true mission of the Sarcoma Alliance; and Jared Holmes, who as Treasurer kept the rest of the board well-informed on our financial condition. Building on the work of the past, we are launching an exciting new way to raise both sarcoma awareness and funds to support our programs: 10-10-10. This newsletter contains information on 10-10-10 as well as our signature event: Ocean of Hope.

On behalf of all of us at the Sarcoma Alliance, I look forward to a second great decade of serving you, the people affected by sarcoma.

sarcoma alliance

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

NONPROFIT ORG
US POSTAGE PAID
PERMIT #191
SANTA ROSA CA

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.