



Letter from the President

We can't do this alone...

Over the years, The Sarcoma Alliance has been fortunate to have the support and dedication of many volunteers — all of whom have added an important 'something' to the organization. This newsletter is dedicated to all those who have given of themselves, their time and their expertise to help strengthen the programs and services of The Sarcoma Alliance. Several of our talented volunteers are featured in this newsletter; please join me in thanking them for their service.

The Sarcoma Alliance's programs and services are expanding and therefore the need for volunteers is growing. Would you like to get involved? There are many opportunities for onsite and virtual experiences. Are you wondering "What can I do"? Here are some ideas: create a fundraising event in your neighborhood or town, write your story of hope and inspiration to be placed on the website, become a "peer" in the network, or call Arthur Beckert at (415) 381-7236. In advance, I thank you!

Ellen Silver

sarcoma alliance

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announcements



Sarcoma support groups meet regularly in Los Angeles, CA; Greenville, SC; Houston, TX and central Wisconsin. Visit our website for meeting times and other details.

sarcoma alliance *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.*

- *August 27, 2006 Ocean of Hope Celebration in Manhattan Beach, CA*
- *October 29, 2006 Spirit of Survival West, Stevens Creek Park, Cupertino, CA See website for details.*

THE SARCOMA ALLIANCE NEWS

2006 Volume 5 No. 2

Spirit of Survival East Caps Sarcoma Awareness Week — June 18th

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ON A SUNNY NEW YORK MORNING in the heart of the city — Central Park — friends, family and sarcoma heroes gathered to share stories, meet others and raise awareness of sarcoma. Sarcoma Awareness Week ended with excitement as 20 advocates walked the reservoir of the infamous park. There was one common thread that linked them all together — sarcoma. The T-shirts (designed by new Board of Directors member Daphne Yousem) told the story

for all to see, “Replacing the scars of sarcoma with the **hope** for a cure”. A stranger in the park approached the walkers to share his story of his wife’s sarcoma many, many years ago. Leading the pack of walkers was Miriam Goldberg, the top fundraiser for this event. Her enthusiasm was shared by all who attended. But no greater energy was exhibited than that of the Cordes family who came from Connecticut to honor their son, Andrew, who is two years disease free from synovial sarcoma. Andrew, 6, was a bundle of energy as he showed off his tattoos marking the site of his radiation treatment. His big brother Tyler watched out for him as they frolicked in the park, chased pigeons and made a valiant effort to scale a tree in the Arthur Ross Pinetum. Many thanks to all those who made this a wonderful day including Susan and Lauren Herzog, Carl and Savannah Lennertz, Nancy Silver, Lissa Scearce, Charles Hochstedlar, Meryl Markay, Shoshana Silver and Board members Michael Ostland and Ellen Silver. SOS-East raised over \$4,000.00 which will support the Sarcoma Alliance programs. The parting words of all in attendance — remain in good health and see you next year in June 2007. ☀



Andrew Cordes

Living with Sarcoma

John Chastain never won the Tour de France...

ON MAY 31, 2006, I CELEBRATED MY FIVE YEAR SARCOMA ANNIVERSARY. For on that same date in 2001, I discovered a tiny lump on the triceps muscle of my right arm, a one centimeter mass that would literally change my life forever.

At the time I received the devastating diagnosis — stage three malignant fibrous hystiocytoma — I was a thirty-seven year old lawyer/writer with a wife, two young kids, a challenging job, and a mortgage to pay.

What followed was a long drawn-out nightmare filled with bad news, surgeries, radiation procedures, recurrences, constant trips to M.D. Anderson Cancer Center, fear, paranoia, melancholy, and steadily increasing debts. We got rid of the cancer with surgery and radiation. It returned one year later. We got rid of it again with a more invasive surgery and a more localized radiation. It returned again in ten months. We had another surgery, removing my entire triceps muscle and permanently handicapping my arm.

Eight months later, the cancer returned once more, wrapping itself around the nerve in my arm. And so, I had to make the most horrible decision: to have my arm removed in an attempt to spare my life.

That was twenty-one months ago. I'm now three months away from being "cancer free" for two full years. And as you surely know, the longer you go without having any sort of recurrence the better.

As I look back now upon those horrific days, when everything was up in the air, when my body had begun to self-destruct, when my family was on an emotional roller coaster that never seemed to end, I sometimes wonder how we ever made it through. I mean, come on... five surgeries and two bouts of radiation within three years? That should have qualified me for the cancer hall-of-fame. The stress and fear and pain were absolutely off the charts.

So how *did* we make it through? How does one face the devastation and despair that cancer brings for years on end, when nothing seems to be going your way?

Well, I don't pretend to have all the answers, but here's some of the things I did. Here are a few of my strategies that seemed to make a difference.

First, I sought out opportunities to laugh. When I went to the bookstore, I chose humorous books by authors like David Sedaris, Ben Stein, and Al Franken, over existential novels. When I went to the movies or turned

on the TV, I chose comedies over dramas. When we went out with friends, we picked the fun ones over the gloomier sorts.

Let's face it, living with cancer can be a grim experience. Cancer means making serious decisions, having heartbreaking discussions with loved ones, waiting nervously for long overdue calls from doctors, and contemplating the future's uncertainties. With all this gravity, my "plan" was to seize every opportunity I could to laugh — even at times at my own situation. Although a cliché in many instances, laughter truly is the "best medicine."

Second, I did my best to be "real." Cancer patients seem to live on a different plane than those who have never been through such a trial. Cancer tests everything we've ever believed about life. Faced with a new awareness of life's fragility, cancer patients experience life's beauty and pain at a deeper level than before. We want to fill our lives with stuff that matters. Consequently, we may bristle at surface-level conversations, relationships that require too much work, or people who obsess about sports, work, or new SUVs.

It seems to me that cancer patients have a profound need to be real, to experience life with brutal honesty and without pretension. For me, this meant saying no to all those endless opportunities life presents to get involved in meaningless "stay busy" activities. Instead, I filled my life up with things I loved to do.

I went on date nights with my wife, spent time with kids, scheduled breakfasts with friends. I engaged in deep, meaningful conversations with those I love. I listened more. I began meeting with a counselor so I could talk openly about my wounds. I searched for God in the midst of it all, contemplating all the "big questions" we often can't find time for.

Third, I tried to reduce my stress through creativity. You may love to draw, or paint, or read, or sing, or compose, or experience the great outdoors. But me? I love to write. So it seemed only natural to spend time writing about my cancer battle. I journaled about my emotional struggles. I wrote poems, some positive, but some bitter and caustic. I began sending e-mails to friends and family to keep them updated on my situation.



And at some point, I began writing a book, a collection of essays and poems, predominantly humorous, concerning some of the most outrageous moments of my battle with cancer. And I'm pleased to report that the book, *I Survived Cancer, but Never Won the Tour de France*, will be published this fall by HAWK Publishing. (If you are interested in ordering one, please send an e-mail with your contact information to jimchastain@cox.net.)

Executive Director's Corner

I AM OFTEN ASKED IF I HAVE EVER HAD SARCOMA AND HOW I CAME TO THE ALLIANCE. Luckily I can answer that neither I nor any of my family members have had sarcoma, cancer yes, sarcoma no. I could answer the second question by

simply saying the job gave me the chance to meld over 20 years in healthcare with six in the nonprofit world. That would be true but only part of the answer. I came to the Alliance because of the compassion of the people and their 'mission'.

During my interview with the Alliance, I had the opportunity to meet a number of members of the Board of Directors, all of whom had in one way or another been impacted by this frightening diagnosis. What really struck me was the depth of their passion and commitment to doing everything possible to make life better for everyone in the sarcoma community — survivors, caregivers, family members and friends. This commitment and dedication is held by every member of the board. Each Director brings unique skills and perspective. Without them in the Alliance would not be where it is today offering many strong programs and providing a wide range of services.

There is another incredible group who contributed immeasurably to the success of the organization in 2005-2006. They are our **volunteers**. These individuals gave hours of their personal time to raise money and provide services so that every dollar of our precious resources is put to the best and most efficient use.

Sharon Leider and Marsha Gandin — These fabulous women are the force behind the fantastic success of our most unique program — *Hand in Hand: The Suzanne R. Leider Memorial Assistance Fund*. Each year this dedicated pair along with an extraordinary committee put together an exciting and very successful event benefiting the Assistance Fund. This program provides financial assistance to those people with sarcoma who are seeking a second opinion not otherwise paid for by insurance and 100% of every dollar raised benefits the Assistance Fund. Due to Sharon and Marsha's efforts, more and more people with sarcoma are able to seek the care they need.



These are only three strategies for helping you find your way through when cancer strikes. There are many others. But for me, these are three that stand out: laughing; being real; and getting creative. If you can do well with these, you might actually emerge from the darkness one day. ☀

Jenny Bolsky — We are a nonprofit, small and not rich, but just like everyone else, we have to file federal and state tax returns. Jenny has ably performed this service for three years now and almost makes the process of filing our returns painless. Jenny has over 15 years experience in governmental and public accounting and specializes in employee benefit plans and nonprofit organizations. She provides volunteer assistance to many organizations and in her spare time is an avid equestrian.

Michael Ward — Our most exciting new program in 2005 was the launch of our Peer to Peer Program. This would not have been possible without Michael's computer programming skills. Michael met many times with board member Michael Ostland and the Alliance staff to learn what we wanted and had many suggestions to assure the program was implemented without a hitch. When not assisting the Alliance, Michael works for Genentech.



Richard Nesbitt — Richard is a malignant fibrous histiocytoma sarcoma survivor and has organized three Wisconsin Walks to raise awareness about sarcoma and to raise funds for the Sarcoma Alliance. When he first began this event, it was a struggle for him to complete the walks. Over the years, as Richard has grown stronger, he is able to complete the walk in record speed and with time the event has grown bigger and more successful.

Mark Schulein — Mark has been a member of our Ocean of Hope team since its inception and team captain since 2003. Mark has been an unwavering supporter of the Sarcoma Alliance and because of his efforts the number of paddlers and the amount of money raised for the Alliance has grown every year. The real story is the exciting, emotional, heart warming day that happens every year at the end of the Ocean of Hope race, when Alliance staff, board members, survivors, family members, and friends converge on Manhattan Beach in California to cheer on the paddlers. I know Mark hopes you will be part of this fantastic event this year on August 27th. When not surfing or paddling in some far off and exotic land, Mark is President of Crown Ace Hardware in Huntington Beach.

We extend our heartfelt thanks to these individuals and to everyone who works to make life better for the entire sarcoma community proving, "You are Not Alone". ☀

Sarcoma Alliance Attends Society of Gynecologic Oncologist's Annual Meeting

By Suzie Siegel

Volunteers and physicians are working hard to improve the treatment of women whose sarcomas arise in their reproductive tract. For the first time, the Sarcoma Alliance sent a representative to the Society of Gynecologic Oncologists' annual conference, which drew more than 1,700 people to Palm Springs, Calif., March 22 - 26 (www.sgo.org). Board member Dave Murphy and I talked to more than a hundred doctors, none of whom knew about sarcoma support organizations, but they welcomed brochures, fliers and wristbands and were happy to discuss sarcoma at length.

One of them was Dr. Michael Friedlander, a gynecologic oncologist from Sydney, Australia, who is president of the International Gynecologic Cancer Society. Its annual meeting will be Oct. 14-18 in Santa Monica, Calif. (www.kenes.com/igcs-11). He welcomed sarcoma advocates to attend and promised that sarcomas would be discussed.

Although carcinomas dominated discussions at the SGO conference, some presentations included sarcomas. Of more than 600 posters, approximately 20 mentioned sarcoma. However, gynecologic oncologists would like to do more studies on sarcoma, but because it's rare, they have a hard time finding patients and funding, said Dr. Edward Trimble, head of the National Cancer Institute's Gynecologic Cancer Therapeutics & Quality of Cancer Care Therapeutics. The conference was his last as a board member of the Gynecologic Cancer Foundation (GCF), which is associated with the SGO (www.thegcf.org).

Dr. Bobbie Gostout, a member of the GCF executive committee and chair of GCF's communications committee, foresees important studies coming to fruition.

"There's a buzz on the street that this will be a big year for sarcoma", she said.

Most studies of gynecologic sarcomas are done through the Gynecologic Oncology Group, one of nine cooperatives sponsored by the National Cancer Institute to do clinical trials, Trimble said. This institutional structure makes it harder to collaborate on research with doctors in sarcoma programs, said Gostout, a gynecologic oncologist from the Mayo Clinic in Rochester, Minn., who was interviewed by telephone. But she said: "The door is not closed to that possibility — not at all. Other groups can adopt our protocols. Cooperation between groups is common... Most of us are very comfortable working with sarcoma colleagues [and] sharing expertise.'

Doctors and researchers who are not gynecologic oncologists also are welcome to submit abstracts on gynecologic sarcomas for consideration at SGO conferences, said GCF Executive Director Karen Carlson in a phone interview from the foundation's offices in Chicago. Additionally, the GCF welcomes grants of \$25,000 or more from individuals, organizations and companies to research a particular subject, she said. No one has donated for sarcoma yet. "It's a wonderful way to pay tribute to someone. [The donor] would get all the credit, and we'd do all the work. If the GCF had the money, it also would love to print a brochure on gynecologic sarcomas, Carlson said.

The foundation will publish its fourth "State of the State of Gynecologic Cancers" report in September, said Marsha Wilson, GCF's director of communications. The 2005 report offered little good news for sarcoma patients, with no mention of studies on AP23573, sorafenib, anti-angiogenesis and aromatase inhibitors. The report isn't limited to the work of gynecologic oncologists, but it only includes studies on gynecologic cancers, Gostout said.

For more information on gynecologic sarcomas see *Papers under Education* on our website. 

Mark Your Calendars

2006 Ocean of Hope

Aloha! Please join the Sarcoma Alliance on August 27th in celebrating the 7th annual Ocean of Hope campaign. This is a day dedicated to the sea of people affected by cancer, and specifically those with sarcoma. It's a day filled with optimism and hope.



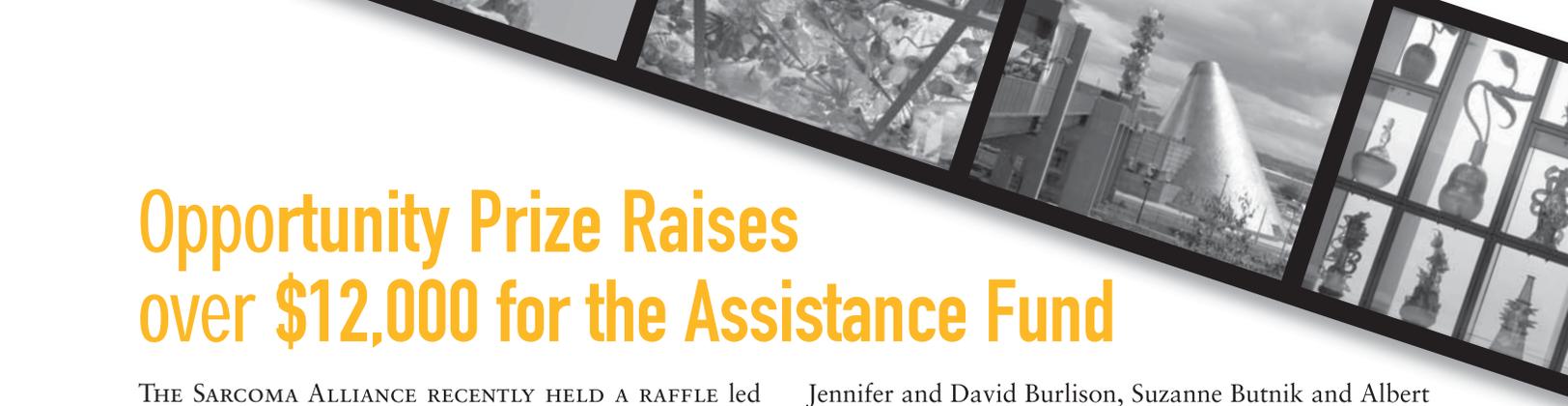
It's a day where sarcoma patients, friends, and families will meet, share stories, and bond with supporters like you. It's a day when you know that "You are not alone."

Please support the Ocean of Hope by donating generously to the Sarcoma Alliance. You can sponsor one of our paddleboards for \$3000 or more and have a family member's or friend's name emblazoned on the tail of the paddleboard.

Spirit of Survival West

Join us this fall for the second annual Spirit of Survival West scheduled for October 29th in Cupertino, CA. This promises to be a fun filled day starting with a fun run or walk and ending with a picnic in Cupertino's beautiful Stevens Creek Park.

Check our website for details about both of these events. 



Opportunity Prize Raises over \$12,000 for the Assistance Fund

THE SARCOMA ALLIANCE RECENTLY HELD A RAFFLE led by Sharon Leider and Marsh Gandin to benefit the *Hand in Hand — The Suzanne R. Leider Assistance Fund*. The prize included limousine transportation for six to the airport, airfare to Seattle, and two glorious days of scrumptious meals and private tours of some of the most exciting local museums. The prize was won by Linda Schulein. Sharon and all of us at the Alliance thank the wonderful committee who gave so much of themselves to this effort including Kim Baltzell, Sue and Neil Bershad,

Jennifer and David Burlison, Suzanne Butnik and Albert Yesk, Stella and Nick Cretikos, Kellie Flynn, Marsha Gandin, Hillary and Jerry Hyman, Carole and Mike Kamper, Denise Lapins, Sue and Dennis Leibel, Jack Leider, Stephanie Leider, Dorothy and Zane Leshner, Ruth and Ira Lott, Edie and Jerry Mintz, Barbara and Herb Stern and Myra and John Stillman. Next year the Roadster Rumble returns on April 21, 2007 so mark your calendars and save the date for a spectacular evening. ☀

Paddleboard Season Opens

THE PADDLEBOARD SEASON GOT UNDERWAY on March 26th with a wonderful party at Mickie Finnz restaurant in Redondo Beach, CA. The festivities were coordinated by Hennessey's Cathie English who served as the evening's most gracious hostess. The Ocean of Hope team gathered to celebrate their past paddleboard accomplishments, the upcoming 2006 Catalina Classic, and each other as the winter months proved to be difficult for many team members; an accident for one, a recurrence of sarcoma for another and new diagnosis of cancer for yet another paddler. The team gathers strength from each other and remains steadfast in its mission to raise awareness and funds for the Sarcoma Alliance. Team Captain Mark Schulein emceed the festivities and mingled with team mates Kelly Brown, Miles Pritzkat, Ron Roebuck, Bob Chambliss, Mike Igloi, Jane Cairns and new team members Jeff Cutler and Joe Arancio. The Sarcoma Alliance wishes to thank O2H team member and Hennessey's Racing coordinator Tim Ritter, and Cathie English and all those who came down to Mickie Finnz to celebrate. The evening raised dollars that will help promote the Alliance's programs and services. See you all at the Ocean of Hope on August 27th at Manhattan Beach. Visit the Ocean of Hope website at www.active.com/donate/hope2006. ☀

Bowling Smackdown — The Lions Roar



Theresa Chu with Board Member Jared Holmes.

THERESA CHU, a member of the San Francisco Bay Area New Century Lions, helped to organize a fund raiser in early June benefiting the Sarcoma Alliance's Assistance Fund. The New Century Lions are part of the Lion Club International which performs humanitarian acts throughout the world. The New Century Lions members are 21 - 35 years old when they join; have helped build homes for Habitat for Humanity and conduct fund raisers for local non-profit organizations. This June was their third annual bowling event. Jared Holmes, an Alliance Board member, attended the event and between slices of pizza did his best to score strikes and spares. The Alliance made lots of new friends and thanks Theresa and all the New Century Lions for their generosity and hard work. The event raised over \$400 and 100% of the proceeds will go to helping sarcoma patients seek second opinions. ☀

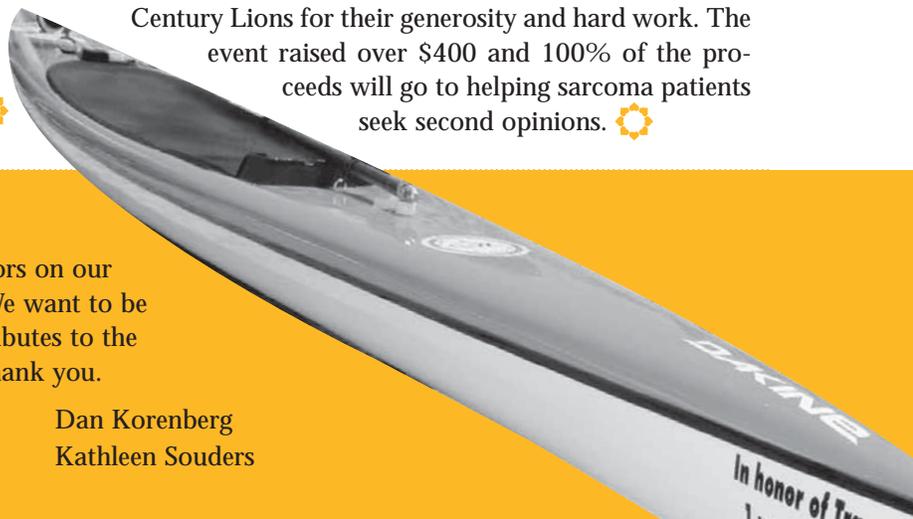
Leadership Donations — 2005

In our last newsletter there were a number of errors on our donor listing. Below are corrections to this list. We want to be sure we recognize and thank everyone who contributes to the ongoing success of our services and programs. Thank you.

Sant P. Chawla
Ivo Labar

Debbie and Tom Cowley
Dennis V. O'Hern

Dan Korenberg
Kathleen Souders



New Board Members

Susan Lowenbraun

Susan has been an oncology nurse for the past 23 years and has specialized in sarcoma management for the last 18. She has had the privilege of working with some of the foremost sarcoma specialists and has been involved in developing many of the treatment protocols that are used today. She helped develop the multidisciplinary sarcoma program at Cedars Sinai Comprehensive Cancer Center in Los Angeles and is currently the nursing director of the program. She is the organizer of annual sarcoma awareness day designed to inform and support patients, families, caregivers and the public.

Recognizing that the internet was the way that many patients and families get information about sarcoma, she became active in many of the online support groups. After finding The Sarcoma Alliance website she was quite impressed with what it offered and has recommended the site to numerous patients

She is looking forward to sharing her experiences, knowledge, resources and energy and to assist in any way she can to enhance an already wonderful organization

Daphne Yousem

Daphne has been working in the field of marketing, communications and journalism for more than 15 years. After starting her career in broadcast journalism as a cut-in writer and producer at KCAL 9 News in Los Angeles, Daphne decided to try her hand in Marketing and Public Relations.

Focusing in the field of health care, Daphne has held positions as Director of Marketing and Public Relations at various medical centers in Southern California, including Providence Holy Cross and Saint Joseph Medical Centers as well as Encino-Tarzana Regional Medical Center. She has also served as a senior brand manager at Health Net. Having worked on both sides of the fence in health care gives Daphne a unique perspective on hospitals and managed care. She understands the insurance side — and also has a keen understanding of the dilemmas that hospitals are facing today. Daphne has launched programs and products in both settings. This experience will be a tremendous help as the Alliance seeks ways to reach more sarcoma patients and to help them navigate the complex health care system.

Daphne holds a Masters degree from the University of Southern California in Broadcast Journalism and her Bachelors from cross-town rival University of California, Los Angeles.

New Staff

Pamela Cresta joined the Alliance at the end of June as the office manager. Pam brings a strong clinical background as a Licensed Vocational Nurse in both the hospital and outpatient settings. She also has been an office manager for a local physician's practice and a quality assurance coordinator for a large medical group. Her blend of patient care and office experience will help to assure that the Sarcoma Alliance continues the high quality services the sarcoma community deserves. 🌻

Corporate Grants

THE SARCOMA ALLIANCE IS PLEASED TO ACKNOWLEDGE OUR CORPORATE SUPPORTERS. We are honored and proud that these companies believe in our mission and have the confidence in our commitment and ability to serve the sarcoma community — a big thank you to each of them.

ARIAD has given the Alliance \$20,000 in support of our Peer to Peer program. We are very proud of this program and pleased that ARIAD agrees that this is an important resource for the sarcoma community. This grant will allow us to make sure that the software is able to keep up with a growing and more complex database and that our outreach efforts reach all segments of the sarcoma community.



Novartis Oncology has supported the Alliance for three years now and in 2006 awarded a \$6,000 grant to the Sarcoma Alliance to update our brochure describing our mission and programs and to support our ongoing activities with other advocacy groups. In 2005, they underwrote the first ever summit of sarcoma advocacy groups.



Pfizer recently donated \$1,500 in unrestricted funds as a sponsor of our Ocean of Hope campaign. Pfizer has a mantra: “The Patient is Waiting”. They realize and appreciate that it’s not just the patient who is waiting, but also their family and friends. Pfizer is pleased to join forces with the Sarcoma Alliance in its mission to improve the lives of all people affected by sarcoma. ☀



Other ways to support the Sarcoma Alliance

We are always honored and touched by the number of individuals and families who choose to support the Alliance by sending in donations. Every donation, no matter the size, is an important part of our growth and success. There are two additional ways to show your support, one old and one new.

eScrip

eScrip has proven to be a fantastic resource for the Alliance where participating business partners contribute a percentage of your grocery loyalty cards, credit card, and debit/ATM card purchases to us.

Here's How it Works

Visit www.escrip.com/ and register any one or all of your existing grocery loyalty, debit and credit cards for use in the program. You can view a complete, national listing of merchants participating in the program.

Participating merchants will make contributions to the Alliance, based on purchases made by you, just by using the cards you have registered.

Your purchases are tracked and available to you online, allowing you to see just how much you are contributing to our programs.

When registering, be sure to designate the Sarcoma Alliance, eScrip Group ID – 10692009 as the recipient for these donations.

Stock Donations

The Alliance recently set up a process to receive stock donations through Bank of America. You can receive a tax deduction for these donations for the market value of the stock and not pay any capital gains tax. If you would like to make a donation of stock, please contact Arthur Beckert at the Alliance office — telephone 415/381-7236 or at info@sarcomaalliance.org. ☀

New: Sarcoma Alliance Note Cards



Are you always searching for a blank note card to write a quick, “Thank You”, “I’m Thinking of You” or “Get Well Soon”? Well, look no further! The Sarcoma Alliance has taken our ‘sunflower’ theme and designed note cards for use any time. Each full color note card also contains one important “FACT” about sarcoma. We’ll send a box of 10 cards for your \$15 donation + \$3 S&H.