2005 CONFERENCES WITH A FOCUS ON SARCOMA MEDICAL RESEARCH

January 12—15, 2005
American College of Surgeons
Oncology Group, Semi-Annual Meeting
San Antonio, TX
www.acosog.org for details

January 20—23, 2005
Radiation Therapy Oncology Group
Oncology Group, Semi-Annual Meeting
Phoenix, AZ
www.rtog.org for details

April 16—20, 2005
American Association of Cancer Research
Annual Meeting
Anaheim, CA
www.aacr.org for details

April 28—May 1, 2005
Oncology Nursing Society
Annual Meeting
Orlando, FL
www.ons.org for details

May 13—17, 2005
American Society of Clinical Oncology
Annual Meeting
Orlando, FL
www.asco.org for details

June 23—25, 2005
American College of Surgeons
Oncology Group, Semi-Annual Meeting
Chicago, IL
www.acosog.org for details

June 23—26, 2005
Radiation Therapy Oncology Group
Oncology Group, Semi-Annual Meeting
Philadelphia, PA
www.rtog.org for details

November 19—21, 2005
Connective Tissue Oncology Society
Annual Meeting
Boca Raton, FL
www.ctos.org for details

Lisa Johnson, Editor
Jody Cummings, Editor
Aldo Bianchi, Contributing Editor
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Welcome to the second edition of In Our Time, the national newsletter of the Sarcoma Foundation of America. I am honored once again to help lead the efforts of SFA. I also am pleased to update the readership on our progress in the War against Sarcoma. Thank you Jody Cummings, our tireless Executive Director, for extending this opportunity to me.

SFA is making steady progress in its mission to raise awareness, increase funding and develop new, effective weapons to fight sarcoma. This year, an increasing number of fundraisers were held across the country, some of which you can read about in this edition and on our website www.curesarcoma.org. The proceeds of these fundraisers are directed almost entirely into translational or “starter” research grants. The idea is to foment thinking among leading cancer researchers and institutions in the United States and abroad; and, more, to tap the concepts and theories of brilliant minds and build, step by step, on their findings.

Each SFA grant is for $25,000. Often, the funding has been established by a SFA member in memory of or in honor of a loved one. Recent recipients of grants included: Jonathan Fletcher, M.D., of the Dana-Farber Cancer Institute, was winner of the 2004 Reid Brecher Memorial Research Award Matt van de Rijn, M.D., Ph.D., of Stanford University; Frederic Barr, M.D., Ph.D., of the University of Pennsylvania; and Lisa Wang, M.D., of Baylor College of Medicine, were recipients of the Elizabeth Shriver Memorial Research Award.

For more information about these and other promising sarcoma research proposals, please visit the SFA website: curesarcoma.org.

During 2004, SFA has welcomed several new members to the Board of Directors: Stacey Breidinger, Jack Brooks, Deborah Buks, Lindy Eddinger, Nancy Hindrickson, Laurie Landes, Colleen Monohan, Patrick Mortimer, Amy Regenstrief and Candace Sue. With their help, we plan to expand our efforts, garner additional corporate financial support, enhance our infrastructure and administrative needs, and increase our support of patient needs.

Our annual gala this year was especially successful, raising nearly $200,000! We are all very grateful to Addie and Gary Tomei, Rachelle Tomei, event planner Lisa Johnson, and the many other hardworking volunteers who helped make the gala such a huge success.

Indeed, the gala was a dramatic and elegant affair. Award recipients included: Karen Antman, M.D., Deputy Director of the NCI, who was presented with the Nobility in Science Award; Ted Kennedy, Jr., who was recognized with the Leadership in Courage Award; and Daniel Demetri, our brilliant young webmaster, who was honored with the SFA Outstanding Service Award.

(continued on inside back cover)

SARCOMA FOUNDATION OF AMERICA GALA 2004

By Addie and Gary Tomei

Having set a very high standard at our first Gala in 2003, it was only natural that our 2004 Gala would up the ante. And indeed it did. It was a celebration of life, of caring, of recognition and of optimism. The elegant event was held at Capitale, a landmark New York building designed by Stanford White. The fundraiser featured the very best of wines, food, performances and the floor-rocking Victor Lesser Band. Once again Ed Fry was our dazzling Master of Ceremonies.

(continued on next page)

From left to right: Mark Thornton M.D., Ph.D.; recipient of the Outstanding Service Award, Daniel Demetri; recipient of Nobility in Science Award, Dr. Karen Antman; Gala Chairs Gary and Addie Tomei; 2003 recipient of Nobility in Science Award, Dr. George Demetri; Executive Director Jody Cummings.
Our goal was to exceed the financial targets reached in 2003 for sarcoma research. And we did that, handily, having raised almost $200,000. What put us over the top was the extremely successful auctions—both live and silent. How inviting it is to bid...and win...on a villa in St. Bart’s, in Tuscany or at the Ritz Carlton in Jamaica.

This year, Dr. Karen Antman received our Nobility in Science Award, and Ted Kennedy Jr. was the recipient of our Leadership in Courage Award.

Thanks to efforts of the board, members, volunteers and supporters, the SFA is becoming the leading national organization in the fight against sarcoma. Our galas have become the major catalyst for this growth.

As chairpersons, Addie and I savored another gratifying experience in our continuing involvement with SFA.
OF AMERICA GALA 2004

Our New Board of Directors

The SFA is proud to announce the expansion of our Board of Directors. We have added nine new voices to the organization, including:

- Stacey Breidinger, Hudson, Ohio
- Deborah Buks, Houston, Texas
- Lindy Eddinger, Houston, Texas
- Nancy Hendrickson, St. Paul, Minnesota
- Laurie Landes, St. George Island, Florida
- Colleen Monaghan, Maple Glen, Pennsylvania
- Patrick Mortimer, Hicksville, New York
- Amy Regenstreif, Oak Park, California
- Candace Sue, New York, New York
- Patricia Thornton, Damascus, Maryland

And four people have remained constants:

- Mark Thornton, M.D., Ph.D., Damascus, Maryland
- Gary Tomé, New York, New York
- Jack Brooks, M.D., Boothwyn, Pennsylvania
- Marny Tobin, Spokane, Washington

We look forward to the next two years and this Board of Directors taking the SFA and the sarcoma community to new heights.

2004 GALA SPONSORS

Special thanks to those companies who stepped forward and said “YES— you can count on us to support the fight!”

NOVARTIS    PFIZER    BRISTOL MEYERS SQUIBB    CACHE’ LILLIE RUBIN    SAVORY SOJOURNS    VERIZON    ZIOPHARM

Above Ed Fry, Marny Tobin, Lisa Johnson, Jody Cummings

Below: Maureen and Frank Fraietta

From left to right: Norma McGrody, Marisa McGrody, Amy Weiss, Anthony Luciano, Toby Thompkins, Robert Oliver, Michael Alge, Darcy Bonfils, Mr. and Mrs David Grecko
A LOOK AT BONE SARCOMAS PAST AND PRESENT

Richard Gorlick, M.D.,
Associate Professor of Pediatrics and Molecular Pharmacology
Director, Sarcoma Research Laboratory
Albert Einstein College of Medicine
Chief, Section of Hematology/Oncology
Department of Pediatrics
The Children's Hospital at Montefiore

The major sarcomas that afflict children and young adults are soft tissue tumors such as rhabdomyosarcoma and synovial sarcoma, and bone tumors, predominantly osteosarcoma and the Ewing sarcoma family tumors.

Before chemotherapy was discovered in the 1950-1960s, the only treatment available for patients with soft tissue or bone sarcomas was surgery. Virtually all patients with bone sarcomas—even in cases where the disease appeared to be localized to an extremity and prone to surgical amputation—died after a short period of time because of metastatic lung disease. Statistically, when combined with surgery and/or radiation therapy, the use of chemotherapy soon after it was identified could cure 30-40% of patients with bone sarcomas.

Over the next several decades, intensification of chemotherapy use improved the outcomes for the majority of patients with bone sarcomas such that some 60-70% with localized disease were effectively cured of their cancers. During the same period, advances in surgery resulted in new limb preserving procedures which could be performed instead of amputation for a majority of patients. Improvements in radiation therapy also led to more focused therapy, which spared surrounding normal tissue and resulted in reduced short- and long-term complications.

Unfortunately, since the early 1990s no major additional improvement in the treatment and outcome of bone cancer patients has been achieved. For a subset of patients—such as those with metastatic disease—the predicted outcome remains poor. Patients with localized disease that relapse also have a very low cure probability. Intensification and other changes in the current chemotherapy treatments have simply not resulted in improved cure rates. This suggests that minimum benefit can be obtained by manipulating current treatment approaches. New treatment approaches are clearly needed.

The Albert Einstein College of Medicine and other centers are conducting research to increase the understanding of the basic biology of bone sarcoma. The researchers are also exploring the bases of chemotherapy sensitivity and resistance, as well as developing model systems for testing the effectiveness of bone sarcoma treatment agents.

Now underway are programs that trace the step-by-step cellular development of a sarcoma. The goal is to inhibit the formation of the sarcoma by use of a drug or other therapeutic approach.

Other studies at Einstein seek to understand why chemotherapy routinely used in bone sarcoma treatment works on some tumors but not others. In addition to helping guide drug development, this information could also be used to develop assays that potentially could tailor chemotherapy to an individual patient’s tumors sensitivity. Other research involves development of a model system for bone sarcomas to test a new agent’s effectiveness prior to clinical trials.

At the Children's Hospital at Montefiore, a range of sarcomas are treated by a multi-disciplinary team of specialists—medical/ pediatric oncologists, radiation oncologists, pathologists, diagnostic radiologists and surgeons. For patients with a high probability of cure, standard treatment approaches or cooperative group protocols are used to treat patients in a manner appropriate for each specific tumor type and stage. For those patients who are not likely to benefit from standard treatment approaches or for those with relapsed sarcomas, the medical team employs novel treatments. Several clinical trials are, in fact, underway and others are in development. Some of the more promising drugs include novel antifolates and new biological agents that inhibit signal transduction pathways.

Another area of advanced therapeutics involves administering chemotherapy as an inhalation rather than intravenously or orally. This provides the advantage of achieving the highest drug concentration in the lungs, which is the most frequent site of metastases and, theoretically, the target area for maximum therapeutic benefit. The lower drug concentrations in the blood stream also should decrease the systemic side effects of chemotherapy.

With more research and support and hope, the coming years will deliver breakthroughs and novel treatments that can be used in tandem with standard chemotherapy, surgery and/or radiation protocols to improve outcomes for patients afflicted with bone sarcomas.

THE ASCO EXPERIENCE 2004

Dear SFA friends:

On June 4 – 8 in New Orleans, Louisiana, the American Society of Clinical Oncology (ASCO) held its annual meeting. This year, ASCO was celebrating 40 years of service to the oncology community. By contrast, 2004 was the SFA’s third year of exhibiting and attending this prestigious meeting.

The success of Gleevec has done so much to focus the spotlight, for the time being, on sarcoma. As many of you may know, there are many new drugs and studies on the horizon for sarcoma. Our job, both the SFA and the sarcoma community, is to continue to push for more research dollars, more research, and more sarcoma awareness. This can only happen by sticking together and having one loud and insistent voice.

I felt this cohesiveness at ASCO this year. At our exhibit booth, both Mark Thornton and I were joined by three SFA members that volunteered to help us man the booth: Lisa Mc Donald of New Orleans, Bob Leeman of Mandeville, and Michael Hartman who came all the way from England to join us. It is often very hard to get sarcoma survivors, caregivers, and friends together face to face, especially in the age of the internet; my time spent with these people was poignant. As we sat there at the biggest oncology conference in the world, in an exhibit hall a mile long, with enormous hundred thousand dollar pharmaceutical extravaganzas exhibiting surrounding us, we were there to make people aware of sarcoma and to share information about the SFA, all of this, while we wage our own personal battle against this disease.

Needless to say, we have our work cut out for us. There is a lot to do. In 2005, the SFA will be back at ASCO in Orlando, May 13 - 17. One we are trying to sustain the momentum in the sarcoma community is by presenting a Young Investigators Award to a new sarcoma researcher. It is our hope that we can create a new cohort of enthusiastic sarcoma doctors to lead this community for the next forty or fifty years.

If you would like to join me in Orlando in May please let me know by emailing me at: jody@curesarcoma.org. It would be great to see all of you there.

Jody L. Cummings, M.PH
Executive Director
Last January, I registered for Ironman USA. Ironman is one of the most grueling sporting events around, and I had dreamt about competing in one since I was a kid. But once I started training I realized this race couldn’t only be about me. My brother-in-law Brad, who was diagnosed with synovial sarcoma at age 43, had undergone surgery and chemotherapy the previous year to remove a tumor only to have four tumors recur seven months later. His courage and determination to beat the odds were so inspiring that I decided to use my training as a platform to raise money for sarcoma since I had to believe—we all had to believe—that anything was possible... whether it was competing in an Ironman or finding a cure for cancer. So while Brad was undergoing a second wave of radiation, chemotherapy and surgery, I contacted SFA and set what I now realize was the lofty goal of raising $100,000 before race day in July. To jumpstart the fundraising, I launched a website www.tri2curesarcoma.com in March and then enlisted the help of my entire family to get the project rolling. Within a month, we had raised $10,000 and checks were coming in from my sisters' communities in Cleveland and Boston, my parents' community in Pennsylvania, and my and my wife's friends and relatives around the country. In an amazing but unexpected turn, we also started receiving notes and checks from complete strangers who had discovered our website and— because sarcoma had touched their lives— were moved to donate.

In the spring, Brad's condition took a turn for the worse and just as our Tri2CureSarcoma campaign passed the $50,000 mark, we learned that Brad's cancer had returned a third time and was no longer treatable. Brad's health degenerated rapidly and on May 25th he died, leaving behind his wife Stacey (my sister) and three children: Alexa (14), Hannah (11), Mitchell (8). At the time, Tri2CureSarcoma unexpectedly gave everyone in our family a way to channel our pain into doing something positive, a way to honor Brad's memory, and some hope for better treatment in the future. During my endless hours of swimming, biking and running training, my resolve grew stronger and I was more determined than ever to reach our goal. In a last ditch effort to complete the task, we actually resolicited everyone who had already donated to the cause and basically asked them pass along word of our efforts to four friends. We estimated that if every individual who had already donated were to ask four more people to each donate just $25 then we could reach our goal. It's hard to believe that by the time I left for Lake Placid, where the infamous 140 mile race would take place, we had actually surpassed our goal and raised $122,000. As a result, I ended up taking first place in the Janus Charity Challenge since I was the top fundraiser participating in the race. The prize was an additional $10,000 donation to my designated charity so at the end of the day we were able to donate $132,000 to SFA. The race took place on July 25th, and I had special Tri2CureSarcoma jerseys designed because my goal had been to not only raise money but also raise awareness about sarcoma. I wore mine on the course alongside the 2000 or so other competitors and my family members wore them as they cheered me alongside the thousands of other spectators. I ended up doing the 2.4 mile swim in a personal best time, then biked 112 miles with a photo of Brad taped to my handlebars, and finally, after completing the marathon (26.2 miles) portion of the event, crossed the finish line with Brad's children and my other nieces to be greeted by my entire family on the other side. I immediately called my wife Alison (who was at home with our daughter because she was expecting twins the following month) with my official race time: 14 hours and 14 minutes. On July 27th, just 45 minutes after I returned home from Lake Placid, my wife gave birth to healthy boy and girl twins. We named our son Brandon, in memory of his uncle Brad.
As I write this article while flying at an altitude of 35,000 feet, I look out the window down at the earth and see how different things look from another perspective. It is with this thought in mind that I attempt to convey to sarcoma patients, families and friends my reflections on being an orthopaedic surgical oncologist. What a privilege it has been to care for patients facing and enduring such challenges.

My journey began long ago when becoming a physician was the fulfillment of a childhood dream. Choosing a surgical discipline was a natural choice for a boy fascinated by taking things apart and putting them together again. Entering the field of oncology was a unique experience that required lifelong learning, built upon skills and life experiences far beyond the ivory towers of medical school. At what point during my medical school curriculum did I learn about telling parents that their precious child has a life threatening cancer? It was through the personal loss of a loved one when I learned that after giving someone such earth shattering news, his or her mind is numb and incapable of absorbing any information for a substantial period of time. After repeated episodes, my patients and their families have taught me — and continue to teach me — the art of medicine.

Richard was the image of strength with a strong muscular build and brimming with confidence. His young wife clearly adored him. He had a number of medical illnesses but diabetes had taken its toll over the years. At this later stage of his life, daily debridements to remove dead tissue from a wound were painful and time consuming. During the afternoons I spent tending to his wound, I got to chat with him frequently. Not being the complaining type, he didn’t take pity on himself for the chronic diseases he has suffered and endured. It was during our many conversations that he taught me both the Yiddish word and act of having pity or compasion on someone else (“rakhmones” ??????) — a lesson I’m thankful to recall to this day.

Brother Neil lived in a monastery and spent his life ministering to others. A sarcoma of his thigh had grown quite large and it wasn’t possible to remove the tumor properly and also preserve his leg. After undergoing an amputation, he seemed dejected during a follow-up visit to my office. I prayed that I might have the proper words of encouragement for him as I realized that everyone needs encouragement, even those who have spent a lifetime giving spiritual encouragement to others.

It was in the emergency room where I first met a distraught teenage girl who would blossom into an angel. The slightest provocation was tumultuous for her. Nonetheless, she bravely began her chemotherapy and then squared the surgery for the bone cancer of her tibia bone. Complications ensued and several more operations were necessary to maintain her walking ability. As the years have passed, this kind angel has engaged me as she celebrated each of her many victories. And I have delighted in her triumphs and openness of her heart.

There are numerous other stories and uplifting experiences I could recount: the young woman with the physical beauty worthy of a model whose inner beauty shinned more brightly as she courageously coped with horrible complications of her treatment and disease; the elderly woman who was at peace with whatever life had in store for her. Indeed, I’ve had the honor of learning, knowing and being blessed by my patients. I have had a front row seat watching heroes day-after-day as they confront the challenges of living with cancer. Victories come in small and large steps. And being the most victorious doesn’t always necessarily mean surviving in the long term.

The daily frustrations of practicing medicine can, at times, be exasperating. And trying to overcome hurdles in research efforts can be daunting, yet the inspiration and gratification received from caring for patients with cancer is a treasured reward. I have profound admiration for cancer patients as they display that great human potential with a spirit unyielding to a terrible disease. Despite the misfortune of having cancer, sarcoma patients can be a beacon of hope to all those around them as they combat their affliction, regardless of the ultimate outcome. As a personal witness to this reality, I thank you for your indomitable spirit.

So, just what is the view from the other side of the bed? Let it be said that it is sobering, spiritual, rewarding and hopeful. God bless.
FROM THE DESK OF THE EXECUTIVE DIRECTOR

What a year! We funded four research grants, expanded our board of directors, conducted several fundraising events, participated at oncology seminars and raised public awareness about sarcoma with dozens of “hits” in the print media.

While 2004 has been a very productive year for SFA and the sarcoma community, there is much more work to do. For starters, we will be unveiling a new Education Page on our website that will focus on 15 distinct sarcoma subtypes. Our Medical Advisory Board is assisting with the design and content. It is our hope that this site will become a place where survivors, caregivers and friends can turn to better understand the specific type of sarcoma they are battling.

In the professional development arena, the SFA is proud to sponsor the “Young Investigator Award.” This honor is awarded to a promising sarcoma researcher at this year’s annual conference of the American Society of Clinical Oncology.

On the legislative front, SFA aims to rally and “push” federal legislators to earmark more dollars to sarcoma research. No doubt, this process will take time, but the more unified the sarcoma community is, the louder we yell, the faster we will see results.

At the individual level, there is much each of you can do to help spread the word about sarcoma, about early diagnosis, about treatment and about cure. Here are just a couple of suggestions:

Raise funds for research – Conduct a fundraising event in your area to raise funds for sarcoma research grants. Get published – Contact your local media and share your sarcoma story. Reaching out to media with press releases and follow-up calls helps raise general awareness. Contact your elected officials – Let your elected representatives know how much value you place on their support for sarcoma research. Support the SFA Gala – Join us on June 6, 2005, when the SFA will host its third annual gala in New York City.

I am delighted with SFA’s achievements this year and very optimistic about our agenda for the New Year. With your help and support, we can continue to make great strides in the battle against sarcoma and, maybe, just maybe, even eradicate this dreadful disease in our lifetime.

Sincerely,

Jody L. Cummings, MPH
Executive Director

THE PRESIDENT’S CORNER

(continued from front cover)

During the last year, SFA is proud to have completed the work of the NC1 Sarcoma "PRG." This program, first proposed by the SFA in 2001, has resulted in development of a clinical trials Consortium dedicated to sarcoma and in coordination with the prestigious Southwest Oncology Group. Larry Baker, Robert Benjamin, Robert Maki, George Demetri, and others in the sarcoma medical community deserve much credit for bringing this to fruition. Already, the new Consortium has attracted the interest of pharmaceutical and biotechnology companies seeking the latest developments in cutting edge therapies for cancer patients. Thanks to the Consortium, sarcoma patient research and care is finally sharing some of the spotlight.

We also made inroads toward the goal of establishing a Congressional Sarcoma "Caucus." Congressman Patrick Kennedy is now among our supporters in the Congress. As a member of the influential House Appropriations Committee, he has agreed to add “mark up” language in the House Appropriations bill next year to press the National Cancer Institute to direct more attention and resources to sarcoma.

On the public relations front, thanks to the efforts of Jody Cummings, Deborah Buks and Lisa Johnson, SFA’s story has appeared in the Wall Street Journal, the Miami Herald and several other influential publications. Exposure about “the forgotten cancer” is critical to raise awareness of the disease and the need for new and better therapies.

Not to go unacknowledged is the SFA Administration Department, which plays a critical and often unheralded backroom role in conducting day-to-day SFA activities. Led by the director, Tricia Thornton, the department seamlessly processes hundreds of donations and correspondence. Of special note, Tricia has recently negotiated the donation of 3,000 square feet of office space in Damascus, Maryland, to the SFA. This space will anchor the growth of SFA in the years ahead.

All in all, it was a productive year in making multi-pronged advances in the battle against sarcoma. Undoubtedly, we realized these wins because of the contribution of time, talent, and financial resources of our membership. Together, we can and will make a difference.

Mark Thornton M.D., PhD

MARK THE DAY
MONDAY, JUNE 6, 2005

Attend the Third Annual Gala for the Sarcoma Foundation of America. This year’s event will be held at the Hammerstein Ballroom, Manhattan Center, 311 West 34th Street.

Honoree Robert Urich, who succumbed to synovial cell sarcoma, will posthumously receive the Sarcoma Foundation of America Leadership in Courage award. Before his death in April 2002, Robert worked with a focused, energetic passion to raise funds for sarcoma research and education. Together with his wife Heather, he established the Heather and Robert Urich Fund for Sarcoma Research at the University of Michigan Comprehensive Cancer Center. Robert served as a symbol of strength, dignity, and above all courage as he waged a public battle against sarcoma. His steadfast commitment to sustained research has given hope and inspiration to countless people stricken with this “forgotten cancer.” Heather Urich will accept the award on behalf of her husband.

Dr. Murray Brennan will be the recipient of the Nobility in Science Award. Dr. Brennan, who has been Chairman of the Department of Surgery at the Memorial Sloan-Kettering Cancer Center since 1985, has been widely regarded as being one of the best and most renowned surgeons in the world. Dr. Brennan has lectured and been a visiting professor throughout the world and has authored more than 800 scientific papers, including 230 on sarcoma. He has served as President of the American Board of Surgery, the Society of Surgical Oncology, and the American Surgical Society; the oldest and most prestigious surgical association in the United States. He is the recipient of numerous honors for his leadership in surgery and oncology worldwide, including membership in the National Academy of Sciences.

For the first time, the SFA will be hosting a special luncheon on the same day of the gala. Families will have an opportunity to learn about the latest advances in sarcoma research and meet others facing the same challenges. Look for details of both events on our web site, www.curesarcoma.org.