OH WHAT A NIGHT!

June 22, 2003. Why was this night different than any other night? It was the evening of the First Annual Sarcoma Foundation of America Gala Benefit. It was the gathering of people who were not only imbued with dedication and commitment but love, joy and hope, as well. As a fund raising event the Gala was more than a success. It was our 1st such event and we raised more than $185,000, but it was the spirit that filled the room that night that was most awe inspiring and which we believe is most significant for the future growth and success of our foundation.

In a few short months, beginning in February our outstanding and hard working Benefit Committee pulled out all stops to create a memorable affair at which we honored two distinguished guests: United States Senator Mark Pryor, a sarcoma survivor who received our “Leadership in Courage” award and Dr. George Demetri, Director, Center for Sarcoma and Bone Oncology, Dana-Farber Cancer Institute at Harvard, who received our “Nobility in Science” award. In accepting his award Senator Pryor gave a speech, which spoke to us of his own travail and triumph and also promised our foundation a voice in Congress for the support of programs for research aimed at the treatment and eradication of sarcoma. Dr. Demetri’s speech was informative as well as inspirational. Dr. Demetri was instrumental in the development of the drug Gleevec which has been a major breakthrough in the treatment of GIST and he explained that because sarcoma gene abnormalities are relatively simple, research into the causes and cures of sarcoma might act as a catalyst or springboard towards finding the cure of other more complex cancers, such as breast, colon and prostate.

THE PRESIDENT’S CORNER

by Mark Thornton, M.D., Ph.D.

Hello, and thank you for reading this inaugural issue of In Our Time, the newsletter of the Sarcoma Foundation of America.

When my wife Tricia and I got involved with sarcoma advocacy in 1998, two striking things we noticed were the dismal prospects of the 50% of patients whose sarcoma was not caught early enough, and also the lack of any cohesive movement within the patient community to do something about it.

So this is why the Sarcoma Foundation of America was created — to do something about it. We wanted to create a War Against Sarcoma. Here was the war plan. Mobilize the 50,000 families affected by this disease. Organize at the state level. Begin a grassroots campaign of awareness. Attempt to attract celebrities willing to raise awareness about sarcoma. Attempt to educate pharmaceutical companies how they could benefit from focusing on sarcoma as an indication for their cancer therapies. Talk to the National Cancer Institute to get them to focus on and plan for a national research agenda against sarcoma. Talk to the Food and Drug Administration about the problems that patients with sarcoma have to deal with in getting new therapies approved for them. Talk to Congress about increased targeted funding to fight sarcoma. And finally — why we all met in New York City on June 22nd — to raise our own funds to channel research money to the many gifted cancer researchers out there and get them to focus on finding new and better weapons against sarcoma.

In the year 2000 we started small, just my wife Tricia and I incorporated the SFA in Maryland. We established our website, partnered with Dr. Jack Brooks, who helped us file papers with the IRS to become a nonprofit charity.

With the enthusiasm of Dana Pearson, Jody Cummings, Marny Tobin and Daniel Demetri, we began to move on multiple fronts. And we were blessed in 2001 to get a call from Dr. Al Sunshine. Al was the spark we needed to organize our thoughts about fundraising. And where would we be today without Addie and Gary Tomei. Gary Tomei joined the board in October 2002 after his son Adam was diagnosed with sarcoma.
Also in attendance were Jacob Press and Shahar Eidelman who had recently completed The Ride for Reid, a cross country bicycle ride from Los Angeles to Washington D.C. to raise awareness about Sarcoma and money for research to treat and cure the disease. What truly touched everyone was the bicycle ride was done to honor the memory of their friend Reid Brecher who died last year at age 24 from sarcoma. Reid’s parents were at the Gala to witness this tribute to their son.

We were also extremely pleased to have Liddy Shriver and her entire family with us that evening. Liddy is suffering from sarcoma. Her family is responsible for raising over $72,000 for sarcoma research by coordinating a bicycle tour of Denmark. It was truly an honor to be among these and other courageous individuals who have been touched by sarcoma in one way or another and who have found in the foundation a sense of purpose, empowerment and hope.

As moving, touching and inspirational as the evening was, it was also exciting, joyful and most of all great fun. The magic of the event began with the venue: Laura Belle, which was dazzling. A 1930s style nightclub filled with beautiful flowers and gorgeous people. The food and wine were superb from the cocktail hour to the exquisite deserts and the entertainment headlined by John Pizzarelli and his wife Jessica Molesky was outstanding. It must also be said that the orchestra headed up by Paul Bernhardt had us all dancing well into the night. For Addie, and myself as chairpersons it was truly exhilarating and rewarding to be part of such a collaborative effort that resulted in such a huge success. We are truly gratified and humbled by the experience.

-Gary Tomei
On behalf of Addie and Gary Tomei –Chairpersons for the 1st Annual Sarcoma Foundation of America Gala-2003

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A very special thanks to our
2003 Gala Sponsors;
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The Second Annual Gala
chaired by Addie and Gary Tomei
will be held on May 23rd 2004 in NYC.
Log ontowww.curesarcoma.org for special weekend packages and information regarding the gala.
Shown, left to right:

1. Gary and Addie Tomei, Dr. John (Jack) Brooks, Patricia Thornton, Brighid Brooks, Dr. Mark Thornton
2. Novartis representatives-Kalvin Kochlar, Johanna Shulman, Paul Boulbee
3. Robin Skye 4. Dr. Marc Ladanyi, Maureen Zolokawski, Dr. Jonathan Lewis and Nancy Lewis
7. Ed Fry, Addie Tomei, Gary Tomei, Dr. Susan Frankl, Dr. George Demetri
8. Ted Federeci, Aldo Bianchi, Laura Fereci, Bob Reitano, Margaret Spinelli, Arlene Bianchi, Eileen Delgado, Bonnie Long and Guest
9. Senator Mark Pryor, Dr. Mark Thornton, Jody Cummings, Dr. Jonathan Brooks
10. Dr. George Demetri 11. Susan and Dan Stone and family
12. Dr. and Mrs. Abraham Sunshine, Addie and Gary Tomei
I wonder who’s reading this? Are you a cancer patient? A long-term cancer survivor? Or someone otherwise abled or disabled? If you are a victim of cancer, I know that you remember the exact time and place when you learned the news. After all, it is the kind of news that grabs you by the throat and doesn’t let go, ever.

My story began in June 1998 on Lake Union, Seattle. This is where I was married—a second marriage to a wonderful man named Tom. It was a perfect and unforgettable ceremony at sunset. Preparing for any wedding, let alone packing to move 3,000 miles across the country, can overwhelm the most stalwartly among us. So I discounted my everyday tiredness and focused on the happiness of my situation. At the time, I was a 33 year old newly married wife and mother of an eight year old daughter, Terra, embarking on my second go at love, with the man of my dreams.

We returned from Jamaica, and spent the next few months unpacking and adjusting to our new lives. I joined a gym and began a workout regimen. Still, I could not shake my tiredness. Also troubling was that I was losing weight but looked somewhat pregnant! I asked the trainer why my belly was protruding yet my body slimming. He said, “You know, everybody’s body is different. That’s life. What the….?”

My fatigue continued to worsen. Even walking felt like traipsing through thick mud. My appetite dwindled after the first bite of food. And the heartburn! I devoured Tums for four months to soothe the burning sensation. When that stopped helping, I switched to Zantac. At my husband’s insistence, I met with a variety of internists. The diagnoses ranged from gastric reflux, to mono, to Epstein-Barr syndrome.

I finally consulted a specialist who ordered a barium test and ultrasound. It was pretty discouraging because no one and nothing seemed to help. From gastric reflux, to mono, to Epstein-Barr syndrome, the Band’s insistence, I met with a variety of internists. The diagnoses ranged from gastric reflux, to mono, to Epstein-Barr syndrome. When that stopped helping, I switched to Zantac. At my husband’s insistence, I met with a variety of internists. The diagnoses ranged from gastric reflux, to mono, to Epstein-Barr syndrome.

It was pretty discouraging because no one and nothing seemed to help. I finally consulted a specialist who ordered a barium test and ultrasound. First, the swallow test revealed an emptying problem with my stomach. Then the ultrasound raised concerns. Then came the follow up I did not want to hear: “Your doctor wants to do a CT scan right away.” It was Friday, late afternoon, and I remember a bunch of white suited technicians all over me.

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Biking for Awareness and a Cure  
by Bruce Shriver

Shortly after getting off the train that took her from Aarhus to Odense in Denmark on July 1, 2003, Elizabeth (“Liddy”) Shriver and 27 other cyclists who formed “Team Sarcoma” donned their biking clothes, mounted their bikes, and began the Shriver Family Bike Tour for Sarcoma Research. The cyclists came from Denmark, Germany, Hong Kong, Norway, Switzerland and the USA. They were joined by more than 230 Virtual Bike Tour cyclists who biked in 11 other countries and in 16 states in the USA. They embarked on a 4-day “world-wide” cycling to raise public awareness of sarcoma and of the lack of young adults in cancer-related clinical trials – and, of course, to raise funds for sarcoma-based research.

Many more bikers -- “Virtual Bike Tour” (VBT) cyclists -- wanted to support the effort but couldn’t manage to join the group in Denmark. So, the VBT cyclists agreed to bike on the very same days Team Sarcoma biked in Denmark; to report to them how far and where they biked; and to tell others about sarcoma. VBT bikers hailed from France, Hong Kong, India, Ireland, Japan, Portugal, Serbia, Sweden, Ukraine as well as from California, Florida, Illinois, Louisiana, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Pennsylvania, Vermont and Washington State. From July 1-4, the Team Sarcoma cyclists and their VBT cyclist counterparts formed a unified, coordinated international group helping to raise public awareness of sarcoma.

This was a particularly important bike tour for Liddy. Because of her diminishing lung capacity, it may be one of the last multi-day bike tours in which she could participate. Liddy was diagnosed with Ewing’s Sarcoma in April 2002. She was 35 years old at the time. Her primary tumor was in the tibial nerve in her leg. This nerve supports the calf muscles and stabilizes the ankle. Surgery last July removed her tumor and 8 inches of nerve. After the surgery, walking became painful because of the contact of bone-on-bone. By August, Tom (Liddy’s husband) and the Shriver family knew that she wasn’t responding to the standard pediatric chemotherapy protocol. By November, they knew that she wasn’t responding as hoped to the 2nd and 3rd line chemotherapy treatment. Her cancer had metastasized to her lungs. Over the months, the tumors continued to grow in number and size.

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THE PRESIDENT’S CORNER  
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The Tomei’s chaired our 1st Annual Gala in NYC which raised over $185,000. Our second Annual Gala will be in May 23, 2004, chaired again by the Tomei’s, which promises to be another memorable evening.

I can report that during this year we have moved forward on all fronts in the War! We’ve organized in all 50 states and are attracting new members each day. We’ve gotten the support of the brilliant sarcoma doctors who are responsible for the 50% of us who are cured each year. Doctors like Karen Antman, George Demetri, Murray Brennan, Marc Ladanyi and Jonathan Lewis, to name a few.

In March, we funded our first 3 sarcoma research grants, exploring the potential of so-called antisense drugs and immunotherapy against sarcoma. These grants, totaling $70,000, would not have been possible without the generosity of Al Sunshine, Daniel Rosenbloom, Lloyd Shulman, Edward Shufro and Millard Pryor.

And on June 21st your Board of Directors voted to fund a $35,000 Young Investigator Award in association with the American Society for Clinical Oncology (ASCO). This award will attract talented young oncologists finishing their training who wish to pursue a career finding new therapies against sarcoma.

We have received help from such celebrities as Marisa Tomei, Peri Gilpin from Frasier, comedian Richard Lewis, recording artists Yoko Ono and Sean Lennon.

Besides teaming up with celebrities, we’ve outreached to pharmaceutical and biotechnology companies such as Novartis, Pfizer/Pharmacia/Sugen, Bristol Myers Squibb, OrthoBiotech, Antigenics and Genzyme, who all graciously supported our first annual gala.

We’ve successfully lobbied with Andrew von Eschenbach, Director of the National Cancer Institute, to organize a national research agenda against sarcoma. This process, to be headed by Dr. Karen Antman, could lead to so-called SPORE federal grants that could provide new funding, possibly millions of dollars, targeted towards sarcoma.

Al Sunshine, our Vice President, has been in contact with Mark McClellan, the Commissioner of the Food and Drug Administration, and is working with him to enlighten the FDA about the needs of the sarcoma community.

And we have embarked on the notion of a congressional sarcoma caucus, where interested members of Congress including our friend Senator Mark Pryor, could help raise awareness of the needs of Americans affected by this heretofor forgotten cancer.

We are united and building significant momentum in letting sarcoma know that we are out to get it. Not by the end of the century. Not in the next 50 years. But now. Right now.

If you would like to join us in any capacity, be it donating services, resources, and/or funds, we welcome you!

Thank you for your time and interest in this most worthy cause.

Sincerely, Mark Thornton

Many thanks to Lisa Johnson and Jody Cummings, who have worked diligently to produce this first edition of the newsletter. We hope you enjoy it!

Sarcoma Foundation of America
P.O. Box 458
Damascus MD 20872
Biking for Awareness and a Cure

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The Shrivers researched the disease and learned that “the 5-year survival rate is 5% for patients who develop metastases while on treatment for Ewing’s sarcoma.” Facing this sobering reality, she began working on a list of things she always wanted to do. Liddy, who is a cycling enthusiast, told us, “On a bike, I get a sense of freedom that I don’t get any other way. Plus, I don’t limp when I bike. I always wanted to ride in a multi-day bike tour. It has to be somewhere flat, since I really only bike with one leg. And, I have to do it sooner versus later since my lungs were already giving me breathing problems.”

Many people shared the Shriver’s goals and were willing to devote time and effort to help make people aware of this wretched disease. Some bike-riders rode tandems, some mountain bikes, some road bikes, and some even stationary bikes. People of all ages and life styles became VBT cyclists. They ranged from a 70-year old bike enthusiast; to some 60-somethings who haven’t biked in more than 30 years; to a group of 20 boy scouts who biked in Portugal; a 7-year old boy biking in Japan; and a pediatric oncologist in the Ukraine. Liddy’s surgeon, Dr. Murray Brennan, and four of his colleagues from Memorial Sloan Kettering Cancer Center in Manhattan were among the VBT cyclists. So far, the Shriver Family Bike Tour for Sarcoma Research has raised more than $72,000 -- all of which has gone to the SFA.

Before departing for Denmark, Liddy said, “Perhaps the best thing about the bike tours is that for several days, I really don’t feel much like a cancer patient. My last chemo is far enough in the past that I feel good. No worry about scans and their results. It’s wonderful while it lasts.”

With steep hills, smokey restaurants, and constant chest pressure, Liddy felt fatugied during the Denmark travail. More, she was about to start another round of chemotherapy. Always hopeful, Liddy and her family believe that medical science will one day, once-again-for-all, arrest the growth of her tumors. The Team Sarcoma cyclists and their VBT cyclist counterparts all have similar hopes and dreams – that is, that their bike ride might bring about a public awareness of sarcoma and, more importantly, a cure in our lifetime.

**Sarcoma Foundation of America**
P.O. Box 458
Damascus MD 20872

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Riding for Reid

by Jacob Press and Shahar Eidelman

At some point while struggling against a fierce head wind in the Eastern Arizona desert, Shahar and I pulled our bikes off to the side of the road to catch our breaths and, to our surprise, suddenly found ourselves laughing uncontrollably. Here we were, over two thousand miles from home, surrounded by yucca and cactus, staring up at mountains just recently dusted with snow, and wondering exactly how we’d arrived in such a place.

Only three weeks before, we’d set out from Los Angeles with the intention of pedaling across the country in order to raise money and establish a research fund in honor of our friend, Reid, who had succumb to sarcoma nearly a year before. Our plans had been rudimentary at best, although our optimism and energy were in almost endless supply. Despite having little idea of what we were getting into, we knew, after spending nearly a year by our friend’s side as he battled for his life against sarcoma, that we had all the inspiration we needed to push us across the country.

When you ride a bike eight to ten hours a day you have a lot of time to think, and both Shahar and I had been left with much to contemplate after watching a close friend taken from us. On the one hand we had a new found appreciation for life, having witnessed Reid’s struggle. He had not only fought until the end, but had lived until the end, making the most of every day and refusing to let his ordeal deprive him of joy. On the other hand, we couldn’t help but wonder why we were able to embark on such a journey while Reid could not. The fact that Reid and I had discussed biking across the country before he got sick made this question that much more difficult to come to terms with.

Over the course of our trip, we began to realize that while we were in a sense biking for Reid and continuing his fight against sarcoma by raising money for medical research, we were also biking to improve ourselves. We were emulating our friend as best we could, trying to take the most out of each day and not letting the obstacles we faced overshadow our experience. And this was essential considering the fact that not one single day of our trip went by without some sort of difficulty. If it wasn’t hills it was rain, and if it wasn’t rain it was a mechanical breakdown, and if it wasn’t a mechanical breakdown it was knee pain.

Despite having to constantly contend with such challenges, we remained in good spirits. Shahar, who had never biked more than thirty miles in one day before the trip, found himself biking ninety miles a day, and, despite constant muscle soreness, waking up the next morning looking forward to more. And as hard as it is to imagine, by the end of the trip I had actually gained an appreciation for and even began to enjoy hills and rain, neither of which were in short supply over the course of the last three weeks of our journey.
Several days later, I was to see the doctor for a follow-up report. It was 6:30 p.m. The office was empty except for the doctor, my husband, and me. The doctor cordially opened the door for us and escorted us into his small office. We had just sat down when he told us that he was very sorry to report that I have a very rare tumor in my abdomen. He called it Retroperitoneal Liposarcoma.

Despite the shock of it all, his diagnosis saved my life. I also am so thankful for how realistic he was in responding to our many questions and how compassionate in dealing with our fears. He even helped arrange my surgery in Seattle. I now was a bona fide cancer patient.

How long would I live? Would I need chemotherapy? How about my thick, beautiful hair? Would I lose it? What about Terra and Tom? Tom already had struggled with the loss of both parents to cancer. And cousins and uncles and aunts and friends. It just wasn’t fair! Why me? Why now? We were only married 3 months. My daughter was only 8 years old!

I returned to the hospital in Seattle where I had worked for 12 years. The surgeon reassured me that he had performed hundreds of surgeries for such a sarcoma. I made the right decision. My surgical experience was as good as could be expected. I was in a familiar environment surrounded by former co-workers and friends who stopped in to visit me non-stop. More importantly, my doctor was confident that he removed the entire tumor and marginal area. It weighed in at over 5 pounds! It’s funny that my daughter weighed only 4 pounds 11 ounces at birth.

We stayed in Seattle until I was strong enough to fly back to Albany. Once in Albany, I began a life as cancer victim. At least that was my mindset. I suffered from a lack of appetite; I slept most of the day and pondered most of the night. I continued to lose weight and remained weak and tired. I would soon learn that these conditions were signs of another problem -- depression.

But I’m not depressed!! Depressed people cry all the time. Then I learned that it wasn’t uncommon for newly diagnosed or recovering cancer patients to become depressed. Fortunately, diagnosis of the problem and appropriate medication helped offset my depression and I slowly began to improve in body and mind.

That was the beginning of my education about sarcoma, depression and survival. I continued to research sarcoma. What’s amazing is how little there is out there about sarcoma. I happened upon a sarcoma chat site where I met some incredible people with stories similar to mine. Incredibly, misdiagnosis was the common denominator among us! As a result, each of us had undertaken a different course of treatment.

The computer became my best friend. Along the way, I found “The Sarcoma Foundation of America.” It’s goal is to raise awareness about sarcoma and raise funds to promote research. “Well, sign me up,” was all I could say. I became an active member and soon thereafter the Secretary of the foundation. What a great feeling it is to be part of a group that shared my experience, reached out to help others, and was committed to cure sarcoma!

Over the years, I have had three recurrences and three more major surgeries. I am currently undergoing chemotherapy for another tumor. And I will need more surgery. But I feel so blessed with the people in my life and with the wonderful care that I’ve received. I expect to beat this thing because there is still so much more to do, so many more people to help, so much more to give. Today, I am very in touch with quality of life, of living for the day, the hour, the moment. Maybe my old trainer was on to something in his reflections that day.
Upcoming conferences with a Focus on Sarcoma Medical Research

November 4 – 9, 2003
Children’s Oncology Group Semi-Annual Meeting
Dallas, TX
www.childrensoncologygroup.org for details

November 6 – 8, 2003
Connective Tissue Oncology Society Annual Meeting
Barcelona, Spain
www.ctos.org for details

January 8-10, 2004
American College of Surgeons - Oncology Group, Semi-Annual Meeting
Miami Beach, FL
www.acosog.org for details

March 27 – 31, 2004
American Association of Cancer Research Annual Meeting
Orlando, FL
www.aacr.org for details

March 30 – April 4, 2004
Children’s Oncology Group Semi-Annual Meeting
Washington, D.C.
www.childrensoncologygroup.org for details

April 29 – May 2, 2004
Oncology Nursing Society Annual Meeting
Anaheim, CA
www.ons.org for details

June 5 – 8, 2004
American Society of Clinical Oncology Annual Meeting
New Orleans, LA
www.asco.org for details

June 17 - 19, 2004
American College of Surgeons - Oncology Group, Semi-Annual Meeting
Chicago, IL
www.acosog.org for details

Lisa Johnson-Editor
Jody Cummings-Editor
Aldo Bianchi-Contributing Editor

Newsletter design and layout courtesy of Patricia Martine Graphics
914-271-5716

Special thanks to Tenny Journal Printers, Inc.