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SFA President's Corner

Despite a gloomy economy and reports of declining donations to nonprofit organizations, I am pleased to report that 2008 was an excellent year for the Sarcoma Foundation of America! This was due in part to the strong leadership of Executive Director Matthew Alsante.

Due to our success, the SFA secured funding for a record 10 "Starter Grants," designed to ignite ideas for new research avenues in our quest to find new and better treatments to eradicate sarcoma. In addition, SFA will fund the second year of its 3-year Advanced Clinical Research Award (ACRA), which has been generously co-funded with the Capon family. The recipient of the ACRA award was Raphaël F. Rousseau, MD, PhD. Dr. Rousseau will use the \$500,000 award to explore "nanotechnology" methods to make surgery for sarcoma more effective. We hope this research effort will mitigate the rates of local recurrence of sarcoma following surgery.

Another exciting development in 2008, was the teaming with our friends at the Sarcoma Alliance for Research Consortium (SARC) in an initiative they launched with the National Cancer Institute. SARC is a consortium of sarcoma centers in North America, and has applied to the NCI for a competitive Specialized Program of Research Excellence (SPORE) grant. This multi-million dollar grant, if awarded by the NCI, would be the final step begun by SFA in 2003 to have the NCI design a plan to distribute resources directly to sarcoma research. The SFA's efforts develop the basic blueprint for the consortium effort that SARC is now trying to bring to reality! To help support SARC, the SFA has agreed to contribute an additional \$500,000 to the NCI funding over the 5-year length of the grant. Let us pray that the NCI judges the SARC research proposal worthy of funding and therefore provide a boon to sarcoma research in the U.S.

Finally, in our never-ending attempts to advocate for more streamlined approaches for regulatory approval of new drugs for patients with rare cancers like sarcoma, the SFA continued to enroll members of the U.S. Congress to sign on to the "Citizen Petition" of the FDA that seeks these reforms. We now have the support of five enrolled members of Congress who are optimistic about statements made during the presidential campaign that the new Obama administration would have as one of its priorities, policies for expanded care and attention to rare cancers.

The SFA begins 2009 poised for sustaining last year's progress. Hopefully, the economy will recover so as to allow your generous contributions to support us even more in our efforts toward the conquest of sarcoma!



Dr. Mark Thornton

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Sarcoma Foundation of America and Capon Family Funded Research

Improving the detection of osteosarcoma tumor margins and metastasis using diagnostic nanoparticles

Aur lie Dutour, PhD – Research Assistant

Rapha l F. Rousseau, MD, PhD – Project Leader, Pediatric Oncologist

The aim of osteosarcoma resection is the complete removal of the malignant lesion with adequate margins. Accurate tumor delineation and metastasis detection is a challenging albeit critical goal having to take into account tumor control and functional reconstruction. To date, no intra operative method is available to assist surgeons in precisely delineating tumor extension in the adjacent normal tissues. Thus, preoperative imaging and extended surgical resection remains the gold standard. For that reason, we propose to verify that fluorescent nanoparticles (RAFT-cRGD₄-ICG') administered intravenously prior to surgery can detect tumor margin and metastases less than 2mm in diameter and facilitate tumor and metastases resection upon intra operative NIR illumination. With the generous support of the American Society of Clinical Oncology, the Capon Family, and the Sarcoma Foundation of America, we are currently confirming our strategy and evaluating the approach of a model of metastatic osteosarcoma model in rats. Shortly, we established that 4-5 mm tumors were not visible under conventional light prior to skin incision whereas transcutaneous near-infrared light revealed tumor/muscle interface. After incision, tumor and its margins appeared under near-infrared light and no abnormal signal was detected in the healthy surrounding muscles. More importantly, complete tumor resection was optimally obtained under near-infrared light, whereas conventional light visualization provided the surgeon with less precise indications regarding tumor margins. The comparison of resected fragments using NIR-guided surgery or conventional pre-imaging magnetic resonance imaging (MRI) showed an improvement in tumor resection (*i.e.*, a significant decrease in the size of the resected tumor within *in sano* margins) when the surgery was performed under NIR imaging.

Importantly, intra operative NIR illumination of exposed lungs revealed unsuspected lung metastasis, whereas surrounding lungs did not reveal any abnormal signal (*i.e.*, auto fluorescence). Since these metastases were not immediately visualized under conventional light, this approach may allow for the intra operative detection of millimetric lung lesions currently difficult to assess by *de visu* observation and palpation.

Our preclinical data confirm the potential of intra operative imaging for improved primary tumor and lung metastasis excision. With the help of the grant received from the Sarcoma Foundation of America, we are now generating clinical-grade RAFT-cRGD₄-ICG' to conduct the mandatory toxicology studies and **further evaluate this approach as a means to improve functional outcome after surgical excision while maintaining tumor control in patients with relapsed/metastatic osteosarcoma.** We hope to obtain approval by French regulatory authorities to start a clinical trial evaluation reveal the potential of this nanotechnology approach during 2010 at the earliest.

New Frontiers in Sarcoma Educational Conference

This year the Sarcoma Foundation of America hosted its fourth annual educational conference for sarcoma patients, their families, caregivers and other medical professionals. The half-day program featured experts in all areas of sarcoma.

Attendees traveled from across the country to learn about the latest research, treatments, and progress surrounding different forms of sarcoma treatments, including predictive markers, SFA funded research, angiogenesis, pediatric sarcoma and new directions for sarcoma research.

Dr. Mark Thornton opened the conference by discussing SFA history and recent projects, such as the half-million dollar Advanced Clinical Research Award with the Capon Family. Dr. John Brooks did an overview of the 2008 grants funded by the SFA and focused on predictive markers of sarcoma. Dr. David D'Adamo focused on research treating sarcoma with anti-angiogenesis drugs. Dr. Paul Myers focused on advances in treating pediatric sarcomas. Dr. Jonathan Fletcher discussed innovative research he has done supported by the SFA. Dr. Robert Benjamin followed with a presentation on how to tell if a therapy is working. Dr. George Demetri closed the program with a discussion on the future state of sarcoma research.

After the presentations, these distinguished doctors fielded questions whereby patients could engage in a more intimate Q&A with each expert. The conference offered patients and their families the opportunity to be face-to-face with the leaders in the field of sarcoma treatment and research and was an overwhelming success.



*Dr. Laurence Baker presents
Dr. Robert Benjamin with the
Nobility in Science Award*

Save the Date: On April 19th, the SFA will host its 5th Annual Educational Conference entitled *Ask the Experts: Advances in Sarcoma Treatment and Research.* The event will take place at the New York Helmsley. For tickets and discounted hotel information, please go to www.curesarcoma.org.

6th Annual Fundraising Gala

The 6th annual Sarcoma Foundation of America Gala was held on May 5, 2008 at the 583 Park Avenue. With over 500 people in attendance representing sarcoma patients and their families, friends, medical professionals, corporate and philanthropic communities, this year's gala was our most successful to date! The evening, which was chaired by JoMarie Pica and Cookie Rumely, raised over \$900,000 to help support sarcoma research. Presenting sponsors of the event were ARIAD, MERCK and the Altman/Kazickas Foundation, with other gracious sponsors including PharmaMar, ZIOPHARM, Pfizer, IDM PHARMA, Novartis, ARC Global Partners, and Genentech.

Mistress of Ceremonies Kris Carr, actress, author, and filmmaker of *Crazy Sexy Cancer* introduced Dr. Tom Tobin, who led a toast to Willow Crest Winery owner Dave Minick. Willow Crest Winery provides the wine for the event and raises funds by producing wine with an SFA label in memory of former SFA board member Marny Tobin. The Vision of Hope Award was given to philanthropist Roger Altman and

the Nobility in Science Award given to Dr. Robert Benjamin of M.D. Anderson Cancer Center. Miles Levin posthumously received the Leadership in Courage Award. His parents accepted the award on his behalf from Bob Woodruff of ABC News. Anne Belk, Leslie Heyison, and Patrick Mortimer each received a Courage award for their valiant battle against sarcoma. A live auction was led by SFA spokesperson and *Deal or No Deal* model and actress Marisa Petrero. A highlight of the evening was SFA board member Gary Tomei introducing the "A Cure in Our Time" video, starring SFA honorary board member Peri Gilpin of the TV show *Frasier*. Music for the evening was provided by the outstanding Victor Lesser and the Manhattan City Orchestra.

The program culminated with two unforgettable moments. *American Idol* finalist and SFA board member Anthony Fedorov performed a song he had written for his brother, Denis, whom he lost to sarcoma. Terra Holloway, daughter of former SFA board member Marny Tobin, toasted her late mother and her years of sarcoma advocacy.



Bob Woodruff, Patricia Thornton, Dr. Mark Thornton, Dr. John Brooks



Candace Sue, Peter Rumely, Cookie Rumely



Roger Altman, Vision of Hope Recipient



Kris Carr, Mistress of Ceremonies



Anthony Fedorov, Marisa Petrero



Dr. George Demetri and Matthew Ross



JoMarie Pica and Cookie Rumely, Co-Chairs

Spokesperson Marisa Petrero



We are excited to announce that film and television actor, Marisa Petrero, has accepted a second term to be our spokesperson. Much like last year, she will be our public voice to raise awareness and funds to support SFA's mission.

"It's an honor to continue my work for this great organization," said Petrero. "I know first-hand what many sarcoma patients are going through and that drives me to perform this role with dedication and authenticity."

This year Marisa will be working closely with Matthew Alsante to fill out an entire calendar year of events and promotions. She will be involved in the spring gala in April, but one of her goals is to make a big splash in July for Sarcoma Awareness Month.

"Marisa has a fantastic team of professionals working for her to support her career. These individuals have already put in motion a media tour and blitz for the SFA," said Alsante. "I'm happy that Marisa has decided to stay in the SFA family."

Marisa is freshly off an outstanding year of acting that includes starring in the feature film, *Everybody Wants to Be Italian*, the story of the struggle of two Italians and their quest to win each other's hearts in Boston's famed North End [available on DVD in February]. On the small screen, she returned for season four as one of the most recognized briefcase models (#18) on NBC's top game show *Deal or No Deal*, as well as landed roles on CBS's popular sitcom *Rules of Engagement*, acting alongside David Spade, and ABC's award-winning comedy-drama series *Desperate Housewives*, acting alongside Eva Longoria Parker.

For more information, go to www.MarisaPetrero.com

Fundraising Events



Educational booth at the Florida Marlins Game
Sep. 1, 2008 in FL



Jon Bowels Texas Hold'em, Aug. 16, 2008, KY



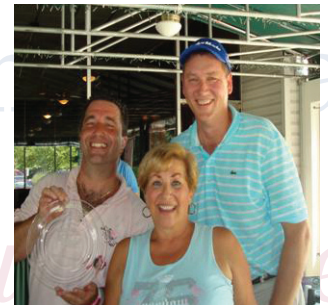
Bud's Run, Jun. 28, 2008,
Carol Stream, IL



Cookies for a Cure,
Jan. 19, 2009, VA



Cocktails for a Cause Sept. 26, 2008 in NY



Shelby Richter Golf and Bar-B-Que
Outing, Aug. 30, 2008 Absecon, NJ



Run for Sarcoma Cure, Oct 18, 2008, FL



Bryan James Memorial Dunk Ball Tournament, Dec. 20, 2008 CA

2008 Sarcoma Research Grants

Raising money for translational sarcoma research is the mission of the SFA. With the help of our fundraising families and generous donors, each year we award established and up-and-coming researchers grants of \$25,000 to help fund their sarcoma-related research projects.

Denis Fedorov Memorial Research Award

Evaluation of flow cytometry for the detection of circulating Ewing sarcoma cell

Steven DuBois, M.D.

University of California, San Francisco

Shelby L. Richter Memorial Research Award

Predicting treatment response of soft tissue sarcoma to neoadjuvant therapy by imaging proliferation with a FLT-PET/CT scan: a pilot study

Frederick C. Eilber, M.D.

University of California, Los Angeles

Brian J. Monaghan Memorial Research Award

CSF1 inhibitors in soft tissue tumors

Paul W. Clarkson, MBChB

British Columbia Cancer Agency

Marny S. Tobin Memorial Research Award

Development of a high throughput screening assay for Ewing sarcoma oncoprotein

Aykut Uren, M.D.

Lombardi Comprehensive Cancer Center

Georgetown University

Brian W. Rybarczyk Memorial Research Award

Analysis of targeted biological therapies in a genetically engineered mouse model of sarcoma

Sam Yoon, M.D.

Massachusetts General Hospital

SFA Research Grants

A mouse model to examine human osteosarcoma therapeutic options

Lawrence A. Donehower, Ph.D.

Baylor College of Medicine

Mechanisms of tumor progression and kinome targeting in peripheral nerve sheath tumors

Cristina Antonescu, M.D.

Memorial Sloan-Kettering Cancer Center

Sarcoma Patient Registry

In January 2007, the Sarcoma Foundation of America began developing a Sarcoma Patient Registry. We started by focusing on five sarcoma subtype groups. In August of 2008, we announced that we would accept ALL sarcoma subtypes into the Registry! Since then, the Registry has quadrupled in size, but is still far short of reaching all sarcoma patients. To reach more families affected by sarcoma, we've partnered with organizations such as the Sarcoma Alliance, Kristen Ann Carr Fund, Liddy Shriver Sarcoma Initiative, Northwest Sarcoma Foundation, the Desmoid Tumor Research Foundation, and the LMSarcoma Direct Research Foundation to support the Registry. The sarcoma advocacy community has rallied around this cause. We ask for your help in informing patients and doctors about this cause. If you would like to participate, please contact us at sfa@registrypartners.org or call toll free at 866-501-6780.



Matthew Alsante
Executive Director

SAVE THE DATE

Seventh Annual Fundraising Gala

Monday, April 20, 2009

Cipriani 42nd Street

New York, New York

Honoring

Carlos Cordon-Cardo, MD, PhD
with the Nobility in Science Award

&

Jonathan Lewis, MD, PhD
with the Vision of Hope Award

Special Performances by
Rufus Wainwright & Anthony Fedorov

Toast To A Cure

Toast with one of two special wines created by Willow Crest Winery in memory of long-time supporter and former SFA board member Marny Tobin. Profits will be donated to the SFA. Order online at www.willowcrestwinery.com then go to Sunflower Series.



Dave Minick, Terra Holloway, and Dr. Thomas Tobin

Our Mission

The Sarcoma Foundation of America (SFA) advocates for increased research to find new and better therapies for treating patients with sarcoma. The organization raises money to privately fund grants to Sarcoma researchers and also conducts education and advocacy efforts that emphasize the needs of Sarcoma patients.

Donate To SFA

Help us fund future sarcoma research by contributing to the Sarcoma Foundation of America. The SFA is a national, nonprofit advocacy group for the increased research and treatment of sarcoma (Tax ID # 52-2275294).

Cut out this form and mail it with your donation or donate online at www.curesarcoma.org

Yes. I would like to make a donation to the Sarcoma Foundation of America Amount: _____

In honor of: _____ In memory of: _____

Name: _____

Address: _____

City/State/Zip: _____

Phone: _____ Email: _____

Contact the SFA about the following ways of giving:

Stock Gifts – Giving appreciated stocks or bonds are excellent ways to support the foundation.

Planned Gifts – Wills, life insurance policies, property, trusts, gift annuities and retirement plans are examples of planned gifts which provide significant tax savings as well. We will be happy to provide you with general information about how to incorporate a planned gift to the foundation into your estate plans.

Matching Gifts – Many employers will match your charitable contribution. This is an extremely effective way to maximize your donation to our cause. Check with your human resources office today to see if your charitable donation can be matched by your employer.

Please charge my credit card: MasterCard Visa American Express

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CID # (4 digit number on front of American Express cards) _____

Credit Card No.: _____ Expiration Date: _____

Signature: _____

Mail to: Sarcoma Foundation of America, 9884 Main Street, Damascus, Maryland 20872 or fax it to: 301-253-8690

finding the cure in our time

www.curesarcoma.org



Sixth Annual Fundraising Gala, May 2008, in NY



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