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SFA President's Corner

It's been a very productive year for your Sarcoma Foundation of America! As you know, the goal of the SFA is to expedite the development of new drugs that target Sarcoma, with the vision of dramatically decreasing the death rate due to Sarcoma during this time in our lives. I'd like to update you on advancements made this year toward our goals.

In February, we welcomed the call of President Obama to establish the goal for the nation of finding a cure for cancer in our time. To our delight, the president had also seen fit, during the 2008 campaign, to specifically call for a focus on rare cancers like Sarcoma during his administration. Our efforts this year and in those ahead are to not let anyone forget the president's (and of course the Sarcoma community's) priority - getting the federal government to do more for those with rare cancers. Not coincidentally, a major piece of legislation toward advancing cancer care, called the ALERT Act, is making its way through Congress. We are working with other rare cancer groups to make sure that NCI funding, and potentially FDA regulatory reform, are features of the bill. Patrick McCarthy, our college intern this summer, has done a great job in communicating with SFA members who live in the districts of key members of Congress that will be involved with this bill. Please stay tuned about the timing of how you can help make a difference.

In addition to working with our federal legislators, the SFA has partnered with the American Society of Clinical Oncology (ASCO) to work with the Food and Drug Administration toward the creation of an FDA/SFA/ASCO Rare Cancers Working Group. This group will be made up of rare cancer patient advocates, physicians and FDA officials, and will be tasked with tackling the issues of how to perform clinical trials in tiny populations such as those for subtypes of Sarcoma. The hope is that consensus can be reached on how best to obtain the minimum data necessary to show that a new therapy has worked in such a small group, such as a Sarcoma subtype that affects only a few dozen to a few hundred patients per year.

In addition to our government outreach efforts, Matt Alsante has been working hard to increase the membership in our Sarcoma Patient Registry. The ambitious goal of the patient registry is to enroll all 50,000 Sarcoma patients in the United States, classify members by their Sarcoma subtype and provide a matchmaking service between members interested in clinical trials and the drug companies that are developing exciting new therapies for those specific Sarcoma subtypes. Because of the research (some of which has been funded by your donations to the SFA!) done on the genomic differences between Sarcoma subtypes, some very special targeted drugs are being discovered that could lead to powerful efficacy for the targeted subtype. We want to make sure the Sarcoma Patient Registry is large and robust, and that clinical trial participation by the Sarcoma community is high, to help us foster in this new generation of targeted therapies.

As always, none of this important work could be done without your generous support. We appreciate your continued contributions of your gifts, talents and resources to our shared cause of eradicating Sarcoma in our time!



Dr. Mark Thornton

Inside this issue:

SFA President's Corner	1	2009 Sarcoma Research Grants	5
Unraveling the Seeds	2	Georgia Event	5
Ask the Experts	2	Save the Date	5
Annual Gala	3	Mission	6
The Making of Nana	4	Donate	6
Fundraising Events	4		

Unraveling the Seeds of Evil in Bone Cancer

By Dr. Nino Rainusso - recipient of the Sarcoma Foundation of America - American Society of Clinical Oncology Young Investigator Award.

Mounting data has shown that carcinogenesis can be driven by cancer stem cells (CSCs), and this special subpopulation may also contribute to therapeutic resistance in a wide variety of solid malignancies. Our research has focused on the isolation and characterization of CSCs in osteosarcoma.

We have found that established osteosarcoma cell can grow in suspension as spherical clones (sarcospheres) under serum-free conditions. The ability to generate spheres after serial passages is due to the properties of CSCs to undergo self-renewal. However, we observed that the ability to form spheres after secondary passage was significantly different among different cell lines and primary tumors. We speculate that this characteristic may be related with the frequency of stem cells in certain tumors and their tumorigenic potential.

Previously, cancer stem cells have been sorted using specific surface markers such as CD133 for brain tumors, CD44+/CD24- for metastatic breast cancer, or CD90+ in hepatocarcinoma. However, during our experiments, we found that this approach is particularly difficult in osteosarcoma. Thus, we decided to functionally label stem cells with PKH 26, a red fluorescent lipophilic membrane dye that has been used for cell labeling and proliferation studies. Our data showed that only a minority of cells were still labeled with the red dye after serial sphere passages, and that the most highly fluorescent cells were able to form spheres more efficiently. Using a combination of cells marked with a lentivirally transduced ZS-Green reporter with the PKH 26 membrane tracking dye, we have been able to identify a subpopulation of stem-like cells *in vivo*. In our orthotopic transplantation model, unsorted cells are injected intratibially into NOD/SCID mice. We have found that these primary tumor cells efficiently metastasize to the lungs.

Surprisingly, the lung metastasis not only expresses the ZS-green reporter, but also still expresses PKH26, suggesting that they represent a quiescent cancer stem cell, which has undergone self-renewal. We've been able to culture cells from the lung metastasis, and we are now in an excellent position to do gene expression profiling on the original cell line, primary tumor and metastasis.



Dr. Nino Rainusso

The ultimate goal of isolation and characterization of CSC in pediatric solid tumors is to design specific treatments to target this special subpopulation. In a parallel collaboration with Dr. Nabil Ahmed and Dr. Steven Gottschalk at Texas Children's Cancer Center, we have found that adoptive immunotherapy targeting HER2 *in vitro* could decrease the tumor-initiating cell population. Our preclinical mouse model appears suitable to test this novel approach *in vivo*.

The last three years of fellowship have been the most important in my career because they have defined the type of doctor that I would like to be. I know now that my next years in the field will be dedicated to basic and translational research. I plan to continue my academic career at Baylor College of Medicine, having recently been admitted to an additional year of training as Pediatric Sarcoma / Solid Tumor Fellow under the close supervision of Dr. Alberto Pappo and Dr. Jeffrey Rosen. In recognition of our accomplishments in the lab, I have received the highly prestigious ASCO Young Investigator Award sponsored by the Sarcoma Foundation of America. I would like to thank all the donors, volunteers, and the scientific committee for trusting in our project.

Ask the Experts: Advances in Sarcoma Treatment and Research



The 2009 Educational Conference Survivors
Photo

The Sarcoma Foundation of America hosted its 5th 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, progress, including genetic findings, SFA funded research, clinical trials, and the origins of Sarcoma and new directions for Sarcoma research.

Dr. Mark Thornton opened the conference by discussing SFA history, highlighting the 40 SFA Sarcoma Research Grants awarded since 2003, three Young Investigator Awards and two \$450,000 American Society of Clinical Oncology Advanced Clinical Research Awards. Dr. Thornton also discussed the SFA's commitment of \$500,000 toward the Sarcoma Alliance for Research Consortium's (SARC) effort of securing a large National Cancer Institute grant. Dr. John Brooks gave an overview of the

2009 grants funded by the SFA and focused on Sarcoma incidence data. Dr. Carlos Cordon-Cardo discussed the origins of Sarcoma and how new ways of looking at cancer will improve outcomes in the near future. Dr. Charles Forscher discussed clinical trials and how they are important for advancing research. Dr. ML Keohan closed the program with a presentation on emerging and targeted therapies in the treatment of Sarcoma.

After the presentations, these distinguished doctors fielded questions whereby patients could engage in a more intimate Q&A with each expert. This 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.

Save the Date: On April 25th 2010, the SFA will host its 6th annual Educational Conference entitled *Ask the Experts: Advances in Sarcoma Treatment and Research*. Tickets and discounted hotel information, will be available soon at www.curesarcoma.org

7th Annual Fundraising Gala

One word, AWESOME!

The 7th annual Sarcoma Foundation of America Gala was held April 20th, 2009 in New York City at Cipriani 42nd street. During a time of economic turmoil, over 500 dedicated Sarcoma patients and families, friends, medical professionals, and corporate supporters attended this year's event. Every year we think it couldn't get better, but this year's Seventh Annual Fundraising Gala was well...awesome.

James Lurie served as Master of Ceremony and managed the flow of the evening. Dr. Carlos Cordon-Cardo received the Nobility in Science Award and Dr. Jonathan Lewis was our Vision of Hope Award recipient. Both gave truly inspirational speeches and are pioneers in the battle against Sarcoma. Beverlye Hyman Fead, Robert J. Alexander, Walter Carucci, Brian Fugere, and Kate McGarrigle were our Courage Award recipients, showing incredible strength in the face of adversity. Beverlye's speech of hope and courage in the midst of the fight of her life inspired the entire room. All the awardee's individual battles with

Sarcoma brought to light the mission of our organization – finding the cure in our time.

Dancing, dancing, and more dancing to the wonderful music of Victor Lesser and the Manhattan City Orchestra kept Cipriani filled with the energy of all supporting the SFA, especially when SFA board member Anthony Fedorov joined them for a couple of tunes. Live and silent auctions and a moving speech by actress and SFA spokesperson, Marisa Petroro, were additional highlights of the evening. A special, very moving performance was given by singer/songwriter Rufus Wainwright, who was also joined by his sister Martha for a tune in honor of their mother and Courage Award Recipient, Kate McGarrigle.

A huge thank you must go out to everyone on the Gala committee, most notably gala chairpersons Alicia Bouzan-Cordon, Nanci Lewis, JoMarie Pica, and Cookie Rumely. More than \$700,000 was raised in the name of Sarcoma research!



Courage Awards Winners



Dr. & Mrs. Jonathan Lewis and Cookie Rumely



Anthony Fedorov



Master of Ceremony, James Lurie



*SFA Spokeperson Marisa Petroro and
Howard T. Spencer, Jr.*



*Vincent Pica, Alicia Bouzan-Cordon,
Dr. Carlos Cordon-Cardo, JoMarie Pica*



*Matt Thornton, Dr. & Mrs. Robert Benjamin,
Dr. & Mrs. Mark Thornton, Dr. John Brooks*

The Making of Nana, What's Cancer?

When I was in Second grade, I needed to do a book report. I wanted to do this on my grandmother's new book *I Can Do This: Living with Cancer, Tracing a Year of Hope*. My mother (Terry Hamermesh) said that that would not work because of the subject. Me, having a family history of cancer, knew a lot about the disease. But, as my mom said, not many children my age knew about cancer like I did. Then, I said "Why don't Nana and I write a book and explain cancer to kids?" My mom loved the idea and told me to call Nana right away. I told Nana it was me and explained my idea to her. She loved the idea. She told me to write down a bunch of questions and when I came up the next time we would pick the most important ones together. Then Nana, with some help from some research, would answer them. We were like a factory of two people. We worked, and wrote, and rewrote. It was the hardest I had ever worked. We talked over cookies and tea about what to say and what to do. We realized that we weren't kidding. This wasn't just a dream. It was for real. One day, in 2008 (I am now 11) I got a call from Nana. She called and said "Tess, Tess! I got the letter back from the ACS (American Cancer Society) they're 99% sure about publishing our book!" "Oh my gosh!" I yelled. "Finally, after months of waiting!" She then told me that they weren't 100% sure that they were going to publish it. Then one day, it happened. The 100% YES! Came. I was as excited as an athlete when they win a competition. My dream was now really, truly, real! YES!

-By Tessa Hamermesh

After I got that call from my granddaughter, I realized what a wonderful idea she had. It was a win-win situation. I would be working with Tess, and we would also be helping other children. Win-Win!

She came up with some wonderful questions that had been rolling around in her head. I realized I now had to go to work to answer them.

I went to the library, and checked out several reference books. I sat there, day after day, and wrote, and found it to be a wonderful zen place to work. I also looked on the internet for information, and went to other books, and asked doctors for some answers. Originally, I thought we would go to Kinko's and make a few copies of our books to drop off at some nearby cancer centers. The more we worked on it together, though, I realized this might be bigger than that! After our third or fourth draft, I sent the manuscript to the ACS because I knew they had a book publishing division. Tess and I held our breaths. They wrote back they really loved the idea, the writing, etc., but they were all filled up for that year. They told me to try again in about eight months and they would take another look. But they also stated, "We can't make you any promises." The time came to send in our manuscript, and then we waited, and waited, some more for an answer. The main people were out of town, they didn't know yet what they were going to do, etc. Months went by. One day, I saw a message on my screen from the head of publishing at ACS. The subject read, "And the answer is..." I brought the message up, and it read, "And the answer is YES!" They were going to publish our manuscript, distribute it by McGraw Hill, and translate it into several languages as well. I called Tess; we were so excited. The publication date is set for this summer, and our dream to help explain cancer to children in a non-scary way will come true. It was worth the wait.

-By Beverlye Hyman Fead, Author of *I Can Do This: Living with Cancer, Tracing a Year of Hope* is a Sarcoma survivor and a recipient of a 2009 SFA Courage Award.



Beverlye Hyman Fead

Fundraising Events



2nd Annual Delores Maxwell Walk, MO



Rae of Hope, NC



365 Cancer Free, IL



Bowling for a Cure, IL



Golf for Alec, PA



Remembrance of Robin, OH



Boston College, Uplifting Athletes, MA



Bud's Run, IL



Jon Bowles TX Hold'em, KY



Black & Gold Affair, UMBC, MD



Two Battles Against Cancer, NY

2009 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.

Shelby L. Richter Memorial Research Award

"A preclinical mouse model for targeted therapy in uterine leiomyosarcoma"

Sandra Orsulic, Ph.D.
Director, Women's Cancer Biology
Women's Cancer Research Institute
Cedar-Sinai Medical Center

Michael Mandell/Run for a Sarcoma Cure Research Award

"Therapeutically targeting aberrant chromatin remodeling in Sarcomas"

Charles W.M. Roberts, M.D., Ph.D.
Assistant Professor, Pediatric Hematology-Oncology
Dana-Faber Cancer Institute

Blake Cadkin Memorial Research Award

"Evaluation of the oncogenic potential of genes within the 1q23 amplicon"

Alexander Besser, Ph.D.
Assistant Professor, Division of Biology
Kansas State University

Mary Beth Knox Memorial Research Award

"Development of novel dual Insulin-like Growth Factor-1 Receptor (IGF-1R)/Epidermal Growth Factor Receptor (EGFR) inhibitors for treatment of Ewing's Sarcoma"

William Bornmann, Ph.D.
Professor, Department of Experimental Therapeutics
M.D. Anderson Cancer Center

Marny S. Tobin Memorial Research Award

"Pharmacodynamic assessment of AKT and SRC inhibitors in primary human Sarcoma xenograft models"

Damon Reed, M.D.
Associate Member, Sarcoma Program
Moffitt Cancer Center

ARIAD and Merck Research Award

"Targeting kinases to reverse multidrug resistance in human Sarcoma"

Zhenfeng Duan, M.D., Ph.D.
Director, Sarcoma Research Laboratory, Department of Orthopaedics
Massachusetts General Hospital

ARIAD and Merck Research Award

"Identification of aberrantly methylated genes in Ewing Sarcoma"

Scott Borinstein, M.D., Ph.D.
Fellow, Pediatric Hematology/Oncology
Fred Hutchinson Cancer Research Center

PharmaMar Research Award

"Targeting the Ras-pathway for the treatment of embryonal rhabdomyosarcoma"

David Langenau, Ph.D.
Principal Faculty Member, Molecular Pathology
Massachusetts General Hospital

Sarcoma Foundation of America Research Award

"Targeting centrosomes in uterine leiomyosarcoma"

Matthew Anderson, M.D., Ph.D.
Director, Gynecologic Oncology
Baylor College of Medicine

Sarcoma Foundation of America Research Award

"Targeting the Wnt pathway in synovial Sarcoma"

Josiane Eid, M.D.
Assistant Professor, Department of Cancer Biology
Vanderbilt University Medical Center

SAVE THE DATE

Sarcoma Foundation of America Eighth Annual Fundraising Gala

Monday, April 26, 2010

The Pierre Hotel
New York City, New York

Mark your calendars!!!

Georgia Event

On Friday, July 24, 2009, Lisa Crocker, Georgia Chapter Leader and SFA Board Member, made history once again by holding her second annual Team Sarcoma Initiative Event "Walk for Sarcoma Awareness" held at Piedmont Park in Atlanta. The turnout was incredible! We doubled our attendance from last year and recorded over 121 people! The weather was truly on our side; it was a perfect day in Atlanta -- blue skies, not too hot and a visible skyline to appreciate the downtown view. The gathering was such a tremendous success with many people walking, laughing, and forming new friendships. Our event t-shirts even captured the attention of onlookers at the park, where we were able to spread further awareness by educating the community as well. I can't wait to see what Georgia can accomplish next year!



Our Mission

The mission of the Sarcoma Foundation of America (SFA) is to advocate for increased research to find new and better therapies with which to treat patients with Sarcoma. The organization raises money to privately fund grants for Sarcoma researchers and conducts education and advocacy efforts on behalf 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 by check or money order 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

CID # (3 digit number found on the back of MasterCard and Visa) _____

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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



*Dr. Keohan, Dr. Forscher, Dr. Brooks, Dr. Cordon-Cardo,
Ask the Expert, 2008 Educational Conference, NY*



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