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President's Corner

10 Years of Hope

It gives me great pleasure to welcome you to this edition of the Sarcoma Foundation of America newsletter, and to report that 2011 marks our 10th Anniversary! Over the course of this short period of time, the SFA has become the nation's leading advocate for increased Sarcoma research, championing the cause for new and better treatments for Sarcoma patients.

We at the SFA are quite proud of the accomplishments realized to date. Not too long ago, Sarcoma patients faced a truly dismal treatment climate: almost no viable therapies, little cohesion within the patient community, and low-level activity on the research front – all of which meant extremely dim prospects for 50 percent of patients whose Sarcoma was not caught early enough. Fast forward to today and the picture, while still highly challenging, is certainly demonstrably brighter due to SFA's efforts.

Those efforts include the following:

- **Funded 57 Sarcoma Foundation of America Research Grants** – The SFA has developed a program to provide grants to investigators interested in translational science – research that will lead to the development of novel agents against Sarcoma.
- **Doubled the dollar amount of its translational research awards** – In 2011, SFA grant awards increased to \$50,000, up from \$25,000 in previous years.
- **Funded two half-million dollar Advanced Clinical Research Awards through the American Society of Clinical Oncology** – a multi-year award designed to fund investigators who are committed to clinical cancer research.
- **Funded five Young Investigator Awards through the American Society of Clinical Oncology** – provides funding to promising young investigators to encourage and promote quality research in Sarcoma.
- **Developed a national Sarcoma Patient Registry** – a systemic collection of data on the occurrence, treatment, physician-reported outcome, and characteristics of Sarcoma. Helping physicians and researchers in every facet of patient care, from investigating the cause of cancer, to making the diagnosis, to tracking the effectiveness of different treatments with the purpose of conducting research to assess and control the impact of the disease and increase clinical trial participation.

With your help, our programs have touched so many lives. Though we have made progress, there is still an urgent need for further Sarcoma research, education, and awareness. I encourage everyone to give generously in support of this cause. Thank you for your continued support. Together, we have the very real possibility of finding the cure in our time.



Dr. Mark Thornton

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Grant Recipient Takes Aim at Liposarcomas

Call for Grants

We will begin accepting grant requests in Oct 2011. Grants of \$50,000 are available to cover equipment and supplies in support of research on the etiology, molecular biology, pathogenesis, diagnosis, and treatment of human Sarcomas.

Preference will be given to proposals that focus on novel agents and/or promising molecular targets. These approaches include, but are not limited to:

METABOLIC TARGETS:
c-Met, HDACs, WNT pathway signaling, rank ligand, IGF2; PI3 kinase, Akt, Hedgehog pathway (Ihh, Shh, Dhh), PARP, Notch, and Beta-catenin.

THERAPEUTIC CLASSES APPLICABLE TO SARCOMA: Immunotherapy, Metabolomics, miRNAs, Cytokines CCL2, and CCL3.

For more information contact Lori Hoffman at lhoffman@curesarcoma.org.

* application deadline is January 31, 2012.

One of the seven 2011 Sarcoma Foundation of America research grants was awarded to Dr. Nita Ahuja, MD, for her proposal entitled, "Epigenetic changes and epigenetic therapy in retroperitoneal liposarcomas." Dr. Ahuja is a surgical oncologist at the Johns Hopkins Hospital and knows very well the frustration of treating liposarcomas. "The problem is that you can never really tell a patient they are cancer free because so many of them come back," she says. "Patients undergo extensive abdominal surgeries and radiation only to have the cancer come back within a few years because our therapies aren't good enough." That is why she has begun a program to study the epigenetics of abdominal liposarcomas at Johns Hopkins Hospital.

Dr. Ahuja received her MD from Duke University and did her surgical training followed by a fellowship in surgical oncology at Johns Hopkins Hospital. She is currently an Associate Professor at Johns Hopkins and directs the gastrointestinal Sarcoma program. She also leads a laboratory in the development of biomarkers for gastrointestinal cancers. "Because I trained at the same institution for nearly a decade, I saw many of the same patients come back with recurrences. I was a part of their continuity of care and their struggle sparked my interest," she explains. Dr. Ahuja is a recipient of the Jeannik M. Littlefield American Association of Cancer Research grant for metastatic colon cancer to develop epigenetics as personalized biomarkers in colorectal cancer. Her work in colorectal cancer recently identified a gene profile that predicts which patients' cancers will come back after surgery. She believes that the study of epigenetics in liposarcomas will similarly increase our understanding of liposarcomas and provide potential novel therapies to these understudied cancers.

Generally, when people think about cancer, they think about mutations in DNA causing the cell's growth and replication to become accelerated, but there are other components. Epigenetics is the study of mechanisms (besides mutations) which can turn genes off and on. The exciting part of this field of study is that the epigenetic changes that occur in cancer can be reversed with medication.

"Right now we are exploring which epigenetic changes take place in liposarcoma cells and how they react to the epigenetic treatment. Our experiments are in the preliminary phases, but we are optimistic. Our hope is that someday we can apply what we see in the lab to patients," Dr. Ahuja explained.

Dr. Ahuja currently has an ongoing national trial of epigenetic therapy in patients with metastatic colorectal cancer funded by a Stand Up To Cancer AACR grant and led by Dr. Stephen Baylin, a world leader in epigenetics. "This therapy is not for everyone," she cautions. "Sometimes the mutations play a bigger role, sometimes epigenetics is the bigger factor. But what we have seen is that in patients who have received epigenetic therapy, their chemotherapy afterwards seems to work better. It's like hitting a reset button on the cancer cell. It doesn't remember that it is supposed to be resistant to the chemotherapy."

Dr. Ahuja's goal of treating patients with abdominal liposarcomas with epigenetic therapies is an ambitious goal, but she hopes that her work in the field will lead to new discoveries to treat this resistant cancer.



Dr. Nita Ahuja

Clinical Trial Navigating Service

The Sarcoma Foundation of America Clinical Trial Navigating Service offers patients, caregivers and health care professionals up-to-date information about Sarcoma cancer clinical trials throughout the United States and Canada. The service is provided in collaboration with EmergingMed and will help you quickly search for clinical trial options that match your specific diagnosis and treatment history.

This free and confidential service is designed to allow you to begin the search process online. However, we recommend that visitors begin the process by calling our toll-free number: 800-536-8718 or go to the clinical trials section of our website at www.curesarcoma.org for more information.

Annual Patient Educational Conference Shares Exciting New Insights into Sarcoma Treatments

SFA's annual Patient Educational Conference (held on May 1) was attended by more than 100 Sarcoma patients and caregivers. As in past conferences, leading experts in Sarcoma presented the results of cutting-edge research to give current and future patients a sense of renewed hope. The presenters were:

Mark Thornton, MD, PhD
SFA President

Topic: *Opening remarks and SFA overview*

John S.J. Brooks, MD
Pennsylvania Hospital

Topic: *Advances in Sarcoma Pathology*

John M. Goldberg, MD
University of Miami Sylvester Comprehensive Cancer Center
Topic: *Advances in Sarcoma Vaccines & Immunotherapy*

Raphael E. Pollock, MD
MD Anderson Cancer Center
Topic: *Advances in Sarcoma Surgery*

Dina Chelouche Lev, MD
MD Anderson Cancer Center
Topic: *Advances in Malignant Peripheral Nerve Sheath Tumors*

Robert G. Maki, MD, PhD
Mount Sinai School of Medicine
Topic: *Emerging Therapies for Sarcoma Patients*



Survivor Photo, 2011

George D. Demetri, MD
Dana-Farber Cancer Institute
Topic: *Future Directions of Sarcoma Therapy*

A lively question and answer session followed the scheduled presentations, offering patients and their families an opportunity to interact with the leaders in the field of Sarcoma treatment and research.

A video record of the day's presentations will be made available on SFA's website www.curesarcoma.org. You'll then have the opportunity to get the information directly from our experts about the challenges and opportunities that lie ahead in the field of Sarcoma research.

SFA Research Grant Leads to Formation of Start-up Biotech Company

An SFA research grant awarded in 2006 to Dr. Brent Stockwell at Columbia University led to promising discoveries culminating in the recent formation of Solaris Therapeutics, a start-up biotech company. Dr. Stockwell, a Howard Hughes Medical Institute Fellow and Associate Professor at Columbia's Department of Biological Sciences and Department of Chemistry, received the SFA grant to support his research into some 40,000 compounds for their ability to inhibit MDM2 E3 ligase activity in a cell-based assay, an unexplored pathway to inhibit cancer. From this research, Dr. Stockwell discovered several drug candidates that were considered potentially suitable for further development. These compounds are

considered to have the potential to reveal a new strategy for eliminating Sarcomas containing the NDM2 oncogene, and might serve as a proof of concept for a new class of anti-Sarcoma agents.

SAVE THE DATE

Californian's for a Cure!
Sunday, Nov 6, 2011

*Featuring: Rufus and Martha Wainwright,
Anthony Fedorov, and Charlie Lustman*
The Music Box
Los Angeles, California

\$1.1 Million Raised for Sarcoma Research

The 2011 SFA gala set new records in attendance and in funds raised for Sarcoma Research. “I don’t think any of us could have expected this event to have been more successful,” says **Dr. Mark Thornton**, SFA President. An overflow audience of more than 600 guests at Cipriani in New York City donated more than \$1.1 million for Sarcoma research, a new record for the SFA.

This year’s gala marks SFA’s 10th anniversary and was co-chaired by **Richard Lobo, Susan Brooks O’Rourke, and LuAnn Woodbury**. Singers/songwriters and SFA Spokespersons **Rufus and Martha Wainwright**, served as Honorary Chairpersons for this year’s spring gala, during which, Rufus gave an amazing impromptu a cappella rendition of “Somewhere over the Rainbow.”

The evening’s gala program was hosted by Mistress of Ceremonies, **Julie Chang**, entertainment reporter for WNYW/Fox 5 in New York. **JoMarie and Vincent Pica** received the *Vision of Hope Award* for their tireless dedication to the SFA and their leadership role with each annual gala. In addition to providing family sponsorships in support of the annual gala, JoMarie Pica has served on gala benefit committees, chaired several galas, as well as served on the SFA Board. This year’s *Nobility in Science Award*

went to **Dr. Raphael E. Pollock** of MD Anderson Cancer Center in Houston, Texas, for his lifetime of professional dedication to care of the solid tumor patient as well as laboratory research.

The evening’s entertainment featured a surprise guest performance by American Idol finalist **Casey Abrams** and a performance by the cast members from the hit Broadway musical **MEMPHIS**. The evening’s program was punctuated by some very poignant moments, especially when SFA invited this year’s Courage Award recipients on stage for well-deserved recognition and a standing ovation from everyone in attendance. **Michael Mandell**, SFA Board member and the Director of the SFA Florida Chapter, was one of the night’s Courage Award recipients. Additional Courage Award Recipients were **Lori Capon, Gail H. Cassell, Gail Palajac, Atara Schweky and Mary Ellen Rumore**. Another Courage Award recipient, **Rita Saverino Romeo**, had a successful 18 hour surgery just a few days after the gala. A powerful video about her story and battle with Sarcoma was shown at the gala and is now available for your viewing at www.curesarcoma.org. Rita’s story is as touching as it is inspirational.



Dr. Mark Thornton, Gary and Addie Tomei, Patricia Thornton, Matt Alsante



JoMarie and Vincent Pica



Dr. Dina Chelouche Lev and Dr. Raphael E. Pollock



Martha Wainwright, Casey Abrams, Julie Chang and Rufus Wainwright



SC Chapter Leader Monna Jones and Kristy Gross



Dancing the Night Away



Charlie Lustman

SFA doubles value of research grant awards to \$50,000 and makes awards to seven top Sarcoma Researchers / Competition for SFA Sarcoma grants intensifies in 2011

In April 2011, the Sarcoma Foundation of America awarded seven highly deserving scientists with SFA research grants. The SFA continues to fund high risk, high reward projects that would not likely be funded by the government or pharmaceutical companies. SFA supported research has led to:

- The identification of novel druggable targets for not only Sarcoma, but for many more common cancers
- The discovery of a new class of cancer inhibitors
- The creation of mouse models for multiple Sarcoma subtypes
- Development of state-of-the-art proteomic approaches
- Multiple gains in gene expression profiling
- Millions of dollars of additional grants based on research findings from SFA research projects

Congratulations to the 2011 SFA research grant recipients!

Alexander Burdo/ZIOPHARM Research Award

"Interrogating the effects of IGF1R blockade on childhood sarcoma fusion oncoprotein stability"

Poul H.B. Sorensen, MD, PhD

Senior Scientist
British Columbia Cancer Research Center

Ashleigh Lau/Morgan Stanley Research Award

"Beta-catenin activation in synovial sarcomagenesis and progression"

Kevin B. Jones, MD

Instructor of Orthopaedics
University of Utah - Huntsman Cancer Institute

Mandell/Kropp Run for a Sarcoma Cure Research Award

"Histone deacetylase inhibitor reprograms hSNF5/INI1 regulated gene expression for the treatment of epithelioid sarcoma"

Quan-sheng Zhu, MD, PhD

Instructor, Department of Surgical Oncology
The University of Texas - M.D. Anderson Cancer Center

Mark Herzlich Research Award

"A small molecule inhibitor of AXL is a novel therapeutic strategy in osteosarcoma"

Edward Greenfield, PhD

Harry E. Friggie III MD Professor of Orthopaedics and Director of Orthopaedic Research
Case Western Reserve University

Sarcoma Foundation of America Research Award

"Comprehensive mutational analysis of gastrointestinal stromal tumors lacking activating mutations in the KIT, PDGFRA, and BRAF genes"

Martin G. Belinsky, PhD

Staff Scientist
Fox Chase Cancer Center

Sarcoma Foundation of America Research Award

"Epigenetic changes and epigenetic therapy in retroperitoneal liposarcomas"

Nita Ahuja, MD

Associate Professor of Surgery and Oncology
Johns Hopkins University

Sarcoma Foundation of America Research Award

"Hedgehog palmitoylation inhibitors to block sarcoma growth"

Marilyn D. Resh, PhD

Member and Professor
Memorial Sloan-Kettering Cancer Center

Research grant proposals are reviewed annually by our Medical Advisory Board members.

Chapters Open in California, Pennsylvania and Texas



Chapter Retreat, March 2011

We are pleased to announce that four new chapter leaders have been added to the SFA's state chapter network in California, Pennsylvania and in Texas.

Joanna and Bryan Brooks of Houston, Texas, Sue Embree-Davis from Vallejo, California, and Stephen Capuzzi from the Institute of Catholic Bioethics at St. Joseph's University in Philadelphia have brought some added enthusiasm in three major markets for SFA's mission to advocate for increased research to find new and better therapies to treat patients with Sarcoma.

According to CA Chapter Director Sue Embree-Davis, "often families and friends of a newly diagnosed loved one feel so helpless to do anything meaningful to be of assistance. A fundraiser can help to gather everyone together to do something positive for their loved one and to promote future research toward finding a cure for these aggressive and rare cancers."

You can reach out to your state directors by going to www.curesarcoma.org and clicking on your respective state. We can always use more help.

2011 SFA Staff

Introducing the Sarcoma Foundation of America, who works for YOU.
Lori Hodo Hoffman, our Manager of Scientific and Government Affairs;
Brent Berwager, Development

Director; Patricia Thornton, SFA co-founder and board member; Matthew Alsante, Executive Director; Mary McCarthy, Office Manager; and Cindy Saunders, Program Specialist. Missing from this picture is camera shy Norine Spencer who is the Fundraising Director



SFA Now a Member of the Combined Federal Campaign (CFC #57785)

The Combined Federal Campaign (CFC) is the world's largest and most successful annual workplace charity campaign, raising millions of dollars each year. Each fall, federal employees – civilian, military and postal – are invited to support eligible national and local charities. More than 1.3 million employees pledge over a quarter billion dollars each year. Beginning this September 2011, federal workers will now be able to make payroll contributions directly to the SFA.

For any SFA supporters who also are federal workers, please try to remember us when you make your annual pledge through the

Combined Federal Campaign. All of us at the SFA sincerely appreciate your generosity. Again, our CFC number is **57785**.

For more information about the Combined Federal Campaign, please visit www.opm.gov/cfc.



April 26, 2011 - The Sarcoma Foundation of America rang the bell at the the NASDAQ MarketSite in New York City's Times Square.

Planned Giving Program

Would you like to make a major gift to the Sarcoma Foundation of America and help find the cure in our time, but believe you don't have adequate financial resources, or believe such a gift would compromise your loved ones' future security? With the planned giving options now available at the SFA, even people of modest means can arrange a future gift that would be received only after loved ones have been provided for.

After first providing for your loved ones, you may decide to make a charitable gift of a specific amount, a percentage of your estate, or all or part of what remains after family and/or friends have been remembered. Many potential donors make use of trusts created during life to provide for the management and future distribution of assets, then, at the termination of the trust, direct that a portion of the remaining assets be used for charitable purposes, including the SFA.

Please contact us if you would like to discuss giving options or have any questions.

We're Moving

As of September 2011, our new address will be:

Sarcoma Foundation of America
9899 Main Street, Suite 204
Damascus, MD 20872

Rufus and Martha Wainwright Concerts Benefit SFA

On May 12 and 13, Town Hall in New York City was filled to capacity with family, friends and followers of singer/songwriter Kate McGarrigle, the mother of Rufus and Martha Wainwright, who died of Sarcoma in January 2010. Performing songs from her impressive catalog, the stage was filled with an eclectic array of musicians including Norah Jones, Emmylou Harris, Antony Hegarty, Jimmy Fallon, Kate McGarrigle's sister and collaborator, Anna McGarrigle, as well as her children Rufus and Martha Wainwright, the SFA 2011 Spokespersons.

The concerts were huge successes for everyone involved, including the Sarcoma Foundation of America, which established the Kate McGarrigle Sarcoma Research Fund from the concerts' proceeds. The SFA wishes to send out an extra special thanks to Rufus and Martha Wainwright, and to Teddy Wainwright, who worked so hard to make these two wonderful evenings come together in such a spectacularly successful way. The SFA will never forget your kindness, and your hard work and dedication on our behalf.



A Celebration of Kate McGarrigle

Fundraising Events



Lady Mavericks, Archbishop McCarthy, FL



Tribute to Lynn Blood, OH



Charlottesville Half Marathon, VA



Walk for Wellness at Stackpole Elementary, PA



Gloucester County Washington Township, NJ



Saddle Up & Get Your Dancing Boots On for a Sarcoma Cure, MN



Quinnipiac Volleyball Team, NY



1st Annual Pittsburgh Cure Sarcoma 5k Run, PA



Outfox Sarcoma, NJ

Upcoming SFA Fundraising Events Nationwide

- Aug 18 - Birdie Tourney - Michigan
- Sep 6 - FL Marlins Baseball - Florida
- Sep 22 - Kickin' Cancer Happy Hour - New York
- Oct 1 - Jared Dane Scotto Fundraiser - New York
- Oct 22 - Brews for a Cure - Maine

- Oct 23 - FL 5k Walk/Run for Sarcoma Cure - Florida
- Nov 6 - Californian's for a Cure - California

On Going Events

- Paul Corliss presents Outfox Sarcoma
- Adventures of Snooky

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

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

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

Credit Card No.: _____ Expiration Date: _____

Signature: _____

Mail to: Sarcoma Foundation of America, 9899 Main Street, Suite 204, Damascus, Maryland 20872 or fax it to: 301-253-8690

finding the cure in our time

www.curesarcoma.org

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www.facebook.com/curesarcoma and www.twitter.com/curesarcoma



Ask the Experts 2011

Top Row: Dr. John S.J. Brooks,

Dr. Raphael E. Pollock,

Dr. Robert G. Maki,

Bottom Row: Dr. John M. Goldberg,

Dr. Dina Chelouche Lev,

Dr. George D. Demetri

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