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President's Corner

Advocating for increased Sarcoma research and *finding the cure in our time* has been our mission and goal since the SFA's inception in 2001. While progress has not been made nearly as fast as we all hope, the SFA is dedicated to leading the fight for new therapies and treatments for Sarcoma patients. This is what we are all about - doing everything we can to have a day where the doctor can reach for twenty or thirty powerful therapies to allow all Sarcoma patients to have a normal lifespan. With the support of our dedicated donors the SFA has been able to again fund 10 "Starter Grants," designed to ignite ideas for new research avenues in our quest to eradicate Sarcoma. In addition, SFA and the Capon family have funded our second three-year American Society of Clinical Oncology (ASCO) Advanced Clinical Research Award (ACRA). The recipient of the ACRA was Dr. David Kirsch of Duke University Medical Center. Dr. Kirsch will use the \$450,000 award to bring personalized medicine to Sarcoma patients with a method to make surgery more effective by detecting microscopic residual cancer cells. We also strive to encourage bright young minds to go into the field of Sarcoma research. We have supported this endeavor by funding our fourth ASCO Young Investigator Award to Dr. Jeffrey Rothman of Memorial Sloan-Kettering Cancer Center. Dr. Rothman is focusing on research to develop therapies that potentially would target just cancer cells without harming normal cells. You can read about these two prestigious awards, along with the SFA directly funded grants, further in this issue.



Dr. Mark Thornton

On the legislative front, due to the inflexibility and inconsistencies in the Food and Drug Administration (FDA) drug approval process, the SFA has been actively petitioning them to produce a guidance document on the development of drugs for rare cancers. Recently, new hope has emerged that a more humane approach might be taken at FDA to help foster approvals for new drugs for exceedingly rare diseases. In an amendment to the 2010 FDA Appropriations law, Senators Sherrod Brown (D-Ohio) and Sam Brownback (R-Kansas) inserted language in the bill for FDA to essentially explain themselves on the unfairness of their policy, which has resulted in only about 200 treatments for the over 8000 diseases categorized as rare. Recently, the new FDA Commissioner, Dr. Margaret Hamburg, appeared before the Senate to provide the plan for how the FDA was going to respond to the new law. In emotionally moving testimony of her own experiences as a doctor dealing with patients in desperate need of new therapies, she promised "innovative if not transformative" approaches to the problem, saying that "new regulatory pathways could be developed... to catalyze activity in areas where there are limited markets. I know that this is (also) of the highest priority in the White House." In Europe, for example, such creative pathways for regulatory approval exist and have resulted in the approval of the drug Mepact in the European Union for osteosarcoma -- a therapy that has been denied approval in the US. Mepact is the poster child for all that needs improvement at the FDA regarding patients with rare and neglected diseases.

As a part of this new energy at the FDA, the SFA took part in a public hearing on this subject at the end of June. We are working with other rare cancer and rare disease patient groups to have our collective voices heard. I look forward to updating you on this effort as they move forward. We always appreciate your contributions of time, talent, and resources toward our mission, goals, and efforts on behalf of all Sarcoma patients.

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Dr. Kirsch Strives to Bring Personalized Medicine to the Clinic for Sarcoma Patients

Dr. Kirsch, the 2010 recipient of ASCO's Advanced Clinical Research Award (ACRA) in Sarcoma, supported by the Sarcoma Foundation of America and the Capon family, hopes that a molecular imaging device he helped develop will one day be used to identify patients with microscopic residual cancer to help guide the use of adjuvant radiation therapy. The ACRA in Sarcoma is awarded to investigators who are committed to clinical cancer research and who conduct original research not currently funded. The three-year grant provides a total of \$450,000 in funding.

As a radiation oncologist, David Kirsch, MD, PhD, knows the benefits of using radiation therapy in combination with surgery for certain types of cancer. Although surgery can remove every cancer cell, microscopic residual disease remains behind for some patients and this can cause the cancer to recur. With currently available technology, there is no way for a surgeon to identify which patients have microscopic residual cancer.

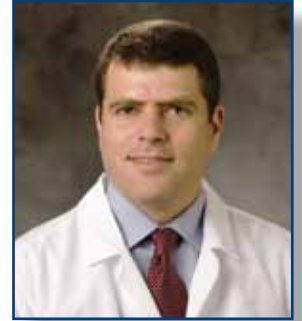
"I'm very excited to move this research forward into clinical trials," said Dr. Kirsch in an interview with the *ASCO Daily News*. "This award will allow us to see if this device can help treat cancer in people."

Dr. Kirsch, who also received the 2004 Young Investigator Award from ASCO, is an associate professor at Duke University Medical Center. Dr. Kirsch traces the origins of his imaging device to his postdoctoral work where he generated a mouse model of soft tissue Sarcoma in the laboratory of Tyler Jacks, PhD, at MIT. Through a collaboration with Ralph Weissleder, MD, PhD at MGH, Dr. Kirsch used novel molecular imaging techniques to detect Sarcomas during surgery in genetically engineered mice. He realized that this technique could be very useful to surgeons if a device could be created with greater sensitivity and a wide field-of-view, allowing the surgeon to quickly scan the tumor bed and detect residual tumor cells. With funding from a Damon Runyon-Rachleff Innovation Award, Dr. Kirsch collaborated with engineers at MIT to build the device and successfully tested it on his Sarcoma model at Duke.

If the device proves effective in humans, the technology could influence cancer therapy in a number of ways. "Right now as radiation oncologists we're treating a lot of patients with no residual cancer in the tumor bed," said Dr. Kirsch. If his device indeed has high enough sensitivity to detect that residual cancer, avoiding unnecessary radiation treatment would be one application.

Another possible application, says Dr. Kirsch, is more targeted treatment for those patients found to have residual cancer cells. "If detected, the surgeon could remove those cells during the same operation, cutting down on the number of re-operations and re-excisions due to positive margins." Dr. Kirsch also noted that if the cancer is found in a region that cannot be resected, the area where it is detected could be marked and later treated with high doses of radiation.

With funding from the ACRA in Sarcoma, the next step for Dr. Kirsch and his research team is to bring this technology into the operating room through clinical trials to test first the safety and then the efficacy of the device in humans. If the first two phases of the trial are successful, the next challenge will be to bring in other investigators to conduct a large, multi-institutional phase III trial.



Dr. David Kirsch

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.

Expanding the Boundaries of Chemistry to Attack Sarcoma

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

For almost an entire century, the general strategy to combat cancer has been to target the faster growing characteristics of tumor cells with cytotoxic chemotherapy. For the past two decades, monoclonal antibodies have been developed to target tumor cell surface markers to incite an immunotoxic response against these cells. Even though these markers are also expressed on normal cell variants, this strategy nonetheless has shown efficacy. Additionally, over the past few years, inhibitors have been developed to target metabolic pathways upon which tumor cells depend more than normal cells. Although such inhibitors can be effective by initially determining whether a particular tumor displays dependence upon a metabolic pathway which can be thwarted, tumor cells may and eventually do employ other pathways to evade such metabolic blockades. ***Regardless of their effectiveness, all of these strategies have limitations related to their nonspecific targeting regarding differentiation between normal and cancer cells and subsequent toxicities/side effects. This means that doses necessary to eradicate confidently all cancer cells are lethal to the patient. This leads us to the question of how we can more effectively kill tumor cells with limited lethality to normal cells.*** Furthermore, this leads us to consider the source of what distinguishes tumor cells from normal cells. In fact, this would be their genes themselves. Due to tumorigenic changes cancer cells have unique genetic signatures. Thus, tumor-promoting genes are distinct and defining of tumorigenesis, which of course normal cells do not possess.



Dr. Jeffrey Rothman

What I propose is a strategy that specifically targets tumorigenic gene sequences (unique only to cancer cells), irreversibly obstructing their cellular function and replication during cell division. Fortunately, nature has already supplied such a means for sequence-specific recognition of genes. By design, complementary recognition of gene sequences through DNA duplex formation is exquisitely sensitive to even just a single base-pair mismatch. Structural analogues of DNA, such as peptide nucleic acids (PNA), are just as sensitive, but bind 1000-fold more avidly to gene lesions thus completely displacing its complementary strand. This strand displacement disrupts transcription, and in this manner obstructs gene expression. In fact many prior studies have proven the effectiveness of PNA oligomers for sequence-specific suppression of gene transcription. These PNA oligomers are unable to be degraded by cellular enzymes and easily delivered into the cells by an attached peptide that is cell membrane permeable. Much of my work entails the modification of these constructs to enable them to irreversibly obstruct the expression and replication of these tumorigenic gene sequences during cell replication.

Unlike many physicians with a research background, my interests lie within the boundaries of organic and computational chemistry and their application to biological systems. Employing chemistry-based tactics to develop novel strategies for cancer treatment is my goal. In particular, this work includes the development of schemes that will ultimately lead towards chemotherapy that specifically targets cancer cells while not affecting normal cells.

I began clinical oncology fellowship training at Columbia University Medical Center (CUMC) and am continuing at Memorial Sloan-Kettering Cancer Center (MSKCC) collaborating with sarcoma research groups in both institutions. Within the Tan and Ouerfelli research groups of the Experimental Therapeutics Division at MSKCC, I shall be synthesizing oligonucleotide analogues targeted against oncogenic translocations found in sarcomas. Their efficacies will be assayed in sarcoma cell lines by the Taub/Matushansky group at CUMC and the Schwartz group at MSKCC. In the long run this project could lead to the 'bench to bedside' development of PNA oligomers that can be delivered systemically to bind a targeted genetic sequence irreversibly in a cell.

With post clinical fellowship training, I would like to focus upon research objectives that link the disciplines of chemistry and cancer medicine. An academic faculty position employing chemistry-based tactics to develop novel strategies for treatment of sarcomas is my goal.

Annual Patient Educational Conference

Ask the Experts: Advances in Sarcoma Treatment and Research

On April 25th at the New York Helmsley Hotel, the Sarcoma Foundation of America hosted its sixth annual educational conference for Sarcoma patients, their families, caregivers and other medical professionals. The half-day program featured experts in all areas of Sarcoma.

Drs. Jean-Yves Blay, John S.J. Brooks, George Demetri, Paul Meyers, Shreyaskumar Patel, Samuel Singer, and Jeffrey Toretsky shared information about the latest advances in Sarcoma research and treatment. Attendees traveled from across the country to learn about the latest research, treatments, and progress, including European drug approval, targeted therapy, subtype specific advances and new directions for Sarcoma research.



Survivor Photo, 2010



Ask the Experts Panel, 2010

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. The event was an overwhelming success.

Do's and Don'ts for Cancer Patients *by Candace Sue*

People diagnosed with Sarcoma often feel a loss of control when they first learn they have a life-threatening condition. These helpful hints are intended to help recently diagnosed patients take actions that can improve their chance of receiving the best care and prognosis.

Do

◆ **Know Your Cancer** – Make sure you know your Sarcoma type, stage of disease and treatment options. Compile a health history notebook and carry it with you to appointments.

◆ **Seek a Second Opinion** – When you have rare cancer like Sarcoma, you quickly realize that doctors don't have all the answers. It's important to get a second opinion, preferably from an oncologist at a research hospital that has ongoing clinical trials for Sarcoma. Let your physician know that you would like to get a second opinion and ask if they can make a referral.

◆ **Get Treated at a Regional Cancer Center** – Not all hospitals are treated alike. Seeking care at a regional cancer center that has ongoing clinical trials for Sarcoma patients increases the likelihood you will have access to the latest treatments and research.

◆ **Get Support** – When you have cancer, it's essential to find a good support system to keep your spirits up and your attitude hopeful. Support can come from family, friends and co-workers but there are also other resources you can turn to. Consider participating in a support group, talking to a psychotherapist or utilizing complementary therapies such as yoga, acupuncture, Reiki, Chi Gong, art therapy or a combination of these.

Don't

◆ **Believe Everything You Read Online** - Though it's essential to understand as much as you can about your diagnosis, don't allow yourself to be overwhelmed by the quantity of information online. The internet is a great patient resource, but you should verify what you learn with your doctor.

◆ **Listen to Negativity** – While you're working on healing your body, it's important to surround yourself with positive people who make you feel good. Avoid people who bring you down with their negative attitudes and fears.

Candace Sue is a board member of the Sarcoma Foundation of America and a seven-year survivor of leiomyosarcoma.

SAVE THE DATE

Ask the Experts...Educational Conference
Sunday, May 1, 2011
The Grand Hyatt Hotel
New York, New York

Spring Gala Raises \$950,000 for Sarcoma Research

The SFA's eighth annual Fundraising Gala, held on April 26th at the Pierre Hotel in New York City, was a phenomenal success, surpassing previous galas by raising more than \$950,000 for Sarcoma research. Over 500 attendees from across the country came together to help honor several distinguished figures in the world of Sarcoma.

The Courage Award is given to individuals that have demonstrated true strength and courage in their battle against Sarcoma. Recipients Alex Burdo, Nadia Hannan, Mark Herzlich, Kaitlyn Liotti, Candace Sue, Luke Weber, and Ashleigh Lau have all exhibited these qualities and more. Susan Rose introduced the honorees, sharing their stories of victory over Sarcoma. Candace Sue delivered a heartfelt speech inspiring the continuation of the fight for our cause.

Dr. Murray F. Brennan, Chairman of the Department of Surgery at Memorial Sloan-Kettering Cancer Center, received the Vision of Hope

Award. Dr. Brennan's amazing leadership and expertise in the field of Sarcoma ensures that future generations of physicians trained under his guidance can become the next generation's leaders in Sarcoma research and care.

The Nobility in Science Award recipient, Dr. Paul A. Meyers, Vice-Chair of the Department of Pediatrics at the Memorial Sloan-Kettering Cancer Center, has made multiple contributions to the medical field that include leading the battle for approval of additional therapies through investigational and clinical trials. Dr. Meyers has focused on treatments for Sarcomas of children and young adults. The evening's Presenting Sponsor, Morgan Stanley, supported the event in Ashleigh Lau's name. Our Platinum Sponsors, ARIAD Pharmaceuticals, ZIOPHARM Oncology, PharmaMar, and John and Judi Hannan, deserve our great appreciation.



Dr. O'Reilly presented the Nobility in Science award to Dr. Meyers.



Dr. Lewis presented the Vision of Hope award to Dr. Brennan.



2010 Courage Award Winners



Patricia Thornton, Dr. Jonathan Lewis, Dr. Mark Thornton, Nanci Lewis



Allison Liotti, Gary Tomei, Kaitlyn Liotti



Rebecca, Natalie, Ashleigh and Yan Lau with Dr. Thornton



PharmaMar Table



Pica Table

Raising Funds for Sarcoma Research

Through your efforts, energy, and time, we've held many fundraising events for Sarcoma research. From California to New York, Arizona to Florida and many other states around the country, we reach out and spread our message of *finding the cure in our time*.

Cookies for a Cure
Bowling for a Sarcoma Cure
UMBC Against Cancer Dance - Black and Gold Affair
5th Annual Marcia Brodsky Memorial Golf Outing
2nd Annual Cousins for the Cure: Helping Hands for ARMS
Jon Bowles Texas Hold'em
Margie Madness Summer Bash
Birdie Tourney - in memory of Mary Beth Knox
2nd Annual Delores Y. Maxwell Walk for Health & Wellness
Rae of Hope in memory of Dr. Rae Lynn Yates

Cocktails for a Cause - Part Deux
Marine Corp Marathon - Team Lori
Fight for a Sarcoma Cure
Thanksgiving Bash
2nd Annual Dunk Contest
Dash for Deb, Debbie LeGette Memorial Walk
Sweetheart Ball
7th Annual Bassett Golf Tournament
5th Annual John Kunz Memorial Golf Outing
Buds Run Memorial 5K Run/Walk



Fight for a Cure, NY



Broadway Play - "Memphis the Musical," NY



Long Stroke for a Cure, MO



New Decade ~ No Cancer, IL



Rae of Hope, NC



5K Run/Walk for a Cure, FL



Thanksgiving Bash, NY



Bassett Golf Classic, CT



New York Marathon



Cocktails for a Cause, NY



Boston College, Uplifting Athletes, MA

Upcoming Events

Moore Than Just Fun Walk...in memory of Dr. Thomas D. Moore - Oct 9, 2010 - AL

Third Annual 5K Run/Walk for Sarcoma Cure - Oct 24, 2010 - FL

Second Annual Rae of Hope in memory of Dr. Rae Lynn Yates - Oct 30, 2010 - NC

For more fund raising information go to www.curesarcoma.org

The ASCO Foundation, Sarcoma Foundation of America and the Capon Family Proudly Present

2010 Advanced Cancer Research Award in Sarcoma for \$450,000 to

David G. Kirsch, MD, PhD

Duke University Medical Center

Department of Radiation Oncology

“Using Molecular Imaging to Identify Microscopic Residual Sarcoma Cells During Surgery”

2010 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. In 2011, our grant awards will be increased to \$50,000!

Alexander Burdo/ZIOPHARM Research Award

“Functional Analysis of Mirk/Dyrk 1B in Osteosarcoma”

Zhenfeng Duan, MD, PhD

Director, Sarcoma Research Laboratory

Center for Sarcoma and Connective Tissue Oncology

Massachusetts General Hospital

ARIAD and Merck Research Award

“How Does a Sarcoma Circumvent Fusion Oncoprotein-Mediated Toxicity?”

Frederic G. Barr, MD, PhD

Associate Professor, Department of Pathology and Laboratory Medicine

University of Pennsylvania School of Medicine

Dominick Rizzi Memorial Research Award

“Identification of Causative Mutations for Ewing’s Sarcoma”

Mizuki Azuma, PhD

Assistant Professor, Department of Molecular Biosciences

University of Kansas Center for Research

Dominick Rizzi Memorial Research Award

“Crosstalk Between EGFR and IGF1R Mediated by Polymorphisms in the EGFR Promoter as a Mechanism for Resistance to IGF1R Directed Therapy in Osteosarcoma”

E. Anders Kolb, MD

Director, Blood and Bone Marrow Transplantation

A.I. duPont Hospital for Children

Jay V. Jackson Memorial Research Award

“Developing a MicroRNA-Based Strategy for Targeting Uterine Leiomyosarcoma”

Matthew Anderson, MD, PhD

Assistant Professor, Division of Gynecologic Oncology

Baylor College of Medicine

Mandell/Kropp Run for a Sarcoma Cure Research Award

“Identification of the Target Genes of the EWS/NR4A3 Fusion Protein Expressed in Extraskelatal Myxoid Chondrosarcoma”

Yves Labelle, PhD

Researcher

Research Center

Centre Hospitalier Universitaire de Quebec

Mark Herzlich Research Award

“Targeting GLI1 in Ewing’s Sarcoma”

William A. May, MD

Associate Professor, Department of Pediatrics

Saban Research Institute

Richard and Kathy Lobo Research Award

“Lipid Metabolism in Liposarcoma: A Novel Target for Therapeutic Intervention”

Nancy B. Kuemmerle, PhD

Research Fellow, Department of Physiology

Dartmouth Medical School

Sarcoma Foundation of America Research Award

“A Quantitative Imaging-based Biomarker for Assessment of Therapy Response in Soft Tissue Sarcomas by Differential Volume Estimation of Viable and Non-viable Tumor Fractions”

Anand K. Singh, MD

Fellow – Radiology, Department of 3D Imaging

Massachusetts General Hospital

Sarcoma Foundation of America Research Award

“Regulation of Sarcomagenesis by the Piwi Proteins and Their Interacting Small RNAs (piRNAs)”

Igor Matushansky, MD, PhD

Assistant Professor, Department of Medicine

Columbia University Medical Center

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

SAVE THE DATE

Ninth Annual Fundraising Gala

Monday, May 2, 2011

Cipriani 42nd Street

New York, New York



2010 SFA Board of Directors

First Row:
Spokeperson Marisa
Petrero; Dr. John
Brooks; Dr. Mark
Thornton; Patricia
Thornton; Candace Sue.



Second Row:
Dr. Thomas Tobin; Alexandra Gillespie; Michael Mandell; Executive Director, Matthew
Alsante; Gary Tomei, Esq; Stacey Breidinger.

Not present are Marianne Bouldin; Lisa Crocker; Anthony Fedorov; Patrick Mortimer.

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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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



Matt Alsante, Gary Tomei, Dr. John Brooks



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