

MRF matters

A MELANOMA RESEARCH FOUNDATION PUBLICATION

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MID-YEAR RECAP

Melanoma Research and Treatment Get Two Major Boosts

September was a particularly exciting month for melanoma research. On the same day, two major milestones were reached that will have an enormous impact on people affected by the disease – one in the legislative space and the other within the research arena.

Moon Shots Program

On Friday, September 21, 2012, MD Anderson Cancer Center announced a plan to accelerate the development of new treatments for melanoma and seven other priority cancers. This program, called the Moon Shots Program, challenges MD Anderson scientists and clinicians to “rapidly and significantly reduce mortality in several major cancers.”

When Dr. Ronald DePinho came to MD Anderson in September 2011 as its new president, he called together key cancer researchers and announced a new challenge. Just as President John F. Kennedy in 1962 promised America would put a man on the moon, Dr. DePinho asked MD Anderson’s scientists and clinicians to make a significant impact in the fight against cancer. The researchers were asked to think big, consider everything from prevention to basic science and research, and be collaborative, innovative and revolutionary.

Each cancer group was tasked with developing a proposal to illustrate why its specific disease type should be included among the program’s targets. The MRF was proud to work closely with the melanoma experts at MD Anderson as they developed their proposal. Those talks covered public policy, prevention strategies and ways the MRF and MD Anderson could complement efforts today and in the future.

As part of the Moon Shots Program, the Center will dedicate \$3 billion over 10 years to advance the treatment and cure of eight cancers – including melanoma. This program will fund clinical trials, behavioral interventions and public policy research, and holds great promise to improve the lives of people with melanoma. To get regular updates on the program and stay connected, follow MD Anderson on Twitter @MDAndersonNews or visit www.MDAnderson.org.

Life-Threatening Diseases Compassion Through Combination Therapy Act of 2012

The same day MD Anderson launched the Moon Shots Program, three members of Congress took a bold step in advancing research in melanoma and other diseases. Representatives Brian Bilbray

(R-CA), Carolyn Maloney (D-NY) and Rosa DeLauro (D-CT) introduced the *Life-Threatening Diseases Compassion Through Combination Therapy Act of 2012* to encourage pharmaceutical companies to conduct more research into the benefits of combining two or more drugs as part of treatment – a strategy that has already shown great benefit to melanoma patients.

The MRF has long recognized the need for cutting-edge combination trials. In 2010, the organization took action by forming the MRF Breakthrough Consortium (MRFBC). Now composed of thirteen institutions, this group’s focus is to design and implement high-impact clinical trials, identify the most promising combinations through pre-clinical work, and catalogue tissue samples across clinical trials in a virtual tissue repository. Working on these efforts has given the MRF unique insights into the challenges of securing buy-in from the pharmaceutical industry to conduct combination studies, particularly if the drugs are early in their development (prior to at least one drug’s

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The MRF is dedicated to improving the diagnosis of melanoma, advancing patient care, as well as preventing the disease by educating the public through awareness campaigns about risk factors, including the dangers of tanning.

MRF EVENTS UPDATE

Marathoners Raise Over \$45,000 for Melanoma Research

Fifty TEAMM4M marathoners and half-marathoners trained for 23 different races this year. Together they raised more than \$45,000 for melanoma research. Led by Coaches Kevin "Stenny" Stenstrom and Kevin Tullier, these athletes will have run nearly 13,000 miles in total.

MRF thanks and congratulates the TEAMM4M members on their great runs!

Patty Briotta
Michele Browne-Appiah
Kimberly Caris
Mary Rose Catena
Maribeth Clissa
Staci Cox
Rebecca Dando
Bill Dando
Andrea Dawson
Katie Debler
Deena Disraelly
Andrea Donovan-DuPont
Heather Drake
Mark Drew
Rich Engelstad
Elizabeth Feldkamp
Ram Gnanadesikan
Elizabeth Gordon-Stoll
Crystal Groesbeck-Mead
Jessica Guaragna
Virginia Habich
Lisa Hancock
Summer Haxby
Anne Holden
Cathy Holden
Jonathan Hopkins
Kelly Kerr
Elizabeth King
Michael P. Kochka
Monica Kohler
Sarah Low
Jamie Luskin
Maureen Nelson
Jessica Petit
Franzi Rattei
Lauren Rottler
Richies Runners
Caroline Schepker
Andrea Simily
Jaime Smith
Jennifer Snellings
Delaney Spencer
Carolyn Spencer
Kevin Stenstrom
Darden Swords
Stephanie Tomasso
Howard Watson
Keesler Welch
Chaquitta Williams
Benjamin Wood

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approval) or if the drugs are owned by different companies.

Early this year, the MRF had the opportunity to meet with Rep. Bilbray on a number of occasions. The congressman has a close, personal connection to melanoma: his daughter, Briana, is currently being treated for Stage III disease. He was, understandably, eager to learn more about and support the research and development of treatment options for this cancer. It was during these meetings that the MRF highlighted the need for more work in combination therapies and the role the congressman could take.

The proposed legislation is a result of those conversations. The idea is simple and based on previous congressional acts. If a company conducts trials of drugs using two or more agents that are not yet approved by the Food and Drug Administration

(FDA), it will receive a number of incentives. These studies will be fast tracked by the FDA and receive priority review. Should the drugs be approved, the company's patent protection will be extended by an additional six months. These incentives are designed to counterbalance the barriers and risks perceived by industry in conducting this research.

The legislation has the potential to spark much-needed clinical trials and make a difference in the lives of many people with melanoma.

A similar program was passed as part of the FDA Modernization Act of 1997, offering extended patent protection for drugs tested in the pediatric setting. The impact of that legislation has been profound and has spurred more research that guides doctors in how to use drugs, originally designed for adults, in children.

In sum, the MRF has had a strong year on the research front. The grants program supported more research than ever before and the MRFBC is on its way to meeting the demand for combination trials. A hallmark of our approach has been to provide scientific leadership through collaboration. The MD Anderson Moon Shots Program and Rep. Bilbray's legislation are clear examples of how that approach can result in major advancements for people with melanoma.



Congressman Brian Bilbray (R-CA)

MRF BOARD OF DIRECTORS PROFILE

Tucker Eskew

Tucker Eskew joined the MRF Board of Directors in 2010 and currently chairs the Governance Committee. He brings to the board many years of experience in politics and marketing. Tucker spent three years as deputy assistant to President George W. Bush, who also asked him to serve for half a year as his communications liaison at Number 10 Downing Street, the official site of the British Prime Minister's office. In that role he worked closely with the Blair government on the early response to the 9/11 tragedy.

Parallel with his interest in politics, Tucker was an early leader in the use of digital communications, and maintains a strong interest in social media as a marketing tool. He is a founding partner at Vianovo, where he consults to a variety of clients on crisis responses, brand messaging and issue advocacy.

Tucker follows in the path of his brother, Rhea, in his service on the MRF Board. As he says, "I learned the power of melanoma – its power to hurt and its power to inspire awesome courage – from my sister-in-law, Kathy," Rhea's wife. Kathy Melia fought



Tucker Eskew

melanoma for nine years before succumbing to the disease in 2010.

Tucker and his wife, Lisa, live in Alexandria, Virginia, and have three fair-skinned, red-headed children. "I'm doing this for them, too," Tucker says.

MAJOR NEW RESEARCH FINDINGS

Charting the Path to Scientific Progress

People with melanoma need more than hope – they need real progress and solutions. In late September, a groundbreaking study was published in the *New England Journal of Medicine* that demonstrated two important things:

- 1) The combination of BRAF and MEK inhibitors can be an avenue to longer and better responses for specific patients.
- 2) The principle that the MRF has been working to advance – combination therapies – without a doubt holds the most promise in transforming melanoma into a chronic, but manageable condition.

The MRF Breakthrough Consortium (MRFBC) has made important progress in tackling the barriers to these urgently needed combination trials. The infrastructure has been put into place for leading scientists to share confidential information, and brainstorm and identify the best trials to undertake. This means that the scientific community is putting its resources into trials that are potential game-changers.

The MRFBC has also established a new set of standards for data collection and created a “virtual tissue bank” to house both tumor samples and the data associated with those samples. This will allow research institutions to track and catalogue information on tissue samples across clinical trials for maximum scientific benefit now and in the future. While that may sound

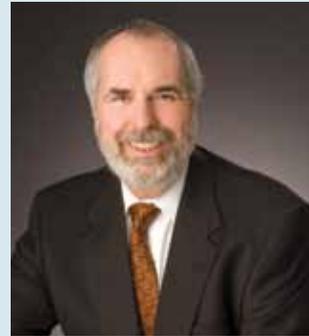
exceedingly dull to the average person, for researchers it builds data that’s consistent and comparable and creates a gateway to critical insights. For people with melanoma, it means researchers working within and outside of the Consortium are able to answer questions faster, smarter and better.

The MRF has also worked to ensure that the legislative and regulatory environment encourages the right type of research. The organization has achieved some critical momentum in this area. In September, the MRF joined Dr. Howard Koh, assistant secretary of the Department of Health and Human Services (HHS), along with leading melanoma researchers and other advocates to address the epidemic rate of melanoma diagnoses and the urgent need to develop better treatments, faster. The MRF demonstrated important leadership by supporting Congressman Brian Bilbray (R-CA) in crafting and introducing legislation that incentivizes pharmaceutical companies to develop combination therapies.

These efforts reflect a reality in melanoma today. It is a time of unprecedented opportunity, and in the near future many – if not most – melanomas will be treatable. This promise is not yet a reality, however. MRF is working in many different arenas to accelerate the progress that is so desperately needed for patients and those efforts are already paying off.

MESSAGE FROM THE EXECUTIVE DIRECTOR

Melanoma: The Great Equalizer



“Not for me,” I said, “for people like your cousin, so they can have a better chance of survival.”

As she spoke, I reflected on other people I had encountered in recent weeks. I met a woman working three jobs to make ends meet; a small town school teacher and a couple whose retirement years were marred by the loss of their son.

Rather than the differences, it was the commonality between each of them that I saw – all changed forever by the tragic loss of a loved one to melanoma and wanting to make a difference.

Melanoma is the great equalizer, uniting rich and poor, famous and, at times, infamous in a common effort to do something – anything – to help stop the ravaging effect of this cancer.

Over the past several weeks, we have seen the incredible efforts of those impacted by melanoma play out in countless scenarios, large and small. We have seen Miles for Melanoma 5K events take place across the country, driven by amazing volunteer committees. We have seen people come to volunteer trainings, write their members of Congress and reach out to support other patients. The efforts of thousands and even tens of thousands of donors, volunteers and advocates are making an impact in the fight for a cure.

The passion, generosity and commitment of these men and women are nothing short of astounding and translate each day into progress toward better treatments. They give me hope that people diagnosed with melanoma tomorrow will have the treatment options they need to live longer and better.

When she came out to meet me she was on her cell phone. She waved for me to walk with her back to her office as she finished up the call.

“I am so sorry; that was rude.”

I explained that I understood. “We are all busy and squeezing in a quick call when you can makes sense.”

She runs a company in a challenging sector and is scrambling to keep the projects moving forward.

“I’ve been juggling things this morning,” she said, “trying to carve out 30 minutes to meet with you.”

The second we sat down, she was all business. “What can I do for you?”

“Tell me your story,” I responded. And she did.

It was her cousin; a bright, energetic young man named after his grandfather. At the young age of 26 he was already making his mark. But, he had a spot on his back. And the spot grew larger. Doctors removed the spot, but it was too late.

“His parents had basically no financial limitations. They flew him to see experts all over the world.” Tragically, nothing worked. “His death,” she recalled, “was the most horrible thing I have ever seen.”

We took up the question from the start, “So, what can I do for you?”

A handwritten signature in blue ink that reads "Tim Turnham".

Tim Turnham, Executive Director

Events

NOVEMBER

November 3

Boston, MA
CURE OM Meet and Greet

November 3

Potomac Falls, VA
4th Annual DC Wings of Hope
for Melanoma Gala

November 3

Panama City Beach, FL
Ironman Florida

November 12

Burbank, CA
2012 Celebrity Golf Classic
Hosted by Kevin Nealon

November 18

Tempe, AZ
Ironman Arizona

November 20

Systemic Therapies for
Ocular Melanoma Webinar

For more information about these
events and others, please visit
www.melanoma.org

OM CONFERENCE

OcuMelUK 2013 Patient Meeting Thursday, Feb. 5

At this important international
meeting, Dr. Sara Selig has been
invited to join other expert
speakers in Liverpool and talk
about turning her personal
struggle into an international
fight against ocular melanoma.

For more information visit
www.ocumeluk.org or
email Kathryn Curtis at
Kathryn@ocumeluk.org.



CURE OM

CURE OM Marks One Year Anniversary

A year ago, the MRF joined forces with Dr. Sara Selig and her late husband, Dr. Gregg Stracks, both passionate advocates in the ocular melanoma (OM) community, to establish a special initiative called CURE OM (Community United for Research and Education of Ocular Melanoma). The intent was to accelerate scientific progress in OM and advance awareness and education.

At CURE OM's one year mark, the MRF reflects on all that it has accomplished to help improve the lives of people with ocular melanoma (OM) – the most common eye cancer in adults and second most common type of melanoma – and support research toward a cure. The MRF team knows that important strides in the fight against melanoma are sometimes marked by personal losses. Many members of the OM community have lost their battles with the disease, including Dr. Stracks. These losses have strengthened the CURE OM community's resolve.

Dr. Selig's leadership and the dedication of the volunteers and staff have brought tremendous early success. In the past year, CURE OM has:

- Established two steering committees – one for patients and caregivers and a second robust, international, interdisciplinary scientific steering committee
- Established the first peer-reviewed research grant specifically focused on OM
- Held scientific meetings to bring researchers together to drive innovative collaborations
- Improved disease awareness and treatment decision-making through coordinated symposia and webinars for patients and caregivers
- Created training opportunities for volunteers
- Launched support resources like the Phone Buddy Program, providing a shoulder to lean on for people affected by the disease

- Shared the latest OM news and connected with people around the globe through the CURE OM online forum, and CURE OM's Facebook and Twitter presence

To achieve its goals, CURE OM is working in partnership with research and patient advocacy groups around the world, including the Monica Jensen Foundation, the International Rare Cancer Initiative (IRCI), OcuMel UK and the European Ocular Oncology Group, as well as a variety of other organizations focused on OM research, education and support. Notably, CURE OM is partnering with the Society for Melanoma Research and the National Institutes of Health to plan an upcoming international and interdisciplinary research meeting.

In the year ahead, CURE OM will leverage this momentum to expand research efforts aimed at finding new treatments and, ultimately, a cure.

MRF ANNOUNCES

New Uveal Melanoma Research Grant Honors Dr. David Eschelmann

In early 2010, during a major drug shortage of a specific liver-directed therapy for people with ocular melanoma (OM), Dr. David Eschelmann, FSIR at Thomas Jefferson University, Philadelphia, PA, went to bat for patients. As a fierce advocate, Dr. Eschelmann collaborated with Guerbet USA, Congress and the FDA to find a permanent new source for this drug. As a result of his perseverance on behalf of people with OM, a new source of the therapy was approved in a very short time.

Because of his dedication to bringing life-changing treatments to people with OM, Guerbet USA created the second CURE OM ocular melanoma research grant in his honor to aide in research and inspire others to continue important work. More information about the grant will be posted on the CURE OM website soon.

The uveal melanoma community, Guerbet USA and the MRF extend their sincere appreciation to Dr. Eschelmann for his work.



Dr. David Eschelmann

MRF STAFF UPDATE

Donna Englander Joins MRF as Director of Individual Gifts

The MRF is pleased to announce that Donna Englander has joined its team as director of individual gifts where she oversees fundraising efforts and stewardship activities. In her role, she is working to strengthen the MRF's relationships with current donors and expand the donor base. Donations to the MRF support medical research to advance treatment options, as well as education and advocacy efforts aimed at prevention and early detection of melanoma.

Donna's drive to support the fight against melanoma comes from a close personal connection. She lost a beloved former colleague to the disease and is honored to join the MRF in working toward a cure in his memory.

Prior to joining the MRF team, Donna served as the first executive director of the Falls Church Education Foundation Virginia from 2004-2012. She worked as major gifts officer of the Levine School of Music, director of development of the Bethesda Academy of Performing Arts (Imagination Stage), as well as the director of development at the Child Development Center of Northern Virginia. In these positions, Donna raised more than \$15 million for education and arts programming in the Metro DC region.

Previously, Donna worked in advertising in St. Louis, Chicago and Washington. She has B.A. in graphic design from Valparaiso University in Indiana and has



Donna Englander

been an active volunteer in various professional associations. She served on the board of directors and committees of the Association of Fundraising

Professionals and National Capital Philanthropy Day (DC). She has two daughters and is a long-distance runner.

FEATURED VOLUNTEER

Kadynce Royer

Seven-year-old Kadynce Royer wants people to know that kids can get melanoma, too. Diagnosed at just two years old, this brave little melanoma warrior is the MRF's youngest volunteer.

Kadynce and her parents came to Washington, DC in May to participate in the MRF's annual Legislative Hill Day. Kadynce drew a picture illustrating the importance of sun safety for her member of Congress, Rep. Charles Boustany, Jr., M.D. and answered questions about what it's like to live with Stage IIIB nodular melanoma.

She said the hardest part of having melanoma is not knowing whether it will come back. She's had seven surgeries and endured a year-long course of Interferon, which she knows is tough, even for adults.

Since she returned home to Louisiana, Kadynce has been sharing her story about the experience in Washington with anyone who will listen. She feels like she has a responsibility to make sure people know what melanoma is, how it has affected her and how it can be prevented. She wants to raise awareness so that fewer people will have to go through what she's experienced.

Recently, Kadynce and her mom, Brenda, fought a battle with the local school board over whether or not she could bring sunscreen with her to school. The school wanted not only a prescription, but a pharmacy label for the sunscreen. They went to five different pharmacies and not one would create such a label. Still, the school insisted they find a pharmacy that would. It wasn't until Brenda threatened



Kadynce Royer

to go to the media that the school board finally relented.

The MRF is proud of Kadynce and her family for being such

fierce advocates and thrilled that they are part of the organization's amazing volunteer family.



More than 200 MRF supporters participated in the Miles for Melanoma "Book it for Bobbie" run/walk in Las Vegas, NV, October 6, 2012



About 1,100 volunteers came out to support the Miles for Melanoma of Delaware's 5th Annual 5K run/walk, September 16, 2012



CURE OM team members (from left) Dr. Sara Selig, CURE OM director, Dr. Thomas Olencki, medical oncologist from Ohio State University, and Dr. Esther Damaser, patient advocate and member of the CURE OM Steering Committee



Team Holly at the 2nd Annual Music City Miles for Melanoma 5K run/walk in Nashville, TN, October 6, 2012



Eighty-five golfers and 15 volunteers came out to raise awareness about melanoma and support the organization at the MRF Golf Tournament in Forest City, NC, September 15, 2012



Team Tumomators at the 2nd Annual Music City Miles for Melanoma 5K run/walk in Nashville, TN, October 6, 2012



Team Willett at the 2nd Annual Music City Miles for Melanoma 5K run/walk in Nashville, TN, October 6, 2012



From left, Dr. Jessica Krant and Jena Dickman spoke with participants about melanoma at the MRF Ironman in NYC, July 8, 2012



Hundreds participated in the 2nd Annual Music City Miles for Melanoma 5K run/walk in Nashville, TN, October 6, 2012



We Thank Our Generous Corporate Sponsors



Join Us! Please Donate to MRF

We put your dollars to work. Please visit www.melanoma.org to learn more about MRF's education, research and advocacy efforts. The MRF is a 501(c)(3) organization. Your donation is tax deductible to the fullest extent of the law. The MRF also welcomes gifts through workplace giving campaigns, including the Combined Federal Campaign (CFC) and employee matching gifts. Contact your HR department for details on designating your contribution.

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Our Mission Statement

To support medical **RESEARCH** for finding effective treatments and eventually a cure for melanoma.
To **EDUCATE** patients and physicians about the prevention, diagnosis and treatment of melanoma.
To act as an **ADVOCATE** for the melanoma community to raise the awareness of this disease and the need for a cure.
MRF is the largest independent organization devoted to melanoma.

