The MRF’s #GetNaked campaign was a big hit during Melanoma Awareness Month! The advocacy community has designated May as Melanoma Awareness Month in the United States, and while the Melanoma Research Foundation (MRF) works to raise awareness throughout the entire year, we recognize this month is incredibly important to those who have been personally impacted by the disease.

To bring attention to this year’s Melanoma Awareness Month and the importance of early detection, the MRF launched a provocative campaign called #GetNaked with the intention of encouraging people to check their skin and eyes regularly for any suspicious signs. This includes self-checks and visits to the dermatologist and ophthalmologist. As part of the #GetNaked awareness campaign, hundreds of melanoma advocates posted messages about the importance of detecting melanoma early. The hashtags #GetNaked and #melanoma were shared extensively on Facebook, Twitter and Instagram, starting on May 1st. Interest in the #GetNaked campaign was contagious - people from around the world posted on social media and changed their profile pictures to one of the MRF’s #GetNaked images. We’ve heard several stories about people who had their skin checked because of the campaign and a few spots came back as potential threats. Thanks to your support, this awareness campaign was able to reach hundreds of thousands of people and possibly even save lives!

The #GetNaked campaign isn’t just for Melanoma Awareness Month! The MRF had ads up in San Francisco throughout March and we’ll have them posted in other markets later this year, including Manhattan and Philadelphia. If you see the ads, take a picture of them and send them to the MRF at media@melanoma.org!

To learn more about the #GetNaked campaign, visit www.melanoma.org/getnaked.
MRF SCIENCE UPDATE
CURE OM Scientific Meeting

On May 2nd the MRF’s CURE OM initiative hosted its bi-annual scientific meeting in Orlando, FL. Fifteen interdisciplinary and international leaders in ocular, uveal and choroidal melanoma attended the day-long meeting. This group of internationally renowned experts shared their knowledge and expertise in highly interactive discussions, highlighting and reiterating the need for increased collaboration and communication in the research and, ultimately, treatment of ocular and uveal melanoma. Several investigators who have been in the field for a significant part of their career shared that collaboration in ocular melanoma research is clearly increasing, thanks to the efforts of CURE OM. Topics discussed included: synthetic lethal interactions, checkpoint blocking antibodies, GNAQ, targeted therapies, needs for animal models in research and collaboration in clinical trials. A special thanks to Keith Flaherty, MD (Massachusetts General Hospital), J. William Harbour, MD (Bascom Palmer Eye Institute), Mike Postow, MD (Memorial Sloan Kettering Cancer Center), Jason Luke, MD (Dana Farber Cancer Institute), Chelsea Place (Dana Farber Cancer Institute) and Scott Woodman, MD (MD Anderson Cancer Center) for speaking, preparing a strong agenda and leading the collaborative session.

MRF RESEARCH UPDATE

American Society for Clinical Oncology Annual Meeting

The 50th meeting of the American Society for Clinical Oncology (ASCO) was held in Chicago May 30 through June 3. Some of the most exciting presentations of the weekend focused on melanoma. Here are a few highlights:

Most of the focus was on a class of drugs called anti-PD1. Several companies are working on these drugs, and products from Bristol-Myers Squibb (BMS) and Merck are likely to be approved within the next several months. Both companies have the drug available now through a program called Expanded Access.

PD-1 drugs engage the immune system to fight against melanoma, and at ASCO we learned that these drugs provide benefit to 30-40% of people who take them. A sizeable percentage of patients have long-term responses – possibly are even “cured”.

BMS is also adding their drug to the already-approved drug Yervoy® (ipilimumab or “ipi”). This combination resulted in a lot of side effects, but had unprecedented results. In one group, 93% of patients with Stage IV disease were alive after a year and 88% after two years.

BMS is also testing ipi in Stage III patients who are at risk of recurrence, to see if taking the drug lowers recurrence rates. The study was positive for ipi being effective, but the dose level used in the study caused a lot of side effects. Another study at a lower dose is currently underway.

Targeted therapy drugs are still being studied as well, with more data supporting the benefit of combining a BRAF drug with a MEK drug for people whose tumors have the BRAF mutation. A small study of a MEK inhibitor and a CDK4 inhibitor shows promise in the 20% of people whose melanoma has an NRAS mutation. A number of early-stage results were also presented. While they are considered preliminary, they are intriguing.

- Pregnancy may impact melanoma. Melanoma cells grown in the lab grow faster in the presence of sera from pregnant women or in the presence of specific pregnancy-related hormones.
- Biologic tests show that patients with brain metastases demonstrate significant levels of compounds related to immune response. This suggests that drugs such as ipi and the PD1 drugs would be effective in treating these tumors.
- Ipi may be just as effective in acral melanoma as in other cutaneous melanomas.
- The level of vitamin D in patients at the time of their diagnosis appears to have no impact on their ultimate outcomes.
- A group of melanoma patients with liver metastases responded better to treatment using microbeads infused with a chemotherapy than did patients receiving other therapies, with about a six month survival advantage.

- Tumor cells isolated from a simple blood sample can be tested for BRAF mutation. The presence or absence of such cells may be an indicator of whether or not the patient is responding to a BRAF inhibitor.

- Stage IV patients with uveal melanoma appear to have similar survival rates as Stage IV cutaneous melanoma patients. Stage IV mucosal melanoma patients, however, tend to do worse.

This is only a fraction of what came out of the conference. The melanoma field is more robust and promising than it has ever been in the past, with no sign that the current rate of progress is slowing. Lynn Schuchter, MD, Chief of the Hematology/Oncology Division and Leader of the Melanoma Program at the University of Pennsylvania’s Abramson Cancer Center, worked with the MRF to record a webinar highlighting the key findings presented at the ASCO meeting. The webinar can be viewed at: www.melanoma.org/understand-melanoma/resource-library/educational-recordings.
The MRF’s “Ask A Nurse” Program

Do you have specific, medically-based questions about melanoma? If so, you can submit your question to the MRF nurse by emailing askanurse@melanoma.org. You can expect to receive a personalized answer from our experienced nurse within 72 hours. The MRF is pleased to introduce the new MRF nurse, Katherine Rosenthal. Nurse Rosenthal is a Board Certified Oncology Nurse and Clinically Certified Research Professional. She currently works as a research nurse at a large non-profit local hospital in Los Angeles. Nurse Rosenthal received her Bachelor of Science in Nursing from Samuel Merritt University and is currently pursuing her Master’s Degree in Nursing Education. She is certified in chemotherapy, biotherapy and radiation therapy. She is also an active member of the Oncology Nursing Society (ONS) and the Society of Clinical Research Associates (SoCRA).

Nurse Rosenthal’s background in clinical research and oncology nursing strengthen her ability to provide direct nursing care to patients with advanced malignancies on clinical trials. She has published in multiple prestigious journals including the *Journal of Surgical Oncology* and the *Journal of Clinical Oncology*.

To learn more about the MRF’s patient resources, visit www.melanoma.org/find-support.

A Million Miles in May

As part of Melanoma Awareness Month, the MRF invited our community members to participate in our Million Miles in May challenge. The goal was to increase awareness of melanoma by signing up and tracking activity miles, whether through running, walking, swimming, biking, or any other physical activity! Almost 600 people from across the U.S. signed up for the challenge, raising awareness of this deadly cancer amongst their friends, family and co-workers. In addition to educating their communities about melanoma, together they raised over $22,000 for melanoma research, education and advocacy!

Thanks to everyone who participated in this fun and important challenge! Each step taken while talking about melanoma, sun safety or cancer prevention, is a step in the right direction toward beating this disease.

Melanoma Awareness Month may be over but that doesn’t mean you have to stop raising awareness. The MRF has run/walks all across the country. With your participation and support, we can keep the momentum going. Join one of our walks near you. Visit www.melanoma.org/get-involved/miles-for-melanoma/5k-runs-walks for more details.

If you’d like to participate in an activity of your own, run a race to raise money, start a walk in your area, or host a fundraiser in your home town, contact events@melanoma.org.

MESSAGE FROM THE EXECUTIVE DIRECTOR

Annual American Society for Clinical Oncology (ASCO) Conference

For many years the melanoma sessions at ASCO were sparsely attended and depressing. A few dedicated researchers would share the results of yet another study that failed to show any benefit in this cancer. This began to change about five years ago. In 2010 we saw data from the first large clinical trial ever to show that the drug being tested extended life in a group of patients with metastatic melanoma. Now melanoma is one of the most vibrant, exciting areas of cancer research. One study had 88% of metastatic patients still alive after two years. Another showed that almost half of patients responded to a promising drug. Over and over, in front of this packed house, researchers demonstrated significant progress that is measured in patients living longer.

Knowing this good news, and seeing the enthusiasm and optimism on the faces of cancer doctors from around the world, made the trek up the stairs to the balcony seem like a walk in the park.

Dr. Mike Atkins (MRF Board Member and Deputy Director of the Georgetown-Lombardi Comprehensive Cancer Center) discussed anti-PD1 research during the main melanoma session at the 2014 ASCO conference.
MRF ADVOCACY UPDATE

Legislative Hill Day 2014

The MRF’s 2014 Legislative Hill Day was a monumental success! Volunteers from across the country attended more than 60 meetings with congressional offices representing 20 different states. Participants focused on key issues such as increased funding from the Department of Defense for melanoma research and the need for tanning bed reclassification.

A personal meeting with members of Congress and their staff is a powerful experience. MRF advocates help congressional offices understand the issues affecting the melanoma community by sharing their personal stories and suggesting ways their representatives can address these issues.

In March the MRF held a “virtual” Hill Day to complement the in-person meetings, which allowed people to make a difference from the comfort of their own home. Volunteers called and sent emails to their representatives’ offices, urging them to support the MRF’s legislative priorities. More than 100 people participated. In honor of Melanoma Awareness Month, the MRF held our second “virtual” Hill Day in May to engage even more volunteers.

MRF advocates are creating and strengthening relationships with their members of Congress, and they will have an immeasurable impact on federal policy surrounding melanoma research.

To join them and the MRF in making a difference against melanoma, visit www.melanoma.org/get-involved.

MRF BOARD OF DIRECTORS PROFILE

Joel Zaklin

Joel Zaklin has served on the MRF’s Board of Directors for 10 years. Motivated by his personal connection with melanoma, Joel joined the Board with the goal of helping turn melanoma into a chronic and manageable disease.

Joel’s career began as a copywriter with Prentice-Hall and moved on to become Creative Services Manager with Volkswagen of America. He began freelancing, which turned into a full-fledged advertising and marketing company for 18 years. Continuing his love of the creative marketing industry, Joel also owned a movie advertising business. He left the advertising world for his wife’s family’s business. He retired as G&W Laboratories’ Vice President of Contract and Sales Development in May 2014.

Joel and his wife of 45 years, Judy, have three children and four grandchildren. In his free time, he enjoys painting, photography, traveling to see his family, gardening and volunteering at the Englewood Hospital and Medical Center in Englewood, NJ. Joel’s paintings have exhibited in Barnes and Noble (NY), Rockland Center for the Arts (NJ), South Central Cafe (NJ) and the Ossining Arts Council Exhibition (NY). He has four paintings in the permanent collection of Englewood Hospital and Medical Center and several are owned by a few private collectors.

MRF EVENT UPDATE

2nd Annual Miles for Melanoma 5k Run/Walk in Washington, D.C.

In its second year, the Miles for Melanoma 5k Run/Walk in Washington, D.C. became the most successful Miles for Melanoma community walk in MRF history by raising over $126,000! More than 600 enthusiastic melanoma patients, caregivers and advocates attended the event in Rock Creek Park on a beautiful Saturday morning. The top fundraising team, “Rob against Rays”, raised over $29,000 in memory of Robert Weinbaum, who lost his battle with melanoma on February 2nd, 2014. Rob’s wife, Caryl, headed this team, which was the largest at 56 people – one of whom was also the overall top fundraiser, Michael Solow, who raised $15,580. The Miles for Melanoma staff team are already hard at work planning next year’s event which will be held on May 3rd, 2015, at West Potomac Park. For more information about Miles for Melanoma 5k run/walks, visit www.melanoma.org/get-involved/miles-for-melanoma.
I was first diagnosed with ocular melanoma (OM) on August 1st, 2011 at the age of 38, although my symptoms started in February of 2011. I was initially misdiagnosed until my retina finally detached revealing a large tumor. I chose enucleation and the surgery was performed August 4th, 2011. My children were 3, 6 and 9 at the time.

Another difficulty we faced is that we are South African citizens and all our family live in South Africa. We had to inform family over the phone about my diagnosis and had to rely on friends to help with the children, of which the younger two had never been away from us at night.

OM is a devastating disease without a cure. I find the “watch, wait and see” approach to having this cancer unacceptable. Most other cancers have adjuvant therapies to prevent metastatic disease, but OM does not and it can metastasize at any point past initial diagnosis. Remission is not a word that a person with ocular melanoma has the pleasure of hearing, even after many years of clear scans. For these reasons I sought out an organization that is being proactive about research and finding a cure. It is only with research and the collaboration of doctors in the ocular oncology and melanoma oncology fields that a cure will become possible. My research led me to CURE OM and the MRF. I feel that CURE OM is leading the field in research initiatives for ocular melanoma and it was with the insight and knowledge of the CURE OM team, under the leadership of Sara Selig, that the first scientific meeting for ocular melanoma was held, bringing together some of the foremost people in the field. This is the reason I support CURE OM and the MRF and will continue to do so, until a cure is found. Since my diagnosis I have taken part in the first Miles for Melanoma Washington, D.C. walk and raised the most money for the event, attended the D.C. music benefit for Sheila Levine and hosted an Origami Owl party with the proceeds going to CURE OM. At this party we designed an “ocular melanoma” locket that I wear to promote awareness of this rare disease. My children and neighborhood friends have raised funds twice with a lemonade stand and an iced tea stand, with funds going to CURE OM. Halloween of 2012 my oldest daughter decided to be an “ocular melanoma awareness” ribbon and walked around the neighborhood with CURE OM brochures. My friend Pamela Wright is donating 10% of all proceeds from her Origami Owl business to CURE OM! In May of this year, I attended the second Miles for Melanoma walk in DC and our team raised almost $10,000! I believe in a cure and will continue to spread awareness and raise funds for a cure.

Written by volunteer Sam Buirski

Sam Buirski with her daughter Shea. Shea dressed up as the MRF’s CURE OM awareness ribbon for Halloween and handed out CURE OM brochures to her neighbors.

Please visit www.melanoma.org to learn more about the 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. CFC #35748
Preschool students at Lemoore Preschool in California raised $1,310 for their teacher “Miss Mary” Rhoads by participating in a bike-a-thon. Mary has taught at the school for 13 years and is currently in the hospital battling melanoma.

A Research Assistant shares an online research tool with Steve Silverstein, the MRF’s Board of Directors Chair, at The Mortimer B. Zuckerman Research Center/Memorial Sloan Kettering’s Immunology Research Lab. This was part of the MRF’s series of research lab tours.

Maryann Farrell and her sons Matt and Luke posed with Todd Pettengill from WPLJ 95.5 radio during their Miles for Melanoma 5k Run/Walk at River Edge, NJ. Maryann, her friends and family raised over $20,000 at this year’s event! Maryann’s husband, Steve, died from melanoma in 2010. In the midst of his courageous battle with the disease, he coined the term “Miles for Melanoma” for the MRF.

MRF Board member and Stage IV melanoma survivor Cheryl Stratos and her son Sergei participated in the 2nd Annual Miles for Melanoma 5k Run/Walk in Washington, D.C.

24 year old Merideth Cooper ran in the Flying Pig Half Marathon in Cincinnati, OH to raise money for the MRF just 6 months after her diagnosis. She raised $1,500 which will go to fund melanoma research, education and advocacy!
Melanoma survivor Kellie Tyler and her friends hosted a Zumbathon to raise money for melanoma research. They raised almost $1,000 and all proceeds were donated to the MRF.

Over 400 melanoma patients, caregivers, researchers and advocates attended the MRF’s patient symposium in Philadelphia, which was hosted in partnership with the Abramson Cancer Center/Penn Medicine.

Mari Short, Lexi Heisdorf, Tina Cielien and Gayla Albrecht participated in the 3rd Annual Miles for Melanoma 5k Run/Walk at Universal Studios to raise money and awareness for the MRF’s CURE OM initiative.

Pictured: Jennifer Green (Clinical Trial Coordinator); Phuong Hoang (Nurse Practitioner); Michele Foust (Patient Care Associate); Janette Cole (Registered Nurse); Jennifer Lantz (Registered Nurse); and Zabrina Hall (Oncology Coordinator), all from The Ohio State University Wexner Medical Center. This team worked closely with the MRF to host our Columbus, OH educational symposium on April 26, 2014.

Melanoma survivor Kellie Tyler and her friends hosted a Zumbathon to raise money for melanoma research. They raised almost $1,000 and all proceeds were donated to the MRF.
The Melanoma Research Foundation (MRF) is working to transform melanoma from one of the deadliest cancers to one of the most treatable. Learn how.

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Our Mission Statement

The MRF is the largest independent organization devoted to melanoma.

The need for a cure.

Community to raise awareness of this disease and the importance of early diagnosis and treatment of melanoma.

To educate patients and physicians about the disease.

To support medical research for finding effective treatments and eventually a cure for melanoma.

Melanoma Research Foundation

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