May is Melanoma Awareness month, a perfect time for volunteers and staff of the Melanoma Research Foundation (MRF) to communicate important messages about the prevention, early detection and treatment of melanoma. These messages are essential to share throughout the year, of course, but they are even more relevant as people gear up for the warmer, sunnier, summer months.

This May the MRF was busier than ever. In that one month we:

- held four educational symposia;
- partnered with actor Rob Lowe and Adam and Hillary Fogelson for the second annual Miles for Melanoma at Universal Studios 5K Run/Walk;
- gathered approximately 30 advocates for the third annual MRF Legislative Hill Day (and another 60 who participated in the first ever Virtual Hill Day);
- hosted a MRF CURE OM educational webinar on liver-directed therapies; and,
- supported more than 15 educational and fundraising events across the country, including the Wings of Hope for Melanoma Gala in San Francisco.

These activities were linked by the common goal of preventing future melanoma diagnoses and raising critically needed research funding.

May also brought the exciting news that the FDA has proposed more stringent regulation of indoor tanning beds – a critical, yet long overdue, step toward fighting this deadly cancer. This action proves that the voice of the melanoma community is being heard.

Still, Melanoma Awareness Month is a reminder that our work will not be done until we find a cure for this deadly disease and prevent new diagnoses from occurring. We are seeing the incidence of melanoma grow at epidemic rates – at least four times faster than any other cancer. We must continue to raise awareness, to generate attention in the media and among the small towns and communities across the country. We must change the conversation about tanning and beauty. We must, together, re-shape the behavior of our society. This is a daunting task, but this May we have taken a number of significant steps toward accomplishing that goal.

In truth, we need everyone’s help if we are to change the world. You can help make a difference in the fight against melanoma – volunteer, educate, sponsor and/or donate. Learn how you can support the MRF’s mission of RESEARCH, EDUCATE and ADVOCATE by emailing info@melanoma.org.

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.
**Upcoming Events**

**JUNE**

**June 21**  
Woodridge, IL  
10th Annual Lawrence Poplawski Memorial Golf Outing

**June 23**  
Coeur d'Alene, ID  
IRONMAN Coeur d'Alene

**June 23**  
Washington, D.C.  
Healing from the Inside out

**June 30**  
Merrick, NY  
1st Annual Benefit for Brett J. Mazimann

**June 30**  
Denver, CO  
Miles for Melanoma Denver  
5K Run/Walk

**JULY**

**July 9**  
Ocular Melanoma Webinar: Living with the Psychosocial Impacts of OM

**July 13**  
Chicago, IL  
Miles for Melanoma Chicago – Teb’s Troops

**July 20**  
Holly Springs, NC  
Wine Tasting to Benefit the Amanda Wall and Corey Haddon Memorial

**July 28**  
Lake Placid, NY  
IRONMAN Lake Placid

For more information about these events and others, please visit [www.melanoma.org](http://www.melanoma.org).

**MRF EDUCATION UPDATE**

**Educational Symposia**

The MRF will have co-sponsored four in-person patient and caregiver educational symposia in May. The first symposium took place on May 4th in Columbus, OH in partnership with The Ohio State University. For the second year in a row, Drs. Sharron Trotter, David Liebner, Doreen Agnese and Evan Wuthrick compiled an exciting and comprehensive agenda that was very well received by attendees.

On May 11th, the MRF partnered, for the 6th year in a row, with Seattle Cancer Care Alliance and the Fred Hutchinson Cancer Research Center. Drs. David Byrd and Kim Margolin took the lead on another impressive agenda beginning with the science behind melanoma and ending with survivorship around a diagnosis. The keynote speaker was Dr. Merrick Ross from MD Anderson Cancer Center, and Dr. Paul Finger of the NYU School of Medicine presented on ocular melanoma. The day ended with a presentation on melanoma and nutrition by Kim Jordan as well as a discussion of hope and survivorship from author and hospice expert, Cathleen Fanslow.

The MRF wrapped up Melanoma Awareness Month with two additional patient symposia – in Philadelphia on May 17th and in Rochester on May 18th. Thanks to all of the speakers, volunteers and attendees who make these important events possible. To learn more about the MRF’s educational efforts, visit [www.melanoma.org](http://www.melanoma.org).

**YOUNG ADVOCATE UPDATE**

**College Student Spreads Melanoma Awareness**

In the spring, the MRF was contacted by Ariel Strieker, a graphic design student at Maryville University in St. Louis. Her father was diagnosed with stage IV melanoma in 2011. After watching her father go through two brain surgeries and an ongoing battle with the disease, Ariel was given an opportunity to enroll in Cherie Fister’s Design for Good course, where her design skills could be dedicated to a non-profit cause. With her personal connection to melanoma, she decided to focus her class time on melanoma awareness.

Ariel turned to the MRF’s website and educational resources. She created a campaign called HIP2B – It’s HIP2B sun smart. It’s HIP2B pale. It’s HIP2B alive. HIP2B is a campaign devoted to spreading awareness of the serious nature of melanoma, while also promoting safe sun tactics and raising money for melanoma research. She designed a variety of items to sell and used the MRF website as the key resource! Thanks, Ariel!

**Pictured left to right: Ariel Strieker, Abby Winkeler, Leann Lohman and Maggie Burton sell items for HIP2B, an awareness campaign referencing the MRF.**

**Ariel Strieker’s melanoma awareness campaign, HIP2B, at Maryville University in St. Louis.**

**Dr. David Byrd welcomes guests to the 6th Annual Northwest Patient Symposium on May 11th.**
On January 1, 2013, melanoma survivor Steve Silverstein assumed the role as the MRF’s new Chairman of the Board. Having served on the board for three years, Steve worked closely with the MRF’s Chairman Emeritus, Randy Lomax, to transition into the position.

Steve was diagnosed with Stage IV melanoma almost a decade ago. When he was first diagnosed, his doctor told him his life expectancy was only a few short months. Steve was stunned by his diagnosis but more so by his limited treatment choices. He tried surgery, chemotherapies and chemoembolization – with no luck. His only remaining option was Interleukin-2 (IL-2), an extremely difficult treatment. Steve responded well to the drug and was pronounced cancer-free after months of intense immunotherapy.

He was lucky – only about 5% of people treated with IL-2 respond that well.

Since his diagnosis, Steve has been actively involved with the MRF. He and his family have dedicated countless hours and unfaltering energy to advancing the fight against this deadly skin cancer so others won’t face such a challenging and heartbreaking diagnosis.

Steve recently retired from his position as President and CEO of Kurt Versen Company after 34 years at the company. He and his wife, Ava, live in Woodcliff Lake, New Jersey. They have two adult daughters named Julie and Nina.

To learn more about Steve, read the “Message from the Chairman” on the MRF’s website: www.melanoma.org/learn-more/message-chairman

In May, the FDA approved two new drugs for treating metastatic melanoma. One is similar to a drug approved two years ago, and the other is a new type of drug. Immediately on hearing the news I wrote a post on the MPIP bulletin board and spoke about the importance of this announcement. Almost immediately someone responded with a challenge. They pointed out, rightly, that the drugs only extend life by a couple of months beyond what is already available. Where, they asked, is the excitement in that?

The story is somewhat more nuanced. Used in combination, these drugs do offer a significant benefit for patients. Nevertheless, the question is valid. After thirteen years in which no new drug was approved, we now have four drugs approved in the space of two years. Despite this, the survival curves for people with advanced melanoma have not shifted and the overall outcomes are only marginally better.

We must – and will – continue to push for additional research. But we must – and will – keep fighting to change our country’s culture around tanning. The majority of melanomas are related to UV exposure, yet we are surrounded by messages that equate beauty with being tanned. We know, too, that catching cutaneous melanoma early means a 90% cure rate through simple surgery, yet far too many melanomas are ignored until the tumor cells have spread through the body.

In May, the FDA approved two new drugs for treating metastatic melanoma. One is similar to a drug approved two years ago, and the other is a new type of drug. Immediately on hearing the news I wrote a post on the MPIP bulletin board and spoke about the importance of this announcement. Almost immediately someone responded with a challenge. They pointed out, rightly, that the drugs only extend life by a couple of months beyond what is already available. Where, they asked, is the excitement in that?

The story is somewhat more nuanced. Used in combination, these drugs do offer a significant benefit for patients. Nevertheless, the question is valid. After thirteen years in which no new drug was approved, we now have four drugs approved in the space of two years. Despite this, the survival curves for people with advanced melanoma have not shifted and the overall outcomes are only marginally better.

We must – and will – continue to push for additional research. But we must – and will – keep fighting to change our country’s culture around tanning. The majority of melanomas are related to UV exposure, yet we are surrounded by messages that equate beauty with being tanned. We know, too, that catching cutaneous melanoma early means a 90% cure rate through simple surgery, yet far too many melanomas are ignored until the tumor cells have spread through the body.

This is why May Awareness Month is important. I am pleased to report that thousands of volunteers across the country engaged in activities to raise awareness of melanoma. Just in the month of May, the MRF organized dozens of people to talk with their members of Congress. We held four patient symposia and a webinar. We convened a science meeting on uveal melanoma, and wrapped up our largest grant cycle ever. We had five Miles for Melanoma 5k run/walk events, were at two Ironman events, and saw volunteers conduct an additional dozen events that ranged from a pancake dinner to a golf tournament. We collaborated with the Shade Foundation in their Pitchin’Posters contest and with the National Council on Skin Cancer Prevention on the annual Don’t Fry Day awareness campaign.

All of this is good, but it only helps if we can somehow turn awareness into changing behavior. The MRF is exploring the science of health education, and working with researchers across the country to understand what it means to have programs that truly change a person’s lifestyle.

We are committed to research as the foundation for treatments that save lives. We are committed to advocacy as an important tool in raising awareness. And we are committed, more than ever, to the prevention of this disease. After all, the best way to beat melanoma is to never get it or to catch it early.

Tim Turnham, Executive Director
THE MRF ON CAPITOL HILL

3rd Annual Legislative Hill Day

For the third year in a row, the MRF brought volunteers to Capitol Hill to urge their members of Congress to join the fight against melanoma. Volunteers from 17 different states met with their legislators, asking them to support the reclassification of tanning beds; to encourage the National Cancer Institute to better focus, expand and target its funding of melanoma research, and to request $10 million for the Department of Defense-funded melanoma research through its Congressionally Directed Medical Research Programs (CDMRP).

Thirty volunteers joined the MRF in person on May 14th and an additional 60 sent emails from their homes, participating in the MRF’s first “virtual” Hill Day. The feedback has been overwhelmingly positive. Two of our advocates were able to get face time with Senator Chuck Schumer (D-NY) who shared that he had a personal connection to melanoma.

We’re making progress but have a lot of work ahead of us. On May 6th, the FDA issued a Proposed Order to reclassify sunlamp products and require labeling to include a recommendation that people under the age of 18 should not use tanning beds. The public has 90 days (until early August) to submit comments on the Proposed Order. These comments could determine whether the FDA moves forward with the proposed changes - or even goes further.

For more information on this Proposed Order, and to find out how you can get involved in the MRF’s advocacy efforts, contact Mary Mendoza, National Director, Volunteer Services, at volunteer@melanoma.org.

Stage III melanoma survivor Jackie Smith and her mother Barbara prepare for meetings on Capitol Hill as part of the MRF’s 3rd annual Legislative Hill Day in Washington, D.C.

FEATURED MRF VOLUNTEER

Olivia “Libby” Kistler

When I was diagnosed with Stage IIIb metastatic melanoma back in 2005, I felt like I had received a death sentence. Statistics showed I would probably live another 6-9 months, 12 months at best. Boy, were they wrong. This year I will celebrate my 8th year of being cancer free. Melanoma is incurable so there is no remission or cure. The best a melanoma patient can hope for is being declared NED which means “no evidence of disease.”

My melanoma started as a small black mole above my left knee. My doctor diagnosed it as benign. I should have sought another opinion, but at the time, I knew almost nothing about melanoma. When it started to bleed I knew something was very wrong.

My surgeon initially spoke about a clinical trial. But when the biopsy showed the cancer had spread, I heard nothing about treatment options. He looked at it every 6 months, but that was it.

After two surgeries, I was left with intense pain from my lower back to the arch of my foot. The pain is caused by extensive nerve damage from my second surgery during which all the lymph nodes were removed from my left groin. Over time I have learned to tolerate it pretty well, except when I have unexpected episodes of unrelenting pain. I get through the episodes by reminding myself that they never last forever. The pain will always be part of my life, but it does not define my life. My life is good, really good. I refuse to let the fear of dying from melanoma affect the quality of my life. Sadly, I cannot say the same for my family. They are afraid every single day.

Lessons learned? If I had been more knowledgeable about melanoma and caught it early, I might not have had to have invasive surgery resulting in post-op pain. If my doctors had known more about melanoma, it would have been diagnosed very early. When it spread, I would have been offered treatment options. Instead, I had to educate myself. I found a clinical trial at NYU, where I met my wonderful oncologist, Dr. Anna Pavlick of the NYU Clinical Cancer Center’s Melanoma Research Program.

Beating the odds feels great. Continuing to survive for almost 8 years makes me wonder why I am still here when too many others are not. Clearly, I am “supposed” to be doing something – I don’t want anyone to walk in my shoes. So I am a Melanoma Research Foundation (MRF) volunteer. The MRF’s mission statement closely parallels my own – “research, educate, advocate.” I am passionate about doing everything I can to raise awareness and educate people about melanoma and the need for a cure.

Written by volunteer Libby Kistler
MRF EVENTS UPDATE

Miles for Melanoma at Universal Studios 5K RUN/WALK

The second annual Miles for Melanoma at Universal Studios 5K Run/Walk took place on May 4th on the Universal Studios backlot in Hollywood, California. The sold-out event raised over $380,000 for melanoma research and education programs. The original target was $250,000!

Actor Rob Lowe, whose wife has skin cancer, welcomed attendees and thanked them for their dedication to fighting melanoma. Other celebrities who lent their support to the event included Adam and Hillary Fogelson, model and actress Molly Sims, Grey’s Anatomy’s Jason George, The Game’s Tia Mowry-Hardrict, The Wonder Years’ Fred Savage, Road Trip’s Breckin Meyer, Life Goes On’s Kellie Martin, Texas Chainsaw’s Shaun Sipos, Falling Skies’ Drew Roy and Shameless’ Stephanie Fantauzzi.

Other entertainment included life-sized Minions from the movie, Despicable Me, a capella group Level, the cheerleading squad from Providence High School in Burbank, CA, the LA Galaxy street team, and one of the cars from the movie, Fast & Furious 6.

Thank you to the event sponsors: Universal Pictures, Pale Girl SPEAKS, Bristol-Meyers Squibb, Amgen, The Angeles Clinic Foundation, Style Network, LA Galaxy, Los Angeles Times, Novartis, ICM Partners, Genentech, MD Solar Sciences, Joe Shade, Rox Cancer Center, UPF SunShop.com, SPF Addict and Skin & Beauty Center.

Visit the MRF’s Facebook page (www.Facebook.com/Melanoma.Research.Foundation) for pictures.

The MRF Thanks Our Generous Corporate Sponsors

MRF SCIENCE UPDATE

Society for Melanoma Research (SMR) Annual Meeting

The Society for Melanoma Research (SMR), which sponsors the premier international meeting for melanoma researchers, will celebrate its 10th anniversary November 17-20 in Philadelphia. The MRF has been a proud sponsor of the SMR since its first meeting in 2003 and was honored to receive SMR’s Partnership Award in 2009. The annual public meeting provides a critically important public forum for multidisciplinary investigators, clinicians and students to share early research results and look for areas to collaborate. Last year more than 700 researchers participated.

In 2012, the MRF supported awards for the best abstracts from young investigators, which facilitates their participation in such a meeting.

For a second year in a row at the SMR annual meeting, the MRF’s CURE OM initiative will hold a meeting focused specifically on ocular (uveal) melanoma. This year, CURE OM is partnering with the National Cancer Institute (NCI) and SMR to co-host this full day session.

The MRF’s other major initiative, the MRF Breakthrough Consortium (MRFBC), will host its biannual meeting at SMR for the third year in a row to report on its clinical trials to date and evaluate new proposals.

Registration is now open. To register or for more information about the annual meeting, visit www.melanomacongress.com.

Make a difference in the fight against melanoma. Please donate to the MRF.

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
11-year-old Jake Buksa and his family team up with the MRF to fight melanoma in memory of John Buksa, III

Attendees of the MRF’s CURE OM Spring 2013 Scientific Meeting

St. Louis-based OUR M.O.M. raised $5,000 for the MRF during its May 11th run/walk

Pale Girl SPEAKS’ Hillary Fogelson, a three-time melanoma survivor, with the MRF’s Executive Director, Dr. Tim Turnham, during the 2nd annual Miles for Melanoma at Universal Studios 5K Run/Walk

The MRF’s Executive Director, Dr. Tim Turnham, with CURE OM Director, Dr. Sara Selig, and recipients of the 1st Gregg Stracks Award for Emerging Leaders in Ocular Melanoma, Dr. Martina Angi and Dr. Mizue Terai
The MRF’s Education Program Manager, Shelby Moneer, describes melanoma educational materials to attendees of the MRF’s first national volunteer summit in Washington, D.C.

MRF Chairman of the Board, Steve Silverstein, chats with melanoma advocate/volunteer, Cheryl Stratos, during the MRF’s first national volunteer summit in Washington, D.C.

Juan Camilo Giraldo, his wife Natalia Ramirez, and children Rebeca and Matias travelled from Columbia South America to participate in the IRONMAN 70.3 Florida event. Juan Camilo’s sister was recently diagnosed with melanoma. Pictured: the Giraldo family poses by the MRF’s tent in the 2012 IRONMAN-Miles for Melanoma tri-tops.

Members of Miles for Melanoma Team Farrell gathered on April 20th to raise money for the MRF in honor of Steve Farrell, who lost his battle with melanoma.
The Melanoma Research Foundation (MRF) is working to transform melanoma from one of the deadliest cancers to one of the most treatable. Learn how.

**In This Issue**
- Melanoma Awareness Month Recap
- Legislative Hill Day
- Featured Volunteer
- Featured Board Member
- Upcoming Educational & Fundraising Events

Find us online: [www.melanoma.org](http://www.melanoma.org)

[**twitter**](https://twitter.com/CureMelanoma)
[**facebook**](https://facebook.com/Melanoma.Research.Foundation)
[**YouTube**](https://youtube.com/CureMelanoma)

**Our Mission Statement**

The MRF is the largest independent organization devoted to melanoma.

- **The Need for a Cure.**
  The MRF is the largest independent organization committed to understanding and raising awareness of this disease and the need for a cure.
- **To Educate.**
  To educate patients and physicians about the prevention, diagnosis, and treatment of melanoma.
- **To Advocate.**
  To advocate for and support biomedical research for finding effective treatments and eventually a cure for melanoma.

Melanoma Research Foundation

1411 K Street, NW, Suite 800, Washington, DC 20005