



## NEWS

# Recent Treatment Advances

**The past year brought a flurry of progress in the melanoma space with new innovative treatments and expanded use of previously-approved drugs. By the end of 2015, the U.S. Food and Drug Administration (FDA) will have approved six new treatments for advanced melanoma:**

- In October, the FDA approved the combination of **Bristol-Myers Squibb's Opdivo® (nivolumab)** and **Yervoy® (ipilimumab)** for patients with previously untreated BRAF wild-type advanced melanoma. For the first time ever, melanoma patients will have access to a regimen that applies two critical findings: 1) the patient's own immune system can be engaged in the fight against cancer, and 2) the right combination of drugs can have a synergistic effect. Data from one study of the combination reported an objective response rate of 61% in previously untreated advanced melanoma patients, a number that would have been inconceivable just five years ago. This approval comes on the heels of the FDA's approval of **Opdivo®** as a monotherapy in December 2014.
- In October, the first-ever cancer treatment to be injected directly into tumors, **Amgen's Imlygic™ (talimogene laherparepvec or T-VEC)**, was approved by the FDA to treat Stage IV melanoma or Stage III melanoma that cannot be removed by surgery. T-VEC uses a genetically modified version of the virus that causes cold sores to attack melanoma. T-VEC also represents an important milestone in using viruses as the vehicle to stimulate immune response and fight cancer.
- For years we have seen a lack of progress in adjuvant treatments — drugs for people whose tumor has been removed by surgery, but are at high risk of having the tumor come back. In October, the FDA approved **Yervoy® (ipilimumab)** as an adjuvant treatment for Stage III melanoma patients, the first new adjuvant therapy in 20 years!
- In November, the FDA approved the combination of **Genentech's Zelboraf® (vemurafenib) with Cotellic™ (cobimetinib)**. This new targeted therapy combination is for people who have advanced cutaneous melanoma and test positive for the most common genetic mutation in melanoma, BRAF V600. Data show patients treated with the combination experienced a median of 12.25 months with no tumor progression, compared to 7.2 months for patients on vemurafenib alone.
- In late November, **Opdivo® (nivolumab)** was approved as a first (or "first-line") treatment for patients with BRAF V600 wild-type melanoma. This marks the second approval of an immunotherapy as a first-line treatment. Following the approval, the FDA requested additional details from Bristol-Myers Squibb to explore expanding the use to other BRAF mutant forms of melanoma.
- In December, the FDA is expected to approve **Keytruda® (pembrolizumab)** as another first-line therapy for unresectable metastatic melanoma. **Keytruda®**, manufactured by Merck, was approved in 2014 for people who had already tried other therapies.

These approvals bring hope and progress to many in the melanoma community, but a good deal of work remains to be done. Currently, the approved drugs provide long-term benefit to only about a third of patients, and they don't address the rarer forms of melanoma, such as ocular, mucosal and pediatric. Thankfully, due to the unfaltering support and dedication of the melanoma community, the upcoming year is slated to bring even more developments in the field of melanoma. Visit the MRF's website, [www.melanoma.org](http://www.melanoma.org), to learn more about what the organization is doing to drive research, education and advocacy for all types of melanoma.

## MESSAGE FROM THE EXECUTIVE DIRECTOR

### An Important Milestone



Recently, my wife and I celebrated our 35th anniversary. During dinner, we spoke about our past, but also of the future – a trip we hope to take, the possibility of grandchildren and other hopes and dreams.

Anniversaries are important. Particularly the “big” anniversaries.

Next year marks the Melanoma Research Foundation's (MRF) 20th anniversary. The MRF was started in 1996 by Diana Ashby, a Stage IV melanoma patient, who was told by her doctors that research was the key to a future without melanoma. In response she formed the MRF to provide patient education and work toward finding a cure for malignant melanoma.

Diana passed away in May 1997, just a short time before the MRF funded its first research grant. Her husband, Jeff, carried on the legacy until his duties as part of NASA's Space Shuttle mission pulled him away. Jeff is still involved with the MRF and is now an active member of the MRF's 20th Anniversary Committee!

Jeff reminds us this important anniversary cannot be just about looking back. We must also look forward. In that spirit, and in recognition that the new treatments are still far from curing every patient, we will use 2016 to renew our efforts in the fight.

In a note Diana sent to the MRF's first board members, she wrote: *“One of the things I do not want is to establish this and then have it just exist, not doing any good for anyone.”* That spirit compels us to keep pushing, to listen carefully to patients and caregivers, to engage the brightest minds in the field.

Soon you will hear more about the 20th anniversary plans. In the meantime, let me offer gratitude that I am sure that Diana would have wanted to express for the way that you have engaged in this struggle. As she wrote in her very first fundraising letter, *“The MRF can only accomplish our objective with your assistance. Your generous donation will enable us to move closer to our goal and will give thousands a chance at recovery. I sincerely thank you for your consideration and hope to hear from you soon.”*



TIM TURNHAM  
Executive Director



MELANOMA  
RESEARCH  
FOUNDATION

Inspiring Hope & Progress

TWENTIETH ANNIVERSARY

## MRF EDUCATION UPDATE

### 2015 Educational Symposia Series

Over the course of the year, the MRF hosted nine in-person educational symposia across the nation convening members of the cutaneous, ocular, mucosal and pediatric melanoma communities. During these events, patients shared inspirational stories, experts participated in Q&A panel discussions and melanoma physicians and specialists gave thoughtful and informative lectures to over 1,000 melanoma patients and caregivers. Thanks to the generosity of dedicated melanoma specialists, social workers, volunteers and patients, the MRF held symposia in Atlanta, Chapel Hill, Columbus, Grapevine, Houston, Philadelphia (twice!), Seattle and Washington, DC.

One of these symposia was the MRF's 2nd Annual Pediatric Melanoma Summit in Grapevine, Texas. Over 30 young melanoma patients and their families from 19 states attended. Adults learned about sunscreen and sun safety in schools, diagnosing pediatric melanoma, how to read pathology reports, the importance of implementing a 504 educational plan and how to get involved in the MRF's efforts. Meanwhile, patients and their siblings participated in a variety of educational and therapeutic activities with social workers and child life specialists.

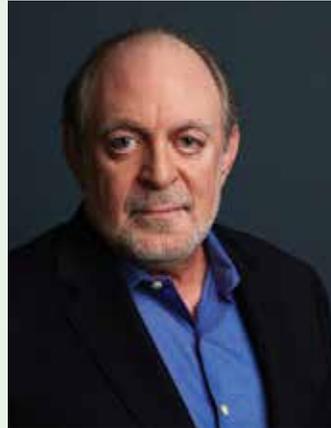
The MRF is excited to continue educating patients and caregivers with the 2016 patient symposia series. To learn more about locations and dates as they're solidified, visit [www.melanoma.org](http://www.melanoma.org), or email Shelby Moneer, Director of Education, at [education@melanoma.org](mailto:education@melanoma.org).



Pediatric melanoma patients (blue shirts) and their siblings (green shirts) show their excitement at the 2nd Annual Pediatric Melanoma Summit.

## MRF BOARD OF DIRECTORS PROFILE

### Stan Adler



As a Stage IV melanoma patient, Stan Adler experienced the helplessness that many patients feel upon their diagnosis and knows how daunting it can be. After successfully completing treatment with Interleukin-2 (IL-2), the first immunotherapy approved by the FDA to treat advanced melanoma, Stan dedicated himself to giving back to the melanoma community that played such an important role in his own battle.

His own experience and his commitment to helping others through their journey fuel his passion for working with the MRF to eradicate melanoma. In 2013 Stan joined the MRF's Board of Directors. He saw the work the MRF was doing and wanted to be a part of the organization's impact as a valuable resource to melanoma patients and caregivers.

Stan has spent the last 36 years as the head of a marketing communications firm in New York, pioneering many of the communications methods that are now commonplace. Despite his many professional achievements, he counts the most meaningful result of his career as being able to contribute the resources of his firm in support of the MRF's efforts to help patients and caregivers.

Stan lives in New York City with his wife of more than 40 years, Aviva, with whom he has three children and three grandchildren. In his spare time, he loves exploring a broad range of hobbies, including golfing, fishing, playing folk guitar and classical piano, making furniture and gardening. He feels fortunate to be a part of the MRF and firmly believes a cure is on the horizon.

"As a board member, it has been an ongoing privilege to see – firsthand – the extraordinary accomplishments that have been triggered by the MRF's critical contributions."

– Stan Adler



MRF Executive Director Tim Turnham and gala co-chair Manny Amezcua join co-chair Hartmut Ott (far right) in presenting the Humanitarian Award to James O. Ertle, MD (center right) as part of the inaugural *Wings of Hope for Melanoma* Chicago gala.

## MRF ADVOCATE PROFILE

### Elise A. Barish

My experience with melanoma began 11 years ago when my brother was diagnosed with Stage I melanoma. Thankfully, his lesion was caught early and he only needed surgery and no additional treatment. Initially, his doctor told him that his ugly black mole was “normal,” but if he and his wife had not insisted that it be removed, his story could have had a very different ending.

As someone with almost all of the risk factors for melanoma (blue eyes, fair skin, multiple blistering sunburns, many childhood summers and vacations spent at the beach, a lot of freckles/moles), I was already fairly cautious about sun exposure. But after my brother was diagnosed, I learned about the serious dangers of too much sun, and I became even more fanatical about protecting my skin. While there are rarer forms of melanoma that are not as well understood, we know that cutaneous melanoma is largely caused by UV exposure. It is critical to limit your exposure, cover up, use sunscreen and see your dermatologist at least once a year.

As a mother of four children with fair skin, I see how easily they



Elise and the Barish family.

freckle and how quickly they burn if we are not diligent with sunscreen. Living in Denver, Colorado, we spend a lot of time outdoors and it is challenging to keep my family covered and protected. I like to think we are trend setters with our big hats, swim shirts, and pale skin but it's very hard to make kids feel comfortable with those choices.

I first learned about the Melanoma Research Foundation (MRF) when my brother was

recognized by the MRF with a Courage Award at the New York *Wings of Hope for Melanoma* gala in 2009, which led me to become a donor to the MRF and supporter of the New York gala. In May 2012, I worked with the MRF to initiate and chair the inaugural *Wings of Hope for Melanoma* gala in Denver. Since then, the event has raised over one million dollars for the MRF! After a couple of years, my passion for the MRF grew and I invested with them to help raise

awareness about sun safety and early detection in my community. It is important to me to teach young children about the importance of sun safety and educate people about the importance of sun protection and early detection. We must protect ourselves and our children so they can hopefully avoid this horrible disease.

I support the MRF because I believe in the importance of the work the organization is doing. They do so much for those who have been affected by melanoma by providing patient support, information and care through programming such as their website, Phone Buddy program, educational materials, and so much more. Because early detection is what allowed my brother to have such a positive outcome from his melanoma diagnosis, I love the #GetNaked campaign that helps remind people to get skin checks. While the MRF has national reach, the organization has a very personal approach to working with individuals and local communities and truly cares about everyone who has been affected by melanoma.

**Written by Elise A. Barish**

## How to Get Involved

In this issue of *Melanoma Matters*, you have read about several of your fellow community members who are taking a stand against melanoma. Have you considered taking part in the fight? The MRF has several ways to get involved:

- Give your time as a volunteer or advocate
- Organize or attend an event near you
- Make a tax-deductible year-end donation
- Remember the MRF in your estate planning

For more information, contact Kyleigh LiPira, Director of Individual Giving, at (202) 742-5904 or [donate@melanoma.org](mailto:donate@melanoma.org)



Dan VanBelleghem and Sheila Traenkle present the proceeds from the incredibly successful 2nd Annual Cascades MelaNoMore 5k to MRF Board member Bill Reilly.



## MRF CHARITY NAVIGATOR UPDATE

### The MRF Receives Fourth Year of 4-Star Charity Navigator Rating!

The MRF recently received a 4-star (out of a possible four stars) rating from Charity Navigator, America's largest independent charity evaluator. This is the fourth consecutive year the organization has been awarded this high honor. A 4-star rating means the MRF consistently uses your dollars wisely by dedicating them to advancing melanoma research, education and advocacy in a fiscally responsible way.

According to Charity Navigator, only 8% of the charities it rates have received at least four consecutive 4-star evaluations, indicating the MRF outperforms most other charities in America.

"The Melanoma Research Foundation's coveted 4-star rating puts it in a very select group of high-performing charities," according to Tim Gamory, COO of Charity Navigator. "Out of the thousands of nonprofits Charity Navigator evaluates, only one out of four earns 4 stars – a rating that demands rigor, responsibility and commitment to openness. The MRF's supporters should feel much more confident that their hard-earned dollars are being used efficiently and responsibly when it acquires such a high rating."



Steve Silverstein (left), Chair of the MRF's Board of Directors, and Joe Fazio (right), Board Secretary, present Emil A. T. Say, MD, from Wills Eye Hospital with the Young Investigator Grant at the 3rd Annual *Wings of Hope for Melanoma* Philadelphia gala.



Volunteer event organizer Jo Ann Rivenbark raised money and awareness in memory of Dean Rivenbark through the Fish for a Cure Tournament in Surf City, NC, in October.



## MRF ADVOCACY UPDATE

### Meet with Congress in March

Throughout the past couple of years, the melanoma community has advocated for an increase in federal melanoma research funding, FDA approval of combination drug treatments and proposed legislation for stricter oversight of tanning beds. A great deal has been accomplished, but there is still more to be done.

Join the MRF on March 13-14 for the annual Advocacy Summit and Hill Day! Don't miss the opportunity to meet face-to-face with your members of Congress and urge them to support the following legislation that could potentially save lives:

- Support \$50 million for the Department of Defense's Peer Reviewed Cancer Research Program (PRCRP) in the Fiscal Year 2017 Defense Appropriations bill; include melanoma as an eligible cancer
- Support melanoma-specific language for the National Cancer Institutes in the Appropriations Committee Report
- Support increased funding for skin cancer prevention activities at the Centers for Disease Control and Prevention
- Enact a ban on the use of indoor tanning devices by minors

This FREE event will begin with a comprehensive training and culminate in meetings with your state legislators, set up by the MRF. A limited number of travel scholarships and first-come, first-served hotel accommodations are available.

To register and for any questions, email Mary Antonucci, Director of Advocacy and Volunteer Services, at [volunteer@melanoma.org](mailto:volunteer@melanoma.org).



Melanoma survivor and advocate, Kadynce Royer, in the office of one of the congressional representatives from her home state of Texas at the 2015 Hill Day.

## MRF EVENT UPDATE

# Grassroots Events

Every year, hundreds of MRF volunteers host events across the country that benefit the MRF's mission of advancing melanoma research, education and advocacy. In 2015, these important grassroots events raised almost half a million dollars! From barn crawls to pasta dinners, the creativity knew no bounds. If you have considered hosting a fun event in support of the MRF, here are some ideas:

- Starting your own event is a great way to get everyone involved in philanthropy, like Brody and Max, who hosted a successful lemonade stand benefiting the MRF.
- One of the MRF's youngest fundraisers, Alec Souders, has organized an annual bike ride since he was 11 years old. He, his friends and his family have raised almost \$75,000 over the past six years!
- When warmer weather rolls around, outdoor activities like Alec's bike ride are a staple of grassroots fundraisers that encourage healthy competition as well as healthy sun practices. Golf tournaments like Ryan Davies' "Driving Away Melanoma" and volunteer-hosted 5ks like the "Cascades MelaNoMore 5k," started by Sheila Traenkle and Dan VanBelleghem, are just a couple of the amazing competitive fundraising events MRF volunteers organize.

Grassroots fundraising events are a wonderful way to raise critically-needed money to fight melanoma and educate your community about prevention and early detection.

The MRF has materials to help you become a grassroots fundraiser and advocate! If you have an idea for an event you'd like to start, contact Katharine Daniels, Program Coordinator, at [events@melanoma.org](mailto:events@melanoma.org).

- If organizing an entire event seems a bit daunting, many fundraise independently, like Rick Bach, who funneled his efforts to "Catch a Cure" by fishing throughout Florida and raising money in memory of his father this past summer.



Brody and Max's lemonade stand fundraiser.



Alec Souders presents the proceeds from the 6th Annual Pedal It Out to the MRF's Executive Director Tim Turnham.



Auction items at Candi Warrington's 13th Annual Operation Wardog benefit.



Rick Bach with one of his catches during his fishing fundraiser.



With 71 members raising almost \$4,000, the Sharon's Cool Runnings team at the Music City Miles for Melanoma in Nashville honored the friend and family member they lost just a week before the race.



Angie Pridmore accepts the award for top fundraiser at the Miles for Melanoma Atlanta. She lost her sister-in-law, Kristi, to melanoma at only 29 years old, one month prior to putting together the biggest and top fundraising team, Kristi's Coyotes, in her honor.



The top team at the Miles for Melanoma New York City was Eyes on a Cure OM Warriors who raised almost \$18,000 and included the top finisher, Isabelle Peeters, an ocular melanoma patient.



For the fourth year, the Society for Dermatology Physicians Assistants partnered with the MRF's Miles for Melanoma team for a 5k. Here they welcome their fellow participants back from the course!



Four-time World Triathlon Champion Leanda Cave speaks at the Miles for Melanoma Miami alongside her co-host, Dave Aizer, melanoma survivor and WFLA-TV personality.

### MRF EVENT UPDATE

## Get Involved in a Miles for Melanoma Event Near You!

The MRF's Miles for Melanoma program is a series of events that allow participants to support and raise funds for the MRF by taking part in athletic activities throughout the country. Funds raised by these individuals support the research, education and advocacy that's zeroing in on important breakthroughs that people fighting all kinds of melanoma so desperately need.

The Miles for Melanoma team is excited to expand to several new cities and will hold events in the following locations in 2016:

- |                        |                            |                           |
|------------------------|----------------------------|---------------------------|
| <b>Annapolis, MD</b>   | <b>Madison, WI*</b>        | <b>Raleigh, NC*</b>       |
| <b>Atlanta, GA</b>     | <b>Memphis, TN</b>         | <b>River Edge, NJ</b>     |
| <b>Boston, MA*</b>     | <b>Miami, FL</b>           | <b>Salt Lake City, UT</b> |
| <b>Chicago, IL</b>     | <b>Morris Township, NJ</b> | <b>San Antonio, TX</b>    |
| <b>Cleveland, OH</b>   | <b>Nashville, TN</b>       | <b>San Diego, CA</b>      |
| <b>Denver, CO</b>      | <b>New York, NY</b>        | <b>San Francisco, CA</b>  |
| <b>Detroit, MI</b>     | <b>Ocean City, NJ</b>      | <b>Savannah, GA</b>       |
| <b>Ft. Myers, FL</b>   | <b>Orlando, FL</b>         | <b>St. Paul, MN</b>       |
| <b>Gahanna, OH</b>     | <b>Philadelphia, PA</b>    | <b>Tampa, FL</b>          |
| <b>Las Vegas, NV*</b>  | <b>Phoenix, AZ</b>         | <b>Washington, DC</b>     |
| <b>Los Angeles, CA</b> |                            |                           |

If you would like more information or to attend a Miles for Melanoma 5k event, visit the MRF's calendar of events: [www.melanoma.org/get-involved/calendar-of-events](http://www.melanoma.org/get-involved/calendar-of-events).

\*New for 2016!

A MELANOMA RESEARCH FOUNDATION PUBLICATION

# MELANOMA *matters*

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



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 awareness of this disease and the need for a cure.

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

