

NEWS

Ongoing Push for Research at ASCO 2016

Every year more than 30,000 professionals in the cancer world gather in early June at the annual meeting of the American Society of Clinical Oncology (ASCO). This conference is an important opportunity to hear the latest updates in cancer research. For the past five years, melanoma has been a key focus, with new treatments being announced each year. This year was different – although no new treatments received FDA approval recently, clinicians have made a great deal of progress exploring how to better use the drugs that are currently available.

The big push from the melanoma research community continues to be in combining drugs. Last year's report about the combination of Yervoy® (ipilimumab) and Opdivo® (nivolumab) made a profound impression on the melanoma community, with very high response rates but also significant side effects. The

consensus among researchers is that Yervoy® makes the other drug better but is also the dominant factor in side effects. This year, researchers heard early data about other potential drugs to combine with Opdivo® or its counterpart Keytruda® (pembrolizumab).

Data was also presented on a study in which Yervoy® is given in combination but at one-third the normal dose. Many researchers believe that better understanding of the drugs already approved in the United States will result in very good five-year outcomes for about half of metastatic melanoma patients.

Unfortunately, this optimistic outcome has not yet extended to some of the more challenging melanoma cases. Data in uveal melanoma, mucosal melanoma and in patients whose melanoma has metastasized to the brain are less positive. For uveal and mucosal melanoma, this may be because these forms of the

cancer have fewer mutations. Cutaneous melanoma that comes from sun exposure has more mutations than any other cancer. These mutations make it challenging to treat but may also make it uniquely susceptible to these immunotherapy drugs. More research is needed to find ways to modify the new approaches so they will be effective for every patient. The focus of that research will be in finding new combinations as well as continuing current efforts to find new drugs.

Finding new and better treatments remains an area of considerable focus. Some work is being done to find drugs that act in the same way as currently approved therapies but work better by having higher response rates and/or fewer side effects. Other interesting research underway includes exploring new ways of attacking melanoma cells using approaches that are currently not being used. Should these latter drugs be approved,

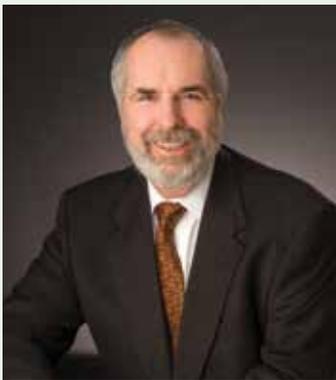
they will offer another option for patients who do not respond to or quit responding to the drugs now available.

Finally, many research projects are looking at providing treatments for patients who are not Stage IV but are at high risk of recurrence. "Neo-adjuvant" studies look at pre-treating the tumor before surgery, while "adjuvant" studies evaluate whether treatment offered after all of the tumor is removed by surgery can lower the incidence of recurrence. Results from these projects will likely be the focus of ASCO 2017.

To learn more about current therapies and emerging research, visit www.melanoma.org.

MESSAGE FROM THE EXECUTIVE DIRECTOR

The Value of Treating Cancer



This issue of *Melanoma Matters* has two dominant themes – an update from the annual American Society of Clinical Oncology (ASCO) conference on the latest melanoma research findings and a focus on the many ways volunteers have engaged in the fight against melanoma in the past few months, including Melanoma Awareness Month.

The melding of these themes is at the heart of one of the most significant debates in cancer care today: What is the value of treating cancer? Much of this debate is being driven by cost. Cancer care in general is very expensive. While cancer drugs comprise only about one-fifth of this expense, the high price of those drugs has generated a great deal of attention.

In response, ASCO, the National Comprehensive Cancer Network and other groups have developed systems to evaluate the relative value of drugs. None of those efforts, however, adequately reflect input from patients.

The question of value will always be personal and does not lend itself well to regimented systems. One patient may be willing to go through the most grueling treatment to carve out a few more weeks so they can attend their child's wedding. Another patient may decide they don't want any treatment at all, so they can finish out their days at home. These choices are informed by age and life-stage, but not in a predictable way.

We need to consider value as we debate the rising cost of health care, but that debate must first and foremost engage real patients in real time who can incorporate the real impact value discussions and decisions have on the lives of the people who are at the heart of the debate. I am pleased that the MRF has been able to convene panels of patients to review clinical trial design, to offer feedback on patient-facing materials that accompany therapies and to dialogue with physicians and with industry. I welcome your suggestions on other and/or better ways to ensure the patient voice is heard around the important issue of value.

A handwritten signature in black ink that reads "Tim".

TIM TURNHAM
Executive Director

MRF BOARD OF DIRECTORS PROFILE

Chad MacDonald



Chad MacDonald joined the MRF's Board of Directors following the loss of his wife, Brenda, to melanoma in 2005. His nearly 10 years on the Board make him one of the longest serving members. He attributes this continuing passion to his goal of ensuring that a cure is found so that no one else has to go through the same devastation of losing a loved one.

While in college, Chad began his career in the service management industry by founding a janitorial service provider that he then sold to a national support services company. Since then, he has founded Encompass Services and provided operational and financial direction to Purchase-Pro, leading it to become the third most successful IPO in 2000. He was a founding shareholder of Access National Bank and is an active member and past Chairman of the

Young President Organization for the U.S. Capital Chapter. His financial and entrepreneurial success throughout the years has been continuously recognized by numerous prominent organizations such as Ernst and Young's Entrepreneur of the Year and various press and industry trade publications.

In both his career and his personal life, Chad is driven by networking and truly devoting himself to everything he undertakes. Through his family's foundation, he has helped raise millions of dollars to fight melanoma and takes pride in the progress that the field has made over the past few years. His investment in helping further education and research around melanoma is driven by the passion from his own experience and he is dedicated to seeing the end of this cancer.

Despite his many professional and philanthropic accomplishments, Chad's priority is spending quality time with friends and his four sons Zachary, Matthew, Kyle and Foster. He also finds time to enjoy various outdoor activities, concerts, restaurants, sporting events and movies.

MRF EDUCATION UPDATE

2016 Patient Symposia Series

May is always a particularly busy and exciting month in the education program, and this year was no different. The 2016 patient symposia series traveled to seven cities throughout April and May, hosting patient symposia in Atlanta, Columbus, Seattle, Chapel Hill, Philadelphia, Houston and St. Louis!

Around 800 people attended these symposia and had a chance to learn from leading melanoma experts on a variety of topics ranging from clinical trials and treatment side effects to navigating insurance issues and proper nutrition. Nearly 60 melanoma researchers, oncologists, dermatologists and social workers volunteered their time to make these events successful.

Two symposia remain this year: the 3rd Annual Pediatric Summit at the Great Wolf Lodge in Charlotte, NC, in September and the Immunotherapy in Melanoma Symposium, sponsored by Bristol-Myers Squibb, in New York, NY, in August.

To learn more about these events and the 2017 series, email education@melanoma.org.



MRF PROGRAM UPDATE

New Virtual OM Support Groups

For the first time, the MRF's CURE OM initiative is partnering with Thomas Jefferson University Hospital to offer virtual ocular melanoma (OM) support groups. Through these groups, patients have the opportunity to connect with similarly staged peers from across the country. Each group is led by oncology social workers who have extensive experience working with people affected by OM. Additionally, these professionals take time to address educational requests from the group. In response to one such request, in June, clinical research nurse Tracy Newhall from Thomas Jefferson University Hospital presented about clinical trials for OM patients.

This pilot program will run until November 2016. For more information about the groups, contact cureom@melanoma.org.

MRF ADVOCATE PROFILE

Linda McCulloch



As a child, Linda McCulloch spent a majority of her time out in the sun partaking in every possible activity she could. At the time, sunscreen was not viewed as a priority, so she reveled in being tan and slathered on tanning lotions instead of SPF as she skied, biked, boated and more. As she got older, she started wearing hats and sunglasses and began getting under umbrellas – but only to keep the aging effects at bay, not because of skin cancer. The idea that she could develop a life-threatening cancer because of her sun exposure was not even a thought in her mind.

Linda would never have known that she had melanoma had it not been for a car accident in June 2015. She had a seizure while driving and passed out at the wheel, ending up in a ditch with a totaled car and a broken back. At the hospital, the cause of the seizure was determined and she was diagnosed with Stage IV melanoma which had spread to her brain.

After her diagnosis, Linda was put on a clinical trial at the University of California, San Francisco, under Dr. Adil Daud and his team. In October 2015, scans showed that the mass in her brain was gone and her lymph node was back to normal. She is currently being treated with nivolumab twice a month, but her broken back has healed and she is cancer free. Because of her treatment team, research and clinical trials, she feels that she's been given a second chance and was honored with the Courage Award at the 2016 *Wings of Hope for Melanoma* San Francisco gala.

Linda is now back to focusing on the personal chef catering company she owns in her home of Sonoma, California, Cuisine by Lela. When not working, she enjoys spending time with her husband, Danny, their two hound dogs, Orson and Basie, and her two children, Jacqui and Trevor.

“Being educated about the serious effects of sun exposure and tanning and getting naked in front of your doctor has to be part of the plan for everyone!”

– Linda McCulloch



TELL YOUR VOLUNTEER STORY!

Are you an MRF volunteer?

Do you want a chance to share your story in a future MRF publication and inspire others to get involved? The MRF highlights volunteers who have gone above and beyond the call of duty to raise melanoma awareness through education and advocacy efforts.

Share your story by going to: www.melanoma.org/get-involved/volunteer-mrf/volunteer-opportunities/your-volunteer-story.

MRF EVENT UPDATE

Upcoming Events

JULY 2016

July 24

San Francisco, CA

Miles for Melanoma San Francisco

July 30

Seattle, WA

9th Annual Steve Casey Memorial Golf Tournament

July 30

Athens, IL

3rd Annual Mary Nickell Barn Crawl

AUGUST 2016

August 6

Memphis, TN

Miles for Melanoma Memphis

August 6

Massapequa, NY

4th Annual Benefit in Memory of Brett J. Mazimann

August 6

Olathe, KS

Corner Kickin' Cancer

August 7

Detroit, MI

Miles for Melanoma Detroit

August 8

Phoenix, NY

3rd Annual Save the Skin Foundation Golf Tournament

August 12-13

New York, NY

Immunotherapy in Melanoma Conference

August 13

St. Paul, MN

Miles for Melanoma Twin Cities

August 20

Hallam, PA

4th Annual Melanoma Awareness Benefit

MRF EVENT UPDATE

Troy Aikman Joins the MRF for #MelanomaChat

On Friday, May 20th, the MRF partnered with Hall of Fame quarterback Troy Aikman, melanoma patient and blogger T.J. Sharpe and renowned melanoma expert Dr. Lynn Schuchter for **#MelanomaChat**, an online Twitter discussion hosted by Novartis Pharmaceuticals.

Held in Philadelphia at the conclusion of the 14th Annual Focus on Melanoma Conference, this chat was an exciting part of "Melanoma Just Got Personal," an online campaign spearheaded by Novartis to raise awareness and support for those affected by advanced melanoma. As a melanoma survivor and campaign spokesman, Troy shared his own experience during the chat as well as what it's been like to work with so many inspiring members of the melanoma community. Tweeting from the MRF's account (@CureMelanoma),

Dr. Schuchter offered insight and expert information about melanoma prevention, research advances and treatment options. In addition to Dr. Schuchter's expertise, the MRF shared helpful information and resources in response to thoughtful questions posed by moderator T.J. Sharpe as well as members of the online community.

The hour-long chat reached an estimated audience of over 36 million Twitter users with important messages about

melanoma education and awareness. The MRF is grateful to Mr. Aikman, Mr. Sharpe and Dr. Schuchter for participating in the chat and extends a special thanks to everyone who joined in the conversation by asking questions and sharing their stories.

Stay up to date on the latest melanoma news and information by following the MRF on Twitter at www.twitter.com/curemelanoma.



T.J. Sharpe, Tim Turnham, Troy Aikman and Dr. Lynn Schuchter at the #MelanomaChat.



Dr. Bertil Damato accepted the CURE OM Vision of Hope Award at the Eighth Annual *Wings of Hope for Melanoma* San Francisco gala at the Terra Gallery. Additionally, Dr. Jeffrey Bortz and Dr. Kevin Kim were honored with the Humanitarian Award, Fred Fanchaly received the Compassionate Care Award and Dr. Clement Donahue, Linda McCulloch, Tessa McMillan and Jackie Imimbo were given Courage Awards at the event.

MRF PROGRAM UPDATE

Announcing 2016 #CUREOM Unite!

The MRF's CURE OM initiative is pleased to announce the continuation of last year's incredibly successful campaign with the 2016 **#CUREOM Unite!** campaign! The 2015 **#CUREOM Unite!** campaign raised \$200,000 to support an Established Investigator Research Award which will provide funding of up to \$100,000 per year for two years to an established ocular melanoma (OM) researcher. The review process for the 2015 award has been completed and the recipient will be announced later in 2016.

This year, the funds raised through the **#CUREOM Unite!** campaign will support the development of a national OM patient registry. This registry will be a centralized and secure database that will store and allow for patient data analysis. Having this database will help address some of the unmet medical needs in the OM community including the lack of robust historical data,

a lack of treatment options in the adjuvant and metastatic settings, the unknown distribution of patients, potential environmental factors that could contribute to the disease and a lack of patient-reported outcomes. It will also allow clinicians to provide more accurate advice to patients and aid in the development of new effective treatments, which will lead to improved care and life expectancy.

The 2016 **#CUREOM Unite!** campaign runs from May 1st to October 15th. All money raised through CURE OM teams at Miles for Melanoma events, as well as other donations and grassroots fundraisers, will contribute to the **#CUREOM Unite!** campaign and the funding of a national OM registry.

Email cureom@melanoma.org for more information about how to keep the momentum going.



The spring CURE OM Miles for Melanoma teams have already raised over \$20,000 for the 2016 **#CUREOM Unite!** campaign.

MRF EVENT UPDATE

Upcoming Events

AUGUST 2016

August 21
Cincinnati, OH
4th Annual PK Memorial Golf Tournament

August 26
Old Hickory, TN
Tom Murphy Classic

August 27
New York, NY
Miles for Melanoma New York City

August 28
Cleveland, OH
Miles for Melanoma Cleveland

August 28
Raleigh, NC
Miles for Melanoma Raleigh

SEPTEMBER 2016

September 3
Dunbar, WV
First Redhead Festival

September 10
Salt Lake City, UT
Miles for Melanoma Salt Lake City

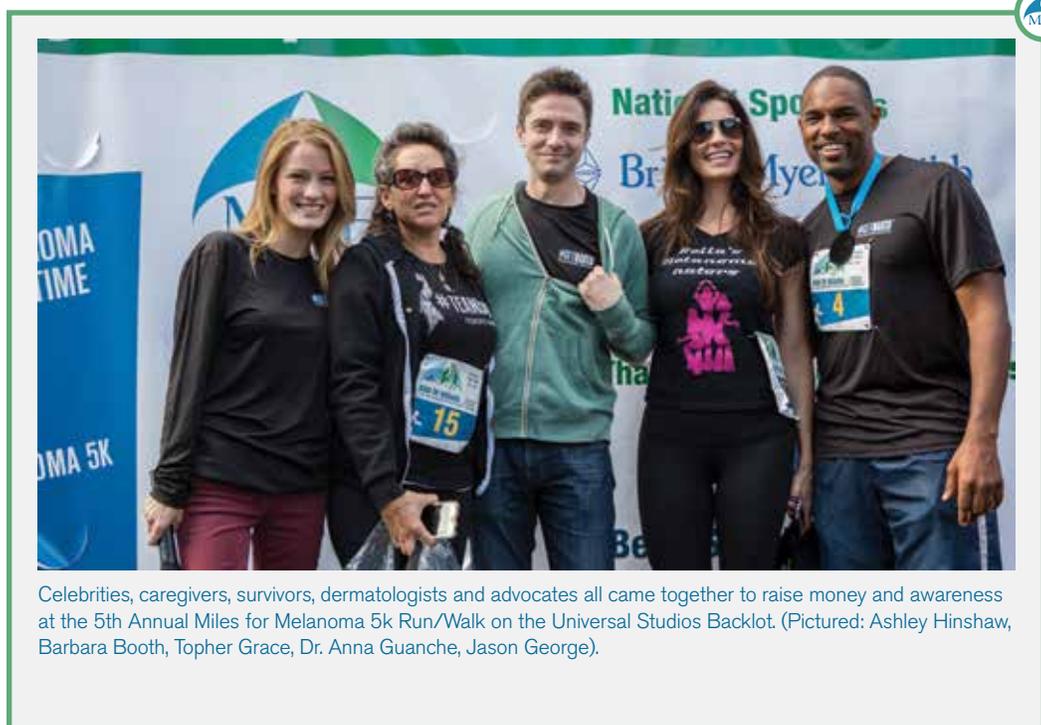
September 11
San Antonio, TX
Miles for Melanoma San Antonio

September 15
Chicago, IL
Wings of Hope for Melanoma
Chicago Gala

September 16-18
Concord, NC
Pediatric Melanoma Summit

September 18
Morristown, NJ
Miles for Melanoma New Jersey

September 24
Gahanna, OH
Miles for Melanoma Central Ohio



Celebrities, caregivers, survivors, dermatologists and advocates all came together to raise money and awareness at the 5th Annual Miles for Melanoma 5k Run/Walk on the Universal Studios Backlot. (Pictured: Ashley Hinshaw, Barbara Booth, Topher Grace, Dr. Anna Guanche, Jason George).



- Look for a broad-spectrum sunscreen of at least **SPF 30**.
- Generously **apply sunscreen** to all exposed skin – even on cloudy days.
- Use approximately **one ounce of sunscreen** and apply it approximately 15 minutes before sun exposure.
- **Reapply every two hours** and after swimming or sweating.
- Remember that the sun’s rays are the strongest between **10 am and 4 pm**.
- Use extra **caution near reflective environments** like water and sand.
- **Wear protective clothing** like a long-sleeved shirt, pants, a wide-brimmed hat and sunglasses, when possible.
- **Seek shade** when possible.
- Avoid intentional tanning and **do not burn**.

Tips for Staying **Sun Safe** this Summer

Summer is here! The warmer weather brings more sunshine and more outside activities which means it’s a great time to remind friends and loved ones about remaining sun safe while enjoying the outdoors.

For more tips on how to stay sun safe this summer – and year round – visit www.melanoma.org/understand-melanoma/preventing-melanoma.



The MRF is asking you to participate in its latest early detection campaign by signing the pledge to check out your skin once a month and see a dermatologist if you find any new or changing spots. Melanoma isn't shy, so you shouldn't be either.

Sign the pledge and tell your friends they should **#GetNaked**, too.

Visit www.melanoma.org/GetNaked.



CNN correspondent Tom Foreman posed for a quick selfie with MRF Board members Tucker Eskew and Alison Martin after emceeding the Miles for Melanoma DC 5k Run/Walk.



After his passing, Adam Turner's family, including his son, Trenton, wife, Emily, and daughter, Emma, organized an enormously successful memorial walk of over 300 people in Luray, VA.



Loyola University Maryland business school students raise awareness of melanoma during Melanoma Awareness Month.



For the past six years, Debra Madill (left) has organized the Greg Maur Memorial Golf Tournament, raising over \$30,000 to fight melanoma in memory of her late husband, Greg (right).



The first Block the Sun Run/Walk 5k in Brookville, Ohio, was a day of melanoma awareness and fun for two and four-legged participants alike.



"Little G' and I are patching for daddy, whom we love and miss dearly, and all who are affected by ocular melanoma. We stand together with our eyes on a cure."

— Dr. Sara Selig, Co-Founder and Director of the MRF's CURE OM initiative.



Drs. John Campana, R. Andrew Gaines, Andrew J. Nemechek and Christopher L. Oliver from the Colorado Head and Neck Specialists were awarded the Humanitarian Award for their commitment to fighting melanoma at the *Wings of Hope for Melanoma* Denver gala. Also conferred that evening was the CURE OM Vision of Hope Award to Dr. Scott Oliver and Courage Awards to Dr. Paul Cohen, Tonya Frank and Liz Reilly.

A MELANOMA RESEARCH FOUNDATION PUBLICATION

MELANOMA *matters*

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MELANOMA
RESEARCH
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Inspiring Hope & Progress

TWENTIETH ANNIVERSARY

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.

IN THIS ISSUE

- Ongoing Push for Research at ASCO 2016
- Troy Aikman Joins the MRF for #MelanomaChat
- Featured Advocate – Linda McCulloch
- Featured Board Member – Chad MacDonald
- Announcing 2016 **#CUREOM Unite!**

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