Over the Past 20 Years…

Since the founding of the Melanoma Research Foundation (MRF), the melanoma community has seen enormous advancements in almost every field. Much remains to be done, but the MRF is thankful for the amazing support of advocates, donors, researchers and the entire melanoma community for making life-saving progress possible since 1996.

- **$14.3 million** awarded in research grants.
- **$1.2 million** awarded in CURE OM-specific research grants.
- **134 research grants** have been awarded.
- **11 new drugs** have been approved by the FDA.
- **14 new treatments** have been approved by the FDA.
- **350 meetings** have occurred between melanoma advocates and their representatives in Congress through the MRF’s Hill Day.
- **42 states** have adopted tanning bed restrictions.
- **12,000 patients, caregivers and researchers** have attended MRF symposia.
- **10 million visits** have been made to www.melanoma.org.
- **400,000 educational materials** are sent out each year.
- **1,000 melanoma advocates** have hosted their own fundraising and awareness events.
- **50,000 people** have participated in a Miles for Melanoma 5k.
- **800 unique melanoma specimens** have been collected by the MRF’s Breakthrough Consortium (MRFBC).
- **32,000 patients and caregivers** have used the MRF’s Melanoma Patients Information Page, www.mpip.org.
When Kevin “Stenny” Stenstrom was first diagnosed with melanoma in 2000, he had no idea of the seriousness of the road he was on. He thought what so many think — “it’s just skin cancer” — but quickly learned that it is not that simple.

To cope with his initial stage III diagnosis in 2000, Kevin began running half and full marathons to raise money for cancer research. After his first recurrence in 2006, Kevin’s wife, Kendel, researched running groups specifically for melanoma and, finding none, they decided to start their own. They had the tool, but did not have a way to funnel the money to melanoma research, which is where the MRF came in — thus, TEAM M4M (Miles 4 Melanoma) was founded. This TEAM ran for five years, raised over $500,000 and had teams in Washington, DC, Denver, CO, Hartford, CT, and Jacksonville, FL. The TEAM lives on through the Miles for Melanoma Champions program.

Despite a second recurrence in 2007, Kevin is currently NED (no evidence of disease) 16 years after his initial diagnosis, but he knows that his fight is not over. He has lost a lot of friends to melanoma and does not pass up a chance to wear his TEAM training shirts and talk to others about the importance of wearing sunscreen and getting their skin checked annually. Additionally, though TEAM M4M was folded into the Miles for Melanoma program in 2011, Kevin remains a presence at MRF events including the Miles for Melanoma DC 5k, the Wings of Hope for Melanoma gala and the MRF’s annual Hill Day.

Kevin is a Navy veteran who currently works as a director of business development in support of the federal government. He continues to be an avid runner in his free time and lives in Burke, VA, with his wife and three teenage children.

Twenty years ago, the MRF was started with the dream that someday melanoma patients would have effective treatments for their cancer. Today, that dream has become a reality in ways that would have thrilled our founder, Diana Ashby. When Diana started the MRF the bright hope was a distillation of a tree bark. Now we have a dozen ways to attack metastatic melanoma.

A look back at our 20-year history makes clear that the MRF has played a pivotal role in this progress by funding research and ensuring that patients have the information and support they need to live longer and better. How do we now build on the legacy established by those who came before us?

First, we recognize that our work is not done. MRF staff work closely with patients and engage with countless others through online communities. We see first-hand the reality that more and better options are needed. Those options will only come through an ongoing commitment to research.

Second, we must remain true to the values the MRF has long embraced — transparency, empathy, efficiency and — above all — a focus on patients first.

Finally, we must remain nimble. The world is changing rapidly. People receive and process information in new and exciting ways. Community is no longer defined by geography or family ties. If five years from now the MRF is still doing the same things we are doing today we will have failed in our commitment to serve the melanoma community.

In this spirit, we are making some changes. We are reworking our Miles for Melanoma program to place a greater emphasis on supporting participants. We are engaging in new ways of gathering data from patients and caregivers so as to ensure that everything we do meets a real, actual need. And we are redoubling our commitment to research, with a goal of increasing research funding significantly over the next few years.

We cannot do these things alone, and I look forward to all the ways you and others in the melanoma space will challenge us and partner with us as we work together. The past 20 years have been great, but I am confident of this — the best is yet to come.

TIM TURNHAM
Executive Director

MESSAGE FROM THE EXECUTIVE DIRECTOR
Building on the Legacy

The MRF is such a great organization. I have been involved with the MRF now for about nine years, and it continues to astound me with all the great things it is doing for melanoma patients and their families, through research, education and advocacy.

— Kevin Stenstrom

The MRF ADVOCATE PROFILE
Kevin Stenstrom

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.
As the first member of the MRF's Board of Directors with ocular melanoma (OM), Mark Weinzierl fulfilled an important need to have all aspects of the melanoma community represented on the board.

When Mark was first diagnosed with OM in 2007, the feeling of the OM community was that researchers were doing wonderful work, but those individual talents and advancements were not being leveraged together. So, in 2011, when Sara Selig recruited Mark to be part of the CURE OM Steering Committee, he could not have been more pleased to be part of such a groundbreaking initiative. He was a perfect fit to join this new committee as his career has been one of lifelong entrepreneurship. The focus of his experience has been to try to come up with better ways to solve today’s problems — searching for that moment when a new product is met with responses of “This is what we were looking for.”

Mark's drive and deep dedication to the cause led him to join the MRF's Board of Directors in 2015, where he has been impressed with the passion and knowledge the other members have regarding the fight against melanoma. He is grateful to have the chance to be a part of such a dedicated group of advocates and, thankfully, there has been no evidence of spread of his disease.

Though his schedule is typically packed, when he does have a spare moment, Mark prioritizes spending time with his wife, Alison, watching their son, Zachary, play baseball and relaxing at home with their three dogs.

“As a board member, the ultimate success would be to contribute in a manner that can best lead to finding a cure and effective treatments for melanoma as soon as possible.”

– Mark Weinzierl

REGISTER FOR HILL DAY TODAY!
Join fellow melanoma advocates for the 2017 Advocacy Summit and Hill Day on March 12–13, 2017! This annual event brings together volunteers from across the country who share a commitment to raising the profile of melanoma. Over the past several years, MRF advocates have successfully pushed for tanning bed relicensing and increased funding for research. With keen competition for federal dollars, a strong showing on Capitol Hill is necessary to represent the interests of the melanoma community.

Register for this FREE summit and meet face-to-face with your state’s legislators. For more information and any questions, contact volunteer@melanoma.org.

REGISTER NOW: EYES ON A CURE SYMPOSIUM
The MRF’s CURE OM initiative will be hosting the 2017 Eyes on a Cure: Patient and Caregiver Symposium in Washington, DC, on March 10–11, 2017, in conjunction with Hill Day.

Attendees will get to learn from some of the leading medical experts in the ocular melanoma field including the 2015 #CUREOM Unite! campaign’s Established Investigator award recipient, Dr. Andrew Aplin.

This exciting event will bring together both medical and research perspectives with a patient-centered approach, promoting increased education, support, advocacy and research in the OM community.

For more information and to register, visit join.melanoma.org/2017EyesonaCure.

MRF Timeline Since Founding

1996
- The MRF is founded by melanoma patient Diana Ashby. She expressed outrage at the lack of treatment options and was told that the only way to have more therapies was to fund research. Diana started the MRF to address that need.
- The MRF’s original logo as designed by Diana.

1998
- The first MRF grant is awarded, funding a study of betulinic acid as a means to stimulate the immune system to fight melanoma.
- The Food and Drug Administration (FDA) approves high-dose IL-2 for the treatment of metastatic melanoma. This treatment had significant side effects, but 15–20% of patients received some benefit and about 5% had long-term responses.

1999
- The MRF funds the online support forum MPIP (Melanoma Patients Information Page). This forum, housed on the MRF website, remains the most widely used online resource for melanoma patients worldwide.
Loree Draeger and her husband, Richard, lived an incredibly healthy lifestyle in Marin County, just north of San Francisco. “Dick” was an avid rower and medaled in the 1960 Olympics, and returned, in retirement, to international competitive rowing. He was an extreme athlete and his conditioning and competitive spirit is likely what helped him through the trials to come. In October 2013, a tumor coiled around his cervical spinal cord was imaged. It was partially resected and came back as malignant melanoma.

His diagnosis came at a promising time for treatments, so Loree, as a family nurse practitioner, began researching available and encouraging treatments as soon as Dick’s care needs would permit. Approximately two months after his initial surgery, a good friend advised them to get involved with an online community, which is how they found the Melanoma Patients Information Page (MPIP) and the MRF. These online pages equipped Loree and Dick with the support, information and questions they needed to make sure they were getting the best treatment possible. They had a wonderful care team through Kaiser in collaboration with UCSF and were able to hold off the progression of his tumor for two and a half years before Dick ultimately lost his battle.

Loree and her husband were deeply touched by how many people on MPIP were young adults with families. They both felt blessed to be able to retire, travel and see their sons grow up, marry and have grandchildren before melanoma came into their lives.

These interactions are what ultimately motivated Loree to stay involved with the MRF even after Dick’s passing. Though she, like all people touched by cancer, would love to find a cure, what Loree prefers is to prevent cancer from ever occurring. She strongly believes that the MRF is the go-to organization if you are diagnosed with melanoma which is why she is proud to be a philanthropic supporter.

Loree recently pledged to fund a future Career Development Award through the MRF to further research into melanoma so that no one has to experience the same loss that she has. She believes that melanoma advocates across the United States have the power to stop this disease in its tracks and wants you to join her.

Please use the enclosed envelope or go to donate.melanoma.org to make your life-changing year-end gift today. Thank you for your part in the fight and for any additional help you can offer.

“I want to give generously to working toward an end to malignant melanoma because, I believe, getting a handle on this most rapidly mutating form of cancer is going to unlock the door to early control of all other cancers.” – Loree Draeger

MRF Timeline Since Founding (continued)

2001
• The first Wings of Hope gala is hosted in NYC. Since then, the event has expanded to six cities across the country.

2002
• Stage IV melanoma patient Steve Farrell decides to run a marathon and raise money for melanoma research. He called his effort Miles for Melanoma.

2003
• The Society for Melanoma Research (SMR) holds its first meeting in Philadelphia with a sponsorship from the MRF. This has since become the seminal meeting for sharing melanoma research.

2004
• The MRF launches its first Patient Symposium, providing cutting-edge information and support for patients. This series now takes place at about a dozen locations each year.
The August 2015 announcement by President Jimmy Carter that he had melanoma pushed the disease into the national spotlight in a way that it had never been before. Everyone from reporters to people who had never heard of the disease before wanted to know more about melanoma. Whether he knew it or not, President Carter’s willingness to speak about his cancer helped thousands of people learn more about, and seek treatment for, melanoma.

On October 20th, the MRF was proud to present a Courage Award to President Carter at the 20th Anniversary Wings of Hope for Melanoma Gala, Milestones and Miracles: Celebrating Two Decades of Ground-Breaking Medical Research, Awareness, Education and Advocacy. The event was emceed by Richard Kind and raised over $900,000! Though President Carter could not be there in person, a pre-recorded presentation was played after Courage Awards were presented to Gail Kar, Susanne Milne and Eugene Hendrickson. Awards were also presented to Merck, Amgen, Novartis, Bristol Myers-Squibb and Genentech for their support of the melanoma community through drug development.

Attendees also had the chance to watch an emotional video featuring Jeff Ashby, the husband of MRF founder, Diana Ashby, recapping the past 20 years of progress in the melanoma space. You, too, can view that video at www.youtube.com/CureMelanoma.

Emcee Richard Kind and Wings of Hope attendees celebrated and raised awareness of melanoma of all forms.

MRF PROGRAM UPDATE

Honoring President Carter and the Melanoma Community’s Fight

The August 2015 announcement by President Jimmy Carter that he had melanoma pushed the disease into the national spotlight in a way that it had never been before. Everyone from reporters to people who had never heard of the disease before wanted to know more about melanoma. Whether he knew it or not, President Carter’s willingness to speak about his cancer helped thousands of people learn more about, and seek treatment for, melanoma.

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MRF SPONSORSHIP UPDATE

2016 Corporate Donors

The MRF offers companies a broad range of opportunities to support patient programs and research grants, develop cause marketing promotions or sponsor events.

The MRF thanks the following companies for their contributions of $5,000 or more during the past fiscal year:

- Amgen
- AstraZeneca Pharmaceuticals LP
- Bristol-Myers Squibb Company
- F. Hoffmann-La Roche Ltd.
- Genentech Inc.
- Guerbet, LLC
- Iconic Therapeutics, Inc.
- Merck & Co. Inc.

To find out how your company can get involved, contact the MRF’s Director of Corporate Relations, Beth Allgaier, at ballgaier@melanoma.org.

2005

- Linda Pilkington is the first employee hired by the MRF and serves as Executive Director for three years.
- The MRF, NCI and SMR develop a national “roadmap” for new opportunities in melanoma research.

2006

- The MRF announces a new level of research funding for Established Investigators — up to $100,000 a year for two years.
- The Miles for Melanoma 5k program is launched.

2008

- MRF grant funding reaches $1 million for the first time.

2009

- The World Health Organization classifies tanning lamps as a carcinogen in the same category as cigarette smoke.
- Congress sets aside $4 million for melanoma research through the Department of Defense.
MRF Timeline Since Founding (continued)

2010
- The FDA holds hearings to solicit comments on the impact of tanning beds on the incidence of skin cancer. Overwhelmingly, the reports and data support stricter regulation of these devices.
- *Cosmopolitan* magazine launches a partnership with the MRF for their Practice Safe Sun program.
- The MRF hosts a Capitol Hill briefing on the dangers of tanning beds for increasing risk of melanoma.
- The MRF Breakthrough Consortium (MRFBC) is launched.

2011
- Ipilimumab from Bristol-Myers Squibb is approved as the first drug shown to extend life for melanoma patients.
- Genentech’s vemurafenib is approved as the first targeted-therapy drug for melanoma.
- The MRF establishes the CURE OM initiative for ocular melanoma.
- The MRF announces a new level of research funding for medical students.

2012
- The MRF’s CURE OM initiative awards its first two ocular melanoma-focused research grants.
- Dabrafenib and trametinib from Novartis are both approved by the FDA.
- The MRF partners with Universal Studios to launch the first Miles for Melanoma at the Universal Studios Backlot.
- The MRF’s CURE OM initiative successfully works with NCI to include ocular melanoma in the Cancer Genome Atlas initiative.

2013
- The MRF launches the Phone Buddy support program, allowing newly diagnosed patients to connect with someone further along in the treatment journey.
- The MRF’s CURE OM initiative successfully works with NCI to include ocular melanoma in the Cancer Genome Atlas initiative.

Thanks to the support of people like you, the Miles for Melanoma program has grown quickly in the past few years. The MRF is so grateful for the opportunity to touch so many communities by hosting 5K events in cities across the country.

This year alone, the fundraising of nearly 10,000 walkers and runners that participated in a Miles for Melanoma event amounted to nearly $2 million to further melanoma research, education and advocacy! These are the top fundraisers, all of whom raised more than $2,000 each!

Bernadette Boyle
Jessica Brens
Michael Brill
Samantha Buirski
Logan Callanan
Karen Danhof
Trish Dresser
Serena Duff
Beverly Famiano
Marc Filiault
Adam Fogelson
Hillary Fogelson
Christine Gill
A. Marie Gillespie
Allan Harrington
Faith Hauss
Skylar Johnson
Charissa Jones
Jennifer Kocour
Lori Kupferman
Abby Leibman
Shaun Marston
Courtney Mehr
Marlene Messner

As the MRF concludes the 2016 Miles for Melanoma season, this has been a great opportunity to evaluate how best to continue that progress and impact. Working with outside advisors, volunteers, participants and staff, the MRF has developed an exciting plan for 2017 which will be announced shortly.

Keep an eye out for more information and email milesformelanoma@melanoma.org with any questions.

See you next year!
2014
• The MRF launches a special program focusing on mucosal melanoma.
• The Pediatric Melanoma Initiative is created and the first Pediatric Melanoma Summit is hosted.
• Pembrolizumab from Merck is the first anti-PD1 drug approved for metastatic melanoma.
• The FDA requires warning of tanning bed use and calls to have indoor tanning be off-limits to teens.
• The MRF organizes the Global Coalition for Melanoma Patient Advocacy which now has representation from nearly 30 countries.
• The MRF announces addition of multidisciplinary team research grants — up to $250,000 a year for two years.

2015
• The MRF launches the #GetNaked awareness campaign, creating a global sensation about early detection.
• President Obama tasks Vice President Joe Biden with creating a Cancer Moonshot, a program charged with generating 10 years of progress in five years.
• The combination of ipilimumab and nivolumab from Bristol-Myers Squibb receives fast-track approval from the FDA because of high response rates in metastatic melanoma.
• The FDA approves the use of Genentech’s cobimetinib with vemurafenib as a combination therapy for melanoma.
• The first use of a cancer-attacking virus, Amgen’s talimogene laherparepvec, is approved by the FDA.
• President Jimmy Carter is diagnosed with metastatic melanoma, elevating the discussion of the cancer on the national stage.

2016
• The MRF celebrates 20 years of advancements.
• The MRF incorporates patient reviews into the research grant review process for the first time ever, through the CURE OM Patient and Caregiver Review Committee.

Nearly 1,000 redheads from across the country gathered in Dunbar, WV, in September for the first ever Redhead Festival! The festival, started by Marti Jones, featured entertainment, music, games and an emphasis on melanoma awareness and raised money for the MRF.

The biggest fundraising team at Miles for Melanoma Las Vegas was Walk for Willoughby who brought out nearly 30 people to run/walk the 5k on a gorgeous morning in November.

Team LoriStrong came out in force at Miles for Melanoma Central Ohio, raising over $4,000 in memory of their friend, Lori Ann Reigert, who passed away from melanoma in March 2016.

For the third year, the MRF hosted its annual Pediatric Melanoma Summit at the Great Wolf Lodge. This year’s event in Charlotte, NC, brought together 22 families directly impacted by pediatric melanoma to network, find support and learn about advocacy, treatment and living with melanoma. Next year’s summit will be on September 8–10 in Colorado Springs, CO! Email education@melanoma.org for more information.
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