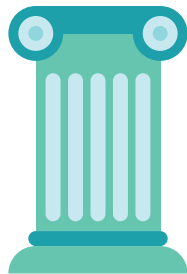


WINTER 2023 / VOLUME 06

# Stewardship Report







## Mission Statement

The MRF's mission is to eradicate melanoma by accelerating medical **RESEARCH** while **EDUCATING** to and **ADVOCATING** for the melanoma community.

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This critical work is made possible by the steadfast commitment, constant innovation and unwavering generosity of a community united in the fight against melanoma.

---

Guided by the principles of responsible stewardship and continued progress, this report shares some recent highlights of what we have accomplished together.



Kyleigh LiPira  
Chief Executive Officer

“ Each and every day, we are inspired and motivated by the melanoma community to fund innovative and impactful research, educate those searching for information about the disease and provide them with the tools they need to make informed decisions regarding care. Our advocates are at the core of everything we do and it is through their collective voice that we enable change for the entire melanoma community. This year, new FDA approvals brought more hope and promise of what lies ahead but our job is not done. We know that Progress is Power and together we can keep pushing until we have a cure for those impacted by all forms of melanoma. ”

The Melanoma Research Foundation (MRF) was founded in 1996 by Diana Ashby, a melanoma patient who was frustrated by the lack of treatment options and support resources available at the time. Diana’s vision was to give melanoma patients and caregivers a reason for hope. Twenty-six years later, her legacy lives on as the MRF has grown into the largest independent organization devoted to all types of melanoma, funding more than \$23 million in life-saving research and offering a powerful voice for the 1.3 million Americans living with melanoma.

“ I first became involved with the MRF like so many others, as a newly diagnosed patient looking for answers. The educational information, support and sense of community that I found at the MRF were invaluable to me during the most challenging time of my life. I’m honored to have the opportunity to give back to an organization that is unmatched in its commitment to melanoma patients and caregivers, while supporting the cutting-edge research advances that will lead us to a cure. ”



Douglas Brodman  
Board Chair



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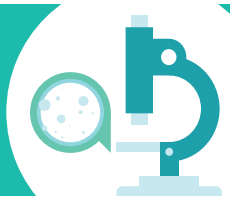
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# Research and Science

## ACCELERATING RESEARCH: GRANTS

From basic science to clinical trials, medical students to established investigators

**27** Grants awarded in 2022, totaling more than \$1.9 million. Includes:

**1** Team Award

**1** Pilot Translational Award

**4** Established Investigator Awards

**1** COVID-19 in Oncology Registry Research Grant with Conquer Cancer

**6** Career Development Awards

**2** Awards funded at the Society for Melanoma Research

**1** Mid-Career Bridge Grant

**11** Medical Student Awards

“ This grant was the first one I was awarded after finishing my medical training, and tremendously helped establish my academic career. ”

— Research grant recipient

## TOTAL GRANT FUNDING IS NOW OVER \$23 MILLION AND AWARDED THROUGH:

**12** Team Awards

**1** Mid-Career Bridge Grant

**37** Established Investigator Awards

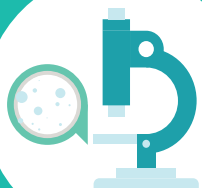
**15** Society for Melanoma Research Awards

**102** Career Development Awards

**5** Donor-Directed Awards

**91** Medical Student Research Awards

**8** Other Awards



# Research and Science

## PARTNERING WITH LEADERS IN MELANOMA

### American Association for Cancer Research (AACR)

One poster presentation of MRF-funded research

April 8-13, 2022, New Orleans, LA



### American Society of Clinical Oncology (ASCO)

Hosted the MRF Breakthrough Consortium Annual Meeting and booth in the Advocacy Pavilion

June 3-7, 2022, Chicago, IL



### International Society of Ocular Oncology (ISOO)

VISION platform presented

June 17-21, 2022, Leiden, the Netherlands



### Society for Melanoma Research (SMR)

- Hosted the CURE OM Science Meeting and Global Coalition Meeting
- Presented 2 MRF-funded research awards
- 3 poster presentations of MRF-funded research

October 17-22, 2022, Edinburgh, UK



### Society for Immunotherapy of Cancer (SITC)

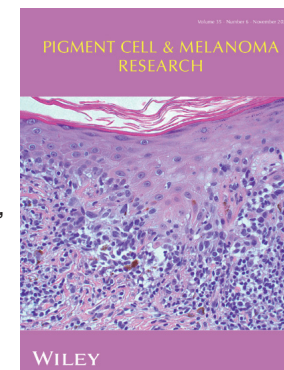
1 presentation of MRF-funded research

November 9-13, 2022, Boston, MA



### Publications

Following the Brain Metastases summit, a white paper titled “Melanoma central nervous system metastases: An update to approaches, challenges, and opportunities” was published in the journal *Pigment Cell & Melanoma Research*.



### Hosted Meetings

- Increasing Access to and Equity of Melanoma Prevention and Care
- Increasing Collaboration Amongst the Mucosal Melanoma Community



November 18, 2022, Chicago, IL and Virtual



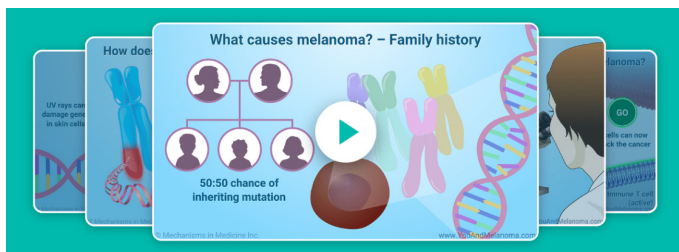
December 16, 2022, New York City, NY





# Education, Awareness and Prevention

## NEW EDUCATIONAL MATERIALS AND RESOURCES



### 2 New Animated Melanoma Patient Videos

Providing an overview of Tumor Infiltrating Lymphocyte (TIL) Therapy, a new type of immunotherapy that utilizes TILs to attack melanoma cells.

- TIL Cell Therapy in Melanoma
- Diagnosing Melanoma (Presented in Spanish)



### UstedyMelanoma.com

A Spanish-language animation describing the tests and procedures doctors use to diagnose melanoma.



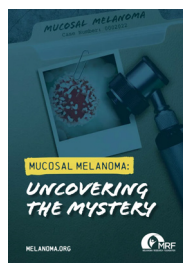
### Education Institute

A new online education platform that hosts Education Institute webinars, symposia and melanoma education courses.

2022 topics included:

- Centering the Patient Voice in Research
- Ocular Melanoma Clinical Trial Overview
- “Scanxiety” and Coping with Stress
- A Road Map for Care Following a Melanoma Diagnosis

Visit [melanoma.org/educationinstitute](https://melanoma.org/educationinstitute) to learn more.



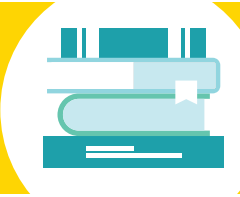
### New Mucosal Melanoma Awareness Brochure

Describing the signs and symptoms of this rare melanoma subtype, and where on the body it can occur.

### SunAWARE

The MRF acquired the sun safety and melanoma prevention program focused on children, adolescents and teens.





# Education, Awareness and Prevention

## PATIENT EDUCATION – CUTANEOUS

### HOSTED 9 PATIENT SYMPOSIA

**YOU'RE INVITED!**  
SATURDAY, MAY 21, 2022  
9:00 AM - 5:30 PM PT

**Northwest Melanoma Symposium: Science to Survivorship**

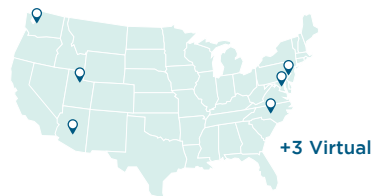
Join Seattle Cancer Care Alliance and the Melanoma Research Foundation (MRF) for a patient symposium about cutaneous (skin) melanoma. Learn the latest in diagnosis, treatment, and supportive care!

**WHERE**  
Virtual Only  
Login details will be sent via email prior to the event!

Register by Thursday, May 19, 2022  
melanoma.org/SCCA2022

The MRF's mission is to eradicate melanoma by accelerating medical RESEARCH while EDUCATING to and ADVOCATING for the melanoma community.

- MD Anderson Cancer Center (Virtual)
- UCSF (Virtual)
- Pediatric Melanoma Summit (Phoenix, AZ)
- University of North Carolina (Chapel Hill, NC)
- UPenn (Virtual)
- Huntsman Cancer Institute/University of Utah (Salt Lake City, UT)
- Georgetown Lombardi Cancer Center (Washington, DC)
- Seattle Cancer Care Alliance (Seattle, WA)
- Thomas Jefferson University (Philadelphia, PA)



### “ASK THE EXPERT” WEBINARS



**Ask the Expert**  
Tuesday, December 13, 2022  
7:00PM ET

Supported by:



### Fear of Recurrence and Scanzxiety



Karen Costello MSS, LSW  
Senior Director Navigation  
at Cancer Support Community



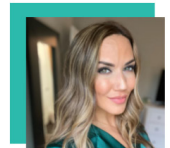
Katharine Laffey  
Melanoma Survivor



Starr Crutcher  
Melanoma Survivor



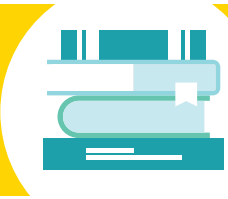
Jennifer Schultz  
Melanoma Survivor



Kelly Pittman  
Melanoma Survivor

## THANK YOU TO ALL OUR EDUCATION INSTITUTE SPONSORS!





# Education, Awareness and Prevention

## MELANOMA AWARENESS

Campaigns dedicated to all forms of melanoma to empower patients and caregivers while increasing education and awareness about each subtype.



### #GetNaked

Cutaneous melanoma awareness and prevention campaign. The 2022 campaign featured two inspirational spokespersons:

- Monique Mack, an “In the Sun” documentary participant and acral lentiginous melanoma survivor. Read her story at [melanoma.org/getnaked-monique](https://melanoma.org/getnaked-monique)
- Summer Sanders, Olympic gold medalist in swimming, American sports commentator, reporter, television personality, actress and cutaneous melanoma survivor. Read her story at [melanoma.org/getnaked-summer](https://melanoma.org/getnaked-summer)



### #OutOfTheShadows

Mucosal melanoma awareness campaign to bring attention to this rare form of melanoma that represents less than 2% of all melanoma diagnoses each year. Read the story of a mucosal melanoma survivor at [melanoma.org/chris](https://melanoma.org/chris).



### #SpotTheDog

Pediatric melanoma and sun safety awareness campaign for patients, pediatricians and dermatologists. Read the story of a pediatric melanoma survivor at [melanoma.org/shannon](https://melanoma.org/shannon).



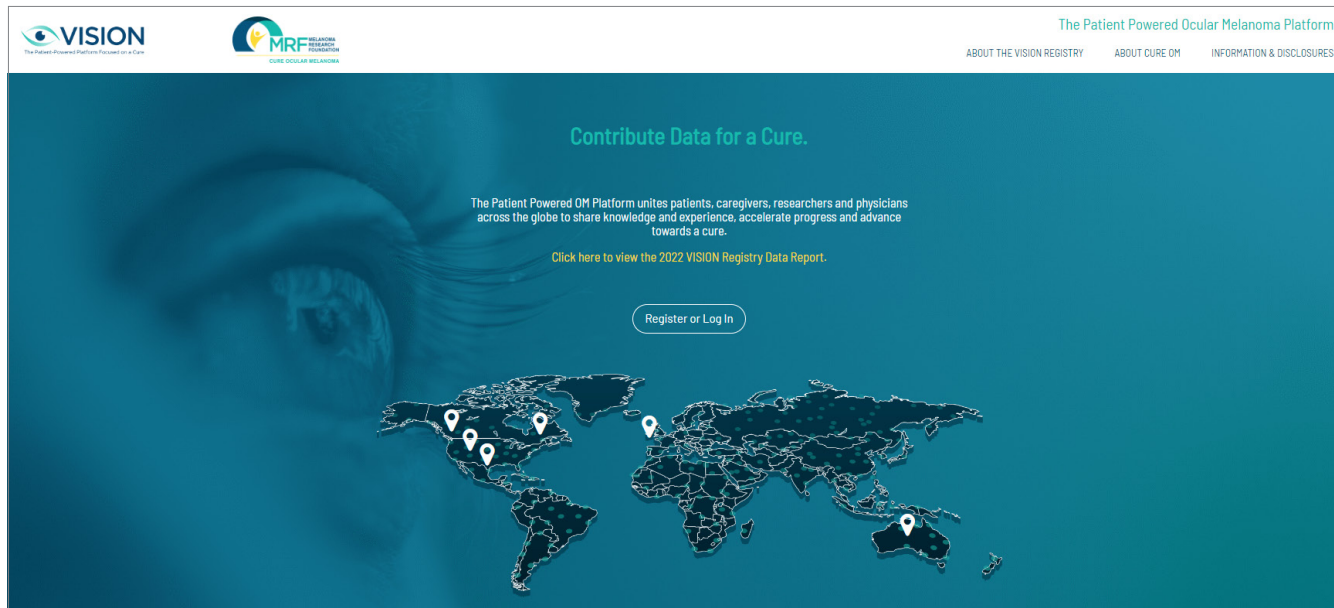
### #EyeGetDilated

Ocular melanoma awareness campaign bringing attention to eye health awareness and encouraging annual dilated eye exams. Read the story of an ocular melanoma survivor at [melanoma.org/katie](https://melanoma.org/katie).



# Rare Melanoma Subtypes

## INAUGURAL YEAR OF THE VISION PLATFORM



### Evolution From Registry to Platform

The VISION Registry was initially launched in 2021 for ocular melanoma (OM) patients globally. In 2022, it expanded to an international platform with additional patient resources including new surveys, a discussion board and updates on current clinical trials and research initiatives.

Key learnings from the inaugural year of the VISION Platform can be found in the VISION Registry Data Report (<https://melanoma.org/visiondatareport>).



### Publication of VISION Data Report

### ENROLLMENT STATS

**327**  
Participants

**37**  
States

**7**  
Countries



# Rare Melanoma Subtypes



## Pediatric Melanoma Summit

July 22-24, 2022

Bringing together more than 20 members of the rare pediatric melanoma community from across the US.

Topics included:

- New developments in research, diagnosis and treatments
- Live Q&A with physicians
- Fun and fashionable sun safety
- Psychosocial support activities for patients and siblings



## Increasing Collaboration Amongst the Mucosal Melanoma Community

December 16, 2022

Hear one of the impactful sessions from the “Increasing Collaboration Amongst the Mucosal Melanoma Community” meeting co-hosted by mucosal melanoma patient advocates:



## Eyes on a Cure

August 26, 2022

- First in-person meeting since 2019
- Over 80 in-person and virtual participants
- View patient testimonials from the meeting here:





# Advocacy

## VIRTUAL ADVOCACY DAYS 2022

“It’s my passion to get out both in my local community and abroad to promote skin cancer awareness, skin cancer prevention and advocate for skin cancer patients like myself. It was an honor to take part in this year’s Advocacy Days where I was able to advocate for more melanoma legislation.”

— Candice M., MRF Advocate



79 participants held 51 meetings with lawmakers.

Key Advocacy Priorities:

- Federal Funding:
  - \$40 million for Defense-funded Melanoma Research Program (MRP)
  - \$3.5 billion increase in NIH funding
  - \$432 million increase in National Cancer Institute funding
  - \$5 million for CDC Skin Cancer Prevention activities
- Urge the FDA to finalize a proposed rule to ban tanning-bed use by minors

## EMAIL AND LETTER-WRITING CAMPAIGN

- 350% increase in response supporting a tanning bed ban for minors.
- Advocates contacted 108 lawmakers urging their support for Rep. Carolyn Maloney’s letter to the FDA to finalize a tanning bed ban for children and teens.

## POLICY HIGHLIGHTS

- Joined Defense Health Research Consortium, One Voice Against Cancer, and Friends of VA coalitions.
- Submitted comments on the NIH’s Strategic Plan for Research on the Health of Women and CMS’s proposed National Directory of Healthcare Providers and Services.

## GLOBAL MELANOMA COALITION



In response to the global need for bringing the patient voice to the melanoma space, in 2014 the MRF brought together organizations from around the world to create the Global Melanoma Coalition. Since its founding, the group has grown to include 44 organizations from 26 different countries and is enthusiastically supported by not only its partners around the world, but also the global patient, healthcare and pharmaceutical communities. Learn more at [www.globalmelanoma.org](http://www.globalmelanoma.org).



# Donor Support and Events

## MILES FOR MELANOMA

# 16

Cities

(2 new events in Seattle, WA and Ft. Myers, FL)



# 4,593

Total participants



# 283

Total teams



Over

# \$967,000

raised

## GALAS

At each gala, we honor melanoma clinician-scientists, leaders in the corporate community who are promoting awareness and prevention and recognize courageous melanoma patients. We consider these events as a platform to educate the public about the risks of melanoma and share important prevention messaging through our awareness campaigns. Two galas were held in 2022, raising more than \$1.34 million for melanoma research, education and advocacy.



**11th Annual Denver Gala**  
*September 15*



**21st Annual New York City Gala**  
**Featuring Emcee Andy Cohen**  
*October 20*



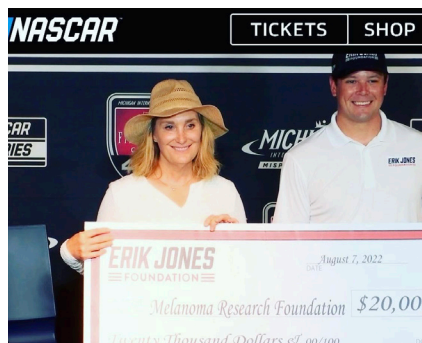
# Donor Support and Events

## CommUNITY FUNDRAISING



### #GetNakedJax

In October 2022, advocate and melanoma survivor Jason Sessions hosted the 2nd Annual #GetNakedJax event in Jacksonville, Florida. Over \$150,000 was raised to support a research grant for Women in Science. Last year, the event proceeds supported the MRF's inaugural pediatric melanoma research grant.



### Erik Jones Foundation Partnership

NASCAR driver and melanoma advocate Erik Jones presented a \$20,000 check to MRF Board Member Cheryl Stratos at the Michigan International Speedway before the August 2022 race.

In October, Erik was a guest at the New York Gala, where he accepted a Courage Award on behalf of his late father, Dave Jones.



### Your Next Step Is the Cure

Hosted by CURE OM Steering Committee members Linda O'Brien and Bernadette Boyle, this CommUNITY Fundraiser raised over \$21,000 for the CURE OM initiative.



### Jam for Cam

Hosted by the brothers of Sigma Nu at the University of Georgia to honor Cameron Fearon, a fellow student, who passed away from metastatic melanoma. This year's event took place in October 2022 and raised \$45,000 for the MRF.



# Donor Support and Events

## ONE FAMILY'S LOVE LEADS TO A TRANSFORMATIONAL PILOT RESEARCH GRANT

Last year, the US Food and Drug Administration (FDA) approved KIMMTRAK, the first and only FDA-approved treatment for metastatic uveal melanoma. This was a historic advance that brought immense hope for the uveal melanoma community, but there is one caveat: patients must have a specific genetic marker to qualify for the treatment. That means that half of all patients, those like Lindsay Zubeck, are still without an approved treatment option. However, as Lindsay would say, “with options comes hope.”

To accelerate progress towards new and more widely effective treatment options, Lindsay's family created the CURE OM Options Bring Hope Award in Honor of Lindsay Zubeck, which will be awarded for the first time later this year. This two-year, \$250,000 award will support research towards a treatment for HLA-A\*02:01-negative patients with unresectable or metastatic uveal melanoma, and represents an exciting step forward in uveal melanoma research. Thank you to the Zubeck family and their supporters for this act of initiative and generosity!





# Leadership

## BOARD UPDATES



Laura Ferris, MD, PhD

Laura Ferris, MD, PhD joined the Board of Directors in 2022.

Dr. Ferris is the Director of Clinical Trials at the University of Pittsburgh Medical College Department of Dermatology and has served as the principal investigator on over 100 clinical trials. Dr. Ferris serves as the inaugural chair of the Dermatology Advisory Council, created in 2022.

Advancing prevention initiatives in our strategic plan, two new committees were created in 2022. The Prevention Committee will be chaired by Elise A. Barish, and Dr. Laura Ferris will lead the Dermatology Advisory Council.

## BOARD OF DIRECTORS — AS OF MARCH 2023

**Douglas Brodman**  
Chairman of the Board

**Michael Atkins, MD**  
Scientific Advisory  
Committee Co-Chair

**Glenn Merlino, PhD**  
Scientific Advisory  
Committee Co-Chair

**Alison Martin, MD**  
Vice Chair

**Cheryl Stratos**  
Secretary

**Jill Wrobel**  
Treasurer

**Stan Adler**

**Elise A. Barish**

**Kristina Baum**

**Laura Ferris, MD, PhD**

**Mark Weinzierl**

**Tom Westdyk**

Learn more about the Board of Directors at: [melanoma.org/board](https://melanoma.org/board)

## THE MRF WELCOMES TWO NEW PROGRAM LEADERS:

**Jess Allison**  
Director of  
Corporate Relations

**Kim Watkins**  
Advocacy Officer

Meet the entire staff at:  
[melanoma.org/staff](https://melanoma.org/staff)



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**THIS LIFE-SAVING WORK WAS MADE POSSIBLE BY YOUR GENEROSITY.**

**PROGRESS IS POWER!**

**VIEW THIS REPORT ONLINE:**



**THANK YOU!**



## MELANOMA RESEARCH FOUNDATION

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