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CURE OCULAR MELANOMA

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Eyes on a Cure: Patient & Caregiver Symposium

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THE UNIVERSITY OF TEXAS
MD Anderson
~~Cancer~~ Center
Making Cancer History™

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9TH ANNUAL EYES ON A CURE: Ocular Melanoma Patient and Caregiver Symposium

NOVEMBER 20-22, 2020
HOUSTON, TEXAS

DoubleTree by Hilton Hotel
6 E Greenway Plaza
Houston, TX 77046

SAVE THE DATE

www.melanoma.org/eyesonacure



Upcoming Events

June 4 - [Virtual Philadelphia Gala presented by Castle Biosciences](#)

New Date TBD - [Miles for Melanoma Chicago](#)

June 13 - [Virtual Miles for Melanoma Denver](#)

June 18 - [Virtual San Francisco Gala](#)

July 11 - [Virtual Miles for Melanoma DC](#)

July 18 - [Miles for Melanoma New England](#)

August 2 - [Virtual Miles for Melanoma Cleveland](#)

August 6 - [Denver Gala](#)

August 15 - [Miles for Melanoma Memphis](#)

August 22 - [Miles for Melanoma Twin Cities](#)

August 29 - [Miles for Melanoma Philadelphia](#)

September 12 - [Save the Date: Miles for Melanoma NYC](#)

In response to national health guidance and travel restrictions, earlier this year the MRF made the difficult but necessary decision to postpone all of our spring events, including the highly anticipated [Eyes on a Cure: OM Patient & Caregiver Symposium](#). While we had hoped to see all of our friends in Houston this April, the time apart has left us only more excited to come together at the rescheduled summit on November 20-22, 2020! The venue and lodging

will remain the same, with information about the discounted CURE OM room block available in the coming weeks - stay tuned! This year, CURE OM will join forces with our partners and friends at [Ocumel Canada](#) and welcome international speakers and guests from that organization. While the agenda is subject to change in accordance with travel restrictions and health care policies, additional speakers currently include **Marcus Butler, MD** (Princess Margaret Cancer Centre), **Dan S. Gombos, MD, FACS** (MD Anderson Cancer Center) **Marlana Orloff, MD** (Thomas Jefferson University) and **Sapna Patel, MD** (MD Anderson Cancer Center).



Note: If you had previously registered for the symposium when it was scheduled for April, we do ask that you complete a new registration for the November event. We appreciate your flexibility as we adapt to and work through changes on the national health landscape, and look forward to seeing everyone this fall!

[Register today for the 9th Annual Eyes on a Cure: Patient & Caregiver Symposium!](#)

September 13 - **[Save the Date: Miles for Melanoma New Jersey.](#)**

September 25-27 - **[Pediatric Melanoma Summit](#)**

October 3 - **[Save the Date: Miles for Melanoma Los Angeles](#)**

October 24 - **[Save the Date: Miles for Melanoma Atlanta](#)**

November 5 - **[Chicago Gala](#)**

November 7 - **[Save the Date: Miles for Melanoma San Diego](#)**

November 15 - **[Save the Date: Miles for Melanoma San Francisco](#)**

November 20-22 - **[Eyes on a Cure: OM Patient & Caregiver Symposium](#)**

January 14, 2021 - **[Save the Date: NYC Gala](#)**

Planning your own CommUNITY Fundraising event? Email events@melanoma.org so we can include it on our online calendar!

Attend a Virtual Gala!



MELANOMA
RESEARCH
FOUNDATION

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During these unprecedented times with COVID-19, many of the larger academic labs have been shut

down and melanoma research has come to a halt. As institutions slowly begin to reopen, it is critical that no more time is lost. With the MRF Virtual Gala events, the MRF will fund a grant to a local institution in support of their melanoma research team.

To support those on the front lines in the fight against melanoma, the MRF is hosting two VIRTUAL Galas in the month of June: Philadelphia on June 4 and San Francisco on June 18. You are invited to join both from the comfort of home!

TONIGHT: The Inaugural [Virtual Philadelphia Gala presented by Castle Biosciences](#) will be on June 4 (today!) at 7pm ET. **YOU** can be a part of giving back to the Philadelphia melanoma community by joining us for a virtual night of fun and celebration. Be a part of funding a grant to the Thomas Jefferson University Melanoma Program by donating to the Fund-A-Grant portion of the event, bid on amazing auction items or purchase a chance to win a once in a lifetime vacation. Join us from the comfort of home as we honor **Andrew Aplin, PhD**, Associate Director for Basic Research at the Sidney Kimmel Cancer Center, with a Humanitarian Award. Dr. Aplin is a member of the MRF Scientific Advisory Committee and an innovative leader in the melanoma research field. Dr. Aplin was the recipient of the CURE OM Unite! research award in 2016 and his lab now coordinates a leading collaboration of OM researchers. The MRF will present a Courage Award to **Robert Kane** in recognition of the inspiring bravery he showed in facing melanoma. Gala attendees will have the opportunity to bid on exciting items in an online silent auction and the chance to win a once-in-a-lifetime vacation package. We do hope you will join in the celebration by joining us online to help us get research back up as soon as possible.

[RSVP today for the Virtual Philadelphia Gala presented by Castle Biosciences!](#)



Following an exciting event in Philadelphia (or wherever you may be!), we're going to the west coast for the [Virtual San Francisco Gala](#) on Thursday, June 18! The MRF will recognize the **University of California, San Francisco (UCSF) Helen Diller Family Comprehensive Cancer Center Melanoma Program** with a Humanitarian Award. In recognition of the strength she exemplified in facing melanoma, **Paige Crist** will be honored with a Courage Award. An exciting silent auction will feature one-of-a-kind items and attendees will have a chance to win their choice of two unforgettable vacation experiences. The Fund-a-Grant will support the UCSF Melanoma Program allowing it to restart the cutting edge melanoma research that has benefited patients across the country.

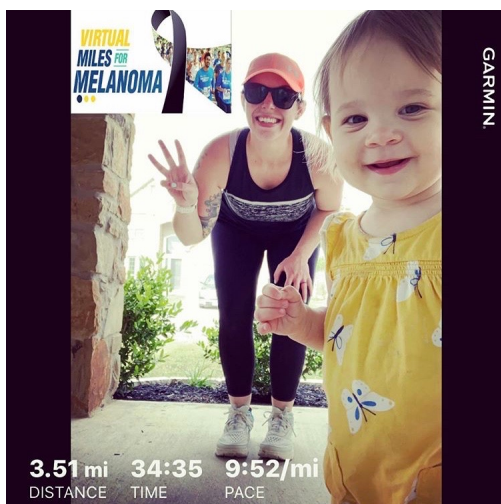
[RSVP today for the Virtual San Francisco Gala!](#)

Don't forget: we're still planning to celebrate in person at our annual galas in Denver (August 6 - [tickets now available](#)), Chicago (November 5 - [tickets now available](#)) and New York (January 14, 2021 - tickets available soon)! To learn more about all five galas, including sponsorship opportunities and custom packages, visit the [MRF Galas](#) page.

Miles for Melanoma - Join Team CURE OM!



The 2020 Miles for Melanoma season was originally scheduled to begin in May but due to social distancing requirements, all of our in-person spring events had to be rescheduled. But just because we can't currently gather together doesn't mean we can't take great strides towards a cure for melanoma. Last month the MRF launched the first ever VIRTUAL Miles for Melanoma run/walk with the ambitious goal of logging 3,000 miles - roughly the distance from coast to coast across the US. Following online opening ceremonies on May 2, our community began adding up the miles as they walked, ran and biked through their communities. Not only did we meet our goal weeks ahead of schedule - our dedicated supporters DOUBLED it before the month was over! Logging over 7,000 miles, the Virtual Miles for Melanoma event covered the distance from the Atlantic to the Pacific Ocean, and then back again! Most importantly, participants raised over \$39,000 for life-saving melanoma research!



Thank you to everyone who stepped up to make this event such a success and shared your progress throughout the month! For everyone who raised \$100 or more, be on the lookout for your official UPF 50+ Miles for Melanoma race shirt from our friends and National Apparel Partner, [Coolibar](#). If you raised \$250 or more, a gift bag filled with skin care products and other treats will arrive in the near future courtesy of the MRF's National Prevention Sponsor, [Neutrogena](#). The MRF is grateful to our partners for their generous support of our community and our shared mission to cure melanoma!

Don't forget that we still have a full calendar of events ahead of us, and we look forward to seeing you all in person soon. Visit the [Miles for Melanoma](#) page to view the updated schedule of 2020 events.

Cancer Has No Curve



The MRF's #CancerHasNoCurve campaign launched on April 1, 2020 in response to a near-global shutdown related to the COVID-19 pandemic. The campaign highlights the need for continued funding for treatments, research and clinical trials for those battling cancers like melanoma, and especially those patients facing rare subtypes like ocular melanoma. Using imagery and stories of patients and caregivers in the midst of treatment we hope the broader community will understand the importance of standing with organizations like the MRF that are supporting these courageous individuals through extremely challenging times.

The MRF team has pulled together the [#CancerHasNoCurve Resource Center](#) which includes webinars on topics including "[Patient Oriented Research Discoveries in Uveal Melanoma](#)," "[Treating Uveal Melanoma During COVID-19](#)," "[Advance Care Planning](#)" and more. Speakers including **J. William Harbour, MD** (Sylvester Comprehensive Cancer Center of the University of Miami Miller School of Medicine), **Marlana Orloff, MD** (Thomas Jefferson University) and **Alan Nguyen, LCSW** (MD Anderson Cancer Center) are among those that donated their time and expertise to create these important resources for the OM community. This campaign will progress as we continue to adapt and recover from having our lives put on hold to bring awareness to ocular melanoma patient and caregiver needs during this unstable time.

[Visit the #CancerHasNoCurve Resource Center!](#)

Ocular Melanoma Support Groups

OCULAR MELANOMA SUPPORT ALLIANCE
VIRTUAL MEETING
OMSA

TUESDAY, MAY 26
6:00 - 8:00 PM MST

VIRTUAL MEETING
VIA ZOOM VIDEO CONFERENCE CALL

All Patients Diagnosed with Any Form of Ocular Melanoma Are Welcome
Complimentary Admission

RSVP TO: Amanda Sisco
Supervisor of Oncology Services at CRA
asisco@retinacolorado.com
(720) 420-3271

Connect with Others Facing OM

At Colorado Retina we recognize that disease treatment extends to the well-being of the whole patient, which is why we started the Ocular Melanoma Support Alliance (OMSA) group. This new program is a collaboration of with the Melanoma Research Foundation (MRF) and the University of Denver Center for Oncology Psychology Excellence (COPE). All patients with ocular melanoma (OM) are invited to participate in this activity which is focused on exploring the emotional and mental aspects of the diagnosis and treatment. It is our hope that this group may offer the hope, support, and camaraderie that patients surviving with this rare disease deserve.

Sidney Kimmel Cancer Center
Jefferson Health | NCI-designated
Until every cancer is cured

MRF
MELANOMA RESEARCH FOUNDATION

Primary and Metastatic Ocular Melanoma (OM) Support Group
(Online/Telephone)

This group provides virtual support to individuals diagnosed with primary and metastatic OM and their caregivers. These groups are held via a virtual platform so that individuals from across the country can join either by phone or online, and are facilitated by the social work staff at Sidney Kimmel Cancer Center of Jefferson Health in Philadelphia, Pennsylvania in partnership with the Melanoma Research Foundation's CURE OM initiative.

Groups sometimes include educational presentations about specific topics, such as living with low vision, coping with scanxiety, or navigating cancer-related financial or insurance concerns. Groups always have time for group reflection, information sharing and peer support.

Groups are typically held on the first Wednesday of the month at 1 pm (Eastern Standard Time).

April 1st, 2020
May 6th, 2020
June 3rd, 2020
July 1st, 2020
August 5th, 2020
September 2nd, 2020
October 7th, 2020
November 4th, 2020
December 2nd, 2020

For more information, please call 215-955-9411 or email molly.vocino@jefferson.edu or ljohnston@melanoma.org

No one has to face ocular melanoma alone. Through new and existing partnerships, CURE OM is committed to providing the most helpful support resources available.

- In February 2020, CURE OM launched the Ocular Melanoma Support Alliance (OMSA) in collaboration with our partners at Colorado Retina Associates (CRA) and the University of Denver Center for Oncology Psychology Excellence (COPE). The OMSA explores the emotional and mental aspects of ocular melanoma diagnosis and treatment while providing hope, support and camaraderie for patients facing the rare disease. The group meets on the third Thursday of the month (June 18 this month) for a two hour session and admission is free. To learn more and get involved, OM community members can email Amanda Sisco, Supervisor of Oncology Services at asisco@retinacolorado.com.
- For OM patients and caregivers across the US and abroad, CURE OM is proud to continue our partnership with the Thomas Jefferson University Hospital Oncology Social Work Program to offer monthly online ocular melanoma support groups. These groups meet on the first Wednesday of the month via a secure online platform, and there are groups specifically for OM patients with primary disease, those with metastatic disease and one for OM caregivers. Each group is facilitated by licensed social workers in a private and confidential setting. For more information and to join a group, email Lauren Johnston at ljohnston@melanoma.org.

For even more support resources, visit the [MRF website!](#)

Update on CURE OM's Historic Trip to the FDA



On January 27, 2020, the Melanoma Research Foundation's (MRF) CURE OM initiative led by Senior Advocacy Officer Cassie Beisel conducted a first of its kind Patient-Led Ocular Melanoma Listening Session at the U.S. Food and Drug Administration (FDA). Patients, caregivers and medical professionals met with eighteen FDA leaders to share their stories and discuss the needs of the OM community. Their stories focused on the lack of standard of care, misdiagnoses, the need for single arm clinical trials, financial toxicity of the disease and the toll it takes on both patients and caregivers who have been impacted by this orphaned disease. Eleven individuals attended in person at the FDA and four community members phoned in to share their journeys. In direct response to the patients' call for action regarding their commonality of misdiagnosis, the MRF has been invited to participate as a patient advocacy voice on the [Collaborative Community for Ophthalmic Imaging \(CCOI\)](#). The hope is to advance earlier detection of OM through AI interpretation.

Due to COVID-19, the FDA had to put the official report on hold to focus on the immediate needs of the pandemic. The MRF is excited to announce that the report from that session is now available on the FDA website and the MRF's website!

[**Click here to read the Executive Summary from the first-ever FDA Patient-Led OM Listening Session**](#)

#GetNaked



The Melanoma Research Foundation unveiled the 6th annual #GetNaked campaign on Melanoma Monday, May 4th, 2020! #GetNaked is the MRF's flagship awareness campaign promoting the importance of full body skin checks for early detection of cutaneous (skin) melanoma. This year's campaign was shared on the MRF website, all across social media and is even currently broadcast as a video PSA in Times Square! The 2020 campaign features Dr. Ellen Marmur, a renowned NYC dermatologist as well as a melanoma survivor. Dr. Marmur's unique perspective as a melanoma survivor influences the dedication and compassion that defines her approach to patient care and you can read her inspiring story [here](#).

The early success of the #GetNaked campaign inspired the creation of the #EyeGetDilated campaign in 2015, promoting the life-saving importance of a yearly dilated eye exam for ocular melanoma early detection. Ocular melanoma can often have no symptoms until the tumor grows large enough to create vision disturbances, but it can be detected during a routine dilated eye exam. Through the #EyeGetDilated campaign, CURE OM encourages everyone to include this fast and easy exam along with a visit with your doctor, dermatologist and dentist each year. Stay tuned for Ocular Melanoma Awareness Month in November to see more of the #EyeGetDilated campaign, and order (for free!) [CURE OM's "checklist" postcards](#) to increase OM awareness in your community! As businesses begin to reopen, you can place these postcards (with permission) at your doctor's office, workplace, local coffee shop or anywhere else you can increase OM awareness in your community.

Uniting the International OM Community








On Thursday, May 14, the founders of [CURE OM](#), [Ocumel UK](#), [Ocumel Irl](#), and [Ocumel Canada](#) met virtually for an international discussion around COVID-19 and its effects on the international OM community. This was the first of a series of meetings planned to unite the OM community regardless of location or borders. United in research, patient advocacy and education, these four organizations continue to work tirelessly for those battling ocular melanoma in their home countries, and now, collectively, are battling as a unified international front during and beyond the COVID-19 era.

April 30 in 30

APRIL 30 IN 30



Support the MRF and our efforts to fund **10 Medical Student Grants** & reach our goal of **\$30,000 in 30 days**

SUN	MON	TUE	WED	THU
26	27 MRF Virtual Bingo Night Hosted by Linda O'Brien & Bernadette Boyle  7:00 pm EDT \$5 to register	28 Ocular Melanoma Info Session #EYEGETDILATED  1:00 pm EDT Hosted by, Dr. Sara Selig	29 Italian Cooking Class Hosted by Chef Justin Gudiel  7:00 pm EDT \$5 to register	[solidcore] 30 Workout Hosted by Coach Hannah 2:00 pm EDT \$7 to register  MRF Trivia Night Hosted by MRF Staff 7:00 pm EDT FREE! 

When the MRF made the difficult but necessary decision to postpone our springtime events - including the annual [CURE OM Symposium](#) - in response to social distancing requirements, the team launched April 30 in 30, a month-long series of virtual events to keep our community engaged, informed, entertained and healthy. In partnership with generous volunteers, business owners and community partners, hundreds of participants enjoyed fitness classes, art lessons, kid-friendly science demonstrations, cooking classes and live webinars with experts in melanoma, wellness, emotional support and more. Through this exciting month-long series, our community raised \$15,000 to support medical students studying melanoma - enough to fund five medical student research grants!

On April 28, CURE OM Co-Founder and Director **Sara Selig, MD, MPH** joined MRF Program Officer for Rare Melanoma Subtypes **Lauren Johnston, MSW** for a live Ocular Melanoma Info Session on

Facebook Live. Thank you to everyone who joined the live discussion, which has now been viewed over 1,800 times! If you weren't able to join live, you can watch the recorded presentation [here](#).

Thank you to everyone who participated in our first-ever April 30 in 30 event series!



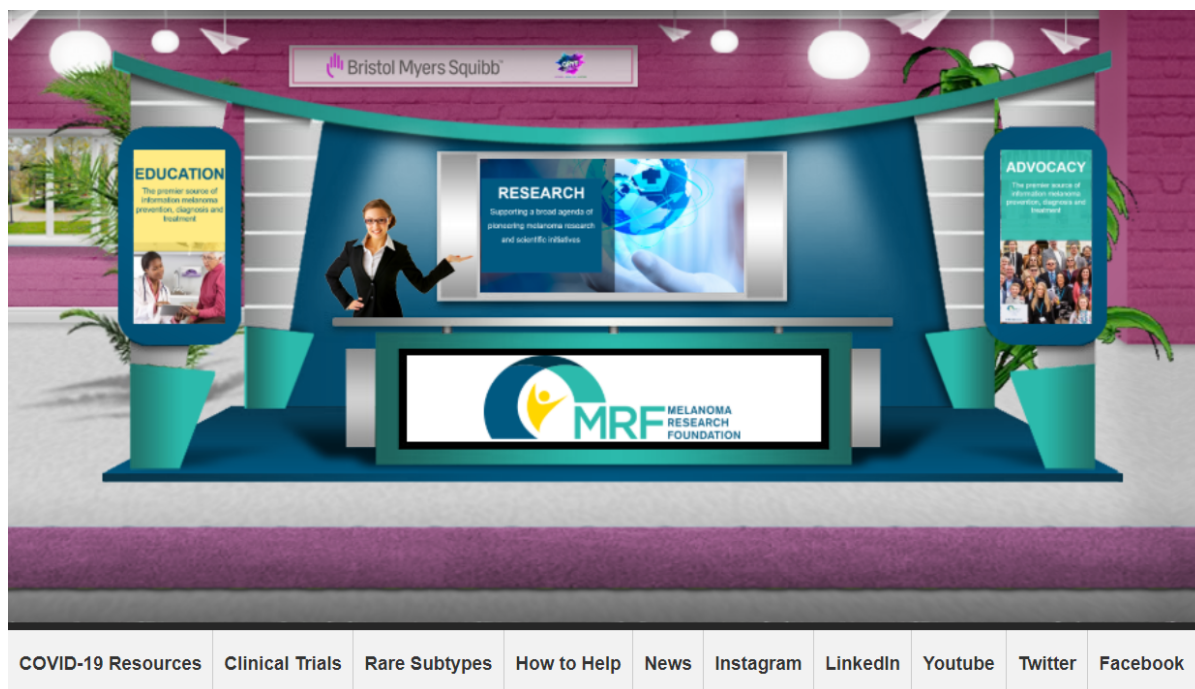
Ocular Melanoma in Huntersville, NC

Strides are being made in the fight against ocular melanoma in North Carolina! OM affects about six people per one million each year but in the Huntersville, NC area alone, there are over 20 diagnosed cases, warranting further investigation into the elevated number of diagnoses.

The North Carolina State Senate passed the first reading of An Act Appropriating Funds to Study and Abate Ocular Melanoma in Northern Mecklenburg County (NC), with the primary sponsor being [Natasha Marcus, NC Senate District 41](#). The bill, still in the early stages of the legislative process, includes a \$100,000 fund from the Department of Health and Human Services to be allocated to the [Nicholas School of the Environment at Duke University](#) for the 2020-2021 fiscal year. The grant would fund the study of potential causes of and solutions for abating ocular melanoma in the towns of Huntersville and Cornelius and the surrounding area.

The MRF is proud to support the continued efforts of those in the Huntersville area! Click [here](#) to learn more about the legislation and how it can advance our understanding of ocular melanoma in North Carolina and beyond.

The MRF at the COVID Advocacy Exchange



In response to the unprecedented and evolving situation related to the COVID-19 pandemic, the MRF has joined our partners at [Bristol Myers Squibb](#), [GRYT Health](#) and advocacy organizations across the globe at the [COVID Advocacy Exchange](#). This virtual platform brings together organizations supporting multiple disease types to share resources and information that may be helpful during the current health crisis. Participants can visit the MRF's virtual booth 24/7, and live panel discussions will be hosted every Thursday featuring experts from a wide variety of patient advocacy organizations.

[Register today for the COVID Advocacy Exchange](#) and be sure to "visit" the MRF booth in the virtual exhibit hall!

Ocular Melanoma in the News

Below is a sample of recent news related to ocular melanoma.

["Study Finds New Clues in Ocular Melanoma"](#) *SCOOP Health*

["Engaged Couple to Host Digital Concert on Original Wedding Date,"](#) *Fox 17*

["Considerations for the Management and Triage of Ocular Oncology Cases During the COVID-19 Pandemic,"](#) *American Association of Ophthalmic Oncologists and Pathologists*

["IDEAYA and Pfizer to Evaluate Combo of IDE196 and Binimetinib,"](#) *thepharmaletter*

["Bevacizumab Increases Visual Acuity in Ocular Melanoma Patients Treated with Plaque Radiotherapy,"](#) *Healio*

["Nonprofit Created to Help Get Answers About Rare Cancer Cases in Lake Norman,"](#) *WSOC*

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