

Subject: A Historic Moment in OM Research Funding!

## HTML



### A Historic First for Ocular Melanoma Research

The Melanoma Research Foundation (MRF) is proud to support a broad array of melanoma science and the dedicated researchers studying rare subtypes such as ocular melanoma. In the latest round of funding, three of the awarded grants will support ocular melanoma research, including a Team Science Award - the largest grant funded by the MRF!



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congratulate **William Sellers, MD** of the Broad Institute for his project titled "[The development and characterization of cellular models of uveal melanoma.](#)" (Co-PI: **Keith Flaherty, MD**)

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### Upcoming Events

November 2 - [Miles for Melanoma San Diego](#)

November 2 - [Miles for Melanoma Denver](#)

November 16 - [Miles for Melanoma Los Angeles](#)

November 17 - [Miles for Melanoma San Francisco](#)

November 20-23 - [Society for Melanoma Research International Congress](#)

March 8-10, 2020 - [MRF Advocacy Summit & Hill Day](#)

April 17-19, 2020 - [Eyes on a Cure: Patient & Caregiver Symposium](#)

Planning your own CommUNITY Fundraising event? Email [events@melanoma.org](mailto:events@melanoma.org) so we can include it on our online calendar!



funding from other sources. The MRF selected **Stefan Kurtenbach, PhD** of the University of Miami for his study titled "[Role of PRAME in Epigenetic Reprogramming and Chromosomal Instability.](#)"

Thanks to the generous support of our community, with this round of grant funding the MRF is excited to invest over a half million additional dollars in ocular melanoma research! For more information on research grants and scientific initiatives supported by the MRF, including current opportunities, please visit the [MRF Research Center](#).

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## Society for Melanoma Research Congress

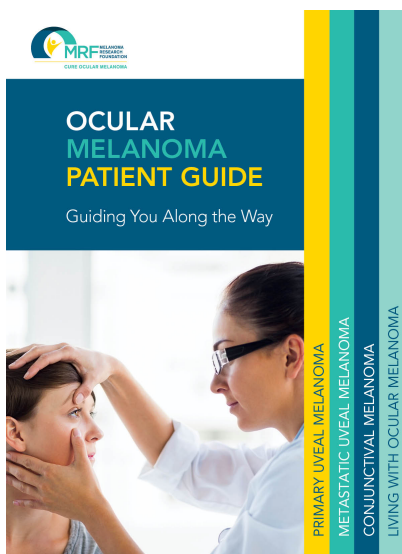


The 16th Annual [Society for Melanoma Research \(SMR\) Congress](#) will meet this November in Salt Lake City, Utah. This international gathering unites over 1,000 melanoma clinicians and researchers to focus on multidisciplinary management of melanoma and provides key insight into the practical advantages of multidisciplinary care for patients. On November 20, the opening day of the SMR Congress, the MRF will host the 10th Annual [CURE OM Scientific Meeting](#) focused solely on ocular melanoma. During this meeting, medical professionals will discuss the latest in clinical trials, research, and additional topics that pertain to ocular melanoma. CURE OM is excited to continue its strong partnership with SMR and once again bring medical professionals together to discuss future advances in ocular melanoma and opportunities to collaborate.

**[If you are a researcher or clinician attending the 2019 SMR Congress, register now for the CURE OM Scientific Meeting!](#)**

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## Coming Soon: Ocular Melanoma Patient Guide



Next month, the MRF will introduce our newest patient education resource: the Ocular Melanoma Patient Guide! Developed in close consultation with a multidisciplinary team of researchers, physicians and ocular melanoma experts, this free patient resource will help patients with all forms of ocular melanoma navigate their care. The OM Patient Guide will cover topics including:

*Diagnosing ocular melanoma*  
*Genetic mutations and testing*  
*Treatment options for primary and metastatic OM*  
*Managing side effects and vision changes*  
*Survivorship*

The MRF is grateful for the expertise and hard work of the many contributors to this new patient resource, and is eager to make it available soon on our [Ocular Melanoma Resources](#) page.

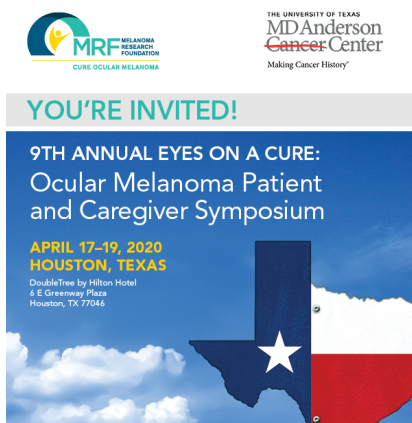
## Treatment Center Collaborative Coalition

The CURE OM team is excited about this new program for medical and academic centers. A year ago, the MRF launched and hosted the first meeting of the Treatment Center Collaborative Coalition (TCCC). This program offers quarterly informational and educational meetings for the frontline staff who interact with patients at participating treatment centers. Participants including social workers, therapists, nurse practitioners, office managers and physician assistants come together to learn the latest information in the world of ocular melanoma. Recent presentations have covered topics such as Therapeutic Needs and Strategies for Ocular Melanoma, presented by **Rebecca Cammy, LCSW**, Thomas Jefferson University; Clinical Trials 101 with **Rich Carvajal, MD**, Columbia University; and in November, **Mathew Rieth, MD** from University of Colorado will be presenting on adjuvant therapy. Currently, 9 institutions are participating in this first year and CURE OM hopes to expand this program so that more patients and caregivers will receive the best treatment and support during their OM journey.

Participating centers include: University of Colorado, MD Anderson Cancer Center, Thomas Jefferson University, Columbia University, University of California Los Angeles, Cleveland Clinic, TN Retina, Colorado Retina, and Emory University.

If you are part of a medical or academic center and would like to get involved in the TCCC, email [cureom@melanoma.org](mailto:cureom@melanoma.org)!

## 2020 Eyes on a Cure: Patient & Caregiver Symposium



Registration is now open for the 9th Annual Eyes on a Cure: Ocular Melanoma Patient and Caregiver Symposium! The event will be held on **April 17-19, 2020, in Houston, TX**, in collaboration with MD Anderson Cancer Center. Speakers will include **Sapna Patel, MD**, **Dan Gombos, MD**, **Marlana Orloff, MD** and more. We hope to see you there! For more information on the agenda, registration and hotel accommodations, visit [melanoma.org/eyesonacure](http://melanoma.org/eyesonacure). Photos from the 2019 symposium are on the [CURE OM Facebook page](#) and the educational presentations can be viewed on the MRF [YouTube](#) channel.

Note: Program registration does not include lodging and hotel reservations must be made separately. A CURE OM room block



is available at a discounted rate; [reserve your room](#) by March 27, 2020 to ensure pricing and availability.

**[Register today for the 2020 Eyes on a Cure: Patient & Caregiver Symposium!](#)**

## #EyeGetDilated

# #EYEGETDILATED

- Doctor
- Dentist
- Dermatologist
- Dilated Eye Exam

**MISSING A CHECK?**

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[@MRFCureOM](https://twitter.com/MRFCureOM)  
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The 4th annual #EyeGetDilated campaign kicks off November 1st! Throughout the month, CURE OM will be utilizing social media, guest blogs, videos and more to promote and educate about the importance of eye health and encourage everyone to include a dilated eye exam in their annual wellness routine. Early detection is incredibly important for many eye diseases, including ocular melanoma. To expand our reach internationally, we are excited to partner with our friends at [Ocumel Canada](#) for this year's awareness campaign! If you'd like to participate, please re-post information from the CURE OM and MRF social media channels during the month to spread the news about the importance of dilated eye exams, and share your own messages too! You can also [request our free "Missing a Check?" postcards](#) to take to your local doctors to include in their annual wellness reminders or [download a PDF copy](#). Suggested places to hand out postcards/flyers (with permission) include your primary care/family physician, optometrist and dermatologist.

To request #EyeGetDilated postcards, please visit our [educational literature page](#) or email Aakshi Sanchowala at [asanchowala@melanoma.org](mailto:asanchowala@melanoma.org). Make sure to include the number of cards needed and a mailing address.

## New Webinar Series: Monocular Vision

Following ocular melanoma treatment, some patients may experience different levels of vision loss in the affected eye, or even have the eye removed completely (enucleation). Adapting to monocular vision can be challenging and will take some adjustment, both physically and emotionally, but most day-to-day tasks will fall back into place as your body and brain compensate for the change. To help with this process, the MRF is proud to share the newest addition to our Education Institute: the [Monocular Vision Webinar Series](#). Hosted by **Fay Tripp, MS, OTR/L, CLVT, CDRS**, Occupational Therapist at Duke Eye Center, this series addresses topics like coordination and mobility, adaptive devices, even getting back behind the wheel of your car.

**[Visit the MRF Education Institute and view the Monocular Vision Webinar Series today!](#)**

## 2020 Advocacy Summit & Hill Day



The federal government is the largest source of funding for melanoma research and each year, your members of Congress determine how much of the budget will be allocated to cancer research. In 2018 melanoma patients, survivors and caregivers made their voices heard and Congress listened: in a historic first, lawmakers awarded melanoma \$10 million in dedicated Department of Defense (DoD) funding. In 2019, melanoma advocates went back to the Hill to rally for continued support and ensured that this critical funding was again included in the annual spending bill. Patients and caregivers with rare melanoma subtypes like OM are critical voices in the melanoma community and to make sure that melanoma research remains a national priority, YOUR VOICE

## MATTERS!

The MRF's annual [Advocacy Summit & Hill Day](#) is your opportunity to bring your story to Washington, DC and make sure that lawmakers hear from the ocular melanoma community. Following comprehensive advocacy training and a thorough briefing on the issues from MRF staff and policy experts, our new melanoma advocates will head to Capitol Hill to share their stories and make their case in face-to-face meetings with lawmakers and legislative staff.

Join melanoma advocates from across the nation at the MRF Advocacy Summit & Hill Day on March 9-10th, 2020! Registration opens on December 3, 2019 so mark your calendar, [bookmark the event page](#) and make a plan to be a part of the largest melanoma advocacy event of the year!

## National Organization for Rare Diseases



On September 1st, 2019 the MRF became a member of the [National Organization for Rare Diseases \(NORD\)](#), joining 23 other organizations representing those facing rare diseases like ocular, pediatric and mucosal melanoma. Additionally, the MRF was selected to join the [Rare Cancer Coalition](#) hosted by NORD to represent all forms of melanoma in the rare cancer community. By partnering with NORD, the MRF is now connected with 80,000 constituents in the rare disease community and joins forces with a network of prestigious organizations to influence legislative action in support of those facing rare diseases like ocular melanoma.

Stay tuned for more information about this exciting partnership! To learn more about NORD and ways to be involved, please visit [here](#).

## 18th Annual New York Gala

On October 17th, 2019, the 18th Annual New York Gala was held in New York City. Emceed by **Katie Couric**, this year's event celebrated the patients, caregivers and researchers leading the fight against melanoma, including three honorees from the ocular melanoma community. The CURE OM Vision of Hope Award was presented to **Alex Shoushtari, MD**, Medical Oncologist with Memorial Sloan Kettering Cancer Center, who has shown exemplary dedication to the OM patients in his care. Courage Award honorees included two OM warriors whose bravery in the face of adversity continue to be a powerful inspiration to our community: **Laraine Pirie** and **Daryl Lynn Pace** (in honor of). It was an unforgettable evening to celebrate our heroes in the melanoma community while raising life-saving funds for research, improved treatments and, one day, a CURE.



## CURE OM in the Community



The third annual [Your Next Step is the Cure](#) run/walk in Florida took place on October 5th and it was a record setting success! Organized by CURE OM community members **Bernadette Boyle** and **Linda O'Brien**, this [CommUNITY Fundraising](#)



event has grown rapidly since the inaugural race, expanding from 40 participants in 2017 to over 130 participants this year! Thanks to the determination and drive of Bernadette, Linda and their friends, family and supporters, *Your Next Step is the Cure* raised over \$13,000 - almost double the amount from the previous year - to support ocular melanoma research. Thank you to everyone who made this year's event such a success, view photos from the run/walk [here](#) and then mark your

calendars for next year's event on October 3, 2020!

On September 1, two amazing CURE OM advocates traveled to Boone, NC, for an ocular melanoma awareness day at Appalachian State University. **Nicole and Earl Bruce** (Earl seen at right with Yosef the Mountaineer) joined head coach **Jason O'Keefe** as the Appalachian State Mountaineers hosted a double header soccer match. The University dedicated the day to Coach O'Keefe's wife, current OM warrior **Julie O'Keefe**, and used it as a platform to educate about ocular melanoma. Nicole and Earl drove to Boone not only to support the O'Keefe family and OM awareness day, but also to spread the word about the resources available through CURE OM and the MRF by hosting a table and talking about OM awareness. The CURE OM team can't thank Appalachian State or the Bruce family enough for allowing us to be part of this amazing day of OM awareness and education.



Do you have a great idea for an OM awareness or fundraising event? Email [cureom@melanoma.org](mailto:cureom@melanoma.org) or visit the [CommUNITY Fundraising](#) page for planning documents, fundraising strategies and more!

## Ocular Melanoma in the News

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

[\*\*"Genetic Sequencing, Soil Tests Provide No Answers in Eye Cancer Cluster Mystery,"\*\*](#) WSOC

[\*\*"Early Detection of Ocular Melanoma Saves Elkhart Man's Vision,"\*\*](#) WNDU

[\*\*"IDEAYA Announces First Patient Dosing of IDE196 for Solid Tumors Outside Uveal Melanoma,"\*\*](#) P&T Community

[\*\*"Pearls for Managing Care of High-Risk Uveal Melanoma Patients,"\*\*](#) Ophthalmology Times

[\*\*"As Cancer Haunts North Carolina Communities, Residents Struggle to Find Answers,"\*\*](#) Southerly

[\*\*"Checkpoint Inhibition Immunotherapy for Advanced Local and Systemic Conjunctival Melanoma: a Clinical Case Series,"\*\*](#) US National Library of Medicine

[\*\*"A 12-Year Study of Slotted Palladium-103 Plaque Radiation Therapy for Choroidal Melanoma: Near, Touching, or Surrounding the Optic Nerve,"\*\*](#) American Journal of Ophthalmology

[\*\*"Research Funded by the Melanoma Research Foundation's \(MRF\) CURE OM Initiative Published in Nature Genetics,"\*\*](#) Melanoma Research Foundation

[\*\*"Kathleen Blanco, Louisiana Governor During Hurricane Katrina, Dies at 76,"\*\*](#) The New York Times

[\*\*"Spotsylvania Man Sees a More Positive Outlook After Rare Eye Cancer,"\*\*](#) Fredericksburg.com

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## Plain Text

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