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CURE OCULAR MELANOMA

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## Eyes on a Cure: Patient & Caregiver Symposium



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## YOU'RE INVITED!

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

**APRIL 17-19, 2020  
HOUSTON, TEXAS**

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

**REGISTER TODAY!**

[www.melanoma.org/eyesonacure](http://www.melanoma.org/eyesonacure)



Join ocular melanoma patients, caregivers, physicians and experts at the [9th Annual Eyes on a Cure: Ocular Melanoma Patient and Caregiver Symposium!](#)

Hosted in collaboration with MD Anderson Cancer Center, this year's conference will be held on April 17-19, 2020, in Houston, TX. In addition to comprehensive updates about OM science in the US, the MRF's CURE OM initiative will

## Upcoming Events

February 29 - [Rare Disease Day](#)

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

April 17-29, 2020 - [Eyes on a Cure: OM Patient & Caregiver Symposium](#)

May 2 - [Miles for Melanoma DC](#)

May 7 - [Denver Gala](#)

May 16 - [Miles for Melanoma New England](#)

May 30 - [Miles for Melanoma Memphis](#)

June 6 - [Save the Date: Miles for Melanoma Chicago](#)

June 13 - [Save the Date: Miles for Melanoma Denver](#)

August 2 - [Save the Date: Miles for Melanoma Cleveland](#)

August 22 - [Save the Date: Miles for Melanoma Twin Cities](#)

also welcome our partners from Ocumel Canada and look forward to sharing the latest information about OM research and treatment in Canada. Speakers currently confirmed include **Sapna Patel, MD, Dan Gombos, MD, Marlana Orloff, MD, Marcus Butler, MD** and more. We hope to see you there!



View a draft agenda and find additional information about the symposium, including lodging and travel discounts, and [register today for the largest OM event of the year!](#)

August 29 - [Save the Date: Miles for Melanoma Philadelphia](#)

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

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

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

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

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

## Exciting News About the CURE OM Patient Registry!



The Patient-Powered Registry, Focused on a Cure

This week, the MRF [announced a transformational new partnership](#) with Massachusetts General Hospital Cancer Center (MGHCC) to advance the development and launch of VISION, the first ever patient-powered and patient-reported ocular melanoma registry! Central to this partnership is a generous financial gift to fund the launch and multi-year maintenance of the registry project. The MRF gratefully welcomes Massachusetts General Hospital Cancer Center as a foundational partner in this historic and critically needed research.

A patient registry is a critical tool to advance medical research, especially for a rare disease. Hosted by Global Vision Technologies' [ClinicalPURSUIT](#) registry platform, the VISION registry is unique in that it is patient powered and reported. In addition to strictly clinical data, patients and caregivers can regularly submit updates that present a holistic picture of their diagnosis, various treatments, outcomes, lifestyle and geographic details. It will also show preferences and other information that may reveal previously unseen patterns, commonalities, potential causes and new treatment targets. This will offer new collaborative opportunities with leading medical and academic partners, reveal a greater understanding of the rare disease and unlock much-needed breakthroughs in OM research and treatment development.

Progress on the VISION registry is accelerating rapidly, and it is expected to launch in the summer of 2020. For more information, visit [www.ocularmelanomaregistry.org](http://www.ocularmelanomaregistry.org).

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## CURE OM's Historic Trip to the FDA



Monday, January 27, was a historic day at the U.S. Food and Drug Administration. Organized by the MRF Advocacy program, FDA administrators participated in the first-ever Ocular Melanoma Listening Session and heard from OM patients, caregivers, researchers and advocates. Participating in person were MRF Officer for Rare Melanoma Subtypes **Lauren Johnston**, **Richard Carvajal, MD**, OM advocate **Aaron Davis**, CURE OM Co-Founder and Director **Sara Selig, MD, MPH**, OM advocate **Sean Hennessy**, OM advocate and MRF Development Officer **Liz Reilly**, MRF Advocacy Officer **Cassie Beisel**, MRF CEO **Kyleigh LiPira**, OM advocates **Sam and Shea Biurski** and MRF Intern **Caileigh Lydon**. OM advocates **Carla Tressell**, **Katie Doble**, **Kristin Nocco** and **Sue Colbert** joined by phone to share their stories. Discussion topics included the lack of standard of care, clinical trials and research funding available to OM patients and researchers. FDA representatives were readily engaged during the meeting and eagerly asked follow up questions to learn how the organization can better support the OM community. Additional details about the meeting, next steps and upcoming ways to get involved will be shared in the near future. Thank you to everyone who made this historic day possible!

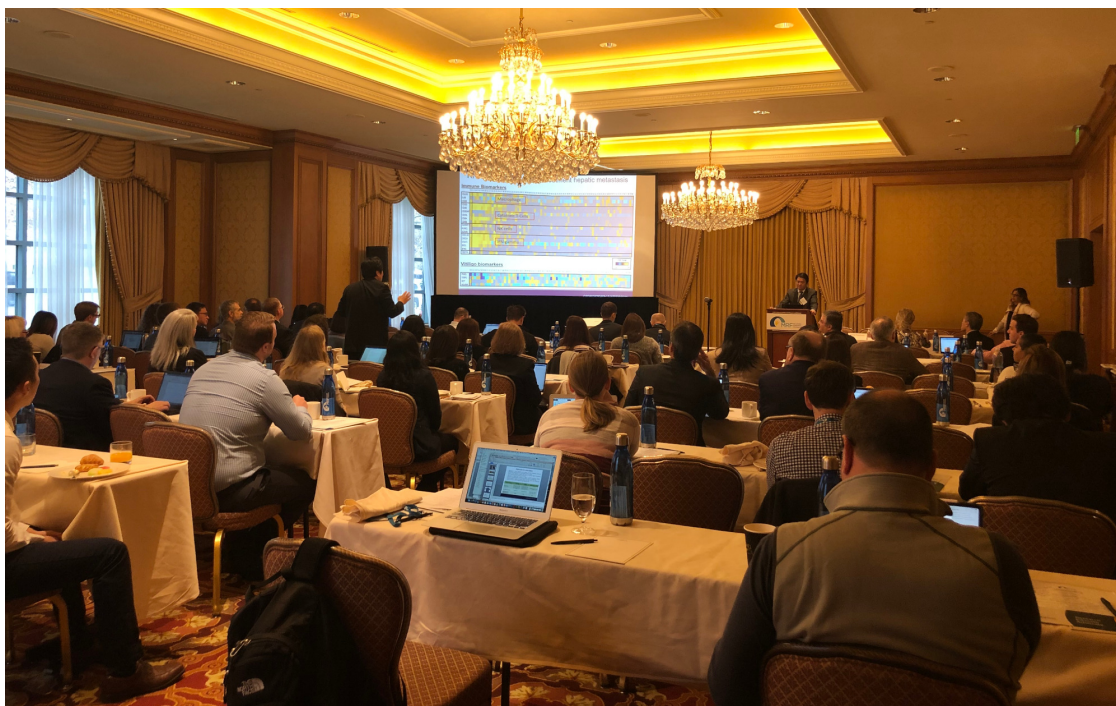
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## 10th Annual CURE OM Scientific Meeting





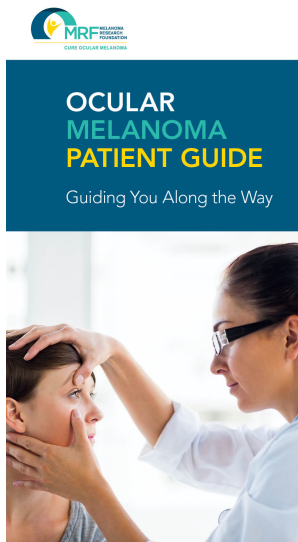
In conjunction with the 16th Annual [Society for Melanoma Research \(SMR\) Congress](#), the MRF hosted the 10th Annual [CURE OM Scientific Meeting](#), bringing together over 75 physicians and researchers to discuss a variety of topics focused solely on ocular melanoma. Speakers included **Takami Sato, MD, PhD**, **Rich Carvajal, MD**, **William Harbour, MD**, **Hunter Shain, PhD**, **Andrew Aplin, PhD**, **Sapna Patel, MD** and **Nadia Arang**. These and other medical experts discussed the latest in clinical trials, OM research opportunities and additional topics that pertain to ocular melanoma diagnosis and treatment.



The session concluded with discussion and commitment to the development of a new white paper focused on ocular melanoma, which will be submitted to journals for review and publication. The CURE OM initiative will assist in the development and oversight of this project and looks forward to sharing additional details as they are available.



## New Ocular Melanoma Patient Guide



The MRF recently introduced the newest addition to our growing library of free educational materials: the [Ocular Melanoma Patient Guide](#)! Developed in close consultation with a multidisciplinary team of researchers, physicians and ocular melanoma experts, this free patient resource can help patients with all forms of ocular melanoma navigate their care. From initial diagnosis to adapting to life post-treatment, the OM Patient Guide covers 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 encourages OM patients, caregivers and physicians to

download a copy from the [MRF Education Institute](#) or on our [Ocular Melanoma Resources](#) page.

## Join the Grant Review Process



Since the first MRF research grant was awarded in 1998, every proposal has been subject to rigorous peer review by a panel of scientists, physicians, researchers and melanoma experts. Because patients and their loved ones are those most affected by research advances and the development of new therapies, the MRF believes their input to be incredibly valuable to the grant review process. Beginning in 2019, melanoma patient advocates were invited to participate in the grant review process to share their perspective on which areas of research should receive grant funding. This program is expanding in 2020, and the MRF is currently seeking melanoma patient advocates to join a research grant review panel. Formal scientific training is not required, but those with a such a background are welcome to apply as well. Additional information on how to apply, eligibility criteria, estimated time commitment and more

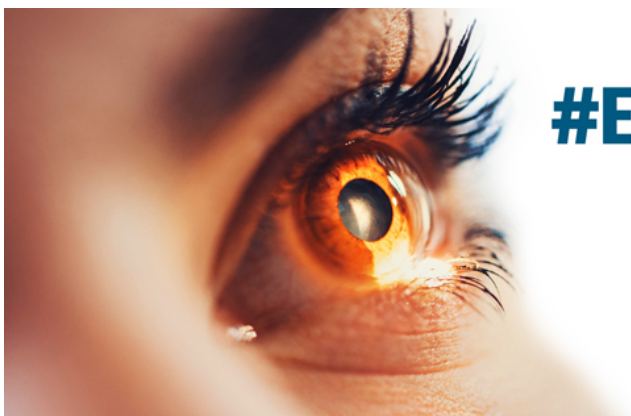
are available in the [MRF Research Center](#). **Completed applications are due by Thursday, April 16, 2020.** For questions about this program or additional opportunities to participate in melanoma science, email [research@melanoma.org](mailto:research@melanoma.org).

### Lab Tour: On the Front Lines of OM Research



Researcher **Jae Hyuk Yoo, PhD** and the **Shannon Olberg** lab hosted members of the MRF team and the Global Coalition for Melanoma Patient Advocacy on November 21, 2019 at the University of Utah in Salt Lake City, UT. Dr. Yoo received a Career Development Award in 2016 for his research on the “Mechanism of Metastasis in a Less Common Molecular Subset of Uveal Melanoma.” Dr. Yoo presented on this research at the 2018 *Eyes on a Cure: Ocular Melanoma Patient and Caregiver Symposium* in Denver, Colorado. The tour was a great opportunity to see how the lab has continued to invest in uveal melanoma, and for the MRF to meet those behind the research. For more information on grant awards and how the MRF continues to advance the most promising research in all forms of melanoma, please [click here](#).

#EyeGetDilated



#EYEGETDILATED





November 2019 marked the MRF's fourth #EyeGetDilated campaign! This year's campaign to increase awareness of ocular melanoma and the importance of dilated eye exams was a huge success thanks to new graphics, awareness materials and an #EyeGetDilated t-shirt! The MRF and CURE OM would like to thank the patients, caregivers, and researchers who allowed us to highlight their fight with this disease. Over 44,000 users clicked on the stories with over 300 shares on Facebook.



Over 1,400 #EyeGetDilated postcards were sent to 20 states. Postcards were placed in coffee shops, primary care physician offices, dermatologist offices, work offices, and more! It was a huge success and CURE OM thanks you, the community, for spreading the word about the importance of dilated eye exams.

Postcards can be ordered throughout the year and ship anywhere in the United States completely free of charge. Visit the [MRF Education Institute](https://www.melanoma.org/education-institute) to place your order and see the additional OM resources available.

## 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 closes soon, so [sign up today](#) and be a part of the largest melanoma advocacy event of the year!

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## Ocular Melanoma Support Groups





/ RE-DEFINING /  
Mental Health  
Psychology for a Complex World

**COLORADO RETINA**  
Creating a community for cancer patients &  
survivors through a free OM support group



Thursday, February 20, 2020  
6:00 PM

Colorado Retina Associates  
800 Englewood Pkwy, Suite C200  
Englewood, CO 80110

All Patients Diagnosed with Any Form of  
Ocular Melanoma Are Welcome

Complimentary Admission  
Snacks Provided

CONTACT: 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. We are excited to announce the start of the Ocular Melanoma Support Alliance (OMSA). 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.

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.

- Earlier this month, 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 will help to explore 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 will meet monthly at Colorado Retina's Englewood, CO office and

admission is free. To learn more and get involved, OM community members in the Denver area can email Amanda Sisco, Supervisor of Oncology Services at [asisco@retinacolorado.com](mailto: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](mailto:ljohnston@melanoma.org).

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

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## Ocular Melanoma in the News

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

["Melanoma Research Foundation to Launch First Ever Patient-Reported Ocular Melanoma Registry"](#) *Melanoma Research Foundation*

["Fighting Cancer with Ultrasound,"](#) *The Ohio State University*

["Conjunctival Melanoma: Unlocking Mysteries of Disease,"](#) *Ophthalmology Times*

["Long-Term Survivors with Metastatic Uveal Melanoma,"](#) *National Institutes of Health*

["Residents Continue to Seek Answers on Local Cancer Cases,"](#) *WFAE*

["Light-Activated Agent Novel Option for Uveal Melanoma,"](#) *Ophthalmology Times*

["Visual Acuity Improved with Prophylactic Bevacizumab for Uveal Melanoma,"](#) *Oncology Learning Network*

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