

Subject: Advancing Research and Celebrating the OM Community

HTML



8th Annual Eyes on a Cure: Patient & Caregiver Symposium

A Community of Partners

<p>Research Collaborations</p> <p>Auburn University Columbia University Duke University State of North Carolina</p>	<p>Thomas Jefferson University University of Alabama at Birmingham University of North Carolina</p>	<p>Social/Emotional Support</p> <p>Duke University Thomas Jefferson University University of North Carolina</p>
<p>Historic Attendance</p> <p>Over 130 ocular melanoma patients, caregivers, researchers and physicians attended the 2019 CURE OM Symposium</p>	<p>International Partnerships</p> <p>OM advocacy groups representing 4 nations exploring global collaboration opportunities</p>	<p>Unique Populations</p> <p>Welcoming the ocular melanoma communities of Huntersville, NC and Auburn, AL</p>

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Upcoming Events

June 22 - [Miles for Melanoma Chicago](#)

June 22 - [Miles for Melanoma Columbus](#)

August 3 - [Miles for Melanoma Memphis](#)

August 4 - [Miles for Melanoma Cleveland](#)

September 7 - [Miles for Melanoma Philadelphia](#)

September 14 - [Miles for Melanoma NYC](#)

September 15 - [Miles for Melanoma New Jersey](#)

September 15 - [Miles for Melanoma Twin Cities](#)

September 26 - [Chicago Gala](#)

October 27 - [NYC Gala](#)

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

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The event included panel discussions on the unique populations of Huntersville and Auburn, clinical trials updates and our first-ever international partners panel with OcuMel UK, OcuMel Ireland and OcuMel Canada. Speakers included Auburn advocate **Ashley McCrary**, Huntersville advocates **Kenny and Sue Colbert, Dr. Miguel Materin** from Duke University, **Dr. Fred Kam** from

Auburn University, **Dr. Jessica Yang** from Columbia University and **Dr. David Eschelman** from Thomas Jefferson University. View a full list of speakers and presentation topics on the [event agenda](#).

[International Congress](#)

Breakout sessions for the event were both informative and provided a powerful opportunity for patients and caregivers to find support from one another. Sessions led by University of North Carolina, Duke University and Thomas Jefferson University representatives included topics like "Scanxiety," "The Many Faces of Grief," "Monocular Vision Loss" and "Advocacy: Diagnosis to Survivorship."

Support groups facilitated by Thomas Jefferson University and Duke University social workers allowed patients, caregivers and those who lost a loved one the chance to come together, offer support and share their experiences.

Photos from the event are on the [CURE OM Facebook page](#). Educational presentations were recorded and can be viewed on the MRF [YouTube](#) channel.

Save the date: The date and location was just announced for the 2020 Eyes on a Cure: Ocular Melanoma Patient and Caregiver Symposium! Mark your calendar for **April 17-19th in Houston, Texas**, and stay tuned for more information about next year's event!

CURE OM Patient Registry Update



In March 2019 CURE OM [Patient Registry Steering Committee](#) member **Dr. Dan Gombos** from MD Anderson Cancer Center presented about the registry at the International Society of Ocular Oncology (ISOO) in Los Angeles, CA. The presentation was co-authored by all members of the steering committee. It was an exciting opportunity to highlight the work of the Patient Registry Steering Committee and was well-received by the audience who expressed strong interest in the development, implementation and long-term goals of the registry.

On April 5th, the CURE OM Patient Registry Steering Committee held an in-person meeting at the Ocular Melanoma Patient and Caregiver Symposium in Raleigh, NC. The committee welcomed three new committee members representing the fields of epidemiology, biostatistics and large data networks, including representation from the National Eye Institute. The new members and their expertise will be invaluable to the project. The group focused its efforts on the upcoming tasks required to launch the registry, especially the development of patient surveys to collect information. In addition to discussing the registry data set, the committee assessed opportunities to collaborate with leading academic and industry partners. Furthermore, participant engagement and retention strategies were considered, including communication materials, a registry logo and effective tools for patient recruitment. The following day at the symposium, **Dr. Rich Carvajal** presented a comprehensive registry update and a panel of committee members addressed questions from the audience, which can be viewed [here](#). Thank you to panel members **Jacqueline Kraska**, **Linda O'Brien**, **Chad Kimbler** and **Dr. Marlana Orloff**!



The MRF is currently finalizing the contract with the registry platform provider; the final stage of securing funding for the first three years of the project; and developing a dedicated page on its website for the registry. For more information about this project, check out [“What Gets Measured Gets Managed,”](#) a blog post by **Dr. Bertil Damato** about his reasoning for supporting an ocular melanoma patient-reported registry.

Advancing Ocular Melanoma Research



On May 31 - June 4, the American Society of Clinical Oncology (ASCO) held its Annual Meeting in Chicago, IL. The MRF participated in a very busy 4 days of meetings, presentations and opportunities to explore how we can support the very latest research in melanoma and its rare subtypes like ocular melanoma. With over 40,000 researchers, oncologists and cancer experts in attendance, the MRF was honored to represent the OM community and explore new ways we can advance towards more effective treatments and, one day, a cure.



Last year, the MRF led a coalition of advocates to [successfully secure \\$10 million](#) in dedicated research funding and the creation of the Department of Defense Melanoma Research Program. This month, the initial round of grant funding was announced via three research awards.

Pre-proposals for each award are due by 5:00pm ET on July 26, 2019. For those invited to move forward, applications will be due on October 23, 2019 by 11:59 pm ET. More information can be found [here](#), and pre-proposals can be submitted on the Congressionally Directed Medical Research Program (CDMRP) [website](#).

In addition to successful advocacy for federal research funding, the MRF and its CURE OM initiative have funded over \$1.5 million dollars specifically for ocular melanoma research. To learn more about the broad range of MRF-funded research initiatives, visit the [MRF Research Center](#).

Advocating for the OM Community



On March 9 - 11, the MRF hosted its annual Advocacy Summit & Hill Day, bringing together over two dozen partner organizations and advocacy experts to train over 100 melanoma patients, survivors and caregivers in preparation for meetings with their lawmakers on Capitol Hill. This year's summit also included three new breakout sessions: Advocacy for Ultra Rare Melanomas, Advocacy for Young Adults and Self Advocacy and Personal Empowerment.

A key priority championed by our advocates was support for \$20 million in Defense-funded melanoma research in fiscal year 2020. Since our advocates met with their representatives, the MRF confirmed new support from over 20 members of Congress! Another key ask was ensuring that students had access to sunscreen while at school – a commonsense measure that is currently prohibited in many school districts. **Mercer Reilly**, the son of OM patient **Liz Reilly** and one of our youngest and most dedicated advocates, met with **Representative Jason Crow** to discuss this important topic. Prior to coming to Washington, Mercer collected 50 letters of support from his classmates and personally delivered these to Representative Crow during his meeting.



The MRF applauds the hard work and dedication of our volunteer advocates for driving progress in melanoma policy and ensuring access to treatments.

Save the date! The MRF will host its 10th Annual Advocacy Summit & Hill Day on March 9 and 10, 2020.

Eyes on the Prize: CURE OM Takes Top Spot at Miles for Melanoma DC



The Miles for Melanoma season was officially launched on May 4 with our first 5k run/walk of 2019 in Washington, DC! The OM community had strong representation and took top fundraising honors in multiple categories! Team CURE OM was the top fundraising team at the event, with over \$10,000 raised for OM research! Team Captain **Sheila Levine** was the #2 top fundraiser with more than \$3,800 raised and CURE OM team member **Gayla Timm** was the top overall fundraiser at the 500-person event with over \$4,800 raised! Thank you to Team CURE OM and everyone who made this such an incredible event!

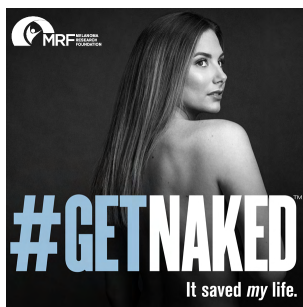


Following a strong start in Washington, DC, next up was the Miles for Melanoma New England 5k! Thanks to the generosity of our community, this run/walk exceeded the fundraising goal by more than 20%, raising over \$72,000! A special thank you to our partners at Aura Biosciences, who had a great turnout and formed the Aura CURE OM team to show their strong support for the OM community.

The Miles for Melanoma season is here and over a dozen events remain in cities across the

US. [Find a run/walk near you!](#)

Melanoma Awareness Month



May was Melanoma Awareness Month and throughout the month, the MRF was hard at work promote awareness around not only cutaneous melanoma, but also the rare subtypes including OM. By increasing education around prevention, early detection and treatment, the public will have a better understanding of all forms of melanoma and the importance of early detection.

Activities included the launch of a brand new, completely redesigned [MRF website](#), a new face and compelling survivor story for the [#GetNaked](#) early detection campaign and support for OcuMel UK's "[iPatchFor](#)" campaign. The iPatchFor campaign is an international partnership to increase OM awareness and the importance of dilated eye exams for the detection of ocular melanoma, and CURE OM was proud to partner with our friends at OcuMelUK again this year.



Celebrating the OM Community



On May 2nd, 2019, the MRF hosted its 8th Annual Denver Gala. It was an inspiring evening with over 300 melanoma patients, survivors, caregivers and supporters united to celebrate the melanoma community and raise life-saving funds for research. At this year's gala, the OM community was front and center with multiple members chosen as 2019 honorees.

CURE OM advocate **Amanda Mason** was recognized with the CURE OM Vision of Hope Award for her work and dedication to OM patients at Colorado Retina Associates. OM warrior **Lindsey Zubeck** was honored with the Courage Award along with former head coach of the Denver Nuggets, **George Karl**, who shared his ocular melanoma story from the gala stage. Prior to the event, MRF CEO Kyleigh LiPira and Coach Karl were interviewed on Channel 9 News about ocular melanoma, which you can view [here](#).

View photos from the Denver Gala on our [Facebook page](#) and visit the MRF website to learn

about [upcoming galas](#).



On Thursday, June 6, the MRF hosted the Sixth Annual Philadelphia Gala. This year's event had a special focus on the OM community, with both OM patients and physicians recognized during the inspiring evening. The CURE OM Vision of Hope Award was presented to Thomas Jefferson University physicians **David Eschelmann, MD**, **Carin Gonsalves, MD** and **Robert Adamo, MD** in recognition of their outstanding commitment to the care of OM patients. The MRF recognized **Margaret Ann Pruitt** and **Jill Wrobel** with Courage Awards for the bravery and grace they have shown in facing OM.

Photos from the event will be available in the near future, and it's not too late to show your support for the OM community! Celebrate our honorees with a [tax-deductible donation](#), or place your bid on some exciting [auction items](#) before it closes on Monday, June 17!

Ocular Melanoma & Eye Health in the News

Below is a sample of recent ocular melanoma news.

[“When You See Uveal Melanoma, You Can’t Afford to Wait,”](#) Think Uveal Melanoma

[“Discussing Melanoma of the Eye with Former Nuggets Head Coach George Karl,”](#) 9News

[“Remembering Allyson Allred, Woman Who Battled Ocular Melanoma,”](#) CBS42

[“Expanding Ocular Melanoma Research Efforts Remain Linked to Lake Norman-area Cases,”](#) Herald Citizen

[“How Running Has Helped Me Through Two Ocular Melanoma Diagnoses,”](#) MD Anderson

[“North Mecklenburg Cases, Concerns Highlighted at National Ocular Melanoma Symposium’,”](#) Herald Citizen

[“Doctors, Patients Discuss Possible Causes, Cures for Deadly Eye Cancer in Raleigh,”](#) WSOC

[“Immunocore’s Lead Asset Tebentafusp Gains Fast Track Designation for Metastatic Uveal Melanoma,”](#) Immunocore

[“Aura Biosciences to Present Interim Phase 1b/2 Clinical Data for AU-011 at the International Society of Ocular Oncology 2019 Annual Meeting,”](#) Business Wire

["Provectus Announces Grant of Orphan Drug Designation in U.S. to PV-10 for Treatment of Ocular Melanoma,"](#) GlobeNewswire

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<https://www.youtube.com/playlist?list=PLqV-0vUISC3YnpSQCoW4YIMdIH9irkEj7>

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