



EYE ON OM

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Summer 2016

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#CUREOM Unite! Update

The 2016 **#CUREOM Unite!** campaign is off to a strong start, thanks to the hard work and effort of the ocular melanoma (OM) community!

Many OM patients, caregivers and advocates are fundraising for the campaign through CURE OM teams at the Miles for Melanoma 5k run/walks around the nation. Already there are 15 official CURE OM teams registered – six more than last year – and, as of July 15, 162 participants have signed up to walk and run in Miles for Melanoma events from New York to San Francisco! Thank you to all who are participating in this campaign to raise funds towards the development of an OM patient registry.

The Patient and Caregiver Review Committee for the 2015 **#CUREOM Unite!** campaign just completed the first phase of the scientific review process. Patient and caregiver participants took part in a two-step process that included a training focused on the scientific grant review process, followed by a call with MRF Scientific Advisory Committee member [Dr. Keith Flaherty](#) to discuss the proposal finalists. The patient and caregiver reviewers provided feedback on the proposals which, in combination with the scientific reviews, will help determine the awardee for the **#CUREOM Unite!** Established Investigator Award. The final announcement will be made later this month.

Online National OM Support Groups

In partnership with [Thomas Jefferson University](#) (TJU) Hospital, the MRF's CURE OM initiative recently hosted the third in a series of monthly online national OM support groups. The support group, facilitated by oncology social workers based at TJU, has been a successful pilot program. Additional support groups will be added this fall, but in the meantime, there is still room in the current primary and metastatic groups. The groups meet online the first Wednesday of each month from 1pm - 2pm EDT. Email CURE OM Program Manager Lauren Johnston for more information at ljohnston@melanoma.org.

CURE OM at Miles for Melanoma

In June and July, the OM community formed multiple teams for Miles for Melanoma events in both Denver and Boston. The Eyes on a Cure for OM team in Denver raised over \$1,200 for the **#CUREOM Unite!** campaign. CURE OM Program Manager Lauren Johnston and MRF Development Officer Liz Reilly joined

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Upcoming Events

July 24 - [Miles for Melanoma San Francisco*](#)

August 6 - [Miles for Melanoma Memphis](#)

August 7 - [Miles for Melanoma Detroit*](#)

August 13 - [Miles for Melanoma Twin Cities](#)

August 27 - [Miles for Melanoma New York City*](#)

August 28 - [Miles for Melanoma Raleigh*](#)

August 28 - [Miles for Melanoma Cleveland](#)

September 10 - [Miles for Melanoma Salt Lake City](#)

September 11 - [Miles for Melanoma San Antonio*](#)

September 18 - [Miles for Melanoma New Jersey*](#)

September 24 - [Miles for Melanoma Central Ohio](#)

*Indicates that an OM team currently exists at this event.

Save the Date

the team of more than 20 people, led by Becky Selig and her family.

In Boston, Team Gabe's Eye On A Cure and Aura CURE OM Team raised over \$9,000 for the **#CUREOM Unite!** campaign. This was the MRF's first Miles for Melanoma race in Boston and it was a huge success! The OM community rallied around the Roy family with 29 people, including CURE OM Director Sara Selig, walking in the race to raise awareness of OM.



March 10-12, 2017

6th Annual Eyes on a Cure: Patient and Caregiver Symposium and Hill Day in Washington, DC



OM Patient Registry Update

The MRF's CURE OM initiative is excited to announce that Jacqueline (Jacqui) Kraska is joining the CURE OM team as a consultant in the role of OM Patient-Centered Research Initiatives Advisor. Jacqui is currently the Research Programs

Manager for the [National Organization of Rare Diseases \(NORD\)](#). Jacqui will advise on the strategic development and successful implementation of the OM patient registry.

Ocular Melanoma in the News

Below is a sample of recent ocular melanoma news.

[“Seeing Life Differently with OM,”](#) AitkinAge.com

[“Biden Threatens Funding Cuts for Researchers Who Don't Report Clinical-Trial Data,”](#) *Washington Post*

[“Driver Mutations in Uveal Melanoma,”](#) *JAMA Ophthalmology*

[“Cancer Drug Keytruda Keeps Some Patients Alive For 3 Years,”](#) NBC News

[“A Scientist's Dream Fulfilled: Harnessing The Immune System To Fight Cancer,”](#) NPR.org

[“First Ocular Melanoma Test Results Normal,”](#) *The Herald Weekly*

[“Rare Eye Disease that Struck Oliver Sacks Gives Rise to New Cancer Treatment Strategy,”](#) MedicalXpress.com

[“Beyond Cancer Podcast – Episode #2: Fear and ‘Scanxiety’,”](#) Dana Farber Cancer Institute Blog

[“Meet Bayern Ryan, the U.S. Super Fan Who Painted the Club Logo on his Glass Eye,”](#) Goal.com