



Update on the CURE OM Patient Reported Registry

The Melanoma Research Foundation's (MRF) CURE OM initiative is, at its core, led by and dedicated to members of the ocular melanoma community. In 2011, CURE OM was co-founded by an ocular melanoma patient and caregiver, husband and wife team, Dr. Gregg Stracks and Dr. Sara Selig, and in every moment since the voices of OM patients, survivors and caregivers have guided the important work of this initiative.

A particularly exciting example of this patient-centric work occurred at the 2016 Eyes on a Cure: Patient and Caregiver Symposium. Following in-depth discussions between researchers, physicians, patients and their loved ones, a national patient-reported registry was determined to be an essential step in advancing OM research and providing critical data on the natural history of the disease thus leading to better treatment options. At that meeting, the MRF's CURE OM initiative committed to leading a project to develop this resource.

Recognizing that this first-of-its-kind patient registry would be a complex undertaking, the first step required two critical elements: funding and expertise. For the former, we looked to our supporters and they responded in a way that is a testament to the eager and unmatched dedication of this community. Through the [#CUREOM Unite!](#) campaign, together we raised \$100,000 in seed funding needed to initiate the development of the registry. This funding was designated to first recruit and assemble the registry team and hire a consultant with expertise in this area. Fundamental to the success of the project is to ensure this patient-centered research initiative is carried out in accordance with best practices in rare disease registries. These include defining clear objectives; identifying a committee of experts to advise on the development; assessing platform providers to build technological programs and host them; engaging with international partner organizations; and conducting surveys to solicit expert opinion from the patient community and other stakeholders. These steps, along with others, are all required to lay the framework for the registry design, development and launch.

To build our registry team, we sought a project leader with extensive knowledge of patient-reported registries. With over 15 years of experience in clinical research as well as several years of experience leading research and registry efforts at the National Organization of Rare Diseases (NORD) and partner organizations, [Jacqueline Kraska](#) was perfect for this important role and we enthusiastically hired her to guide the team. As this is a community-guided project, a panel of patients, caregivers, CURE OM staff and ocular melanoma experts were recruited to join Jacqueline and form the [Patient Registry Steering Committee](#). This committee meets regularly to review their progress and guide the next steps in the project.

As this first phase comes to completion, we recognize that much of the extensive work has taken place behind the scenes. A [comprehensive update](#) of our progress was presented in April at the CURE OM Symposium, and included the key accomplishments listed below.

After securing startup funding and assembling the project team, we have:

- Identified international resources and additional subject matter experts to collaborate on the project.

- Closely assessed multiple existing registries and platform providers, studying models from the non-profit, private and academic sectors.
- Conducted a thorough questionnaire that gathered patient community input to direct key elements of the registry design.
- Launched a partnership with an academic, multi-center study of researcher reported registries.
- Development of the registry protocol and data set is underway by the Patient Registry Steering Committee.
- Developed an online library of resources to support the project and the registry team.
- Identified key industry partners and hosted discussions about ongoing collaborations and corporate sponsorships to provide long-term registry funding.

To date, this work has used approximately 57% of the initial funding and the remaining funds will be applied to the final tasks of set-up and the launch of the registry. Looking ahead and drawing ever closer to the launch of the CURE OM Patient Registry, we anticipate the completion of some exciting steps in the coming months. Among these will be the Steering Committee's completion of the Institutional Review Board (IRB)-approved registry protocol and data set, training sessions with the technology provider and finalizing funding agreements for long-term registry hosting and maintenance. Multi-year funding has been budgeted at approximately \$300,000 per year, and multiple industry partners have communicated strong interest in providing this financial support. Formal proposals have been submitted to these organizations and we will share further information as the agreements are finalized. With these final details in place, CURE OM will publish an online educational webinar for the patient community to explain the registry and how to participate, as well as important data management and sharing policies to ensure total patient safety and confidentiality.

While the launch of the CURE OM Patient Reported Registry will represent successful project completion for the hundreds of individuals who have worked incredibly hard to support this program, in truth it is only the beginning. The data collected by this registry in the coming months and years will revolutionize the scientific community's ability to access information, collaborate in research and accelerate the pace of treatment development. This is why these foundational steps are so critical and require a thoughtful and thorough process. This registry represents a transformative moment for those fighting ocular melanoma, and the MRF's CURE OM initiative is both exceedingly proud and immensely grateful for the incredible patient, caregiver, provider, and research communities whose contributions, together, will lead us to a cure.

We look forward to sharing additional updates as the project moves toward completion and welcome any questions or feedback that you have at cureom@melanoma.org.

Sincerely,



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