



The Patient-Powered Platform Focused on a Cure

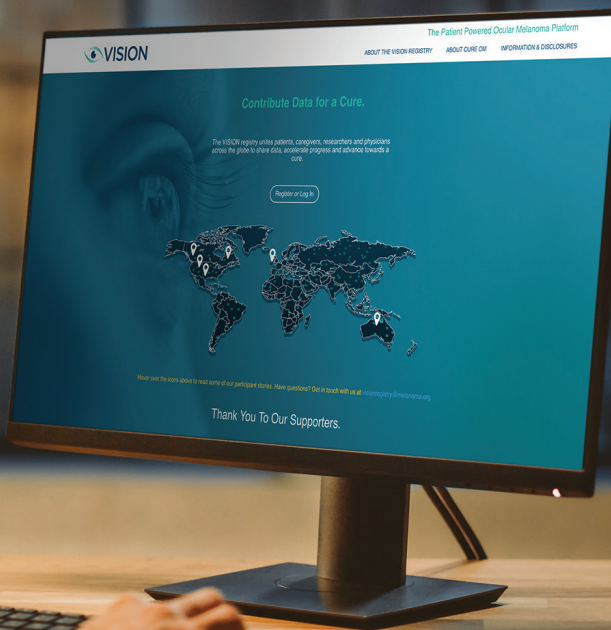


MRF MELANOMA
RESEARCH
FOUNDATION

CURE OCULAR MELANOMA

The VISION Platform

Patients, caregivers, researchers, and clinicians around the world are uniting to advance ocular melanoma (OM) research, provide support, inspire hope, and change the course of OM forever.



About the MRF

The **Melanoma Research Foundation (MRF)** is the largest independent organization devoted to melanoma. Committed to the support of medical research to develop effective treatments and eventually a cure for all forms of melanoma. The MRF also educates patients and physicians about the prevention, diagnosis and treatment of melanoma. The MRF is a dedicated advocate for the melanoma community, helping to raise awareness of this disease and the need for a cure.

About the VISION Platform

The **Virtual Information System to Improve Outcomes and Networks (VISION) Platform** was built in collaboration with patients, researchers and clinicians to create a central place for the OM community to come together, support one another and share their knowledge and experience to advance research. In addition to advancing research through the VISION Registry, the Platform has a number of useful resources for patients and caregivers including a secure discussion forum as well as a clinical trial connector tool.

About the MRF's CURE OM Initiative

Ocular melanoma (OM) develops in the eye and is the most common form of eye cancer in adults and the second most common type of melanoma. Approximately 2,000 Americans and more than 5,000 people globally are diagnosed each year, with thousands more living with the disease. In about half of all OM cases, the disease will spread to other parts of the body. When this occurs, it is almost always fatal. CURE OM (Community United for Research and Education of Ocular Melanoma) was established under the umbrella of the MRF by an OM patient and caregiver in 2011 to accelerate research, find new and effective treatment options and to increase awareness, education and support of patients, clinicians and researchers.

To date, CURE OM has funded over \$2.1 million in ocular melanoma research and pioneered international collaborations, innovative patient support resources and patient-powered scientific initiatives like VISION.

“The FDA increasingly looks to patients to understand how patients describe their health status, because patients are the experts in living with their disease or condition.”

US FOOD AND DRUG ADMINISTRATION (FDA)

“Empowering patients in research means recognizing them as full and equal partners, developers and funders of research in Rare Diseases.”

EURORDIS, RARE DISEASES EUROPE “THE VOICE OF RARE DISEASE PATIENTS IN EUROPE”

Uniting the Global OM Community

The creation of an innovative online platform for the global OM community provides a central place where dispersed patients and their caregivers from around the world can access disease-specific resources and tools and share their knowledge and experiences.

The VISION Registry

The VISION Registry was developed in collaboration with patients, caregivers, researchers and clinicians and is a patient-reported, patient-powered online database designed for patients to share their experiences with OM. Patients fill in a series of surveys that capture their journeys with OM.

Participants can complete the surveys at their own pace and are encouraged to update their records periodically. The Registry has ethical oversight by a central Institutional Review Board (IRB) and the highest standards of security and governance.



How It Works

It is easy to participate. All participants start by registering at visionregistry.org and completing a personal profile that includes selecting preferences for their involvement with VISION. They will then be directed to the VISION dashboard where the Registry surveys and all its tools and resources are housed.



VISION Discussion Forum

The VISION Discussion Forum is a private and safe online forum where the OM community can ask questions, connect and share their experiences and knowledge of OM. There is one forum for patients and caregivers and one for clinicians and researchers. Both forums encourage mutual support for participants and facilitate open and productive conversations.

Why Join the VISION Platform?

- 1** VISION is a **free resource** with information and tools for OM patients and caregivers worldwide.

- 2** VISION provides a **central place** for the global OM community to meet and support one another.

- 3** VISION houses the **patient-reported VISION Registry** which has the power to help reveal disease patterns and potential causes, help improve patient experiences and outcomes, and eventually find a cure for OM.

“It is astonishing to me that the secrets of this cancer are taking so long to unravel. Our very small numbers are certainly to blame so we should all summon up the courage to stand up and be counted. Let’s stand together, work together, and hope to live. Please put your heart into telling your story. Take a moment, however long it takes, to record the history of your disease in the VISION Registry. It will make a difference.”

NIGEL DEACON, OM PATIENT AND VISION REGISTRY PARTICIPANT



Who Should Join?

All OM patients and their caregivers are especially encouraged to participate as they are at the heart of VISION. In addition, all healthcare professionals who would like to experience VISION for themselves are welcome to register as a collaborator. Finally, researchers who are interested in utilizing the data can join as a collaborator and request to have de-identified reports shared with them. All participation is welcome and entirely voluntary.

“Alongside dedicated researchers and physicians working towards new treatment breakthroughs, OM patients and caregivers have always been vital partners in identifying priorities and advancing our understanding of this disease. After witnessing their commitment to the development and launch of the VISION Registry, I have never been more confident that OM patients and those who love them will lead us to a cure.”

SARA SELIG, MD, MPH, CO-FOUNDER AND DIRECTOR OF THE CURE OM INITIATIVE

VISION Clinical Trial Connector

The VISION Clinical Trial Connector is a user-friendly tool built for patients to help identify clinical trials for which they may be eligible. The tool draws from personal patient information entered into the VISION Registry and combines this with information from clinicaltrials.gov.





www.cureom.org



The Patient-Powered Platform Focused on a Cure

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