MRF Melanoma Research Foundation





Melanoma is relentless—but so are we. At the Melanoma Research Foundation (MRF), we know that clinical trials are essential in the fight to turn the tide on this disease. They are where hope meets science, and where tomorrow's treatments begin today.

Clinical trials are more than a research mechanism, they're a lifeline. For patients with advanced, rare, or treatment-resistant melanoma, clinical trials often provide access to groundbreaking therapies that are not yet widely available. These studies pave the way for new immunotherapies, targeted treatments and combination strategies that can change—and even save—lives.

Participating in a clinical trial means contributing to research that could improve outcomes for yourself and for future patients.

Access Made Easy: The Clinical Trial Finder Tool

Finding a clinical trial that's right for you or your loved one shouldn't feel overwhelming. That's why the MRF offers the Clinical Trial Finder Tool—an easy-to-use, personalized resource that helps connect patients to actively recruiting studies based on their melanoma subtype, diagnosis, treatment history, geographic location and more.

Whether you're newly diagnosed or exploring additional options after standard therapies, our tool empowers you to take an active role in your care and find opportunities that might make a difference.

A Critical Time: How the Federal Government Shutdown Impacts Clinical Trials

The importance of clinical trials is now clearer than ever—but so is their vulnerability. During a federal government shutdown, the clinical research ecosystem faces serious disruptions, including:

· Delays in new trial approvals and launches

· Interruptions in trial staffing and oversight at federally funded institutions

· Reduced patient access to government-supported studies

· Backlogs at the FDA, slowing down promising treatment reviews

If you are a patient with questions about access to clinical trial sites at federally funded institutions, reach out to education@melanoma.org.

These setbacks don't just affect researchers, they impact patients. When trials stall, so does progress. That's why continued advocacy and awareness are critical during these times.

Advocating for Continued Progress

The MRF's Advocacy and Policy Team is actively engaging with lawmakers and agencies to underscore the importance of uninterrupted clinical trial operations. We're fighting to protect the future of melanoma research and ensure that no patient's access to care is compromised.

Want to learn more? Read our FAQ on the Shutdown's Impact on Melanoma Patients and Research here.

Be a Part of Progress

Whether you're a patient, caregiver or supporter, you can make a difference:

· Use our Clinical Trial Finder Tool to explore your options or share it with someone who needs it.

· Speak to your care team about whether a trial could be right for you.

· Join our advocacy efforts – TAKE ACTION to help protect melanoma research funding and patient access to clinical trials.

Together, we can ensure that clinical trials continue to bring hope, healing and innovation to the melanoma community.



Kyleigh LiPira, MBA

CEO

Adam Kautzner's Life-Changing Clinical Trial Experience



More than a decade ago, Adam Kautzner, PharmD, President of Evernorth Care Management and Express Scripts, was diagnosed with stage IV melanoma after exhausting all available treatment options. His only hope was a clinical trial, and it saved his life. The therapy tested in that trial is now part of today's standard of care, made possible by continued investment in melanoma research. Adam's story is a powerful reminder of why funding research is vital: every discovery, every clinical trial, brings us closer to new treatments and more survivors. Click below to read Adam's full story and learn how your support helps move life-saving research forward.

Read Full Story

FDA UPDATE
RP1



In the July edition of the SPOTlight, we announced the Federal Drug Administration's (FDA) decision to not approve the pioneering treatment known as RP1 (vusolimogene oderparepvec) in combination with nivolumab (Opdivo) in its current form. The decision was issued via a complete response letter regarding the RP1 sponsor's Biologics License Application (BLA). The MRF received hundreds of responses from you, the patient community, expressing frustration and concern with efforts to thwart this promising and innovative therapy.

We are excited to share that this month the FDA accepted the resubmission of the BLA for RP1 paving the way for more hope for many stage IV melanoma patients and their families. RP1 addresses the unmet medical need in patients with advanced melanoma who have progressed after PD1 therapies and offers hope to patients with limited treatment options. We will continue to provide pertinent updates.



Honoring Courageous Melanoma Patients at the 24th Annual New York Gala, Tomorrow!

Each October, the MRF honors the melanoma community including patients, caregivers, researchers and clinicians at the New York Gala, and we are elated to welcome all on October 30 for an evening of inspiration and hope! Tomorrow we will honor three brave melanoma warriors with Courage Awards, including: Jimmy Hexter, Dr. Allie Dashow and Amy Lipin. Each patient has been tremendously impacted by melanoma but through sharing their remarkable stories, they are driving awareness around melanoma and fostering financial support for critical research.

Jimmy Hexter was diagnosed with mucosal melanoma, a rare and aggressive form of melanoma, during a routine dental visit. He relied on chemotherapy, a regimen that included IV and oral treatments in 21-day cycles until his melanoma returned to his lymph nodes. Jimmy turned to immunotherapy to treat the recurrence and has been in remission since 2022. Dr. Allie Dashow was diagnosed with choroidal melanoma, a rare form of ocular melanoma that affects the choroid, in 2022. Allie underwent plaque brachytherapy to radiate her tumor, though she developed radiation retinopathy approximately one year after diagnosis. Allie still undergoes frequent anti-VEGF injections to slow down disease progression and is regularly scanned to ensure her melanoma has not spread. Amy Lipin was diagnosed with acral amelanotic melanoma on her palm in 2005 and the melanoma spread to her lymph nodes in 2017 and ultimately to her brain in 2018. Amy relied on several therapies including surgery, Gamma Knife sessions targeting her brain tumors and immunotherapy to ultimately treat her melanoma.

We encourage you to learn more about these incredible warriors and to help continue funding for more innovative clinical trials, treatments and hope for others facing melanoma. Click below to donate to the MRF's 24th Annual New York Gala and make a difference today!

Purchase a Ticket or Donate Today!

The 5th Annual #GetNakedJax Enables Hope for the Melanoma Community!



What an inspiring event in Jacksonville! Thanks to your generosity, the 5th Annual #GetNakedJax, presented by Dream Finders Homes, raised an incredible $228,520 (and counting!) to fund groundbreaking melanoma research that brings us closer to better treatments and more survivors.

We were honored to hear from Bill Daley, a Stage IV melanoma patient now NED (no evidence of disease), whose powerful story reminded us exactly why this work matters, research saves lives. Funds raised will support 2025 Career Development Awardee, Dr. Dan Erkes of Thomas Jefferson University, whose innovative study is exploring ways to reduce the side effects of immunotherapy and help patients tolerate treatment longer with stronger outcomes. There's still time to make an impact — every dollar fuels life-saving research and hope for those facing melanoma. Click below to donate and help us continue driving progress toward a cure.

Donate Today!

Education Corner

Understanding Mucosal Melanoma: Advancing Research, Treatment and Hope in our Latest Ask the Expert



Kasey L. Couts, PhD

Assistant Professor; Co-Director, CU Center for Rare Melanomas; Assistant Director, CU Skin Cancer Biorepository



Toni English

Patient Advocate, Mucosal Melanoma Warriors Foundation

ASK THE EXPERT

Mucosal Melanoma – Current and Emerging Treatments, Research and Patient Perspectives

October 16, 2025 **7:00 PM ET**

If you missed our recent Ask the Expert webinar, "Mucosal Melanoma: Current and Emerging Treatments, Research and Patient Perspectives," the full recording is now available to watch! This educational session explores one of the rarest and most challenging melanoma subtypes, mucosal melanoma, offering both scientific insight and lived patient experience. Kasey L. Couts, PhD, Assistant Professor and Co-Director of the CU Center for Rare Melanomas, shared informative updates on treatment advances and emerging research. Toni English, a stage IV mucosal melanoma survivor, shared her deeply personal story of hope and survivorship after participating in a lifesaving clinical trial.

Together, they shed light on how science and advocacy are driving progress for patients facing this rare form of melanoma.

Watch Here

Registration Now Open: Together Against Melanoma Symposium at Saint John's Cancer Institute, Santa Monica, CA



Knowledge, connection and support can make all the difference throughout the melanoma journey. Join the MRF and Saint John's Cancer Institute in Santa Monica, CA on November 22 for the next Together Against Melanoma: Patient & Caregiver Symposium, a special event created for the melanoma community.

This in-person and virtual program will bring together patients, caregivers and clinicians to explore the latest advances in melanoma diagnosis, treatment and supportive care. Attendees will hear from leading experts, connect with others who understand their experience and gain tools to help navigate their melanoma journey.

Learn More

Patient Forum: Foster Community, Share Milestones, and Discover Resources in the MRF's Patient Forum



The MRF Patient Forum is a safe, supportive space for patients, survivors and caregivers to connect, share and learn from one another. Whether you're celebrating a milestone like a clear scan or birthday, taking a mindful moment to breathe and reflect, or exploring the latest resources and educational materials, the Forum offers a place to find encouragement and community.

Members can exchange experiences, discover wellness tools and take part in conversations about future Ask the Expert topics and MRF initiatives. It's also a welcoming space for those navigating rare melanoma subtypes, fostering understanding and connection among peers who truly get it. Join today and be part of a community that listens, supports and grows together.

MRF Patient Forum

Stepping into the Home Stretch: Miles for Melanoma 5K Events



We're heading into the home stretch of our Miles for Melanoma 5K season and there's still time to join the movement! Lace up and be part of the journey in Atlanta, GA (Nov 2), San Francisco, CA (Nov 16), Tampa Bay, FL (Dec 6) and Fort Myers, FL (Dec 13). Plus, we're not done yet: Miami, FL and Orange County, CA 5Ks are coming this February, with registration opening next month! Don't wait and sign up today, rally your team and earn exciting incentives while helping fund life-saving melanoma research and patient support.

Register Today!



Research Grantee Announcement: Central Nervous System (CNS) Brain Mets Collaboration

The MRF and the entire Metastatic Brain Tumor Collaborative (MBTC) are proud to announce the first-ever CNS Metastasis Research Grantees—a milestone in advancing research for the more than 200,000 patients in the US affected by CNS metastases each year. Through the MBTC, two investigators have each been awarded $50,000 grants for projects focused on improving the diagnosis, treatment and understanding of CNS metastases. This grant marks an important step forward in accelerating progress through collective impact. Learn more about each award here.

We Invite the Ocular Melanoma Community to Attend the Australian Ocular Melanoma Alliance (AOMA) Summit



Ocular melanoma (OM) patients, caregivers, clinicians and researchers are invited to join the AOMA 2025 Virtual Summit on Saturday, November 8—a global event dedicated to advancing care, research and hope for the OM community.

Hosted by Melanoma and Skin Cancer (MASC) Trials and the Australasian Ocular Melanoma Alliance (AOMA), this free virtual event brings together leading experts and inspiring patient voices from around the world. Participants will explore the latest updates in clinical trials, treatment advances and research discoveries shaping the future of OM care. Register now to be part of this international conversation.

Register Here

Upcoming Events

October 30: 24th Annual New York Gala

November 2: Atlanta Miles for Melanoma

In the News

FDA Accepts Resubmission of BLA for RP1/Nivolumab in Advanced Melanoma - *Cancer Network*

November 9: Brain Metastases Summit 4.0

November 13: DC Wings of Hope Reception

November 16: San Francisco Miles for Melanoma

November 22: Saint John's Cancer Institute Patient & Caregiver Symposium

December 6: Tampa Bay Miles for Melanoma

December 13: Fort Myers Miles for Melanoma

Metastatic Brain Tumor Collaborative Announces First-Ever Collaborative Grant Opportunity Focused on CNS Metastasis - *Yahoo*

A Memoir That Dares to Hope – Discover the Power of Survival in "Terminal Hope" by Cheryl Stratosv - *The Cine Talk*

New Genomic Test Could Spare Some People with Melanoma From Lymph Node Biopsy Surgery - *Mayo Clinic*

How You Can Prevent Skin Cancer - *Cleveland Clinic*

Is Your Commute Putting You at Risk of Skin Cancer? - *Health Central*



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The Melanoma Research Foundation (MRF) is leading the melanoma community to transform melanoma from one of the deadliest cancers to one of the most treatable through research, education and advocacy.

The Melanoma Research Foundation is a 501(c)(3) non-profit organization.

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