MRF Melanoma Research Foundation



FDA UPDATES RP1 AND DECISIONDX-MELANOMA



Last week, the Federal Drug Administration (FDA) initiated two decisions – let's dive into the impact for the melanoma community and how you can lend your voice to help foster continued treatment progress.

On Tuesday, July 22, the FDA issued a complete response letter regarding a Biologics License Application for a promising new treatment intended for advanced melanoma patients. The pioneering treatment known as RP1 (vusolimogene oderparepvec) in combination with nivolumab (Opdivo) was not approved by the FDA in its current form, despite showing positive results for patients who had failed first-line therapy. While the FDA has stated no safety concerns related to RP1, the sponsor will have to address several items the FDA has raised about the IGNYTE study design. As a patient advocacy organization, the MRF is deeply concerned by the FDA's decision to not approve this promising treatment that may benefit countless melanoma patients.

The MRF invites patients living with advanced melanoma who did not respond to or have stopped responding to current therapies, those who received RP1 + nivolumab as part of a clinical trial, those who lack access to a viable treatment option and any others who have been impacted to submit their story. The MRF has partnered with other advocacy groups (AIM at Melanoma, Melanoma Research Alliance, Impact Melanoma, Cancer Support Community, Cancer Care) to share these stories as a united advocacy community to urge the FDA to reverse this decision.

Submit Your Story

In promising news, on Wednesday, July 23, the FDA granted Breakthrough Device designation for Castle Bioscience's DecisionDx-Melanoma test, an innovative gene expression profile (GEP) test that evaluates 31 genes in primary cutaneous melanoma tumor tissue to understand an individual's patient's risk. This test helps clinicians, particularly dermatologists, understand the likelihood of sentinel lymph node (SLN) metastasis and recurrence and develop treatment plans that improve patient outcomes and reduce morbidity.

According to the FDA, Breakthrough Device designations are granted to select qualifying devices that may offer improved treatments or diagnosis of life-threatening or irreversibly debilitating diseases when compared to currently available alternatives. Furthermore, the designation speeds up medical device development, assessment and review. To read more about the DecisionDX-Melanoma test, click here.

Kyleigh LiPira, MBA

CEO

MRF-Funded Researcher Milad Ibrahim, PhD Featured in *Cancer Research* for Innovative Melanoma Study



Although recent treatment innovations such as targeted therapies and immunotherapies have improved outcomes for many melanoma patients, those with neurofibromin 1 (NF1) mutations currently lack effective treatment options. Patients with NF1 mutation have few treatment options when they don't respond to immunotherapy.

A recent study led by 2024 Resident/Fellow awardee Milad Ibrahim, PhD of NYU School of Medicine, identified EGFR as a potential drug target for NF1-mutant melanoma. His findings may pave the way for the development of new treatment options for melanoma patients with NF1 mutation.

Read More Here

The "Big Beautiful Bill" And What It Means For Melanoma

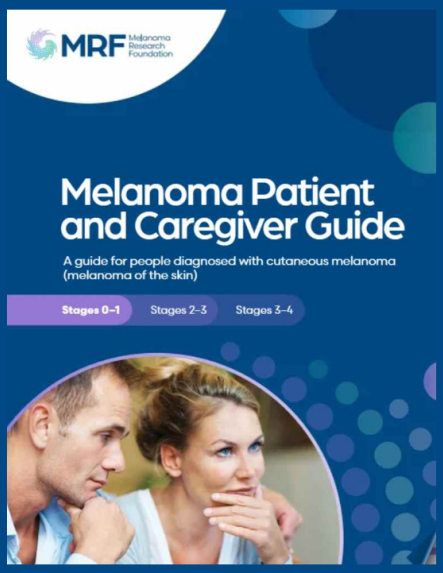


On July 4, President Trump signed HR 1, also known as the "Big Beautiful Bill", into law including sweeping cuts to public health insurance programs and healthcare marketplace insurance plan subsidies. According to the nonpartisan Congressional Budget Office, at least 10.5 million people will lose access to Medicaid, health insurance for low-income Americans, and CHIP, health insurance for low-income children, by 2034 and the Kaiser Health Foundation estimates that number to reach 16 to 17 million when taking into account those who will lose access due to provisions of the bill that reduce access to the Affordable Care Act (ACA), or Obamacare, marketplace subsidies.

A recent article published in the Journal of Clinical Oncology demonstrated the positive impact that Medicaid expansion, or raising the income threshold to 138% of the Federal Poverty Level (FPL) for Medicaid eligibility so that those earning too much to traditionally qualify for Medicaid but not enough to traditionally afford to purchase their own plan on the ACA marketplace could be eligible for Medicaid in states that opted to expand their Medicaid eligibility, had on detecting and treating melanomas at earlier stages. Access to health insurance leads melanoma patients to detecting and treating their melanoma in its earliest and most survivable stages. Like many patient advocacy organizations, the MRF is deeply concerned that this bill will undo decades of progress for patients and lead to loss of coverage, delayed care, and needless loss of life.

While this bill has been signed into law by President Trump, the MRF is continuing to look for solutions to restore access to care for melanoma patients and encourages the melanoma community to share their Medicaid stories with their lawmakers.

Education Corner



We are thrilled to share our newly updated Cutaneous Melanoma Patient & Caregiver Guide: Stages 0–1!

This comprehensive resource is designed to help patients, caregivers and their loved ones better understand the early stages of cutaneous melanoma, including diagnosis, treatment options, follow-up care, prevention education and more. The guide also includes tips for finding support, questions to ask healthcare providers and a glossary of key terms to aid in navigating the melanoma journey with greater confidence and clarity.

Download Melanoma Patient and Caregiver Guide: Stages 0-1

Patient Perspective Panel:

Have you received TIL (Tumor-Infiltrating Lymphocyte) therapy for melanoma? We want to hear from you. The MRF is inviting 10 melanoma patients to join a one-time TIL Cell Therapy Patient Focus Group to share their experiences and help shape future education efforts.

We want to learn:

- How you were introduced to TIL therapy
- What you wish you had known before treatment
- What educational tools would have helped
- Your advice to other patients considering this option

You are eligible to participate if you are a metastatic cutaneous melanoma patient or survivor and you have received AMTAGVI (Lifileucel), the FDA-approved TIL Cell Therapy treatment. The TIL Cell Therapy Patient Focus Group will take place in September and will be held virtually. If you're interested in participating, please email education@melanoma.org by August 15.

Understanding the Psychosocial Impacts of a Melanoma Diagnosis on Family Planning Decision Making

The University of Chicago Medical Center is conducting a study to learn how a melanoma diagnosis may influence family planning decisions.

Individuals who have been diagnosed with melanoma are eligible to participate if they:

- Are over 18
- Live in the United States
- Speak English
- Can carry children

The questionnaire takes approximately 10–20 minutes to complete and includes questions about dermatology history and perceptions of family planning. All responses will be kept confidential. Those who complete the survey will be entered into a raffle for a $25 Amazon gift card. Take the survey here.

Watch Now: Ask the Expert Recaps



What Do the Latest ASCO 25 Findings Mean for Melanoma Patients?

This Ask the Expert webinar featured Dr. Katy Tsai of UCSF Cancer Center, she shared key insights and research highlights from the ASCO Annual Meeting, tailored specifically for the cutaneous melanoma community.

Watch Now



Focusing on the Liver — Treatment Approaches in Metastatic Ocular Melanoma

Learn about the first FDA-approved treatment for ocular melanoma and how physicians are using liver-directed therapies to advance innovative OM care in our recent webinar, sponsored by Delcath Systems, Inc.

Watch Now



What Do the Latest ASCO 2025 Findings Reveal About Advancements in Ocular Melanoma Treatment?

Watch our latest Ask the Expert session with Dr. Inderjit Mehmi as he breaks down key findings from ASCO to help the OM community stay informed and empowered in their treatment and care.

Watch Now



Upcoming National Make-A-Will Month

(Pictured: Christy Dawn Fowler (back right), Will Fowler (back left) and their three daughters' pictured in front)

August is National Make-A-Will Month — a powerful reminder that creating a will isn't just about planning for the future; it's about protecting the people and causes you love most. While the task can seem overwhelming, it's one of the most meaningful ways to ensure your wishes are honored and your legacy lives on.

Many members of the melanoma community have chosen to include the MRF in their estate plans—helping to fund groundbreaking research, support patients and caregivers and bring us closer to a cure. One of those supporters is Will Fowler, who chose to honor his late wife, Christi, in a deeply personal and lasting way.

Christi Dawn Fowler was the kind of person whose laughter could fill a room and whose kindness left a mark on everyone she met. In a moving tribute, Will shares their 24 years of life together—raising five children, dancing in the kitchen and navigating Christi's seven-year battle with melanoma. Despite a late diagnosis and a long road through countless treatments and clinical trials, Christi faced every challenge with grace and strength. Since her passing in 2018, her legacy has lived on—in their children, their grandson and a willow tree planted in her honor that now stands over 40 feet tall. Including the MRF in his estate plan was Will's way of continuing Christi's lifelong commitment to giving. As he shared, "Christi's still fighting—just from a different angle now." Click below to read his full story.

Read Will Fowler's Full Story

Their story is a powerful testament to how a planned gift can keep a legacy alive and create real impact for future generations.

To make creating your will easier, the MRF has partnered with FreeWill, a free and trusted tool that helps you write a legally valid will in just 20 minutes. If you have questions or would like more information, please reach out to Dave at dwiemer@melanoma.org.

Create Your Free Will Today

Get Ready – Miles for Melanoma Is Just Getting Started!



Our Miles for Melanoma 5K season is on fire! We're thrilled to share that our Chicago event this month raised an impressive $87,562 — and there's still time to help them reach their $100,000 goal! Donations remain open until August 20, so click here to support the Chicago melanoma community and make a lasting impact.

Next up, we're heading to Cleveland (August 3), Twin Cities (August 10), Philadelphia (August 23), New York City (September 13), New Jersey (September 21), Seattle (October 4), Los Angeles (October 5) and San Diego (October 18). Now's the time to build your team, start fundraising and step up for melanoma awareness, research and support. Every dollar moves us closer to a cure — join us and help make a difference!

Register Now



Patty Pophal's Interview with New Day Cleveland and Apex Skin!

Patty Pophal, MRF Board Member and Cleveland Event Chair, has been a driving force behind the Cleveland Miles for Melanoma community, leading the charge toward an ambitious goal of raising over $130,000 for critical melanoma research. In a recent interview with New Day Cleveland and Apex Skin, Patty shares what fuels her passion for this cause and why she's calling on others to join the movement—by participating, donating and spreading awareness. Watch the full interview below and see how you can help make an impact.

Watch Full Interview

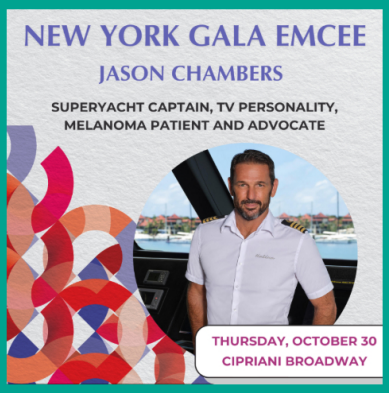
Celebrate Strength and Progress at the Denver Gala!



The countdown is on! We're just under two months away from the unforgettable 14th Annual Denver Gala on Thursday, October 18 at Asterisk Denver. This inspiring evening will shine a spotlight on progress, purpose and the people powering our mission. We're thrilled to welcome Jacquie Palisi, Mrs. Legacy United USA and a courageous melanoma warrior, as this year's emcee. Jacquie brings a compelling voice, unwavering passion and a deeply personal story that will resonate with all. Click here to watch her message and hear how her melanoma journey fuels her drive to raise awareness and inspire change. This gala is more

than a celebration—it's a call to action. Together, we'll raise critical funds to support research, patient education and advocacy efforts that bring us closer to a cure. Secure your ticket or sponsorship today and be a part of an evening that truly makes a difference.

Purchase a Ticket or Sponsorship



Jason Chambers to Emcee the 24th Annual New York Gala!

We're thrilled to welcome Superyacht Captain, TV personality, melanoma patient and advocate, Jason Chambers, as the emcee for our 24th Annual New York Gala, taking place on Thursday, October 30 at Cipriani Broadway. With heartfelt purpose and an inspiring story, Jason brings energy and authenticity to the stage. Click here to watch his message—hear why he's thrilled o be part of the event, the incredible support he received after his diagnosis and why advancing melanoma research and awareness is more important than ever. This inspiring evening will honor the melanoma community — from brave patients and dedicated caregivers to pioneering clinicians — while raising critical funds to support groundbreaking research and treatment advancements.

We're also proud to have our 2025 #GetNaked Spokesperson, Ian Michael Crumm, join us as Gala Co-Chair. Hear from Ian about why this event is so meaningful to him and why he encourages you to join us by purchasing your ticket or sponsorship today.

Purchase a Ticket or Sponsorship



Save the Date for 2026 Advocacy Days: March 1–3 | Washington, DC

Join melanoma patients, caregivers, advocates and supporters from across the country for the next Advocacy Days. Help advance melanoma advocacy by connecting with lawmakers on Capitol Hill and sharing your story.

Registration opens soon, stay tuned and check back on our event page.

Sign up for Advocacy Action Alerts

Upcoming Events

August 3: Cleveland Miles for Melanoma

August 10: Twin Cities Miles for Melanoma

August 23: Philadelphia Miles for Melanoma

September 13: New York Miles for Melanoma

September 18: 14th Annual Denver Gala

In the News

A Miss Universe who thought it was just a mole, a college cheerleader who loved to tan: 4 women on having melanoma - *Yahoo!Life*

Mineral v chemical sunscreen: Which one should you be using? - *BBC*

Medical Student Organizes Annual Pickleball Tournament to Raise Funds for Melanoma Research - *Georgetown University*

September 21: New Jersey Miles for Melanoma

October 4: Seattle Miles for Melanoma

October 5: Los Angeles Miles for Melanoma

October 16: 5th Annual #GetNakedJax

October 18: San Diego Miles for Melanoma

October 30: 24th Annual New York Gala

Fox 8 News/New Day Cleveland: Miles for Melanoma - *Fox 8*

Teddi Mellencamp's Health Ups and Downs: Skin Cancer Battle and More - *US Weekly*

Rethinking Skin Cancer: It's Time to Double Down on Prevention - *Global Health Now*

Skin cancer prevention expert on the importance of sunscreen - *The Harvard T.H. Chan School of Public Health*

Incidence and Factors Associated With Second Primary Invasive Melanoma in Norway - *Jama Network*

Psychosocial wellbeing in people with melanoma in-situ: a systematic review - *Melanoma Research*



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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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