



Melanoma Research Alliance's RARE Registry for Acral & Mucosal Melanoma Surpasses Industry-Leading 100-Patient Milestone

WASHINGTON, D.C., July 10, 2023 – The Melanoma Research Alliance (MRA), the largest non-profit funder of melanoma research, today announced that the [RARE Registry](#) for acral and mucosal melanoma has officially surpassed 100 patients, making it the largest registry of its kind in the world and marking an important milestone in advancing cutting-edge research for these rare and difficult-to-treat melanoma subtypes.

The MRA began work in 2020 to launch RARE, a direct-to-patient interactive portal, to advance its mission of accelerating treatment options, supporting cutting-edge research and ultimately finding a cure for all types of melanomas.

While roughly 90% of melanomas form on sun-exposed skin, rare melanoma subtypes, such as acral and mucosal, form in parts of the body that are shielded from the sun such as the palms of hands, soles of feet, under fingernails, or in mucosal linings of different tissues. Approximately 5,000 patients are diagnosed with these melanoma subtypes annually, and due to their obscurity, patients often face later detection and poorer prognoses, despite positive advancements for treatments for cutaneous melanoma in the last decade. What's more, people of color are also disproportionately affected by acral melanoma, largely due to the misconception that melanoma only impacts people with lighter skin and lighter colored eyes. The lack of awareness around rare melanomas compounded with misconceptions about the risks of melanoma makes the registry even more vital for these underrepresented populations.

"We started the RARE Registry to bridge this divide and address the unmet needs of the rare melanoma community, from patients and caregivers to leading researchers and physicians. There's power and strength in each individual facing a rare melanoma sharing their story, and we're so grateful to the patients so far who are already driving this critical research forward," shared Dr. Joan Levy, Chief Science Officer of the MRA and co-principal investigator of RARE.

Through the RARE web portal, patients provide information on their demographics, diagnosis, treatment history, lifestyle and quality of life factors. All information collected is de-identified and made available through an open-access portal so that researchers and clinicians gain key insights into tumor genomics, epidemiology, diagnosis pathways, treatment effectiveness, adverse events, natural history of disease and risk factors. While other registries are focused on a single point in time, RARE encourages patients to continuously update the registry with new information.

"Because acral and mucosal melanoma are so rare, every single patient participant and data point they're willing to provide about their melanoma journey has the potential to help researchers better understand the origins of the disease and most promising treatments. This is just the beginning of our fight to ensure rare melanoma patients are no longer left behind in the mission to end suffering due to melanoma," says MRA Chief Executive Officer Marc Hurlbert, PhD.

In addition to launching the RARE Registry, MRA has invested more than [\\$18,575,000 through 45 research awards](#) specifically focused on all rare melanoma subtypes to spur the field. MRA has also advanced understanding of rare melanomas by regularly bringing together researchers and patient advocates to share findings and progress, produced a review article highlighting gaps in existing pre-clinical models, and fostered collaboration between cancer centers and academic institutions through innovative partnerships.

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About Melanoma Research Alliance (MRA)

The Melanoma Research Alliance (MRA) stands as the largest non-profit funder of melanoma research. Founded in 2007 by Debra and Leon Black, MRA's mission is to end suffering and death due to melanoma by advancing the world's most promising science and research. MRA provides critical funding for melanoma cancer research that propels advances in prevention, diagnosis, treatment, metastasis, and survivorship. MRA-funded researchers have been behind every major melanoma research breakthrough. Since MRA's inception, more than 15 new therapeutic approaches for melanoma have earned FDA approval. MRA is recognized as one of the most fiscally efficient non-profits in the country. Because the Black Family generously underwrites 100% of MRA's administrative and operating costs, every dollar donated is invested directly into MRA's scientific and research program. For more information, please visit: www.CureMelanoma.org.

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