Highlighting Patient Voices in Rare Melanoma Research

Data about rare skin cancers was highlighted at this year's Journal of the Advanced Practitioner in Oncology (JADPRO) Annual Meeting.

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When it comes to melanoma — the deadliest form of skin cancer — around 90% of cases are linked to ultraviolet (UV) radiation from the sun or indoor tanning devices and are known as cutaneous melanoma. The remaining 10% represent the rare melanoma subtypes: acral, mucosal, and uveal melanoma. These subtypes arise in areas rarely exposed to UV rays, such as the palms, soles, nail beds, mucosal linings, and eyes. Though less common, patients with these subtypes often face delayed diagnoses, fewer treatment options, and poorer outcomes than those with cutaneous melanoma.

Recognizing these challenges, the Melanoma Research Alliance (MRA) has made advancing rare melanoma research a priority. MRA is the largest nonprofit funder of rare melanoma research globally, and to date has invested over $22 million in this area. Beyond funding, MRA has developed tools like the Acral, Mucosal, and Uveal Melanoma Model Catalogs to facilitate preclinical research and collaboration across the melanoma research community.

Building on this commitment, MRA's efforts to advance rare melanoma research were highlighted at this year's Journal of the Advanced Practitioner in Oncology (JADPRO) Annual Meeting. There, MRA's Associate Director of Rare Melanoma Research Dr. Jessica Scales presented data and insights from one of the organization's core initiatives: the RARE Registry — a patient-powered effort designed to close critical knowledge gaps in rare melanoma research.

A Collaborative Approach to Understanding Rare Melanomas

Launched in October 2022, MRA's RARE Registry is the first direct-to-patient registry dedicated to acral and mucosal melanoma, including participation from individuals with cutaneous melanoma to help broaden understanding and contextualize findings across the subtypes.

The RARE Registry is more than just a database — it's an evolving collaboration inspired by patient

advocates who wanted to bring greater visibility and research attention to these rare and often misunderstood melanoma subtypes. From its inception, the effort has been guided by an Oversight Committee composed of patients, caregivers, and medical advisors who help ensure that every decision centers on bridging the divide.

“The RARE Registry Oversight Committee brings the patient perspective to every stage of the registry’s development,” shared Dr. Scales “Their collective input draws attention to critical yet potentially overlooked challenges faced by patients diagnosed with these rare melanoma subtypes. These perspectives are essential for how the RARE Registry operates in order improve health outcomes and quality of life for patients.”

RARE Registry participants are asked to complete eight detailed surveys that capture data on demographics, disease and treatment history, genetic and biomarker testing, and health and quality of life. Participants can also share their medical records – either manually or through an electronic health record (EHR) integration tool – to validate and enrich their self-reported data.

Turning Data into Rare Melanoma Discovery

Three years after its launch, the RARE Registry has grown to include 625 participants, including:

- 219 with mucosal melanoma (MM)
- 180 with acral melanoma (AM)
- 226 with cutaneous melanoma (CM)

This allows for data analysis across cohorts and within each subtype, using tools like R and Tableau to visualize trends and uncover patterns.

Accompanying charts in Dr. Scales’ poster illustrated early findings from this growing dataset:

Details gathered from the RARE Registry on rare melanomasCourtesy of CureMelanoma.org

Check out Dr. Scales full poster!

Data from the RARE Registry is already shaping new questions and collaborations. This approach aims to help bridge a major gap: rare melanoma research has historically been hindered by small patient cohorts and limited access to data. By empowering patients to share their experiences directly, MRA is creating a resource that accelerates research while keeping patients at the center.

“As the RARE Registry expands, its integration of patient-reported, clinical, and genomic data will enhance our understanding of the biology of these rare melanoma subtypes and enable a more personalized approach for treatment and disease management for patients worldwide,” said Dr. Scales.

Building the Future of Rare Melanoma Research

MRA is building on the registry’s foundation with two major initiatives:

- A biorepository, designed to collect both archived and prospective tissue samples from melanoma patients, launching in the final months of 2025.

- A research portal, where clinicians and scientists can access de-identified patient-reported, clinically abstracted, and molecular data to fuel new discoveries.

Together, these developments illustrate the RARE Registry's evolution from a data collection effort into a dynamic research ecosystem that connects patients, advocates, and scientists in MRA's shared mission of improving outcomes for all melanoma patients.

Dr. Scales shared, "Our hope is that over time, the RARE Registry will enable researchers and clinicians to eliminate barriers to equitable care and effective treatment options for patients affected by these rare melanomas."

Dr. Scales' JADPRO presentation reflected MRA's dedication to translating patient experience into measurable progress. The RARE Registry exemplifies how patient-powered initiatives can accelerate discovery and collaboration – not only in rare melanoma, but across rare cancer as a whole.

Interested in Getting Involved with Rare Melanoma Research?

Patients and caregivers can learn more about the RARE Registry at RareMelanoma.org or contact rare@curemelanoma.org for more information.

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