



FOR IMMEDIATE RELEASE

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Nevus Outreach Launches Nevus Owners Outcomes Registry (NOOR) in Partnership with the Pediatric Dermatology Research Alliance

Jonesboro, AR – Nevus Outreach, a patient advocacy organization dedicated to supporting individuals affected by congenital melanocytic nevi (CMN) and related conditions, is excited to announce the launch of the Nevus Owners Outcomes Registry (NOOR). This groundbreaking initiative, created in partnership with the Pediatric Dermatology Research Alliance (PeDRA), will officially launch September 27, 2024.

NOOR is a first-of-its-kind patient registry that aims to collect comprehensive data on individuals living with CMN and neurocutaneous melanocytosis (NCM) and other related conditions. By gathering critical information on the experiences, treatments, and outcomes of those affected by these rare skin conditions, NOOR seeks to advance the understanding of CMN and NCM, drive research, and improve patient care.

“This registry is a significant step forward in our mission to foster a supportive community, drive awareness, and advance research for those living with CMN and related conditions,” said Lauren Isbell, Executive Director of Nevus Outreach. “Through our partnership with PeDRA, we will be able to leverage NOOR to better understand the needs and outcomes of individuals within our community and use this information to advocate for new treatment options and improved care.”

The data collected through NOOR will be accessible to researchers and clinicians via a Scientific Consortium, a multi-disciplinary team of experts in the space, ensuring that the insights gained can contribute to bolster the body of knowledge on CMN and NCM. Additionally, NOOR will empower individuals and families affected by these



conditions to share their experiences and help shape the future of CMN research and treatment.

"We believe that NOOR will be a vital tool in improving the lives of those affected by CMN and NCM," said Dr. Mike Siegel, PeDRA Executive Director. "By collaborating with Nevus Outreach, we are leveraging the vast research-ready infrastructure of PeDRA to amplify the voices of those living with these conditions and improve outcomes for patient care."

To learn more about the Nevus Owners Outcomes Registry (NOOR) and how to participate, visit [www.nevus.org/noor](<http://www.nevus.org/noor>).

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About Nevus Outreach:

Nevus Outreach is a non-profit organization dedicated to driving awareness, fostering a supportive community, and advancing research for people affected by congenital melanocytic nevi (CMN) and related conditions. Established in 1997 and headquartered in Jonesboro, Arkansas, Nevus Outreach supports individuals and families worldwide through advocacy, education, and research initiatives. For more information, visit [www.nevus.org](<http://www.nevus.org>).

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