



FOR IMMEDIATE RELEASE

Nevus Outreach, Inc., Releases Best Practice Guidelines

The Research Committee¹ of Nevus Outreach, Inc. in conjunction with the Expert Committee² has proposed a ‘Working’ model of best practices for persons born with Congenital Melanocytic Nevus (CMN). **These practices reflect the opinions of the world’s leading experts for CMN but should not be construed as a substitute for the guidance and opinion of you or your child’s physician.**

This model applies to every child born with at least one CMN >3cm, >20 satellites, or both. This is to establish a baseline for the patient given the understanding that developmental delays, disease and even death are possible sequelae.

0 – 6 Months

- Ophthalmologic consultation referral
 - Melanocytic lesions may be found on the retina
- An MRI study, with and without gadolinium contrast, of the brain and complete spine before 6 months of age with secondary review by an expert center
 - Melanocytic lesions are defined as Neurocutaneous Melanocytosis (NCM)
 - NCM can be symptomatic or asymptomatic but requires closer monitoring either way
 - Anesthesia to be considered and determined in light of ASA guidelines for pediatrics.
- Pediatric Neurology referral
 - Interpretation and guidance for NCM findings or neurologic symptoms
- Pediatric Dermatology referral
 - Interpretation of/and coordination of referrals and findings
 - Regular follow up for skin evaluation
- Pediatric Plastic surgery referral – regardless of the ultimate decision, the knowledge of an expert is best in determining if this is even an option for the patient.
 - The only source of valid information on whether removal (if elected as an option) is even possible.
 - The best source of valid information on surgery is a surgeon experienced with nevus.

Before Age 3

- Audiologic consultation referral – if failing Newborn Screen or any delayed speech
- Child Psychology referral – even if asymptomatic

Optional

- Genetic counseling referral
 - CMN is not a germline trait.

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- Identification of trigger genes and epigenetics is promising but currently more relevant to research than to diagnosis or treatment

These best practices are meant to establish an accurate baseline and to identify those patients who warrant closer follow up due to possible complications. They reflect from the considered opinions of the experts we rely on to guide best outcomes for our constituents.

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Nevus Outreach, Inc. is a 501(c)(3) nonprofit corporation headquartered in Bartlesville, Oklahoma. Nevus Outreach deals with large congenital melanocytic nevi. Nevus Outreach is dedicated to bringing awareness, providing support, and finding cures for people affected by congenital melanocytic nevi and related disorders.

While Nevus Outreach does not advocate for any one position for every patient, nor any one physician, these best practices represent a consistent basis for initial evaluation of a patient with Congenital Melanocytic Nevus. This is a dynamic model due to the continuing landscape of evidence; however, currently these are our recommendations for our constituency of patients and their providers.

Citations

Marghoob, A. A., Orlow, S. J., & Kopf, A. W. (1993). Syndromes associated with melanocytic nevi. *Journal of the American Academy of Dermatology*, 29(3), 373-388.

Barkovich, A. James. *Pediatric neuroimaging*. Lippincott Williams & Wilkins, 2005.

Becher, Oren J., et al. "Large congenital melanotic nevi in an extremity with neurocutaneous melanocytosis." *Pediatric dermatology* 26.1 (2009): 79-82.

Price, H. N., O'haver, J., Marghoob, A., Badger, K., Etchevers, H., & Krengel, S. (2015). Practical application of the new classification scheme for congenital melanocytic nevi. *Pediatric dermatology*, 32(1), 23-27.

Bauer, B. S., Few, J. W., Chavez, C. D., & Galiano, R. D. (2001). The role of tissue expansion in the management of large congenital pigmented nevi of the forehead in the pediatric patient. *Plastic and reconstructive surgery*, 107(3), 668-675.

Kinsler, V. A., Thomas, A. C., Ishida, M., Bulstrode, N. W., Loughlin, S., Hing, S., ... & Chanudet, E. (2013). Multiple congenital melanocytic nevi and neurocutaneous melanosis are caused by postzygotic mutations in codon 61 of NRAS. *Journal of Investigative Dermatology*, 133(9), 2229-2236.

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