



What is a Congenital Melanocytic Nevus?

- A congenital melanocytic nevus, also referred to as “CMN,” is a birthmark that is caused by the excessive accumulation of benign pigment producing cells called melanocytes. It usually has varying shades of brown color, and the size can range from the size of a freckle to encompassing large areas of the body.
- Often, people with one or more large CMN will also have many smaller nevi scattered over their skin. These smaller nevi can continue to appear after birth.
- About 1 in 100 people are born with a CMN, but most of these are small in size. Large and giant nevi are extremely rare. Large nevi occur in approximately 1 in 20,000 births.
- Congenital melanocytic nevi form in the womb during fetal development. They are caused by a mutation that may be inherited or happens by chance and is not due to anything the mother did while pregnant.
- Nevus Outreach is bringing awareness of congenital melanocytic nevi to the medical community so that people with nevi will be provided with accurate medical information and treatments.

My child was born with a nevus! Now what?

- If your child was born with one or more large brown to black birthmarks, the anomaly was probably a surprise to you and the delivery team present at the time of birth of your child. Needless to say, this can be overwhelming for new parents, resulting in an avalanche of emotions. You will likely have a lot of questions. One of the reasons Nevus Outreach exists is to help parents like you! Please connect with us at www.nevus.org to get support and find answers. You are not alone!
- There is medical information that you will need as a new parent of a child with a large nevus. Nevus Outreach can help!

Related Medical Disorders

- Some people with nevi may also have pigment cells on the brain and spinal cord. This is called neurocutaneous melanocytosis or “NCM.” NCM can cause complications in some people, and it is important to be aware of the symptoms and seek medical attention immediately if they occur.
- People with large nevi have a slightly increased risk for developing melanoma in the nevus. It is therefore important that the nevus be monitored by you and your physician for changes that may be clues to melanoma. Uncommonly, melanoma can occur in other areas outside of the nevus, such as in the brain.
- Other challenges can be encountered in people with large CMN, including excessively bumpy skin texture, delicate nevus skin that tears or cuts easily, overheating, and itching.
- Nevus Outreach funds research toward finding treatments and cures for these conditions so that all people with nevi can live fulfilling lives.



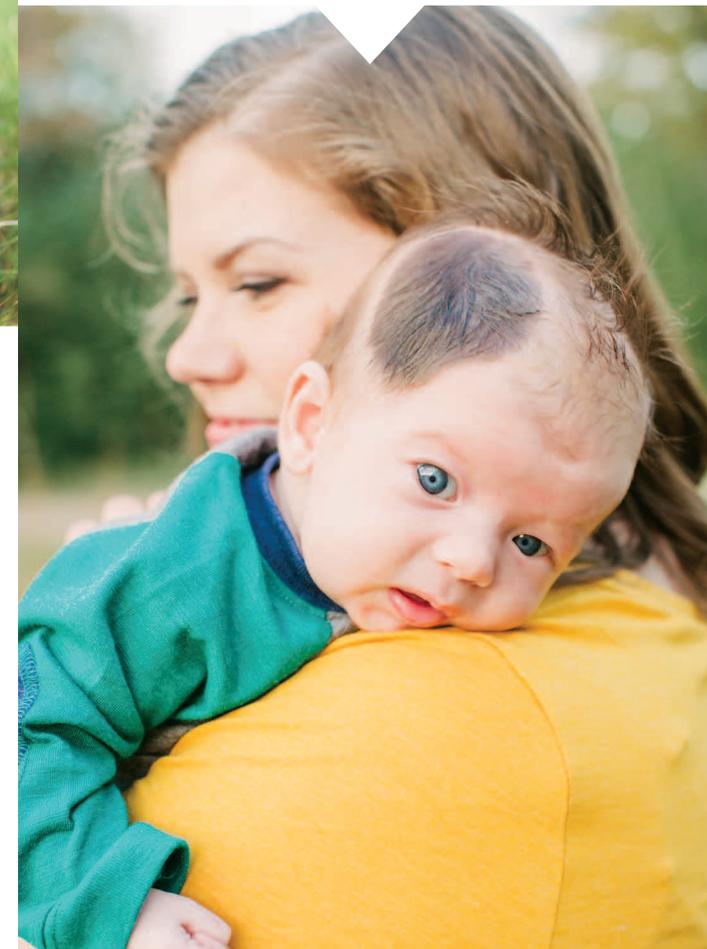
Nevus Outreach, Inc.
The Association for Large Nevi & Related Disorders

Nevus Outreach is dedicated to bringing awareness, providing support, and finding cures for people affected by congenital melanocytic nevi and related disorders.

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Treatment Options

- **Can a nevus be removed?** In many cases, the answer is yes. However, whether or not a nevus can be removed will ultimately depend on a host of factors. Some of these factors include the location of the nevus, the age of the person, the size of the nevus, and the overall health of the individual. It is important to consult with a physician with expertise in caring for patients with CMN to discuss the risks and benefits of removing the nevus.
- **Can we choose not to remove the nevus?** Yes. In the absence of melanoma and other distressing symptoms such as pain or bleeding, a nevus can be left alone and observed. In fact, removing a nevus is only one option, and many people with nevi do not remove them for various reasons. It is important to discuss the options of management of nevi with your doctors.



About Nevus Outreach

Nevus Outreach is dedicated to bringing awareness, providing support and finding cures for people affected by congenital melanocytic nevi and related disorders, such as NCM.

Nevus Outreach was founded in 1997 by three families of children with giant nevi. Since then, Nevus Outreach has worked tirelessly to improve the lives of people with large nevi. Members of the Board of Directors come from several different regions of the US and Canada, and represent both parents of children with nevi and adults with nevi. Nevus Outreach regularly consults with leading physicians and scientists worldwide working in the field of pigment cell research and treatment.

Nevus Outreach is a 501 (c)(3) nonprofit corporation.

Psychological Challenges

- Having a visible difference can be challenging and emotionally draining at times. It helps to know others who are dealing with similar issues and to connect with them. Nevus Outreach provides networking and support for people with nevi through our online support groups, local gatherings, and conferences.
- Depending on where the nevus is located, it may attract unwanted attention from others. It can be comforting and helpful to share experiences with others who have a child with a nevus. You may want to develop a strategy to deal with people who may be uninformed, which in turn may lead to them being afraid or merely curious.
- When a child is born with a rare medical condition it can be scary and isolating. Nevus Outreach is here to help parents connect and answer questions. Sometimes the best advice and support comes from others who have gone through the same situation.
- At our conferences, people with nevi have the unique and wonderful opportunity to meet and interact with others with this rare condition. It can be a life-changing experience to meet and talk face-to-face with someone who has gone through what you have.

Nevus Outreach Initiatives

Awareness—Nevus Outreach seeks to promote awareness of congenital melanocytic nevi, both in the medical community and in the world at large. We hope to create a future where people with nevi can easily receive treatment for their condition by informed medical personnel and have their distinctive appearance accepted and celebrated.

Support—Nevus Outreach provides support to people affected by nevi by offering an online support group through Facebook. We also host a biennial conference, giving people the opportunity to connect and meet in person. For people affected by nevi, our conference can feel like a family reunion.

Finding cures—Nevus Outreach seeks to improve the lives of people with CMN by funding and supporting research efforts aimed at investigating the cause and potential treatments for the medical complications associated with CMN and NCM. Nevus Outreach supports an International Nevus Registry to gather data, and helped found the Gavin Bailey Tissue Repository where people can contribute their precious tissue for research.



We need your help to do all of the above! Please make a generous tax-deductible donation today to support our important work! Or better yet, become an Outreach Angel by making a commitment to give monthly. Donations may be made at nevus.org or by phone or mail.

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