About Nevus Outreach

Nevus Outreach deals with large congenital melanocytic nevi. Nevus Outreach is dedicated to improving awareness and providing support for people affected by congenital melanocytic nevi and finding a cure.

Founded in 1997 by three families of people with giant nevi, Nevus Outreach has worked tirelessly to improve the lives of people with large nevi. Members of the Board of Directors are located throughout the USA and Canada, and the Nevus Outreach Science Group is made up of top pigment cell scientists and physicians worldwide.

Nevus Outreach is a 501(c)(3) nonprofit corporation headquartered in the United States of America.

International Initiatives

Nevus Global - Until they have given birth to a child with one, most people have never heard of or seen a giant nevus. It is important to meet others who can share experiences and help you feel you are not alone. In 2011, Nevus Outreach pulled together the leaders of other nevus organizations in other countries to talk about working together for the benefit of all.

The Nevus Global Registry - It is very important to have as much information about as many people with nevi as possible. In partnership with the National Institutes of Health and with an all-expert team, Nevus Outreach is working to establish a single worldwide data and tissue repository so that people with nevi from anywhere in the world can contribute to scientific research. The information gathered will lead to a better understanding of large nevi, help doctors care for their patients better, and shed light on cures and treatments.

Starting in 2014, doctors will be able to go to our web site and submit data about their patients with nevi. If you have a nevus, be sure to tell your doctor you want them to do this for you.

Nevus Facts

- Large Congenital Melanocytic Nevi (LCMN) are found in every race, and strike genders equally.
- There is no evidence that LCMN are hereditary.
- LCMN form in the womb very early in development, within the first twelve weeks of pregnancy. They are caused by a defect during embryologic development. There is no known method of prevention.
- LCMN are rare, and occur approximately once in every 20,000 births.
If you are a new parent of a child with a nevus, you are taking in a lot of information at once. Your emotions are on a roller-coaster, and you have so many questions you may not know where to begin. It is important to stop and get yourself oriented. Focus on your new bundle of joy, then begin to sort out the most pressing questions you have and start there. 

To the thousands of other people who know what you are going through via the Support Groups at www.nevus.org. There is a massive amount of reassurance available to anyone who simply gets connected.

Don't go it alone!

A wealth of additional information can be found at nevus.org.

- Childhood Moles (CM)
  - Can range in size from small, common forms that cover part of the body surface to the largest ones described medically as giant.
  - People born with LC MN are more likely to develop melanoma than people born without them.

- Neurocutaneous Melanocytosis (NCM)
  - Large nevi can be delicate and tear easily, requiring restricted activity.
  - They can lighten over time, but the birthmark remains unless it is treated.

- Psychological Challenges
  - People with LC MN sometimes attract looks, stares, whispering and finger-pointing.
  - When small nevi are removed, the surrounding skin is simply pulled together and stitched up. Removal of a large nevus involves the replacement of the affected skin. Lasers are successful for many superficial skin imperfections, but generally cannot remove a pigmented nevus. Lasers can destroy most of the cells of some nevi. Some people report successful results with laser treatment, but others report poor results. There are no creams, lotions or other products that can remove a nevus. Yet.
  - Lasers are used to treat large congenital nevi.
  - People born with LC MN are more likely to develop melanoma than people born without them.

- Medical Challenges
  - Because of the way they are treated, and/or the way they perceive themselves, a person with a large nevus may experience significant anxiety, depression and social isolation. Large nevi can also be a problem for parents, who often report feeling isolated and fearful.
  - Large congenital nevi can be especially difficult to treat.
  - Many people with large congenital nevi have problems with itching and other skin irritation. Other treatments that can be used to alleviate these discomforts include lasers, which can destroy most of the cells of some nevi, but generally cannot remove a pigmented nevus. Lasers can destroy most of the cells of some nevi. Some people report successful results with laser treatment, but others report poor results. There are no creams, lotions or other products that can remove a nevus. Yet.
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- Treatment Options
  - When small nevi are removed, the surrounding skin is simply pulled together and stitched up. Removal of a large nevus involves the replacement of the affected skin. Lasers are successful for many superficial skin imperfections, but generally cannot remove a pigmented nevus. Lasers can destroy most of the cells of some nevi. Some people report successful results with laser treatment, but others report poor results. There are no creams, lotions or other products that can remove a nevus. Yet.
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