



## 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.

## How Can You Help?

Nevus Outreach is leading the charge to understand and eliminate congenital melanocytic nevi (CMN) and improve life for those with this challenging condition. Your support is vital to us.

- Join our online support group
- Fill out the Nevus Registry
- Attend a conference
- Donate
- Spread awareness
- Purchase from our website affiliates
- Volunteer your time

## 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.

## Donate To Nevus Outreach

Make a generous tax-deductible donation today. Better yet, become an Outreach Angel by making a commitment to give monthly, quarterly, biannually or annually. These dedicated supporters are the backbone of Nevus Outreach. Donations may be made at [nevus.org](http://nevus.org) or by phone or mail.



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

dedicated to improving **awareness**  
and providing **support** for people  
affected by congenital pigmented  
nevi, and finding a **cure**

600 SE Delaware Ave., Suite 200, Bartlesville, OK 74003  
Phone: (918) 331-0595  
[www.nevus.org](http://www.nevus.org)

## 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.



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## What is a Large/Giant CMN?

- *Nevus* (also spelled *naevus*; plural *nevi* or *naevi*) in the broad sense, means “birthmark”, and can be used to describe virtually any mole or birthmark.
- If a birthmark is caused by a pigment-producing cell, it’s called a pigmented or *melanocytic* nevus.
- If it is present at birth, it’s called *congenital*. One in every 50-100 people is born with a mole.
- CMN can range in size from small, common forms the size of a pinhead up to *large*, rare forms that cover most of the body surface. The largest ones are described medically as *giant* nevi.

## Medical Challenges

- Common challenges include decreased body cooling (fewer functioning sweat glands), and too little fat where the nevus is located. Large nevi can be delicate and tear easily, requiring restricted activity.
- In a small percentage of cases, pigment cells can also be found in the brain and spinal cord - a complication of large nevi called *neurocutaneous melanocytosis (NCM)*.
- People born with LCMN are more likely to develop melanoma than people born without them.

## Psychological Challenges

- People with LCMN sometimes attract looks, stares, whispering and finger-pointing.
- Because of the way they are treated, and/or the way they perceive themselves, a person with a large nevus may suffer from anxiety, depression or a self-esteem deficiency.
- Family members sometimes hope that a nevus will ‘fade’ and the other potential medical challenges will also disappear. Some large CMN can lighten over time, but the birthmark remains unless it is treated.

## How to Deal With LCMN

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.

Please don’t try to do this by yourself. Get connected to the thousands of other people who know what you are going through via the Support Groups at [www.nevus.org](http://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](http://nevus.org).

## Treatment Options

One of the most frequently asked questions is “What can be done about it?” We all want to think modern medicine has miracles to offer us, but in a nutshell, there are no magic answers. Yet.\*

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.

Many people with large nevi have problems with itching and other discomfort. Lotions and creams can alleviate some discomfort. It is important to note that there are no creams, lotions or other products that can remove a nevus! Yet.\*

## Nevus Removal

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. Skin can be transferred from another area of the body (grafting), or adjacent skin can be stretched, then used to cover the area where the nevus was removed (tissue expansion). There are many details about the surgery you should consider and it is best to consult a surgeon experienced in the treatment of giant nevi.

It is important to remember that a nevus cannot be removed without leaving a scar. Scarring may be minimized at the hands of a highly skilled, experienced surgeon, so it is recommended you seek out a surgeon you will trust.

\*Nevus Outreach has raised over one million dollars for research, and funds more LCMN research than any other organization.

Name \_\_\_\_\_  
 Address \_\_\_\_\_  
 City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
 Email \_\_\_\_\_

Check enclosed (payable to Nevus Outreach, Inc.)

Please bill my:  Mastercard  Visa  Discover  American Express

Credit Card # \_\_\_\_\_ Expires \_\_\_\_\_

Signature and billing address (if different than mailing address) \_\_\_\_\_  
 Nevus Outreach, Inc. is an IRS 501(c)(3) and contributions are tax-deductible.

## Yes! I want to help Nevus Outreach!

Through your contribution, you will:

1. Help find cures and treatments for neurocutaneous melanocytosis (NCM) and large congenital nevi by funding research grants.
2. Improve public awareness and patient services through the distribution of literature to medical professionals and new parents.
3. Be invited to Nevus Outreach events and Conferences.

- Sponsor \$1000  Contributing \$100  
 Sustaining \$500  Individual \$50  
 Supporting \$250  Other \_\_\_\_\_

I want to become an **Outreach Angel**. Please contact me about becoming a monthly donor.

Please mail completed form and check, if applicable, to  
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