



About NCM

What is Neurocutaneous Melanocytosis?

Some people with congenital melanocytic nevi (CMN) also have a neurological condition called neurocutaneous melanocytosis (NCM). This means that excess pigment cells (melanin) are present in the brain or spinal cord. This condition is usually discovered on an MRI of the brain and spine. Approximately 1 in 20-25 people with multiple nevi have NCM. People with larger or more numerous nevi and those with nevi in certain locations are more likely to have NCM. Some patients with NCM are neurologically normal while others may have neurologic issues.

How can you tell if someone has NCM?

The best way to determine if NCM is present is for people born with more than one nevus to obtain an MRI of the brain and spine preferably at birth and certainly prior to six months of age. This test can be done later but results may not be as precise. The reason for doing the scan is to pick up the rare cases of tumors, cysts and extra fluid on the brain that may require treatment, and to allow more careful neurological monitoring of those children with MRI findings.

Nevus Outreach has collaborated with Dr. James Barkovich, the pediatric neuroradiologist who developed the protocol for how these MRIs should be done. You can view this protocol at www.nevus.org in the resource section. Nevus Outreach also offers members the opportunity to have an MRI sent to an expert neuroradiologist for their opinion. Our website explains this program and how to access it.

My child has NCM. What do I need to know?

The first thing to know is that 50% of people who have NCM will never have any resulting symptoms. If your child's NCM was detected on MRI but he or she is not having any of the symptoms listed below, there is nothing you need to do right now other than keep an eye out for any changes. It is quite likely that the deposits on your child's brain will never cause him or her any problems, just like the nevi on the skin often do not cause any problems.

When the melanocytosis does cause symptoms directly, they can come in different forms.

- **Seizures** are the most common complication of NCM. This symptom tends to occur most often when the melanin deposits are located in the temporal lobe. Seizures can be serious but are usually treatable. When a child has seizures, a neurologist (preferably pediatric) should be consulted. Seizures can often be successfully treated with medication. Some people have found success with epilepsy surgery, which removes a portion of the brain that is found to be causing the seizures.
- **Hydrocephalus** (too much fluid in the brain) – this symptom is caused by melanocytosis in the leptomeninges (the coverings of the brain and spine), which is not always visible on MRI. Hydrocephalus typically needs treatment with a special operation to shunt the fluid out of the brain. Signs of hydrocephalus in a baby include: sunsetting eyes (the irises of the eyes seem to be sinking under the eye socket and only the top portion is visible), intractable or projectile vomiting, inconsolable crying, extreme sleepiness, bulging forehead or fontanel. Signs of hydrocephalus in an older child include: intractable or projectile vomiting, severe or prolonged headache, and extreme sleepiness. If your child has nevi and is exhibiting any of these symptoms, he/she should be evaluated by a medical professional. Hydrocephalus can be successfully treated but it must be done without delay.
- **Cysts or malformations of the brain, spinal syrinx or tethering.** Cysts or brain malformations can be found in people with NCM. Excess pigment cells in the spinal cord can cause syrinx, a fluid filled cavity within the spinal cord. They can also cause tethering, which means that tissue attachments are limiting the movement of the spinal cord. Symptoms of these issues can include late bed wetting and toe walking. These behaviours can also be normal childhood issues but should be checked by a pediatrician or child neurologist if the child has nevi.
- **Melanoma** can occur in the brain. This complication is rare but can occur at any age.



No one seems to know about this condition. How can I get advice and support?

NCM is a rare condition which until recently has been poorly understood, even by many medical professionals. Very few medical professionals see these patients, but Nevus Outreach can help connect you with medical professionals who can help you and your child understand the condition and get treatment. Additionally, our experts can help educate your medical team about NCM.

NCM can be a difficult diagnosis to receive. Although most people who have this diagnosis never experience any complications, for a small number of people, complications can become severe. Dealing with symptomatic NCM can at times feel very stressful, for both parent and child. Talking with other parents of children with NCM can help. Often other parents have insight that is not available anywhere else, and it can be invaluable. Nevus Outreach can help connect you with other parents who have been in similar situations and are willing to offer advice and support. In addition, Nevus Outreach hosts a biennial conference where you have the opportunity to meet others with nevi and NCM in person.



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 is the premier organization in the United States doing this work.

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

Nevus Outreach Initiatives

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

Support-Nevus Outreach provides support to people affected by CMN by offering an online support group as well as a biennial conference to connect and meet in person. For people affected by nevi and related disorders like NCM, our conference can feel like a family reunion.

Finding cures-Nevus Outreach seeks to eliminate the medical complications, such as NCM, that arise from having CMN. To do this, we support and fund research projects to develop cures and determine the efficacy of different treatment options. Nevus Outreach supports the Gavin Bailey Tissue Repository, so people can contribute to research aimed at finding cures.

We need your help to do all of the above! Please make a generous donation today to support our important work! Donations may be made at nevus.org or by phone or mail.



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