



Naevus International is an equal partnership between 5 important working groups:

- Patient support groups
- Doctors
- Psychosocial professionals
- Scientists
- Communications experts

The aims of Naevus International in the first 5 years (2018-2023) are:

- 1 To improve access to, and dissemination of, information about CMN, across and between groups of professionals, patients and families;
- 2 To extend the international reach of those groups to include new members in different countries around the world.



Naevus International aims to support CMN patient support groups across the globe by the dissemination of excellent CMN medical information, CMN research findings and CMN support resources.

**Global CMN Patient Support Groups include:**

<b>Argentina</b> .....	Nevus Argentina
<b>Australia</b> .....	Nevus Support
<b>Belgium</b> .....	Flying for Lily
<b>Brazil</b> .....	Associacao Nevus Brasil
<b>Canada</b> .....	Association Naevus Quebec
<b>Colombia</b> .....	Fundación Lucas Quiere Prevenir
<b>Czech Republic</b> .....	<i>PSG expected soon</i>
<b>France</b> .....	ANGC Association du Naevus Géant Congénital
<b>France</b> .....	Naevus 2000 France Europe
<b>Germany</b> .....	Nävus-Netzwerk Deutschland
<b>Italy</b> .....	Naevus Italia Onlus
<b>Israel</b> .....	Children of Light
<b>Netherlands</b> .....	Nevus Network Nederland
<b>Portugal</b> .....	Associacao Nevo Portugal
<b>Republic of Ireland</b> .....	Caring Matters Now
<b>Spain</b> .....	Aso Nevus
<b>South Africa</b> .....	Nevus Association South Africa
<b>United Kingdom</b> .....	Caring Matters Now
<b>United States of America</b> .....	Nevus Outreach
<b>United States of America</b> .....	The Nevus Network

*Please check the Naevus International website for the most current list of patient support groups.*

Join our mailing list today by visiting our website:

**Website:** [www.naevusinternational.com](http://www.naevusinternational.com)

**Email:** [info@naevusinternational.com](mailto:info@naevusinternational.com)



The primary aim of Naevus International is to improve the lives of those affected by Congenital Melanocytic Naevus (CMN)

[www.naevusinternational.com](http://www.naevusinternational.com)





### What is a CMN?



**CMN** stands for **Congenital Melanocytic Naevus** (or naevi), which is a brown or black mole present at birth. They can be very large, covering up to 80% of the body, and very numerous – up to hundreds in one individual. People with large or multiple CMN have an increased risk of melanoma (a type of cancer). At the moment, large or multiple CMN are mostly untreatable.

### What is CMN Syndrome?



CMN syndrome is the association of these birthmarks with brain and spine problems including tumours, and/or characteristic facial features, or subtle problems with hormones.

### Why does it occur?



It has been discovered that multiple CMN and CMN syndrome are usually caused by a mutation in the gene NRAS that occurs when the baby is developing in the womb. NRAS is a very important gene in fetal development and is involved in melanoma. Much more rarely, it can be caused by a mutation in gene BRAF. In around 25% of cases the gene is not yet known.

### What does a CMN look like?



CMN can be on any part of the skin, including the face and the scalp. They are often hairy and the texture tends to be softer, looser and more wrinkled than normal skin. CMN are permanent.

### What size and how frequent are CMN?



CMN almost always grow in proportion to the child, so continue to cover the same area of skin as at birth. The number of naevi can increase after birth.

Single small CMN are found in 1% of all newborn babies but large or very numerous CMN are rare, occurring in around 1 in 20,000 births.

### Can CMN be treated with surgery?



Large or multiple CMN do not need to be removed medically unless there is a concern for melanoma (a type of cancer). Surgical removal is not known to alter melanoma risk. Any surgery is for cosmetic or psychosocial reasons only, and it does not need to be performed at an early age. It can be performed at any age and therefore there is no rush to make the decision. For some patients and/or families having surgery for cosmetic reasons is important, and we believe that people should be supported in whatever decision they take. It should however be an informed decision, which takes into consideration the risks and benefits of surgery, and the alternatives of good family and patient support, psychological interventions for coping, and acceptance of visible difference within the growing culture of body art. In general surgical excision of smaller naevi is technically easier and may therefore be more obviously beneficial, however multiple and larger naevi require major surgery. In addition surgery can sometimes cause an increase in smaller naevi to appear. Superficial removal techniques such as laser or curettage or dermabrasion have been found not to change the final colour of the CMN, even if they make it lighter in the short term. Those techniques are therefore not recommended.



### What are the practical difficulties of CMN?



CMN can be shocking for other people to look at if it has never been seen before. As a result, it can be difficult for people with large or multiple CMN (or their families) to keep explaining about their birthmarks. CMN skin is often more fragile than normal skin and can therefore tear easily if traumatised. Some CMN can be dry and/or itchy, and therefore are best washed with a moisturising soap-substitute rather than a normal soap or bodywash. Some require regular moisturising. In larger CMN there can be an underlying decrease in fat resulting in the affected limb or body part appearing thinner than normal.

### What are the medical complications of CMN?



Most commonly there are no medical complications of CMN. However, if there are problems the most common one is brain or spine abnormalities. These include collections of pigment-containing cells (like a CMN) in the brain or spinal cord, and much more rarely brain or spinal tumours; too much fluid around the brain, or abnormal brain structure. All of these neurological problems are more common with larger and more numerous CMN. Current published recommendations based on the largest prospective cohort of CMN, demonstrate clearly that babies born with two or more CMN at birth should have a screening MRI of the brain and spine, to find brain abnormalities that require surgery, and to be able to give accurate prediction of risk of neurodevelopment and melanoma risk for that child.

The second most common complication is melanoma of the brain or skin. Overall this is rare, of the order of 1-2% for the whole group of everyone with CMN, and is low in children

with normal screening MRI scans. However it can occur in approximately 10% of children with congenital neurological abnormalities on the screening MRI scan. It is during childhood the risk of developing melanoma is at its highest and it is particularly aggressive and resistant to treatments. Children at high risk are reviewed regularly to check for signs of melanoma.

