

# Giant congenital melanocytic nevus <sup>1i</sup>

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*Report for North American Organization for Rare Diseases*

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(<https://www.rarediseases.org/rare-disease-information/rare-diseases/byID/1271/printFullReport>)

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**ICD 10** codes (<http://apps.who.int/classifications/icd10/browse/2010/en>) are not particularly adapted to CMN. They account for: Congenital non-neoplastic nevus (Birthmark NOS) but excluding melanocytic and pigmented nevi (Q82.5); congenital malformations of the skin (unspecified) (Q82.9), or melanocytic nevi according to site (D22.1-8) or multiple nevi (D22.9) but not necessarily congenital. ICD 11 will probably have a specific code; see <http://apps.who.int/classifications/icd11/browse/-m/en#/http%3a%2f%2fid.who.int%2fcd%2fent%2f618273329>

## Summary

Congenital melanocytic nevi (CMN) are visible melanocytic proliferations in the skin that are present at birth. CMN can be light brown to black patches or plaques, can present in variable ways, and cover nearly any size surface area or any part of the body. The incidence of CMN seems to be independent of skin color or other ethnic factors. Small to medium CMN are predicted to occur in more than one in a hundred births (Kanada et al., 2012). Large and especially giant CMN, exceeding a predicted diameter at adult age of at least 20 cm on the body, form a much rarer subset, with prevalence estimated at around 1 in 50,000 births (Price and Schaffer, 2010). Non-pigmented or small incipient congenital lesions can also be present – these are known as “tardive”; the emergence of so-called “satellite” nevi throughout the first few years of life in conjunction with larger CMN probably reflects the postnatal maturation of such precursors. On occasion, even a primary CMN can appear in a tardive manner. Treatment options currently are exclusively surgical. Neurocutaneous melanocytosis, cited in earlier literature as neurocutaneous *melanosis* (NCM), is a neurological and cutaneous disorder characterized by abnormal aggregations of nevomelanocytes within the central nervous system and the skin. NCM is a complication of the larger forms of CMN, or multiple smaller CMN, in a fraction of patients. Recent studies find the incidence of symptomatic and asymptomatic NCM together to range between 5 and 15 % of all persons with large and giant CMN (Agero et al., 2005; Bett, 2006; Kinsler et al., 2009). Melanoma develops in an estimated 1-2% of patients with LCMN or NCM, more frequently and at earlier ages than in the general population (Krengel et al., 2006; Shah, 2010).



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## Introduction

Congenital melanocytic nevi (CMN) are benign, tumor-like malformations resulting from faulty development of pigment cell (melanocyte) precursors in the embryo, and composed of an abnormal mixture of skin elements. Defined areas of these melanocytic proliferations cover surfaces at the base of the epidermis ranging from a few millimeters in diameter to large sectors of the body. In the larger forms, the CMN (single or multiple) also extend(s) vertically into the deeper dermis and more rarely, into the hypodermis or even subcutaneous tissues. Unlike blue nevi, it is the most superficial component of the CMN that is the most highly pigmented, conferring brown-to-black shades to the overlying epidermis.

The first recorded descriptions of children with large CMN date from observations published by the Count of Buffon before the French Revolution (Leclerc, 1777). One was of Marie Sabina, born in 1736, to African-heritage parents of dark skin (p. 566-568), who seems to have had vitiligo, a disease with autoinflammatory components where melanocytes are eliminated from patches of the skin<sup>2</sup>, in addition to “*large dark patches over all the rest of her body, arms, legs and thighs within which there are small nevi (“tâches”) that are even blacker*”. Associations of vitiligo with large or multiple CMN (Gulati et al., 2000) and melanoma (Schallreuter et al., 1991) have been since described dozens of times in the modern literature. Buffon’s second description (page 571-573; Leclerc, 1777) is of a fair-skinned Alsatian girl, Anne-Marie Hérig, aged 3.5 years, whom he examined personally in 1774<sup>3</sup>:

*“None of her relatives had nevi on the skin [...] this little girl had her whole body, face and limbs sprinkled or covered with more or less large nevi, of which the majority had hair [...]; all these nevi were fawn-colored in both skin and hair; there were also hairless nevi, and the skin in these bare areas resembled tanned hide; [...] the nevi with more hair were a little raised above the bare skin. [...] The heat bothered her a great deal [...] Her back appeared covered with a tunic of hairy skin, that was mostly formed by a great number of neighboring, raised tubercles that began under her armpits and covered all her back to her kidneys. These outgrowths of skin [...] did not hurt her even when pinched; they were all covered with hair on a bumpy, wrinkled hide in certain areas, and the wrinkles had longer hair than the other areas: at the level of the kidneys and upper shoulders this hair was more than two inches long, thick and dark brown [...] All the parts of the body without nevi were of a very delicate, pale skin, even more attractive than that of other children.”*

Other giant, sometimes rugous CMN were described in the early 19<sup>th</sup> century (Alibert, 1835). Among the earliest photographs published of a giant CMN were of those of a “cape” or “tippet” distribution (see below; Rolleston, 1915).

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<sup>2</sup> <http://gallica.bnf.fr/ark:/12148/bpt6k97517m/f575.image>

<sup>3</sup> <http://gallica.bnf.fr/ark:/12148/bpt6k97517m/f580.image>,  
<http://gallica.bnf.fr/ark:/12148/bpt6k97517m/f581.image>

CMN are usually classified according to their predicted largest diameter in adulthood, as if they were circular (predicted adult diameter or PAS) (Kopf 1979; Ruiz-Maldonado 2004). The most used classification assigns small CMN as less than 1.5 cm PAS, medium sized CMN between 1.5 to 19.9 cm, and large CMN 20 cm or greater. CMN measuring 50 cm or larger in PAS have been referred to as 'giant nevi'.

CMN tend to grow in a proportional fashion to the child's growth; occasionally growth appears out of proportion to the child during periods of particularly rapid growth such as early infancy (Rhodes et al., 1996). A new size/color/texture classification, recently developed by experts in the field (Krengel et al., 2013), may eventually help in better predicting patients at the greatest risk for developing melanoma or neurological disease by more reproducibly classifying similar patients<sup>4</sup>. This study provides nomograms that can assist clinicians in easily determining the PAS of a nevus examined at any point during childhood, as has been recently tested by the authors in a pilot study (Price et al., 2015).

## Symptoms

Large/giant CMN are obvious at birth, most commonly covering an aspect of the trunk and less common on the head, neck and extremities (Castilla et al., 1981). Affected areas of large CMN have been designated as "cape", "bathing trunk", "tippet" or "garment" CMN due to their respective distributions. Lesions may have irregular or geographic borders. In about 75% of cases, multiple small CMN will accompany the large CMN, usually in a generalized manner. "Satellite" is a commonly used description of discrete small or medium CMN or tardive nevi in the presence of a large/giant CMN, though semantically and molecularly, it is more accurate to refer to "disseminated" lesions (Kinsler, 2011). These additional smaller, disseminated CMN may be present at birth and/or may increase to significant numbers over the first few years of life. These multiple CMN should be noted in number, as greater numbers (>20) have been correlated with neurological anomalies.

In general, CMN can be tan, brown to dark-brown or black and rarely blue in color and may be flat, raised, or even quite thickened at birth. Color may be quite uniform throughout, or consist of multiple colors including shades of brown, black, red or blue. Texture may be smooth, highly nodular or cobblestone-like; hair may or may not be present at birth and may or may not develop as the child

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<sup>4</sup> Calculation of PAS can be done by assuming the area of the head/face grows between infancy and adulthood by a factor of 2.8, trunk and arms by a factor of 8, and lower extremities by a factor 12 (Krengel et al., 2013). Based on this, and assuming the nevus is a circle ( $A=\pi r^2$ ), a CMN in a newborn will reach a diameter of at least 20 cm in adulthood if its largest diameter is 6 cm on the leg (diameter of lesion on the leg will grow by a factor of 3.3), 7 cm on the trunk and arms (factor of 2.8) or 12 cm on the face and scalp (factor 1.7) (DeDavid et al., 1997).

ages. This hair is fine (vellus) or more often coarse (terminal) in texture. A “cerebriform” or brain-like texture may be present, particularly in large scalp CMN. Areas of the nevus may be infiltrated by overgrowths of fatty or nerve tissue, so-called lipomatous or neurotized areas respectively, features that can be seen most often in larger CMN.

Over time, CMN may become darker or lighter, more or less heterogenous in color and the surface texture may change. CMN can also develop superimposed nodules, which are usually benign but require surveillance. The CMN-involved skin can be dry and develop overlying eczema, resulting in intermittent or chronic itchiness (pruritis). CMN may also have fewer sweat glands than unaffected skin, resulting in potential overheating episodes or increased sweating in other areas of the body to compensate. Areas of larger CMN may have notably less fat under the skin, particularly around the flanks, limbs and buttocks.

At birth or within the first few weeks of life, transient erosions or ulcerations may develop over large CMN due to incomplete maturation of the skin during this period (Giam et al., 1999; Gonzalez et al., 2003). Healing usually occurs over days to weeks. Also notable during the infantile period are rapidly growing ‘proliferative nodules’ within the CMN that mimic melanoma but show benign features when examined microscopically (Mancianti et al., 1990; Phadke et al., 2011). Evaluation of these nodules by a dermatopathologist with expertise in pigmented lesions is recommended to avoid unnecessary surgery and possible toxic adjuvant therapy if misdiagnosed as melanoma (Tromberg et al., 2005).

Significant lightening of color in large CMN can also be seen in the first few years of life, especially those that involve the scalp.

## Causes

Both CMN and acquired melanocytic nevi are associated with somatic mutations in intracellular proteins of the microtubule-associated protein signal transduction pathway. For 4 in 5 cases, a single mutation in the DNA encoding the NRAS enzyme can be found (Bauer et al., 2007; Dessars et al., 2009; Kinsler et al., 2013), and for up to one in 6 cases, a single mutation in the DNA for the BRAF enzyme (Dessars et al., 2007; Dessars et al., 2009). The currently identified mutations cause the enzymes to become permanently active, and have been found in many apparently unrelated cancers as well, perhaps driving cells to proliferate. These findings imply that other, less common and not yet identified, mutations may also contribute to cause CMN.

Both CMN and normal pigment cells (melanocytes) come from an embryonic cell population that separates from the future central nervous system before the end of the first month of pregnancy,

and as it multiplies, the population colonizes all the tissues of the body. Within the skin, these cells then become pigment cell precursors that are both between and at the base of hair follicles. Constant activation of NRAS or BRAF may drive the prenatal proliferation of this cell population. A second mutation that occurs in the other copy of the NRAS or BRAF gene in a CMN cell may be responsible for the onset of malignant melanoma (Kinsler et al., 2013), which happens more frequently in children affected with large/giant CMN than in the general pediatric population, where melanoma is exceedingly rare. Recent results indicate that the same NRAS mutations may be also be responsible for nevomelanocyte proliferation within the central nervous system, causing NCM (Kinsler et al., 2013).

Large/giant CMN usually happen sporadically, but familial occurrence has been rarely reported. One of the first reports that families of patients with giant CMN had relatives with multiple small pigmented nevi was made over 40 years ago (Goodman et al., 1971), and this observation has been made many times since (Krengel et al., 2011). Affected siblings (Voigtländer and Jung, 1974) and first cousins (Hecht et al., 1981) have also been observed. Thus, a predisposing background of autosomal dominant inheritance in other genes may explain these rare familial recurrences.

### **Affected Populations**

People of all races and colors of skin can be affected with large/giant CMN.

A slight female preponderance has been noted in large/ giant CMN (male/female ratio of 1 to 1.4) (Bett, 2005; Kinsler et al., 2009), but is not observed in the smaller population of people affected by NCM (Reyes-Múgica et al., 2012).

### **Related Disorders**

Neurocutaneous melanocytosis is present in an estimated 5-15% of patients with large/giant CMN (Agero et al., 2005; Bett, 2006; Kinsler et al., 2009), while melanoma can occur in an estimated 1-2% (Krengel et al., 2006; Shah, 2010).

### **Melanoma**

The development of melanoma is a significant complication in people with large/giant CMN. The risk of melanoma development (cutaneous or extracutaneous) in large CMN is at the most 5% over a lifetime, considering prospective and retrospective cohort studies with significant follow-up (Price and Schaffer, 2010), possibly less, and seemingly independent of ethnicity (Chan and Giam, 2006). About half of these melanomas occur in the first 5 years of life (Egan et al., 1998; Hale et al., 2005;

Krengel et al., 2006). Cutaneous melanomas tend to arise deep in the skin or residual fatty tissues of a large CMN, making early detection difficult. Melanomas may also arise in other non-cutaneous areas such as the brain, and sometimes the primary location of melanoma is not found. Other malignancies such as liposarcomas, rhabdomyosarcomas and malignant peripheral nerve sheath tumors have been described in association with large CMN (reviewed in Reyes-Múgica et al., 2012). No reliable case of melanoma arising within an associated small CMN has yet been reported.

### *Neurocutaneous melanocytosis and central nervous system malformations*

In addition to melanoma, patients with large CMN and multiple medium CMN are also at risk for developing neurocutaneous melanocytosis (NCM), estimated to occur in 7% of individuals born with large CMN (Ramaswamy et al., 2012). NCM is a proliferation of pigment cells in the leptomeninges or brain parenchyma due to abnormal migration or differentiation of their precursors, which normally invest these tissues to become mostly vascular pericytes with a few melanocytes (Kadonaga and Frieden, 1991; Frieden et al., 1994; Etchevers et al., 2001). Rokitansky is credited with the first description of NCM in a teenaged girl with hydrocephalus, giant CMN and developmental delay, complete with autopsy after her death from tuberculosis, that confirmed the meningeal melanocytosis (Rokitansky, 1861).

Although pigmented deposits are generally benign, symptoms such as hydrocephalus and seizures indeed can occur, or intracerebral melanoma develops in a small proportion of cases (Hale et al., 2005). NCM has been classically defined by Kadonaga and Frieden as the co-existence of large or multiple CMN ( $\geq 3$ ) in association with meningeal melanocytosis or melanoma, with no evidence of cutaneous melanoma, except in patients whom the examined areas of the meningeal lesions are histologically benign (Kadonaga and Frieden, 1991).

Magnetic resonance imaging (MRI) with contrast of the brain and spine may be recommended for any individual with multiple CMN, or a large CMN with > 20 "satellite" nevi, as those with 20 or more disseminated nevi are 5 more times likely to have NCM than those with less (Marghoob et al., 2004). Individuals with giant CMN > 40cm PAS, or those with a CMN over the posterior axis (according to some authors) may also be at increased risk for NCM (Kinsler et al., 2008; Marghoob et al., 2004). Only about 4% of these 'high-risk' CMN individuals will develop symptomatic NCM; for these, prognosis can be poor, even without melanoma development, although many symptomatic patients survive with various neurological deficits (Agero et al., 2005; Bett, 2006; Hale et al., 2005; Reyes-Múgica et al., 2012).

Ideally, MRI should be done in the first 4-6 months of life, prior to full myelinization of the brain, which may obscure the melanin signal. Technical suggestions by an experienced radiologist in

demonstrating NCM (Foster et al., 2001; Frieden et al., 1994) are available at this link: [http://www.nevus.org/page\\_file\\_download.php?id=30](http://www.nevus.org/page_file_download.php?id=30) (accessed 30 Jan 2013). Based on previous studies, approximately half of those individuals with NCM will become symptomatic, often before the age of 5 (Agero et al., 2005; Foster et al., 2001; Lovett et al., 2009; Ramaswamy et al., 2012; Reyes-Múgica et al., 2012). Patients can present with hydrocephalus or other signs indicating increased cranial pressure, such as headaches and vomiting, or seizures. Mild to severe developmental delay and abnormal tone have also been described in children with high-risk CMN (Kinsler et al., 2008; Ramaswamy et al., 2012). Asymptomatic NCM (positive MRI without clinical symptoms attributed to NCM) has been diagnosed in up to 30% of patients with supposedly high risk CMN, and the percentage of patients that may eventually develop symptoms from NCM is currently unknown. Epilepsy can be responsive or refractory to standard medications and also can be treated favorably by surgical approaches used in other forms of epilepsy (Reyes-Múgica et al., 2012).

Other CNS tumors and malformations found often incidentally during brain and spine imaging of CMN patients have included Dandy-Walker malformations, lissencephaly, Chiari I malformations, posterior fossa cysts, spinal and other lipomas, arachnoid cysts and tethered spinal cord (Foster et al., 2001; Ahmed et al., 2002; Kinsler et al., 2008; Ramaswamy et al., 2012).

The differential diagnosis of small and medium CMN includes smooth muscle hamartoma or Becker's nevus, mastocytoma, variants of dermal melanocytosis, and café au lait macules. Large CMN may be confused with a pigmented, plexiform neurofibroma (Schaffer et al., 2007). Histologic evaluation, dermoscopic evaluation and the development of typical CMN features over time may clarify the diagnosis.

## Diagnosis

Making the diagnosis of a CMN is most often done by examining clinical and dermoscopic features. The larger CMN can easily be diagnosed based solely on their size. For smaller CMN, their history of presence since birth, surface topography, presence of hair or globular dermoscopic pattern can assist in diagnosis. When biopsied, the histological features of CMN are similar to those found in common acquired nevi which arise later in life; however, CMN tend to have a greater cellularity with deeper extension of nevus cells into the deep dermis and subcutis, and cells extend along adnexal structures such as hair follicles and around blood vessels and nerves. Histological criteria alone cannot be used to dictate with absolute certainty whether a nevus is congenital or acquired (Zalaudek et al., 2012).

## Clinical Testing and Workup

Magnetic resonance imaging (MRI) with contrast of the brain and spine is recommended for any individual with multiple CMN, or a large CMN with > 20 satellite nevi, as those with 20 or more satellite nevi are 5 more times likely to have NCM than those with fewer, and some of these will become symptomatic (Marghoob et al., 2004). Any patient with new onset of neurological symptoms, such as enuresia (extended night-time bed-wetting) or tiptoeing which indicate the possibility of a tethered spinal cord, epilepsy, or “sunset eyes” (indicative of increased intracranial pressure due to hydrocephalus) should also undergo a neurologic evaluation and appropriate imaging. Patients with asymptomatic NCM should also be followed by a neurologist, on a yearly basis or more frequently if concerns exist. The need for subsequent MRIs in those asymptomatic patients is not clear; however, most experts will not recommend further MRI unless symptoms arise. Patients with significant symptomatic NCM should consider foregoing elective surgical removal of the CMN until prognosis is clear.

Lifelong monitoring in patients with extensive CMN is mandatory regardless of the treatment employed, both with self-skin examinations and in an experienced dermatologist’s office. Serial photographs, the use of dermoscopy, palpation of nevus and scars, examination of lymph nodes and a thorough review of systems may aid physicians in early detection of melanoma. Suspicious lesions should be removed and examined histologically by an experienced pathologist.

## Treatment

Treatments currently rely on the arsenal of plastic surgical techniques. While partial-thickness grafts or ablations, using dermabrasion or curettage, have been used in the past and are still occasionally relevant, the gold standard is to replace the skin in its full thickness. Replacement skin can be generated from other zones by natural forced expansion from adjacent areas, or implanting expanders either adjacent to or in a donor graft site. Artificial dermis is currently an inadequate replacement for most nevi. Simple surveillance is an option for extensive, technically inaccessible and homogeneous nevi. Psychological accompaniment is highly recommended for both patients and families, irrespective of physical treatment options. Each treatment regimen is unique as a result of the highly individual distributions and combinations of textures, nodules and other attributes of CMN.

## **Investigational Therapies**

Information on current clinical trials is posted on the Internet at <http://www.clinicaltrials.gov>. All studies receiving U.S. government funding, and some supported by private industry or foreign governments, are posted on this web site.

For information about clinical trials being conducted at the NIH Clinical Center in Bethesda, MD, contact the NIH Patient Recruitment Office (<http://www.cc.nih.gov/recruit/>) tollfree: (800) 411-1222 TTY: (866) 411-1010 E-mail: [prpl@mail.cc.nih.gov](mailto:prpl@mail.cc.nih.gov)

For information about other clinical trials sponsored by private sources, contact:  
[www.centerwatch.com](http://www.centerwatch.com)

## Resources

### Associations :

- *Naevus Global* (International Federation)
  - <http://www.naevusglobal.org>
- *Nevus Outreach* (U.S.A.):
  - <http://www.nevus.org>
  - <https://www.facebook.com/groups/45259998392/> = administrators Ms. Rita Pink, Ms. Megan Fields, Ms. Kathryn Rose Stewart
- *Nevus Network* (U.S.A.)
  - <http://www.nevusnetwork.org/>.
- *Nevus Support Australia* (Australia) :
  - [www.nevussupport.com](http://www.nevussupport.com)
  - <https://www.facebook.com/groups/116208321729274/>, administrator Ms. Michelle Sibbons
- *Caring Matters Now* (UK):
  - [www.caringmattersnow.co.uk](http://www.caringmattersnow.co.uk)
  - <https://www.facebook.com/groups/11606190690/>, administrators Ms. Lucy Hardwidge, Ms. Jodi Unsworth
- *Nevus Argentina* (Argentina)
  - <http://www.nevusargentina.com.ar/>
- *Nevu Chile* (Chile)
  - <https://www.facebook.com/profile.php?id=100003336945674>, administrator asonevuchile@hotmail.com
- *Asociación Española de Nevus Gigante Congénito (AsoNevus)* (Spain)
  - <http://www.asonevus.org/>
- *Nevus Canadians* (English and a bit of French):
  - <https://www.facebook.com/groups/164957260227457/>, administrator Danielle Vidaurre-Stamatiou
- *Nævus 2000 France-Europe* (France)
  - <http://www.naevus2000franceeurope.org/>
- *Association Nævus Géant Congénital* (France)
  - <http://www.naevus.fr/>
- *Association Nævi* (France)
  - <http://www.naevi.com/>
- *Nevus Netwerk Nederland* (Holland):
  - [www.nevusnetwerk.nl](http://www.nevusnetwerk.nl)
  - <https://www.facebook.com/groups/nevusnetwerk/>, administrators Stefan Wilms, De Regelnevus (this is an alias)
- *Nävus-Netzwerk Deutschland* (Germany):
  - <http://www.naevus-netzwerk.de/>
- *Children of Light* ילדי האור (Israel):
  - <http://www.nevus.org.il/>
- *Naevus Italia* (Italy):
  - [www.nevogigante.it](http://www.nevogigante.it)
  - <https://www.facebook.com/groups/35657019117/>, administrators Mr. Ruggero Pedrazzini, Ms. Stefania Tedoldi, Ms. Jessica Sottura

### *Facebook interest groups:*

When written “-based” this means that the majority of users and the founders are based in these regions. Thus although open to people from around the world, such groups may have a cultural bias toward language(s) used, region-specific recommendations for care and psychosocial management.

Updated 16 April 2015; latest version at <https://www.facebook.com/notes/naevus-global/congenital-melanocytic-naevus-groupspages-on-facebook/768053603284137>.

Other structures concerning n(a)evus associations exist on Facebook but may have been set up as personal accounts, initially.

For incorporated association websites, see <http://naevusglobal.org>. [contact@naevusglobal.org](mailto:contact@naevusglobal.org)

### *Not regionally-based but with an emphasis on English*

- *Nevus Adults* <https://www.facebook.com/groups/nevusadults/>
- *Nevus Youth Chat* <https://www.facebook.com/groups/117734914912760/> “A group specifically for young people 13-25 years old with a CMN to chat to each other and share stories and suggestions...”
- *CMN Lost Loves* <https://www.facebook.com/groups/186238451434304/> For those who have lost someone to a condition associated with CMN. Contact [msibbons@naevusglobal.org](mailto:msibbons@naevusglobal.org) to be added
- *Parents of Children with NCM (Neurocutaneous Melanocytosis)* <https://www.facebook.com/groups/142208265830723/> Contact Jennifer King (<https://www.facebook.com/jennifer.d.king.50/>) to be added

### *North America-based*

- *Nevus Outreach* <https://www.facebook.com/groups/45259998392/>
- *Nevus Canadians* <https://www.facebook.com/groups/164957260227457/>
- *Association Naevus Québec* <https://www.facebook.com/groups/associationnaevusquebec/> L'Association Naevus Québec a pour mission de soutenir les familles et gens atteint de Naevus Congénital Géant au Québec
- *Nevus Mexico* <https://www.facebook.com/groups/974971152528328/>
- *Giant Nevus Removal Support Group* <https://www.facebook.com/groups/121056618033119/> “This group is a support group for anyone (the nevus "owner" themselves or parents of a child with a giant nevus)...”
- *Nevus Love* <https://www.facebook.com/groups/288186231304511/> “This group is mainly a group to promote positive parenting to create strong, confident, happy nevus owners.”
- *Nevus Prayer Partners* <https://www.facebook.com/groups/420319924769942/> “This is a safe haven for our Nevus families and friends in need of positivity, prayer and support. We welcome all Christ-centered comments and prayers requests. Most ...”
- *Nevus Friends* <https://www.facebook.com/groups/167397373277111/>

## South America-based

- *Associação Nevus Brasil* <https://www.facebook.com/groups/216116191846132/> "Comunidade criada para trocar informações e relatos sobre o nevo melanocítico congênito, que faz parte da Associação Brasileira do Nevo Gigante. Se você é novo, seja be..."
- *Nevus Brasil* <https://www.facebook.com/groups/605660126158640/>
- *Nevus Argentina* - <https://www.facebook.com/nevus.arg> Página "personal" Nevus Argentina en Facebook dirigido por Constanza Danielsen (<https://www.facebook.com/constanza.danielsen>)
- *Nevu Chile* <https://www.facebook.com/profile.php?id=100003336945674> Contact asonevuchile@hotmail.com to be added

## Oceania-based

- *Nevus Support Australia* <https://www.facebook.com/groups/nevussupport/>
- *Nevus Nexus Australasia* <https://www.facebook.com/groups/814621145231063/>
- *Nevus New Zealand* <https://www.facebook.com/groups/NevussupportNewZealand/>

## Europe-based

- *Nevus Netwerk Nederland (NNN)* <https://www.facebook.com/groups/nevusnetwerk/> "Dit is de besloten ontmoetingsplek op Facebook voor leden van Nevus Netwerk Nederland (NNN)."
- *Nevus Jeugd Nederland* <https://www.facebook.com/groups/453146474720872/>
- *Flying for Lily NaevusBe* <https://www.facebook.com/flyingforlily> "Belgische Vereniging / Association Belge voor/pour Congenital Melanocytic Naevus syndroom/syndrome" - Groupe sur invitation: <https://www.facebook.com/groups/flyingforlily/> demander accès à Anne Dekerk (<https://www.facebook.com/adekerk>).
- *Nevus Norge* - stor og gigant congenital melanocytic nevus <https://www.facebook.com/groups/1377323552479968/> "En gruppe for oss som er født med Nevus,er foreldre eller har tilknytning til Nevus."
- *Le naevus géant congénital - les francophones du monde réunis* <https://www.facebook.com/groups/naevus/> « Ce « groupe » Facebook existe pour les francophones qui voudraient discuter en français sur des questions du nævus... »
- *Naevus Italia Onlus* <https://www.facebook.com/groups/35657019117/> "La Prima Associazione Italiana del Nevo Melanocitico Congenito Gigante."
- *Caring Matters Now* <https://www.facebook.com/groups/11606190690/> "The Congenital Melanocytic Naevus Support Group Caring Matters Now Support Group aims to offer support to sufferers of Congenital Melanocytic Naevus."
- *Adults with CMN - Caring Matters Now support group* <https://www.facebook.com/groups/522234171252994/> "Adults with CMN is a group set up by Caring Matters Now Support Group to allow adults affected by Congenital Melanocytic Naevi to communicate and support one another."
- *Naevus 2000 France-Europe* <https://www.facebook.com/groups/175866009124370/> "Naître avec un nævus géant congénital, parcours du combattant !"
- *Tierfell Naevus Magyar / Hungary* <https://www.facebook.com/groups/391928510883141/>
- *Nevus Sverige* <https://www.facebook.com/groups/309857979162931/> "En grupp för oss där någon i familjen har Kongenitala Melanocytära Nevus. Här kan vi dela erfarenheter, diskutera och fråga kring allt som har med Nevus att göra."
- *Children of Light – Nevus Israel* <https://www.facebook.com/groups/nevusisrael/> secret group; request invitation to Inbal Engler at [iengler@naevusglobal.org](mailto:iengler@naevusglobal.org)

- *Naevus Netzwerk Deutschland* <https://www.facebook.com/NaevusNetzwerkDeutschland>
- *AsoNevus España* <https://www.facebook.com/pages/AsoNevus-Asociaci%C3%B3n-Espa%C3%B1ola-de-Nevus-Gigante-Cong%C3%A9nito/261498287281125> "AsoNevus, La Asociación Española de Nevus Gigante Congénito, reúne a los/las afectados/as por esta enfermedad."
- *Association Nævi* <https://www.facebook.com/asso.naevi> - Page "personnelle" de l'Association Nævi France sur Facebook, gérée par Barbara Carpentier.

#### Asia-based

- *Nevus India* <https://www.facebook.com/groups/1609720025939294/> "Creating awareness among fellow Indians about Various types of Nevus. The group is for people who themselves are suffering from a Nevus or for their family members."
- *Nevus Arabia* <https://www.facebook.com/groups/557578904268528/>
- *黑色素痣-琪琪寶貝* <https://www.facebook.com/pages/%E9%BB%91%E8%89%B2%E7%B4%A0%E7%97%A3-%E7%90%AA%E7%90%AA%E5%AF%B6%E8%B2%9D/1475130519389517> *Taiwanese blog* about Kiki, a little girl with a CMN. « 希望能夠幫助一樣情況的小天使們!讓他們能夠快樂的成長跟接受正確的治療! » [achiang88@yahoo.com.tw](mailto:achiang88@yahoo.com.tw)
- *CMN Support Singapore/Malaysia/Indonesia/Philippines* <https://www.facebook.com/groups/306595146206975/> "This group is to try to help unite families with someone with CMN in the Asian region so that you can share information with each other and get to know each other. Please add anyone that you think should be a part of this group."

#### Africa-based

- *Nevus Support South Africa* <https://www.facebook.com/groups/256812154425109/>
- *Naevus Maroc* <https://www.facebook.com/groups/826806094028719/> « Ce « groupe » Facebook existe pour les marocain(e)s qui portent le Naevus Géant Congénital et qui voudraient discuter et avoir des informations sur cette maladie rare. Ne soyez pas timide et Venez joindre à nous. bienvenue Merci »

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<http://www.diseaseinfosearch.org/Neurocutaneous+melanosis/5161>

<http://www.diseaseinfosearch.org/Giant+Pigmented+Hairy+Nevus/3048>

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