

A graphic of two interlocking puzzle pieces representing the world map. The left piece is light brown and the right piece is light blue. A horizontal dashed line in a dark blue color runs across the top of the puzzle pieces.

EFFECTIVE COMMUNICATIONS

NAEVUS INTERNATIONAL CONFERENCE 2018

Jodi Whitehouse

THE COMMUNICATION TEAM



JODI WHITEHOUSE – Leader

KATHY WRIGHT (Nevus Outreach, USA) – NEWS / SOCIAL MEDIA

MICHELLE SIBBONS (Nevus Support Australia) – EMAIL MANAGEMENT

LUCY HARDWIDGE (Caring Matters Now, UK) – WEBSITE MANAGEMENT

AIMS FOR FIRST 12 MONTHS

- DESIGN & LAUNCH NAEVUS INTERNATIONAL WEBSITE
- PRODUCE A NAEVUS INTERNATIONAL INFORMATION LEAFLET
- ESTABLISH A MAILING SYSTEM
- PRODUCE AN ANNUAL NEWSLETTER
- ESTABLISH A SOCIAL MEDIA PRESENCE

NAEVUS INTERNATIONAL WEBSITE

info@naevusinternational.com



[Leader Team](#)

[Key Objectives](#)

[Patient Support Group Network](#)

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Welcome to Naevus International

Naevus International is a new organisation established in 2017 by a multi-disciplinary team of individuals.

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

To get involved, or just to stay in touch, sign up to our mailing list.

[Join Our Mailing List](#)



Please complete the form below to receive updates and information from Naevus International.

Title

First Name *

Last Name *

Nationality *

Email Address *

Your Association To CMN



- Person with CMN
- Patient Family Member
- Patient Support Group Representative
- Medical Professional
- Scientist
- Other

Use at Naevus International we take your privacy seriously and will only use your personal information to

WHAT IS CMN

[Home](#) / [What Is CMN](#)

▼ What is a CMN?

▼ How often do CMN occur?

▼ What does a CMN look like?

▼ The size and growth of CMN

▼ CMN Classification

▼ Spontaneous lightening of CMN

▼ Problems with CMN

▼ Complications of CMN

▼ Sun protection

▼ Can CMN be treated with surgery?

▼ What can we do about hairiness?

▼ Psychological issues

▼ What causes CMN?

▼ Family history of CMN and the red hair gene

▼ The genetics of CMN

▼ CMN syndrome



Jun • 23 • 2018

Naevus

INTERNATIONAL

Join us for the first Naevus International Conference

[Latest News](#)

Naevus International (NI) is a new cross-disciplinary initiative which aims to disseminate information on Congenital Melanocytic Naevi (CMN) to a global audience of patients, families, support groups, psychologists, social teams, doctors and scientists.

[Read article ▶](#)



Apr • 25 • 2018

Naevus

INTERNATIONAL

Naevus International launch!

[Latest News](#)

We are thrilled to announce the launch of Naevus International – a new international cross-disciplinary initiative related to congenital melanocytic naevi (CMN).

[Read article ▶](#)

PATIENT SUPPORT GROUP NETWORK

[Home](#) / [Patient Support Group Network](#)



Argentina



Australia



Belgium



Brazil



Canada



Columbia



Czech Republic



France



Germany



Italy



Israel



Netherlands



Portugal



Republic of Ireland



Spain



South Africa



UK



USA

WHAT NEXT



- Continue to update the website
- Seek contribution from you (news stories)
- Develop a research section
- Develop a support material section
- Develop an area specifically for PSG updates

INFORMATION LEAFLET



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:

ArgentinaNervus Argentina
AustraliaNervus Support
BelgiumFlying for Lily
BrazilAssociação Nervus Brasil
CanadaAssociation Nervus Quebec
Czech RepublicFundación Lucas Quiroga
FranceF30 expected soon
FranceANVC Association du Naevus Séant Congénital
FranceNervus 360 France Europe
GermanyNervus Network Deutschland
ItalyNervus Italia Onlus
IsraelChildren of Light
NetherlandsNervus Network Nederland
PortugalAssociação Nervus Portugal
Republic of IrelandCaring Matters Nerv
SpainJas Nervus
South AfricaNervus Association South Africa
United KingdomCaring Matters Nerv
United States of AmericaNervus Outreach
United States of AmericaThe Nervus 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

Email: 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



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 CMNs have an increased risk of melanoma (a type of cancer). At the moment, large or multiple CMNs are mostly untreatable.

What is CMN Syndrome?

CMN syndrome is the association of these biomarkers 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 CMNs 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. CMNs are permanent.

What size and how frequent are CMNs?

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

Can CMN be treated with surgery?

Large or multiple CMNs 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 psychological 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. These 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 CMNs (or their families) to keep explaining about their biomarkers. CMN skin is often more fragile than normal skin and can therefore tear easily if traumatised. Some CMNs 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 CMNs 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 CMNs. Current published recommendations based on the largest prospective cohort of CMN, demonstrate clearly that babies born with two or more CMNs 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 20% 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.



EMAIL SYSTEM



Email groups:

- Person with CMN
- Patient Family Member
- Patient Support Group Representative
- Medical Profession
- Scientist
- Other

SHARING NEWS



NAEVUS INTERNATIONAL NEWSLETTER

- Newsletter to be sent out following the annual conference
- Contribution from each Naevus International group

REGULAR UPDATES FOR TARGETED AUDIENCES

- Regular team updates sent via email
- Use of Social Media

SOCIAL MEDIA PRESENCE



Follow us on Facebook



Coming soon!

HOW WILL WE ACHIEVE EXCELLENT COMMUNICATION



COLLECTIVE CHARACTERISTICS TO ACHIEVE EXCELLENT COMMUNICATIONS





THANK YOU

Maevus