

Your details

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Gift Aid your donation

☐ Please treat all donations I have made over the previous six years and all future donations to Caring Matters Now as Gift Aid donations. Please remember to inform us of any changes in your tax status. To qualify for Gift Aid, what you pay in income tax or capital gains tax must at least equal the amount we will claim in the tax year.

Keep me updated

Caring Matters Now takes your privacy seriously and will only use your personal information to create your personal profile, fulfil any requests, and to help deliver and improve our services to you.

By submitting this form, you consent to us contacting you about our services and ways you can help.

We promise to always keep your details safe and we will **NEVER** share or sell your details with unauthorised third parties. If you change your mind about hearing from us, you can stop receiving our updates at any time by emailing info@caringmattersnow.co.uk or calling **07786 458883**.

To receive the best support and services we recommend you select all the contact options below.

Please contact me by (please tick):

| | |
|--------------------------------|-------------------------------|
| <input type="checkbox"/> Email | <input type="checkbox"/> Text |
| <input type="checkbox"/> Phone | <input type="checkbox"/> Post |



Aims of the support group



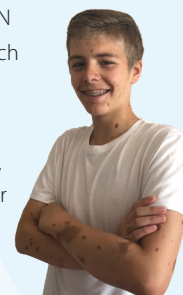
The support group has three main aims which are:

- To support those affected by CMN
- To raise awareness about CMN
- To raise funds for CMN research

The support group today



Caring Matters Now became a registered charity in 2007. Today, the CMN support group has over 250 registered families and operates through a team of support contacts across the UK. Although the charity primarily supports those living in the UK, it also has an international support contact who is happy to provide support and information to families outside the UK.



What we fund



Caring Matters Now is committed to raising funds each year to further the CMN medical research, led by Dr. Veronica Kinsler at The UCL Great Ormond Street Institute of Child Health (ICH) and Great Ormond Street Hospital for Children (GOSH). Caring Matters Now charity is a substantial and crucial funding source for CMN research.



www.caringmattersnow.co.uk/cm-n-research/introduction/

How you can help



Caring Matters Now is a not-for-profit organisation and relies entirely on kind donations from members and supporters. We are committed to spending donated funds as wisely and effectively as we can in order to fulfil the 3 main aims of our charity.

For ideas on how you can help, take a look at our website www.caringmattersnow.co.uk/get-involved/how-you-can-help/

✉ **Caring Matters Now** | PO Box 732 | Cambridge | CB1 0QF
☎ 07786 458883 @ info@caringmattersnow.co.uk 🌐 www.caringmattersnow.co.uk

Registered Charity No: 1120988

Research programme undertaken by:

Dr Veronica Kinsler

Paediatric Dermatology Department, Great Ormond Street Hospital, London WC1N 3JH



UNDERSTANDING Congenital Melanocytic Naevi



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. Some 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 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 are often difficult to treat with surgery, but some surgical treatments are available for smaller naevi. 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.

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, but the site of the CMN doesn't make any difference to the chances of brain problems.. Babies born with two or more CMN require a single screening brain and spine MRI scan to look for these complications, so that they can have treatment if necessary for hydrocephalus, brain malformations or tumours, and because the scan is the best predictor of neurodevelopment and melanoma risk. Older children who are well and have never had a scan do not need to have one routinely.

The second most common complication is melanoma of the skin or brain, which can occur in up to 10% of those with the largest or most numerous CMN, and particularly in children with complex abnormalities on the 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.



Donation form

We welcome any kind donations to support the work of Caring Matters Now and the CMN medical research.

Please detach and return this form to:

Caring Matters Now, PO Box 732, Cambridge, CB1 0QF

Thank you for supporting Caring Matters Now!



Become a CMN Hero

I would like to become a **CMN Hero** and pledge to make a monthly donation of:

£5 ☐ **£10** ☐ **£15** ☐ **£20** ☐

Direct Bank Transfer

Transfer your donation directly to our bank account by completing this form and returning it to us. We will make contact with you on receipt of this form to set up your monthly pledge donation.

Online

Monthly donations can be set up with **Just Giving** by visiting www.justgiving.com/caringmattersnow

Give a one-off donation

I would like to make a one-off donation of: £

By Cheque


Simply send us a cheque made payable to **Caring Matters Now** to PO Box 732, Cambridge, CB1 0QF along with this form.

Online

By visiting www.justgiving.com/caringmattersnow

Text

Text CMNL18 £10 to 70070

 JustTextGiving by Vodafone. Terms and conditions apply www.vodafone.co.uk/about-us/just-text-giving/donors/index.htm

You really can make a big difference to the lives of those with Congenital Melanocytic Naevi

