

How you can help

Caring Matters Now is committed to raising funds each year for the CMN medical research which is taking place at Great Ormond Street Hospital. We are the sole funding source of CMN Research at GOSH which amounts to approximately £30,000 per annum. Without this funding, all research would cease.

Caring Matters Now is a not-for-profit organisation and relies entirely on the kind donations from family members and friends. We spend our funds as effectively as we can – we have no paid staff and administrative costs are kept to a minimum, representing about 4% of income to cover the costs of our family day events and marketing. Many other costs are covered without reimbursement by our volunteers and sponsors.

Here are some ideas to show how YOU can help:

- ▼ **Direct Debit** - a regular direct debit which can start from as little as £2 per month
- ▼ **www.charitychoice.co.uk** - search for 'Caring Matters Now' as your chosen charity and donate online
- ▼ **www.easyfundraising.org.uk** -shop online with virtually any company and with each purchase you make, a contribution will be made to Caring Matters Now – without any extra charge to you.

But the best way of raising funds is to get involved and organise an event yourself! In every case you will be amazed how many of your family and friends want to support and help you. Take a look at the website (www.caringmattersnow.co.uk) and click on 'Fundraising' for tips.

Where can I get more information?

The patient support group Caring Matters Now produces a detailed information booklet about CMNs. Signing up for their newsletter means you can also keep up to date with the research. For more information visit our website www.caringmattersnow.co.uk



Congenital Melanocytic Naevi



Caring Matters Now

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Charity No. 1120988

www.caringmattersnow.co.uk

Great Ormond Street Hospital for Children, London,
and St John's Institute of Dermatology, St Thomas' Hospital, London

What is a CMN?

CMN stands for Congenital Melanocytic Naevus. A CMN is a brown or black mole present at birth. They can occur anywhere on the skin including the scalp and can be any size. The largest can cover up to 80% of the body surface area and often there are also many small CMNs (satellites).



Why do they occur?

It is not yet known why CMNs occur and research is underway to try to establish the reason. The likely cause is due to a change in the instructions of how to make the skin when a child is developing during pregnancy. This type of change is called a gene mutation.

What size and how frequent are CMN?

A 'small' CMN is one that will measure less than 2.5cm (1 inch) across in adulthood; a 'medium'-sized CMN measures between 2.5-10cm across, a 'large' CMN is between 10-20cm and a giant CMN will measure more than 20 cm across. Using these definitions, a small CMN will be found in about 1 in 100 newborn babies and giant CMNs only occur in 1 in about 20,000 newborns making these more of a rare occurrence.

Will the CMN shrink as the child grows?

No, the CMN will grow in proportion to the child. This means it will always cover the same part of the body as it did at birth. However, the colour often becomes lighter with age.

Can the CMN become malignant or cancerous?

This is a rare complication of CMNs and most CMNs will never become malignant. However, all people with CMNs should take

good sun protection measures. The overall chance of malignant melanoma is around 1%, but this is higher in very large CMNs.

Are there any other complications of CMNs?

Most people with CMNs will not have any associated complications. Although in some cases, people with CMNs may have the same moles on the brain or spinal cord which can cause complications.



An MRI scan can determine whether this has occurred at a young age. Some children who suffer with CMN can have delayed development or fits.

What treatments are available?

Depending on the size, site and colour of CMNs, they can be unsightly. Some are highly disfiguring and therefore, a potential cause of great distress. Unfortunately, CMNs cannot be completely removed without trace, but some surgical and laser treatments are available for smaller, easy site removal. Please refer to our more detailed booklet for information.

Can I be involved in the research?

Yes. There are two important ways to get involved:

- 1 By taking part in the research studies. For this you need to be referred by your doctor to:

**Dr. Kinsler, Paediatric Dermatology Department,
Great Ormond Street Hospital, London WC1N 3JH.**

- 2 By helping the Caring Matters Now support group to raise funds to support the research.

Details can be found at www.caringmattersnow.co.uk.

How was the support group set up?

In 1998 Dr Atherton, who was then the leading medical Congenital Melanocytic Naevus (CMN) skin specialist in the UK, asked Jodi Unsworth, a CMN sufferer, to provide support for those affected by CMN throughout the UK. There was no support for sufferers or parents of children suffering with the rare skin condition at the time. Jodi, who was 18 years of age, started offering support along with her parents to those affected by CMN. It became obvious that those affected were desperately needing support, advice and to be in contact with others affected by the same condition.



Jodi Unsworth

Jodi was born with CMN covering 80% of her body and understood the physical and emotional strains associated with the condition firsthand. As a result, the Caring Matters Now Support Group was established in 2000.



Aims of the support group

The support group has three main aims which are:

- ▼ To support CMN sufferers and their families
- ▼ To raise awareness about the CMN skin condition
- ▼ To raise funds for the CMN research

The support group today

Today the CMN support group has over 180 families registered with 12 regional support groups in operation. A small team of those with CMN and parents of children with CMN run the support group throughout the UK. Caring Matters Now became a registered charity in 2007.

