

# CONGENITAL MELANOCYTIC NAEVI

- INFORMATION FOR FAMILIES -

**Dr David J Atherton MA MB BChir FRCP, Consultant in Paediatric Dermatology,  
Great Ormond Street Hospital for Children, London, and St John's Institute of Dermatology, St Thomas' Hospital, London**

.....

## *What are they?*

A *congenital melanocytic naevus* (often abbreviated to *CMN*) is one of many different types of birthmark that may be found in newborn babies:

- *congenital* indicates that the abnormality is present at birth
- *melanocytic* is the adjective derived from the word *melanocyte*, a type of cell present in normal skin and in certain other organs, whose function is to produce *melanin* - a brown pigment
- *naevus* is the technical (Greek) word that dermatologists (skin specialists) and paediatricians use to describe any type of birthmark that occurs in the skin', the plural is *naevi*

Birthmarks are really just manufacturing mistakes, the visible effect of errors that have occurred during a child's development before birth. The causes of such developmental errors are not known for certain, but may include exposure to radiation during pregnancy, infections during pregnancy, and exposure to certain drugs and, perhaps, certain chemicals including some that may sometimes be present in food.

A CMN is composed of a large collection of melanocytes, and is regarded as a type of benign tumour. Why such a collection develops is still unknown. Melanocytes originate in the region of the developing spine, and migrate along nerves that emerge from the spinal cord and connect it with the skin. As they arrive in the skin, they normally spread out and are evenly and thinly distributed among the other skin cells. Their function in the skin is to produce pigment, which protects the skin from damage by the ultraviolet rays in sunlight. The amount of pigment they produce depends on skin colour and the degree of exposure to sunlight. It seems likely that a CMN reflects a failure of the normal process of migration of melanocytes into the skin. Instead of flowing out smoothly into the skin, many cells gather at the same spot. This might happen because their progress is somehow impeded, or because they are actually attracted to this site and collect together there voluntarily.

### ***How common are they?***

CMNs are quite a frequent type of birthmark, occurring in about 1 in 100 newborn babies. However, most of them are small, less than 2.5cm (1 inch) across at birth.

Larger ones are rarer. What dermatologists regard as a medium-sized CMN (2.5-20cm) will be seen in approximately one in 1,000 newborns, whereas what would be regarded as a large (sometimes called 'giant') CMN (greater than 20cm across) would only be seen in one in about 10,000 newborns.

### ***Characteristics of CMNs.***

Although a CMN is primarily a collection of melanocytes in the wrong place, to gain some understanding of what one sees when one looks at a CMN, it is important to be aware while this is quite true, there is more to it than this basic fact. A CMN may show a number of characteristics which vary considerably from CMN to CMN, and which may change somewhat in a single CMN over a period of time. Features which parents need to understand better include:

- **size**

CMNs vary greatly in their size, from a few millimetres to many centimetres across. The very largest may cover most of a limb or much of the trunk. However, as the figures above indicate, the smaller ones are far commoner. As the child grows, the CMN will enlarge in proportion to the child's general growth. Occasionally, during the first year or two there may be some true extension of the pigmentation at the outside edge, but this does not usually lead to a substantial increase in the overall size of the CMN.

- **site**

In my own work in a clinic with CMNs, more of the children I see have lesions on the head and neck than anywhere else, but this may simply reflect the greater potential for disfigurement when the lesion involves the face. After the head, the commonest site is the trunk, where most CMNs occur in the mid-line of the back. However, CMNs can occur at **any** site on the skin.

- **pigmentation**

The colour of a CMN depends to a great extent on the background skin colour of the child. CMNs therefore tend to be lighter brown in blond-haired children, and almost black in Orientals.

Initially, they may have a rather purplish hue. Generally, they appear darker at birth, and become lighter over the next year or two. It is very rare, though not completely unheard of, for them to disappear altogether.

Their colour is rarely even, and usually varies somewhat in different parts of the CMN. Darker areas usually indicate that the thickness of the collection of melanocytes is greater.

Over the years, there may be frequent changes. Darker areas may appear, but this generally seems to have little significance.

- **hairiness**

CMNs are usually hairier than normal areas of skin, but this is very variable. In some cases, the increased hair growth is barely perceptible, whereas in others hair may grow profusely from the surface of a CMN. This increased hair growth may not be apparent in the first few weeks or months of life.

The colour of the hair over a CMN is generally relatively dark. If a CMN is on the scalp, this may result in an area of darker, more luxuriant hair growth over the lesion, which may itself be invisible under the hair.

This hair growth seems to be the result of stimulation of the hair roots (*hair follicles*) by the melanocytes in the CMN. To have this effect, at least some of the melanocytes must be situated in the deeper parts of the skin where the hair follicles are located.

- **lumpiness**

Smaller CMNs are generally more or less flat, flush with the surrounding normal skin. However, when the CMN is more extensive, quite often there are raised or lumpy areas. This doesn't imply any special medical problem, just that there are larger and deeper collections of melanocytes in these areas. Some lumps are paler and softer than the rest of the CMN, and some are firmer and darker.

- **eczema**

The skin overlying a CMN is often rather dry and itchy, and may sometimes develop eczema. This is best avoided by regular application of a moisturiser as soon as any dryness becomes apparent. Avoid the use of soap. If eczema becomes a problem, you may need to see your GP or speak to a dermatologist.

- **underlying absence of fat**

This is something that is generally only seen in the case of quite extensive CMNs, particularly those that are more than about 20cm (about 8") across. For some reason, the presence of so many melanocytes interferes with the development of the layer of fat which is normally present between the skin and underlying muscle and bone. This can result in the CMN actually appearing to be depressed below the general skin surface, or it may cause a noticeable thinness in an affected leg, for example. This has no special significance other than its aesthetic effect.

- **'satellites'**

Many children who have a CMN - particularly when this is an extensive one - will have a scattering of smaller pigmented spots elsewhere on the skin. These are known as 'satellites'. While these will usually look quite similar to ordinary 'moles', they are likely to be bigger. When they first appear - and some may already be present at birth - they are

most frequently about 0.5-1 cm across. As the child grows, they become progressively, but proportionately larger. In the end, some may be up to about 10 cm (4 inches) across. The larger ones - which tend to be present at birth - may be hairy.

These satellites can be expected to increase in number over the years, but it is impossible to predict how many are likely to appear in any individual. Their final number may be as many as a few hundred. There is a strong suspicion that exposure to sunlight increases the rate of their appearance locally, and this is one of the reasons why anyone with a large CMN should minimise sun exposure.

### ***What are the medical implications of a CMN?***

There are 3 principal implications for health of which parents should be aware:

- **risk of malignancy**

The question is whether there is a risk of malignant tumours in those with a CMN. The medical literature on CMNs has been preoccupied with this issue for many years. There has been a general assumption that larger CMNs (ie. those with a diameter greater than a few inches) carry a risk of 5-10% of becoming malignant at some time in the patient's life. It has also been assumed that the larger the CMN, the greater the risk.

In my own view, these assumptions are unreliable because they are based on information which is inadequate both in quality and in quantity. The way this risk has been calculated is to count up all the patients who have been seen in a particular hospital with CMNs, and to make a note of all those in whom malignant melanoma was diagnosed. This method can be expected to produce a very distorted picture of the situation, because patients are more likely to attend a hospital if they have a serious complication, particularly malignancy. This effect will automatically inflate the apparent frequency of malignancy in CMNs if there is a significant proportion of patients with uncomplicated CMNs who did not turn up at the hospital. In countries where patients have to pay to go to a hospital (ie. most countries in the world), they are unlikely to do so unless they can afford to, or have a serious medical problem that makes medical advice seem a priority.

Readers will understand therefore how the estimates we have are unreliable. Although it is clear that malignancy is a risk of having a CMN, we really do not know the scale of the risk based on the data currently available, and I personally believe that the risk is much smaller than has been suggested.

What is needed to sort this out is a large-scale prospective study. 'Prospective' means that one looks at this problem in a forward direction, rather than looking at it retrospectively. Patients need to be identified early in their lives, entered into a register and then followed up at annual intervals, in order to record over a period of many years just what proportion develop malignancy. We call such a group of patients 'unselected', in contrast with a group of patients who are more 'selected', ie. they have some special reason for being part of a survey.

This type of 'special reason' might include the fact that many of them were sent to hospital precisely because there had been some change in their CMN or because they had become ill. It is a fact that in retrospective surveys, the patients have usually been selected in a way that produces a bias in the results of the survey, and that bias will usually make the situation look worse rather than better than it really is.

My view, and that of Mr Bryan Mayou, the plastic surgeon with whom I have worked closely for many years, is that the risk has been exaggerated in medical books and articles, and that it is probably no greater than about 1 % - even in large CMNS. This means that perhaps one person in 100 with a large CMN will develop a malignant melanoma at some time during their life. The risk for those with small CMNs is probably **much** less. When considering these risks, you need to bear in mind that every one of us has a risk of about 40% of developing some kind of malignant tumour at some time in our lives. Having a large CMN may therefore only put up the risk from 40% to 41 %, which I think you would agree is not a great deal.

Even though it may be very rare, how does a person with a CMN know that a malignant melanoma has occurred? From many years of experience and of asking questions of my medical colleagues, I have gained the strong impression that when malignant melanoma occurs in a person with a CMN, this has usually spread into many parts of the body before there is any visible sign of a problem. It appears that there is unlikely to be any noticeable change in the CMN or in any satellites that may be present, and no real indication therefore of where the malignant melanoma started. Today it remains the case that malignant melanoma, once it has spread into internal organs, is untreatable and will almost invariably prove lethal. The only time that one will be able to cure malignant melanoma is when it takes the form of a nodule appearing within an established CMN, which may be able to be removed surgically before it spreads to internal organs. But, malignant melanoma arising in this way appears to be very much the exception. Where it does happen, a nodule may appear within a CMN and grow quite rapidly, usually soon ulcerating and bleeding. The problem is that nodules very frequently appear in CMNs which are completely harmless, harmless nodules probably outnumbering malignant ones by about 1000:1. It is worth saying, however, that ulceration of a rapidly growing nodule is a potentially serious warning and should lead to early diagnostic removal by a dermatologist or surgeon.

This situation is one that both patients and their doctors must face up to. It is a situation that has important implications in terms of how families should react and how the medical profession should manage CMNS. I will come back to these issues when I consider management.

- **risk of involvement of the brain or spinal cord**

Just as a CMN is an abnormal accumulation of melanocytes in the skin, so one can have a similar accumulation of melanocytes in the surface of the brain, where it is called *intracranial melanosis*. This condition will generally occur in combination with CMNs in the skin, and the combination is called *neurocutaneous melanosis (NCA4)*.

Intracranial melanosis may interfere with the brain's function, and the principal problems that may result are fits and developmental delay. The fits may have their onset at any age, but one would expect that this would be most likely to happen during the first few years of life. In a young child, slow attainment of developmental milestones might provide an important clue, or educational difficulties in an older child. Other symptoms that might be provoked by intracranial melanosis include unsteadiness or clumsiness, but the wide variety of possible locations of the accumulations of melanocytes is reflected in an equally wide variety of possible consequences.

Until the advent of the method of imaging the brain called magnetic resonance imaging (MRI) - also known as nuclear magnetic resonance (NMR) - it was usually impossible to identify intracranial melanosis during a person's life, and it was only ever diagnosed during postmortem examinations. There have now been a limited number of studies to try to establish just how commonly it occurs, but the results have varied by a surprising amount. Our own studies in London suggest that intracranial melanosis is relatively rare. We scanned all young children who saw us because of a CMN having a diameter greater than 2cm in diameter on the head or over the spine. In this group of patients we found evidence of intracranial melanosis in around 1 in 10 children. We had expected to find that this could occur without the child having any symptoms from the intracranial melanosis, but in fact all our patients in whom this abnormality was visible on the scan had already developed symptoms of the type I described above by the age of 18 months. However, we know that symptoms may sometimes not occur until later. How great the risk is in those cases in which the child's CMN occurs in sites other than on the scalp or over the spine is unclear. I would think that there probably is a risk, but that it would be much smaller.

Another finding in our study and other studies was that about 1 in 10 of the children did not have intracranial melanosis but did have other apparently unrelated brain abnormalities, including tumours and structural malformations. We suspect that study of larger numbers of children will show that finding was a fluke, and that the true risk of these apparently unrelated abnormalities is actually lower than this. However, it is well known that where a baby has one type of 'manufacturing error', the risk of another is always higher, and this is probably the explanation for our finding. A particular type of problem that appeared relatively frequent was the development of *hydrocephalus*, a situation in which the pressure inside the head increases because of accumulation of fluid. This can result in symptoms of the type outlined above, but also vomiting. If a baby with a CMN on the scalp starts to vomit frequently, this should therefore be brought to medical attention fairly urgently.

Currently, it is our policy to do brain scans in children with CMNs on the scalp or on the back close to the midline. We believe that the best time to scan is probably in the second year of life. It is now clear that the immaturity of the brain during the early months of the first year can lead to apparently abnormal scans which will subsequently become normal, so we find we can avoid any confusion by waiting.

We are not sure that we will find everything in the second year that could be found later, but we are keen not to miss tumours or malformations that might be removed surgically before they cause too much of a problem.

- **risk of involvement of the eye**

We have found that when a CMN is very close to an eye, there is a small risk of an abnormality in the eye known as *glaucoma*. Glaucoma means that the pressure of the fluid in the eye is increased, either because of overproduction of the fluid, or because it cannot drain out of the eye in the usual way. It is perhaps most likely that the glaucoma we occasionally see in this situation is due to interference with the drainage process, but the exact reason is unknown. Glaucoma of this type can be treated surgically; it is important to do so as soon as possible after it is recognised because, after a period, the increased pressure can begin to damage the eye and reduce vision. For this reason, it is important to have the pressure in an eye checked when there is a CMN very close to it, and even if the pressure is normal at the time, it is probably wise to re-check every year in the early years, and regularly, but perhaps less frequently, in older children and adults.

When a CMN is close to the eye, there may be accumulations of melanocytes in the outer part of the eye, causing darker -often blue - patches over the white areas (the *sclera*). These almost never have sinister implications. Although they may be aesthetically undesirable, they cannot be removed.

### ***What treatment is available, and should my child have treatment?***

The majority of CMNs are unsightly. Some are disfiguring, and these may be a cause of great distress. If CMNs could be completely removed, easily and without trace, there would be little for us to discuss here. Sadly, for the time being this is not the case. Removal of the full thickness of a CMN cannot be achieved without a degree of scarring, and partial thickness removal, while it may result in little or no scarring, produces rather variable reduction in pigmentation and hairiness. Therefore, difficult decisions may have to be made in many cases, in an attempt to balance the pro's and con's of treatment or inaction. The situation is not made easier by the very patchy availability of the full range of treatments around the UK.

Let us start by considering the 2 principal methods, full-thickness and partial-thickness removal. To understand these terms requires a basic knowledge of the way the skin is constructed. The skin consists of 2 layers, the *epidermis* on the outside surface, and the *dermis* immediately below. The deepest layer of cells in the epidermis is called the *basal layer*. This layer produces cells at a rapid rate. These cells are known as *keratinocytes*, so named because they produce proteins called *keratins*. As these cells mature, they are continually pushed upwards by the cells that have been most recently produced, until they reach the surface. As they mature, they become increasingly flatter and waxier, so that the surface of the skin is protected by a layer of these waxy plates, a layer that is called the *stratum corneum*.

The toughness of these plate-like cells is a function of the keratin proteins with which they are packed. When the skin is damaged to such a depth that some of the epidermis is lost, repair occurs by means of basal layer cells from neighbouring epidermis spreading out on to the surface where they start to produce keratinocytes. This spreading out takes place from the nearest site at which these basal layer cells remain intact, and they cannot travel very far very quickly.

To understand this process better, you need to be aware that the epidermis is not simply a thin, flat layer like butter on bread, but a more complex structure with parts that penetrate more deeply. The parts that penetrate deeply are the hair follicles and sweat glands. These are extensions of the epidermis that have special functions, but they nevertheless have the ability to provide basal layer cells to help with healing after an injury. Full-depth skin loss implies that these structures have all been lost, so that the only source of basal layer cells is from the periphery of the wound. Healing from the edge of a large full thickness wound would take so long that infection and other complications would be invariable, and the quality of the wound would be very poor indeed, even if the person survived. Therefore, full thickness loss of skin requires the wound to be closed either by bringing the edges together in some way, or by bringing in skin from some other site to cover the denuded area.

Partial thickness skin loss will heal quickly, because there will be plenty of hair follicles and sweat glands remaining, which can provide basal layer cells to repopulate the area of loss. This is the way a graze heals.

- **full-thickness removal**

The surplus melanocytes in CMNs often reach a considerable depth in the skin. Generally, the more extensive, the lumpier and the hairier the lesion will be and the greater the depth to which these cells will be situated. To remove all the cells will invariably mean full-thickness excision of the skin, as defined above. The defect left in the skin will not heal unless it can be closed, either by stitching up the edges or, where there isn't enough normal skin left, introducing a piece of skin from elsewhere. The ways in which skin closure can be achieved requires further explanation.

Where there isn't enough skin to stitch together the edges of the area, there are 3 main ways in which this could be overcome: grafting, rotation flaps, and tissue expansion.

**Grafting** means that skin is removed from another site, known as a donor site, and placed on the defect. This is an easy and quick way of covering large areas, so long as there are suitable donor sites from which normal skin can be harvested. The graft is usually partial thickness so that the donor site will heal quickly and without scarring. Full-thickness grafts are sometimes used; these will generally be smaller and will have to come from a site where the resulting defect can be closed easily, usually behind the ear, or in the groin, for example.



The problems with grafts are mainly that they don't always 'take' as well as one would wish, and the final aesthetic appearance is not that good. Grafted skin tends to look a little unsightly, and for this reason, grafting is generally avoided where excision is planned primarily on aesthetic grounds.

**Rotation flaps** are areas of full-thickness skin that are partially lifted off the underlying tissues, and moved with their blood vessels still connected, to fill a defect in the neighbouring area. It is rather difficult to describe exactly how this is done, but whether it is an option depends very much on the site. The scalp and the face are, for example, good sites for this technique.

**Tissue expansion** is a relatively new technique in which the amount of skin available to close a defect is increased by stretching the normal skin around the site where excision is planned. Usually this stretching is achieved over a period of weeks. The first stage is the insertion, at an operation, of a 'balloon expander' just beneath the skin. The balloon is made of thick expendable rubber, and has a 'reservoir' attached, also under the skin, through which the balloon can be filled by injecting it with water at regular intervals. The injections can be undertaken by parents or by a nurse. When the skin has been adequately expanded, the excision of the CMN is scheduled and the balloon will be removed during the operation. The main problems that are encountered during tissue expansion are the unsightliness of the swelling that is visible while the balloon is in place, infection of the tissues around the balloon, and death of the overlying skin if the stretching is too great. Like rotation flaps, this is a technique that is only suitable for certain sites.

Occasionally, where the amount of extra skin required is not great, the expansion can be done quickly during the operation itself.

- **partial thickness removal**

If the skin overlying a CMN is removed to partial thickness, it will only be possible to remove a proportion of the melanocytes. Healing will be quick, as in a graze, generally within about 10 days, and will not require any of the techniques described above. The healed skin may be sufficiently opaque to conceal the remaining pigmentation below.

In the past, partial thickness ('superficial') removal of a CMN was done by a technique known as *dermabrasion*, using a rotating abrasive ball. As you can imagine, this was messy. Another technique is to remove a thin layer of skin with a special blade called a *dermatome* - the same type of blade that is used to take partial thickness grafts. Yet another technique is to use a *curette*. A curette is like a very small spoon with sharpened edges, that can be used to scoop out bits of skin. This has the advantage of allowing variation in the depth to which skin is removed. However, today the preferred technique for superficial removal is usually the carbon dioxide laser. This also allows controlled depth of removal, without bleeding, and with less pain after the procedure.

The results of superficial removal are very variable, and fairly unpredictable before surgery. The main problem is that the treated site can be painful and oozy for a few days afterwards.

The treated area may look good initially, but later on pigmentation may occur around the edges (what we call a 'tide-mark'), and spotty pigmentation may recur in the treated area. This technique will not of course deal with hairiness, because the hair follicles are not removed.

In reality, it is possible to use combinations of these techniques to treat a CMN, either at once during a single operation, or at different times.

### ***Does treatment reduce the risk of malignancy?***

It is known that removal of CMNS, even to full depth, does not completely eliminate the risk of malignancy. It is unclear whether it has any benefit at all in this respect, though it is generally thought likely to do so, and it is thought likely that the deeper the excision the greater will be the benefit. Because of these doubts, and because the malignancy risk has in any case probably been exaggerated, I do not personally recommend excision on the grounds of reduction of malignancy risk alone. We believe that the principal reason for surgery must be aesthetic, and if there is an associated reduction in risk of malignancy, it would be a bonus.

### ***At what age should CMNs be treated?***

I would always favour early treatment.

In the case of full thickness excision, this means that treatment should ideally be completed, or at least started in the first 4 years of life. Early treatment has many advantages. The lesions are going to become larger with growth, and therefore more difficult to remove. The skin is more distensible in early childhood, and therefore it is easier to close up defects. The psychological impact of surgery is less; this is particularly important in cases in which tissue expansion is to be employed. There will be less interruption of education or employment.

In the case of partial thickness removal, it appears that the results are only really worthwhile if the surgery is done in the first 2 years of life, and many believe that the results will be best if the procedure is undertaken within the first few months. The reasons for this are unclear.

### ***What treatment is available for 'satellites'?***

For some reason or another, satellites do not appear to be very responsive to superficial removal, and the only satisfactory method is to cut them out altogether. This may be worthwhile for a small number of these lesions, but if it is envisaged that large numbers will be removed, the appearance of the scarring that will result will almost certainly be unacceptable.

### ***What can we do about hairiness?***

Permanent hair removal is currently not available. Although much has been said about laser hair removal, it is not yet a really satisfactory treatment for large areas, nor is the effect usually very long-lasting. Neither is electrolysis suitable for large areas. Electrolysis could be used to remove hair from small areas, but it is uncomfortable, usually too uncomfortable for children. In general, the most satisfactory methods of hair removal are by shaving or by use of depilatory creams. Because the creams can irritate the skin, I feel that shaving is usually going to be the best option. An electric shaver is probably best, and the models designed for use on women's legs are probably best of all. It is important to be aware that shaving will not result in the hair coming back more stiffly or more thickly. In practice, the hair tends to regrow rather slowly and with just the same texture as before. Most parents find that they do not need to shave an area more often than once every month or two to maintain a satisfactory appearance.

### ***Are there any special precautions my child should take?***

The most important precaution is sun protection. This is to do with the risk of malignant melanoma, which we discussed earlier. Although it is not absolutely clear, the evidence suggests that it is not just the CMNs themselves which are at risk of developing malignant melanoma. It seems likely that the risk also applies to the areas of skin that look perfectly normal. We should probably think of a CMN as an indicator of increased general risk of malignant melanoma, just as we do for blond or red hair, blue eyes, and skin that goes red quickly in the sun and rarely tans. If this is true, and it does seem to be, then it is clear that sun protection is required for **all** areas of the child's skin, not merely the CMNS. We know that the greatest risk factor for malignant melanoma is sunburn and this has especially to be avoided. However, the presence of the sun is a fact of life, and complete avoidance of exposure of any part of the skin at any time is an impossibility. Therefore one has to achieve a compromise. When considering this subject bear the following general rules in mind.

- the sun is most harmful during the months April to October, inclusive
- on a daily basis the sun is most harmful during the hours 10am-4pm, inclusive
- exposure is increased greatly by reflection when beside water or snow
- the sun is more harmful at higher altitude
- the sun remains almost as harmful in cloudy conditions
- the best protection is clothing, which is most protective when of dark colour
- shade (including hats) provides some protection, but less when near water or snow, or when the weather is cloudy
- sunscreens are only the last barrier, and are not a substitute for other forms of protection
- the best sunscreens contain a reflectant barrier such as titanium dioxide, and it is best to select a high protection factor, ideally above 25
- sunscreen needs to be refreshed every 2 hours or so, more often when swimming or sweating

### ***Will our next child be at risk of having a CMN?***

CMNs appear to be largely one-off manufacturing errors. One would therefore anticipate that the risk to any further children of a couple who have a child with a CMN would be very small. Similarly, one would anticipate that the risk of a person with a CMN themselves having a child with one would be very small. Readers need to bear in mind that small CMNs are common, while large ones are not.

### ***Is there a support group?***

The Birthmark Support Group

Address:

BM The Birthmark Support Group  
London  
WC1N 3XX

Phone: 0845 045 4700

Website: [www.birthmarksupportgroup.org.uk](http://www.birthmarksupportgroup.org.uk)

Email: [info@birthmarksupportgroup.org.uk](mailto:info@birthmarksupportgroup.org.uk)

### ***Is any research being done, and can we help?***

Sadly, a great deal of research is not currently being undertaken in this field. However, a register of affected people has been established to help those who might wish to undertake research projects. The Registry is based at Great Ormond Street Hospital for Children in the adjoining research wing, the Institute of Child Health. It is run by Mrs Jan Birley, who can be contacted by post as follows: Mrs Jan Birley, CMN Registry, Dermatology Unit, Institute of Child Health, 30, Guilford Street, London WC1N 1EH.

We have for a few years been undertaking a long-term project through the Registry which aims to collect information about:

- the site and size of CMNs
- the pregnancy of the mothers
- the presence of pigmented skin lesions in other family members
- the type of treatment that has been offered, and whether it was a success
- the way that CMNs change over the years
- the development of 'satellite' lesions
- the development of complications, particularly malignant melanoma

Anyone who has a CMN greater than 2 cm in diameter is invited to contact the Registry in order to join in the project, which is going to provide very important data. All information held by the Registry is completely confidential and will not be released to

anyone without express permission. If other researchers wanted to invite registrants to take part in a project, a letter would be sent to Jan Birley to registrants to seek their permission, in the absence of which no information would be released.