



The Birthmark Support Group

ISSUE 3 / JULY 2002

Welcome Back

Hello again everyone and welcome back.

First of all, I must apologise for the long delay in the production of this newsletter.

It's all my fault, I'm afraid. I've moved house, had another baby and with my other BSG duties I've not been able to concentrate my time on the newsletter.

I guessed you'd want to read something a bit more interesting than an episode of 'Bill & Ben', so decided to delay this publication and (hopefully) get it right.

Since our last Newsletter, the group has achieved two major goals:-

- **The launch of our website**
(full story on page 4).
- **Charity status**

I do hope you enjoy this newsletter and please let us know if you have anything you want us to include.

Don't forget, this is YOUR support group and YOUR Newsletter so go on, don't be shy.

New Committee

We have had a bit of a change-around since our last Newsletter.

To introduce ourselves, we are:-

- Mark Lingfield**Chairman
- Sylvia Carpenter**Secretary and CMN Contact
- Louise Busfield**Treasurer, Publicity
and Merchandising
- Ian Clover**IT Development and Support
- Nicky Pilmoor**Northwest Regional Coordinator
and Haemangioma Contact
- Jane Linward**Nursing Advisor
- Toni Lingfield**Group Representative
and PWS Contact

Charity Status

Yippee! After inches of paper work and reams of red tape, your Birthmark Support Group is at last a registered charity (No 1090952).

Now that we are 'official' we can focus more closely on raising the funds needed to expand the range of services we offer.

Talking of funding (oh no, she's after our money again) - if you're a taxpayer, by completing the attached covenant form and returning it with your donation, the government will top-up your contribution by 28%.

We rely entirely on your generous donations and every single penny raised goes directly into the group.

Please Help

As you know, we are run by a small group of families who give their time and hard work completely free.

Our group is rapidly growing and developing and so is the workload.

I know we all seem to lead incredibly busy lives - we work, run a home and family, juggle hospital appointments,

etc - but maybe you feel you would like to 'do your bit'.

You don't need to commit to a regular amount of time, but perhaps you could take on a one-off job. How about helping us with our mailing list, selling raffle tickets or helping at the next family day? You don't have to take on a whole task, just a small part.

I promise you, helping these kids is one of the best 'feel good' things you will probably do in your whole life - don't sit around and think about it - *do it now*.

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Our Motto
Smile & Face It

Flyers

Please (with appropriate approval) could you display our flyer in your GP's surgery, Health Centre or (even better) on the notice board of your local maternity hospital.

Remember how you felt when your child was born - all those questions nobody seemed to have answers to, not knowing where to turn for help and advice? No family needs to feel isolated again. Display this flyer and if you help even one family, one child, it will have been well worth the effort.

Your Stories

We have two "Your Stories" in this CMN edition of the Newsletter. The first is about little Harriet who is only eighteen months old and still has a long way to go with her treatment. The second story is about Robert who is now seven and whose treatment is almost complete.

I would like to thank both Harriet's mum Paula and Robert's mum Grace who have taken the tears and time to write these moving accounts of how CMN has touched their children's lives.

HARRIET

We were expecting our second child on April 20th 2000. We already had a son, Joseph, and though two boys would have been fun, we were hoping to give him a sister.

Harriet was born on the 17th April 2000 at 5.20pm. We could not believe our luck - a little girl!

Straight after delivery, we knew something was wrong by the behaviour of the midwife. She kept calling and calling for a paediatrician.

We asked what was wrong and she told us our baby had some marks on her. "What sort of marks?" we asked. She picked Harriet's little body up and held her high in the air - an image that is still with me.

We could not believe what we were seeing. Three quarters of her back was covered with a black/brown mark, like a giant mole. She also had about fourteen large round marks on her head; she had a large one on the side of her face, and various ones on her arms and legs.

Two paediatricians examined Harriet but had no idea what the marks were, so a consultant paediatrician then came to look her over. She told us Harriet was fine but still could not put a name to these marks. As Harriet lay in my arms she looked so beautiful.

Andrew (my husband) went to let the family know we had a baby girl, and that she had a few marks but hadn't told them to what extent.

My sister and brother arrived as I was crying on the phone to my mother. We were both in a state of shock. My husband was fantastic, saying how lovely she was, which was of course true. The midwives were lovely but again no one had seen anything like it.

We were told that a dermatologist was visiting another baby the next day and that she would try and see us as well.

The dermatologist came and she gave Harriet's condition the name of CMN. Her knowledge of the condition was limited and she basically told us that Harriet would have to learn to live with her marks. The dermatologist had not set our minds at rest - in fact, we were more upset after seeing her.

Luckily, another consultant paediatrician offered to refer us to a plastic surgeon as she felt sure something could be done for Harriet.

Two weeks later we saw our plastic surgeon. He was great. He was totally honest, told us what he could do for Harriet, but warned it would take time. I can't believe all that happened in the first year of Harriet's life and we have now come such a long way.

Little Harriet has so far had five operations but the results are truly amazing. She still has many more operations to face but seeing the astonishing results prove it is so worthwhile.

Her last operation was to have her tissue expander taken out and some of the large nevi removed from her back. The plastic surgeon has managed to remove half the mark which is just amazing and the skin now looks completely normal.

This is going to make such a difference to her life. I do have trouble with myself and whether I should be putting my daughter through this, but as a mother I feel it is my duty to do the best for Harriet and this surgery is the best, though it breaks my heart each time I leave her in the anaesthetic room.

Harriet's battle with CMN is far from over - there is a risk it may affect her nervous system. To cap it all, a chance of more marks appearing one year on.

We feel very lucky to be under the care of a fantastic plastic surgeon who has worked such miracles with Harriet.

My husband and I have struggled through the last year asking ourselves nearly every day, "Why?" Of course there is no answer. We look at life very differently now, we appreciate what we have, and we consider ourselves to be lucky. We have two lovely children who bring us lots of love and happiness.

Your Stories *(continued)*

ROBERT

Our son Robert was born with a birthmark - this covered most of his cheek, under the eye and looped slightly over the nose. It was a dark brown mark and was covered in hair.

Robert was born by caesarean section and because my husband wanted to watch the birth I stayed awake.

When Robert was born my husband told me he had a birthmark under his eye. I just thought this would be a small red mark, so it was a bit of a shock when I saw the type of mark and how large it was.

I had never seen a birthmark like this one before, it was very dark almost black. As I am a diabetic Robert was taken straight to the baby care unit, which is a normal procedure for babies with diabetic mums.

My husband went home and I was on my own - I just sat and cried. I went through all the questions: Why me? Why my baby? They finally brought Robert to me, and as I'd had a caesarean we had to stay in hospital for seven days. We were put in a room by ourselves and I felt most people seemed to be avoiding us. This made me feel very alone.

My husband and I made several attempts to see the doctors but were only seen by a paediatrician the day before we were discharged. I was unhappy and felt I had been fobbed off with excuses and told them so. They apologised and told us they had been short staffed and busy dealing with very sick premature babies and did not have time to come and see us.

We were unhappy at this, as it implied Robert's problem was 'only a birthmark'. Whilst we appreciate it may not have been as urgent as other cases we had never seen anything like this before and had no idea what we were dealing with. I wondered if it had been anything to do with something I had eaten or done during pregnancy.

We were finally referred to a laser doctor at our local hospital. He did a dermabrasion on Robert's face when he was six weeks old and another at ten weeks. He told us this may lighten the mark but it would not remove the hair. After two treatments it did seem lighter but now was more scarred and even hairier.

We then started going to a support group where we finally found out that Robert's birthmark was called a Congenital Melanocytic Nevus. We also learned of tissue expansions and were fortunate to see firsthand the results; we were impressed! We were told this treatment was done at St Thomas's Hospital, London.

When we saw our local doctor we spoke about tissue expansion but he was not interested. At a later appointment he said 'he did not think he could do anything for Robert that he could be proud of'. I think this finally made up our minds to have Robert transferred to London. We got our GP to refer us.

What a difference - how nice to be treated as though our son's problem mattered. They were very kind and seemed to understand everything we were going through.

They told us of other people with the same problems and explained what could be done to improve the situation. They explained fully about tissue expansion and the operations Robert would need. So we went ahead. We did not do this lightly but felt we had to consider Robert's future.

To us he was our son - it didn't matter about his birthmark, we loved him whatever - but when we took him out and had to answer all the endless questions and put up with the stares, we realised we had to go ahead. I think the hardest part was having to constantly explain to people why we were doing this.

Robert's had a lot of operations since he was six months old. It's surprising how quickly he bounced back and how fast the surgery has healed.

He is now seven and all his birthmark has been removed. We are very pleased with the results and feel it was all worthwhile, especially when we compare the before and after photographs. We are in no doubt that we made the right decision.

People seem able to accept scars but have more difficulty dealing with anything that is different. Robert still has a problem with his eye, and we are waiting for him to go in to have it treated.

It has not all been plain sailing and there were times when we wondered if we had done the right thing, but if we had to choose again we would make the same decision.

Family Day

I am pleased to announce the details of our next Family Day and AGM from noon - 5pm:-

Sunday 8 September 2002

Corams Fields - 93 Guilford Street, London WC1

Corams Fields is a seven acre park two minutes' walk from Great Ormond Street Hospital. We are very lucky as some of the team from the Great Ormond Street Birthmark Unit will be with us joining in the fun.

We have organised a small hall (in case it rains) and will have a face painter and free gift for every child. Within the park are small animals, swings, slides, 'sand & water' for the under 5s, climbing frames, monkey slides, fountains and a cafe.

I forgot to tell you the best bit - *IT'S ALL FREE!* **PLEASE COME AND JOIN US.**

Website

www.birthmarksupportgroup.org.uk

1st March 2001 saw a huge step forward for our group with the launch of our website.

The site contains lots of useful information including all our newsletters, medical information provided by the Great Ormond Street Hospital team, how and where to get treatment etc. We also list the activities of the group and links to other related support groups.

We hope you find it informative, and if there are any topics you would like to see included within the website, please let us know.

An enormous expression of thanks goes to Ian Clover who produced and manages the site. It took the best part of a year to set up, with much midnight oil burnt and many sunny Sunday afternoons spent locked away researching information and co-ordinating the whole project.

We also extend our thanks and admiration to the medical staff and administrators at Great Ormond Street Hospital and the fantastic staff at the BBP&H Design Agency for their design ideas, web site development and consultation ALL FREE.

If you don't have a computer at home, why not pop into your local library and use theirs? They will be happy to offer advice on finding our site and navigating through the pages - believe me, if I can do it you will have no problems!

Changing Faces

If your child is about to start school/nursery or change schools, I recommend you contact another charity, Changing Faces.

They offer a counselling service, advice on how to talk to your children about their birthmark and produce excellent literature, including packs to help both the schools and our children ease their way into their new lives.

Their details are:-

Changing Faces

1 & 2 Junction Mews, London W2 1PN

Tel 020 7706 4232 • Fax 020 7706 4234

E-mail: info@changingfaces.co.uk

Website: www.changingfaces.co.uk

Penpals

I know at times we all feel it, but YOU ARE NOT ALONE!! Why not write to someone in a similar situation as yourself? I can promise when you have a bad day, receiving a letter from another group member can turn your day around.

I know the majority of details here are of families with young children, but if you have older children, it may be nice to encourage them to write to Callum - imagine the strong friendships that may begin. Most adults can express themselves reasonably easily to one another, but it may be nice for our kids to talk to each other.

Shaun & Susan Lawrence
8 The Avenue, Moordown
Bournemouth BH9 2UL

Charlotte, aged 3 - Two Haemangioma
(One Capillary/One Cavernous)

Miss C Hinman
17 Walkers Gate, Wellington
Somerset TA21 8DJ

Georgia, aged 4 - Haemangioma

Karen & William Leed
4 The Glebe, Leigh, Surrey RH2 8NK
Danniela aged 4 - Strawberry Mark

Callum Heywood (aged 9)
105 Grappenhall Road, Stockton Heath
Warrington, Cheshire WA4 2AU
Port Wine Stain

Steven & Deborah Harper
2 Brindley Avenue, Latchford
Warrington, Cheshire WA4 1RU
Emma, aged 2 - Port Wine Stain

Paul and Debbie Trower
22 Suffolk Drive, Basildon
Essex SS15 6QG

Amber, aged 3 - Cavernous Haemangioma

Our group is not just for parents and children. We also have members who are grandparents and adults who have gone through life with a birthmark. We have not published their details, but if you would like to make contact with them, please get in touch.

Our Supporters

A staunch supporter of the BSG is Branksome & Pinewood Lawn Tennis Club in Poole, Dorset.

Many thanks to Giles Cooper for allowing the use of the Club for the 4th Annual Charity Tennis Event which raised £1900.

Thank you also to Jo Salmon, Darren & Michaela Richardson, Mr & Mrs Prince and Janine & David Newman.



The **Birthmark** Support Group

What are they?

A Congenital Melanocytic Naevi (CMN) is a type of birthmark that may be found in newborn babies:

- Congenital indicates that the abnormality is present at birth,
- Melanocytic is a type of cell present in normal skin and in certain other organs whose function is to produce melanin - a brown pigment.
- Naevus is a term used to describe any type of birthmark.

A CMN is composed of a large collection of melanocytes; why such a collection develops is still unknown. Their function in the skin is to produce pigment, which protects the skin from damage by ultraviolet rays in 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 many cells gather at the same site causing a CMN birthmark.

How common are they?

Small CMNs (less than 1 inch across) occur in about 1 in 100 newborn babies, the larger ones are rarer.

Do they vary in size?

Yes, the largest can cover most of a limb or trunk. As the child grows, the CMN will enlarge in proportion to the child's general growth.

Where do they occur?

The most common sites are the head and neck, then the trunk followed by the mid-line of the back, however, but they can occur anywhere.

Pigmentation

Initially they may have a purplish hue but generally appear darker at birth and then lighten over the next year or two. In rare cases they can almost completely disappear.

Hairiness

They are usually hairier than normal areas of skin, but this does vary from barely perceptible to quite profuse. The increased hair growth may not be apparent in the first months of the child's life. The colour of the hair is generally dark but this does vary.

Permanent hair removal is currently not available and although much has been said about laser hair removal and electrolysis, there is not yet a really satisfactory treatment for large areas. In general, the most satisfactory methods are shaving or by use of depilatory creams.

Lumpiness

Small CMNs are generally flat, but larger ones often have raised or lumpy areas. This does not imply any special medical complications.



Satellites

Many children will have a scattering of smaller pigmented spots elsewhere on the skin, these are called satellites. They usually resemble ordinary 'moles' but are likely to be bigger. There is a strong suspicion that exposure to sunlight increases the rate of their appearance. Anyone with a large CMN should minimise sun exposure.

What are the medical implications of a CMN?

Risk of malignancy

It seems likely that less than one person in 100 with a large CMN will develop a malignant melanoma 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%.

Currently it is our policy to do a brain scan in children with CMNs on the scalp or on the back close to the mid-line. We believe 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 until the child is at least one year old.

Risk of involvement of the eye

We have found when a CMN is very close to an eye there is a small risk of an abnormality known as glaucoma (increase in pressure within the eye). Glaucoma of this type can be treated surgically; but it is important to act quickly because after a period of time, the increased pressure can begin to damage the eye and reduce vision. For this reason, it is important to have the pressures in the eye checked regularly.

What treatment is available?

The majority of CMNs are unsightly and sadly at the moment cannot be completely removed easily and without trace. Removal of the full thickness of the CMN cannot be achieved without a degree of scarring. Partial thickness removal, while it may result in little or no scarring, produces rather variable reduction in pigmentation and hairiness.

Are there any special precautions my child should take?

The most important is sun protection. 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.

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 of 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.

Many thanks to Dr David Atherton, of Great Ormond Street Hospital for Children for supplying this information. A fuller version can be obtained from our website www.birthmarksupportgroup.org.uk



The **Birthmark** Support Group

Membership Form

Please complete boxes in block capitals.
Any boxes that are not applicable should be marked N/A

Parents' Full Names - or adult's full name and D.O.B. if applying for adult membership.

Mr/Mrs/Ms _____ Mr/Mrs/Ms _____

Address _____

_____ Postcode _____

E-Mail Address _____

Telephone Number _____

Child's Full Name _____ **Date of Birth** _____

Type of Birthmark (Medical Diagnosis) - include location and any associated problems

GP's Name and Address _____

Hospital referral details (if applicable)

Name of Consultant _____

Hospital Name and Address _____

Comments _____

Signature _____ Date _____

Registered Charity No. 1090952

ALL INFORMATION SUPPLIED WILL NOT BE SHARED WITHOUT YOUR EXPRESS PERMISSION.

Please return to: P.O. BOX 3932, Weymouths DT4 9YG
or submit online form from our website: www.birthmarksupportgroup.org.uk



The **Birthmark** Support Group

Gift Aid Declaration

(registered charity no. 1090952)

TitleForename(s)Surname

Address:

.....

.....Post Code

I want the charity to treat the enclosed donation of £..... and all donations I make from the date of this declaration until I notify you otherwise as Gift Aid donations.

Signed

Date

Notes

You must pay an amount of income tax and/or capital gains tax at least equal to the tax that the charity reclaims on your donations in the tax year (currently 28p for each £1 you give).

You can cancel this declaration at any time by notifying the charity.

If in the future your circumstances change and you no longer pay tax on your income and capital gains equal to the tax that the charity reclaims, you can cancel your declaration (see note 1).

If you pay tax at the higher rate you can claim further tax relief in your Self- Assessment tax return.

If you are unsure whether your donations qualify for Gift Aid tax relief, ask the charity. Or ask your local tax office for leaflet IR 65.

Please notify the charity if you change your name or address

The Birthmark Support Group

Adult Hooded Sweatshirt

Black, Navy or Red (*White Logo*)
Grey or White (*Burgundy Logo*)

£19

Adult Sweatshirt - Open Hem

Black, Navy or Red (*White Logo*)
Grey or White (*Burgundy Logo*)

£19

Adult T Shirt

Black or Navy (*White Logo*)
Olive (*White Logo*)
Grey (*Burgundy Logo*)
Mid Blue (*White Logo*)
White (*Burgundy Logo*)

£11

Kids' Hooded Sweatshirts

Black, Navy or Red (*White Logo*)
Grey (*Burgundy Logo*)

£14

Kids' Sweatshirts - Open Hem

Grey (*Burgundy Logo*)
Navy or Red (*White Logo*)

£14

Kids' T Shirts

Red, Burgundy, Sky Blue or Navy (*White Logo*)
Grey or White (*Burgundy Logo*)

£ 8



Kid Sizes

Age & Height

3-4 (104 cm)
5-6 (116 cm)
7-8 (128 cm)
9-11 (140 cm)
12-13 (152 cm)

Adult Sizes

Chest Size

Small (36 in)
Medium (38 in)
Large (40 in)
XL (42 in)
XXL (44 in)

The Birthmark Support Group Order Form

www.birthmarksupportgroup.org.uk

Name Tel

Address



Postage and Packing: One item £1, two items £2, three items £4.50

Quantity	Description	Colour	Size	Price

POs/Cheques made payable to:

The Birthmark Support Group (Promotions), P.O. Box 5109, Poole BH14 9WG

Email Queries to: funding@birthmarksupportgroup.org.uk

Postage & Packing

Total



The **Birthmark** Support Group

If you would like information, advice or help on any type of Birthmark, or if you would like to contact a family in similar circumstances for support, please write to:

The Birthmark Support Group

PO Box 3932

Weymouth

DT4 9YG

e-mail: info@birthmarksupportgroup.org.uk

www.birthmarksupportgroup.org.uk

When contacting the PO Box, if possible
please enclose an A4 SAE



The **Birthmark** Support Group

Family Day & AGM

Sunday 8th September 2002

Corams Fields

93 Guilford Street

London WC1

from noon to 5pm

A 7 acre landscaped park with animals
Sun & sand for the under 5's, monkey slides,
activity toys for all ages, indoor facilities,
With face painters and a free gift for every child.
Why not bring a picnic and join us??
Everyone is welcome and it's all FREE

Return to The Birthmark Support Group, PO Box 3932, Weymouth DT4 9YG
or via e-mail to info@birthmarksupportgroup.org.uk

Name & Address: _____

Number attending Adults _____ Children _____