

# The Birthmark Support Group

ISSUE 2 – PAGE 1

MAY 2000

## Welcome Again

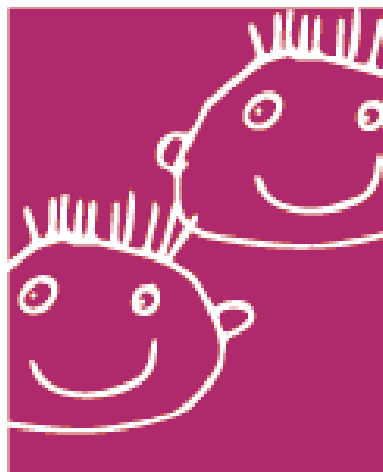
Thank you all so much for your kind letters of support in response to our first Newsletter.

I'm very pleased to say our Group is flourishing with the membership growing almost daily. Our Committee is also expanding and new members are always welcome.

We aim to provide support and information in laymen's terms on all types of birthmarks.

We understand what you are going through as we have experienced similar challenges with our own children. We want to take away the feelings of unease and isolation that can exist.

With this in mind we are introducing two new features: Penpals and Organised Events. We can meet each other and some of the medical professionals who treat our children, our teenagers can make new friends and of course it will be great fun for the kids.



## Our Motto

Smile & Face it

Thanks to Hannah Todd

Imagine how they will feel to be surrounded by such an accepting group.

We are also hoping to introduce a Telephone Help Line, but it all takes money.

Each Newsletter issue will focus on a different birthmark. Last time it was port wine stains and this issue haemangiomas.

Remember this is YOUR Support Group and YOUR Newsletter. Any ideas or suggestions you have would be much appreciated. Please just write in to PO Box 3932, Weymouth DT4 9YG or e-mail us at [birthmarksupportgroup@btinternet.com](mailto:birthmarksupportgroup@btinternet.com)

## Our Committee

I would like to introduce you to our Committee:-

Andy Marchese - Chair  
Gill Marchese - Vice Chair  
Sylvia Carpenter - Secretary  
Mark Lingfield – Treasurer  
Ian Clover - IT Specialist  
Toni Lingfield - Newsletter

We also have some new families currently joining our Committee. We will give them time to settle in before introducing them in our next edition

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## Your Stories

We have used two very different Your Stories in this edition of the Newsletter.

The first is from little Amie Jane and the second is from Jennifer, who is 40 years old. Jennifer's story gives us a fascinating insight into how treatment has changed over the years.

Jennifer has a very unusual and complex vascular malformation extending down the left-hand side of her face and within her body. As well as being a courageous lady she is very sensible and sensitive to others.

Amie Jane's haemangioma covers her eyelid and eyebrow and I'm pleased to say is responding very well to treatment.

I would like to thank both Jennifer and Nicky (Amie Jane's Mum) for taking the time to write their stories.

### **Amie Jane - 9 Months**

At 1.15pm on 28th June 1999, Amie Jane was born. My hus-

band Neil and I were delighted, and as we gazed at our little girl we noticed a red mark on her eyelid. We asked the midwife about it, but she assured us it was a pressure mark due to the birth, the Dr said '..don't worry it will fade'.

Every day we examined the red mark, but sadly it just got larger, redder and became more swollen as the days went by. We were now becoming very worried, and spoke to anyone who we thought could help, but were still assured it was just pressure mark and would fade.

When Amie was three weeks old the haemangioma had grown so large her eye was half closed. Despite this we were still told not to worry, but of course we did.

At this stage no-one had suggested it may be a haemangioma. I was alarmed that there seemed no urgency to investigate the damage it may be doing to Amie's eyesight.

I voiced my concerns and Amie was given a second opinion by another doctor in

the same practice. He again assured me it would fade and these problems were not normally referred, but agreed to refer me to a Paediatrician.

It was a relief that something was at last being done to help Amie. The Paediatrician said we needed to get her eye open fast because the eye needs light to enable it to start functioning properly.

He referred us to Mr Lloyd at Manchester Royal Eye Hospital who saved my daughters sight.

At only 8 weeks, Amie had a general anaesthetic so the haemangioma could be injected with steroids to reduce the swelling and enable the eye to open.

About a week after the first injection, her eye started to open. It was a wonderful feeling, as I knew we now stood a chance of saving her eyesight.

From that moment on her eyelid has steadily flattened, enabling her eye to open. (The haemangioma covers her eyelid and extends to above her eyebrow).

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When Amie was 20 weeks, she had another injection and now her eye is open wide enough to see her pupil. The haemangioma has halved in size, is less red and not as angry looking. We're finally through the other side of the tunnel.

One of the hardest things for us now is how to keep the patch over her good eye! The beautiful little monkey keeps ripping it off now she has sussed how to do it. We've gone through 8 new patches in 3 days!

My daughter is a beautiful little girl with a wonderful personality, she is also very sociable as so many people pay her loads of attention.

I just wish people would not stare and then looked away. If they would approach me and ask I would quite happily explain about haemangiomas.

## *Eds comment*

I'm sure we can all empathise with Nicky's last comment ". - if they would just approach me and ask..'. One thought I would like to add is some adults could learn a lot from young children.

I have seen many children at my daughter's nursery ap-

proach her **and** ask about her birthmark. She simply tells them it's her birthmark and she was born with it and they (and she) happily walk away.

## **Jennifer - Born 1960**

I was my parents' first child - after a difficult labour, forceps delivery and my cord wrapped around my neck, I arrived. Due to the forceps, the only visible damage was a grazed chin and forehead otherwise I was perfect.

After about four days a bruise appeared on my left cheek around my ear region. My parents were told *don't worry it will fade*, there seemed no other explanation, though my parents were beside themselves with worry. The doctors could not offer any more information on what this was or the possible cause so so they tried to put it out of their minds.

When I was eight months old and teething, my Nan put her fingers inside my mouth to feel my gums, but to her shock the inside of my left cheek was lumpy and puffy (like a bunch of grapes), this turned out to be the first signs of what was initially thought

to be a haemangioma, but what is now considered to be a complex vascular malformation.

After great insistence by my parents, I was referred to Gt Ormond Street Hospital. My haemangioma had spread to my eye and outside and inside the whole of the left side of my face, which was swollen and discoloured. You could have drawn a line down the centre of my face the left and right sides are completely different.

At Gt Ormond Street I saw two specialists, Mr Matthews and Mr Broomhead. My parents were told it could be a haemangioma as the swelling was due to pockets of blood entwined with muscles and nerves.

It was suggested it be left for a couple of years to see what happened, but at no time should there be any surgery (that has stayed the same until present day)

In 1968 when I was eight, I went to Great Ormond Street Hospital to have treatment by means of injecting a steroid fluid into the veins on my face to clot the blood. The

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side effects were large swellings which went down after ten days whilst clotting the blood, this was done at regular intervals until 1981 when I was 21 and grew out of the Great Ormond Street beds!

The treatment continued at Guys Hospital, London for a few years then transferred to St Andrews Hospital, Bille-ricay, Essex.

In 1985 I was referred to The National Hospital, London, there I had an embolisation, (a pipe inserted in my groin and micro pellets fired up to stem the blood flow). This continued for a few years and now I am under the watchful eye of Dr Wendy Taylor who is marvellous.

Dr Taylor has tried out a new treatment on me, a glue embolisation, similar to an embolisation but using glue to stick the veins together, this will be ongoing.

There are a couple of points I would like to make - at no time has my treatment been for cosmetic reasons, although some haemangioma can be helped by plastic surgery, mine can't.

I have learned to live with this and looking different, and

your children like myself may look different but we are very special people.

This is very important, it can give you strength when life can be unkind.

All my life I have only been treated by NHS doctors within the NHS service. I feel these doctors and my treatment have been second to none, they have been excellent and I don't believe I could have received any better treatment anywhere else in the world.

Now 40 years on I have found my own ways of coping and am very grateful to my parents who were so insistent all those years ago to ensure I was sent to Great Ormond Street to begin my treatment, which I feel has greatly improved my quality of life.

### *Eds comment*

We receive many letters and calls from parents who worry about letting their children go through surgery. If you have had that nagging feeling, I would recommend you reread Jennifer's last paragraph **THANKING** her parents for their persistence in seeking treatment - I'm sure your children will feel the same.

Every edition of the Newsletter will contain a *Your Story*, but only if you send your experiences in to us.

As we have already covered port wine stains and haemangioma, we would especially like to hear from you if you have experience of another type of birthmark.

We would not publish anything you are not completely happy with and the draft would be returned to you for final approval. Why not share your experiences with us?

**Logo**

I am sure you have noticed our new fantastic logo proudly displayed on the front cover.

It was designed and donated by Charles Hicks and his team at BBP&H Design based in Clerkenwell, London and we send our most sincere thanks to them.

But their kindness did not stop there, as they have given Ian our technical expert, further time and invaluable advice on setting up our web page.

**THANK YOU!**

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## Penpals

As we spread throughout the country, we are introducing this new section to help you contact other families with similar problems to your own.

You may feel quite isolated but for all you know there may be another family in a similar situation to yours living 10 minutes away.

We will only include you in this section if you specifically request it. We will publish names, addresses age of child and type of birthmark.

Kim Coombe (aged 14)  
90 East Weare Road  
Foruneswell  
Portland DT5 1EX  
Strawberry mark

Sharon & Chris Thompson  
4 Mill Farm Drive  
Randlay, Telford  
Shropshire TF3 2NA  
Emma aged 2  
Cavernous Haemangiomas.

Dawn & Graham Hunter  
177 Bosworth Gardens  
North Heaton  
Newcastle NE6 5UP  
Faye aged 18 months  
Cystic Hygroma

Hannah Todd (aged 6)  
Highwood  
Willingford Lane  
Brightling  
Robertsbridge  
East Sussex TN32 5UP  
Port Wine Stain

Jo Roeg & Peter Baker  
97 Brading Road  
Brighton BN2 3PE  
Saskia aged 8 months  
Cavernous Haemangioma

## Our Motto

You will have seen our new motto on the front page. It was taken from an article sent to us by Kirsty and Hannah Todd. I would like to thank them both for their permission to publish; 'it touched our hearts and I'm sure it will touch yours.'

'Mummy, they are all looking at my birthmark' said Hannah quietly, self consciously tucking her hair behind her ear.

We were squeezing our way through a restaurant in search of the WC's. 'Nonsense' I replied quickly, 'they are looking at your lovely golden hair'.

'No Mummy' she said firmly, 'they are looking at my birthmark.'

'Oh Hannah, I bet they are just all wishing they had blue eyes as large as yours.'

'Mummy, LISTEN to me'.

We reached the WCs and re-treated to a space where we could address this issue I drew breath and smiled down at my 5 year old bombshell.

'Mummy, they were looking at my birthmark and they weren't smiling.'

'Well.... that's just because they don't know the secret', 'What secret?' the question cracked back.

'THE secret', I replied frantically formulating an answer that was credible.

'Well...', I started slowly '..people don't look at your face first.'

'What do they look at then?'

'They look at your smile', I finished,

'Oh' silence.

Now you go back into the restaurant to see how many people know the secret.

With that Hannah swung open the door and off she stomped staring hard at everyone who glanced in her direction muttering 'He knows the secret, she doesn't , she does, does, does, doesn't .....'

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A few weeks later when returning from holiday we were walking through an airport waiting area. 'Mummy nobody is smiling'.

'Well maybe they have forgotten the secret',

'How do they remember again?'

'You remind them by smiling at them'.

A few minutes later 'Mummy, everyone is smiling'.

## Flyer

Please (with appropriate approval) could you display our flyer in your GP's surgery, 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. Now though, 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.

If anyone needs additional copies of our flyer - please e-mail us or write to our usual address.

You may have noticed our flyer has been updated and re-designed. We would like to send our thanks to Hayley Bebb for the original ideas and to BBP&H who took these ideas and designed the new flyer and our logo.

**THANK YOU.**

## Coming Events

We are (at last) holding a **Family Day** on Sunday 3rd September 2000 from noon 'til 5pm. It will be held just around the corner from Great Ormond Street Hospital at Corams Fields, 93 Guilford Street, London WC1. The day is completely free of charge and everyone is welcome.

Corams Fields is a 7 acre landscaped park. It has small animals, a monkey slide, plenty of activity toys for all ages, an astro-turf football pitch and a water & sand feature for the under 5's (don't forget their swimming costumes).

There is a cafe located within the park or why not bring a picnic? If the weather is unkind, we have an indoor section that holds 200 (and our face Painter and entertainers)!

Some of our Medical Advisory Board will be attending. It will be a good opportunity to ask all the questions you remember when you are on your way home from your hospital appointment. It's all free, so everybody **PLEASE COME ALONG.**

To give us an idea of numbers attending, if possible, please return the tear-off slip at the back of the Newsletter.

To ensure you are included in future events please complete and return the membership form which is also attached to the back of the newsletter.

**Changing Faces** are a marvelous National charity that provides free and confidential information, support and advice to children, adults and their families who have a condition that affects their appearance.

They are holding an event on 24<sup>th</sup> June 2000 at Sandbanks Hotel, Poole, Dorset. There will be sessions for children, young people, families, local and national support groups and health/social care professionals.

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The Birthmark Support Group will be represented by Sylvia Carpenter, our secretary and Changing Faces are inviting everyone to attend.

The day will provide an opportunity to share ideas and experiences and find out about some of the practical strategies and effective interventions which can enable everyone to face their problems with confidence.

If you wish to attend, places need to be booked in advance by contacting..

Helen Smith,  
Changing Faces  
1 & 2 Junction Mews  
Paddington  
London W2 1PN

Tel 020 7706 4232

On September 16th Kirsty Todd has organised a **Masked Ball** in aid of The Birthmark Support Group. All 200 tickets have already been sold (very well done and thanks to Kirsty!).

There will also be a short auction and raffle. If anyone has any ideas for unusual, highly desirable auction prizes or items they could donate for the raffle, please write to us at our

usual address or send us an e-mail.

## Thank You!

**We have no funding, and exist solely on your very kind donations** – without your generosity our much needed group would have folded. For every pound, every pack of envelopes and book of stamps sent to us, you help so many.

If you saw some of the heart-wrenching letters we receive you would realise how important it is for families to have access to a group such as ours.

The Committee would also like to thank the following companies, **BBP&H Design** for all their help with our website and donating our new logo, **Xerox** for donating the copying of this and the last edition of our Newsletter and **Cross Medical Limited** for their donation and offer of a computer.

Cross Medical based in London NW10 specialise in marketing, distributing and servicing Medical Equipment par-

ticularly Lasers, Lithotripters and Microwave Thermo Therapy Systems.

The Committee would also like to thank:-

Architon Group Practice  
Peter Baker & Jo Roeg  
Keith & Allison Maxwell-  
Jones

Louise Busfield & Nigel Curtis  
Mr & Mrs Rowe  
Denise MacKenzie  
Dawn, Graham & Faye  
Calam Davis & Hayley Bebb  
Mr & Mrs Stephens  
B & PA Bridges  
Val Morseman  
Dina Burnstock

And a special thank you to Louise Busfield and The Branksome & Pinewood Lawn Tennis Club, Poole, Dorset.

Louise managed to persuade the Tennis Club to donate half the proceeds of their Charity day to us with the other half being donated to the Loddon School for Autistic Children.

On behalf of everyone who has been helped by The Birthmark Support Group -

**A VERY BIG THANK YOU!**

# The Birthmark Support Group

## Information Sheet – Haemangiomas

### **What is a haemangioma?**

- A haemangioma is a collection of small blood vessels (capillaries) that produces a mark in the skin. Haemangiomas that are on the surface of the skin are called capillary haemangiomas. Deep (Cavernous) haemangiomas are similar to capillary haemangiomas but they are bluish in colour in the skin.

### **How common are haemangiomas?**

- Approximately 1 in every 20 babies born will have a haemangioma. They tend to be more common in girls than boys and more common in premature babies.

### **What do haemangiomas look like?**

- Capillary haemangiomas are raised and bright red, because the abnormal blood vessels are close to the surface. Unlike port wine stains, they are not usually present at birth but develop a few days to weeks later. At first, they usually resemble a small area of pale skin followed by a red spot.

- Deep (cavernous) haemangiomas are bluish in colour and tend to be deeper into the skin.

- They grow rapidly in the first three months, increasing in size and may intensify in colour. After this the haemangioma tends to have a rest period, when the rate at which it grows slows down. Occasionally a haemangioma may continue to grow after six months.

- The next stage is when the haemangioma shrinks. It usually disappears completely leaving little or no mark on the skin. Most haemangiomas disappear on their own, usually by the time the child goes to school, but others may not disappear completely and may leave a mark on the skin. In this situation, some plastic surgery may be necessary. Rarely, complex haemangiomas may continue to be troublesome into adulthood.

### **Where do haemangiomas occur?**

- Haemangiomas may appear anywhere on the body. Most appear on the child's head or neck, but they can develop anywhere on the skin or in very rare cases in the internal organs. A child can also have more than one haemangioma. The doctor may organise an ultrasound examination if he or she thinks there is a chance of internal haemangiomas.

- Haemangiomas may need to be treated soon after birth if they interfere with feeding, breathing or other body functions. If a haemangioma grows on your child's eyelid, it will need to be treated as soon as possible otherwise it may interfere with their vision.

# The Birthmark Support Group

## Information Sheet – Haemangiomas

### **Can haemangiomas be prevented?**

- There is no known way of preventing haemangiomas, although there are several research programmes looking at the possible causes.

### **How are haemangiomas diagnosed?**

- Superficial capillary haemangiomas or strawberry marks are obvious and sometimes recognised by parents. In the case of deep cavernous haemangiomas, your baby may require an ultrasound to confirm the diagnosis and check the depth in the skin. Occasionally they may be associated with other rare syndromes. Your doctor will carry out other tests to see if this is the case and may organise a CT or an MRI scan if indicated.

### **How are haemangiomas treated?**

- In around 80% of cases, your child's haemangioma will need no treatment. However, in about 20% of cases, there may be complications that need treatment. Each case is different, so the doctor will decide which treatment or combination of treatment is best suited. The treatment may consist of one or a combination of laser treatment, or drugs such as steroids. In very rare cases alpha interferon may be indicated.

### **Are there any complications of haemangiomas?**

- You may be concerned that your child's haemangioma will bleed. They tend to bleed after injury and in some cases due to rapid growth. If bleeding starts, apply pressure to the haemangioma until it stops bleeding. It should stop within 5-10 minutes. If you are concerned, get medical attention.

- Occasionally a haemangioma that is growing may form an open sore or ulcer - these can be painful and may become infected. If it becomes sore, it is important to see your doctor. You should keep the ulcer clean and covered with a dressing. Ulcers usually heal in 7-14 days, otherwise laser treatment should be considered.

- If your baby has a haemangioma near the eye, nose or the mouth or in the nappy area, this can cause special problems. Your doctor will examine the haemangioma and decide if your baby needs more treatment, in which case you will be referred to the Hospital. Complicated haemangiomas need to be referred to a specialist centre for further management.

**Many thanks to Dr Syed, Great Ormond Street Hospital for Sick Children, who is on our Medical Advisory Board, for supplying this information.**



# 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: [birthmarksupportgroup@btinternet.com](mailto:birthmarksupportgroup@btinternet.com)

If possible, please enclose an A4 S.A.E.

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**BIRTHMARK SUPPORT GROUP  
MEMBERSHIP FORM**

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

Parent's Full Names	Mr/Mrs/Ms		
	Mr/Mrs/Ms		
Address			
Post Code		Telephone Number	
Child's Full Name		Child's Date of Birth	
Type of Birthmark (Medical Diagnosis) Include any associated problems			
Name of G.P.			
G.P's.. Address			
<b>If your child has been referred to a hospital:</b>			
Name of Consultant			
Hospital Name and Address			
Comments			
Signature		Date	

**ALL INFORMATION SUPPLIED WILL NOT BE SHARED WITHOUT YOUR EXPRESS PERMISSION.  
PLEASE RETURN TO P.O. BOX 3932, WEYMOUTH, DT4 9YG or  
birthmarksupportgroup@btinternet.com (Electronic version of the form can be requested from this email address)**