

The Birthmark Support Group

ISSUE 1 – PAGE 1

AUGUST 1999

A New Beginning

Welcome to the first Newsletter of the New Birthmark Support Group. The Support Group exists to bring together families with children who have any type of birthmark and to provide information in laymen's terms.

We are closely supported by senior medical professionals but are run by families who face the same problems and situations that we, and our children, face every day.

We have all experienced the initial shock at birth, of seeing our children's birthmarks and realising we need some form of medical help. But where and to whom do we turn?

Many of us have found it difficult to find reliable information on how best to help our children.

Birthmarks need to be treated by specialists and the sooner your child can be referred the better.



No doctor can specialise in every medical condition, so we need to raise awareness of the correct contact points. Just think of all the children whose lives can be improved if we can speed up this process.

None of the Support Group have any special qualifications but we have all seen the fantastic results the treatments can bring and want to make everyone who has a birthmark aware of how they can be helped.

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Many thanks to Xerox who are donating the photocopying of this document

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Past History

The Naevus Support Group was founded and run by John and Renata O'Neil.

Many of us owe a great deal of thanks to this exceptional couple who put so many of us in touch with the people who could help our children.

When John & Renata finally gave up the reins, the Great Ormond Street Team stepped in and brought together a group of families who wanted to help. And so the Birthmark Support Group was formed.

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Your Story

Sophie Lingfield

At 9am, after a 36 hour labour, our little girl was born. When she was, at last handed to me, I gazed down into her tiny face wondering what colour her eyes would be, if she'd have any hair and who she would resemble, but what stared back at me was not what I expected.

'What's that mark on her face?' I heard a voice asking. *"It could be bruising"*. was the reply from the doctor. *"It could be a port wine birth mark"*, was the reply from the midwife - perhaps as a result of my questioning look the midwife then quickly said *'or it could be bruising'*. We decided it was bruising and put it out of our minds.

The doctors did not examine Sophie until 11:30pm, when they confirmed it was a port wine stain on her face.

Everyone wants a perfect child, and I was starting to come to terms with Sophie's port wine stain when the doctors dropped the bombshell.

'As the mark is over her eye, she may develop glaucoma and as it's over her head she could have brain damage - but don't worry about it, we'll come and see you again in the morning - goodnight'

I was lost for words. I watched dumb struck as the doctors left my room. The tears now began to run down my face.

This could not be happening. Why Sophie? It must be my fault. What had I done during my pregnancy to cause this? I felt terribly guilty and was desperate for some answers.

The following day the doctors returned; I questioned everyone to try to find out how best to help Sophie. The answers varied from *'wearing thick actors' make-up'*, to *'come back when she's five'*. Nobody seemed able to help. We felt very isolated.

While flicking through *Bounty*, the ante-natal booklet, I discovered the address of the Naevus Support Group.

I contacted my GP, who was marvellous. Armed with the

information received from the Support Group, I told my GP where help was available.

We were first sent to our local hospital for a brain scan (which was fine) and a few weeks later we were at Great Ormond Street Hospital for our first meeting with Drs Harper and Syed and of course, Sister Jane.

The team explained that Sophie would have laser treatments under general anaesthetic, and the pressures in her eye (glaucoma tests) would be checked during the operation.

We were worried about her first treatment, about how a general anaesthetic would affect so young a child (9 months old).

While we were waiting for our first operation, I noticed while out shopping that people would stare at Sophie, and a young child came up to me and asked what was wrong with her face. It was only then I considered how other people see Sophie and how we owed it to her to continue with the treatments.

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We were so scared for her. We imagined her being really sick after the anaesthetic, but how wrong we were! Twenty minutes after the operation she was giggling and back to her old self. We were amazed.

Her 'dots' looked more painful than they felt to Sophie. We were amazed at how quickly the redness faded and overjoyed when the clearer spots underneath started to appear.

Sophie, now three, has had four treatments and the improvement is wonderful. She is continuing her treatment and we are confident of a happy ending to this story.

Let's hope through the Newsletter we can continue to show people there is light at the end of the tunnel.

Logo

We are initiating a competition to design a logo for our Group. Please send all your entries to the Editors.

Flyer

Attached to this Newsletter is a flyer which (with your GP's approval) could be put up in the surgery, or even better on the notice board of your local maternity hospital.

Remember how you felt when your child was born. No family needs to feel isolated again. Put up this flyer and if you help even one family, one child, it will have been well worth the effort.

Contacts

If you would like to be added to our mailing list, please write to the Editors or better still, complete the attached membership form and, if possible, enclose a stamped self-addressed envelope.

Mark & Toni Lingfield,
Newsletter Editors,
Birthmark Support Group,
PO Box 3932,
Weymouth,
DT4 9YG

We Need You

I hope you have enjoyed our first Newsletter. But, this is all there will be without your comments and articles.

We are not looking for the next Jilly Cooper, just people who feel as we do; that sharing their thoughts and experiences may help others.

Your contribution may be of any length; serious, funny, medical, or educational. Please, no matter how small it may reach out to somebody somewhere.

This issue of the Newsletter has concentrated on port wine stain birthmarks. Future issues will concentrate on other types, but to do so we need your help. **So it's over to you.**

Funding

And of course, no Support Group can exist without funding. Anything you can do to help would be much appreciated. A book of stamps, or bunch of envelopes would be as warmly welcomed as a donation or an offer to organise a fund-raising event.

The Birthmark Support Group

Information Sheet – Port Wine Birth Mark

What is a port wine stain?

- A birthmark of blood vessels under the surface of the skin that affects three people in every 1 000. It is a red or purple flat area of skin which can occur on any part of the body, though 65% of cases appear on the face. It is present at birth and persists though life.

Why do they occur?

- Port wine stains occur as a result of an abnormality in the formation of the blood vessels in the skin during the development of the baby in the womb. It is not something that the child has inherited from either parent nor is it caused by anything related to the mother in pregnancy. *No parent should feel responsible for these blemishes.*

Do they change with age?

- Yes, In babies and young children port wine stains are flat and pink. With increasing age, they become more purple, thickened and may develop small surface lumps.

Are there any associated problems?

- *Most port wine stains have no associated medical complications.*

- Individuals with a port wine stain adjacent to the eye should be seen by an eye specialist to make sure the eye is not involved. Occasionally a port wine stain near the eye may be associated with glaucoma. This is potentially serious if missed and requires early detection and treatment.

- A port wine stain over the scalp and/or forehead may rarely be associated with a deeper blood vessel malformation affecting the brain, sometimes referred to as the **Sturge-Weber Syndrome**. This can cause epileptic fits and affected individuals may need to take anti-epileptic drugs.

- An extensive port wine stain on an arm or leg can be associated with enlargement of the limb, known as the **Klippel-Trenaunay-Syndrome**, This is thought to be due to the increased blood flow. If the leg is affected, it is important that the length of the leg is measured regularly and if there is any significant discrepancy between the two legs, expert advice is needed from a bone specialist with an interest in this condition.

Is treatment available and successful?

- Yes, the *Pulse Dye Laser* can effectively treat port wine stains.

Cosmetic Camouflage

- This can be helpful to older children and adults. Advice is available from specialist centres and as a service run nationally by the British Red Cross, also Sister Jane Linward of Great Ormond Street Hospital has been specially trained in this area.

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Information Sheet – Port Wine Birth Mark

Which patients benefit from this form of treatment?

- The majority of patients will benefit from laser treatment, especially young children. The response varies from making the stain paler and less conspicuous to complete clearance in some patients. Occasionally there is no response. Experience has shown that the pulse dye laser is safe and effective in treating port wine stains in children, with evidence that younger children (3 months to 6 years) tend to have a better response than adults. Ideally, port wine stains should now be treated early in childhood.

Where can this treatment be obtained?

- Young children should be treated by a specialist centre in a hospital unit designated for children, where there are all the facilities necessary to obtain a successful outcome both for the patient and the family. Most young children require a general anaesthetic and therefore the involvement of an anaesthetist used to dealing with children, although older children can be treated using local anaesthesia (EMLA or Ametop cream). For those patients with problems associated with other abnormalities, they need assessment by other experts such as a paediatric neurologist, ophthalmologist or plastic surgeon.

What does the treatment entail?

- After an initial assessment, a test patch is performed with the laser and the results assessed 6-8 weeks later. This determines the energy dose required. A plan is then made for a course of treatment. The number of treatment sessions needed depends on the size of the birthmark.

What happens after treatment?

- Immediately after treatment the laser areas look like small bruises and the skin can be slightly swollen. This settles in 7-10 days and the treated area will fade in colour over the next 2 months. For this reason treatments are scheduled a few months apart. The amount of improvement will vary and several treatments are usually needed.

An active approach to the management of these lesions by a multi-disciplinary team is important. Children with birthmarks should be referred early to a specialist centre for assessment.

Many thanks to Dr John Harper, Great Ormond Street Hospital for Children, 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

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

**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			
If your child has been referred to a hospital:			
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)**