



The Birthmark Support Group

ISSUE 4 / JULY 2004

Welcome

Welcome to our 2004 newsletter!

Following on from the decision to re-define roles within the Birthmark Support Group, it was decided to 'sub-contract' the newsletter to a third party. Not, I might add, someone that is outside the group but to me, Alana Smith. My family and I became aware of the BSG when our son was, finally, diagnosed as having multiple cavernous haemangiomas. After all the scare mongering sites we'd looked at, it was a relief to find the Birthmark Support Group's site and support network – unfortunately, we were not aware of it whilst our son, Theodore, was going through the agony of repeated ulceration to his facial haemangioma – all part of the healing process according to our Consultant Paediatrician, a 'fact' put right by our first visit to Great Ormond Street!

There's a lot to tell you about this time around including write-ups on the Family Days held last year – both very different but exactly the same in terms of support given by members; the Committee and, of course, the team from Great Ormond Street Hospital – Professor Harper, Dr Syed, Dr Glover, Sister Jane Linward and Hilary Kennedy.

We'd also like to take this opportunity to welcome Jane Coultrup, our new Treasurer.

Finally, this is your newsletter – we need you to tell us what you want to see included (and excluded) – what would be of most benefit to you and your families?

In This Issue:

Family Days.....	Page 2
Penpals.....	Page 3
Grateful Thanks.....	Page 3
Parliamentary Group on Skin.....	Page 4
Cosmetic Camouflage.....	Page 4

Congratulations to:

Sister Jane Linward who was crowned in January 2004, an 'NHS Hero'. This is an especially wonderful achievement and one where the nomination came from the readers of the Evening Standard. Jane, as many of you know, is a children's clinical nurse at GOSH and has held many a child's hand (and parents!) during her 10 years service at the Birthmark Unit which she helped to set up. The Award is a joint venture given by the Evening Standard and the King's Fund (an independent health think tank) designed to honour those London health workers whose dedication and care go beyond the mere call of duty. Jane won the Nursing category.

Dr Samira Syed who was nominated for an Asian Woman's Achievement Award.

'One Life' Documentary

The Group were asked to collaborate on a documentary with the BBC dedicated to Birthmarks which was shown on Tuesday 27th April 2004. This was a very exciting opportunity for the Group and members have contributed to the making of the programme. The aim of the programme was not particularly geared towards the medical angle but more towards what it's like to either

live with a birthmark, like Ros Pryor whose journey was the main theme of the programme or a child who has the same, Alexander.

Congratulations to all who took part in the programme – your courage in allowing the cameras access to your lives has resulted in a large number of calls to the Group.



Our Motto

Smile & Face It



Family Days



Those of you that have attended the family days will know just what an important event they are not just from a social point of view but from a supportive angle.

We want to be able to extend the opportunity to attend such days to more of our members and realise that, to do this, we need to look at other parts of the country. The London venue will continue but there may be other suitable parks/areas for us to hold our days. If anyone knows of a suitable location near to them, then please let me know and we can investigate the possibilities. Also, if you want to become more involved, then don't hold back!

Suffolk 2003 & 2004

A drizzly day dawned on Sunday 18th May 2003, but what a tremendously warm welcome we were all given by Nick, Jane and the pupils of The Royal Hospital School. The gardens were safe and inviting which meant that the grown ups could relax and catch up with old friends or strike up new friendships whilst the children were able to charge around. If this wasn't their scene, then what about the Bouncy Castle? Giant board games? Disco musical statues? Face painting? The Harry Potter big screen? An indoor swimming pool? All available completely free of charge and greatly used by the children (and some of the adults!) For a very small charge, there was hot and cold food available, so there was no need to pack lunch before leaving home. As if that wasn't enough, delicious homemade cakes miraculously appeared in the afternoon, courtesy of Jane Ward. If you haven't guessed it already, we were thoroughly spoiled by everyone involved at the school.

Professor Harper; Dr Syed and Hilary Kennedy were on hand to advise or discuss any health issues - and we do appreciate how lucky we, as a group are to have such dedicated professionals who have given up their own time to support us in so many ways.

A fundraising concert performed by the School's world famous choir was held in the school grounds during the evening and was, by all accounts, magical. Toni Lingfield spoke on behalf of the group, both to raise awareness and acceptance of birthmarks and to thank all who supported and performance in the concert. The location of the school is magnificent and remarkably easy to get to.

It seems almost distasteful to talk about money but without fundraising the group cannot function as it would wish to or achieve its aims. The BSG are delighted to announce that in excess of £1700 was raised over the course of the day/evening.

We are indebted to Nick and Jane for what was a most fantastic occasion and special thanks to the numerous students who were on hand during the day helping out with all events and, more especially, making sure that the children had a wonderful time.

Even more families enjoyed a second visit to The Royal Hospital School on 23rd May 2004. What a contrast in the weather - this year the weather was beautiful and the Family Day proved to be a great success. Again, we were fortunate to have Dr Samira Syed; Dr Loshan

Kangesu and Sister Jane on hand to advise.

An important announcement was made during the day which I am delighted to confirm in this newsletter:-

Nick Ward, Headmaster of The Royal Hospital School, very generously agreed to become Patron of the Birthmark Support Group. Nick will be a great asset to the group and we look forward to working with him over the coming years. Our congratulations and thanks to him for taking on this role and to his family for supporting him.

London 2003

If it's September, it must be London. The usual venue for the group Family Day and AGM was Corams Field close to Great Ormond Street Hospital. It really is a peaceful haven in a busy part of town. The rain held off, just, and over 50 families from the UK and Europe enjoyed all that was on offer and were able to swap experiences; pass on advice or catch up from their last meeting in Suffolk. It was lovely to see all the children playing so well and happily together.

The day also included the AGM and members were invited to attend and participate.

As usual, we were supported by the team from Great Ormond Street, Professor Harper; Dr Syed; Dr Jane Glover and Sister Jane Linward. There were so many people desperate to speak to the specialists that a booking system was set up to ensure that no-one was missed.

Thanks to all who supported the day - Carole Vincent our face painting lady; the guinea pig man from Great Ormond Street Hospital; the tea makers (Carol Busfield and Glenda Burren); the raffle ticket sellers (John Burren and Neil Pilmoor); the merchandise sellers (Jordan Curtis) - all providing much needed and appreciated support for the group. Also, a big 'thank you' to those people who donated raffle prizes - the trip to the Cotswold was won by Sister Jane - thank you to Ron and Jean Prince for donating this prize.

Date For Your Diary:

**Sunday 26th
September 2004**

Corams Field



Penpals

Those members who have been lucky enough to attend the Family Days organised each year will know that you don't have to be alone with your worries. However, for those that can't make the Days to meet physically, we are pleased to pass on details of members who would like to become Pen Pals:-

Jo Stevenson's son Oliver is 10 years old and has a PWS on the left side of his face. Oliver would like to be a Pen Pal and he can be contacted at The Compasses, Wooburn Common, Bucks. HP10 0JS (Telephone 01628 520563) or e mail johannastevenson@aol.com

Alison Peace has a daughter, Jasmine, who is 16 months old and has a haemangioma on her cheek. Jasmine attends GOSH and Alison is keen to share experiences via e mail at stu@potman.freemove.co.uk

Our Grateful Thanks to:-

All who contribute to the Group whether it be financial or through time given. Details are on the website of some of those who have donated to our Group but we would like to draw your attention to the following achievements:-

Rebecca King's family	£1,500 raised by the Masons
Jenny O'Donoghue	The London Marathon (£1,700 and counting)
Nick Ward	Mini Marathon (£750)
Grace Woolley	Coffee Morning (£50)
Jackie Fraser	3 Peaks Challenge (£910)
David Todd	Supporting Christmas Cards (£125)
Nick & Jane Ward	Organising the Family Day and Charity Concert at The Royal Hospital School (£1,711)
Helen Travers, Mrs. Jarvis-Reid, Mrs. Watson and Mrs. Bookbank	Summer Safari Sale (£650)
Ian McNally	Bristol Half Marathon (£180)
Ruth Willis	Coffee Morning (£30)
Jo & Ben Salmon	with Support from Business Express (£130)
Rosie MacDonald	Bellahouston Park 10km run – is running this again in May & September – (£360)
Orla Morris	Selling BSG pins (£157)
Christchurch Police Station	for displaying charity box special thanks to CJ (£28)
Messy Play, Loughton	Donations from their Teddy Bears picnic (£229)
A very special thank you to Mrs Donna Barker	who sent £122.40 in memory of Mr. John Barker
Jenny O'Donoghue	who raised £2001 by running the London Marathon
Her neice Leigh Byas's son, Alexander, has a facial birthmark and Jenny ran the event for him	
£1,140 raised by a disco held by our Treasurer, Jane and her husband Michael on 17th July	

Through your generosity we were able to support the Congress in New Zealand. We were also able to arrange for the reprinting of various booklets, including the excellent 'Living with a Child Who Looks Different'.

Tracy Mason is interested to hear from anyone in Glasgow or Scotland. She has a 2 year old son who has a PWS on his face and has just started laser treatment at Yorkhill Hospital. Tracey can be contacted via e mail on Tracymason930@aol.com or at 15 Quarryknowe, Rutherglen, Glasgow, G73 2RN

Deborah Harper's daughter, Emma (aged 4) has a PWS. The Harper family can be contacted via e-mail on Deborah.harper@ntlworld.com or at 75 Richmond Avenue, Grappenhall, Warrington, Cheshire. WA4 2NX

Jodie Clarke is 9 years old and would love to hear from you. She can be contacted via e-mail at tw.Clarke@ukgateway.net

Penpals

www.birthmarksupport.org.uk



All Party Parliamentary Group on Skin

The BSG was invited by the Government to submit evidence to the above group which had been set up to look at the social and psychological impact of skin disease on the sufferer and their families/friends.

The group reported back and whilst the published findings tended to focus on 'disease' of the skin e.g. psoriasis; eczema etc., there were common areas identified, for example, the staring; lack of information etc.

There were also some interesting facts – most trainee Doctors receive 1 – 2 weeks training on dermatology, with Nurses receiving even less. Unlike Europe, there is no focus on the psycho-social aspect of skin disease for those training to become Consultant Dermatologists. A lack of properly validated, patient assessed Quality of Life data is also highlighted as being a weakness.

The report concludes:

'Relatively few skin diseases are life-threatening but, nevertheless, they can all have severe psychological, physical and social effects. These aspects of having a skin condition need to be understood and given due priority, so that patients with chronic skin diseases are provided with adequate and appropriate support to manage, control and live with the condition'.

A full summary of the report is available from Alana Smith (smithr@ricsonline.org) if anyone wishes to see the same

Funding Appeal

Dr Syed launched an appeal for funds in order to facilitate the attendance and participation of herself and Sister Jane Linward at the 15th Annual ISSVA Congress. This was held in February 2004, in New Zealand.

They presented four papers based on ten years' work in the specialist area of vascular birthmarks at this international forum which is a unique opportunity for birthmark specialists to share information and experience. Dr Syed says, 'the information we gain from attending these Congresses significantly enhances our understanding of vascular birthmarks and their development. Consequently our treatment and management can be as effective as possible.'

The BSG donated £2700, with £635 being donated by individual members and we were keen to support Dr Syed in her appeal for £3000. This enabled full participation at the Congress. Dr Syed and Sister Jane regularly give up their time to involve themselves in the Group's activities and we were delighted to be able to reciprocate. Thank you to all who donated.

A full report from the GOSH team is attached to this newsletter.

Cosmetic Camouflage

This ties in nicely with the article on the All Party Parliamentary Group on Skin as it deals with image and the fact that our self-perception takes a battering at the best of times when bombarded with stick-thin, 'beautiful' models. What about if you are born with or develop a noticeable skin condition or disfigurement – how does society's obsession with image affect you then?

One answer, maybe, is to seek help from the British Association of Skin Camouflage (BASC). Skin Camouflage was pioneered during the Second World War to help the pilots both here and in America who had been badly burned by making use of plastic surgery and camouflage creams. Remedial cosmetic camouflage is defined by the BASC as being, 'the art of concealing a discoloration, blemish or scar with the application of specialist camouflage creams that are matched to the surrounding skin tones.'

The BASC was formed by Joyce Allsworth who was instrumental in training members of the British Red Cross in cosmetic camouflage and was involved in setting up the initial clinics in hospitals around the country. This work was complemented by a comprehensive training programme set up in 1986, designed to increase the number of trainees in this specialist area. The pioneering work by Joyce Allsworth has resulted in a network of practitioners being set up in many parts of the country.

If you are interested in finding out more about this service, check with your local hospital to see if they have a camouflage clinic or contact the office of the BASC who will be able to put you in touch with your nearest BASC practitioner (details at the end of this article). A detailed consultation will take place during which time the correct creams/shades etc., will be determined and advice will be given on skin preparation and application. There may be a charge and you should determine this from the outset.

For birthmarks in particular, Port Wine stains can be partially disguised by trying a green cream (sold by Boots or the Body Shop) that can be applied sparingly to the reddened area with the foundation on top of that. Again this should be applied sparingly. If you have had laser treatment, camouflage can help hide the redness caused by the laser.

This service can be used by men, women and children and, with the growing range of shades, no-one need be excluded. The BASC sum up their work by saying, 'disguising a disfigurement allows a person to present themselves to others in a less surprising way, reduces anxiety and inhibition on both sides, and goes a long way to restore confidence and self-esteem.'

For more information please contact:-

**British Association of Skin Camouflage
C/o Resources for Business Ltd.,
South Park Road, Macclesfield, SK11 6FP
Tel:- 01625 267880 Fax:- 01625 267879
Email:- basc@resources.demon.co.uk
Website:- www.skin-camouflage.net**



The BSG website also has a section on camouflage which gives product details and information regarding the Red Cross and their training resources.