



Birthmark Support Group

The newsletter for all members of The Birthmark Support Group

Summer 2008



I hope that the holidays are going well. For many, there may be a change of school ahead – if so, if you haven't already made contact with TeenTalk, why not do it now? The team will be only too pleased to hear from new members and they can put you in touch with those in a similar situation or those who have already made the

move.

We just wanted to officially mark Summer with a quick newsletter to let you all know what the Group has been up to – as usual, we will be distributing this newsletter via email.

Whilst mentioning the sun (although it has completely disappeared at the moment) we wanted to let members know that whilst it is important anyway to use sun cream, it is imperative that birthmarks are screened from the sun. If you or someone in your family has a birthmark, it should be possible for you to obtain sun cream on prescription from your GP from March to October each year (factor 40 to 60). Check with your local surgery.

Thanks also to Christine Bleasdale for submitting a very emotionally charged article which has a fantastic positive edge to it.

We have also been approached by Maverick Television who are currently working with Gok Wan (of How to Look Good Naked fame). Details of the programme they are currently involved in making have been sent to members via their email addresses – who knows, you may have entered same? If you did, please let us know how you get on and what the experience was like for you.

Alana

Fun Day Dates for 2008

21st September 2008 (date confirmed) – we will be returning to Chigwell. Watch out for details on the website and via the email to members. We will also be holding our AGM at this Fun Day.

News

We are delighted that Alex Pratt has begun working with Ian Clover looking at the upkeep of the website. Ian is still looking to resign from the Committee in September 2008, so we still have that vacancy as advertised in our February 2008 newsletter (see below). In fact, we are still looking to fill two of the vacancies we previously advertised and we have another one to add to the list. Quite simply, we are a very small organisation looking after a huge number of members. All members of the committee have jobs and families to take care of and we would really appreciate some help – we don't bite, honestly! Details of all the roles are published below.

Website & Email Administrator

Do you have IT Skills?

Would you like to help the Birthmark Support Group by maintaining their website and email accounts?

We urgently need to find a volunteer to take over the position as the Group's website and email administrator from Ian Clover.

Ian has ably fulfilled this role for the last 10 years but because of other commitments, now feels he must step down.

The role includes the maintenance and updating of the Group's website and maintenance and administration of the Group's email accounts. On average this requires 1-2 hours effort per week.

If you have IT skills and some experience of websites and you would like the opportunity to help the group in this important role please contact Ian Clover on web@birthmarksupportgroup.org.uk for a full job specification and further details.

Media Co-ordinator

This position requires the person to respond to enquiries from various different media sources; from weekly magazines to in-depth documentaries, the BSG receives requests for case studies and stories.

The role requires the co-ordinator to establish through contact with the BSG Committee if in doubt, that the request is the type of feature that would be beneficial to participate in.

The BSG does not condone sensationalism and has never knowingly participated in such a media request, the BSG will also not actively participate in any media request which casts a negative view of living with a birthmark.

The media co-ordinator will have access to the BSG membership database, and will contact via email or phone any member within the relevant age group or birthmark type, and then act as a point of contact for both the BSG member and the journalist concerned. It would be beneficial also to build up a database of contacts within the media to whom Press Releases could be sent for forthcoming Fun Days and BSG events.

This position currently necessitates no more than a few hours a month, but the co-ordinator has the potential to develop the role in order to generate greater media exposure for the BSG, and birthmarks in general. Due to the nature of the role, full references will need to be obtained by the BSG. You will also be required to undergo a Criminal Records Bureau (CRB) check.

For further information please contact Louise Busfield at media@birthmarksupportgroup.org.uk

TeenTalk Co-ordinator

We are looking for someone to head up the TeenTalk team as a co-ordinator.

We have not been able to fill this role for some time now and whilst we are ensuring that cover is maintained, we feel that this job is more suited to someone who is within an age range that can identify with the issues that teenagers might be experiencing. This role involves answering the TeenTalk e-mails, putting members in touch with one another, producing the TeenTalk newsletter and, when demand allows, organizing events for members. It is hoped that the important service which we offer to those with birthmarks aged between 10 and 21, can be expanded to provide a secure 'message board' facility to allow members to share thoughts and provide mutual support more easily.

The person who takes this on needs to be able to draw on their experiences of growing up with a birthmark whilst a teenager. As the role involves working with children, you will be required to undergo an Enhanced CRB check because of the nature of the role and activities which may result from working in such a post.

If you are interested or would like to discuss this role further please contact Nick

chairman@birthmarksupportgroup.org.uk

Applications for the posts should be put in writing to the Secretary (either by post or email) in the first instance.

sec@birthmarksupportgroup.org.uk

DVD Update

After what seemed like an interminable amount of DVD stuffing, we completed the task and, thanks to the generosity of members were able to complete our objective. To re-cap 32,000 copies were sent to the British Medical Association (BMA) where they were distributed via the BMA Journal, to the 28,000 GPs and 4,000 to hospital paediatricians in the UK and a further 5,500 went via a mailing company to the Headteacher of every secondary school. In addition, we are also able to send one to the Senior Midwife in every hospital maternity unit. Our next objective is to complete a distribution exercise to Medical Schools – this will be carried out in line with the commencement of the next academic year.

At the beginning of July, Nick Ward 'manned' the BSG stand at the British Association of Dermatologists (BAD) Conference held in Liverpool. He received some favourable feedback from professionals at the event and was able to hand out additional copies of the DVD to nursing staff.

Help Raise Awareness

This is a repeat of the article from our February newsletter. The response was good with articles appearing in many publications, however, Emily would particularly like to hear from young adults as she has come to the end of the case studies she has for this age group.

The Birthmark Support Group is currently working with media consultancy Medavia to help raise awareness of birthmarks and to highlight the support offered by the BSG. Medavia is a team of journalists who work with national newspapers and magazines on a daily basis, writing features on a whole range of subjects. They have already placed some of our members' stories in the national press and are interested to speak with anyone else who would be happy to talk about their experiences. Perhaps you are a mum or dad who struggled to come to terms with your child's birthmark? Maybe you received negative and unpleasant comments from strangers, friends or family. Or perhaps your child's birthmark in some way had a positive effect on your life, relationship or career? Perhaps you learnt from your child's own resilience and positivity? Or maybe you are a woman who struggled with your own birthmark for years but have finally come to terms with it. Maybe your partner or job helped you regain your confidence.

If you would like to speak to one of Medavia's team in confidence to find out more about telling your story email Emily@medavia.co.uk or call 0117 985 8709. to find out more about the organisation and how it works visit www.medavia.co.uk.

Medavia's aim is always to write sensitive and thought provoking pieces for the national press, including the

contact details of the Birthmark Support Group. Magazines and newspapers will also make a financial offer to you for your story.

Fundraising Activities

One from Christmas 2007 (to get us in the mood for 2008) – we weren't able to run this 'thank-you' in our last newsletter because we ran out of space, however, we are very grateful to the Chigwell School for their generosity in donating the monies collected (£2,100) from the School Pantomime. Sophie Lingfield (daughter of Mark & Toni Lingfield) is pictured below alongside cast members receiving the cheque on the Group's behalf.



School Charity Ball

On the 3 May this year Crawley Ridge Infant School Association (CRISA) held a charity fundraising event at the Frimley Hall Hotel. The school PTA (CRISA) holds an annual ball, proceeds from which are divided between the school and a nominated charity. This year it was the turn of the BSG nominated by one of the parents who is a BSG member and also a Committee Member of CRISA.

As is always the case, CRISA were keen to have a representative from their nominated charity attend the event as their guest and Stanford Jeffrey (a BSG member with a port wine stain) very kindly offered to represent our cause and say a few words. He will, apparently, do almost anything if it involves a free meal!

Funds are raised for the event not only through ticket sales but also from an auction that takes place on the night. Naturally, there are many other manner of ruses employed to encourage people to give generously, with the sale of raffle tickets being just one such example.

The event room and tables at the hotel were decorated by a team of ladies from CRISA and the effect was both stylish and impressive. The auction items were varied in the extreme, ranging from a day's accompanied fly fishing

through to an exclusive visit to the air traffic control tower at one of London's prestige airports.

The event was very well supported by a host of dedicated and committed parents, supporters and friends of CRISA and the entertainment, which included a live band, was thoroughly enjoyed by all who attended. In fundraising terms, the highlight of the evening was the auction, most ably 'called'.

Just prior to the auction those attending were reminded of the BSG element of their charitable provenance for this event. Stanford took the opportunity to briefly outline the incidence of birthmarks amongst the general population as well as to highlight the lack of research and accurate information available to medical specialists in particular. Not surprisingly, mention was made of the new BSG DVD being distributed to schools, GP practices and other medical specialists and the very valuable contribution that CRISA funds would make towards the ever increasing campaign of awareness that has now begun in these key areas.

All present were warmly thanked by Stanford for their very kind support and their most generous donations towards BSG and its ongoing work. The ball was obviously a social success but encouragingly, a fundraising success too, generating a total of £2000, of which £1000 has subsequently been donated to BSG. We owe a very special thanks to the family concerned and well done CRISA! Many, many thanks!!!!

School Fundraising

We are grateful to The Davenant Foundation School in Loughton for their very generous donation of £600. Sophie Lingfield is a pupil at the school.

Diamond Wedding Anniversary

Thanks too must go to Fred and Beryl Burton, the grandparents of Sarah Jones, who celebrated their 60th (yes, Diamond) Wedding Anniversary in April of this year. As you would expect, there was a huge party to celebrate the occasion and, rather than gifts, Mr & Mrs Burton asked that donations be given to be shared between the Birthmark Support Group and another charity very close to the family's heart. We were delighted to receive £300 from them. Sarah, Huw and their daughter Olivia-Mai joined the group in 2005.

Walk for Skin

To all those who walked their socks off raising money for the BSG, we would like to offer our thanks. As soon as we have a total for the amount raised, we will pass on the good news.

The British Skin Foundation has advised us that, on some occasions, participants using the Justgiving mechanism have inadvertently been sending 100% of their

sponsorship monies to their chosen nominated charity. As you know, this is a 50/50 split.

Thank You!

Finally, thank you to all families, friends and colleagues of our members who have donated money to the Group over the year. We are very grateful to you all for thinking of our charity and, quite simply, we would not be able to continue our work were it not for your generosity and support.

Website Updates

Ian and Alex have been hard at work making improvements to the website – you will also be able to find an article on the most recent Fun Day held on a gloriously sunny day in Birmingham. Again, our thanks must go to Sarah Evans, headmistress, and her team of very willing helpers at the King George V Girls School.

On the website you will also find a link to be able to pay via the JustGiving site for any donations towards DVDs (there is also the facility to order via Snail Mail).

****News and Articles from You****

GOSH Laser Fundraising

Some of you may have seen some cast members from EastEnders on a recent 'Weakest Link' charity special hosted by Anne Robinson. The cast raised a very credible £23K for a charity raising money to purchase a new Cynergy Cynosure Laser Machine for The Birthmark Unit at Great Ormond Street Hospital. The fundraising venture is being run by Lindsay Weinstein, mother of Cosima (whose story was featured in one of our newsletters last year).

In addition, some of you may have seen Cosima and Lindsay who appeared on 5 News recently.

Jacob's Story

by Christine Bleasdale

As per my introduction, we are very grateful to Christine for sharing her family's story with us. I was lucky enough to meet Christine and her family at a Fun Day in Manchester a couple of years ago.

At 3.03pm on Friday 13th July 2001 after a normal pregnancy our second son Jacob was born. A brother for Tom (then aged 6). As the midwife held him up we could see his bottom, legs and feet were purple. As she turned him round, I could see his face and scalp were also purple with two huge beautiful blue eyes looking inquisitively at me. I think I was still suffering the effects of gas and air as I said 'Oh is he bruised?' Well I had been pushing for what seemed like hours! Logic then took over and we realised something was seriously wrong. Several paediatricians came and went with no firm diagnosis. By this stage my husband and I agreed it must be some kind

of birthmark. We then tried to console ourselves with the fact that at least he was healthy, little did we know!

The bombshell was dropped a day later when a senior paediatrician confirmed Jacob had extensive Port Wine Stain (PWS) birthmarks and they would need to do an MRI scan to examine his brain as there was a very rare syndrome associated with such birthmarks causing numerous serious medical conditions. It was so rare we shouldn't worry about it. We tried to put it out of our minds and carry on as normal. The possibility that Jacob might have this condition was too awful to contemplate. From the beginning, we were determined to treat Jacob just like any other child, so we did all the usual things such as going out for walks despite all the comments about 'sunburn' and what was wrong with our baby's face. I also went to the 'Baby Club' at Horwich clinic as I had with my first son Tom (now 13). I won't pretend it was easy but felt strongly that Jacob deserved the same experiences that Tom had.

The first few months passed by in a blur with lots of hospital appointments. Not the relaxing maternity leave I had planned. I also did lots of research regarding the condition, which we were told was Sturge Weber syndrome. It was extremely frightening to read words such as mental retardation, calcification of the brain, Epilepsy and Glaucoma. We were glad we had an appointment with the paediatrician to discuss this further. However, this was not as reassuring or as informative as we hoped. The local hospital decided they would not do an MRI scan at this stage as Jacob wasn't showing any symptoms. However, they did agree to refer us to an eye specialist regarding the Glaucoma, as I had read that PWS on the eyelid can cause this. To our dismay, when Jacob was 8 weeks old, the eye consultant confirmed he could see signs of Glaucoma and referred us to Manchester eye hospital where we have made many regular trips since under their expert care.

When Jacob was 12 weeks old we saw the Dermatologist at Bolton who organised a referral to Great Ormond Street Children's Hospital in London. We travelled down 4 weeks later where they explained laser surgery may reduce the redness of the birthmark over time, with the first treatment being at 18 months of age. They also suggested Jacob should have an MRI scan as he was at high risk of having Sturge Weber syndrome because of the bi-lateral facial birthmark and the fact that it covered his scalp and forehead.

After 2 traumatic attempts at obtaining a successful MRI scan in London we nervously awaited the results. My husband and I had discussed this in depth and decided that whatever the outcome we would continue to treat Jacob (now 7 months old) just as we always had and give him the same experiences and opportunities already given to our other son. Despite trying to prepare ourselves we were devastated when the Consultant at

Great Ormond Street Hospital told us that Jacob did have Sturge Weber syndrome. She informed us about the high risk of developing Epilepsy (which he now has) and possible learning difficulties, by this stage we already knew he had Glaucoma. The only reassuring factor, which we desperately clung onto, was the fact that children with SWS varied as to how they were affected by the condition. No one could give us any guarantees or tell us what would happen. We had to wait and see how things developed.

This has been very difficult to cope with - trying to prepare ourselves for what may or may not happen. We have experienced a huge range of emotions - taking comfort that Jacob appeared to be developing as he should but also being afraid of what might develop. I was worried about Epilepsy - how would I know when he had a seizure? (there are many different types) and would I be able to cope? I have coped because I have had to and at times have surprised myself, finding reserves of strength to deal with some very difficult situations.

As the condition is rare it's only within the last year that we have met parents and other children with SWS, through attending a Birthmark Support Group Fun Day in Liverpool and attending the Sturge Weber Foundation UK family weekend. We have recently met a family with a little boy who has SWS living only seven miles from us and we keep in regular contact.

Jacob is now seven years old and is a delightful affectionate little boy, very strong willed and stubborn but with a wicked sense of humour and a beautiful smile. We wouldn't change him for the world. Of course we would prefer if he didn't have the syndrome but he does and that is part of who he is.

He has now had 8 sessions of laser surgery which have helped to lessen the redness of the birthmark on his face, but we have had to accept that it, and the conditions it causes, will never go away. We have learned to deal with people's reactions which range from staring, pointing and all kinds of comments such as: He's been sunburned, had his face painted (as what?), got chicken pox, eczema or measles. Although this is not always easy to cope with and I'm afraid my response to this ignorance does depend on how I'm feeling at the time. I have had to learn to control myself as I wouldn't like Jacob to repeat some of the things I've said in the past!

With regard to Sturge Weber Syndrome, Jacob does have Epilepsy and Glaucoma and although he has met most of his developmental milestones it became apparent when he started mainstream school that he would need extra help. After quite a struggle, we have now been successful in obtaining a special needs assistant for a number of hours each week to support him in class. Jacob has also had surgery to try to reduce his eye pressure with possibly more to follow and has to wear glasses and a patch on his right eye due to poor eyesight,

which is easier said than done. My sister brought him a special Captain Hook pirate patch from Disneyland which I thought he'd love. He took one look at it and said 'I'm not wearing that!'

We still have to attend many hospital appointments in Bolton, Manchester and London and do not know what the future holds - does anyone? We have also got used to administering the quantities of medication Jacob needs each day. If we go out, the medicine bag comes with us. We just try to get on with things, focus on the positive and enjoy our time together as a family, although this can be difficult at times. It helps not to look too far ahead or become complacent as with SWS things can change rapidly. We also have to consider our other children, Tom (13) and Eve (5) as we are conscious they often don't receive as much attention as their brother.

Jacob has brought us much love and happiness and also taught us some very valuable lessons in life: We are all



individuals and should accept and value each others' differences and never take anything for granted, particularly good health. We have also been in contact with many lovely people whom we wouldn't have met but for Jacob. It has been quite an emotional rollercoaster ride and the journey's continuing,

but Jacob is such a wonderful brave little boy who just gets on with life with a smile. We are so grateful for everything he can do and just want him to achieve the best he can, whatever that may be.

Christine Bleasdale

That's all from this newsletter. I'll leave you all with Jacob's beaming smile.

Have a great Summer and hope to see as many of you as possible at the next Fun Day on 21st September 2008, at The Chigwell School.

Take Care, Alana

Stop Press

Simon McDonnell is running the Windsor Half Marathon on 21st September 2008, and is raising money for the group. Simon is a friend of Michelle & Stuart Field who have a son, Ben and a daughter, Millie. Millie has a haemangioma and her parents received help from the BSG in getting treatment for Millie at Great Ormond Street Hospital – the half marathon is the family's way of thanking the group. Simon has set up a justgiving page <http://www.justgiving.com/simonmcdonnell> for sponsorship.