



Birthmark Support Group

The newsletter for all members of The Birthmark Support Group

Here Comes the Summer!



Well, it's fair to say that there is every likelihood that there won't be any hosepipe bans this year. For those of you that have suffered as a result of the unseasonably wet weather, our sympathy. We

ended up with 4" of clean rainwater in our basement (husband decided not to go for the sump pump with the battery back-up) which would have proved more than useful during the four hour power cut we experienced at the same time! Needless to say, we are now fully prepared.

Thank you to those members who have submitted articles for inclusion in this newsletter – they are always gratefully received and are, I believe, an invaluable part of the newsletter, especially for our newer members.

One thing to draw your attention to – the 'Situations Vacant' section. As you all know, the Birthmark Support Group is totally run on a volunteer basis with our committee performing their duties alongside work, family and other commitments. We are looking to fill some key roles within the BSG so please take some time to look through this section to see if you can help.

Alana

Dates for your Diary

Sunday 16th September 2007 – South East (venue – The Drama Centre, Chigwell School, The High Road, Chigwell, Essex, IG7 6QF).

Glasgow Fun Day - Saturday 17th November 2007 – With 'Caring Matters Now' going its separate way from the BSG, we are

left without an organizer for this Fun Day. If you live in Scotland and feel that you would be able to take this on (we are likely to be able to use the same venue as last year in Cambuslang), then please let us know by emailing me –

secretary@birthmarksupportgroup.org.uk

The proposed venue will be St Brides Church, 21 Greenlees Road, Cambuslang, Glasgow, G72 8JB).

Times for all the events are between 12 noon and around 5 p.m. The dates are published on the website and full details will be e-mailed/published prior to the Fun Day itself.

Proposed Dates for 2008

11th May 2008 – we will be returning to King Edward VI High School for Girls, Edgbaston Road, Birmingham, B15 2UB. Thank you to Sarah Evans (Head).

We will also be hosting a 'London' day with the AGM – the date for this is to be finalised but it will be in **September 2008**.

South West Fun Day

It's probably safe to say that it hasn't stopped raining since May 13th and, boy, did it rain! The sun eventually came out late in the afternoon but it did mean a complete re-think in terms of our order of play. Fortunately, it didn't stop our members from attending and, we hope, enjoying the hospitality of Clayesmore School and making full use of their fantastic sports facilities. A full report has already appeared on the website – thank you again to all those involved in organising and helping at the event and to those brave members who made the journey – it was a very successful day with many friendships being struck up and, hopefully, continuing.

We had twenty two families and their friends making a total of over one hundred attendees join us for the day.

Thank you to Julia Cadogan (Clinical Psychologist from Outlook based at the Frenchay Hospital in Bristol) who attended with her daughter & friend. Julia passed on details of our Fun Day to some of her families who attended for the first time. Our thanks too to Jane Linward for taking the time out of her weekend to attend the day – I know that many people benefited from being able to spend time talking through concerns with her.

Walk for Skin

Thank you very much to those members who put their best feet forward to take part or marshall at the recent British Skin Foundation 'Walk for Skin' sponsored walks. We haven't been able to get a definitive total of exactly how much money was raised (this will be confirmed around September). Apparently there were 18 charities represented and fundraising is around £100K in total across the groups. Due to data protection, we are not allowed to know exactly who walked for the BSG – so if you did and we didn't know about it – again our thanks. Please see the FIT newsletter for further details and photographs.

Situations Vacant

We are looking to fill the following roles, on a voluntary basis, within the Birthmark Support Group:-

Treasurer **Media Co-ordinator**

TeenTalk Co-ordinator

FIT Team Member

(please see FIT newsletter)

Treasurer

It is with great reluctance that we have accepted the resignation of Jane Coultrup, our existing treasurer who has worked so hard to ensure that our accounts remain legally viable and are completed in line with the legislation laid down by the Charities Commission. We are, therefore, looking for

someone to take up the mantle who is able to fulfill the following duties:-

Job Description - Treasurer

- Payment of invoices/processing of expenses
- Processing donations, including acknowledgement of same
- Reconciliation of Bank Statements
- Monitoring Justgiving Donations
- Annual audit duties
- Provision of fundraising activities for web page
- Periodic Gift Aid claim to ILR
- Draft budget/financial forecast
- Administrative duties

In addition, the role of Treasurer carries with it Committee Member responsibilities with the following requirements:-

- Participation in periodic Committee telephone conferences.
- Preparation of accounts/budgets for Annual General Meeting and attendance/participation at same.
- Dealing with email correspondence as part of Committee

To fulfill the above, you will need:

- Accounts/book-keeping experience
- Be computer literate (word, excel, emails)

Due to the nature of the role, full references will need to be obtained by the Birthmark Support Group. You may also be required to undergo a CRB (Criminal Records Bureau) check.

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 Birthmark Support Group. You will also be required to undergo a CRB (Criminal Records Bureau) check.

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

TeenTalk Co-ordinator

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

Jacki Lovelidge, who has been running Teentalk so ably for the last year or so, now feels that she needs to take a bit more of a back seat and so we are looking for someone who can take over from her as

co-ordinator. 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 this 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 the role further, please contact either Jacki via teentalk@birthmarksupportgroup.org.uk or Nick via chairman@birthmarksupportgroup.org.uk

Applications for the posts should be put in writing to the Secretary (either by post or email). For each role, an interview will be carried out either in person or via the telephone by members of the existing Committee.

Articles submitted by Members

I have chosen two articles to publish in this newsletter – both are from families who have experienced living with haemangiomas – the first piece is from Lindsay Weinstein about her daughter, Cosima (aged 16 months) and the second is from the family of Hannah Hutchinson (aged 4). As Lindsay points out, there are some haemangiomas which are bigger and found in different places – it is also worth mentioning that most do not exhibit the complications that Cosima has suffered. Thank you to both Lindsay and Kirsty for taking the time and trouble to prepare the articles and for letting us share your very personal stories.

Cosima's Story

My daughter Cosima Chaya Wiltshire was born on 4/3/2006 at 7.27pm naturally in a birthing pool in our lounge with music and candles. It was the best day of my life. When I scooped her up out of the water my first words were, "I have been waiting for you all of my life."

Shortly after the birth I was admitted to hospital with complications. At the same time Cosima was admitted to Intensive Care where she stayed for 8 days. On about the 6th day I noticed a mark on her right cheek. One of the doctors said it was a birthmark. At that stage it was the size of the nail of my little finger.

Three days after coming home the mark started to grow fast and we were really frightened. By 10 days it was raised and blood red. All of this was "normal" according to the hospital and didn't require any treatment. These intermediate 10 days were the only carefree days we have had since her birth.

At 4 weeks I woke up in the middle of the night to the sound of her whimpering. Her head and body were covered in blood and the mattress was soaking. The birthmark had bled massively. She was rushed to hospital but thankfully no blood transfusion was necessary.

Following the first bleed the surface of the haemangioma became ulcerated. The hospital that we went to "advised" us that she was not in pain: she had colic! I wasn't prepared to accept this diagnosis. Eventually a consultation was arranged at GOSH, and since mid April Cosima has been a patient of GOSH as she needed weekly care. Cosima was on morphine for 6 months as the ulcerated surface exposes nerve endings, which is excruciating.

Cosima's 'birthmark,' is an haemangioma, which is a group of capillaries that are tangled beneath the skin and protrude through the surface of the skin. Cosima has 5 in total on her body. Cosima was treated

with oral steroids for 6 months, to try to stop the growth of the Haemangioma on her face as it started to grow onto her mouth, twisting her lips. They feared it would then grow onto her eye.

So far, she has had 2 laser operations designed to accelerate the healing of the ulcers, temporarily deaden the nerve endings and to try to prevent further ulcers.

Following the first op. she suffered another big bleed so it was back to A & E. The hospital did little to help. About 10 days later she began to refuse feeds and was being sick. We attended GOSH for our weekly check-up and she was admitted immediately. The doctors knew something was terribly wrong. Cosima was found to have a serious infection which resulted in her being placed in isolation for 3 weeks, the first 2 spent being treated with intravenous antibiotics. The second laser op had to be delayed, as it was feared that infection could be passed into her lungs whilst ventilating her during the operation. Fortunately within 2 weeks we started to get back negative swabs, suggesting she was clear of infection. This meant the haemangioma could be lasered again.

The surface was healed for the first time for perhaps as much as a month. In mid October she began screaming again and it's such a unique cry, I knew something was wrong. I called out the emergency doctor and took her to the GP as at that time, we were changing her dressing every 3 to 4 days. As soon as I left the GP I knew it was her face as nothing else was visibly wrong but she was still crying, and I didn't accept it was just bad teething.

Cosima was admitted to GOSH the next day and the swabs then came back diagnosing a serious infection. I just felt like we were in a black hole and were never going to get out. Two weeks later after intravenous antibiotics negative swabs came back again. Thankfully on that occasion, she did not have to have it lasered.

In between admittances we started to go out, but only "out" as we could not go to enclosed public places when she was on steroids as she has depleted immune system. All baby groups and activities were therefore off limits so; if we could we went to the park or to people's houses. Basically, we just wanted to join in with the every day things.

In January 2007, her face was ulcerated again. This time it happened as she played with a toy train at a friend's house and she must have pressed onto it at some point. The haemangioma bled internally which then led to it ulcerating and 3 weeks later, it had still not healed.

We have more appointments at GOSH for possible laser treatment. It just seems to be never ending and the thought of ever being able to relax and not watch her like a hawk is just that, a thought.

I am a barrister by trade but have had to learn new skills such as administering her medications [17 times a day at one point], make the complex dressings, daily clean and change the dressings [which can take up to 2 hours] and stop bleeds. This is not how I envisaged spending my maternity leave. As you will appreciate like any mother, I would do anything and everything that is needed without question, as I, like you would lay down my life for my baby. I would not swap Cosima for anything. To me she is unique, beautiful, funny, spirited and so incredibly brave.

I am aware that we are really very lucky compared to other families, whose children suffer haemangiomas much bigger than Cosima's and in places such as their lips, eyes & bottoms. The good news is that haemangiomas do begin to recede into the body from about 3 years onwards. I know we need to be patient and hope that her care can be managed conservatively, without resorting to plastic surgery now. This is not a viable option at present as hers is too deep in her face.

At GOSH, we have been under the care of **Dr Syed, Professor Harper and a Specialist Birthmark Nurse, Jane Linward** with the rest of their team, who have "saved us." We have the best treatment, advice and support that you could ever wish to have if you were in such a position. Nothing is too much trouble including weekend visits at home from Jane! They truly are an outstanding credit to the medical profession, GOSH and the NHS.

Meet Cosima:-



Hannah's Story

We were overjoyed to find out we were pregnant again after an unfortunate miscarriage. The pregnancy went well until my waters broke at 36 weeks. The doctors managed to keep the baby safe inside until at 37 weeks I was induced. It wasn't a straightforward birth but after a ventouse delivery I gave birth to a beautiful, perfect baby girl, named Hannah. She unfortunately spent the first week in and out of the special baby care unit but after a couple of days of light therapy to treat jaundice we were allowed to take her home.

The first two weeks were as trying as they are with a new baby to get used to but we were just beginning to get to grips with everything.

At the end of Hannah's second week I noticed, what looked like, a dry patch appearing on her ear lobe. I applied various baby creams but it didn't help. The 'dry patch' began to change. It now was red in colour and getting larger by the day. I showed it to the health visitor who told me it was a strawberry mark and said that it would go on its own eventually. There was no mention of how large it would probably grow and how it would behave. By this time it was covering almost half her ear and protruded out quite far.

Personally, Iain and I found it very difficult to cope with. People would stare in the supermarket and every one wanted to look at our 'new' baby but was shocked when they saw her. To us she was still perfect and beautiful.

As the weeks passed by the haemangioma grew steadily and ulcerated. This led to 3 stays in hospital while they treated the infection with intravenous antibiotics. The third trip to hospital the doctors informed us that Hannah's birthmark was infected with a nasty flesh eating infection and that no drugs were licensed to be used with children. We were then referred to a plastic surgeon and treatment began with the paediatric outreach nurses. The nurses called everyday for 3 months to pack and dress the ulceration. Hannah was in pain and was obviously upset every time they visited. She was only 4 months old.

It was about this time when I found out about the birthmark support group through the Internet. I wrote to them and asked for more information about the various types of birthmarks. Then one Saturday teatime I got a phone call from a lovely lady whose name I can't remember. She discussed the problems we were having and gave me some reassurance. She put me in touch with a sister at great Ormond Street Hospital who telephoned me later that evening. It was so good to hear from someone who had expert knowledge in this field and she gave me some very good advice.

Thankfully the daily treatment of cleaning, packing, using gels and creams and finally dressing the infected birthmark began to make a difference. Slowly the daily treatments reduced to three times a week, to twice a week and eventually the infection was cleared up. The birthmark was huge at this point, covering all her ear and sticking out about an inch or more from her head. We made 6 monthly clinic appointments to see a plastic Surgeon at our local hospital. Eventually he said the birthmark would reduce on it's own and it did. Hannah was about 1 year old when we noticed a reduction in the size of the birthmark and the colour began to change from purple/red to pink.

When Hannah was 3 the birthmark had reduced dramatically and was skin coloured. It was leaving scars and wrinkly skin where the infection was and the bottom half of her ear had lost its shape. She had her first surgery in the summer after she was three and the surgeon re-shaped her ear giving her an earlobe and taking away a lot of the baggy, wrinkly skin. Six months later he did another operation taking away more loose, scarred skin. Hannah now has an almost perfect ear that people don't notice has ever been different. She is very proud of her 'special ear' and takes pride in showing everyone how beautiful it now looks. Through all this Hannah has taken everything in her stride, never complained and continued smiling.



Hannah Aged 10 Months and aged 3 years

Birthmark Contacts – Please note change to CMN

Congenital Penny Wall
Melanocytic cmn@birthmarksupportgroup.org.uk
Naevus

DVD Update – Launch Date

Our Patron, Esther Rantzen, plans to launch the DVD, on the afternoon of the 12th October 2007, at Great Ormond Street Hospital where so much of the filming took place. We hope that those of you who took part in the filming will be able to join us for this occasion and details will be sent to you nearer the time.

Now, we need your help, please.....

The final DVD will contain three chapters, one for general viewing (lasting about 30 minutes); one aimed specifically at the medical profession and one at schools (each of these lasting around 10 minutes). The DVD will be accompanied by an explanatory booklet and sent to every GP, paediatrician and secondary school in the country; if funds were to permit then we would also like to send one to every primary school. We estimate that the cost of production and distribution of this package will be getting on for £2.50 and for some 40,000 copies to be dispatched, that is far more than our funds can currently stand. It is a major undertaking but we believe that raising the profile of birthmarks in this way will be of enormous benefit to those with birthmarks, both now and in the future. We therefore need YOUR help in raising additional funds to help us achieve this and one way will be to 'buy' a DVD (or more if you'd prefer!) at a cost of £2.50 each. You won't actually receive a DVD but you will be given a certificate showing that this money allowed a DVD to be sent to someone in one of our target groups. An ideal gift for family or friends? Full details of the scheme will be published after the launch in October and we thank you in advance for the support we know you will give this project.

Close

Thank you to all our members who continue to support our activities throughout the year – please take some time to consider whether you would like to join us by applying for one of the vacancies we have.

Enjoy the summer and we look forward to seeing you in September for our Chigwell Fun Day and AGM.

Alana