



Birthmark Support Group

The newsletter for all members of The Birthmark Support Group

2008 – Where Did 2007 Go?



I hope that all our members had a good 2007, and are looking forward to 2008 – the weather seems to be on our side at the moment!

The Birthmark Support Group ended a busy year with the official launch of the DVD. This was held at Great Ormond Street Hospital and was undertaken by our Patron, Esther Ranzen. Thank you again to all those who participated in the filming, both behind and on-screen – the results have been well worth the wait. A very big thank you must also go to all of you who responded to our request for donations to enable us to distribute the same. Please see the progress update towards the end of this newsletter.

We would like to take this opportunity of welcoming our new Treasurer, Karen Barter, to the committee of the Birthmark Support Group. Some of you will have met Karen and her family at the Fun Day held in the very wet South West (Clayesmore) – a subtle reminder, Karen was the 'Cake Lady'! And



for those of you that weren't lucky enough to be there here is a picture of Karen & Jane at the official

handover of the cheque book over to Karen! The appointment of Karen means that we will be losing Jane Coultrup from the Committee; however, we are delighted to advise that Jane will be taking on the Admin Support Role for the CMN team. I am sure that all

members would join us in thanking Jane very much for her hard work and enthusiasm during the four years she has been in post.

Having congratulated ourselves on filling such a vital role, we were hit by another loss to the team – Ian Clover, a familiar face to so many of our members, has decided to hang up his webmaster hat. Ian has been a vital part of the BSG for over 10 years and, as a team, we are sorry to lose him. Ian has been a good friend to us all over the years. We are therefore looking for a replacement for the role of Website and Email Administrator – please see our advert later in this Newsletter.

Thank you to Pauline Aberley who has kindly submitted an article for inclusion.

We are also taking the opportunity to introduce Medavia to you – please take the time to read Emily's article and see if it is something you would like to become involved in.

Slight change to this edition in that we are combining all three copies – the general, FaceltTogether and TeenTalk – into one Newsletter. Also, we would very much like to say 'thank you' to our sponsor who has arranged for the printing of all our March newsletters and to the company who have distributed the same at a greatly reduced rate.

Alana

Fun Day 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 be advertising details on the website.

21st September 2008 (date to be confirmed) – we will hopefully be returning to Chigwell

Situations Vacant

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

Website & Email Administrator **Media Co-ordinator**

FIT Team Member
(please see FIT newsletter)

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

For further information please contact Louise Busfield at

media@birthmarksupportgroup.org.uk

Following on from our Media request for help, I would like to take this opportunity to introduce our members to Medavia. Emily's article gives you details of what the company are about and, if you are interested, what you can do to help them.

Medavia

HELP RAISE AWARENESS

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 person 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 with 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 organization 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.

Walk for Skin 2008

Thanks to all of you who participated in last year's Walks and we are happy to report that we have decided to participate in this year's ventures.

There are nine walks this year in country parks across the UK. Walks are generally 3 – 4 miles long, with shorter and longer options available at most venues. This year the Walks will include added attractions at the Walk for Skin village; live music; entertainment; refreshments and goody bags for all participants.

If you would like to join the Walk for Skin, just choose your venue and register, free of charge, either online at www.walkforskin.org.uk or phone 0207 391 6341. Please make sure that you complete

the box which asks who you would like to contribute 50% of your sponsorship money to. Once you are registered, you will be sent a sponsor form, pack and information about your chosen venue.

The Venues are as follows:

AREA	VENUE	DATE
London	Regent's Park	27 Apr
Glasgow	Pollok Country Park	11 May
Bristol	Ashton Court Estate	11 May
Birmingham	Sutton Park	18 May
Manchester	Heaton Park	18 May
S'hampton	Itchen Valley Country Park	8 Jun
Newcastle	Tyne Riverside Country Park	15 Jun
Leeds	Temple Newsam	22 Jun
Cardiff	Bute Park	29 Jun

DVD Update from our Chairman The saga continues...



You hardly notice the weight of a DVD, do you? And one certainly doesn't take up much space. And an 8 page A5 brochure isn't much bigger or heavier is it?

So when a pantechnicon drew up outside the house, disturbing us from our slumbers at 7.00 o'clock one morning just before Christmas (yes, that's one of the benefits of retirement), we assumed the driver had the wrong address. But no, we were to have a rude awakening to find that when multiplied by 40,000 a DVD and brochure actually weigh quite a lot: 2.5 tonnes to be precise! So the long running saga of our DVD continues: it has been filmed, put on to DVD, officially launched in October at Great Ormond Street Hospital by our Patron, Esther Rantzen, and now 40,000 copies of it, and the accompanying brochure, are

sitting in a shippen in North Lancashire as DVDs and brochures are slowly united. Perhaps it was a rash decision to have the DVDs pressed in the Netherlands, the brochures printed in Norfolk, and the one stuck inside the back cover of the other in a barn on the edge of the Lake District, but it has saved about £1,000 on the other quotes we received, and Jane does manage to do about 150 each evening...

But we are getting there, albeit slowly. We have now enlisted the help of others, including students from Capernwray Bible Study School, girls from Lancaster Girls Grammar School and even some of the inmates of the Lancaster Farms Young Offenders Centre, but so far the record is held by our village primary school where 8 children, 4 mums and the headteacher managed to do 2,225 in one and a half hours. So, at the start of February, we are about 13,000 down and 27,000 to go!

What then? 32,000 will go to the BMA where they will be distributed via the BMA Journal to the 28,000 GPs and 4,000 hospital paediatricians in the UK and another 5,500 will go via a mailing company to the headteacher of every secondary school; it is also planned to send one to the senior midwife in every hospital maternity unit. Then, when funds permit, maybe we'll think about getting some more produced to send to primary schools, but I'm not sure we'll be going for the cut-price option this time...

PS Anyone in North Lancashire with a few hours to spare do give us a call...

Tom's Story

We are delighted to include this very powerful and deeply emotional article written by Tom's mum, Pauline. It really is a tale of triumph over adversity and full credit must go to Tom's parents, Pauline and Simon, for their determination in getting treatment for their son. The family contacted the BSG last year and, after the initial shock of hearing their story, we were pleased to support them in their fight for treatment. We would like to thank Pauline

and Simon for their very kind donation to our funds and also take this opportunity to thank all those who responded to our call for help and provided help in the form of first hand experiences, medical journal articles and letters of support to produce at the Appeal.

Tom was due on Friday 13th October - what a date! From the moment I was given this date I knew things would go wrong. I struggled with high blood pressure towards the end of my pregnancy, and I spent a week in hospital at around 36 weeks. On the Thursday night I had a splitting headache all night and couldn't sleep so I went into hospital on the Friday morning. I was induced. Nothing seemed to happen all day and all evening, then at around midnight, just after my husband had gone home, my waters broke and we were off. However, I only got to 4cm and Tom's heartbeat was dropping along with his oxygen levels. By the Saturday lunchtime the medics finally made the decision to perform an emergency section. What a relief. Tom was born at 2.20pm and when they passed him to me I cannot express my sheer disappointment. Where was my perfect baby I'd been waiting for? All I could see was a bright red face; I couldn't focus on anything else. I was devastated. I didn't want him. I was moved to the recovery room where a doctor came into us and "informed" us that our baby had a port wine stain birthmark and that he'd probably have fits, glaucoma and suffer from mental illness.

This was within about 30 minutes of the section. Another major blow. I felt as though my whole world had just fallen apart. In my mind I had given birth to a child who would be blind and mentally disabled. What was meant to be the happiest day of our lives was turning into my worse nightmare. What had I done wrong? I'd eaten sensibly, not drunk alcohol, I don't smoke, kept exercising. Why us? How do women who seem to do everything wrong have perfect babies? I felt as though I'd let the whole

family down. They were all expecting a perfect bundle of joy and, to my mind at the time, I'd not produced this. My husband went home and he told me later he cried all the way home through sheer disappointment.

As the days went by I didn't really want Tom, other mums on the ward were cuddling their newborns, I was just attending to him, feeding and cleaning him. During this time on the ward the consultant dermatologist visited and told me again it was a port wine stain and not to worry because treatment was available to reduce it. A glimmer of hope. Tom had his eyes checked for glaucoma before we left the hospital, everything was ok.

Once at home I just couldn't bond with Tom, my midwife was fantastic and kept me under her care for an extra week. My in-laws visited me everyday knowing that due to this I was very likely to suffer depression. I felt like I was trapped in the house. I didn't want anyone to see him I was embarrassed of him. I didn't want friends to visit and I didn't go into work to show him off like all other mums do. I wanted to hide away.

My husband went out with friends about a week later and I got straight onto the internet. I frightened myself to death with stories of terrible cases and Sturge Webber syndrome. By the time he came home I was sobbing my heart out. All my spare time was spent on the internet looking for answers as to what I'd done wrong during the pregnancy, was it the high blood pressure? All I actually did was get myself in more of a mess. I did however make contact with a couple of other mums through the Bounty web site. One gave me the contact details of Dr Lanigan at Birmingham City Hospital. It appeared on further research he was one of the leading doctors in the field of treating birthmarks.

I visited my GP in December 2006 and asked for a referral to Birmingham which she did. We then waited, and waited. But heard nothing. I started to chase the

referral up and was told by Birmingham that they were waiting for funding from our Primary Care Trust (PCT) and they expect it to be sorted in the new financial year. No problem I thought. The weeks passed by and I kept chasing Birmingham. Birmingham kept chasing the PCT then the bomb was dropped, the PCT refused to pay for Tom's treatment. They didn't tell us, just wrote to the GP. It was June 2007. We were devastated, all our hopes dashed.

After we got over the shock I decided to fight it. I knew other children were getting the treatment in other parts of the country so I wasn't accepting postcode medicine. I made contact with PALS (Patient Advice and Liaison Service) explaining the situation; they would help to fight our corner. In the meantime I think I must have phoned every hospital and private clinic in the UK to enquire about private treatment. None of the NHS hospitals carried out private work and the clinics didn't treat babies due to needing the general anaesthetic. We were distraught. Stuck between a rock and a hard place.

The case went for review and again they turned us down saying that the treatment is purely cosmetic. I asked who carried out the review and it was the same Doctor who refused the first time so I put it to the PCT that it couldn't be a fair review. In the meantime the PALS officer found the aesthetic procedures guidelines and it clearly stated in that, that patients with PWS on their face should be referred to a specialist laser centre. This was something to hang our hats on. I wrote to our MP, got a petition going on the Prime Minister's web site and wrote to the chief exec of the PCT. I was told by the PCT that the case would go through a complex case panel and that I could submit evidence to support the case. My GP, Dr Lanigan and two other very kind Doctors, Dr Evans and Dr Liew also wrote on our behalf questioning the reasoning behind the decision. The PCT wouldn't tell me what I needed to do to support the case but by now I had gathered a plethora of

medical journal articles and names of other PCTs that did fund the treatment. I put my report together, which was rather like my dissertation. Dr Evans proof read my report as did my GP's practice manager. This was put together in break neck time and even that wasn't without problems. I couldn't get journal articles out of the medical school library because I'm not employed by the NHS. It seemed that everything was colluding against us. Eventually my report was complete referencing a total of 21 other medical papers, detailing the facts of possible complications, psychosocial and psychological problems of a pws. The original decisions had been made by medics who hadn't seen even a photo of Tom so I believed that if the facts were presented clearly using real medical papers they would find it hard to refuse treatment.

The Chief Exec sat on the appeal panel personally (probably due to the MP being on the case) and we got the phone call in early October whilst we were away on holiday that they had agreed to fund Tom's treatment. Tom has had his first test treatment and goes for his first proper treatment in early Feb, so by the time you read this we will have been through our first treatment. Still as I write this story I have not had a response from the PCT to questions I put to them 6 months ago. My advice to anyone who is in the same boat is to fight every step of the way and don't take no for an answer. The fight was stressful, mentally tiring and very emotional but worth it and something I can say I am proud to have achieved for my precious son Tom. I have now bonded and love him to bits; I think the fight has actually brought us closer. He so far has shown none of the medical complications I was so worried about from that day in the recovery room. He a normal, mischievous toddler with a smile that melts hearts.



CMN Team Update

We are delighted to advise that Jane Coultrup, our outgoing Treasurer, has agreed to take on the role of CMN Support Team Administrator. Jane can be contacted on:-

CMN@birthmarksupportgroup.org.uk

Equally good news is that Penny Wall has agreed to continue to provide support within this team. We are very grateful to Penny for her time and commitment to the CMN@ role for the Birthmark Support Group.

Close

We look forward to seeing as many of you as possible throughout the year. If you believe that you have got some spare hours and would like to become more involved with the BSG – don't hesitate. This is a purely voluntary organisation and only exists because of the efforts of our team.

Anyone with IT skills who believes that they could take on the role vacated by Ian, are urged to get in touch with him to talk through the proposal.

Thank you again to those who have contributed to our newsletter – we hope you've found it interesting and, who knows, maybe you feel you've got a story to share.

Take care,

Alana