



Birthmark Support Group

The newsletter for all members of The Birthmark Support Group

Welcome



I hope that all our members have had a good summer. Things have been a little quieter for the Group this year, time to consolidate on the work undertaken so far with regard to the DVD and revised leaflet printing and distribution. Our thanks to everyone who support us through donations – without your support, we could not

achieve what we do.

It was good to see some members at the Fun Day in Manchester, although numbers were down on our last visit, we hope that those in attendance felt that it was a worthwhile day. Thanks to Samira Syed and Jane Linward (from GOSH) for giving up their Saturday and taking time to speak to anxious parents. We also extend our thanks again to the Head and all the staff at Manchester High School for Girls – they were, quite simply, brilliant and nothing was too much trouble for them. A full report of the day can be found on the website

Date for your Diary! - Fun Day

The following date/venue is confirmed for this year's Fun Day and AGM:-

27th September 2009 Chigwell School – this will be the date for our Annual General Meeting as well. Again, a note will be sent out nearer the time.

We are indebted to the Head of Chigwell for supporting our Fun Day.

Next year plans include returning to Clayesmore School in the South West (hopefully without the torrential rain).

At the risk of repeating myself – if you know of a venue near you which you think would be suitable for a Fun Day, please do not hesitate to let us know.

Volunteer Update

In our last newsletter, we asked for your help in filling vacancies within the PWS support team and a media co-ordinator.

Support Teams - PWS

I am delighted to advise that Gill Marchese has joined the PWS support team.

Media Co-ordinator

Also, our search for a Media Co-ordinator resulted in Caroline Thomas agreeing to join the team. I will leave Caroline to introduce herself through the article below as she says, your experience could appear in a women's magazine or national paper – and you could be paid.

Hi, I'm Caroline Thomas, Media Co-ordinator for the BSG and mum to a 4 year old son who has a port wine stain which covers most of his right cheek. I wanted to join the efforts of the BSG and use my marketing experience to raise awareness for both people with birthmarks and their families. To do this, we need the stories of our members to be published by the media, gaining attention and communicating how life is living with a birthmark. We have published a few stories this year in 'Pick Me Up' and 'That's Life' magazines and our thanks goes out to those members who have already shared their experiences - but we need more. We are regularly contacted by

journalists for both national magazines, newspapers and TV who are ready to write articles on the subject of birthmarks and this is where we need your help.

The process isn't time consuming and you remain in control of your story at every step. It usually involves having a simple chat over the phone with our media agency, supply photographs and then, if your story was successfully placed in the media, you would take part in another telephone interview and possibly a photo shoot. At each stage you would give your permission to go ahead - nothing is rushed through without your approval.

So if you're the mum of a baby with a severe birthmark or one of many children with birthmarks - or a man or woman who is willing to talk openly about living with a birthmark and you are willing to share your experiences with others - please get in touch by emailing me at media@birthmarksupportgroup.org.uk. (The only criteria is that you have not told your story before to a national newspaper or magazine).

I look forward to meeting many of you at the BSG Fun Day, please come and say 'Hello!'

Volunteer's Still Needed Treasurer

It is with regret that we have to announce that our Treasurer, Karen, has indicated her wish to stand down from the Committee and relinquish her role within the Group. During her time with us, Karen has worked incredibly hard and we are very grateful to her for her efforts. The Treasurer is responsible for the following:-

- 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, email, pc based accounting systems)

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

If you feel that you could take on this role and have the necessary skills, please contact Nick Ward in the first instance.

Chairman

AND our Chairman Nick Ward has said for the last two years he felt it was time for him to stand down, so if you fancy taking this on please do get in touch with him.

New Leaflet

We have had an excellent response to our newly designed leaflet and have had repeat requests for further supplies from a number of GP surgeries and hospitals.

We have received a number of applications to join the BSG as a result of our leaflets being on display.

Please check to see if your GP's surgery is displaying them and if not, ask them "why not?" If you would like further copies then please send a stamped and addressed envelope to BM The Birthmark Support Group, London, WC1N 3XX saying how many you would like.

Fundraising Activities

We recently received the following email from Lorna:-

'My name is Lorna Hutchings, I have a place in the Great North Run and would love to try and raise some sponsorship for the Birthmark Support Group. My colleague, Sharan Eves, has a daughter, Claudia, and she has treatment for a birthmark and Sharan told me that it is non government funded. So I would therefore love to help and raise as much as I can for this organisation'.

If anyone would like to sponsor Lorna, please get in touch with her via her email address lornah6@hotmail.com

London to Paris Bike Race

Leslie Pendlebury-Bowe, who helps on the fundraising side of the BSG, is aiming to raise his own funds for the group by participating in the London to Paris bike race next year between the 5th and 9th May 2009. Leslie is aiming to raise £2000 and has a page set up on Just Giving where you can sponsor him. The link is as follows:-

<http://www.justgiving.com/leslie-pendlebury-bowe/>

To Lorna and Leslie – the very best of luck and thank you both very much for your help.

London Marathon

You will recall from a previous newsletter that Cath Harrison ran the Marathon on behalf of the BSG. Her total sponsorship, to date, is just shy of £1,600. Our thanks and congrats to Cath.

Thanks to All

Our thanks to all of you who fundraise on behalf of the group. We have seen many innovative ideas from you, such as surprise birthday parties (Yvonne Bennet), coffee mornings, boot fairs, sponsored events.

Articles from you!

Fab Favours

We are delighted to include the photo below sent to us by Rachel Field. As you can see, Rachel and Phil got married on the 8th August 2010, and gave BSG pins as their table favours for the wedding guests.



My Laser Treatment

My name is Andrew Jenkins; I have a birthmark (which is a form of haemangioma) on my right cheek. Which I had when I was born. A port wine stain is a build up of blood vessels in the skin. My port wine stain was looked at regularly until I was nine years old by a plastic surgeon at Gloucester Royal Hospital called Clive Reid. Who intended to do a skin graft on my birthmark but decided against it because of the position, and we decided to put my name forward for laser treatment so that if any hospitals in the area were to obtain a laser machine I would be placed on the list to be seen.

In November 1992 I received a letter from a Mr J M Kenealy, offering me some laser treatment on my birthmark. In the letter there was a map on how to get there and a brief synopsis of what would happen. This was to do a test laser treatment.

I attended the laser frenchay at Bristol's Frenchay Hospital, where I met Mr J M Kenealy and he did a test patch on my left arm to see how my body would react to the treatment. As there was no adverse reactions to my skin Mr Kenealy decided to go ahead with the treatment.

The way laser works is by heating up the blood vessels which are close to the skin and causes them to shut themselves down and create new blood vessels deeper in the skin where they should be. I have now been going to the laser frenchay for over 12 years. Each treatment can last up to an hour and then I go back in 8 - 10 weeks.

During each treatment Kay Thomas or any of the other clinical research fellows will ask me if there was any scarring or scabbing after the last treatment. Then she will decide if we need to go ahead with the next treatment. If we both agree, Kay will get me to sign a consent form so the treatment can go ahead. Then I will either put on a pair of goggles or have contact lenses put in, which means having local anaesthetic drops in both eyes. Then Kay will place the contact lenses in my eyes and set up the laser machine to the right settings then put the chair to the right height. The chair is like one that you would

find at the dentists. To begin the treatment which consists of about 10-15 blasts of the laser every 30 seconds. When the treatment is finished Kay will place a cooling gel over the treated area to allow it to cool down. Then she will take out the contact lenses and show me the area she treated, and then give me a sheet of paper with the relevant information on for me to give to the receptionist who will then give me the date and time of my next appointment, which is roughly in eight weeks time.

I have been treated by a number of different people including Kay Thomas, Andy Pay, Andy Peach, John Kenealy and Nick Reynolds. I have always got on well with the staff at the laser frenchay and always followed their instructions. When I first started having treatment I had to have photographs taken twice (once before the treatment and again after each treatment), then it went to once before every treatment, now they taken before every other treatment.

At the laser frenchay for the south west they now have a new laser machine which can penetrate deeper in to the skin than the one's that they have used before. I will be one of the first patients to be treated with it. All the other laser machines they have used on me, have left me with hypo-pigmentation in and around my birthmark.

Hypo-pigmentation means a lightening of the skin cells so I now have to wait a year for the skin cells to repair themselves before any more treatment can be done.

I now only have a small area of my birthmark left on my right cheek. Which hopefully will all or most of it will be removed within the next few years. Now that I only have a small amount of birthmark left to be treated I'm not worried about the bit near my eye it can be left as a memento of the pain and suffering that I had to go through, the last 10-15 years. Now that my birthmark has nearly all gone I feel much better in myself. And I have more confidence in myself to do and try new and exciting things. Hopefully I will be able to go out and not have strangers look or stare at me or take the mickey out of me.

TeenTalk Update

Is going to be going through some changes in the next few months... stand by for something different!

We have a new team comprising of Jacki Lawson, Ash Marchese, Lydia Stafford and Emma Gallacher and with the support of Nick and Jane Ward are looking to completely re-vamp, re-energise and re-launch TeenTalk.

We've held a number of meetings to discuss different aspects of this element of the BSG and will be presenting our plans at the AGM on 27th September - please come along and join us to hear the vision!

See you in two weeks!

Alana