



Birthmark Support Group

The newsletter for all members of The Birthmark Support Group

April 2010



Welcome

Welcome to our first newsletter of 2010, if you remember, our initial newsletter of the year is a combined effort (main group, TeenTalk and FiT).

We have got much to tell you including news on our main project for 2010, the production of a DVD which will be sent to all primary schools – see later article. We've also got some dates to let you know about and some great articles from contributors so thanks to everyone who has had an input. Also, Nick Ward has written a piece for inclusion which outlines what the future holds for the Birthmark Support Group – this won't amount to a great deal if we do not have volunteers coming forward to take on key roles including that of Chairman, Secretary and Marketing. Nick, myself and Louise (respectively) all wish to step down this year after many years of enjoyable service but we need people to hand over to.

Sad news for the Group – Orla Checksfield, whom many of you will have met at various events over the years, took on and grew the role of Face It Together Co-ordinator but has handed over the reigns to Jane Walker. Also, Petra Hardie who maintained our database and sent out all the group notices has also had to step down from the role – we are indebted to both Petra and Orla for the incredible amount of commitment and loyalty they gave to the Group. Fortunately, we have managed to find people to take over their roles – details below. Thanks too must go to Karen Barter who took on the role of Treasurer but has now had to step down.

Karen will always be known, and held in great affection by all who knew her, as the Cake Lady! Wendy Lawson has been co-opted onto the Committee as Treasurer and we welcome her.

Dates for your Diary

Fun Days

We had a fantastic day in September last year at Chigwell – the sun shone down on us and many families were able to join us for a relaxed and informative day. Thank you to those who attended the AGM.

We are indebted to the Head Teachers of the schools at which we hold our Fun Days for their generosity.

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.

Next Fun Day

The forthcoming Fun Day is to be held on Sunday May 9th from 11-4.30 at Clayesmore School, Iwerne Minster, Near Blandford, Dorset.

Clayesmore School is in a beautiful setting, and if the weather is fine we will have free run of the school's beautiful playing fields and gardens.

There will be entertainment for all ages, with a bouncy castle, indoor and outdoor games, fantastic indoor swimming pool with giant inflatables and we are very fortunate as well to be able to offer the opportunity of either indoor climbing or kayaking!

We will also be providing a barbecue with organic produce from Hockeys Farm in the New Forest (vegetarian option available) and other refreshments. A small charge will be made for food and drinks.

There will be ample opportunity for adults with a birthmark to meet others, for parents to make new friends and for children to have fun! Medical experts will also be on hand to offer informal consultations and advice, and we will also be holding cosmetic camouflage demonstrations. All the family is welcome; all we would ask is for an indication of numbers to assist with catering.

Merchandise will be limited on the day, so in order not to disappoint why not order your t shirt or sweatshirt in advance and collect it on the day? Please contact buy@birthmarksupportgroup.org.uk for details.

If you would like to attend but are unable to due to travelling or accommodation costs please email chairman@birthmarksupportgroup.org.uk

For any queries (or offers of help!) or to confirm your attendance please contact Louise Busfield buy@birthmarksupportgroup.org.uk

We look forward to seeing you. Louise

Walk for Skin 2010

Area	Venue	Date
Cheddar	Cheddar Gorge	Sun 9 th May
Leeds	Temple Newsam	Sun 16 th May
Midlands	Ragley Hall	Sun 23 rd May
Manchester	Manchester Canal	Sun 23 rd May
S'hampton	Royal Victoria Country Park	Sun 6 th June
Fife	Fife Coast	Sun 13 th June
London	London City	Sun 27 th June

The Birthmark Support Group is pleased to announce its affiliation again with the British Skin Foundation "Walk for Skin 2010". There will be seven fabulous walks in country parks across the UK themed around gorges, country parks, coasts, and cities. Walks are generally 3-8 miles long, with shorter and longer options available some venues.

This year the Walk will include added attractions and a Walk for Skin 2010 t-shirt free of charge.

Joining the Walk for Skin couldn't be easier – simply choose a venue and register free of charge, either online at www.walkforskin.org.uk or by phone on 0207 391 6341. Once registered, entrants will receive a sponsor form, walkers' pack and information about their chosen venue.

Whilst the BSG support these Walks, we do not run them and we have no influence over the way in which they are organised.

Media Update and Request for Assistance – Caroline Thomas

Firstly, let me say "thank you" to those who responded to our media request in the September newsletter. Some of you have been working with Producers of TV documentaries and film and we will be publishing some articles in national magazines in the next couple of months. But as ever, we always need more inspirational stories and experiences to help us generate awareness in the media to help support those who live with their birthmarks and raise awareness for the BSG.

We are currently working with a producer from MentornMedia (www.mentorn.tv), who recently produced a Channel 4 documentary covering the story of Katie Piper who was scared during an acid attack. The programme has received some fabulous reviews in the way it covered the issues and how inspirational the programme and Katie have been to people

with similar experiences.

They are looking to make an observational film following the journeys of people with birthmarks. Originally they were thinking of talking to younger people who are taking their first steps into careers, education and relationships. However, following discussions with them they would also like to talk to people who are about to make a massive change in their lives, perhaps changing careers (leaving a familiar environment and moving onto something new) or perhaps you are having treatment for your birthmark for the first time.

Also, we are looking to support a student who is in her final year at university and currently writing her dissertation. She would like to speak to people with facial birthmarks who could share their experiences with her (some photography is necessary for her to complete her studies). This would be a closed interview and would not be published in the media. This would a great opportunity for anyone who is thinking about sharing their experiences to a wider audience, but has been nervous about speaking to a professional journalist.

If you would be prepared to discuss your experiences with the Producers of MentornMedia or with the student, please contact Caroline Thomas at media@birthmarksupportgroup.org.uk.

New DVD for Primary Schools

Following the launch of our DVD for secondary schools in 2008 we received a number of requests for a similar one which would be geared more to children in primary schools, in the age-range 6 to 11. This first DVD, which also went to all GPs, paediatricians, dermatologists and maternity units in the UK, followed by our new flyer produced last year, reduced our funds dramatically. However, the magnificent fund raising activities of our members have meant that we have now been able to commission the primary school film.

Filming took place in January at two primary schools, one in Cambridge attended by our member Fay Hardwidge, and another in Bolton, attended by Jacob Bleasdale. The aim is to produce a film lasting about 15 minutes which can be used by primary schools to promote discussion and understanding about those who may look different from others and, in particular, those who have birthmarks. It will also contain some of the footage from our filming at Great Ormond Street in 2007.

The finished film will be put onto DVD and enough copies made to send to each of the 21 500 primary schools in the UK. At the moment our funds are sufficient to pay for the making and replication of the DVD but we don't have enough to pay for the cost of the mailing out to primary schools, so if you have a fund raising activity coming up then we'd love to hear from you!

We were delighted to receive several offers from members for their children to take part in the film and the final choice was governed mainly by the logistics of keeping the film crew's expenses to a minimum but of course having children in the right age-range whose birthmarks would readily show up on the film. So if you volunteered but didn't get used, a big thank you! Also to those two members who volunteered but never received an acknowledgement, my apologies; between receiving your email and replying we had a problem with emails which caused them to be deleted and there was no way of recovering the data to be able to reply. Sorry!

We will let you know when our funds are sufficient to be able to distribute the DVD and at that stage we will also have copies available for those members who would like to have their own copy. Although another big project for us, we do hope that the end result will help to ease the path through school for children with birthmarks.

Nick Ward

Are you prepared to help run the Birthmark Support Group in the Future?

Over the last few years the BSG has had a remarkably stable committee, with only the occasional change of officer. Although in many ways this is good news for the group, it is no bad thing now and again to have a bit of a change round to bring in new ideas and perhaps a change in direction. It is also good for the individuals concerned to regain some of their personal time to pursue interests other than BSG! These last five years have been particularly busy for the group with the establishing of 'Teentalk' and 'Face it Together' and the DVD and leaflet projects, not to mention a near quadrupling of the membership! It is maybe now time for some consolidation before deciding on the next step forward.

Louise Busfield has been a committee member for many years, initially responsible for both media and merchandise but latterly has passed on her media responsibilities to Caroline Thomas. She would like to resign at the AGM in September.

Alana Smith has been secretary of the group for 6 years and would also needs to hand over her responsibilities in September, or before, as would Nick Ward, who has been Chairman for the last five years.

If you feel you may be interested in taking over any of these positions and would like to find out more of what is involved please contact Louise, Alana or Nick, in the first instance by emailing them at buy@birthmarksupportgroup.org.uk sec@birthmarksupportgroup.org.uk or chairman@birthmarksupportgroup.org.uk respectively.

Please don't be shy in coming forward, your group needs you!

New Appointments

We welcome Caroline Thomas to the committee.

Wendy Lawson in place of Karen Barter as treasurer.

Gemma Adams in place of Petra Hardie as membership secretary/database manager. By way of an introduction, Gemma has sent through the following:

Hi, my name is Gemma Adams, I am a 29 year old mother of two boys, one of whom was born with a vascular birthmark to the left side of his face which is known as a venous malformation. After attending the Birthmark Support Group fun day last year, I really wanted to do something to help other people and families cope with birthmarks and be part of a fantastic organisation. Nick Ward advised me of the opportunities available at that time, and here I am now taking on the role of Membership Secretary. I now feel as though I am helping towards the struggle of getting people more clued up about birthmarks and hoping that other people's ignorance may become a thing of the past.

Jane Walker in place of Orla Checksfield as FiT co-ordinator

Teentalk

As some of you may know, we are in the midst of planning a re-launch of TeenTalk in 2010. Although TeenTalk has been around for some time, but has not been as active as we would have liked for the last couple of years and now we have a new team full of energy and passionate about providing a service and helping the younger members of the BSG.

In the pipeline are ideas for a new website, a support service just for teens and to get in line with today's teen culture a TeenTalk online forum where members only can get together to talk, chat, discuss and get to know each other.

As I'm sure you can appreciate these things do take time. However, we are trying as hard as we can to keep everything moving and find time in our busy day to day schedules to put everything together. Please bear with us as at the end of the day we are positive it will be well worth the wait!

Stay tuned for more information in the near future...

The TeenTalk Team Jacki, Ash, Lydia & Emma

p.s. we are really hoping to find a patron specifically for TeenTalk. If anyone has any ideas, suggestions, thoughts or contacts on anyone that may be willing to do this for us please let us know - our only criteria is that they are current and demonstrate positive self-image.

Please see photograph below of the new TeenTalk team



Camouflage make-up

Having a Birthmark can mean different things to different people, though something we all have in common is that at some point in our lives we have probably felt self conscious. As individuals we deal with this in our own ways, and one way to ease the embarrassed feeling and stunt the stares and glares, may be to utilise the tool of camouflage make-up. Having used this myself from the age of 13 it is now an everyday part of my life, and something that comes as second nature in colour matching and application. For many though this is not the case. It can be a daunting thought, and there is a lack of help and support systems that specialise in this area. Camouflage make-up may not be for everyone and dealing with confidence and self esteem issues should always be focused on, with the help of peers and family and working on that from within. However, I feel that camouflage is an option that can and should be explored. If it makes you feel good then why not! So the first step is to find yourself a good brand that works for you; it should be easy to use and consist of no more than two to three steps. Getting the correct colour is essential and a light application is needed that you can then work up for just the right coverage; the most important rule is to play and practice to make it work for you. Please contact me for brand suggestions, where to buy and application methods more specific to you and your birthmark.

Emma, TeenTalk

Emma Gallacher is one of our Teentalk coordinators and is professionally trained in camouflage make-up techniques. You can contact her by email at teentalk@birthmarksupportgroup.org.uk

News & Articles from you

London Paris Bike Ride

Leslie Pendlebury-Bowe and his father, are aiming to raise funds for the group by participating in the London to Paris bike race this year between the 5th and 9th May 2010. Their aim is to raise £2000 and Leslie 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/>

We will keep you updated on their training progress

Ethan Edwards – Tells us about his laser treatment without anaesthetic



Hi, my name is Ethan. My favourite hobby is running. I am a good sportsman!

I have been going to Great Ormond Street since I was 6 months old, to have treatment to a port wine birthmark on my face. I have had 10 laser treatments with anaesthetic, but I don't like it and it makes me feel quite sick.

In October 2009 I went for my first laser treatment without being put to sleep. I had cream put on my face which made it numb. It was a bit boring waiting around, but finally Hillary came to take me to laserland. I was a bit anxious, but went in and my Mum had one dot on her hand, and said it didn't hurt. I had one dot, and it didn't hurt!! So I had 6 dots and it was fine. Two of the dots I felt a bit, but it was really much better than getting put to sleep. I am 9 years old and I like the treatment much more without anaesthetic!

That's it for this issue. Enjoy the spring, if it ever gets here! – *Alana*