



Birthmark Support Group

The newsletter for all members of The Birthmark Support Group

Welcome



I would like to take this opportunity, on behalf of the Committee, to wish you all well and hope that 2009 is a good year for you.

Hopefully, an action packed newsletter, thanks to those who have contributed articles – it does make it so much more interesting than just reading what I've

got to say!

We are delighted to announce that Michelle Deacon will be joining our Haemangioma Support Team. Her contact email will be haemhelp4@birthmarksupportgroup.org.uk Michelle and her family are based near Manchester.

Dates for your Diary

Fun Days

The following dates/venues are confirmed for this year's Fun Days:-

9th May 2009 – Manchester High School for Girls, Grangethorpe Road (off Wilmslow Road), Manchester, M14 6HS. Time: 12 noon till 5 p.m. A note will be sent out nearer the time but please put this date in your diaries.

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 Teachers of both schools for their generosity in supporting our Fun Days.

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.

Walk for Skin

This has become a regular feature on our calendar – the dates for this year's Walk for Skin are as follows:

Area	Venue	Date
London	Kensington Gardens	10 th May
Glasgow	Mugdock Country Park	31 st May
Cheddar	Cheddar Caves and Gorge	17 th May
Midlands	Coombe Country Park	17 th May
Manchester	Heaton Park	17 th May
S'hampton	The Common	31 st May

Area	Venue	Date
Newcastle	Tyne Riverside Country Park	17 th May
Leeds	Temple Newsam	7 th June
Cardiff	Bute Park	17 th May
Edinburgh	Holyrood Park	31 st May
Dundee	Camperdown Country Park	31 st May

We will be issuing further information regarding the Walks and how to make efficient use of the JustGiving website. Also, we will have T shirts available for purchase, at cost for the walks.

Help – We still need VOLUNTEERS!

This is fast turning into a Groundhog Day newsletter but we still have vacancies and we still need volunteers to fill the same. Where else would you get the opportunity to work with such fantastic people? Can anyone help with the following:-

PWS Support Team (team of 3)

Our support teams are a key part of our offering as a Charity and we are looking to build a team of 3 people who can provide telephone support to people who contact us with concerns about Port Wine Stain birthmarks in particular. Don't worry about the medical side – we cannot give medical information regarding any birthmarks – but what we can, and do give, is time to listen and lend support. All our support teams undergo training with Jane Ward, a trained Counsellor, and receive support from her on an on-going basis.

For further information please contact Nick Ward at chairman@birthmarksupportgroup.org.uk

Media Co-ordinator

This position requires the person to respond to enquiries from various 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 who Press Releases could be sent for forthcoming Fun Days and BSG events.

The 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

New Leaflet

If everything has gone according to plan, you should have received with this newsletter a copy of the revised leaflet which is designed to replace the existing. Those of you that have seen the DVD booklet will notice that we are trying to 'brand' our documents.

Copies of the leaflets will be distributed to all GP surgeries over the coming weeks so do check your own surgery when you next visit them. A small poster for display is also being sent.

If anyone would like additional copies of the leaflet for fundraising events, please do not hesitate to contact me.

As usual, we would not have been able to produce and distribute this leaflet if it were not for the overwhelming generosity of our members so thank you again for helping us spread the word.

New Website

Another new and, we hope, improved communication tool to let you know about. Our existing website has served us well for many, many years but we have grown as a charity and the requirements of the website have also grown within that time.

BSG member Monika Lempinska is a website designer by profession and she has used her skills to build the new website, based upon a layout designed by Ian Clover, Monika and Alex Pratt.

The rationale for this new layout is to make it much easier for people with birthmarks to locate and receive help, guidance and support, in addition to learning about our group activities.

The website has two main header categories 'Help and Support' and 'Group Activities'.

We are sure that the new website design will meet our current and future needs. It will be much easier for us to maintain and to add new functionality.

Monika has added a Content Management System (CMS) which is a very powerful and flexible facility that enables individual webpage owners to update photos, images, links and PDFs without needing to learn web development skills.

Authorised webpage owners will be able to maintain their own support role pages without being dependent on the website team. This will simplify and speed up the process of updating the website.

We hope you like the new BSG website. We are indebted to Monika for her skills and commitment. Insert Text Here

Requests for Assistance with Research Projects

Research Request (1)

Anna Fussell, University of Exeter

A note has already gone out to all members regarding this request, but in case you didn't spot it.....

Anna is a Trainee Clinical Psychologist at Exeter University and is looking for young people aged between 11 and 13 who are at school and have a birthmark on their face. Anna would like to talk to young people with birthmarks about what it's like to be moving from KS2 to KS3.

The research will take the form of a meeting with the young person either at their home or at a convenient place. She is also able to offer you £20 for taking part in this project.

Postal address:

Anna Fussell
University of Exeter
School of Psychology,
Washington Singer Laboratories
Perry Road
Exeter
EX4 4QG

Email: af258@exeter.ac.uk

***** Because you are under 16, you need your parent/guardian's permission to take part in this research *****

We do have further information on this research, including a FAQ sheet – please contact me for a copy of this prior to volunteering.

Research Request (2)

Rebecca Bellew, University of the West of England, Bristol has been in touch with the following request:-

Children who look different from their friends as result of scarring, a birthmark or a skin condition, may sometimes experience teasing or bullying. Some children seem to have found ways to cope well with these experiences. Researchers from the University of the West of England, Bristol are carrying out extremely valuable work investigating the way families deal with each other and family life when one or more of the members of the family have a visible difference of appearance. The hope is we can learn from the current experiences of families to help other children to deal with difficult experiences in the future.

We are looking for children aged between eight and eleven years old, who have a birthmark and live in the Bristol or Reading, areas, who can help with this project. Children and parents will be asked to fill out some questionnaires. We hope this will be an enjoyable experience. Many children have found being involved in research is a positive experience, giving them a chance to express their own feeling and thoughts.

We have the difficult task of trying to talk to around 120 families, including those who cope well as well as those who find it harder. Therefore your help would be invaluable. If you are interested in receiving more information about the work, please contact Rebecca Bellew using the details below. By contacting her you are **not committing** yourself and your family to being involved with the work.

Postal address:

Faculty of Health and Life Sciences
University of the West of England
Coldharbour Lane
Bristol
BS16 1QY

☎ 0117 328 2839

Email: rebecca2.bellew@uwe.ac.uk

Articles From You!

BSG gets its first Silver Bond Place for the 2009 London Marathon

This year we have been awarded a silver bond place for the London Marathon and this has been taken up by our member Cath Harrison. We wish her every success in her preparation for this and of course for the race itself.

If you would like to sponsor Cath you can do so using her [Justgiving](http://www.justgiving.com/cathharrison1) webpage: www.justgiving.com/cathharrison1 or donations may

be sent to her care of BM The Birthmark Support Group, London, WC1N 3XX. We won't be eligible for another silver bond place until 2014 so we must make the most of it this year!

Exclusive Report from our Marathon Runner!

Hi my name is Cath Harrison, I am 38 years old and I am running the Flora London Marathon this year for The Birthmark Support Group.

I've not really done much running (if any) before although I did do a midnight half marathon sponsored walk last year for the local Hospice, I have, in the past watched the London marathon on TV and like many people thought that maybe someday I would like to do that. I suppose you could say it was/is on my to do list!! You know the one that everyone has – mine is as long as your arm and does also include swimming with dolphins see the pyramids and walking the Great Wall of China!

Anyway I received an email quite late one Friday night in late November asking if anyone would like to run the Marathon for the BSG and like you do on a Friday evening I might have had one or three glasses of wine, so when this email came I though 'oh wow I could do that' so I fired off a quick reply, to be honest not expecting to hear anything about it again – but in early December I got another email asking that if I still wanted to do the run then I could – I ummed and ahed for a while before thinking that I may never get this opportunity again and I replied that yes, ok I'll do it. I didn't stop laughing nervously for quite a while afterwards – and well my hubby is still chuckling away to himself now. Family and friends have been very supportive and have promised to sponsor me. I need now to go round them all with my sponsorship forms and/or justgiving details.

I got a training programme from the internet which has me running this week 2 short runs of around 5 miles each, 1 medium run of 7 miles and one long run which today was 12.5 miles. I completed that in 2hrs 34 minutes(I got one of those Nike+ things for Christmas and it is quite accurate) the programme also includes 3 rest days, which are a welcome relief for my aching muscles. I'm not looking forward to next week though – 16 miles for my long run!! One of the hardest things is finding the time!

Don't be fooled into thinking that I will be running the whole way, my current running style is run for a while, walk for a while, run some more, then walk some more so I don't think I will be setting any records, my aim is to complete it – hopefully in under 5.5 hours but I don't really care how long it takes, whether I am running, walking or crawling the most important thing is to finish it and raise as much as possible for the BSG.

We booked our hotel in London the other night and our train tickets (Hubby is coming with me but the children are staying with the Grandparents) so it is beginning to feel real – I am actually going to do the London Marathon.



One of my biggest dilemmas has been make up – or no make up, I don't feel very comfortable with the idea of not wearing it but I know that by the time I have done the 26.2 miles there will be very little left on my face and what is there wont look good so I may as well not bother but....you know how it is.

Anyway if you would like to sponsor me please visit my Justgiving page.

Thanks

Cath Harrison

How birthmarks can help!

My 11 year old daughter has a birthmark on one side of her face that covers her cheek, upper lip and lower eye. She has always been brought up to believe that it is what is "on the inside" that matters and is a confident child that has made the move to Secondary school without any problems.

She dreams of getting a part on Eastenders (she wants to be Phil Mitchell's daughter) but until then she applies for every audition she sees on the internet! In 2007 we went to watch "Are you Smarter than a 10 year old" with Noel Edmonds and Dick and Dom. During one of the breaks I started talking to a lady who was standing next to me and she told me she was "part of the show" and could she talk to Lisa (who was then 10) to see what she thought of the series. Lisa chatted away and the next day she was asked back to the studios, screen tested and asked if she wanted to be a "reserve" school child on the show - they needed extra kids due to illness and we lived very close. So a week later Lisa was off to make-up and costume for her debut. The make up artist covered her birthmark but Lisa protested and the show's Directors were approached - their answer was "We hired a child with a birthmark and it is up to her if she wishes to have it covered". Lisa's view was the more public awareness there is to birthmarks the better and Sky 1's new hit show would be the perfect platform to show it off. Lisa filmed for three weeks and had the time of her life and was then asked back for filming the Christmas highlights show.

Last year she auditioned for the BBC hit show "Raven" and when asked why she wanted to be a warrior – well the usual line came out "You have never had a warrior

before with a birthmark and I want people to see that it does not make you any different" - needless to say she was called back for a three day second audition in Aviemore, Scotland and was then chosen to appear in the spin off series. She spent three weeks away from home filming and again loved it. The "Dragon's Eye" is due for screening on March 2nd 2009 so watch out for the warrior with the birthmark!

Lisa has now taken up serious drama and has an agent which in an industry that is very concerned about "looks" is a brave move! She has also done work for Tikkabilla, TMI, Sky News, Crufts and The Mighty Truck of Stuff. Apart from giving Lisa even more confidence, when she gets paid she always donates a percentage of her "earnings" to Great Ormond Street, Birthmark Unit of course.

As far as Lisa is concerned, long live Birthmarks and she hopes her tiny contribution will help change public awareness and understanding that having a different colour on your skin does not make you any different as a person. Lisa is determined to educate and wants all children with birthmarks to know that they should be proud to be different as they will be the ones that are remembered for all the right reasons.

