



Birthmark Support Group

The newsletter for all members of The Birthmark Support Group

Happy New Year



I hope that everyone enjoyed the Christmas break and that you have managed to avoid the threatened bad weather. No doubt, the children were very disappointed not to

have woken up to the blizzards promised on the weather forecast!

Well, as promised, this is the first Newsletter of 2007 and the one that gets posted to everyone on our database. If you no longer wish to receive the same, please let us know, we won't be offended and it will save us costs in the long-run.

We've managed to fit in a fair few things since the last newsletter – so please read on. The dates for the Fun Days have also been agreed – again, as promised, we're coming to the South West for the first time. We have tremendous support from our members at our Fun Days so thank you for that – we hope to meet up with you around the country this year and, if you think you know of the ideal venue, let us know.

Again, if you would like to submit an article for the Newsletter, please send it to me via the above e-mail address or to the postal address.

Alana

Dates for your Diary

Saturday 10th March 2007 – Liverpool (venue – The Bridge Street Chapel Centre, Heath Road, Garston, Liverpool, L19 4XR).

Sunday 13th May 2007 – South West (venue – Clayesmore School, Iwerne Minster, Blandford, Dorset, DT11 8LL).

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

Saturday 17th November 2007 – Scotland (venue – 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.

Christmas Cards

As you will have seen from the email that was sent out prior to Christmas, we did not feel that we had given ourselves sufficient time to do this project justice. For this reason, we took the decision not to go ahead with a print run as retailers had a headstart on us.

However, we did have some lovely entries and we did award prizes. Thank you to everyone who took the time and trouble to send us a card – we enjoyed looking at them very much.

Contact Update

We're delighted to advise that the Haemangioma team has grown by two – Alison Jones and Bev Woodward. This brings the team to a total of three with Nicky Pilmoor completing the group.

Email:

Jodi Unsworth – cmn@birthmarksupportgroup.org.uk

Alison Jones, Bev Woodward & Nicky Pilmoor - haem@birthmarksupportgroup.org.uk

Toni Lingfield - pws@birthmarksupportgroup.org.uk

Update on Research into Large Congenital Melocytic Naevi (CMNs) at Great Ormond Street Hospital (GOSH)

Dear All,

This is the first update on this new research, and there will be a regular update in the Newsletter from now on. The research started officially in June 2006, thanks to a fantastic grant of £20,000 from the (then) Caring Matters Now support group. This grant was given to fund my salary for a year. My background is that I did my Science and Medical degrees at Cambridge University, finishing in 1994. I then passed more exams to become a Paediatrician in 1997. I have been working in the Dermatology Department at GOSH on and off since 1997. I have 2 children, ages 6 and 3, and as a result I work part-time (now 20 hours per week). Thanks to Dr. David Atherton I have developed a particular interest in CMNs, and we both feel that it is a condition that has been relatively under-researched.

The research we have begun focuses on 2 main areas:

The first is the Genetics of CMNs. Although CMNs are not inherited in a parent-to-child way, this does not mean they do not have a genetic basis. CMNs are present at birth, and they must therefore have been caused by something happening to the developing skin cells. This is probably some sort of change in the genes in those or other cells. This change then makes the cells develop in a slightly different way, and produces a CMN instead of normal skin. We do not think this change is caused by anything the parents or anyone else has done. It is most likely to be caused by chance, although that chance may be greater in some families than others. If we can find out what the change in the developing skin cells is, we will be able to understand CMNs better. Ultimately that may help us to develop treatments for CMNs, although this is a long way off. Obviously the more people who take part the better the study will be, and

we are hoping for 100 in total. We already have 25 which is a great start.

The second area of research is to look at the surface of CMNs in the laboratory, to see if they have certain proteins on them. If they are there we may be able to use the body's own immune system to fight the CMN cells. This sort of treatment is a type of "immunotherapy", and is a sort of vaccine against the CMN. Again the use of this vaccine would be a very long way off, but we have to start with this study to see if it is a possibility. This study is being done using pieces of CMNs which have been removed in previous operations (as you know many children have some or all of a CMN removed), so we do not need volunteers for this study.

I hope this information is interesting – we are very excited about the new projects and we hope to get some good results from these studies.

Veronica Kinsler

Glasgow Fun Day

Well, our luck had to break with the weather and I'm afraid that it did just that for Glasgow. The weather didn't affect the success of the day though and special thanks to Anne McIntyre for organising the day.

At the moment, the venue for this year's Glasgow Day is shown as St Bride's Church, this may change but the date is set for Saturday 17th November 2007.



DVD Filming

This has been an extremely exciting project for the Group and filming took place over the weekend of 20th/21st January 2007, at Great Ormond Street Hospital. The launch of the DVD is planned for April and the aim then is to initially distribute this to all GP surgeries. We will let you have further details on the launch and how you can help once these have been finalised.

Thanks are very much due to Nick and Jane Ward for the work in setting up this project and securing the services of Paul



Paul Heiney

Heiney as the presenter. Nick was also instrumental in finding a company to film the DVD at a greatly reduced rate – huge thanks to Bill Smith and all at Great Takes TV for their help and kindness over the two days. In addition to members who volunteered to take part in the filming, we were also supported by the team at Great Ormond Street so thanks are very much due to Professor Harper, Dr Samira Syed, Dr Atherton and Sister Jane Linward for giving up their time at the weekend. Special thanks to Jane for her work before the two days and over the weekend.

Ian (Clover) and I met many of the volunteers during the filming on the Sunday – Ian was present whilst the film crew completed their 'fly on the wall' shots of the young BSG members and we were both privileged to watch the babies and their families being filmed.

We know from Órla that the previous day's filming was every bit as meaningful. Ian and I found ourselves agreeing with every word that was being said as we had said it ourselves before. Proof, if proof were needed, that we have to get this DVD out there to doctors, schools, midwives, health visitors etc.

One thing that really struck me from the filming was a comment made by Lindsay, who is mum to a fabulous baby girl,

Cosima, she said that when you're expecting, amongst the things you wonder is whether the baby will look like you (i.e. the Mum) or the Dad, no-where in this thought process do you factor in that there could be a birthmark.

A final thank you then to all those who took part in the project (whether direct involvement with the filming or in a supporting role) – it was a very courageous thing to do and I'm sure will be of benefit to many people in the future.

From One of our Members

Alison Merrick very kindly submitted the following article for the newsletter. Alison is a member of our FiT group and attended her first Fun Day in September 2006. She has written of her experience in an article printed in the Face It Together newsletter.

Birthmarks and Glaucoma....



"I have a very large port wine stain Birthmark covering most of my head and face.

It was February half term, I was 16 at the time and as the children left school there was a snowball fight in the play-ground and I was unlucky enough to have one snowball hit my right eye. The following day, I had a beautiful black eye and my mother insisted on taking me to our GP who sent me straight to the North Middlesex Eye Hospital. My response – 'but I'm going shopping with my friends' – his response was 'no, straight to hospital'. Once at the hospital they measured my eye pressure and told me to lie down and not to move. The pressure was dangerously high – I had glaucoma!

Three days later I had an operation to try and unblock a passage at the back of my eye. The operation was not successful and eye drops were prescribed. I was told that the drops would control the glaucoma for the rest of my life.

Thereafter, I had an appointment to see a Consultant every six months and I found out that my glaucoma was caused by the cells of my PWS birthmark behind my eye.

My Consultant considered me a test case and he mentioned it at a Conference he attended in America. I understand he also wrote an article for 'The Lancet' alerting opticians to check patients with birthmarks around the eye to check if they had glaucoma.

So, my snowball in the eye proved not to be unlucky after all. If it hadn't happened, I could have found out too late I had glaucoma and lost the sight in my right eye." - Alison

Chigwell Fun Day

Aside from the fantastic surroundings, the kindness of the staff & pupils and the superb organisation on the day (thank you Toni) – I think that most people (young and old) will state that their overriding memory of the day was Marco the Clown. Oh for half of his energy – it was like meeting a whirlwind! It seemed that the adults were terrified and the children were totally enthralled. It was a brilliant day, with wall-to-wall sunshine – in fact, it was so good we decided to go back again this year! If you missed last year, don't make the same mistake this year. The venue is easy to find, there's plenty of parking – we can't promise a repeat performance from our performer this time around, but we can promise you a relaxing time in safe surroundings.

If you don't believe me – check out the Website report.

We also held our AGM at this Fun Day and September will now be the month that our AGM is held. Full details of the meeting can be found on the website but I would like to publicise two events from that meeting:

Toni Lingfield – after many, many years dedicated service as a Committee Member, Toni decided to formally step down from the Group. We were delighted to embarrass

her in front of everyone by presenting her with a bouquet of flowers and saying lots of nice (and very true) words about her and the work she's done on our behalf. Fortunately for the BSG, Toni will continue her work as the PWS co-ordinator and will still be looking after the support phone line and info@birthmarksupportgroup.org.uk e-mail address.



Órla Checksfield (nee Morris) – at the meeting, was officially invited to join the Committee in her capacity as Face It Together co-ordinator (our adult group). Órla has been instrumental in growing the group's membership and is of tremendous support to the BSG in general.

Close

I hope we've given you a flavour of what's been happening within the Group over the past few months and also what will be coming up in the months ahead.

Hopefully, we will meet new members during our Fun Days and catch up with old friends at the same time.

Our next publication is due around March – if you've got something you would like to submit, then please let me know.

Kind Regards

Alana

Email: sec@birthmarksupportgroup.org.uk



British Skin Foundation “Walk For Skin” & The Birthmark Support Group

Following the outstanding success of the first ever British Skin Foundation (BSF) Walk for Skin, the BSF are pleased to announce that the event will again take place in 2007, on May 13th and 20th. You can register online or by phone from 8th February 2007. Just go to www.britishskinfoundation.org.uk/walk/registration/ or call 0207 391 6355. Seventeen different charities, including the **Birthmark Support Group**, will be uniting for the 2007 Walk for Skin, and we really hope to see you there!

When you register you can select the charities you wish to sponsor and how you would like to split your sponsorship money among them. So please register now and select the **Birthmark Support Group** as your favourite charity.

The 2007 event, proudly supported by Sanex, will take place at the following locations:

Sunday May 13th

Beamish, the North of England Open Air Museum, near Newcastle
Wollaton Deer Park, Nottingham
Bramham Park, near Leeds
University of East Anglia, Norwich
Belfast Castle, Belfast
Holyrood Park, Edinburgh

Sunday May 20th

Regent's Park, London
Beaulieu Motor Museum, near Southampton
Cosmeston Lakes County Park, near Cardiff
Cheddar Gorge, Somerset
Tatton Park, near Manchester
Windsor Great Park, Thames Valley
Lickey Hills Country Park, Birmingham