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The Birthmark Support Group

Newsletter Feb 2006

### From The Editor:-

A rather belated but nonetheless heartfelt Happy New Year to all our members. As is always the case, we have got a lot of information for you regarding the Group and development ideas for the same. We do need your feedback too – the Committee and everyone involved with the Group is working on your behalf, make sure we are doing what you want of us.

Not for us the High Protein/Low Carb diets in an attempt to reduce that Christmas excess – we're delighted to say that **we've just got bigger!** Caring Matters Now (CMN), a group dedicated to the research and support of those with Congenital Melanocytic Naevi, has now joined forces with the Birthmark Support Group to form one organisation. More details can be found later in the Newsletter but a warm welcome to new members is extended.

Face It Together and TeenTalk (our Adult and Teenage sections) continue to develop – a separate newsletter is enclosed from both the FIT and TeenTalk teams. On the subject of newsletters, we have set ourselves the target of producing 3 newsletters per year for our members, excluding the updates that we send out during the course of the year. We'd really appreciate some input from the members so if you have something to say, or want to prepare an article, please do not hesitate to send it to me.

We will also take the opportunity to update you on some personnel changes and a very exciting project involving ourselves and Great Ormond Street Hospital, which I am sure, will be of great interest to everyone.

There will be more opportunities for us to meet throughout the year as the Fun Days have increased in number from two to four in 2006.

All in all, it was a very busy 2005, which laid the foundation for the work to be commenced in 2006. As far as we are all concerned, despite the challenging times ahead, it is still very much 'business as usual' with our Group Aims remaining exactly as they have always been. We look forward to meeting as many of you as possible during the year.

Kind regards

Alana

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## Who's Who?

As our Group has grown, the number of people who are required to make it function to the high standards set by, and expected of us, has increased. Below is a table showing who is responsible for what – these details will also be appearing on the website.

Chairman	Nick Ward
Secretary	Alana Smith
Treasurer	Jane Coultrup
Membership Administrator and Web Site	Ian Clover
Assistant Database Administrator	Petra Hardie
Publicity/Media	Louise Busfield
Merchandise	Louise Busfield
Funding co-ordinator	Leslie Pendlebury-Bowe
Newsletter Editor	Alana Smith
Birthmark Support Information Contact	Toni Lingfield
Port Wine Stain Support co-ordinator	Toni Lingfield
CMN Support co-ordinator	Jodi Unsworth
CMN Contacts	Penny Wall/Jane Coultrup
Haemangioma contact	Nicky Pilmoor
Support monitor & supporter	Jane Ward
Medical Adviser	Jane Linward
Fun/Family Day Organisers 2006	L'pool/Glasgow Jodi Unsworth Birmingham Nick Ward London A. Smith/T. Lingfield
FIT (Face It Together)	
Database & Newsletter	Orla Morris
Administration assistant	Julia Higley
Events	Suzanne Notley
Adult support	Bev Fulker
Teentalk	
Caretaker contact	Nick Ward
Newsletter editor	Maddy Burgess

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### Caring Matters Now

'Caring Matters Now' was set up in 1998 by Jodi Unsworth, herself a CMN patient of Dr Atherton at GOSH. Since then the group has grown to over a hundred members providing support and holding regular family days around the country. During 2005 Jodi and the group raised £20 000 for research into the causes and treatment of CMN birthmarks and are committed to raising a similar amount during 2006.

Following discussions between Jodi and the BSG committee it has been agreed that Caring Matters Now should become part of The Birthmark Support Group; our aims are similar and will be better met if we pool our resources.

The immediate effect of this is that the BSG membership will increase from some 528 members to over 630, as will the number of 'Fun' (family) Days, with four planned for 2006, in Liverpool, Birmingham, London and Glasgow. Jodi, who currently works as Disability Liaison Officer for Liverpool Football Club, has also joined the BSG committee and will be responsible for providing CMN support, assisted by Penny Wall and Jane Coultrup.

This is an exciting development for both groups and we do welcome most warmly all the 'Caring Matters Now' members as they become part of the Birthmark Support Group family.

### Fun Days – Dates for Your Diary

The bigger the Group, the more opportunities we have to meet and share experiences. The four Fun Days will be held at the following locations on the dates shown during 2006 – if you know of a venue which you believe will be perfect for your part of the country, let us know. We are especially keen to hear from members who live in the South West of the country.

18th March 2006	The Bridge Chapel Centre, Heath Road, Liverpool, L19 4XR
14th May 2006	King Edward VI High School for Girls, Edgbaston Park Road
17th Sept 2006	Chigwell School Essex (to include the AGM)
18th Nov 2006	Glasgow

We've also changed the name – of these events. Traditionally, we have always referred to them as Family Days; however, the way in which the Group has evolved with FIT and TeenTalk means that this is no longer appropriate. We want every member to feel that they want to attend and that we can provide something for everyone.

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What, no Coram's Field this year? Listening to comments from our members and based on our own opinion of the shortcomings of the venue we made the decision to move away. The 'London' event will be replaced by the Chigwell School venue – this venue will be for the exclusive use of the BSG and boasts open playing fields, a swimming pool and tennis courts. Those of you who came to Manchester Girls School last year or have attended Nick's old school in Suffolk will know just how much more enjoyable the day and how welcome the Group is made to feel by the host schools.

Further details about the programme, travel directions, etc for these events will be available on the website and on request via the PO box address and on the enclosed flyer.

### **A National Centre for Birthmark Research**

Professor John Harper, head of the Birthmark Unit at GOSH and Professor of Child Dermatology at the Institute of Child Health, has asked the BSG if we would lead an appeal to establish a National Centre for Birthmark Research at the Institute of Child Health. The reason for this is that although some birthmarks are genetic, at present the cause of most birthmarks is unknown and:

- There is no laboratory work being done within the U.K. on birthmarks and very few research centres worldwide
- There is a real need to look at the embryology behind birthmarks and to carry out comparative studies on treatment
- The Birthmark Unit at Great Ormond Street Children's Hospital (GOSH) is an active department with a national reputation for dealing with complex birthmark problems; it has a very strong, and growing, clinical base
- The most appropriate place for a national centre to carry out this research would be within the Institute of Child Health (part of University College London); not only is this physically adjacent to GOSH but the two are inextricably linked through current research activity

The National Centre for Birthmark Research (NCBR) would, on its inception, require:

- A developmental biologist (a permanent post)
- A post-doctoral biologist (3-year renewable)
- A research assistant
- The necessary equipment and materials

It is likely that a figure of up to £1m will be required as a 'pump-priming' amount to establish and fund for 5 years; thereafter it would be self-funding with research grants etc.

Although a major fundraising task, it would clearly be a tremendous project for the BSG to facilitate. Our Patron, Esther Rantzen, has declared her support for this and a small committee (Nick Ward, Leslie Pendlebury-Bowe, Stanford Jeffrey and Phil Stevens) has been established to get things started. It is planned to produce a glossy brochure and short video (to be presented by Esther Rantzen)

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and then to hold an appeal launch later in the year. If you are, or know, an expert in fundraising appeals, or have high profile contacts who may be prepared to publicly support this venture, or you would like to assist with it in some other way then please contact Nick on [chairman@birthmarksupportgroup.org.uk](mailto:chairman@birthmarksupportgroup.org.uk)

Without doubt, this is going to be a tremendous opportunity for the Birthmark Support Group – I'm sure that everyone of us has asked, at some stage, why do birthmarks occur? If we can resource the above, then we do at least have a chance of finding some answers.

Speaking of fundraising, we are indebted to everyone who contributes to the Group – all monies raised are ploughed straight back into the Group to fund activities, print newsletter, run the website etc. Everyone involved with the Group does so on a voluntary basis so there are no hidden costs. Huge thanks to the following for fundraising in so many interesting and diverse ways:-

Type of Event	Thanks to:
Sporting	Sally Crick – Coventry Half Marathon Karen and Dani Leed – Kelloggs Great Walk Emily Stevenson – Active Women's Challenge Nick Ward & Petra Hardie – London Marathon
Organised Fundraisers	Alison French – Greyhound Pub Fun Day Jayne Cook – fundraising Summer Evening Bev Fulker – Boat Party Railston – BSG was the Company's nominated charity for the year Genesis Mother & Toddler Group Rob & Jo Salmon Manchester High School for Girls Margaret Hancock – Christmas Stall Tania Allen – Christmas Sale Steven & Claire Porter – Ballroom Dancing Extravaganza
Merchandise Sales	Sincere thanks to the following who have raised funds and awareness by selling vast numbers of BSG wristbands to friends, family & colleagues:- <ul style="list-style-type: none"><li>• Annie Sly and Lucy Hartwidge</li><li>• Brian &amp; Julia Higgins</li><li>• The Richards Family</li><li>• Angela Carey</li><li>• Laura Busfield &amp; friends at St Mary's &amp; St Peter's School, Teddington</li></ul>
Corporate Support	Thanks to the following companies for their support:- Merrill Lynch Plc <ul style="list-style-type: none"><li>• ESAB Sports &amp; Social Club</li><li>• EASB</li><li>• J Sainsbury – Local Heroes Award Scheme</li></ul>

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Thanks also to Liverpool Football Club who have paid for and printed this newsletter.

Donations	<p>Thank you so much to the following whose donations have been so gratefully received:-</p> <p>R B Willis, Remko Eddes, Dr Samira Syed, Paul Brown &amp; Family, Mrs G C Davidoff, Richard Murgatroyd &amp; Melanie Griffiths, Jason &amp; Debbie Coombes, Paul Edwards.</p> <p>Patrick &amp; Vanessa Quill for the fantastic 'We Will Rock You' musical tickets</p> <p>Warmest wishes and thanks also go out to the families of the late Ada Nuttall and Edna D Westwood.</p> <p>..... and finally, our youngest fundraiser yet – 3 month old Alannah Leslie Seaton made the decision to forego all Christening presents and asked for donations to the BSG instead!</p>
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If any of the above inspire you to fundraise, please contact Leslie Pendlebury-Bowe at the following e-mail address [funding@birthmarksupportgroup.org.uk](mailto:funding@birthmarksupportgroup.org.uk) who will provide you with inspiration, collecting boxes and whatever else you need!

For those of you keen to sell BSG merchandise at your school or place of work – which raises both funds and awareness – then please get in touch with Louise Busfield at [buy@birthmarksupportgroup.org.uk](mailto:buy@birthmarksupportgroup.org.uk)

There is a Gift Aid form on the Funding Page of the website which can be used by all those who donate and are UK Tax Payers. This allows our charity to claim back the tax and, therefore, increase the donation. If you have any queries regarding this, please get in touch with Jane Coultrup on [treasurer@birthmarksupportgroup.org.uk](mailto:treasurer@birthmarksupportgroup.org.uk)

### BSG DVD

As well as supporting and informing the families of children with birthmarks the BSG has amongst its other aims those of informing and educating the medical profession and public generally about birthmarks. The committee has therefore decided that its main project for 2006 will be the production of a DVD which can be used not only to inform new parents about birthmarks and their treatment, but also nurses and doctors, and be suitable to use as a teaching resource in schools. We would then endeavour to get a copy into every GP's surgery, maternity unit and secondary school within the UK.

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This will clearly be a major undertaking and so as to keep costs to an affordable level we will be delighted to hear from any member who has, or has access to, any of the professional expertise or services needed for this project,. Journalist and broadcaster Paul Heiney ('That's Life', 'Hometruths', 'Watchdog' etc) has kindly agreed to give advice and to present the final version. Please contact Nick on [chairman@birthmarksupportgroup.org.uk](mailto:chairman@birthmarksupportgroup.org.uk)

### **Getting in Touch – It's good to talk**

#### **Face It Together**

Membership of this group is open to anyone over the age of 21, or is approaching that age, and is free! For further details email [faceittogether@birthmarksupportgroup.org.uk](mailto:faceittogether@birthmarksupportgroup.org.uk) , or write via the BSG PO Box address.

#### **TeenTalk**

Membership of this group is open to anyone aged between 11 and 21 who has a birthmark and also those in their twenties who would like to help with the running of Teentalk. This group will only function properly once it has a sufficient nucleus of members covering the whole age range, so if you are eligible, please join us! Further details, and offers of help in running the group, [teentalk@birthmarksupportgroup.org.uk](mailto:teentalk@birthmarksupportgroup.org.uk)

### **Research Project**

We have been approached by Annie Boulter who is undertaking a PhD within the department of Human Sciences at Loughborough University. She is looking to 'explore how people construct experiences of altered appearance and how this is orientated into their talk'. If you would like to take part in this research, which consists of a semi-structured interview lasting between 30 – 60 minutes, please contact Alana at [sec@birthmarksupportgroup.org.uk](mailto:sec@birthmarksupportgroup.org.uk) She has further details on the same and can pass on the information provided by Annie. We are assured that this project will be undertaken within all ethical guidelines and data will be made anonymous after collection.

### **Media – Message from Louise Busfield**

'We endeavour to collaborate with the media wherever possible, particularly to ensure the accuracy of their medical information! Any feature about birthmarks in the national press usually means that we receive an influx of emails and phone calls, so we are very keen to publicise details of our existence. Recent articles about birthmarks have been published in The Daily Mirror, Daily Express, News of the World, Woman and The Guardian which have resulted in many new members of the BSG.

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However, the nature of the job is that journalists often require the information 'now!' so it would be really useful to have a list of members who I could get in touch with as & when a journalist contacts us with a brief. If you feel that you or your family would be prepared to be contacted in the event of a media enquiry could you please email me at [media@birthmarksupportgroup.org.uk](mailto:media@birthmarksupportgroup.org.uk) with a brief 'case history' and contact details. Rest assured I would never pass your details on to a third party without your prior permission.'