



Face It Together

The newsletter for adult members of The Birthmark Support Group

Welcome

Welcome to the first edition of the Face It Together Newsletter. As you will remember the group was launched on the 18th April 2005 at Great Ormond Street Hospital by our new patron Esther Rantzen. This group will focus on the "over 21's". The aim of the newsletter is to stay in touch on a regular basis, keeping everybody informed about the day to day goings on of the group as well as the more obvious things such as new treatments, camouflage, the BSG in the media, every day issues etc.

You will notice on page 2 that various members of the group have volunteered to put a mini biography in the newsletter. The aim is to put a "face" to all the names you hear mentioned in the newsletters and the website. We think this should be a regular feature of the newsletter and aim to get round to as many of the group as we can. Please email faceittogether@birthmarksupportgroup.org.uk if you wish to volunteer for the next edition or post your bio to the address below.

Why a Newsletter?

Representatives of the Face It Together group met in London in September 2005 and decided to send out a questionnaire to each member to decide what is generally wanted from the group. A newsletter appeared to be the most popular way of keeping in touch. Don't worry, social events ranked a very close second and we will be organizing a get together very soon.

Remember this group is very much about what you want from it so please send in your suggestions.

If you didn't receive a copy of the questionnaire just let us know and we will get one to you.

BSG in the Media

Suzanne Notley has very kindly sent us the article she contributed to in a national magazine, and we have attached it at the back of this newsletter. Please send anything you wish to publicise to the email address above.

BSG 'Fun' Days

In the past these have been aimed at families with young children. We hope that in future members of Face It Together will also attend and if there are sufficient numbers that it can perhaps be combined

with a FIT social event. If you are coming along then please let us know in advance so that we can ensure that there are other FIT members present.

Saturday, March 18th in Liverpool This will be held at the Bridge Chapel Centre, Heath Road, Liverpool, L19 4XR, between 1.00pm and 5.00pm.

Sunday, May 14th in Birmingham. This will be held at King Edward VI High School for Girls, Edgbaston Park Road from 12 noon to 5.30 pm.

Sunday, September 17th in North London. This will be held at Chigwell School, Chigwell, Essex from 12 noon to 5.30 pm. It will also be the BSG AGM and replaces the event previously held at Coram's Field.

Saturday, November 18th in Glasgow Venue to be arranged

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.

Face It Together in 2006

With "Caring Matters Now" joining the Group a necessity has arisen for an organising committee. Please see the main newsletter for full details on the arrival of the CMN members, which in short increases the BSG membership to over 630 people. The following members have kindly agreed to help:

Orla Morris, will take care of the Adult membership database and this Newsletter, you can contact her on faceittogether@birthmarksupportgroup.org.uk

Suzanne Notley, shall be Events organizer extraordinaire, Suzanne can be reached on her email events.fit@birthmarksupportgroup.org.uk

Bev Fulker will co-ordinate all Support, and can be reached on her email address support.fit@birthmarksupportgroup.org.uk

Julia Higley will assist with FIT Group Administration, and can be reached on Orla's email.

Volunteers & Ideas Always Needed

If you would like to help with FIT, or with Teentalk, the BSG groups for teenagers, then do let us know.

Please, please send all suggestions you may have to any member of the committee, remember this group is all about the members. Sometimes the most obvious things are the things that need pointing out.

Meet Some FIT Members:



Nick Ward - Chairman of The Birthmark Support Group. I have a facial Port Wine Stain and following ineffectual radium isotope treatment as a small child have lived quite happily with it for the last half-century or so.

I joined the group about five years ago after reading an article on laser treatment for birthmarks in which the BSG was mentioned. At the time I was headmaster of a large boarding school in Suffolk and thought this a good venue for 'Family Days' and fundraising activities. I also felt that I could perhaps offer an alternative perspective on living with an untreated birthmark. I am married to Jane and we have a daughter, Emma (33) and a son,

Simon (30) and two grandchildren.

Following my retirement from The Royal Hospital School I was invited to take over the chairmanship of the BSG from Mark Lingfield, which I did in January 2005.

Although the support of families with young children has been the core activity of the group I am very keen that the membership should continue to expand to include more teenagers and adults with birthmarks. I am sure that those of us who live with a birthmark have a role to play in not only offering support to others but also in furthering the aims of the BSG of informing and educating the medical profession and the public generally about birthmarks. I hope that FaceItTogether will also provide a fun and relaxing environment for social activities in the future.

Email: chairman@birthmarksupportgroup.org.uk

Bev Fulker - My name is Bev and I have a facial port wine stain. I live at Leigh on Sea, Essex. I did have a test patch with laser when I was 13 years old but I decided I could live with the birthmark rather than spending hours at the hospital. I used to wear light make-up to work but I threw my make up away two years ago.

I joined the BSG in January 2005 and I am also a volunteer for Beat Bullying, a mentor at Birthmarks.com and I have my own website (www.loveyourmark.com). I have changed my career to become a Mentor and Confidence Coach and I hope to help children and adults realise that it is possible to have a birthmark and have confidence.



In the last year I have been in several newspapers, spoken on the radio and made a brief appearance on TV speaking about bullying. Sometimes people feel very isolated and may feel they are the only one with a birthmark. However, when they discover the fact that there are actually thousands of us it helps them enormously!

I think it is important for us as a group to get together as much as possible, share information and support each other (and of course have fun along the way!).

Email: support.fit@birthmarksupportgroup.org.uk



Julia Higley - Hi my name is Julia. I am well over 21 (50 to be exact) and I work part time as a nurse in my local day surgery unit. I have recently become a Christian. I have been married to Brian for nearly thirty years and we have three daughters. I have a portwine stain covering my left leg, and have needed surgery during my teenage years. This was due to an increase in growth of my leg, directly caused by my birthmark.

I only heard of the BSG after searching the internet and contacted the BSG, I think in 2002 to ask for one to one support via e-mail. Nick and I were put in touch and we e-mailed for a while. I went to the first adult meeting in Winchester and met some lovely people. It was

the first time I had really talked about my birthmark and met other people with birthmarks. It was a special day and a few tears were shed.

I was then contacted by Nick and asked if I wanted to become a committee member. I am so pleased to have the opportunity to assist and support the work of the BSG. I hope to meet members at events in the future.

Email: faceittogether@birthmarksupportgroup.org.uk

Suzanne Notley - Hi there, I'm Suzanne, I'm 29 and live in Wisbech, Cambridgeshire. About a week after I was born, an outline appeared on my face around my right eye. This developed into a strawberry haemangioma, which grew and became very heavy, sealing my eye shut. As the mark was over my eye and there was a risk of losing my sight, I had an operation to remove some of the birthmark – but unfortunately my sight could not be saved and I cannot see out of my right eye at all. I then had two further operations to “tidy up” the quarter of my face that was affected by the mark. Like many of us, I suffered times of low self-esteem – during my teens I wore my hair over my face, and even refused to put make-up on my “bad eye”, thinking that if I ignore it everyone else would as well! I also have further birthmarks down the right side of my body, from my bottom to my toes, which made P.E. and swimming at school a real misery. I did try camouflage make-up and laser treatment, but soon gave up – it just wasn't for me.



With lots of love and support from my family and friends, and a growing self-belief, over the past few years my confidence has grown and grown. I went to University, and even fulfilled my dream to become a dancer, before following a successful career in fashion. I now run my own fashion label, Fashion Junkie (www.fashionjunkie.net), for women sized 10-32, alongside being mummy to baby Olivia Grace. I used to be so nervous of being photographed, but have now appeared in various articles in national newspapers and magazines about my birthmarks – talking about it all has been such a liberating experience, and I hope that reading about me has helped others too. I wish that the Birthmark Support Group had been around when I was a child, having people with similar experiences to talk to would really have helped my parents and I in so many ways. I am just so glad that I am part of the Group now, and look forward to meeting you all and sharing stories!

Email: events.fit@birthmarksupportgroup.org.uk



Orla Morris - I am 30 years old and have a facial Port Wine Stain. I am currently undergoing treatment, using pulse dye laser, at St Thomas's Hospital in London. As you can see I always wear make-up but to give you an idea of the size of my mark I have 1,200 zaps each time. I have now had 13 treatments and just had a patch test to see if my PWS is still responding. Please keep your fingers crossed for me!

I joined the group a few years ago. The main reason I joined is because of my Mam & Dad, they have always said that they wished that they had people to talk to about birthmarks when I was born. All the time I was growing up they worried that they had made the wrong decision about make-up. I think they made the right decision for me. I want to have enough people with different sides of the same story to help all the other “Mammys and Daddys” to make the best decision for their child and their family in the early years when the most affected, the child, can't make the decision for themselves.

Email: faceittogether@birthmarksupportgroup.org.uk

I HID MY FACE

20 YEARS

SUZANNE NOTLEY, 28, FROM WISBECH, CAMBRIDGESHIRE, TELLS US HOW...

SHE GREW UP HATING THE BIRTHMARKS ON HER FACE AND RIGHT LEG THROUGHOUT HER TEENS. SHE DID ALL SHE COULD TO COVER THEM UP SHE'S NOW A CONFIDENT BUSINESSWOMAN AND IS EXPECTING A BABY

When Suzanne Notley spotted a group of young men bundling through the nightclub door, she waited for them to sit down before striding over to greet them.

She flashed them a smile, held out a bottle of tequila and asked if they wanted shots. They nodded, so she placed a row of small glasses on the table. As she did so, they started sniggering and gesturing towards her face. Then one demanded that she look at him while he was talking to her. Suzanne managed to hold back the tears, but it was a bitter

reminder that she was different from the other waitresses. Suzanne had been born with a large strawberry birthmark on her face. She'd had surgery to remove it, but the right side of her face was baggy and scarred. It had also left her blind in one eye, which meant the iris sometimes darted to the edge of her socket and made it hard to tell where she was looking.

'My birthmark had blighted my life,' says Suzanne. 'I'd grown up riddled with insecurities, worried about what people thought of my face.'

'In my late teens, I started to gain a little confidence and working at the nightclub helped. That night, when those men jeered at me, I could have been back where I'd started – but I refused to let them get to me. Of course their jibes upset me, but they also made me angry. I decided enough was enough – I wasn't going to let other people ruin my life.'

Suzanne was born a healthy baby, but when her mum

hurling abuse. My dad, Ian, snatched me up and carried me back to the changing rooms.'

Fearing the kind of abuse she might suffer at school, Suzanne's parents went ahead with surgery. Suzanne, then two, was taken to Norfolk and Norwich Hospital for a one-hour operation. It was impossible to remove the whole birthmark, but a wedge was taken out via an incision in her eyebrow line.

The problem now, however, was what was left behind – she had no sight in her right eye, the eyebrow was missing and the skin was loose, uneven and pink.

'As a result, I was very shy at school,' says Suzanne. 'Aside from my face, I had another birthmark down the whole of my right leg, which gave it a mottled appearance.'

'I tried to hide the marks in swimming class by shielding my

Angela, now 48, first held her, she noticed a faint pink patch on her daughter's face.

Doctors said there was nothing to worry about – it might grow larger at first, but it was harmless and would probably shrink over time.

But back home, the birthmark quickly spread. By three months, it was a deeper shade of pink, and flopped down from the top of her head over her right eye.

'My parents had a dilemma on their hands,' Suzanne says. 'They were told the birthmark could blind me in one eye, but removing it could also be risky.'

All the time, the couple battled a tide of hurtful remarks aimed at their baby daughter. Strangers would peer into my pram then recoil in horror,' says Suzanne. 'Once, I was splashing in a swimming pool when a gang of teenagers started

THROUGH THE YEARS Suzanne's attempts to hide her scars



REAL LIVE

struck up a bond,' says Suzanne. 'With him, all my fears about my body melted away. He was very understanding and kept telling me I was beautiful.'

'We started dating and early on I realised I wanted to be with him for the rest of my life.'

In 2003, Suzanne started work as a buyer for a department store. It was a job that would change her life even further.

'I began to think about starting my own fashion label,' she explains. 'Ten years ago, I'd never had the confidence to work in an industry so dominated by appearance. But I turned the way I looked to my advantage.'

'I wanted my company to reflect some of the challenges I'd faced. My clothes would suit women of all shapes and sizes.'

In August 2003, Suzanne chose the name 'Fashion Junkie' for her clothing label, drew up a business plan and entered a competition to encourage young people to set up their own companies.

Three months later, she was announced the national winner, receiving a cash prize and a huge amount of publicity.

'I realised how far I'd come when I saw the pictures of myself in the papers,' says Suzanne. 'My mum pointed out that my scars were visible – but I was now so confident, I didn't care.'

A year on, Suzanne's business is thriving. In August she and Steve received more good news – they're expecting their first baby in April next year.

'I've got so much to look forward to now,' says Suzanne. 'The fact that I'm going to be a mum has helped me to put the past behind me. I want to prove to my child that it is what's inside that counts.'



FOR

legs with a towel and I wore opaque tights, even for PE.

'My parents lavished me with compliments and I was never bullied, but my insecurity was deep-rooted.'

When Suzanne reached her teens, her confidence dropped to a new low.

'At 15, I grew my hair and let it fall over my face,' she recalls. 'Although boys showed an interest in me, I was sure my scars would freak them out if we were to get physically close.'

But Suzanne turned a corner when she left school at 18 and started a course in Media Technology at Leeds Metropolitan University.

'It was a fresh start,' says Suzanne. 'It meant moving away from home and becoming the person I wanted to be.'

'One day, I noticed a nightclub advertising for dancers. I had always loved dance and with my new-found confidence, I decided to apply.'

'To my surprise, I was offered the job. On my first night, I slipped into a tight pair of black

trousers, careful to hide the marks on my legs. I then applied lashings of foundation and combed my fringe over my scars.

'When I first stepped up on to the podium, I felt a bit shaky. But I soon got into it and enjoyed it.'

Soon after I was offered extra work as a "tequila girl". I carried little shot glasses in a holster belt and offered them to groups of people.

In a matter of weeks, I took to wearing skimpy hot pants with flesh-coloured tights underneath and swept my hair back into a ponytail. Both were unheard of for me, as it meant all my scars and birthmarks were on display.

'I began to see myself as others saw me – bright, funny and even pretty.'

And on that night at work

when the group of men poked fun at her, Suzanne refused to let their cruel jibes get to her.

'Instead of dissolving into tears, I held my head up and pushed past them,' she says. 'I loved my job so much,

there was no way a few nasty comments was going to make me give it up.'

From then on, Suzanne progressed in leaps and bounds. After graduating in 1997, she started a career in retail and in 2002, she was working as a fashion buyer when she met Steve Rodriguez, 27.

'We started chatting and

Today, in confidence Suzanne barely notices her scars

1976, aged 2

1978, aged 18

1979, aged 19

1977, aged 21

For information about Suzanne's fashion label, visit www.fashionjunkie.net