



July 2007

Welcome to the first Caring Matters Now (CMN) Support Group newsletter!

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The feedback I received from families was for a smaller, personal, CMN specific, support group.

You may be wondering why you are receiving a 'Caring Matters Now' newsletter, when 18 months ago the CMN Support Group merged with Birthmark Support Group? Well, I am happy to announce that the CMN Support Group is now re-established.

When I first agreed with the merge of both support groups, I planned to review the progress of the support CMN families were receiving on a regular basis. The feedback I received from families was for a smaller, personal, CMN specific, support group. I could empathise with these views, as CMN is a rare condition, which requires specific emotional support and medical information.

Before merging with BSG, 'Caring Matters Now' had eight regional CMN family contacts, which were beneficial to new families, as they were able to receive support on 'their doorstep'. However, the regional groups did not work as efficient due to BSG providing support in a different manor. BSG support was efficient and effective, but families who were custom to the support 'Caring Matters Now' offered, did not feel that BSG support was beneficial to them.

Therefore I, and a small number of parents who have children with CMN, felt it necessary to re-establish the regional contacts, which will eventually become personal and family orientated regional support networks.

One of the main aims for the CMN Support Group is to raise funds for CMN medical research. Dr Atherton has pioneered CMN research at Great Ormond Street Hospital and Dr Kinsler has taken the research onto another level. Dr Veronica Kinsler is working two days a week to study the cause and effects of CMN. The CMN support group raised £20,000 in 2005 to fund the research for one year. At present CMN families are continuing to raise funds for the research to continue another year. CMN families' obvious desire is to have answers to this condition and therefore feel committed to raising funds for Dr Kinsler's research.

Therefore, myself and a number of CMN families, felt that re-establishing the CMN support group would give CMN members more freedom to raise funds specifically for CMN research.

It has been very beneficial to be a part of Birthmark Support Group over the past 18 months, as they are a professional organisation with many similar goals to 'Caring Matters Now'. I, on a personal note, would like to thank them for the support they have given me in pursuing and developing the CMN support.

With the re-establishment of 'Caring Matters Now', you will continue to be a member of Birthmark Support Group. However, you will also become an automatic member (for some, again) of the CMN Support Group. Therefore, you will be able to benefit from BSG support and 'Caring Matters Now' support.

I have established a CMN core team, which consists of parents of children with CMN. As a team, we aim to offer support to you as a CMN sufferer, parent, sibling or friend. Our first Caring Matters Now family afternoon will be held in Liverpool at the Marriott Hotel - I do hope to see you there!

Jodi

My Story...



“For the first 15 years of my life I was lead to believe that I was the only person to suffer with CMN”

My name is Jodi Unsworth (26) and I have a large CMN, which covers 80% of my body. For the first 15 years of my life I was lead to believe that I was the only person to suffer with CMN and my parents and I were not even told what the condition was called! During the first 15 years of my life I underwent 30 plus operations, resulting in missing 3 years of school. The medical staff believed that the operations were necessary, as they did not know if the condition could be life threatening. I therefore undertook many types of surgery to remove the CMN including, excisions, dermabrasion and skin grafts. I guess you could say that I was treated like a guinea pig, as the doctors didn't really know what kind of treatment would remove the CMN.

During my school days I experienced bullying and feeling isolated from all my peers. I had good friends throughout school, but there was always a group of children, young people and even adults who would react to the skin condition in an unkind manner. I remember on one occasion, when I was 10 years old, wearing a bikini on a Cornish beach and being starred at by not only children but adults too. I guess that was the first time I decided that I would try not to be effected or ruled by the thoughts of others, but instead I would rule my life and not other people or my condition.

On another occasion a bus driver wouldn't let me on the bus in case my skin condition was contagious. However, the story ended positively as all my friends and other young people from my school got back off the bus and told the driver that he was very unpleasant!

Throughout my teenage years I had good times and difficult times. The difficult times were due to peer pressure and the constant battle in wanting to look like my friends. Like most teenage girls, I bought magazines

and watched teen programmes and this upset me, as I would want to look like the other girls in the magazines and on television. I always remember thinking that I would never be successful in life because I didn't have stereotypical looks.

However...I can now look back at those difficult times and realise that my life has been blessed due to having CMN.

In 1996, when I was sixteen years old, I came into contact with Dr Atherton, the leading CMN skin specialist. He was able to give me a name for my condition and tell me that there were actually other children, young people and adults with CMN. I couldn't believe my ears, as I had come to terms with the fact that I was more than likely the only one with this particular skin problem. Dr Atherton asked if I would help support other sufferers of CMN and I agreed straight away, as I didn't want others to go through the same difficult times as I did.

Since agreeing to help support others with CMN I have been in contact with over 100 sufferers and their families. I established a nationwide support group for CMN sufferers and their families called Caring Matters Now (CMN). The support group held family days throughout the year in different parts of the country. Eight regional support groups were also formed, which enabled CMN sufferers and their families to develop friendships within their home areas.

Ten years on...I won Young Person of the Year Award 1999, have completed a BTEC in Childhood Studies and a BA HONS in Educational Studies, worked at Liverpool FC as the Disability Officer for four years (yes, I did get to meet all the good looking footballers!), won Merseyside Women of the Year Award 2006 and I now work as a Student Support Coordinator at a local Comprehensive School.

I do believe wholeheartedly that due to my CMN skin condition I have been able to achieve more things in life than the majority of my friends. It has given me confidence and a personality to live my life to the full and not let anyone

undermine who I am and what I can achieve. I had to make a decision during my teenage years not to let my condition make me a bitter person but instead a better person.

Update on CMN Research at Great Ormond Street Hospital - Veronica Kinsler



Exactly a year ago I started a dedicated Research post at Great Ormond Street Hospital working with Dr. David Atherton, funded by the Caring Matters Now support group. The CMN clinic was established last June, and has been very successful. It enables us to see familiar patients and their families in a clinic focused on CMNs and the research we are doing, and to allow rapid access to new patients. We have made many new observations about CMNs even in the last year, partly due to seeing just those patients all together.

The first research project to get off the ground has been the genetics project. We are trying to find out if there is a gene that is not functioning properly in patients with CMNs. If we can find this gene it will help us to understand the condition much better, and ultimately to help us find treatments. We have had an amazing response from patients and their families – more than 95% of families asked to join in the research have agreed, which is an incredible statistic for a research project. We have enrolled 55 patients in the study so far, and collected a teaspoon of

blood off each. We are expecting preliminary results from the first batch of 48 samples by the end of 2007. Setting up and investigating this study has allowed me to suggest a way that CMNs may have been caused. This new project is currently being developed.

The second project is looking at whether we could eventually use a type of vaccine to encourage the patient's own body to reduce or reject the CMN. This project is in very early stages and will take a long time to get to a vaccine stage even if it produces good results, because of the rules surrounding new treatments for children. It is however very exciting and again should produce first results by the end of 2007.

Thanks to everyone for their support for this research. It has made a very encouraging start and we aim to continue at this pace.

If you are not yet on the register and wish to be, you can contact Mrs Jan Birley, by post at CMN Registry, Dermatology Unit, Institute of Child Health, 30 Guildford Street, London WC1N 1EH.

“Thanks to everyone for their support for this research”.

Scarlett

NAME: Scarlett Elizabeth Clarke

AGE: 20 mths

DOB: 18/8/05

PARENTS: Lucy and Stephen Clarke



"She is 1 in a million, our very own Scarlett O'Hara".

My daughter Scarlett was born nearly two years ago with a very rare skin condition called Congenital Melanocytic Naevus (CMN). No one in Cheltenham hospital had ever seen the condition and therefore were unsure where to send Scarlett, as she was not actually ill. To cut a long story short eventually we got to Great Ormond Street where a number of tests were taken. It was a nightmare having a child with something so rare that even in the medical dictionary it is only one paragraph long.

Through GOSH I have meet a couple of other people with CMN, and the same story is told, that after giving birth you are left, not knowing who to turn to with a disfigured baby in your arms. So we

have decided to re-launch the charity Caring Matters Now to support sufferers of CMN and their families and

also to raise money for the research, taking place at GOSH.

As yet Scarlett is still unaware of her appearance and as a family we are trying to make her as confident and outgoing as possible so when the name calling and bullying starts (as it will because she is different) she hopefully! will be able to handle it. As a family we are learning to cope with a baby that's different, especially our older daughter Isabella who found it hard in the beginning as her sister didn't look like her doll (baby Annabelle)

Scarlett is 1/50,000 with her marks, but to us, she is 1 in a million, our very own Scarlett O'Hara and as a family we are trying to give her the attitude and personality to say

" Quite frankly my dear I don't give a dame!!!!



This is Scarlett when she was first born.



The Marriott Hotel Supports 'Caring Matters Now'



The Liverpool Marriott Hotel South has offered its support to 'Caring Matters Now' for the next 12 months. The Hotel Staff chose the CMN support group as its designated charity and has offered many types of support.

Mr Byram, the hotel manager, has confirmed that our CMN family afternoons can be held at the hotel and the hotel will cover all costs, including room hire, refreshments and activities. Therefore our family afternoon will be held on Sunday 18th September at the Liverpool Marriott (South). Further details can be found below.

Mr Byram has also offered other forms of support such as, enabling us to use the Marriott staff for events we may hold, organising fund raising events and funding the printing and stationary costs.

The CMN support group would like to take this opportunity to thank the Marriott Hotel staff for all the support they have shown - it is very much appreciated!

Upcoming events

Date: Sunday 16th September

Time: 1pm - 5pm

Location: Liverpool Marriott Hotel South, Speke Aerodome, Speke Road, Liverpool, L24 8QD

For further information call 0151 494 5000 or visit the website: <http://www.marriott.com/hotels/maps/directions/lplms-liverpool-marriott-hotel-south/>

Alternative accommodation: The Express by Holiday Inn is 5mins from the Marriott and is reasonably priced. For further information call 0870 400 9093 or visit the website: <http://www.ichotelsgroup.com/h/d/ex/925/en/hd/lplap> or.

Light buffet will be provided.

Children's crafts and activities.

Launch of the CMN website.

Dr Atherton and Dr Kinsler will be present.

Can members inform us if they are attending by calling me on 07812467809 or emailing me at jodi.unsworth@googlemail.com

SEPTEMBER 2006

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The New Caring Matters Now

As you may have already noticed we have a new logo for the Caring Matters Now Support Group. This is all due to the generosity of a design company I work with, CBA Design & Marketing in Stapleford, Cambridge.

CBA are a great supplier of mine and have worked with me on many marketing projects over the past few years. They first became aware of the charity when my daughter Fay was born with a Bathing Trunk Naevus. I approached them for support and assistance when I organised my first large charity event last summer. They kindly designed some great posters and tickets for the event.

Since then they have been hugely supportive and their latest offer is something quite special. They have been working hard to re-design a new logo, create some standard stationery and have also been working closely with myself, Jodi and Dr Atherton on a new CMN booklet, which is due for release later this year. In addition to all of this great support they have also assisted me in raising awareness of the condition through features in the local papers and on local radio. We are extremely grateful to them and I would like to say on behalf of all in the CMN Support Group:

THANK YOU

Caring Matters Now

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Liverpool
L19 4XR

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Fax: 0151 281 9717
Email: jodi.unsworth@googlemail.com

We're on the web!

See us at
www.caringmattersnow.co.uk

CMN Brand Identity

This is how we decided on the new Caring Matters Now logo:

The new CMN Logo doesn't need to say exactly what CMN do, but needs to convey an overall message – the logo can't and shouldn't do it all.

The CMN brand identity is iconic and memorable; it is pictorial in how CMN are formed using 'C', 'M' and 'N' to create an adult and child image.

The brand essence here is caring, protecting, loving with a fairly informal tone, which is central to the CMN Campaign; this is a 'hands on' charity that encourages involvement from all. The choice of soft text also gives the feeling of caring and nurturing.

We hope you like the new look 'Caring Matters Now' and are currently working hard on posters, and various stationery templates to assist you all in promoting your fundraising events.

Caring Matters Now Website

We are now working hard on updating and re-branding the current website which we hope will be launched at the forthcoming Family Day.