



December 2008

WE NEED YOU!

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...we have a very unique opportunity here, to fund pioneering medical research into a skin condition, which has never had such medical attention before.

As you know, the Caring Matters Now Support Group is currently funding the Congenital Melanocytic Naevus medical research at Great Ormond Street Hospital. Every year we must raise at least £30,000 for the research to continue. This £30,000 funds Dr Veronica Kinsler's salary, necessary medical equipment and the hire payment of the medical laboratory.

In April this year the Caring Matters Now Support Group presented Dr Veronica Kinsler with £12,000. However, this fund is running out fast! If we are unable to support Dr Kinsler, the CMN medical research will come to an end as will the CMN clinic at Great Ormond Street Hospital.

Therefore, it is vital that we, as members of the support group, help raise the funds needed.

There are 180 members in the CMN support group. Therefore, if every CMN member can raise £170 each year, we would reach our target... with a bit to spare!

I have and always will want the main aim of the CMN support group to be about supporting CMN sufferers and their families. Raising funds has always been a secondary aim and I am still keen for this to remain. However, we have a very unique opportunity here, to fund pioneering medical research into a skin condition, which has never had such medical attention before. With Dr Kinsler's expertise, the Caring Matters Now Support Group is able to fund medical research which may be life changing for those born with CMN... please support us by helping to raise as much funds as possible. We cannot do it without your help!

I would like to take this opportunity to thank all those who have so kindly donated in the past 12 months.

Jodi Unsworth



Charlotte held a cake stall at school and raised £35

For more information or to receive a fundraising pack which includes a step by step guide on organising an event, contact Lucy Hardwidge.
lucy.hardwidge@btinternet.com
01954 719612

Fundraising Ideas

The key aims of the formation of Caring Matters Now as a charitable trust is to provide support and advice to families and those affected by CMN, and to raise funds into the research for understanding as to the causes and potential treatments.

We have made a commitment to sponsor Dr Kinsler at Great Ormond Street Hospital to conduct specific medical research into CMN. We need to raise funds every year of approximately £30,000 to continue this research and every little effort helps.

Jodi and the team of trustees have set up some ways to help you contribute to this excellent cause.

- **Direct Debit** - a regular direct debit which can start from as little as £2 per month
- www.justgiving.com/cmnsupportgroup - You can donate online
- <http://www.easyfundraising.org.uk/> - If you shop on the internet with virtually any company from ebay and Amazon to Tesco and Next. Any purchase you make can contribute to Caring Matters Now without costing you a penny.

But the best way of raising funds is to get involved and organise an event yourself! In every case you will be amazed how many of your family and friends want to support and help you; it is just having the idea and getting going is the hard part.

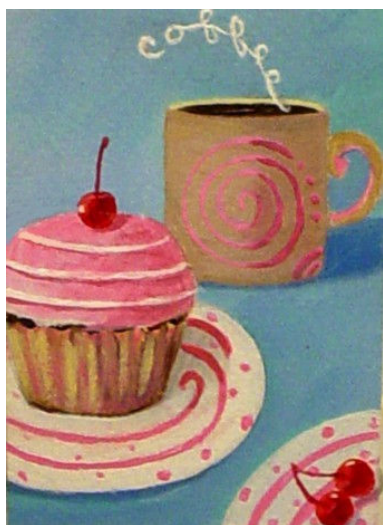
Coffee Morning News

On **Saturday 24th January** the Caring Matters Now support group are asking all members to hold a coffee morning to help raise funds for the CMN medical research.

The idea is that you invite your family, friends, neighbours and work mates to your home for coffee and cake. All those who come along can pay £1 for coffee and cake. During the morning you could hold a fundraiser activity, like a raffle to help raise more funds for CMN.

If you would like to receive CMN literature to have available on the morning, then please contact Jodi and she will be able to send you posters, CMN medical booklets and the most recent CMN newsletters.

This is a fun and easy way for all of us to help raise funds for the CMN medical research.



Welcome - New Trustee

Since the sad departure of Steve and Lucy Clarke to Hong Kong earlier this year we had a requirement for a new Board of Trustee member and we would like to say a big welcome to Jessica Ma.

Steve and Lucy will still keep their positions as trustees and will still be involved in the general running of the charity, but Jessica has stepped in to be more involved in the day to day financing and fundraising for the group.



Introduction – Jessica Ma

My husband and I are from Canada now living near Sevenoaks, Kent. We have two children – Jasper, 4 1/2 and Pascale, 3 years. We went to our first Caring Matters Now Family Day event in November 2007 and feel so fortunate to have been put in touch with the organisation.

As a recently appointed Board of Trustee member, I am now delighted to take on a more active role in providing support to our members and also ensuring that the important research continues in the area of CMN. This amounts to securing annual funds of about £30,000 per year to support Dr. Kinsler, our dedicated medical researcher at Great Ormond Street Hospital. We need your support as £30,000 is a huge sum to raise annually for a small charitable organisation like ourselves with only 180 registered families.

Following this you will find a copy of my “story” which was originally written for my NCT class. At the time of my daughter’s birth, I found it very difficult and traumatic to process having a baby with a physical disfigurement and uncertain medical needs. Looking back, reaching acceptance was a journey. Writing was actually a therapeutic exercise at the time and I encourage others who might be looking for different coping strategies to consider gathering thoughts to paper as part of any “healing” process. We would love to hear from you as it is always comforting to share experiences.

Baby Pascale by Jessica Ma



They told me they had never seen anything like it, which was not very reassuring.

Mole? Lasers? Skin grafts? Plastic surgery? Why is he talking about all of this?

I was aware that the midwives were not handing her to me right away. One midwife mentioned the baby was a bit slow to cry so she was going to administer some facial oxygen and did so. Then I heard the baby cry but they still did not bring her to me. The two midwives and my husband were hovering around the corner of the room with the baby and I heard them talk about a “birthmark”. Finally, they brought her to me wrapped in a towel. I could see what was indeed a very big, dark mark on her abdomen.

The midwives left my husband and myself alone and told us they would call a consultant to look at the baby’s mark. It was not until the consultant came and examined her that I realized the extent of her mark. It was a dark brown almost black, hairy mark that covered more than half her backside, over her buttocks, upper thigh and over her abdomen and front genitalia – the area was extensive. The consultant was visibly puzzled and called for another consultant. This was the moment when I started to get anxious. The second consultant came after some time and also did not have a name for the “disorder”. She looked over the baby and very mechanically tested her limbs and pronounced she was otherwise “normal”. They told me they had never seen anything like it, which was not very reassuring. They said there was nothing more they could do for the moment and that they would ask for the

Paediatrician to see the baby in the morning.

My husband acted as though nothing was wrong – he said nothing to me about the mark and just said the baby was beautiful. He picked up my mother and son and brought them to the hospital. He had told my mother about the mark but not the extent. It was not until my mother arrived in the evening and I showed her when I burst out in tears. I felt overwhelmed but had no words to describe what I felt. Everyone around me was acting so normal but I knew there was something wrong with my baby. It was a very lonely night in the hospital after my family left for the evening. My baby cried throughout the night but I felt too exhausted and emotionally vacant to respond.

The next morning, the paediatrician came by with the two consultants who were at the delivery suite the previous afternoon. He very objectively examined my little girl – turning her on her front side then back --and announced that what she had was “Congenital Naevi”. He explained that this was a medical term for a “mole”. It did not sink in -- what she had was definitely not what I knew a “mole” to be. The consultant went on to say that there was no immediate health danger but some people believed there was an increased risk of malignancy. He knew that it required more than simple laser treatment and that he would refer us to a plastic surgeon. As it was not a life threatening condition, he said



....and wondered what on earth I did during my pregnancy to cause this mishap.

not to expect a call back immediately – it could take four to six weeks. His mouth was moving but I could barely understand the words. Mole? Lasers? Skin grafts? Plastic surgery? Why is he talking about all of this? I did not feel comforted by his assessment – instead I felt even more anxious and cried after he left. I could not even remember what name he used to describe the disorder and did not feel any more informed about my baby's condition than before his visit. He took pictures as though she were a rare specimen. He wrote a referral letter but we did not receive a copy – we had no idea who we would see or when.

The next few weeks were very difficult. The challenges of post-partum recovery -- managing a newborn, sleep deprivation, thinking about the medical uncertainty of my daughter's condition, fluctuating hormones – felt to be over the top. The different coping strategies my husband and I had also added strain on our relationship. Outwardly, he showed no emotions as he was not saying anything about Pascale's condition whereas I was overcome by my feelings – I felt like I was barely functioning during the day and then every evening after I put her down for sleep, I would cry and cry. I managed to do internet research on the CMN condition having figured out what the mole was called and it was so distressing to learn that many doctors in the US propose radical surgery during the early days of the baby's life yet we did not even have a date to see a specialist. Should we be heading to the

US for an assessment? I struggled with the question of why this would happen to our family and wondered what on earth I did during my pregnancy to cause this mishap. Life just did not seem fair. Fortunately, I was able to recognize early on that what I was experiencing was more than the normal "baby blues" and I sought help in the form of counselling from week two as clearly, post-natal depression was triggered by all the events. I reluctantly went on anti-depressants at week four and got some help for the night feedings so I could get some sleep. Bonding with Pascale was already a little slow to come due to the stress and the medication meant stopping breastfeeding. But in hindsight, I absolutely do not regret my choice. At the end of the day, my daughter and son needed me to take care of them and I had to do what I had to do to get myself back to a state where I could cope -- and fast. To this day, I do not know how much of my recovery can be attributed to the medication but I don't think it is important. When the fog I was experiencing gradually lifted, I was in a much better position to put all into perspective and enjoy life with my new baby like every mother should (those early weeks pass by quickly and no second chances if missed). I would not compare my ordeal to losing a child, but in a way, absorbing and digesting my daughter's condition was like a grieving process. Though emotionally painful, I found I had to go through each step (denial, anger, guilt), before I eventually reached the level of full acceptance.

....we remain very optimistic that her issues remain purely cosmetic and do not involve any health ones.

Pascale has just started pre-school and she is an extremely happy, good natured, strong-willed little girl.

After an agonizing two months, we were put in touch with leading dermatologist, Dr. David Atherton, at Great Ormond Street Hospital who explained Pascale's "Giant Congenital Melanocytic Naevi", also referred to as "Bathing Trunk Naevi". Aside from the obvious cosmetic issues, we were concerned with health risks associated with the condition. The medical literature seemed to be concentrated on the melanoma risk but of bigger concern was the possibility that there could have been abnormalities in her central nervous system. Fortunately, this could be detected early on through MRI scans. When Pascale was five months old, she had a completely normal scan. That was a huge turning point in terms of "moving on" and now we remain very optimistic that her issues remain purely cosmetic and do not involve any health ones. Given the fact that we have not been advised of any procedure that can guarantee a safe and good result (due to the risk of serious scarring, infection, the pigmentation returning), we have decided against pursuing any cosmetic surgery. We would like to hope (but do not expect) for non-surgical treatments available in her lifetime and we feel not pursuing surgery for the time being keeps her future options open.

Pascale has just started pre-school and she is an

extremely happy, good natured, strong-willed little girl. I think of her mark as her unique "tattoo". Our focus ongoing will be to raise a young girl who will have high self-esteem, confidence, poise and all the appropriate social skills to deal with life's big and little challenges. And actually, this is no different than if she did not have her skin disorder. I think she will develop some very special qualities to her personality because of the CMN -- compassion, empathy, an early lesson in life that beauty is much more than skin deep. Of course, I worry about teasing and bullying. If I could just make it go away, I would. But I can't and so I think all that can be done is to deal with the psychological issues when and if the time comes. I think the CMN group will offer great support for her - just knowing she is not alone will help. Every parent worries about bullying these days -- children get ostracized for wearing the wrong type of trainers, for being too fat, too skinny, having pimples. If Pascale did not have the CMN, it would likely be something else. I have already learned lots from my two year old -- living in the moment and being grateful for all that I possess -- material goods mean nothing compared to my family's well being and health. In my eyes and in my heart, I have an absolutely beautiful daughter who is perfect in every way. I am so lucky and thankful.

CMN Regional Support Contacts

The Caring Matters Now support group want to ensure that all members are receiving support in many different ways. Support is given through, CMN family days, CMN newsletters, CMN email updates and CMN website information. The CMN team would like to offer a more personal form of support through regional support contacts. We have 11 regional contacts in place at present.

*Your regional
contact is there to offer
one-to-one
support through phone
calls, emails and visits*

The regional support contacts are in place to offer you more personal support. You are more than welcome to get in touch with your regional contact at anytime. Your regional contact is there to offer one-to-one support through phone calls, emails and visits. The CMN team hopes that friendships will be developed and CMN members will receive personal support at any time it's needed.

Each regional support contact is a member of the CMN support group. All contacts are parents of children with CMN or those who suffer with CMN. All 11 contacts cover the majority of the United Kingdom with an International Representative too. However, there are a few areas that could do with a support contact. If you would like to be a regional support contact for your home town/region then please do contact Karen Millen at karen.millen@talk21.com or 01494 870173.

Support area: South

Contact: Hannah Woods

Contact number: 01837 871282

Contact email address:
hanex20@aol.com

Support area: Highlands & Islands

Contact: Jenny Irvine

Contact number: 01397 712181

Contact email address:
jenirfeen@hotmail.com

Support area: Thames Valley,
Surrey and Hampshire

Contact: Karen Arthey

Contact number: 01494 870173

Contact email address:
karen.millen@talk21.com

Support Area: Yorkshire &
North East England

Contact: Nick and Rosinha Gollop

Contact number: 01262 601944

Contact email address:
NGollop@aol.com

Support area: Scotland

Contact: Anne MacIntyre

Contact number: 0141 646 1069

Contact email address:
anne@macintyre1150.fslife.co.uk

Support area: North West England

Contact: Jodi Unsworth

Contact number: 0151 281 2820

Contact email address:
jodi.unsworth@googlemail.com

Support Area: North Midlands

Contact: Julie White

Contact number: 01636 611 361

Contact email address:
andrew@awhite46.orangehome.co.uk

Support Area: London & Kent

Contact: Jessica Ma

Contact number: 01732 760029

Contact email address:
Ppottierjma@aol.com

Support area: North Wales

Contact: Judy Sealey

Contact number: 01244 815 997

Contact email address:
judy.sealey@dsl.pipex.com

Support area: South Wales

Contact: Lynne Davies

Contact number: 01656 870 511

Contact email address:
Andrew3davies@btinternet.com

Support area: East Anglia & South
Midlands

Contact: Lucy Hardwidge

Contact number: 01954 719612

Contact email address:
lucy.hardwidge@btinternet.com

Support area: International

Contact: Lucy Clarke

Contact email address:
lucyandstephen@btinternet.com



2009 Family Days

FEBRUARY 2009

S	M	T	W	T	F	S
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28

Date: Saturday 7th February 2009

Time: 1pm - 5pm

Location: Glasgow

Venue: Saint Brides RC Church, 21 Greenlees Rd, Cambuslang, Glasgow G72 8JP – www.saintbrides.com

Date: Saturday 9th May 2009

Time: 1pm - 5pm

Location: Cambridge

Venue: The Hub, High Street, Cambourne, Cambridge, CB3 6GW.

Date: Saturday 4th July 2009

Time: 1pm - 5pm

Location: Bristol

Venue: TBC

Date: Saturday 19th September 2009

Time: 1pm - 5pm

Location: Birmingham

Venue: TBC

Date: Saturday 21st November 2009

Time: 1pm - 5pm

Location: Liverpool

Venue: Bridge Chapel Centre, Heath Road, Liverpool, L19 4XR

All family days will include:

- Light buffet and refreshments
- Children's crafts and activities
- Presentation from Dr V Kinsler and CMN trustees

Can you please inform Jodi if you are planning on attending any of the family days by calling 0845 458 1023 or email

jodi.unsworth@googlemail.com



CMN Research at Great Ormond Street Hospital for Children, London

Veronica Kinsler



The CMN research at Great Ormond Street Hospital continues to go well. We have had very good feedback from the publication of 3 large studies in the British Journal of Dermatology in the last few months.

We have finished recruiting the main body of families to the Genetics project and have a total of 98, which is a fantastic number for such a rare condition. This week we are sending out letters to those 98 families to start to recruit control families. Control families are families who do not have a child with a CMN. All the 98 families will have to do is give out 3 letters each to their friends – they won't have anything else to do after that. The control families will not need to come to Great Ormond Street and will only fill in a questionnaire at home and do a cheek swab (like a cotton bud on the inside of the cheek). The reason that control families are so important is that we can compare the genes of the families with CMNs with the families who don't have CMNs, and that can make the results much more meaningful. We hope to have some results from the genetics study by next summer.

Caring Matters Now

Bridge Chapel Centre
Heath Road
Garston
Liverpool
L19 4XR

Tel: 0151 281 9716
Fax: 0151 281 9717
Email: jodi.unsworth@googlemail.com

We're on the web!

See us at
www.caringmattersnow.co.uk

We are starting to recruit 20 families to our study looking at how much CMNs can lighten on their own. This needs to be families whose child is under 1 year of age. We will automatically send information to families we already see who fall into that category, but anyone not currently seen at Great Ormond Street who would like to take part would need to ask for a referral to our CMN clinic from the GP or Dermatologist. This is a very important study as we need to begin to understand what makes some CMNs lighten dramatically, with the long-term aim of perhaps being able to cause CMNs to lighten.

Thank you all for your continued support in this new research.

Registered Charity No: 1120988

FROM ALL THE TEAM AT
CARING MATTERS NOW
MERRY CHRISTMAS
& A HAPPY NEW YEAR

