

July 2010

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Donate any money raised through Justgiving http://www.justgiving.com/cmnsupportgroup. It's quick, easy and totally secure. It's also the most efficient way to donate your raised funds: Caring Matters Now gets your money faster and, if you're a UK taxpayer, Justgiving makes sure 25% in Gift Aid, plus a 3% supplement, are added to your donation.

NATIONAL CMN COFFEE MORNING

SATURDAY 21st AUGUST 2010

The Caring Matters Now Support Group Trustees would love all our members to get involved and organise a coffee morning or afternoon to help us raise funds for the research programme and provide support to our members.

You could put a twist on this and hold a strawberries and cream afternoon or even strawberries and pimms garden party, the choice is yours but I am sure your taking part will be an opportunity to get together with friends and family for a great cause.

Ask for raffle donations and hold a raffle or tombola to raise a little more, maybe an activity for the kids, name the teddy, guess how many sweets in the jar. The list of ideas to make the event as big as you wish is endless.

Let's maintain the superb momentum we have all achieved in raising the funds needed for the research programme at Great Ormond Street Hospital. By taking part in this national event, we can all be involved in achieving the massive fundraising target this year of £45,000. We only need to achieve £225 per family this year if all of our members take part.

Your fundraising effort to date has allowed Dr Kinlser to take a great leap in the amount of research taking place and the findings are an example of the progress being made. In addition, the money has given us the opportunity to hold more family days to reach more members and to produce the new literature which I am sure you will all benefit from or use at some stage to help people to understand this rare condition.

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

We understand that this date may not be convenient to everyone but this doesn't mean you can't take part. Change the date to a more suitable date for you, but don't miss taking part.

Thank you for your support.

Jodi Unsworth



NEW FUNDRAISING PACK

AVAILABLE

Request a fundraising pack and join in the fun of raising money for a very worthwhile cause.
Please email either Lucy at lucyh@caringmattersnow.co.uk or Jodi at jodi@caringmattersnow.co.uk to receive a pack. Also available to download www.caringmattersnow.co.uk

Funding Update

Our 2009 financial year (April 1, 2010 YE) was the best ever and everyone who raised funds last year needs to be congratulated. £48,000¹ was raised and this impressive amount well exceeded our £30,000 annual target. The funds will be going towards Dr. Kinsler's research at GOSH and also be invested towards support for our members, including training for our regional support contacts and developing and creating support documentation. We are offering more family day locations this year and next year, we are looking into the possibility of an activity weekend.

In terms of research, the search for the cause and effective treatments for CMN needs to continue. And until this objective is achieved, the fundraising needs to continue. The people we are counting on to raise these funds are all our members – the families and individuals most affected by CMN. Those with the disorder do not need reminding that Congenital Melanocytic Naevus is an extremely rare disorder. But the fact that the disorder affects so few of the general population does highlight the reason why fundraising and winning grants for this disorder will always be challenging. This is why we need to emphasise how essential it is to have the continued help of all our members. We need YOU to ensure research and support is sustained.

This year, the fundraising target is set at £45,000. With 200 families on the register, this amounts to £225 per family.

Is that an amount you and your family can find from your own pockets, your friends', your families', your workplaces, your schools ... and any others who understand and empathise with CMN sufferers? Let's keep up the momentum and let's do it!

Please make Caring Matters Now your charity of choice!

1/ excludes Hoar Family donation

Stuck on You!

A new addition to the many ways to raise money for CMN is to order your everyday labels from 'Stuck on You'. Whether you are labelling school uniform, water bottles, household containers or looking for star charts, decoration stickers, plus lots more, then order from Stuck on You and we can get up to 20% commission per pack for Caring Matters Now.

The new school term starts in September so this would be a great opportunity to ensure you minimise lost property and support CMN at the same time.

Visit the dedicated website www.stuckonyou.biz/caringmattersnow







CMN Charity Challenge

- Who's up for the ultimate challenge?
- Want to help raise a staggering amount of funds for Caring Matters Now?
- Enjoy a trip of a lifetime?
- We are planning an experience you will never forget, to reach the ultimate peak!

The peak of Mount Kilimanjaro

Mount Kilimanjaro is among the tallest freestanding mountains in the world and the highest mountain in Africa at 5,895 metres. This is a literally breathtaking camping trek up Africa's most famous mountain. The Rongai Route provides an accessible, scenic and exhilarating journey to the 'roof of Africa'.

More information can be found on the website www.caringmattersnow.co.uk/cmn-charity-challenge.html. We are awaiting the release of flight prices in the next few weeks before advertising estimated prices for this ultimate challenge.

We need to gauge numbers, so if you are interested, please register NOW by emailing lucyh@caringmattersnow.co.uk or complete the no obligation registration form on the website www.caringmattersnow.co.uk/cmn-charity-challenge.html

Regional Support Training Day

Saturday 22nd May saw the first Regional Support Training and Information Day for our Regional Support Contacts. This is a very exciting development and hopefully shows how important we feel it is to build a strong communication strategy for all of our members. Ten of the current regional support contacts travelled to Birmingham, some setting off at 4.30am! Thank you to those who attended.

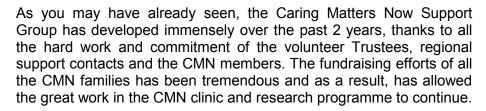
The regional support contact team is made up of parents of children with CMN and also two sufferers of CMN who are a huge asset to the team.

We spent the day discussing how we can best support our members, build stronger communications, support all of our families in their fundraising efforts and generally shared ideas. Jodi's mum also attended as a trained counsellor to give a brief session on listening skills. We believe this is a vital skill that our regional support contacts should have and we will be re-visiting this section in detail in the future.

We have most areas in the UK now covered with our new team and we are truly grateful to them all for their time and commitment. Your regional support contact will be in touch in due course, if you have not yet heard from them.

Details of our new dedicated team and the areas covered can be found at: www.caringmattersnow.co.uk/support.html

Exciting Charity Developments



We have built a superb and informative website, a regional support network across the UK, increased the number of family days to reach as many members as possible and developed many detailed and useful support materials and fundraising tools. In addition, we have collaborated with Jeans for Genes which has allowed us the opportunity to increase awareness of CMN and to accept a large grant from them to help continue the good work. Dr Kinsler has also managed to secure a substantial grant from the Wellcome Trust which will allow the continuation of the research programme which is fundamental.

The work achieved to date has all been done by a team of volunteers, as well as the fundraising efforts of all the families. As the support group grows and reaches a wider audience, the administrative workload increases. So with a very kind and considerable donation from the Hoar family, members of the CMN support group, the decision between the family and the trustees was made to put in place a charity development officer. This person would carry out the day to day administrative tasks and develop the support group in many ways, such as increasing support events across the UK, supporting all the members in their fundraising activities and increasing the awareness of CMN through the media and within the medical community.

After much consideration as to who would be the most appropriate person to fulfil this role, I am pleased to announce that Lucy Hardwidge, a mum of a child with CMN, has accepted the position. The trustees and I are all very excited with the development and to have Lucy on board to dedicate her time to CMN.

Thank you all for your continued support Jodi





Message from Lucy:

My husband Anthony and I have two beautiful daughters Fay and Amy. Fay, who is now 5 years old, suffers from a Bathing Trunk Naevi which stretches from her shoulder blades, round her tummy, and down to her knees. She also has several hundred satellites all over.

I had been involved with the support group initially just fundraising and increasing awareness of CMN in the local media, but as time went on I seemed to be dedicating more and more time to CMN. I found myself with such enthusiasm for the work and knew that what I was doing could potentially help present and future sufferers of CMN and their families.

I worked in Marketing before having my second daughter Amy 18months ago. Having contacts in the printing and design field gave me the opportunity to do a bit more for Caring Matters Now and so with CBA Design and Marketing we developed a logo and since then, with the help of the other trustees and CMN members have created the newsletter, developed the school and teacher packs, fundraising packs, re-designed the booklet, created DL sized leaflets, updated the website and provided support to other families.

I have thoroughly loved every minute of my time working with Jodi and the team and am delighted to take on a more permanent and dedicated role to develop the Caring Matters Now support group further.

If you wish to contact me or have any ideas or suggestions that you think would help develop Caring Matters Now then please call me on the NEW dedicated Caring Matters Now number 07786 458883. Alternatively you can email me at lucyh@caringmattersnow.co.uk.

I look forward to meeting and working with you all in the future.

Do we have your correct email address?

At Caring Matters Now, we aim to keep administrative costs to a minimum leaving the majority of our fundraising dollars to go directly to CMN Research. That's why we prefer to communicate with our CMN families via "no cost" email and so the best way to stay in touch with Caring Matters Now is to ensure we have your correct email address. If you have not been receiving messages in the past or you have a new/changed email address, please let us know by sending a quick note to: lucyh@caringmattersnow.co.uk with "Email Update" in the Subject box.

Thanks!



My Story — Lucy Hardwidge

I had a very good and healthy pregnancy and I was a little upset at the thought of loosing my bump but at the same time extremely excited about meeting our new arrival. I was four days overdue and with my blood pressure rising, the decision was made to induce so on Sunday 13th labour, February 2005 we were admitted Addenbrookes Hospital in Cambridge and I started the induction process. We were thinking that we would be welcoming a valentine baby into the world the following day! Hmmm, well things never seem to go according to plan and Monday 14th February came and went, still no sign of baby. Tuesday 15th February was still an unproductive day, although my contractions were increasing and very painful baby was still not ready to make an appearance.

Eventually at 5.30pm things seemed to be progressing and Fay finally arrived at 4.04am on Wednesday 16th February. To be honest, I was in such a state of shock and so exhausted from the labour and immediate aftermath it didn't even register when the midwife said, 'she has a mark on her skin, but nothing to worry about!' It was only when I looked at my husband's concerned face that I began to worry.

We actually had a very good experience compared to some, in that Fay was born at a leading University Teaching Hospital and so I believe were probably exposed to more rare conditions than some hospitals.

Fay was born with a very large black, lumpy, disfiguring mark covering probably about 60-65% of her body! I thought babies were born with pure white, blemish free skin, well that was my experience with many friends and family members having had babies. I was so tired from the labour and the events of the previous days that I was slipping in and out of sleep and was shocked to be woken by Anthony saying that they wanted to take my baby for a scan of her head. Why? Because of the CMN on the top of her head, they were worried about the implications and whether there was anything on her brain.

Problem with her brain? I was so worried and from that point my mind was playing tricks and I was thinking the worst.

We were transferred to the ward later that morning. We were visited by many specialists and students during the time on the ward, a photographer taking photos of her skin and each time someone came down to see us, the curtains were pulled round our bed and it was drawing attention to us.

Other patients on the ward were asking if everything was ok, to which I would answer, 'yes everything is fine'. I was not at this stage prepared to discuss anything about my baby with anyone!

I was eager to get home and wrap my little family in cotton wool and not have to see or explain this whole experience to anyone.

By the time we were home I had mentally erased the birthmark from my mind and wanted to just concentrate on my baby and making sure she was feeding as she should be, sleeping etc, all the normal worries of bringing home a baby for the first time.



I just wanted to cocoon Me, Fay and Anthony and prevent anyone from coming in

...when Fay was 3 weeks old, she underwent her first operation to remove the growth. It was always at the back of my mind and I was just trying to get on with being a new mum and not thinking about the implications of this thing on my daughter's skin until I had to and that was 9 days later when we returned to the hospital.

Anthony had been brilliant, very supportive, holding everything together even though I knew he was worried sick. As a new mum you feel emotional anyway, the hormones, lack of sleep etc, but having these additional worries plays havoc on your emotions and mind and you tend to think the worst of everything.

I was concerned about the many friends and family that would want to come and visit, I wasn't prepared at this stage to see anyone; I just wanted to cocoon Fay, Anthony and myself and prevent anyone from coming in. I didn't want to face people's reactions, I wasn't ready. It was only our closest family that were aware of Fay's CMN at first and they thankfully were great, very accepting and supportive. My sister was the first family member to change Fay's nappy at the hospital and I just handed her over with no thought to what she was going to uncover, but without hesitation Helen just whipped her off, changed her nappy and returned her with no question. The reaction or lack of reaction from our closest family I think helped us immensely in the early days.

We returned to the hospital 9 days after Fay was born to be presented with the facts of Fay's condition. All I can recall from that meeting was the word 'CANCER'. Thankfully Anthony took in more information than me as I seemed to sob my way through most of the consultation, I blame the hormones!! Fay had been born with a suspicious lump on her

lower back and they wanted to do a biopsy and remove it immediately, just to be sure. So, when Fay was 3 weeks old, she underwent her first operation to remove the growth. How do you explain to a 3 week old baby that you can't feed her for 6 hours prior to her op! Thank god for dummies! Thankfully she was in and out quite briefly and we then had the waiting game for the biopsy results.

All results returned as clear which was encouraging and from this we were offered a referral to Great Ormond Street Hospital.

Following this, I realised I had to just get on as usual and fight back my feelings and try to be just a mum. I would take her to clinic for weighing and strip her off as the other mums did with their babies. The health visitor had offered to come and weigh her at home, but I was offended at the offer and thought, no, I had to face this sometime and all of these experiences, however bad, had to help me become stronger in dealing with this. I couldn't tell you if they were staring when we did go as I had my blinkers on and Fay was the only one I was concentrating on. I would normally attend clinic with a local friend that I had first met at antenatal. She proved to be a great friend and helped me carry on as normal, attending lots of local groups with our girls and allowing me to act as if my baby was no different to anvone else's.

To be honest during the first few months I found it easier surrounding myself with new friends rather than seeing old friends. I felt I could not be judged by new friends that did not know me previously, I was so terribly guilty for what had happened to Fay that I thought our friends would judge me and think it was

My concern was infection in this area and my worries became reality!!!



Fay and Daddy recovering after 5 day hospital stay, Fay 3mths old



Liverpool Family Day Mar 06, Fay 13 mths old

something I had done during my pregnancy that had caused this. I have since found out this is not the case, either with our close friends judging me or the fact that it was my fault, but I will carry the guilt with me forever, if not for a very long time. As a mother you want to protect your children and I had failed to do this.

We had, like many I am sure, had not been given any guidance on how to care for Fay's skin so when she was 12 weeks old her skin began to break down. I rushed her to our local GP, who I have to say has been absolutely tremendous throughout Fay's care accommodated us in anyway they could. They saw her immediately and dressed the wounds around her nappy area. My concern was infection in this area and my worries became reality!!! The same day I visited the GP I also called the Dermatologist at the hospital, who again has been great and has given Fay great care and attention, we have been very lucky with the medics we have encountered.

Anyway, I took her straight in to see him and he re-dressed the wounds and advised me to monitor them. On leaving the hospital the strangest thing happened, which I have to tell you about. My mum and I were queuing to pay for the car parking and an elderly lady approached us and popped her head in to see Fay in the pram. Fay was wrapped up with a little hat on, so fully covered with only the small CMN on her face below her eve visible. She said to me, I had a mark like that on my head, and pointed to the exact same position on her head, where Fay's is!!! I looked at my mum and the lady went on to say that her mum had taken her to have it removed when she was younger, by freezing and removing it! Anyway after a brief chat she

touched Fay's head and said 'She will live a long and happy life, don't worry about her'. Maybe a guardian angel! I felt quite comforted by the whole experience.

Following our visit I kept a close eye on the wounds and the next day thev were getting progressively worse SO we decided to take her to A&E. Within minutes of being there the small spots on her wounds began to spread in front of our eyes! I panicked and glad I did as up until this point no one seemed to be too concerned. Following a harrowing experience in A&E Fay was admitted and spent 5 days on IV antibiotics with a sceptic infection.

After a rather difficult and very emotional 6months we eventually got our appointment to see Dr. David Atherton, at Great Ormond Street Hospital who explained Fay's CMN in great detail and answered all of our questions. The information given to us highlighted the additional health implications but we were told this could be detected by an MRI scan. So at 8 months old Fay underwent a scan and thankfully the results were clear. We were now understanding of the condition our daughter had, the fact that at this stage it was just cosmetic and allowed us to move forward.

I found it a great help to have Jodi and her family there to support us. We attended our first family day when Fay was 7 months old and the one thing I remember most of all was what Val, Jodi's mum said to us – 'Never cover her up, treat her like any other child, if you go swimming choose the communal changing area do not go into a lockable cubicle'. That has stayed with me from that moment and we have stuck to that. I threw myself fundraising and raising awareness in the local media and



Fay and Amy

found this helped me tremendously to deal with Fay's CMN.

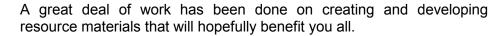
We have had a great deal of support from all of our close family and friends, to whom we are truly grateful and I don't believe they realise how much they have helped us both over the years.

Fay is now 5 years old and we are extremely proud of her. She started primary school last September and loves it. I looked very closely at schools in the area to be sure that she would be

comfortable with the teachers and her surroundings. She has many friends in and out of school and I am so happy with the support she has received to date from all of our friends.

She is becoming much more aware of her 'Chocolate Mark' as she calls it, but to date it has not caused her any concern. I am fearful for what the future holds especially in her school years but Fay is a very pretty, happy, confident little girl and is surrounded by friends, which I believe to be a blessing.

New Support Materials



The Teacher and Parent/Carer Guides are designed to help and support a child with CMN. These packs have been grouped by age and each document is developed to hopefully address issues and concerns experienced by children from childhood through to adolescence. All of these documents have been developed in conjunction with Changing Faces, a UK charity that supports and represents people who have disfigurements of the face or body from any cause.

We have also created a Fundraising Pack. We can't emphasise enough about the need to maintain the momentum on raising funds. The two important reasons for this are:

- Costs will be incurred as we shift some more focus on our support aims. In the past, we have relied on many gratuitous contributions from our suppliers. It's getting harder to rely on freebies!
- ➤ Secondly, we've had great luck this year in grant applications (2 for 2 is a pretty good hit rate!) however the success of future grant applications is extremely uncertain. So essentially, maintaining the momentum and carrying on with fundraising and adopting a business as usual attitude would be prudent and would allow us to cover those rainy days. There may even be an opportunity to fund research outside of that which is taking place. We all want to ensure that research into CMN continues for the foreseeable future -- understanding the cause and developing effective treatments remains the same goal.







The Fundraising Packs are there to make your experience as easy and simple as possible. The pack includes fundraising ideas, CMN booklet, CMN leaflet, poster template, sponsorship form and a disk containing the CMN logo to create your own event materials, sample documents from previous events and a media press release.

Copies can be downloaded from the website www.caringmattersnow.co.uk/support.html, alternatively email Lucy at lucyh@caringmattersnow.co.uk for copies.

CMN Research at Great Ormond Street Hospital for Children, London - Veronica Kinsler

I would like to give everyone the CMN research email which I check on a regular basis: CMN@ich.ucl.ac.uk. This is for any questions about the research. If you have questions about appointments with the hospital it is still best to contact the Dermatology secretaries at GOSH directly.

The CMN genetics project is still underway, with the first results posted out to all the families who took part in April this year. The overall results of the first phase will be explained in the newsletter next January. We have now moved on to looking at other genetic changes we have found in the samples, and the results of these findings should be available to the families involved during 2011. Very importantly if any of the children involved in the genetics study is due to have routine surgery on their CMN please let me know via the email address, as I will speak to you about using the CMN sample for the genetics study.

The CMN Registry which collects long-term data on people and families with CMNs was relaunched last year. This involves filling out a questionnaire once a year, but we are only allowed to send these out to families who have completed a consent form to say it they would like to take part. We will be sending out one more consent form this Summer to everyone on our lists, but if you do not get one and would like to take part please email me and I will send one out. The real power of this database is in the numbers of people who take part.

The results of the study into the faces of children with CMNs have been submitted to be published in a medical journal. Many thanks to all the families who agreed to have their child's photograph included in the article. The finding that many of the children have similar facial features (while still looking like their families) is helping us to understand how and when the CMN developed.

A new study has started in April of this year. This involves children between the ages of 1 and 6 who are already taking part in the genetics study. Many thanks to all of you who have already made appointments to take part. Anyone who thinks they are eligible but has not received a letter of invitation please let me know, as it can take the place of your next appointment but needs to be organised in the morning.

Many thanks for everyone's continued support – the research could not happen if you families did not participate.

As you know the ultimate aim of this research is to find out as much as we can about CMNs so that we or other people may be able to develop better treatments, and better ways of working out which people need what sort of investigations or appointments. At the moment, we know a lot more about the condition than we did 10 years ago, but it is still frustrating not to be able to give families more accurate information about their particular child, and not to be able to offer good and safe treatments. This will take many years to achieve but this sort of research should help to move us in that direction.

Jodi and Dr Kinsler travel to the USA

Nevus Outreach, Inc. The Association for Large Nevi & Related Disorders

On the 6th July I am travelling to Dallas, USA with my mum and Dr Kinsler to attend the Nevus Outreach Conference 2010. The conference attracts hundreds of people with CMN across the USA. The conference is only held once every two years and if you have been to one of our family days, it's a bit like that... but on a much bigger scale.

Our aim for attending the conference is to see how we can better the CMN support group in the UK, by observing the Nevus Outreach support network. I will be taking some of our CMN support literature which will be distributed during the 4 day conference to the attendees.

This is a great opportunity to increase awareness of our support group across the globe and to build partnerships with other CMN organisations. I will let you all know how I get on... I must remember to pack my shoulder-padded tops!

Activity Weekend

We have been looking at ways we can improve on our family days and maybe encourage more teenage groups to attend. We thought it would be a good idea to consider a Family Activity Weekend for the whole family. This would include a one or two night break in central England.

Activities could include:

Abseiling, Aero ball, Archery, Ball Sports, Canoeing, Challenge Course, Climbing, Fencing, Giant Swing, High Ropes, Initiative Exercises, Jacob's Ladder, Kayaking, Low Ropes, Motorsports, Orienteering, Problem Solving, Raft Building, Rifle Shooting, Sensory Trail, Swimming, Trapeze, Zip Wire

We understand that a decision on this will depend on cost, so if we were to suggest a family unit price of approximately £400, inclusive of accommodation, meals and activities, would this be a consideration? This is a very ball park figure and more confirmed prices will be published once we know how many people are interested.

This is a great opportunity, but as a new venture we really need to gauge numbers to see if you are interested.

Please register your interest ASAP with lucyh@caringmattersnow.co.uk

FRIDAY EVENING

ARRIVE

SATURDAY MORNING

08.15 - Breakfast (English or Continental, cereal, toast and drinks)

09.00- First activity session

10.30 - Break

10.45 - Second activity session

12.15 - Hot lunch or packed lunch

13.45 - Third activity session

15.15 - Break

15.30 - Fourth activity session

17.00 - Free time

17.30 - 19.00 - 2 course evening meal

19.00 - 20.30 - Evening entertainment.

SUNDAY MORNING

08.15 - Breakfast (English or Continental, cereal, toast and drinks)

09.00- First activity session

10.30 - Break

10.45 - Second activity session

12.15 - Hot lunch or packed lunch

DEPART







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 Lucy if you are planning on attending any of the family days by calling 07786 458883 or email lucyh@caringmattersnow.co.uk

Cambridge Family Day Review

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

Date: Saturday 17th April 2010

The Cambridge family day was another very successful day with many old and new faces. Thank you to everyone who attended, especially the new families for making that step as it's not an easy step to make into the unknown. But the feedback has been very positive and we hope that you all feel very welcome and at ease.

A big thank you to Dr Kinsler, who travelled up from London for the day and spent the entire time talking to all the families and presented her latest research findings, which was very interesting.

The weather was great and we had many activities for the kids inside and out, including bouncy castle, ball games, arts and crafts and Easter egg hunt which always proves to be great fun.

I would personally like to say a big thank you to my friends and family who always make me very proud and never fail to pull out the stops to ensure they help provide a great deal of support on the day.

Thank you to everyone for attending, to the trustees, and Dr Kinsler for their hard work and dedication.

Lucy







Please note London venue & time change to that previously advertised

2010 FAMILY DAYS

Date: Sat 26th June Time: 12pm - 4pm Location: London Venue: Seven Dials Club, 42 Earlham Street, London, WC2H 9LA

Date: Sat 21st August Time: 1pm - 5pm Location: Glasgow Venue: St Brides RC Church, 21 Greenlees Road, Cambuslang, G72 8JB

Date: Sat 25th September Time: 1pm - 5pm Location: Birmingham

Venue: TBC – check website for details

Date: Sat 20th November Time: 1pm - 5pm Location: Liverpool Venue: Bridge Chapel Centre, Heath Road, Liverpool, L19 4XR