

July 2009

Strawberries and Cream Tea Afternoon

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Upcoming Family Days



The Caring Matters Now Support Group has a very worthwhile fundraising event coming up in August and the trustees and I would love all our members to join in!

Caring Matters Now was established in 1998 and one of the first families to join the support group were Martin, Jackie and Holly Thirkettle. As you are aware, the majority of CMNs are not life threatening but unfortunately, in Holly's case, the condition led to associated complications and she passed away at an early age.

On 10th August this year Holly would have been celebrating her 10th birthday, so Martin, Jackie and the CMN support group trustees would like to mark the anniversary by organising a 'Strawberries and Cream Tea' afternoon. We would like all our CMN members to invite family and friends to their homes on Saturday 8th August for Strawberries and Cream Tea. Those who attend can make a donation towards the CMN support group.

Martin and Jackie are planning to mark the anniversary by taking part in a 25 mile bike ride on Sunday 9 August to raise funds for the CMN support group. They have set up an on-line fundraising page. The CMN trustees thought it would be nice for Martin and Jackie to see all those who had raised funds by holding a 'Strawberries and Cream Tea' afternoon in memory of Holly, so we would ask that those who are able to, please donate the funds raised from 8th August via Martin and Jackie's on-line fundraising page, which is <http://www.justgiving.com/martinthirkettle>

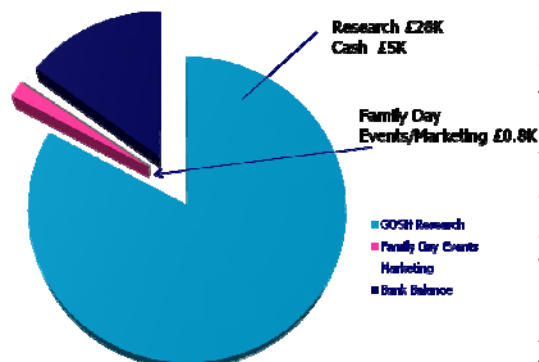
Donating through Justgiving is quick, easy and totally secure. It's also the most efficient way to donate your raised funds: Caring Matters Now gets your money faster and, if you're a UK taxpayer, Justgiving makes sure 25% in Gift Aid, plus a 3% supplement, are added to your donation.

Thank you for your support.
Jodi Unsworth

On 10th August this year Holly would have been celebrating her 10th birthday, so Martin, Jackie and the CMN support group trustees would like to mark the anniversary...

Send pictures of your event to lucy.hardwide@btinternet.com and we can feature them in future newsletters

Financial Update



Congratulations to all our CMN supporters! For the financial year ending in April 2009, a phenomenal £34,000 was raised through your fundraising efforts.

Virtually all the monies have gone directly to CMN research at Great Ormond Street -- £28,000! We spent less than £1,000 in marketing and administrative costs and the remaining cash balance of £5,000 will go towards this year's campaign.

As at the end of May, we are at £9,000 versus our £30,000 fundraising target. It is a great start but we will need to enlist the help of all our members to ensure we reach our goal and commitment to GOSH.

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.charitychoice.co.uk/donation.asp?ref=156514 - 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.

New
Fundraising Packs
available later this year

For more information or to
request a pack, contact Lucy
Hardwidge.

lucy.hardwidge@btinternet.com

Attention EBay Sellers!

Caring Matters Now is now a listed charity on EBay. If you are selling items on EBay, you can donate a percentage of your final selling price to CMN. You will also receive a fee credit on your basic insertion and final value fees equal to the percentage you donate every time you list an item for charity. It's simple!

1. Once you're ready to sell your item, go to the Sell hub and select 'Advanced Sell'.
2. As you're filling out the details, look out for the charity box just below where you set your price. Select "Caring Matters Now" to support and the percentage (10%-100%) of your final selling price that you'd like to donate. Note: The minimum donation is £1 per listing.
3. A week after your item sells; Mission Fish (eBay's charity partner) will automatically collect the donation from you.

Earn a bit and Give a Bit -- we hope you can support Caring Matters Now as your charity of choice for all your EBay sales!

Rachel's Fundraising Walk for CMN



On Saturday 11th April 2009, Rachel Ilhan raised over £500 for the CMN research by walking 5 miles along the English coast. Rachel is 11 years old and has CMN covering her back and stomach. Rachel's mum, Wendy, said "Rachel is a happy, confident, outgoing 11 year old who just happens to have CMN."

When Wendy first spoke to Rachel about doing some fundraising for the CMN research, Rachel wanted to help and she decided a sponsored walk would be best for her. Wendy said "I've always been proud of her, never more so than now."

The Caring Matters Now Support Group wants to thank Rachel for raising over £500 for the CMN research.

Jeans for Genes Awards Grant



*We would like to show
Jeans for Genes that
CMN families have what it
takes -- **we need
volunteers!***

We are very pleased to announce that Caring Matters Now has been awarded a £4,000 grant from Jeans for Genes -- a national children's charity which raises money for the care of children with genetic disorders. In return for the grant, we need to raise awareness about Jeans for Genes Day and to motivate the public to raise money for this campaign. We have a strong incentive to do this -- an additional £5000 is going to be awarded to the charity deemed to be contributing most to this year's campaign success. We would like to show Jeans for Genes that CMN families have what it takes -- **we need volunteers!**

- Organise a Jeans for Genes Day at your school or work
- Volunteer at J4G events (e.g. Shopping Mall events or take part in a sponsored run/walk (British 10K – July 12/ Adidas Women's 5K in Hyde Park – September 6)
- Help us with media interviews

More details can be found on the website www.jeansforgenes.com

Additionally, a very important way to support the campaign is to volunteer as a school speaker. The school speaker programme presents a unique opportunity to visit your local school(s) and lead a brief assembly about Jeans for Genes Day to explain why the day is both fun and important. As speakers are encouraged to insert their own personal experiences, we feel it is an extraordinary opportunity to talk specifically about CMN and the challenges our children face in your community. School speakers are invaluable in engaging the teachers and pupils in understanding what it's like to have a genetic disorder like CMN and to motivate the schools to raise money. Most of the assemblies are done in September, during the weeks leading up to Jeans for Genes Day.

Volunteering couldn't be easier! Visit the Jeans for Genes website www.jeansforgenes.com/getinvolved/volunteer/speaker, click on "register" and be sure to enter "Caring Matters Now" as your charity organisation. Once you register, the Jeans for Genes team will match you to a school in your area that is participating in Jeans for Genes Day. Together with the school, you arrange a convenient date for your assembly. You will be sent a ready-made PowerPoint presentation along with speakers' notes and some top tips to boost your confidence and help you to deliver your powerful message. There will also be a one day public speaking seminar for people wanting to attend in the London area.

Be sure to let us know how you are supporting the campaign so we can tell the Jeans for Genes team and increase our chances of claiming the additional £5,000 for CMN!

Please take advantage of this wonderful opportunity -- by partnering with this well-recognised children's charity, our participation in this year's Jeans for Genes campaign has the potential to go a long way in raising national awareness about CMN and the issues faced by CMN sufferers. So please mark your calendars and join us in supporting Jeans for Genes Day, October 2, 2009.

Story of Katy Jackson



It was lasered off, using CO2 and Ruby Lasers, and then I had various bandages and dressings for 3 months ...

My CMN does not really affect my social life or my hobbies.

My CMN does not stop me making friends either.

My name is Katy Jackson, and I am 11, nearly 12, years old. I have a CMN on the back of my right knee. When I was 18 months old, I had an operation to remove it. It was lasered off, using CO2 and Ruby Lasers, and then I had various bandages and dressings for 3 months which involved going back to the hospital to have my leg redressed and treated. Immediately after the operation, however, it started to grow back. Since then, I have had a range of treatments to help me with the problems that I have with it; most of the time, it itches and sometimes I get some pus filled spots that really hurt to pop.

My CMN does not really affect my social life or my hobbies. Sometimes I get asked a few questions about it, or some strange looks, but now I have learnt to ignore them and not let them get me down. I do a lot of dancing (modern, tap and ballet), and since I was 4 years old, I have been dancing on stage showing my birthmark to the whole audience. When I was 10, I danced on stage with the English Youth Ballet, as a Scottish Doll in the ballet Coppélia, and my CMN did not affect my performance in any way. Then, when I had just turned 11, I danced on stage with the Southern Youth Ballet, in the ballet La Fille mal Gardée, as a villager.

For the last four years, I have been dancing in competitions throughout the south-east of England. Sometimes my costumes cover my birthmark, but sometimes they don't. My teacher and I don't think about the fact that I have a birthmark and we don't let it dictate what I wear!

My CMN does not stop me making friends either. In September 2008, I started at Tonbridge Grammar School, and almost instantly, I made a whole group of friends. At first they questioned my CMN, but now that they know what it is, they don't worry about it, in PE lessons, or anything else that they see it in. When I go swimming with my friends, they don't worry about it then either. I do get a few glances from other people in the swimming pool, but I just ignore them.

Most of the things that I get asked or told are 'What's on your leg?', or 'You've got mud on your leg'. Sometimes it can get quite annoying, but my instant reaction is just to say 'It's a birthmark', and then most people just get on with the fact that I have a birthmark. Some people keep pestering me about it and then I just keep telling them the same thing, 'It's a birthmark'.

If you have a birthmark, then I would just say to you, don't let it worry you, nobody's perfect, so just go out and enjoy yourself.

CMN Regional Support Contacts

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

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. Each regional support contact is a member of the CMN support group and are either parents of children with CMN or those who suffer with CMN.

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.

We still have some 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 Jodi Unsworth at jodi.unsworth@googlemail.com or 0151 281 2820.

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: Andrew3d Davies@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

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



1. The CMN Registry

The CMN Registry is a database of people with CMNs which has been collecting information since 1988. It has been a vital source of information to help work out what are the real long-term complications of CMNs, and how often they occur. It has also helped to change the management of CMNs.

The Registry has been revamped over the last year and is now ready for a relaunch. Everyone who is already on the Registry or anyone who has been seen at GOSH will be sent an information letter about the new Registry before the end of 2009, along with a consent form to sign if they want to continue taking part. Taking part in the Registry involves filling in a postal questionnaire once a year.

In order to improve the quality of the information in the Registry anyone new who wishes to join has to be seen at least once by Dr. Kinsler at Great Ormond Street.

2. CMN Genetics study

This is looking for the genetic basis of CMNs – in other words trying to work out which genes are responsible for a person developing a CMN. This study is going very well. 100 families have joined via the GOSH clinic and we hope to sign up another 50-100 families via the new research clinic (see below). We are currently trying to collect control families for this study (families who do not have a child with a CMN) to compare the results of the CMN families with families who do not have CMNs. If you are in the Genetics study you should have received a letter about this – if not contact Dr. Kinsler.

How to take part in the research studies

Dr. Kinsler will see any child (under 17 years) with a CMN in the dedicated clinic at GOSH. This requires a referral from your GP or Dermatologist to Dr. Kinsler. In addition the following people will be sent an invitation (by the end of 2009) to attend a single appointment in a separate research clinic:

- anyone who has previously been seen at GOSH for their CMN but is no longer seen regularly, even if they are over 17
- anyone who has taken part in the Registry study, even if they are now over 17

If you think you are in one of these categories and you do not receive a letter by the end of 2009, or if you do not fall into one of these categories but particularly want to take part in the research please contact Dr Kinsler directly at the Paediatric Dermatology Department, Great Ormond Street Hospital, London WC1N 3JH.

Dr. Kinsler would like to thank everyone involved in Caring Matters Now for funding this important research, and everyone involved in the studies for taking the time to contribute.



CMN Family Day Review – Lucy Hardwidge

Venue: The Hub Community Centre, Cambourne, Cambridge

Date: Saturday 9th May 2009

Review: The family day was very well attended, with many new families, Dr Veronica Kinsler and the CMN team.

The Cambridge family day was a huge success and I would like to thank everyone who attended. There were many new faces, providing a great opportunity to meet and chat with other families and make new friends.

There was a lot going on... Easter egg hunt, craft activities, bouncy castles (with slide!), light buffet, refreshments, raffle, and CMN medical information and support group up-date presentation.

We managed to capture some great photos of everyone having fun, so be sure to check out our promotional material and see if you can spot yourself! Thank you Jessica for your superb photography!

The CMN team gave a short presentation on the support group's progress over the past 12 months and Dr Kinsler gave an up-date on the latest medical research findings, which was very interesting.

Thank you too all those who attended, enabling the day to be a great success and a huge thank you to my family and friends who help tremendously in making this day run so smoothly. A special thank you to the kitchen staff, my Dad and Auntie Annie, my Mum for her babysitting services to my baby girl Amy, mother-in-law and sister-in-law for setting up assistance and also Julian and Shelley for childcare services during the presentation!

UPCOMING FAMILY DAYS

Date: Sat 11th July **Time:** 1pm - 5pm **Location:** Bristol

Venue: The Cornerstone Ministries Church, Redland Road
Bristol. BS6 6AG

Date: Sat 19th September **Time:** 1pm - 5pm **Location:** Birmingham

Venue: TBC

Date: Sat 21st November **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

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: jodi@caringmattersnow.co.uk with "Email Update" in the Subject box. Thanks!

A Special thank you Fred of The Printworks, Litlington, for kindly sponsoring the printing of this newsletter