CARING MATTERS NOW NEWSLETTER
VOLUME 1 ISSUE 8

January 2011

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Check out the PGL website:
http://www.pgl.co.uk

FRIDAY EVENING - ARRIVE

SATURDAY MORNING
08.15 - Breakfast
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 - Evening meal
19.00 - 20.30 - Evening entertainment.

SUNDAY MORNING
08.15 - Breakfast
09.00 - First activity session
10.30 - Break
10.45 - Second activity session
12.15 - Hot lunch or packed lunch
DEPART

Family Activity Weekend

BOOK NOW!

Friday 1st – Sunday 3rd July 2011

We are so excited to inform you that we have made plans for the very first CMN Family Activity Weekend in 2011. All age groups welcome. Jodi and Lucy visited the proposed site, Boreatton Park situated in 240 acres of Shropshire countryside. The site is just fantastic and we can assure you fun will be had by all that come along.

Attending an activity weekend like this could potentially make a huge difference to a persons self esteem and confidence in dealing with a disfiguring condition such as CMN. The activities planned would allow both children and parents to bond and in many cases, long term friendship could develop and flourish.

Being given the opportunity to talk to someone who may have or is encountering the same experiences, whether positive or negative of living life with CMN can benefit those affected immensely and would prevent the feeling of isolation.

Following discussions with the company we have secured a great deal of £99 per person. This price includes:

Food

Accommodation

Activities

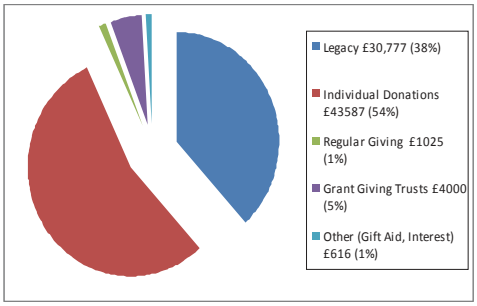
Evening entertainment

The exact itinerary of activities is yet to be decided but could include any of the following:

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

For the younger ones that will not be able to take part with the bigger kids we will be providing fun games, arts and crafts and other activities for them to enjoy.

To confirm your place please complete the enclosed booking form and return it with a non refundable cheque deposit (made payable to Caring Matters Now) of £24 per person to Lucy Hardwidge, CMN, PO Box 732, Cambridge, CB1 0QF.



How we raise our money?

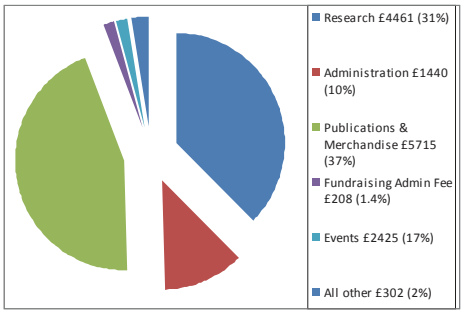
The short answer is - we rely on you!

Last year, we were really worried that Dr. Kinsler's research would stop due to lack of funds. We asked everyone to pitch in and you did!

As a result, we had our best fundraising year yet. Over £44,000 was raised. Later in the financial year came a very generous legacy donation from the Hoar Family and success with grant applications including the Wellcome Trust Grant (Nov09) and Jean for Genes (Nov09).

In total, £80,000 was raised – an incredible result.

Well done to everyone involved.



In the year ended March 2010, we spent £14,500

How we spend our money

This pie chart shows you where we spent our money the past financial year (Apr09-Apr10). Administration and fundraising costs are kept to a minimum – these costs are primarily the fees we need to pay to use 'Just Giving' (an online charity fundraising platform and Gift Aid claims process) and to carry out the day to day running of an expanding charity such as postage, stationery, phone bills, etc.

Thanks to the Wellcome Trust Grant for the CMN Research received at the end of 2009, Caring Matters Now was required to pay a smaller percentage of our funds than originally anticipated to research.

So, the trustees agreed to use some of the funds to develop and produce the age specific support materials, update the medical information booklet/leaflets, strengthen our brand awareness and web presence and increase our branded merchandise. We were able to increase the number of family days across the UK and organise a regional support network training and information day.

We need the support of the CMN families to ensure this important research and support continues

CMN research and support

Caring Matters Now has contributed over £76,000 towards CMN Research conducted at GOSH. Research costs are approximately £30,000 per annum … but increasing each year.

2011 fundraising target - £45,000!!

We've set the fundraising target this year at £45,000 which would cover additional research we want to fund for Dr. Kinsler. With 240 families on the register, it amounts to **£188** per family. **Don't you think this is achievable?**

Fabulous fundraisers

£1040 – Stephen Dobbs and the team – 3 Peaks Challenge

£1200 – Helen Taylor, Claire Cooke, Fiona Hardman, Keith Hardman, Sarah Stevenson – 10k Run

£8500 – Susanna Hoar and Clare Twigger-Ross (The Pink Chicks) – 10 runs in a year

£4655 – Rick Fish & Mark Joy – Coast to Coast across Scotland on bike foot and in canoe. Funds raised split between GOSH and CMN.

£500 – Liz Harding– Netball Tournament

CMN Charity Challenge




Well, we are pleased to report that we have 16, yes 16 remarkable people taking on the challenge of reaching the summit of Mt Kilimanjaro, all in aid of Caring Matters Now. This really is truly incredible and we would like to say a huge thank you to you all for enrolling on this amazing expedition.

As we have reached the minimum group size of 16 this will now definitely operate as a dedicated CMN Charity Challenge, so only those raising money for CMN will be part of this trek.

We have chosen a truly unique and experienced company to support our trekkers on the challenge ahead. Charity Challenge is a company that has an excellent success rate (96%) of trekkers reaching the summit, but do not underestimate the challenge our current team of 16 face – hours of trekking, extreme weather conditions, high altitude, all of which can cause any number of difficulties.

Charity Challenge has also recently been involved with the Denise Van Outen and Fearne Cotton Machu Picchu Trek and before that the Comic Relief Red Nose Day challenge. So, if Chris Moyles and Cheryl Cole can do it, what's stopping YOU!

A truly staggering achievement, summit the world's highest freestanding mountain, bush trekking in unspoilt wilderness, experiencing every eco-system known to mankind and the unique opportunity to share this with fellow trekkers with the same goal - to help and support those with CMN. An opportunity not to be missed.

We would like to reach 20 trekkers, this is our ultimate aim, so if you are still interested check out the Charity Challenge website http://www.charitychallenge.com/expedition.html?id=1418 or call Lucy on 07786 458883 for more information.

Celebrity Charity Fundraising Event

Celebrity stars such a **Sharron Davies MBE (Olympian & Presenter), Lisa Maxwell (Actress & Presenter), Emma Samms (Actress) Dynasty, Murder She Wrote, Holby City** and **BBC sports presenter Manish Bhasin** supported the event at Five Valleys Conference Centre (Forest Green Rovers FC) on 12th September.

Jodi Unsworth and Lucy and Scarlett Clarke attended as CMN representatives. Proceeds from the fashion event are expected to reach a fantastic £4,000. Thank you to everyone involved.

My Story – Sheila Mackenzie

I am an older mother; Eva was born when Colin and I were in our forties. She was the little girl we had waited for, for so long!

I went into hospital on the eve of my birthday. The labour was long but little did I know that this procedure would go on through the night and into my own birthday!... and so Eva and I share the same birth date.

Colin was with me throughout and knew as she was being born that she had marks on her skin but he didn't say anything. We enjoyed the moments immediately after birth thoroughly. Eva was laid on my chest and remained there for what seemed like ages. I didn't see any marks and no one said anything. I just smiled and enjoyed this special time. This is very much the way things have been ever since!

"During those early days and weeks, we realised that we had a special little girl."

The first I knew of marks on Eva's skin was when a senior midwife came in and said that she "must point out these marks." The way it was said, I thought that this was some everyday occurrence. Within a short time, I realised that this was something different and a registrar informed Colin and I that the condition was potentially cancerous. I didn't quite take things in; I was overwhelmed and confused as it was so soon after giving birth. I cried at this point. Looking back, my situation was the same as others I've heard of, the information was conveyed clumsily, the doctor was ill informed and there were more questions than answers.

"must point out these marks"

The three of us were taken up to a private room where we settled into the usual early family moments, cooing at our baby and phoning relatives. I was on a high but with very nagging questions in the back of my mind.

Some time later, a consultant came in and was able to tell us that the registrar's earlier prognosis was completely wrong, that the condition was called CMN and that it was not life threatening. We were greatly relieved, tired and ready to go home!

The consultant made an appointment with the dermatology department at our local hospital for the following week. In the meantime, Colin was able to go on the internet to find out more, something I didn't feel ready to do. I could only take on board very little information at a time and needed time to think through each new piece before I could handle the next. I was therefore glad to take care of Eva's everyday needs, visits from family and friends etc. and keep my mind occupied on other matters. Colin was the one who found out about Dr Atherton at Great Ormond Street Hospital. Finding such a reputable link was a huge step forward and a great relief. Our local dermatology appointment was a complete disaster as the consultant had not made any effort to find out about the condition. We were told to undress then dress Eva and nothing constructive or supportive was said as two colleagues fleetingly looked at her. It was very upsetting. Colin, who by now was angry and frustrated, asked if we could be

"She is still fun and feisty…. and very beautiful!"

referred to Dr Atherton and fortunately we were. Six weeks' later, we were in Dr Atherton's surgery, the best result we could have had!

During those early days and weeks, we realised that we had a special little girl. She was feisty, strong, fun and a first class patient. Our trips to GOSH became a bit of an adventure.

I also realised that people didn't give more than a fleeting look at Eva, if any at all. Inside, I had been wondering how her everyday life might be affected and felt tentative and nervous in those early days. But I soon came to realise that I had every reason to be confident and relaxed, proud of my child and each step of her journey.

Eva has a bathing trunk naevus and satellites over her limbs. One or two satellites were large and prominent; she also had a mole in the centre of her forehead. Dr Atherton recommended that some work could be done in her early years to remove these smaller marks and Eva had 3 successful operations and we still believe that this was the right thing for her.

Wanting to find out all the options, we had a private consultation with someone who could work on the large mark but we decided that the risks were too high and that we would instead wait for developments which might bring about a safer and more satisfactory result for Eva should she want it in later years.

Eva had an MRI scan when she turned two which was clear. She was developing normally and we established a routine of 6 monthly visits to GOSH for checks and to be part of the research programme.

We have enjoyed the support of the network and have been very excited by the work of Dr Veronica Kinsler. Her dedication and support have been invaluable and we are eager to see what outcomes await all of us.

So, what of our everyday lives? Eva is now 71/2, an age when she is becoming more aware of her marks. She is still fun and feisty…. and very beautiful! She has also developed a large amount of common sense and has taken strategies for managing her situation with great poise and strength. She joined a new swimming class last weekend and her marks were on her mind. I noticed a couple of children look as Eva took off her robe and entered the water. However, it was only a momentary glance. Afterwards, Eva said that she noticed them look and that she turned away and got on with things. They didn't look again. Eva was in and out of the water and I didn't notice *anyone* look. Her confidence and the fact that she behaved like everyone else meant that she was just the same. She LOVED her lesson and Colin and I are very proud of how she is managing this stage of her life.

I don't know what the future will bring. Eva may be given the opportunity to have her birthmarks all removed and we will work hard to give her that choice. In the meantime, Colin and I don't look ahead to potential worrying times too much, why worry about something which may never happen? As parents, we know that there will always be things

to deal with at each stage, everyday things that other parents and children have to deal with. Each one will be dealt with at the time and a satisfactory way ahead found. Usually, it is our sensible daughter who comes up with the solutions!

My Story – Eva Mackenzie

Eva with Harry from McFly

I am happy with my birthmarks because I am myself. It is hard to get confident when something new is happening because you can get a bit shy!

If your friends or strangers ask why you have birthmarks just say “Because I was born like that!” If you don’t say that they will keep on asking you.

When I was six, I was asked to a friend’s swimming party. I didn’t want to go because I was shy but Mummy and I talked. She came with me into the water. Nobody noticed anything and I was glad I went! I felt great.

Yesterday, Dad took me to The Lord Mayor’s Day. I went on the bouncy castle and my birthmark showed a little. I looked at Dad and I felt okay.

Nevus Outreach Conference in Dallas

Over the past 12 months Caring Matters Now has been developing contact with Nevus Outreach, which is a US based support group for CMN. In November 2009 Mark Beckwith, the Executive Director of Nevus Outreach, attended our CMN Liverpool family day. He was so enthused having met our families and seen what our support group does, that Mark invited Dr Kinsler and myself to attend the Nevus Outreach biannual conference in the United States. The CMN trustees thought it would be worth our while to attend the 3-day conference in Dallas, as we could learn from each other, resulting in strengthening both support groups.

Dr Kinsler, my mum and I travelled over to Dallas, US, on 6th July. We spent 4 days with Nevus Outreach staff and family members who had travelled from many states in the US to be at the conference. This is the main event for families to meet each other and to gain medical advice from the world-leading CMN medical experts.

Dr Kinsler spoke twice during the conference to all those who attended, including other medics from Europe and America. She spoke confidently and passionately about her CMN research. All those listening to her were very impressed with her work. As I listened to Dr Kinsler speaking, it just re-confirmed how ‘priceless’ her CMN research is... my mum and I were very proud of her!

Dr Kinsler and World leading Medics in CMN

I also had the opportunity to speak during the conference about our support group and the US families were very impressed and encouraged with the support we offer to our families. In fact, one set of parents from New York said that when their little girl was born with CMN, they started to look for answers about the condition on the internet; our website was the first they found! The little girl's parents said that our downloadable CMN support packs were what got them through the very difficult first few months of their daughter's life. The support packs were so useful that they printed off lots of copies and gave them to their extended family and all their friends. This was so encouraging to me because what Caring Matters Now offers is not just support in the UK, but across the world. Caring Matters Now is making a bigger difference than I ever realised and we now have a lot more support and friends from across the pond... which is great!

Jodi Unsworth

CMN Research at Great Ormond Street Hospital for Children – Veronica Kinsler

We have had a very busy year with CMN research this year. There are 4 big studies on the go, and a new one in the pipeline for next year. My CMN research email is CMN@ich.ucl.ac.uk in case anyone has any questions, or if anyone who is a Great Ormond Street Hospital (GOSH) patient is having routine surgery and wants to have the removed CMN used for the research.

The CMN genetics project has finished the first phase and entered the second. Let's do phase two first:

Phase two of the genetics project is looking for other genes which make the CMN happen. This is being done using 3 different techniques. Caring Matters Now is funding the most expensive of these, and the one which is also most likely to be helpful. This project is actually running on the super-douper machines as I am writing this so we are very excited to see the results. Of course we may still not find what we are looking for but this greatly increases the chances. Full results of this will take at least a year to come through.

In the first phase 110 families gave us blood samples and lots of information about their families, and we were lucky enough to find a gene that influences how big the main CMN becomes and how many satellites develop. As lots of you will know this is the MC1R or red hair gene, and we found that most people with CMN have at least one change in this gene. We then found that certain changes in it are associated with having a larger main CMN and more satellites. This is important because it is telling us one of the ways in which the CMN developed when the baby was in the womb and how the CMN continues to develop after birth. We have now had approval to extend the genetics study to include another 60 families. The reason for this is to try to see if the same changes in the red hair gene make it more likely to have an abnormal MRI scan of the brain and spine. If we did find this we could use that test when a baby with a CMN was born to say

FUNDRAISING PACK

Want to help us to continue the research programme & provide vital support to families? Then why not request a fundraising pack and join in the fun of raising money for a very worthwhile cause.
Please email Lucy at
lucyh@caringmattersnow.co.uk
to receive a pack.
Or download from the website
www.caringmattersnow.co.uk

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

whether they needed to have a scan. This would reduce the number of children who had to have a scan which would be better for everyone. Anyone who comes to GOSH who is not already in the study will be asked if they would like to take part when they come to their appointments. Anyone who has not ever been to GOSH but would like to take part would need a referral from their GP or other doctor and we will arrange an appointment for them.

CMN Hormone study: This new study started in April of this year and so far 30 families have taken part. Thank you so much to those 30 families – we have already found a very new and exciting finding which will change the way we think of CMN. We still need another 20 families, and anyone in the genetics study should already have had an invitation. If you would like to please do make an appointment to take part as we hope to finish collecting this data quickly. The number to phone to book an appointment is 020-7762-6892 – ask for Mark and say it is the CMN study. This appointment can take the place of your normal appointment (so that you do not need to come up more often) but has to be booked into a separate clinic as the hormone levels have to be measured in the morning.

The CMN Registry: This collects long-term data on people and families with CMNs and 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 if they would like to take part. We will be sending out one more consent form shortly to everyone on our lists, but if you do not get one and would like to take part please email me and we will send one out. The real power of this database is in the numbers of people who take part. Do not underestimate the importance of this study although it has been running for a long time.

CMN Faces study: The results of this will be published in 2011. Many thanks to all the families who agreed to have their child's photograph included in the article. As many of you will know we have found that many of the children have similar facial features (while still looking like their families). We will continue to collect photos of the faces of people with CMN as it is helping us to understand how and when the CMN developed.

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.

All family days will include:
- Light buffet and refreshments
- Children's crafts and activities
- Presentation from Dr Kinsler and CMN trustees

2011 Family Days

Date: Sat 26th March Time: 12pm - 4pm Location: London
Date: Sat 20th August Time: 1pm - 5pm Location: Glasgow
Date: Sat 19th November Time: 1pm - 5pm Location: Liverpool
Please see the website for more details www.caringmattersnow.co.uk