



July 2013

## 24 PEAKS CONQUERED!

### Amazing £22,000 raised for Caring Matters Now!

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I had the great honor, yet again, of taking part in another CMN Charity Challenge, climbing 24 peaks in 24 hours. Beforehand I must admit I underestimated the difficulty of the challenge. I thought “24 peaks can’t be as tough as Mount Kilimanjaro”, however, I was soon to be proved very wrong!

Caring Matters Now has set a rather BIG challenge of undertaking 7 challenges on 7 continents. In 2011 a team of trekkers summited Mount Kilimanjaro, ticking off our first continent, so it was time to continue in our 7 continent challenge and tick off our second continent, Europe. We wanted to make this challenge as accessible as possible to all our members and supporters, therefore we thought 24 peaks in the Lake District over one weekend would be manageable for most. As a result we had 22 trekkers sign up and take part in the challenge. This included CMN dads and mums, adults with CMN, plus friends of CMN families within the charity. I was again astounded by how quickly these 22 individuals moulded as a strong team, working together to achieve one goal!

The challenge itself was the most physically tough activity I have ever done. People have asked how does it compare to Mount Kilimanjaro and I can only say that both challenges are very tough but for different reasons. The 24 peaks in 24 hours challenge was very tough due to the sheer amount of steep climbing we had to undertake in a very short space of time. Both days of the challenge included 12 hours walking up and down in weather conditions that were treacherous, so much so we lost our bearings on top of one of the mountains! This resulted in us descending down a particularly dangerous route. It was a blessing that the clouds were low, covering up the path we were taking, as when the clouds cleared we got to see exactly what we had just done... I was shocked!

The team was just amazing and they all pulled together, encouraging and motivating one another. When any one person was struggling, the rest of the team would be there to help in whatever way, through encouraging talk, carrying bags, giving up medicines or snacks... everyone was a real inspiration to me and I felt blessed to be a part of such a wonderful team.

Thank you to all the team for taking part in the 24 peaks in 24 hours challenge and for raising over £22,000 for Caring Matters Now! Well done everyone.

Jodi Whitehouse



Cheque for £800 presented to Jodi by Jeremy Hoar on top of Helvellyn



This is all part of the Charity's ultimate aim of 7 Challenges across 7 Continents. We want to be the first charity to achieve the unthinkable and you can be a part of this! Check out our goal <http://www.caringmattersnow.co.uk/7-challenges-across-7-continents/>

**Keep your eyes peeled on the CMN website for details of the next challenge.**

## Dancing with Sky's Stars

**What a night we had! Celebrity stars dancing to raise money for Caring Matters Now and Rett Syndrome Research Trust UK.**



Based on the Strictly Come Dancing programme, this was a fun-filled event which ran over 2 nights and consisted of a panel of celebrity judges including **Arlene Phillips** CBE famous for Strictly Come Dancing and So You Think You Can Dance; **Dan Lobb** retired tennis player and TV presenter; **Brendon Cole** well known ballroom dancer famous for Strictly Come Dancing; **Mark Foster**, British championship swimmer and **David Roberts** and **Andrea Law** British Dance Champions. They spent the evening judging the team of celebrity dancers from Sky Sports and their partners from Step by Step Dance School.

Thank you to Mel Bartlett whose daughter Ava has CMN and who was the driving force behind this event for CMN. Also, a huge thank you goes to Marc Souter and Mike Wedderburn.

Overall the event raised a fabulous £15,000, which is being used to part fund the research assistant for Dr Kinsler.



## Caring Matters Now Funds Research Assistant

The money raised from the 24 Peaks Challenge and the Dancing with Sky's Stars event will be used to fund a research assistant for Dr Kinsler for a year.

The post will start in September 2013 and Caring Matters Now will fund the position for one year. Another children's skin disease charity has funded a further six months and the Research Assistant will be able to do work for both skin projects. This is very cost effective as often research projects have pauses waiting for reagents to be delivered or for more people to give a blood sample, etc. This is a fantastic help to Dr Kinsler as it means a lot of the routine lab work will be done by the RA, e.g. sample processing, labelling, freezing etc, which will allow Dr Kinsler to do more of the new lab studies into treatments.



## CMN research at Great Ormond Street Hospital (GOSH)/Institute of Child Health (ICH)

Email: [ICH.CMN@ucl.ac.uk](mailto:ICH.CMN@ucl.ac.uk) (please note changed recently)

Any families with children with CMN who want to take part in any aspect of the research at Great Ormond Street Hospital (GOSH) are very welcome and only need to have a referral from their GP or hospital Doctor to me, Dr. Kinsler, at the Paediatric Dermatology Department, GOSH, London WC1N 3JH.

### CMN genetics study

Thank you to everyone who sent back consent forms allowing us to test for the new gene finding *NRAS*. We had originally tested *NRAS* in 15 patients' skin and found that 12/15 (80%) had the mutation in all the different CMN and in the brain when it was affected. We have now tested around 80 in total and it looks like the figure is more like **90-95% are positive for this gene**. *NRAS* is therefore the cause of CMN in most cases. We are now looking for the genes in the few patients who are not *NRAS* positive. We are also looking at the interactions between the red hair gene (*MC1R*) and the *NRAS* gene.

I would just like to say again how grateful I am to all the children and families for donating small parts of their CMN during surgery they were having, and in some cases also donating small parts of normal skin. This is a very brave and selfless thing for these children and families to have done and it has led directly to this important finding.

**So we now know the cause – a great step forward!**

### New studies

There are three new important studies to take part in. **Please plan to leave at least an extra hour for your next appointment if at all possible.** We have incorporated the tests into the clinic to try to make things easier and avoid extra trips.

### CMN growth and hormonal study

The first phase of this study finished last year but we are now starting a new phase which is very important. Everyone coming to the CMN clinic from May 2013 will be offered the opportunity to take part. **We are trying to work out why some children with CMN have a tendency to put on a lot of weight.** It is of course optional as the research studies always are. It will involve having a scan of body fat and muscle mass taken after the clinic (which is non-invasive and completely pain-free) as well as offering height and weight measurements to parents.

### CMN blood glucose study

This **is only for children who have gone through puberty**, i.e. girls who have started periods or boys whose voice is breaking. As there are far fewer of these children I would really like you to consider taking part in this as it is a very important study. It may explain the weight gain and may also explain why some people have fits. This study cannot be done at the same time as clinic, but would be done on our ward over a period of about 4-6 hours. **It involves a blood test and drinking some lucozade!** We will be sending out information about this study directly to people we

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

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### Prestigious Poster Prize for NRAS Findings

Dr Kinsler's CMN research work has recently been awarded one of five prestigious equal poster prizes at the Academy of Medical Sciences meeting for Clinician Scientists 2013, which is a national meeting of clinical researchers. This was awarded for the recent NRAS findings.

think are the right age, but if you don't get information and would like to take part please let me know.

### CMN photographs

This study will be done when you come to clinic. It involves having photos taken with what looks like a normal camera but is actually a clever camera to measure things about the CMN. We will tell you about it in clinic.

### Where this is all heading

As you know the ultimate aim of this research is to find out as much as we can about CMN so that we and/or other groups can develop better treatments and better ways of working out which people need what sort of investigations or appointments. At the moment we have made great breakthroughs but we need to keep going - together we are a powerful team. Many thanks for everyone's continued support – the research could not happen if you families did not participate.

### Special Thanks

You have read about the recent research findings above, but without the participation of two incredibly special girls we could not have reached this milestone in the CMN research.

Caring Matters Now would like to express huge gratitude to Leah Wigmore and Hannah Bostock, whose participation in the research, without doubt, led to these findings. We owe these two families a great deal of thanks.

Those involved with Caring Matters Now have worked tirelessly to raise funds for research into the CMN condition and we will continue to do so until we have successful treatments available. These findings bring us closer to discovering such treatments.

Please be assured, Hannah's and Leah's legacies will live on and will never be forgotten by all at Caring Matters Now.

### Hannah Bostock – by Diane Bostock

My daughter Hannah was born on the 26th January 2001 with multiple extensive CMN (Congenital Melanocytic Naevus) covering approx. 70 – 80% of her body with about 100 - 200 small naevi (satellites).

Hannah was the most precious gift life could give to me. She was a wonderful baby and very contented, as she grew into a beautiful child inside and out.

Hannah loved life; she was always on the go, with lots of energy and effortless fun. Hannah loved to sing and dance, also enjoyed her Brownies and cycling. Hannah was bright, articulate and wise beyond her years. She just had to walk into a room and she would light up everybody's day. Hannah would get up in the morning and say "When I wake up in the morning the world shines on me!" Hannah was so thoughtful and kind, the welfare of others was very important to her.

During Hannah's short life she was put forward to the Make a Wish Foundation and it





was her wish to write and publish a book for children "Scary but Happy".

Tragically and devastatingly Hannah's health deteriorated in the summer of 2010 and she passed away in my arms on the 18th April 2011.

Hannah would not have wanted her life to be defined by her condition. The biggest legacy she can leave is raising awareness, educating and promoting further research into CMN, especially within the medical profession.

### Leah Wigmore – by Lynne & Justin Wigmore



Our daughter Leah was born 16th June 2005, at Frimley Park Hospital and from the very first moment we laid eyes on her, we knew she was special. It looked as though she was born with a full head of hair, but it turned out to be a CMN, which covered some of her forehead and scalp, as well as "satelite naevii" all over her lower body.

We referred to them as her beauty spots. Within days of her birth, we were referred to GOSH and we first met Dr Veronica Kinsler.

Over the next couple of years, Leah had 6 monthly checks for her eyes, brain and skin abnormalities, but all was fine apart from a few lumps being removed. Her next 4-5 years were care free and all was well.

Leah was a bubbly, confident and outgoing girl, who everybody loved. School was made easier by her wealth of good friends that she made. Leah could light up a room, as soon as she walked in and many, many people often commented on how beautiful she was. On family trips, strangers would stop us and comment on her stunning looks. One of her best qualities, was the fact that she was a "straight talker" and said exactly what was on her mind, however good or bad her assessment was!! This gave us many a laugh over the years and her brutal honesty was Leah all over. She loved to sing and dance and was a member of various different dance clubs, which gave us great pleasure in watching.

Near the end of 2011, Leah was booked in for a "tissue expansion" operation, to remove a large portion of the CMN on her head, because a large lesion had grown on the centre of her head. The initial operation went well and was a huge success. 2 months of expanding went well and the reversal operation was booked in. However, just before the reversal operation, a lump grew in her neck and they decided to remove the suspicious growth during the reversal operation. Unfortunately, the lump turned out to be Melanoma and our world was shattered!

Over the next 7 months, Leah had weekly visits to GOSH, for trial treatments and experimental drugs, because Leah's cancer was as bad as it could get. But on the 31st July 2012, Leah lost her battle with cancer, despite the best efforts of doctors and specialists at GOSH. Our beautiful daughter displayed bravery beyond her years, throughout her illness and we will be forever proud, to call her our little girl.

Since Leah's death our family and friends have worked hard in raising funds to support the CMN research. Although Leah is no longer with us, her legacy will live on through the efforts of many good people who help to raise much needed money for Dr Kinsler's research.

A heart-felt message from Jodi Whitehouse...

I am overwhelmed by the incredible unity our CMN members, families and supporters have within Caring Matters Now. What an amazing journey we have been on over recent years, with such dedication in raising funds to continue the CMN research... Dr Kinsler and her research are priceless!

We have just read from Diane, Lynne and Justin of the devastating reality in losing their beautiful daughters, Hannah and Leah, as a result of Congenital Melanocytic Naevus. We **MUST** continue to fund the CMN research! We have found the **CAUSE** now we must find the **CURE**. A cure will save lives. Please support at [www.justgiving.com/cmnresearch](http://www.justgiving.com/cmnresearch)

## How You Can Help!



### Direct Debit / Standing Order:

This can start from as little as £2 per month. If this is something you would like to do, please email [lucyh@caringmattersnow.co.uk](mailto:lucyh@caringmattersnow.co.uk) for bank details required.

### Payroll Giving:

A very easy, tax effective way to donate to charities, so, it costs you less to give more. For more information visit: <http://www.payrollgivingcentre.com/employees.htm>.

### Online Donations:

Direct Donations can be made through any one of these secure online services:

Charity Choice - <http://www.charitychoice.co.uk/charities>

PayPal - [https://www.paypal-donations.co.uk/pp-charity/charity.jsp?NP\\_ID=30959](https://www.paypal-donations.co.uk/pp-charity/charity.jsp?NP_ID=30959)

Just Giving - <http://www.justgiving.com/caringmattersnow>

### Send a Donation:

Please make cheques payable to "Caring Matters Now" and post to:  
CMN, PO Box 732, CAMBRIDGE, CB1 0QF

### Gift Aid:

Gift Aid increases the value of donations to UK charities by allowing them to reclaim from the UK Government an additional 28 pence for every pound donated if you are a UK tax payer. Remember to indicate if you are Gift Aid eligible on the Just Giving website or fill out a Gift Aid Form [http://www.hmrc.gov.uk/charities/appendix\\_b1.pdf](http://www.hmrc.gov.uk/charities/appendix_b1.pdf) if making any donation, alternatively use the form on the CMN leaflet.

### Donate whilst shopping online:

Set yourself up as a new user and you will automatically donate a percentage of your retail purchase towards the CMN support group with absolutely no extra cost to you.  
<http://www.easyfundraising.org.uk>





### Organise a Fundraising Event:

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. Having the idea and getting going is the hard part. Visit the website for support and ideas.

### 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. I

**So, take on the challenge and raise some money!**

**The tools are there, no excuses!!**



## Become a CMN Champion!

You, your school, your place of work can become a CMN Champion in 2013

'CMN champions' is an awards programme for those who **commit to giving** and **campaign to the cause** of Caring Matters Now. Individuals, schools and work places can become CMN Champions by supporting Caring Matters Now throughout 2013. There are a number of awards that can be gained; Bronze Award, Silver Award and Gold Award. The award presented, will depend on how much support individuals give to the charity during 2013. Sign up on our website or by emailing Jodi at [Jodi@caringmattersnow.co.uk](mailto:Jodi@caringmattersnow.co.uk)

Many congratulations and huge thanks to:

[Lewis North](#): Bronze Award

[Fay Hardwidge](#): Bronze Award

[Paul Mein](#): Bronze Award

[Stokenchurch Junior School](#): Bronze Award

[Croft Prep School](#): Silver Award

[Team of 24 Peaks Trekkers](#): Challenge Champion Award

## New CMN Materials

We have recently launched the new CMN Medical Booklet written by Dr Kinsler. This booklet is very detailed and will be used to inform new families of CMN and to raise awareness in the medical profession. Please do help us to spread the word about CMN and distribute copies to your local GP's, Dermatologists and Delivery Units.

The smaller 3-fold leaflet is to raise awareness of the condition and the support group. These are a great handout at fundraising events. The new addition to this leaflet is the tear off donation slip which allows people to donate and also select the gift aid Option.

We have new money collection boxes for collecting all your loose change. It all adds up!!



We can also now supply labels for buckets and collection tins and hire out a small supply of buckets and tins for your specific events. All of which are returnable to us.

Email Lucy if you require buckets, tins or labels on [lucyh@caringmattersnow.co.uk](mailto:lucyh@caringmattersnow.co.uk)

## Calling on Your Skills, Expertise and Connections!

### We need you!



You all do an exceptional job raising funds for Caring Matters Now and we are so grateful to you for the huge contribution you make, but now we are asking for your professional skills, expertise AND business connections.

You will probably agree that all the money raised by you needs to be better utilized going forward, especially as we are growing at a very rapid rate. Funds need to be directed to specific research projects for treatments; developing specific support strategies to better inform and support all those affected by CMN; getting the message out there and raising awareness.

Ideally we need to be spending less (or to be honest nothing) on producing materials, cheeky, I know!!! So anyone out there that owns a photography or print business, graphic design company, or has any other business connections that you think would be beneficial to the charity, please step forward. Alternatively, if your company or the company you work for is willing to make a financial contribution, maybe to fund the production of some merchandise or a print run of posters, we welcome your assistance.

Let us know what you can do to help, contact me on [lucyh@caringmattersnow.co.uk](mailto:lucyh@caringmattersnow.co.uk) or 07786 458883, alternatively email Jodi at [jodi@caringmattersnow.co.uk](mailto:jodi@caringmattersnow.co.uk).

## Living with CMN – by Donna & Frances Wood



Hi, my name is Frances Wood and I am a 19 year old female singer/songwriter from Yorkshire & here is my CMN story. For the beginning of my life I can't really remember too much, so I asked my mum to write her version of events of my upbringing and the struggles she had to face with me having CMN. Here is what she wrote...

My name is Donna Wood, my husband is called Robert, and we have two beautiful daughters: Frances and Alexandra, not forgetting Harvey our little dog.

Before Frances was born, Robert and I had just bought our first house; we were very excited but had a lot of work to do. We both worked fulltime but were surrounded by good family and friends who were helping us to get the house into shape. We got our due date for Frances on the 4<sup>th</sup> January 1994. My pregnancy went well and I had no problems throughout.

We had just got settled into our new home in the early hours of Christmas Eve when Frances decided to come early and I went into labour. Everything was quite natural at birth,



but half way through the labour my heart beat increased and Frances's heart beat was faint. She was born at 2:55am and they laid her on my stomach but quickly took Frances away to be checked by doctors. The next thing I remember was Robert sitting next to me, holding her in his arms, crying. At this point I didn't know what was wrong, as the medication they gave me to relax me during birth was only just wearing off.

I was then told she had marks on her body and that a doctor would come round to see me to explain it all that morning. But when he came round he had a team of people with him, he pulled the curtain open from around us. I could see all the other mums looking and remember thinking she isn't in a zoo, as I laid there feeling very venerable. I hadn't seen the marks at this point as I was too scared to look, but she was very beautiful with big blue eyes and lots of black spiky hair. I was then told she had a condition named CMN and was told the next stages of the procedure. I was unsure of the procedure and blamed myself for the condition, but never understood why as I've never had drugs or smoked and never drank throughout the whole pregnancy. I felt resentment towards other mums who did any of those things whilst pregnant and had babies that turned out fine; not that I would wish this on anybody but it was hard for me to understand why it had happened to me.

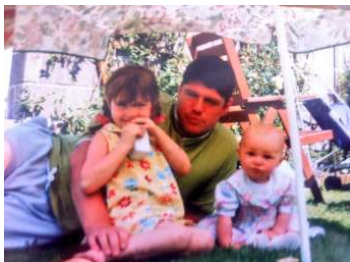
Frances had her first operation at just 6 weeks old - dermabrasion of the bum and thighs, which is where the top layer of the nevus is removed and her bum is left raw. We couldn't touch Frances due to any infection and it was a very scary time for us. They had to give her morphine for the pain and I remember one night they phoned me from the hospital to inform me Frances had stopped breathing but was now

stable again. The following day I, Robert, my mum, sister and brother all came to see Frances and the machine that she was attached to started going crazy. I fetched the nurse who explained to us that the machines can be temperamental and then it went back to normal again. However within five minutes the machine went crazy again and I ran to get the nurse who then told us all to get out of the room quickly, as they had to get the crash team in and take Frances into another room. We weren't allowed to see her until they had warmed her body back up again. They finally brought her out of the room attached to a drip and we were informed that she had reacted to the morphine they had given her. From that point on, the only pain killer she could have was paracetamol. Later that year, on two different occasions, she had two tissue expanders to remove the nevus. They thought Frances was remarkable as she recovered so quickly.

The following year Frances had a further three tissue expanders and they were all very successful. However the last tissue expander got very infected and had opened up which left Frances with an infected hole in her back which was very unpleasant. This then, when treated, left a nasty scar on her lower back. We then noticed as she was getting older more marks started to appear on her face, arms and legs and was told by the doctor that this would keep happening up until the age of 18 or when she was fully grown.

In 1997 Frances's little sister was born and didn't have CMN. We weren't sure how Frances would react to her but she loved her straight away. We never treated Frances any differently because of her condition.

I remember taking Frances and Alexandra on their first holiday when





Frances was just 4 years of age. There was a talent competition where we were staying and Frances told me off because I hadn't entered her in it. I explained she was too young but she went straight to the entertainers and entered herself singing a rendition of the Spice Girls – "Stop Right Now". She got up and performed the number and we were in complete shock, as we didn't even know she knew all the words and everyone was on their feet applauding her. We knew from then on she was going to be very successful.

A year later we all went on our second holiday and I remember a little boy calling her mucky and his Dad just sitting there not even telling him off. Then there was a woman pointing at her in the pool and talking to another woman. It upset me that people could be so rude and this was the moment when Frances realised she was different.

When Frances attended junior school, she would always ask if she could change behind a curtain for P.E or sports day and hated wearing shorts. When she finally went up to high school, Frances was bullied in her first few years on several occasions and name calling would sometimes become a daily thing. She was taunted verbally; followed home; filmed on phones whilst older years would push her and call her name. If she took a different route after school there were still groups of bullies there. This became very intense for Frances and knocked her confidence a lot - joining high school is hard enough without becoming an easy target for all the year groups to pick on at every given chance.

From this part of Frances's story she knows the version of events much better than me, so I shall let her take it from here...

I told my parents about the bullying as it was only getting worse and I hated going to school. I asked them not to come into school, as at that age I felt embarrassed by the whole situation. However when my mum heard about the events she rang up the school straight away. They said they would sort it but never did and the bullying just continued. When my mum was told it hadn't been sorted she was forced to inform the police - especially when she heard I was being filmed whilst crying and getting bullied on my walks home. The police then told her to ring the school one last time to inform them that the police knew. Once she had done this the bullies were then pulled aside straight away. One of them turned out to be an A\* student in the older years, so this came as a huge shock to the school.

I had put up with the bullying for the first two years of school and whilst all this was happening, I put my emotion and passion into my singing and acting. I joined theatre groups, auditioned for acting agencies and was becoming known for my talents at the high school. I performed many lead roles and performances around theatres and in school, and was even put forward for TV series. Focussing on what I wanted to achieve really took my mind off the bullying and made me a stronger person, whilst it helped me to meet new friends and gain confidence.

At the age of 14 going on 15 I was told I could have my moles shaven off, making them less visible ( a type of dermabrasion), so I did it at the word go and ended up having 163 removed. I was bedridden for a while but was due to perform the lead role of 'Rizzo' in a professional performance of Grease at the theatre. I was told it was too soon to do anything but after being bedridden for so long and my marks healing over I decided to do it



anyway. Everyone couldn't believe I was already back at it, but the show went amazingly and I coped no problem.

After this I went onto song writing and learnt to play the piano. I uploaded YouTube videos of myself singing covers and got myself into recording studios to put emotion and past experiences into the songs I was writing. I started performing in local pubs, clubs and venues as well as continuing my acting in school. I would stay behind at school to make sure I got all my grades in Maths, English, Science and all my other lessons and I had already passed my drama A level before my last year of school, which meant during my last year I was studying the same level of acting as the 6<sup>th</sup> formers.



I was putting my heart and soul into my education and my hobbies as I wasn't going to let my past beat me or get me down, I felt I had even more to prove to everyone. I was getting top grades and really making a local mark for myself with my talents.

After high school I auditioned for a performing arts college and got a place. This brought me into vocational training, which meant long hours, intense work out sessions, strict teachers and training to a very high standard of performance level. I did this for two years and at the time of my big exams my mum told me about The Voice UK auditions, a new TV series coming to BBC. I went in for the audition and got down to the final 100 out of 28 thousand candidates, from this I got to the final 40 out of the 100 and went to the TV auditions. I got chosen for team Will.i.am - a multi-

platinum producer/songwriter and rapper from America - and I made it all the way to the quarter finals. During this time I was juggling my school work and revising whilst backstage or at rehearsals. I passed my exams with A\* and learnt a lot from my time on the show. I then focused on getting myself playing at top events alongside big names like, One Direction, stooshe, Labrynth, Little Mix and many more, in front crowds as big as **70 thousand** people.

I turned down my university offer as I am now writing my own material for a possible future album. I am back and forth between London and my hometown, trying to gather the right team of people around me who can help me succeed in my career and the right producers to help me get the sound I want for my songs.

Don't ever feel afraid to talk to family or close friends about what you're going through and make sure you put your emotion into something you want to achieve, as this all helps you gain strength from the struggles you face and helps you to grow as a person.

This is the first time I have ever publically shared my story but I want to inspire anyone with CMN - or any other condition for that matter - because as cliché as it sounds, you really can do anything you want when you put your mind to it. I am still left with many marks & nasty scars on my body but I have never let my condition get the better of me. As hard as it has been, and as much as it is even a struggle to this day, I am more determined than ever and you should be too!



## CMN Support Days (formerly known as Family Days)

CMN support days are held in London, Liverpool and Scotland each year. The days include a light buffet, children's activities and a presentation from Dr Kinsler and CMN trustees.

**Glasgow:** Saturday 10<sup>th</sup> Aug 2013, 1pm to 5pm @ St Brides RC Church, 21 Greenlees Road, G72 8JB

**Liverpool:** Saturday 9<sup>th</sup> November 2013, 1pm - 5pm @ Bridge Chapel Centre, Heath Road, L19 4XR

## Chat & Play Days

CMN Chat & Play Days are family fun days arranged by the dedicated Regional Support Contact for CMN. They give an opportunity to get together with others and chat and play in a relaxed atmosphere.

Our first ever Chat & Play Day happened on 18<sup>th</sup> May 2013 at Nailsea Methodist Church, covering the Bristol area and beyond. The event was organised by Sheila MacKenzie, the CMN Regional Support Contact for this area. It was a huge success and we would like to express our gratitude to Sheila for arranging this day.

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Hi Sheila

Just thought I'd let you know a little success story from Saturday's get together. Joshua took the new info book into school today because he wanted to show his class a picture of Dr Kinsler! It ended up turning into an impromptu proud 'showing off' of his CMNs (and there's a lot of them) in front of the class and an in-depth (well, as in-depth as 5 year olds can get with a rare skin condition) Q and A session! He wasn't asked to do it; just did it off his own back which wouldn't have happened if we hadn't had the Play and Chat day. Many thanks for organising the day and we very much look forward to the next one. Take care, Ricky, Claire and of course Joshua Ford

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## Thank You Lucy!



Lucy Clarke has been on the board of trustees since 2007, when Caring Matters Now first registered with the Charity Commission. She has been such a happy, bubbly member of the board and a fantastic support to many. She played an integral part in the development of Caring Matters Now support group, in particular the regional support strategy. Lucy's cheerful personality and friendly manner has provided many families with a great deal of comforting support and has made people feel very welcome at all our CMN events.

Lucy has recently decided to step down from the board of trustees due to home and work commitments. Although she will no longer be on the team of trustees, she will still play a pivotal role within the support group. We are very grateful to Lucy for all her help and support over the years. I am sure this 'thank you' not only comes from the board of trustees, but from all the CMN members too.

