

July 2014

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## YOU ARE INVITED TO THE CMN CHARITY DINNER DANCE

For the very first time, we are organising a dedicated Caring Matters Now Charity Dinner Dance, which will be taking place at the exclusive **Intercontinental Hotel, Park Lane, London**.



The charity dinner dance will include, drinks reception, 3-course dinner and drinks, live acoustic music, auction, entertainment, finishing off with a live band and dancing.

This is a huge event, which will require support from ALL our members, especially those who are based in the city of London and our members who work for large corporates. To make the night a success we would like to ask for your help in the following ways:

### Attendance

This event is mainly aimed at corporates based in the city of London. The aim of the event is to raise the profile of our charity and to raise funds for the ongoing CMN research. However, the trustees and I would like to invite all our members to attend the event. The hotel can cater for up to 600

guests, so let's try and fill it! If you would like to attend this event, please book online here: <http://www.caringmattersnow.co.uk/cm-n-charity-dinner-dance-2014/>. **NOTE:** you get a £50 discount if you book a table of 10.

### Corporate attendance

If you work for, or have close links with any large companies, please inform them of this event. We have Corporate Invitational Packs, which we can send to you to pass onto your contacts. We need your support in this area, so please do have a think about any links you may have. Personal contacts are always the best!

### Auction items

We are going to be holding an auction on the evening. We already have some fantastic items but if you think you could gain any credible auction items please do let Lucy or I know.

### Celebrity Attendance

We are working very hard on celebrity attendance and are awaiting confirmation on who will be there! The more the merrier, so if you have a celebrity friend or two, please let us know, we will be sure to send them a personal invite.





Finally, our main aim for this event is to raise the profile of CMN and to raise funds for Dr Kinsler's research. Dr Kinsler is making HUGE strides with the CMN research - **it is only the lack of finances that is holding up her progress!**

Therefore, the CMN trustees are motivated to raise more funds for the CMN research in 2014-15 financial year. The ultimate aim of the research is to try to develop treatments for CMN, including the neurological complications and the devastating, fatal malignant melanoma, which can affect individuals with CMN. **To contribute to this we want to fund a unique Caring Matters Now Fellowship at Great Ormond Street Hospital.** This Fellowship would be for one year, for a doctor to work alongside Dr Kinsler on the CMN projects. The CMN Fellowship is a great opportunity for us to keep up the extraordinary momentum that has changed the understanding of the condition in the last decade, and really move things forward. The CMN Fellow would be involved in all the CMN projects, but the ultimate goal is to understand the condition well enough to treat it. Caring Matters Now must raise **£50,000** to make the CMN Fellowship 'dream' become a reality. Please help us achieve this goal by supporting the charity dinner dance. The only way we can make this event a huge success is by the support of ALL our members.

***Let's not fall into the trap of this quote:***

*"Anybody thought Somebody would do it, Somebody thought Everybody would do it, Everybody thought Anybody would do it, so eventually Nobody did it!"*

If you require any further details about the event, you can contact me at [jodi@caringmattersnow.co.uk](mailto:jodi@caringmattersnow.co.uk).

I look forward to hearing from you and working with you to make this event a huge success!

Jodi Whitehouse

**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)



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wellcome trust



Between these grants I have obtained my salary from the Institute of Child Health and Great Ormond St, and the cost of the CMN laboratory research has been paid by Caring Matters Now and the Leah Wigmore Melanoma Fund. Getting this new grant would therefore not have been possible without your support, both financially and from patients participating in the research. Thank you all very much.

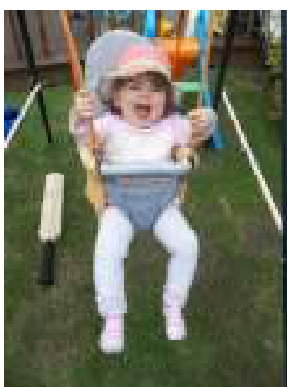


The Leah Wigmore Melanoma Research Fund was set up following the devastating loss of Leah on 31<sup>st</sup> July 2012 aged just 7 years old. Leah had congenital melanocytic naevus and passed away following a brave battle against a rare melanoma disease.

Lynne and Justin, Leah's parents want to ensure she has a lasting legacy and so set up this fund to help Dr Kinsler research the condition and hopefully give a brighter future to children who are suffering from the disease.

**TOGETHER WE WILL MAKE A DIFFERENCE**

## Our Dearest Holly – by her mum and dad



Holly was born 1<sup>st</sup> December 2011. She was our second child, a little sister to Callum who at the time was 18 months old. Holly didn't have a straight forward delivery and she was three days old when we were informed of her exact condition before she was transferred to Birmingham Children's Hospital for an MRI and possible surgery. Holly had a Dandy Walker Cyst, secondary hydrocephalus, a coloboma in her left eye, epilepsy, CMN and Neurocutaneous Melanosis meaning there were moles on her brain and spine as well.

At BCH we were told surgery was not yet needed, that her conditions would be monitored and Holly had her first MRI. We were discharged 18<sup>th</sup> December and enjoyed her first Christmas at home.

Although Holly's life was hectic with appointments we managed a quiet first three months. Holly was a typical baby

apart from she never smiled. During a routine check, Holly's head circumference had increased, a lot, and by the evening we were back at BCH. An MRI showed her cyst was filling with fluid and putting pressure on her brain. Four days later Holly had a shunt fitted into her cyst to correct this. Five days after surgery Holly was discharged and the second day home Holly smiled!! It took three months and surgery but she did it, we were so happy, the camera never left me until I caught that smile! From that moment on we constantly asked her for a smile. During the summer, we went out more. Holly got stared at and I was constantly asked if she had chicken pox, as over these first months Holly's CMN had multiplied considerably and now she was covered from head to little toes in spots. But we didn't let it stop us, Holly truly was beautiful.



We began our own research and soon learnt of Dr. Kinsler, Jodi and Caring Matters Now (via Deal or No Deal!). At our next dermatology clinic we requested a referral to Dr. Kinsler and our appointment came through for October 2012 and another MRI was requested.

She had the MRI in February and it showed potential spinal problems but as the results were unclear, another scan was requested for April along with a skin biopsy. Holly couldn't sit unaided, so we lived with worry of spinal problems until April, when results indicated no significant change in the NCM. We continued physio to help with her delayed development.

It was during the spring/summer of 2013 that Holly really came into herself. She was happiest at home and although she never learnt to crawl she could roll and this is how she got about and into mischief. Her hair was unruly and seemed to come from nowhere but just added to her beauty. She rambled all the time and loved her "Mama"; she didn't like it if I left her and would be very vocal in telling me off when I returned. Her favourite words were definitely "more bic pease" or "more coc" (chocolate)! Holly loved her food and you couldn't eat in front of her without sharing! She loved her kisses and cuddles too but was no pushover. At age 20 months, Holly finally managed to sit unaided and I was so proud.



She was doing really well at this point, we felt positive, and Holly even started to weight bear a little on her feet. She loved to be sat on the sofa only to roll herself off into a standing position. We really believed that one day she would walk. In October 2013 Holly had a routine MRI; she was doing so well we weren't worried. But it all went wrong. Ten days later we were told there was a tumour at the top of Holly's spine, sitting under her cyst. Due to its location the surgery was very risky; paralysis and brain damage both being high risks if she made it through. She was booked in for surgery the following Wednesday. Our heads were spinning, not our little princess.

Surgery took over five hours. I cannot describe the feelings we had walking into the operating room. Her head was heavily bandaged and her beautiful



face was swollen but she was alive and she was moving. Surgery wasn't a complete success; they were unable to remove the entire tumour as it posed too much risk. Just seven days later Holly was discharged, my brave little girl was recovering so well. Now we awaited her biopsy results. The surgeons had already expressed their opinion; they expected the results to be "unusual". They expected cancer. A week later, that's exactly what we were told and that all treatments available for this type of melanoma were experimental. We were referred back to GOSH and met with Dr. Kinsler to discuss Holly's options. Our only option was an unlicensed drug, still in trials, but first we had to get the pharmaceutical company's permission. We were told that untreated, Holly had maybe six months but at the same time we were told there is no treatment. How do you process that?

A week later Holly had a massive seizure and I called an ambulance. I honestly thought those six months had come early. A CT scan revealed a white mark on her brain and we were sent to BCH to stabilise Holly and then back to GOSH. The day we were to be discharged Holly spiked a fever and so, sadly, she spent her second birthday in hospital, something we tried desperately to avoid. Once home, Holly settled and we celebrated her birthday late; her cheeky smile was out in full force! By the weekend I noticed that Holly had stopped rolling and wasn't using her arms. All of Holly's care was now at GOSH and we had a clinic appointment on the Monday but while en route I received a call to say Holly's MRI had been scheduled for the next day. I explained Holly's deterioration to her oncologist and the MRI was amended to include her spine as well. The scan revealed her spinal tumour had already regrown, just six weeks post-surgery and that she had a second tumour on her brain; the white mark. We left GOSH the next day completely and utterly devastated. The only hope we had, that Holly had, was that we had been given verbal consent to use the trial drug. Holly remained seizure free on her meds and she started the trial drug on 20<sup>th</sup> December. Holly hated being in hospital and the only way to calm her

was to walk her around the ward in her pushchair. By now Holly had lost the ability to sit unaided, to roll and to lift her arms. It was heart-breaking to see her deterioration.

Over the next six weeks or so, we had weekly clinics at GOSH and Holly appeared to improve slightly. She began to raise her arms, just a fraction, and even managed to roll a very short distance and so her next MRI was scheduled for February 11<sup>th</sup>. This was the big one; it would tell us if the drug was working. In the lead up to the scan Holly was miserable, and had begun to vomit. We needed that MRI but at the same time we didn't want it. She had the scan and we got the results quickly. We never even discussed the spinal tumour as the one on her brain appeared to have

grown from roughly the size of a coin to the size of an apple. The drug wasn't working and there was nothing else they could do. Holly had weeks, at best, left. We left GOSH as soon as we could and that night I booked us a family photo session.

Three days after our photos Holly fell asleep and four days later she passed away peacefully, in our arms. I have no words to describe the loss we constantly feel but now we have a choice, we can let our grief consume us or we can ensure Holly's memory lives on by fundraising and that's what we've chosen to do. We want Holly to be a part of finding a cure and this way she can.

**WE CAN MAKE A DIFFERENCE; WE HAVE TO.**



## Want to do something extraordinary and help make a difference?

**Join our team on the next CMN Charity Challenge!**

**Avenue of Volcanoes in Ecuador - 28th June to 9th July 2015**

Your challenge trekking in the spectacular Avenue of Volcanoes begins with Pasochoa and El Corazon volcanoes, followed by Iliniza and culminates in the world's highest active volcano, the magical Mt. Cotopaxi (5,897m, 1 metre higher than Kilimanjaro summit!). Much of the final climb to the summit of Mt Cotopaxi is on its glacier! Sound like an exciting challenge?

- **Push yourself to the limits**
- **Achieve an incredible personal goal**
- **Lose weight, get fit, get out of your comfort zone and raise vital funds for a worthwhile cause...CARING MATTERS NOW!**

For more information visit [www.caringmattersnow.co.uk/cm-n-charity-challenges/](http://www.caringmattersnow.co.uk/cm-n-charity-challenges/)

## Become a CMN Champion!

'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 2014. Visit the website for more information.

Come on, we need more Champions! Whatever your event, sign up now! <http://www.caringmattersnow.co.uk/fundraising/champions/>



### **Bronze Award presented to:**

Walton on the Hill Primary School  
Lily-Mai  
Charlotte  
Ad Place Marketing and Media Ltd

### **Silver Award presented to:**

Phoebe Simcott  
Jasmin Chance  
Blackheath High School  
St. Mary's P.S. Draperstown,  
County Derry, Northern Ireland

### **Special Award presented to:**

CMN Sky Divers

## THEY DID IT!



So the 22<sup>nd</sup> March arrived and the 18 strong team descended on Langar Airfield from far and wide to do something amazing; **The CMN Sky Dive!**



The weather was changeable so it was 'stop, start' throughout the day which added to the nerves! The first to jump went at 9am and the last at 5pm! It was a tense day for those still waiting to jump but the excitement was building.

All 18 of the team jumped that day thanks to the expertise and skills of the team at Langar Airfield.



**Over £15,000 has been raised by the team!**

**WELL DONE TO ALL THE CMN TEAM**

## Grant Success

It is with great excitement to announce that Caring Matters Now has been successful in receiving two amazing grants.

The first is for **£4,000** from Genetic Disorder UK. This grant is to cover the costs of the CMN Activity Weekend 2014. The funds will pay for all our children and adults with CMN to attend the weekend free of charge.

The CMN trustees are very pleased to be working in partnership with Genetic Disorder UK. We would like to encourage all our members to support their work by getting involved in the Jeans4Genes day 2014 <http://www.jeansforgenesday.org/>. Get your school or workplace to support.

The second is for a whopping **£10,000** from Children in Need. This grant will fund all our support days in 2014. This is AMAZING news as the grant will help increase the profile of our charity, as well as funding our work!

We are so grateful to Children in Need for accepting our grant application and awarding us this sum of money. We would like to encourage our members to support the work of Children in Need <http://www.bbc.co.uk/programmes/b008dk4b>

## CMN Support Events - Our first ever CMN adult get together!

So far, this year has been a big year for our adult support developments, which I am pleased to be able to share with you all.

In 2013, the trustees and I decided we wanted to expand our adult support, as in recent years our adult membership numbers have grown. Therefore, in 2013 we developed an adult online community forum, which we encourage our CMN adult members to join. This is a safe arena to share experiences and support one another. We also emailed all CMN adult members informing them of the charity's plans in holding our first adult get together in March 2014.

The trustees and I want to take this opportunity to bring the adults we are in contact with together and listen to what support they would like to see in place. We want to very much gain an understanding as to how adults would like to see the support develop and work with them to achieve this. This is a very exciting development for



Caring Matters Now.



On the 29<sup>th</sup> March, 6 CMN adults met in a Central London pub along with Dr Kinsler and Val Unsworth. It was a great opportunity to chat in a relaxed environment and get to know one another a little better. Having Dr Kinsler there provided an opportunity for our CMN adults to ask their many questions and gain an update on the research.

The feedback we have received from the adults that attended the event has been positive and all the adults would like a similar event again next year. We will plan to organise our second adult get together in 2015 and will confirm details later in the year.

Thank you to all the adults that attended and I look forward to seeing you all again next year!

Jodi Whitehouse

## CMN Support Days

**Glasgow**      **Date:** Sat 9<sup>th</sup> August 2014      **Time:** 1pm to 5pm  
**Venue:** St Brides RC Church, 21 Greenlees Road, G72 8JB

**Liverpool**      **Date:** Sat 8<sup>th</sup> November 2014      **Time:** 1pm - 5pm  
**Venue:** Bridge Chapel Centre, Heath Road, Liverpool, L19 4XR

## CMN Activity Weekend

**When:** 1st – 3rd August 2014  
**Where:** Caythorpe Court PGL, situated close to Sherwood Forest in Lincolnshire.  
**Price:** £126 per person. Under 3yrs go FREE and 4-5yrs get a £24 reduction.

THOSE WITH CMN GO FREE! That's one FREE place per family! Book Now!

Don't miss out book today! [www.caringmattersnow.co.uk/family-activity-weekend-aug-2014/](http://www.caringmattersnow.co.uk/family-activity-weekend-aug-2014/)

Check out the videos of previous weekends on the website  
[www.caringmattersnow.co.uk/support/supportevents/](http://www.caringmattersnow.co.uk/support/supportevents/)

## Caring Matters Now welcomes Didier to the UK

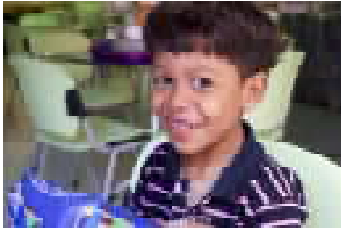
We are extremely excited to announce that a very special little boy is coming to visit us here in the UK! On the 6th July, Didier and his mum are travelling to the UK and spending a week in London.

Didier became a much-loved little boy across the UK, after the documentary 'Turtle Boy' was aired on Channel 4 in 2011. The documentary focused on Didier's life and how he lives with his large Congenital Melanocytic Naevus. Caring Matters Now and Dr Kinsler were also featured in the documentary, along with some of our children who attended the Liverpool Support Day, where part of the documentary was filmed. The documentary was very well received in the UK, and the profile of Caring Matters Now grew. In fact, on the night the 'Turtle Boy' documentary was aired, the Caring Matters Now website had over 2000 hits!

Since the 'Turtle Boy' documentary was aired, Caring Matters Now has kept in contact with Didier and his mum Luz. We have been keen to support Didier and to keep up to date with his progress.



Amazingly, we now have the opportunity to support Didier and his mum in travelling to the UK. They have never left their home country in South America, so this trip is a once in a lifetime experience. Caring Matters Now are helping to host Didier and his mum whilst they are in the UK. We have arranged for Didier to meet other children with CMN Syndrome for the very first time as well as visiting Dr Kinsler and Dr Bulstrode at Great Ormond Street Hospital.



This is a wonderful opportunity for Didier and his mum. They are both looking forward to visiting London and experiencing our culture.

Excitingly, on Thursday 10th July, Caring Matters Now will be featured on national television with Didier and his mum. This will help to raise awareness of CMN Syndrome and our charity.

Caring Matters Now have opened up a fundraising page, which 50% of all donations will go directly to supporting Didier and his mum. The further 50% of all donations will go towards the work of Caring Matters Now. If you would like to give please go to [www.justgiving.com/didiervisit](http://www.justgiving.com/didiervisit).

To keep up to date with Didier's trip, please follow us on [Facebook](#) and [Twitter](#).

## Introducing our new CMN Trustee – Ian Chance

I would like to welcome Ian Chance as our newest CMN Trustee. Ian came on board earlier this year and is a great asset to our charity. Ian has a daughter with CMN and has been involved in the charity for a number of years. Ian's wife, Michelle, is also very involved with the charity, as Michelle is one of our regional support contacts.

As our charity grows, so do the demands for our trustees. Therefore the trustees thought through our strengths and also thought through areas where we needed more support. We asked Ian to join us as he has expertise in finance and in the regulatory environment.

We are very thankful to Ian for joining our board of trustees and look forward to having his insights and expertise as part of our ever growing charity.

### From Ian

I was thrilled to be asked to join the CMN board of trustees and I will enjoy supporting this fantastic charity and working closely with Jodi and the other trustees as the charity grows.

My daughter Jasmin is also very proud of my new role in the charity - she said that she was very pleased that she had been born with a CMN as it helped us find out about the charity and it led to mummy (Michelle) becoming a regional support contact and to me becoming a trustee. How sweet is that! :-) Jasmin also has an ambition to become a paediatric plastic surgeon so that she can help other children. Her surgeon at Great Ormond Street Hospital, Mr Bulstrode, has offered Jasmin work experience when she is at university!!

As a family we have been active in fundraising for the charity. Michelle's firm Kingsley Napley LLP in which she is an employment partner raised just over £6,000 last year and Jasmin held a cake sale at her school which raised around £600. Jasmin has also enjoyed participating in presentations at her school to raise awareness of CMN and Ian makes regular monthly tax-free donations to the charity through the 'give as you earn' (GAYE) payroll giving facility (see [www.workplacegiving.co.uk](http://www.workplacegiving.co.uk) for more information).

