

July 2011

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## European Conference 2011

### Report by Lucy Hardwidge

Jodi, Dr. Kinsler and I travelled over to Tübingen, Germany for the first ever dedicated CMN Conference. It was a great experience to be a part of this exceptional event, rubbing shoulders with representatives and trainees from a wide range of specialist fields.

One specialist in particular both Jodi and I were very pleased to see was Dr. Atherton, the former leading medical Congenital Melanocytic Naevus (CMN) skin specialist in the UK who managed the original CMN registry prior to Dr. Kinsler. Dr. Atherton was the first consultant I saw who could provide answers to my questions when my daughter Fay was born with CMN six years ago and for Jodi it was fifteen years ago. We owe a great deal of gratitude to Dr. Atherton for his interest in CMN and for suggesting and supporting Jodi and her parents in setting up a support group. That was how Caring Matters Now evolved. It was a privilege for me to be surrounded by such good company with Jodi, Dr. Atherton and Dr. Kinsler.

Presentations were held from lunchtime on the Friday through until late Saturday afternoon on a variation of topics relevant to CMN and given by a large collaboration of expertise from many different countries. Dr. Kinsler spoke very passionately about the CMN condition and her research and it was so encouraging to see the interest shown from other specialists in her work. We are very fortunate and honoured to have Dr. Kinsler; she is a huge asset to the group and to the pioneering research programme.

Jodi and I were there to represent Caring Matters Now and we set about meeting with other patient support organisations from Spain, The Netherlands, France, Portugal, Israel, USA and Australia. It was very interesting to see what the other organisations do and to share information and ideas between us. Collaborating with other organisations can only strengthen us as a support group and between us, we can build a strong network of individual support groups for all of those families worldwide affected by CMN.

Discussions are in progress to maybe create a global umbrella organisation where there is an easily located webpage which then features all the different global organisations and links to these individual groups. We can also share news and features with one another and promote our family gatherings and events.

Thank you to Nevus Outreach for sponsoring our participation at the event and we look forward to future conferences and to building partnerships with other international groups.



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

Anyone who wants to take part in any part of the research at Great Ormond Street Hospital (GOSH) is very welcome, and only needs to have a referral from their GP directly to me, Dr. Kinsler, at the Paediatric Dermatology Department, GOSH, London WC1N 3JH. The research is going very well and there have been significant developments in the last six months. The full results of these will be available by the end of this year. Everyone participating in the research will be informed of the results in writing, as well as discussing these at clinic appointments. In addition, we will circulate the overall results via this newsletter, and eventually also on the website.

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*“.....and should improve care for CMN patients both in the UK and abroad.”*

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There will be large new studies opening from this time next year. It will take this long to get the ethical approval and the large grant required to set this up. The year from now till then will be devoted to getting results out to participants, published in medical journals, and presented at conferences. These are very necessary steps to ensure good communication about CMN as we now understand the condition, and should improve care for CMN patients both in the UK and abroad. They are also necessary steps in applying for our next big grant.

### **The CMN genetics study**

We are still offering every family who attends the CMN clinic at GOSH the opportunity to take part in this study. Lots of new families have signed up recently, which is a fantastic boost to our numbers and makes a big difference to the results. This is a joint effort between families and doctors – neither of us could do the research without the other, and enthusiasm on both sides is the reason for our success so far.

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*“Caring Matters Now contributed an incredible £16,000 to the genetics study in the last year,.....”*

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Caring Matters Now contributed an incredible £16,000 to the genetics study in the last year, and has pledged to contribute another similar amount when we need it – this is likely to be very shortly. This money has been crucial in allowing us to do very high level testing on the samples from the families, and is advancing the research at a great rate. The results from the genetics study will be investigated in more detail in next year's studies.

### **CMN Hormone study**

This study closed at the end of 2010 and we are still getting the final results through. 47 families participated which was fantastic, as it required arriving at the hospital very early in the morning, and all the family giving a blood sample. The families who take part will all receive their results by the end of 2011, and the overall results will be available at the same time. Any parents with abnormal results would have been notified by now, as would their GP. As a parallel study we have been monitoring growth of all the CMN children who have been attending the GOSH clinic. This has produced some very interesting results and these will be investigated in more detail in next year's studies.

### **The CMN Registry**

At a recent CMN conference there was a move to start a new International CMN Registry. It has been recognised that the one we have

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*“As you know the ultimate aim of this research is to find out as much as we can about CMN....”*

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been running at GOSH for more than 20 years was the best model to use to create the new Registry, and as a result I have been asked to run it. This is an exciting opportunity to offer a chance to participate in CMN research to CMN families from around the world, something which many of them are very keen to do. This will also take at least a year to set up, mainly because of ethical approval for many different countries. Anyone participating in the current Registry will be offered the option to be included in the International Registry (with plenty of information and time to decide, and new consent forms), and ideally everyone would take part. The strength of this project will be in the numbers we are able to collect from around the world.

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 know a lot more about the condition than we did 10 years ago (and indeed more than 6 months ago), and we will continue to strive for these aims. Many thanks for everyone's continued support – the research could not happen if you families did not participate.

## Research Recruitment

We have had an exceptional period of fundraising and in the year 2009/10 a massive £44,000 was raised and so far for 2010/11 year end we have exceeded £60,000.

Due to all your hard work and commitment in raising these funds, we are now in a very encouraging and positive situation with regards to being able to offer the support needed and also having the funds available to support the research programme (our ultimate achievement), but now.....

## WE NEED YOU FOR RESEARCH!

What we now also need from you is your participation in the research itself! Raising the money is only part of the project; we need people with CMN and their families to help with the research. This means giving a little of your blood on occasions and completing the annual registry consent forms. Also, keeping an eye out for letters from Dr. Kinsler requesting your participation in a specific segment of her research and responding.

The research has been moving forward at a rapid rate and that is with huge thanks to everyone who has taken part again and again and who has given up so much of their time and money to attend for research, also to all of you who do so much to continue the fundraising. But it is vitally important to keep the momentum going. Recruiting people to these studies is the slowest step.

This research cannot continue without your participation.

Thank you

## Fabulous Fundraisers

### 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](mailto:lucyh@caringmattersnow.co.uk) to receive a pack.  
Or download from the website [www.caringmattersnow.co.uk](http://www.caringmattersnow.co.uk)

Well, you have all been actively fundraising for Caring Matters Now and we would like to say well done and...

### thank you, it means so much

Here is just a selection of the activities that have been taking place!

- Tricia Hardwidge (Grandma to Fay Hardwidge) and the staff at Barclays Bank, Cambridge held a fundraising raffle and raised £234
- Fran Cull (Grandma to Scarlett Clarke) held a raffle in celebration of her retirement at Blackminster Middle School raising £165
- Mateus Solheiro aged just 1 year and 11 months has donated £200. What a very generous little boy

### Julie Farr – 2011 London Marathon

You may recall Julie Farr won the ballot we held for the one and only CMN place in the 2011 London Marathon. Julie is a close friend to the Clarke family who have a daughter Scarlet with CMN.

I would like to say huge congratulations to Julie who, in very hot and humid conditions, completed the full 26miles in a very respectable 4 hours and 32minutes. In completing the marathon Julie raised a staggering **£2649**. A massive achievement; from all at Caring Matters Now, thank you and well done.

### 40<sup>th</sup> Birthday Celebrations

Ket Chauhan and Mike Audis, friends of Melissa and Aidan Bartlett decided to have a joint 40th birthday party and kindly asked their guests to not give gifts but to donate to Caring Matters Now. Melissa and Aidan have a beautiful daughter called Ava who has CMN. Melissa said "Ket and Mike have known Ava since the day she was born and both they and their families have been really supportive to us and Ava".

### Maja Bigazzi – 2<sup>nd</sup> Birthday



Maja is two years old and wonderfully enthusiastic about life. She was so keen to come into this world that when it was time to be born (on a frosty December night) she allowed mum and dad a full 45 minutes to get dressed, arrange childcare for her sister, drive to hospital, get admitted to the labour ward and deliver the baby. Since then she has been living every day of her life with such energy that we sometimes wonder – is there an end to it?

Maja was born with CMN on her belly and leg. We had never heard of the condition before and neither had the nurses and doctors with whom we first talked about the large black mole on her skin. We then spoke to other doctors at Chelsea & Westminster hospital who knew a lot about it and offered us the option to perform surgery (dermabrasion) on Maja.

For a number of reasons we had to take this decision within a

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matter of hours. With the great support of our family and that of the wonderful team at Chelsea & Westminster we decided to go ahead with the procedure. By the time Maja went into the operating theatre she was just over a day old. She would spend the following two weeks of her life in the neonatal intensive care unit.

The doctors and nurses at Chelsea & Westminster were magnificent. The care and attention for Maja and for us parents was simply extraordinary and we felt very lucky that given Maja's condition she had been born in one of the few hospitals in the UK (and probably the entire world) that had the expertise and equipment to perform surgery on a newborn to treat CMN. The surgery was initially very successful, although with time Maja's pigmentation has to a certain extent re-appeared.

In the months that followed we started looking for other specialists who could shed more light into CMN; as a parent you can't stop wondering whether somewhere in the world there is someone who can do something. We spoke to paediatricians, dermatologists and plastic surgeons; we looked in the UK, our country of residence, and in Italy, our home country. We sought referrals from all those who we spoke to and, finally, we were directed to Dr. Veronica Kinsler at Great Ormond Street Hospital.

Meeting Dr. Kinsler and learning about her research into CMN gave us comfort, hope and renewed energy. It was heart-warming to find that unique clinical research into our daughter's skin condition was being carried out so close to where we live. It was comforting to learn that we were not alone, and that so many CMN families had come together to provide support for this research. It was a privilege

to become part of the research itself.

At that point we began thinking of how we could help support Dr. Kinsler's work. We learned that Caring Matters Now provided significant funding for her work and started looking for ways to raise awareness of the charity's existence with friends and family. At first, Chiara (Maja's mum) tried to get friends to make online purchases through websites that would remit a percentage of their sales to Caring Matters Now. It was a start, but any progress was linked to friends actually needing to buy things, and the amount raised was a small portion of the money spent. Then, one of our friends told us that he was not interested in buying anything from these websites but was really eager to donate to Caring Matters Now; he made a £50 donation through the charity's website. That was surely the way forward!

Shortly thereafter Chiara set up a page for Maja on the Justgiving website. It was designed as a birthday page and we asked friends and family to contribute to Dr. Kinsler's research rather than buying presents from Maja. We felt that by giving our fund-raising effort a personal touch, we would allow friends and family to show closeness to Maja while at the same time support the great work done by Caring Matters Now; this, we thought, would generate greater involvement. We also thought that setting a deadline for people to make contributions would be an incentive for those who wanted to make donations to act. We told everyone that the page would close on 16 December 2010, on Maja's second birthday.

The participation and generosity that followed was overwhelming and the donations received far exceeded our expectations. We

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*“...we achieved it three times over, raising around £15,000 with contributions from people in tens of countries on three continents.”*

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had set ourselves a fundraising target of £5,000 and were wondering whether we would get anywhere near it. Well, it turned out we achieved it three times over, raising around **£15,000** with contributions from people in tens of countries on three continents and not just through Maja's Justgiving webpage, but also directly to Caring Matters Now. It truly was the most extraordinary

present our friends and families could give to Maja.

What initially triggered our efforts to raise money for Caring Matters Now was the real and hard work that is being carried out by Dr. Kinsler. In hindsight, we believe it has been our ability to convey to people close to us that this work is really something very special from which our very special little Maja, and others with CMN, will receive a tangible benefit in the future.

## Silence is Golden

### **A sponsored Silence £1000 raised for CMN – by NOT speaking for 24 hours**

This challenge may sound easy for many, how difficult can it be? But for an experienced sales person not speaking is like asking an accountant to not use a spreadsheet or painter not to use a brush. Paul loves his Rugby and is known for leading the Rugby team songs some would describe him as super extrovert others as London Geezer.

What started as an idle challenge during a sales meeting turned into a 24 hour charity challenge where Mr Paul Brooker did not speak for the entire day. Paul has been with his company for 13 years and would be described by many as a larger than life Sales leader who loves to talk! His commanding voice is one of the key tools of his trade.

In the face of much friendly barracking Paul was being tempted into taking the challenge on of keeping silent for the day, he jested that he would do it no problem if all the people 'prodding' him gave a charitable donation expecting no-one to put their money where their mouths were....., after a short pause the pledges came flooding in and approximately £1000 was raised in minutes. The Silence started!!

### **The next day taking the pain**

The following day Paul was in a Sales planning workshop Paul could only communicate via email, messenger, writing and the power of mime. At one point he did try the Stephen Hawkins approach and use a computer software freeware which converted his emails to electronic voice, this was immediately dismissed as not sporting.

Paul is known to many across his business who will know this was a particularly tough task to overcome especially when some of the subject matters needing to get resolved were very close to Paul's heart Sales commission pay plans. One of Paul's 'Friends' Tom Edmonds also added to the tension by contacting his wife Mrs Brooker to ensure that the challenge continued at home until Midnight, Mrs Brooker was very pleased to help out.

Paul successfully completed the task and took great pleasure in letting as many people as possible know at 1 minute past midnight.



## My Story – Zelma Jooste



My name is Zelma Jooste, I am from South Africa, and this is my personal story.

I remember the overwhelming joy my husband and I felt when I found out that I was pregnant. We were married only for 3 months, but we could not wait to start a family.

I had a pretty normal pregnancy, without any complications.

The due date was 15 January 2005, however, Jason was born on the 30th of December 2004, it was unexpected when I went into labour, but I was amazingly so excited about my little boy's birth.

I was in labour for an entire day when eventually Jason was born at 9:20 PM that evening.

I remember the doctor mentioned a birth mark, but I didn't notice anything, I was too exhausted to feel anything but relief that my child was born.

The love I felt when I took Jason in my arms was like nothing I could have ever imagined, in my eyes he was my most precious gift and I was so proud to be his mommy.

My husband was also proud of his little boy, we were aware this stage of the birthmark but it was as though it did not even exist, the joy of having a son was greater than anything we ever experienced.

Later that night, after everyone left, Jason and I were alone. I remember thinking about the future, happiness soon turned to fear and this turned into sadness. I did not know what to expect, I felt so helpless. I started to think of the future, I was so confused, I

did not know what to expect all I wanted to do was cry.

Our first night, I struggled with Jason. My first instinct as a new mom was to feed my child, I held him close as I tried to breastfeed him, but he resisted and eventually the nurses prepared a bottle for him which he also refused. The night was long and hard for me; I did not sleep at all.

The next morning I received further bad news, my child had a cleft palate.

My heart went out to my child that next day, doctors came and went, tests and photos were taken of him all day, and I felt so alienated and helpless towards my child.

It was then that I decided, never in my life would I treat him any differently, or let him feel different, because I realised then, that Jason was and still is, special and precious to me.

Eventually my son was diagnosed with Neurofibromatosis.

This is a life threatening disease, something I never signed up for, I was devastated. We received the same diagnoses from 3 different doctors, but Jason's paediatrician referred us to his dermatologist, Dr Pieter du Plessis from the Little Company of Mary Hospital.

He took away all fear when he told us this was NOT neurofibromatosis, but CMN.

My child is different from others, but one of the most loving and caring little boys I know, as a family we just support Jason and try our best to give him a positive outlook in life, we treat him just the same as his little sister, and in our eyes he is a normal little boy.





To all other parents I just want to say, always keep the faith, never give up and support your child with a positive outlook in life, we will always go through challenges, but we should be proud and remember; God blesses us with these children and these children with us as their specially chosen parents. Jason received surgery for his cleft

palate after 7 months which was a successful operation.

Thank you to Caring Matters, which is my only support at this stage, without your organization, I would not have had the resources to support my child.

It's a wonderful source of support emotionally to me and my child that there are other children as special as him out there.

## CMN Charity Challenge



Just to keep you all posted we now have 20, yes 20 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.

We will be setting up a Blog on the website to keep you all up to date with the team's progress as they take on the ultimate challenge.

**We wish them all the very best of luck on their challenge and look forward to receiving regular updates on their progress!**

## 2011 EVENTS

**Event:** Family Activity Weekend

**Date:** Fri 1<sup>st</sup> July – Sun 3<sup>rd</sup> July **Time:** 3pm **Location:** near Shrewsbury

**Venue:** Boreatton Park, Baschurch, Shrewsbury, Shropshire, SY4 2EZ

**Date:** Sat 20<sup>th</sup> August **Time:** 1pm - 5pm **Location:** Glasgow

**Venue:** St Brides RC Church, 21 Greenlees Road, Cambuslang, G72 8JB

**Date:** Sat 19<sup>th</sup> 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. Kinsler and CMN trustees

### 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 money to go directly to CMN Research. That's why we prefer to communicate with our CMN families via "no cost" email and so the best way to stay in touch with Caring Matters Now is to ensure we have your correct email address. If you have not been receiving messages in the past or you have a new/changed email address; please let us know by sending a quick note to: [lucyh@caringmattersnow.co.uk](mailto:lucyh@caringmattersnow.co.uk) with "Email Update" in the Subject box.

Thanks!