



January 2014

Inside This Issue

1. WE NEED YOU!

1. What are CMN Charity Challenges?

2. 2013 International Experts Conference

3. CMN Research Update

4. How Your Money Helps

4. Get Involved

5. Become a CMN Champion

5. CMN National Coffee & Cake Morning

6. Caring Matters Now Partners

6. My Story by Amanda Smith

7. CMN Support Events



2011 saw the CMN Team reach the summit of Mt Kilimanjaro



The 2013 CMN Team conquered 24 Peaks in a mere 24 Hours

WE NEED YOU!



To 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). 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/cmn-charity-challenges/

What are CMN Charity Challenges?

CMN Charity Challenges consist of 'once-in-a-life-time' experiences, such as treks, bike rides, mountain climbs and community challenges in over 30 countries worldwide. All challenges are organised in partnership with Charity Challenge (www.charitychallenge.com), the world's leading fundraising challenge company arranging over 100 expeditions each year.



CMN Charity Challenges are all part of the Charity's ultimate aim of 7 Challenges across 7 Continents. We want to be the first small charity to achieve the unthinkable and you can be a part of this.

The two CMN Charity Challenges to date have raised over £100,000!

Come on be a part of the 2015 CMN Team!

2013 International Experts Conference



In September Lucy Hardwidge and I attended the International Experts Conference in Marseille, along with Dr Kinsler and Dr Atherton. The conference was attended by the leading CMN medical experts from across the globe as well as representatives from all known CMN support groups worldwide.



The conference lasted 3 days, during which the medics gave reports on their specific line of work with regards to CMN. Dr Kinsler was the keynote speaker and kick-started the conference by sharing her most recent CMN research findings. It was plain to see how well respected Dr Kinsler is within the medical world and her presentation, yet again, reminded me how blessed we are to have Dr Kinsler as our CMN specialist.



During the conference, the support group representatives gave presentations on the work that is carried out in each country. There were 18 countries represented and during our time together, we officially established and launched a worldwide CMN support network called Naevus Global. Naevus Global aims to be an organisation by which all CMN support groups can be associated. The more we all support each other, the more efficient and effective we will become! The Naevus Global website has been launched, in which Caring Matters Now appears on the homepage. As a charity, we have given Naevus Global access to all our support material, which has been translated into various languages so more CMN families will be able to benefit from them. I have been selected as one of the Naevus Global board members, so I will be able to keep you all up to date on any international developments. For more information about Naevus Global, please go to www.naevusglobal.org.



Attending the 2013 conference has been very beneficial for Caring Matters Now. We have been able to continue building good relations with other CMN support groups and with the CMN medical experts.

It was so good to see the progress internationally in the understanding of CMN and its associated complications and how things are progressing with the investigation of treatments. Successful collaborations are key to future developments in treatments and this was present at the Marseille Conference.

Great to see!

Jodi Unsworth



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

Email: ICH.CMN@ucl.ac.uk

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.

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

To view the whole of this section of the newsletter, please email us at info@caringmattersnow.co.uk for a hard copy. Thank you

Caring Matters Now funding for research assistant

Ms Lara Al-Olabi, the new research assistant, half funded by Caring Matters Now, started in September 2013 and has been a fantastic boost to the research in the



Lara Al-Olabi

Institute of Child Health (next door to GOSH). She is a genetics graduate with a Masters degree, and who is very organised in the laboratory. This has really assisted the research as she has been able to process all the recent samples and help with the genetics research.

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, as we are a powerful team.

How Your Money Helps!

The money you raise is essential and we are very proud to say that we are still a substantial funding source for the CMN research in the UK! In addition we are also a substantial funding source for very important melanoma/CMN research; this could potentially be life-saving!

Your money also funds a team to support Dr Kinsler in her work and who work tirelessly, as she does, to research treatments for those with CMN.

Regula Waelchli from Zurich has been working hard on important neuro analysis which we will hear more about in the near future, as well as the growth and hormonal study.

Lara, the research assistant is funded by Caring Matters Now for six months in partnership with another children's skin disease charity called The Butterfly AVM Charity. Lara will be working on both skin projects, making this cost effective as often research projects have pauses waiting for reagents to be delivered or for more people to give a blood sample, etc.

The money raised from the 24 Peaks Challenge and the Dancing with Sky's Stars event earlier this year will be used to fund Lara for a year, so with the same commitment from The Butterfly AVM Charity we can together fund Lara for two years.

In addition to these two important posts we also fund Lorraine Rowe six hours a week to assist Dr Kinsler in her administration. This is imperative to allow Dr Kinsler to concentrate on the lab and research work.

We could not provide Dr Kinsler with this support to move the research forward at such a fast rate if it wasn't for the funding that you provide. Thank you!

Get Involved

Our annual fundraising target is
£70,000

How will we reach this? We need each family on our membership list to raise **£201.00** a year! This equates to just **£16.75** per month or **£4.20** a week!

Achievable?

Check out the new website full of ideas and stories to help you as well as the NEW fundraising toolkit! <http://www.caringmattersnow.co.uk/get-involved/>



Regula Waelchli



Read how Emma Weaver got on with her Crabtree & Evelyn fundraising event on the website 'Get Involved' 'Inspiring Fundraising Stories'



Here are some ideas of what you can do to raise the funds, but look at the website for more inspiration:

CMN Charity Challenge

Participate in a CMN organised event

Organise your own fundraising event

Recommend us as charity of the year at your workplace

Make a monthly Direct Debit/Standing Order

Arrange for Payroll Giving

Make a direct donation - online or by post

Gift Aid your donations

If you shop online then use Easyfundraising

Sell items on EBay and make a donation

Leave a Legacy

So, take on the challenge and raise some money!

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/>

National CMN Coffee & Cake Morning

Saturday 14th June 2014

In 2014 we are launching our first National CMN Coffee & Cake Morning happening on **Saturday 14th June 2014**, so put the date in your diary now!

This is a fun and easy way for **all** of us, regardless of where we are in the UK, to help raise funds for Caring Matters Now.

Taking part will be an opportunity to get together with friends and family for a great cause. Ask for raffle donations and hold a raffle or tombola to raise a little more, maybe an activity for the kids; name the teddy, guess how many sweets in the jar. The list of ideas to make the event as big as you wish is endless.

To make it easy for you, we have produced small flyers, which you can use to invite your family and friends. To receive a copy of these promotional flyers to print off yourself, please email info@caringmattersnow.co.uk. We also have CMN posters, balloons and collection boxes which you can use on the day.

Please get involved. Use this event to become a CMN Champion!



Bronze Award presented to:
 Finlay Helliwell & Dexter Fletcher
 Callum Leamey
 Poppy White
 Lewis North
 Fay Hardwidge
 Paul Mein
 Stokenchurch Junior School
 Eva Mackenzie
 Ryan Potter

Silver Award presented to:
 Croft Prep School
 Cross Country

Special Award presented to:
 Team of 24 Peaks Trekkers

Crabtree & Evelyn



selected Caring Matters Now as their Charity of the Year, many fundraising events going on in 2014.



in Ipswich held a Christmas raffle for staff which was a huge success.



had a dress down day raising £250.



Midas and Klark Teknik heard about CMN through Sue White. They gave us five, 'One 4 All' gift cards to the value of £50 each. These will be used to raise funds in raffles and auctions.



Caring Matters Now Partners

In recent months we have seen an increase in support from corporates, schools and large organisations. It is amazing that, as a small charity, we are receiving such support! Thank you to all our members and supporters for getting our name out there!



This month Caring Matters Now has been awarded 'Charity of the Year' for Lincoln City FC Youth Academy. In fact, not just for this football season, but for the one after too... up until summer 2015! This new partnership will help raise awareness of CMN along with substantial funds for the charity. Thank you to Julie White and family for introducing Caring Matters Now to the football club. Here's to a blossoming partnership!



Thank you to Cross Country for raising £1000 towards the work of CMN! Cross Country were introduced to Caring Matters Now by Malcolm Cotterell, whose daughter has CMN. They raised £1,000 by 'Dress Down Friday', a money raffle and selling homemade smoothies to staff.

Kingsley Napley Raised a substantial amount of money in 2011/12 which funded our support days in 2013 as well as those with CMN to attend the activity weekend.

These are just a few of the companies that have got on board and raised funds for Caring Matters Now. We are truly grateful. Thank you

My Story by Amanda Smith

Hi, I'm Amanda and I was born on October 12th 1967 and one of identical twins. A few hours after my birth my parents were told that I had been born with what they called a 'Swimsuit Naevi'. It covered my back, round my tummy, buttocks and half the tops of both legs. Also, large satellite naevi on my lower legs and 70-80 smaller satellite naevi from head to toe. The doctors were baffled, as back then a CMN like mine was so rare.

My parents couldn't understand why I had been born with this, let alone my identical twin born clear. My parents were given a referral for me to a plastic surgeon, who advised them to keep an eye out for any changes or lumps.

Even though it was so shocking for them to try and get over all the questions of 'why' and 'how' it happened, they raised me and my identical twin as normal as possible.

People would stop my mother in our

pram and coo, but in the summer months, people would comment on the marks, but she would just ignore anything nasty said.

When I was about 18 months old they noticed a large lump on my right buttock, which kept bleeding and became sore. So at 18 months old I had my first operation. As the lump was big I ended up with half a buttock, but at least the lump was benign to my parents' relief.

As the years went by I had operations to remove naevi from different parts of my body and replace with skin grafts.

Unfortunately when I had the large naevi on my back removed aged about 8 years old, I developed impetigo (an infection of the skin) and due to all the itching the skin graft that was used was destroyed and I was left badly scarred. Of course I still continued to have further surgery to help my condition, but on my legs the naevi grew back. My last operation as

a child was to have some large naevi removed from my face.

I was always envious of my sister for being born clear and even though we sometimes wore identical outfits, I always felt she looked better than me, but she would comfort me as she knew how upset I got. She would do her best to make me feel better and also tried to protect me from the bullies, sometimes nearly getting into trouble herself. Teachers were understanding and my parents knew how difficult it was for both of us.



I recall my school days, which were difficult due to name calling, such as 'spotty dick', 'scar face' and 'scabby'. So while at senior school, I joined the Gymnastics club during lunchtime with my twin. I thoroughly enjoyed it and even though I wore a leotard which showed my CMN, I didn't need to listen to the bullies outside, I couldn't hear them as they peered through the gym window at school! Don't get me wrong it was upsetting but I chose to ignore the points and stares and enjoy myself.

I was asked by our coach to represent the school at a local gym competition. I agreed even though I was concerned about showing my lower legs. My Nan made me some blue leggings to match my leotard and nobody even noticed. I was presented with a medal which was truly a special moment for me and my family. That medal will always be a reminder of how I overcame the bullies and pursued something positive for me!

There was still always one thing that played on my mind as I grew up and that was the future and what it held for me.....

All I ever wanted when I was a child was a lovely wedding and children. I accepted as I got older that this would never happen for me.....but it did!

When I was 15 years old I developed a crush on Paul, the son of my Dad's

friend who used to babysit me, my sister and brother. He was ten years older than me, so I never thought he would be interested in me. My family moved away up North when I was 17 years old and it was then that I realised just how much I missed him. I wrote to him asking if he had any feelings for me, even with my birthmark, to which he replied expressing his feelings.

I moved back down to my Nan's who was local to Paul and we started to date. We dated for four months and then got engaged. We got married four months later and had the wedding I had dreamed of. I had found a man, a wonderful caring man who loved me for me.

We have two children, a daughter Natalie and son Paul and two beautiful grandchildren, 4 year old Molly and 4 month old Oliver.

When I was carrying both Natalie and Paul we were worried about whether they would be born with CMN, but they were both born healthy and Paul with just a couple of birthmarks on his head. Nothing to be concerned about.

After everything I have been through and my worries about the future, I am delightfully happy with Paul, my husband, who sees me for me and not 'the mark'. He is devoted to me and cares for me since developing medical complications associated with my CMN.

I want to tell all the parents of young children to teens and beyond, that there is someone special out there for everyone and that you can lead a normal, happy life even with CMN. Paul and I recently celebrated our Silver Wedding Anniversary and look forward to many more happy years together.

I am so glad that children and parents affected by CMN have the support of Caring Matters Now, as do my family and I. I hope my story will help and inspire others.

All I ever wanted when I was a child was a lovely wedding and children.

CMN Support Events

Adults with CMN

As a charity we want to increase our support for adults with CMN by organising a small event whereby adults with CMN can all meet, for what may be the first time.

This event will be very relaxed, and we will make it as comfortable as possible for all to attend. Dr Kinsler will be there too! She will be able to offer advice to you individually and tell you all about her CMN research.

If you are 18 years and above, we would love you to come along and join us.

Please email info@caringmattersnow.co.uk if you are interested in coming. You are welcome to bring your partner or a friend with you.

London - Adults Only

Date: Sat 29th March 2014

Time: 4pm to 6pm

Venue: The Crown Tavern, 43 Clerkenwell Green, Clerkenwell, London, EC1R 0EG

CMN Family Support Days

London

Date: Sat 29th March 2014

Time: 12pm to 4pm

Venue: Crypt on the Green, Clerkenwell Close, London, EC1R 0EA

Glasgow

Date: Sat 9th August 2014

Time: 1pm to 5pm

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

Liverpool

Date: Sat 8th November 2014

Time: 1pm - 5pm

Venue: Bridge Chapel Centre, Heath Road, Liverpool, L19 4XR

Chat & Play Days

Bristol

Date: Sat 17th May 2014

Time: 1pm – 5pm

Venue: Nailsea Methodist Church, 74-76 Silver St, Bristol, BS48 2DS

Nottingham

Date: Sat 17th May 2014

Time: 1pm – 5pm

Venue: Every Day Champions Centre, Jessop Way, Newark, NG24 2ER

Dublin

Date: Sat 17th May 2014

Time: 1pm – 5pm

Venue: Tallaght Adventure World, Unit 1, Whitestown Business Park, Tallaght, Dublin 24

CMN Activity Weekend

Booking is now open for the 2014 activity weekend. Please book as soon as possible.

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.

Book by 1st February 2014 and Caring Matters Now will subsidise those with CMN. That's one FREE place per family! Be Quick!

Don't miss out book today! 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/

