



July 2012

7 Challenges Across 7 Continents

Yes, you read the title correctly, 7 challenges across 7 continents, a unique theme for future CMN Challenges.

Over time we plan to conquer seven varied challenges on seven continents allowing everyone the opportunity to participate, so no excuses!

www.youtube.com/watch?v=SzF67PDIAwg&list=HL1335859173&feature=mh_lolz

Mt Kilimanjaro – Done and Dusted!

With thanks to the hugely successful and dedicated team back in 2011 we have already conquered Mt Kilimanjaro and in doing so have raised in excess of £80,000. WOW!

If this is not encouragement enough to sign up then check out the following daily blog of the challenge and the video footage.

www.youtube.com/watch?v=MzXqVeG-50M&feature=youtu.be

www.caringmattersnow.co.uk/mount-kilimanjaro-done-and-dusted/

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24 Peaks in 24 Hours! - 14th-16th June 2013

So, why not be a part of the next successful CMN team and challenge yourself to 24 Peaks in 24 Hours!

Help us to raise money for Caring Matters Now, to fund pioneering research at Great Ormond Street Hospital and support all those affected by Congenital Melanocytic Naevus.

www.charitychallenge.com/expedition1.html?id=1697



My Story – David Taylor



No-one can deny that it is a tough journey. But it's a journey with a clearly defined goal following endless hours of preparation and training. But while climbing Kilimanjaro with my new-found "Kili family" was a once in a lifetime experience, the journey cannot match the beauty of raising a child with CMN.

Our daughter, Jessica, was born in July 2006 and became an instant hit with her older sister Emily who was born 5 years previously. Emily's birth had been a fairly inauspicious event, in that everything seemed to progress as planned. However, when Jessica was born the blank expressions and whispered tones led me to believe that something was not quite right.

I had noticed a "dark mark" when she was born but had not thought too much of it until the on-duty paediatrician was called for a few minutes later. It turned out that the paediatrician needed to "look it up" in the medical literature first and then she attempted to put our minds at rest as best as she could. She explained that this "mark" was in fact a mole and that we would be referred to surgery in due course. Fair enough we thought-not the best of starts, but at least something was getting done.

It's awfully easy for me to sit here and use the cruel gift of hindsight and state that we should have been referred to the dermatology department and not the surgeons. However, the information we were given at the time suggested that we were on the right course. Hindsight can be a cruel mistress however.

It was partly for this reason that I agreed to undertake the arduous task of climbing Kilimanjaro with the other 18 members of my Kili family, people who have now become part of my everyday life. One of the key aims and principles of Caring Matters Now is to raise awareness of CMN. It's certainly safe to say that our decisions would have been markedly different had we become aware of Caring Matters Now earlier. I am sure that the outcome would definitely have been different.

As it is, Jessica now has a large scar from the surgery running across her back. One day she will be asking those awkward questions I have been dreading. One day I will need to apologise and attempt to justify my actions. One day I hope she can understand.

Now, she's starting to make her own journeys. Primary 1 can be a traumatic event in itself for any 5 year old, but it may be particularly so for any child who is "different". Luckily, Caring Matters Now had the foresight to provide literature for education professionals and teachers. I personally feel that this has gone a long way to easing the concerns we felt about her formative years at school. We also provided her GP with Caring Matters Now material which has been tremendous in raising the awareness of CMN in the area.

Yes the journey is tough and it has its ups and downs, but climbing Kilimanjaro for CMN was the least I could have done to thank Caring Matters Now for the help they've given.

Funding – Your Help Needed?



Liverpool Schoolboys Football Team, sponsoring Caring Matters Now throughout the forthcoming season (2012-13).

Paul, a friend of Jodi's coaches the team and wanted to promote the charity.

The boys are the best 20 young footballers in Liverpool and play in a league against other cities across the country.

Superstars in the making.

We are all so grateful to Dr. Kinsler for her on-going efforts and fantastic achievement in obtaining the Wellcome Trust Grant that we featured in our January 2010 newsletter.

This grant is due to come to an end this year and although we hope to be successful in future grant applications this cannot be guaranteed.

The CMN Charity Challenge Team did a superb job in raising a substantial amount of money in climbing Mount Kilimanjaro and we are truly thankful, as we are to all our fundraisers this year, but we need more fundraising from **ALL** of our families.

Don't forget why we raise funds:

- To support those affected by CMN
- To raise the much needed awareness about CMN
- To raise funds for the pioneering research programme

These aims remain fundamental to Caring Matters Now and with more funds, we can achieve more. We want to be in a position where we can really expand our reach with new projects – have more family day locations, improve publicity to raise awareness, refine and keep up to date the support material, be a part of the International support network and a part of the international registry construction. Such projects require investment.

Check out the CMN fundraising page for ideas, www.caringmattersnow.co.uk/fundraising/how-you-can-help. Alternatively if you are up for a challenge and our 24 Peaks in 24 Hours is not what you fancy, then check out the other challenges available at www.charitychallenge.com/index.html. You can book onto any open challenge and raise money for Caring Matters Now.

National CMN Coffee Morning

Saturday 8th September 2012

Join in the fun and help us raise the much needed funds.

You could put a twist on this and hold a strawberries and cream afternoon or even strawberries and pimm's garden party, the choice is yours but I am sure your taking part will be an opportunity to get together with friends and family for a great cause.

This is a fun and easy way for all of us to help raise funds for the CMN medical research and support group.

THANK YOU TO ALL WHO HAVE RAISED MONEY FOR CARING MATTERS NOW. LETS KEEP UP THE MOMENTUM, NO MATTER HOW BIG OR SMALL YOUR EVENT, IT ALL HELPS AND MAKES A HUGE DIFFERENCE TO THOSE AFFECTED BY CMN.



New Website

Well you may have noticed some changes to the Caring Matters Now Website! We have been working hard on developing the site to include more content for you and to allow more interaction with our members and donors.

New video footage, interesting news features, online merchandise order capability, to name just a few additions.

Please take a look www.caringmattersnow.co.uk

We hope you like it.

Exciting Developments

As you are probably already aware, Jodi Unsworth is the original founder of Caring Matters Now back in 1996. Jodi, who was only 15 at the time and her parent's took on the role of supporting other families affected by CMN.

Since then the support group has developed immensely and today has over 350 families registered and 11 UK regional support contacts in operation.

As the support group grows it brings new challenges and much additional work and having been made aware of some changes happening in Jodi's work-life, we collectively thought this was a great opportunity for Jodi to increase her role within Caring Matters Now. Jodi's employment as Chief Executive of Caring Matters Now will inevitably support the new stage of development and allow us to continue to strive to achieve the best for our CMN families.

All whom have met Jodi will know that she is passionate about Caring Matters Now and with her enthusiasm and strengths we can concentrate on developing areas such as International communication, raising awareness and support by speaking and presenting to large audiences, fundraising management and better developing our support strategy.

I am sure you will all join the Trustees in thanking Jodi and her family for all they have done and continue to do.

From Jodi

15 years on since the establishment of Caring Matters Now Support Group, and not in a million years did I ever think the charity would be where it is at today. It only feels like yesterday when I was sitting in Dr Atherton's CMN clinic at Great Ormond Street Hospital with my parents in 1996, when he asked if we would be willing to talk to other CMN patients he was coming into contact with. When my parents and I gave Dr Atherton our telephone number, I never thought I would now be writing this small article announcing my employment within the charity!

It is overwhelming to see how, as I believe, God has truly blessed me over the years BECAUSE of my CMN and not in spite of my CMN. Being able to support so many families over the years has been nothing but a privilege and blessing to my family and I. I have seen the support group grow from strength to strength... far beyond what I had ever imagined, and this is because of the fantastic families, members and trustees we have supporting the charity.

As the support group now faces a new stage of development, nothing thrills me more than the opportunity to dedicate more time in helping the charity to reach its full potential in supporting our members, raising awareness of CMN and raising funds for the CMN research at GOSH.

New Chair of Trustees

As a result of Jodi coming into the exciting post of Chief Executive for Caring Matters Now Support Group, she is now unable to continue being Chair of Trustees, which is the position Jodi has fulfilled since the support group was established. As I'm sure you are aware, the Chair of Trustees has the responsibility to oversee the development of the charity and to ensure the charity is fulfilling all its aims and ambitions. After much thought and consideration, we are very excited to announce our NEW Chair of trustees... Mrs Val Unsworth.



Val is Jodi's mum and she has been a vital part in the establishment of Caring Matters Now. Both Jodi's parents have supported the charity over many years and are overwhelmed by how the charity has grown from strength to strength.

Val has all the qualities and skills which will make her a great Chair of Trustees. Not only is Val a mum of a 'child' with CMN, so therefore knows the struggles parents face, but she is also a highly trained counsellor and has developed many support-orientated works within her professional capacity.

At present Val works for Salford Hope Hospital in a pastoral role and has recently helped to develop the regional support network for Caring Matters Now, by offering listening and counselling skills to all our CMN regional support contacts.

Val is very passionate about Caring Matters Now as she has had first-hand experience of bringing up her daughter with CMN and has also supported the charity in its establishment and development.

All the CMN trustees are very excited to have Val on board as Chair of Trustees and Jodi in a more prominent position. We are very much looking forward to working together as the charity steps into a new phase of development.



From Val

I have never forgotten the day, fifteen years ago, I was sitting alongside Jodi in a small room at St. Thomas' Hospital in London, having just come to the end of a consultation with Dr. Atherton. He then said to Jodi "I have something I want to ask you....." Little did either of us realise the impact his question would have on the course of our lives!

On that day fifteen years ago Dr. Atherton asked Jodi if she would be willing, with the support of Joe and I, to set up a support group for those affected by Congenital Melanocytic Naevus. Quick as a flash ... without a moment's hesitation ... Jodi said "Yes! Of course I will!" From that simple "Yes" Caring Matters Now was born but as we stepped out of that room neither of us could have foreseen how it would grow and develop from its birth to be where it is today! Little did I realise too that her quick response would result one day in me writing to you all as the newly appointed chair of trustees for Caring Matters Now.

So what can I say... other than it is most humbling and an enormous privilege to be given the opportunity to serve Caring Matters Now in this role and I want to assure you all that I will endeavour to do it conscientiously and with integrity, seeking always to do what will best serve the aims of the charity, all of which are dear to my heart.

Please do contact me if you have anything you wish the trustees to consider or if I can be of help to you in any way regarding CMN.

Best wishes

Val Unsworth

val@caringmattersnow.co.uk

Warm Welcome to our new CMN Trustee by Jodi

As Caring Matters Now continues to grow from strength to strength, it is vital that we have a strong team of trustees who are dedicated to developing the charity, enabling our members to receive the best possible support.

It gives me great pleasure to introduce our most recent trustee to join the team, Andy Selwood. I approached Andy to come on board as a CMN trustee as a result to his recent involvement with the charity through his nephew's daughter (Lois) who has CMN. Andy undertook the amazing challenge of climbing Mount Kilimanjaro for CMN last year and after witnessing Andy's enthusiasm for the charity, I felt he would be

able to bring many strengths to the board of trustees.

Andy's responsibility as a trustee is to arrange further charity challenges on behalf of CMN which will ultimately enhance the profile and raise much needed funds for CMN research and support.

Andy currently holds a senior management position within a manufacturing environment and can offer organisational structure and project management techniques to ensure that the charity's future planned challenges run as smoothly and efficiently as possible, therefore maximising fundraising potential.

From Andy

Just a few words to say how honoured I am at becoming part of the CMN family.

For me climbing Mt Kilimanjaro was a life changing experience on many levels. Not only did I discover that the mind is more powerful than my (exhausted!) body, I also discovered that a group of like minded people can make a big, big difference. The enthusiasm and passion from everyone I have met connected with CMN is truly amazing and something that one rarely encounters.

Suffice it to say, I am really looking forward to not only developing future challenges but also working with such committed and dedicated people.

Introducing Our New Teenage Support Contact by Jodi

For the past number of months, the CMN trustees have been keen to increase the support for our teenage members. All our members are very important to us and we are very aware that teenage years can be difficult, so it gives me great pleasure to introduce our new teenage support contact, Katie Arends.

Katie (22) knows first-hand the difficulties that are attached to having CMN, especially throughout the teenage years. I have had the privilege of knowing Katie since she was just a small baby, as her mum got in touch with my parents when Katie was born. It was amazing at the time, as Katie's family only lived a 10 minute drive away from my parent's house.

I have seen Katie grow into a lovely young lady and I am confident that she will give great support to all our teenagers. Katie has recently graduated from university, after completing a teaching degree in secondary education and is a great example of someone who has successfully reached her personal goals and aspirations. The CMN trustees are thrilled to have Katie on board in supporting our teenage members.

From Katie

My name is Katie Arends (22) and I was born with CMN covering both my arms, shoulders and head.

Between the ages of two and four, I had several operations to remove some of the larger moles from my arms and shoulders. My mum has always worried whether it was the right decision but I believe that it was. At the age of 11, I also had laser treatment for around two years on my arms to reduce the appearance of the pigmentation.

My mum was introduced to Jodi and her family when I was a few weeks old through the help of Consultant dermatologist Dr Julian Verbov. Throughout the time I had my operations, Jodi and her family provided invaluable support to my



parents for which myself and they are extremely grateful.

When I was growing up, I found that younger children were always more accepting of my CMN than the older children and adults. During primary school, if someone would ask why I had marks on my arms I would say that I was born with them and they would just say ok and no more would be said. However, with older children and adults, they would stare and whisper things. My mum has also told me when I was a baby she experienced more problems with adults than anybody else.

When I moved to secondary school, I was worried that it would be difficult to make friends, but the school were extremely supportive with any problems I experienced and I enjoyed my time there.

As a child, I was always shy about showing my birthmark and scars, but as I got older, I stopped being bothered about what others thought and I am happy with who I am today. My parents have always been very supportive of me and have encouraged me to believe anything is possible. My mum once said to me 'Shoot for the moon and if you fail at least you will fall in the stars'.

Now, as an adult, I have a good group of friends who are the same friends I made in secondary school. They are very supportive and understanding. I am currently training to be a secondary school teacher which I find to be a very rewarding career to be able to help children succeed.

I am privileged to have been given the opportunity to work with everyone involved with caring matters now and I hope that I can make a difference.

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

Note email change: CMN.ich@ucl.ac.uk



IF YOU WISH TO VIEW THIS PART OF THE NEWSLETTER,
PLEASE EMAIL lucyh@caringmattersnow.co.uk AND WE CAN
FORWARD A COPY TO YOU.

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

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Family Activity Weekend

Fri 21st – Sun 23rd September 2012



The CMN Activity Weekend (21st - 23rd September) is open to all ages and is a weekend not to be missed. A break away from the normal routine, a weekend full of fun and laughter, an opportunity to make friends and chat and spend quality family time together.

Don't forget those with CMN **go FREE OF CHARGE** (funded by Caring Matters Now), that's how important we think it is for those with CMN to attend.

If you don't believe it could be that much fun then check out the photos from last year's trip www.caringmattersnow.co.uk/family-activity-weekend-1st-to-3rd-july-2011

Secure your place, **£119 per person**. This price includes: Accommodation, Food, Activities, Evening Entertainment.

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

We have agreed a reduction in the costs for our younger members, so children 3yrs and under go FREE, children 4 and 5yrs get a £24 reduction.

Complete the booking form (www.caringmattersnow.co.uk/family-activity-weekend-fri-21st-sept-sun-23rd-sept-2012) and send it with a deposit cheque for £60 per paying person to CMN, PO Box 732, Cambridge, CB1 0QF. Any queries please call 07786 458883.

2012 Family Days

Date: Sat 11th August **Time:** 1pm - 5pm **Location:** Glasgow
Venue: St Brides RC Church, 21 Greenlees Road, G72 8JB

Date: Sat 24th 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

Can you please inform Lucy if you are planning on attending any of the family days by calling 07786 458883 or email

lucyh@caringmattersnow.co.uk