



Caring Matters Now
is the only dedicated UK charity
supporting those affected by
Congenital Melanocytic Naevi

The 3 main aims of the charity are:

- To support those affected by CMN
- To raise awareness about CMN
- To raise funds for the CMN research

NEWSLETTER

January 2016

Jessica Ma Award 2016

In December 2014 one of our founding trustees Jessica Ma lost her battle with cancer. Jessica was not only a trustee to the Caring Matters Now charity, but also an amazing, courageous and inspirational friend to many in the charity and beyond.

Due to Jessica's wise and tireless work in managing the charity's finances over the years, Caring Matters Now has been able to grow from strength to strength.

The Caring Matters Now trustees want to publicly acknowledge and remember Jessica's outstanding and unique

contribution to our charity. In 2016 we will

be presenting the Jessica Ma Award to an individual or group who have gone above and beyond in raising funds for Caring Matters Now. Five finalists will be selected by the CMN trustees and from those five finalists, Jessica's husband, Peter, and their two children, Jasper and Pascale, will choose a winner who will be presented with the Jessica Ma Award 2016.



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CMN Coffee & Cake Morning

2015 didn't see the huge success of the 2014 Coffee and Cake Morning. Although many took part and raised a substantial amount, we did have a reduced number of participants so lets **all** get involved and do our bit!

2016 needs to be better than ever - we can do it!

The dates for the 2016 Coffee & Cake Morning are **Friday 24th June** or **Saturday 25th June 2016**, so put these dates in your diary now!

This is a fun and easy way for all of us, regardless of where we are in the UK, to get

involved and help raise funds for Caring Matters Now.

Taking part will be an opportunity to get together with friends and family for a great cause, whether at home, school, or your place of work there are many possibilities.

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.

We want to raise funds to continue funding research into life-saving treatments, in particular for melanoma, which we know

can be fatal in those with CMN.

To keep this charity running, provide support, and fund research we have to raise a minimum of £100,000 each year! To reach this it would be great if each family could raise £268 a year.

Achievable?

This equates to just **£22.40** a month or **£5.60** a week.

So give it a go!

Download our Coffee & Cake Morning Toolkit from the website

<http://www.caringmattersnow.co.uk/cmn-charity-coffee-morning-2016/>

Join in with us by holding your own

COFFEE & CAKE MORNING

in aid of

caring matters now

Friday 24th June & Saturday 25th June 2016

Eat tasty cakes, have a lovely cuppa, chat with friends and help raise money for Caring Matters Now

To register please contact info@caringmattersnow.co.uk

Caring Matters Now is committed to supporting those affected by Congenital Melanocytic Naevi and funding research to find the cure.
www.caringmattersnow.co.uk
Reg Charity No. 1120588

CMN Research

Dr Kinsler

Work continues on the CMN blood samples that people have kindly donated as part of the research over the years.

There will be the opportunity for new families to give a blood sample at future appointments once our Research

Coordinator Jane White

starts work one day a week in February 2016. Jane

was one of the

Dermatology Specialist

Sisters on the Dermatology

ward at GOSH for many

years, and is coming back to work after having her own children. She will be in the CMN clinic and will be able to help with recruiting families and gaining their consent for research.

Lorraine Rowe who has been CMN

Research Database Manager funded by

Caring Matters Now over the last few years

has been a wonderful and indispensable

member of our team. At the age of XX (I

won't tell her secret as no-one can believe it as she looks so young), Lorraine is going

to officially hand over to Jane White, but

she will still be available to help when we

have one of our regular surges of activity.

We are very grateful to Lorraine for all her



hard work for CMN over many years.

Last month we had a new PhD student starting on funding from the 3-year Caring Matters Now fellowship, William Baird. He has begun working in the laboratory to grow up cells to start testing different ways of trying to correct the NRAS gene mistake that leads to most CMN. He is jointly supervised by myself and Prof Steve Hart

in the gene therapy

research department in the Institute of Child Health.

This study will only be in the laboratory, not in patients, but it is a first opportunity for us to look

for ways of treating the problem of CMN at its source. As part of this study we will be hoping that some CMN patients would give us a skin sample (skin biopsy, similar to having a blood test) so that we can grow some of their CMN cells in the lab. This will be completely optional and part of the research, not part of normal medical care which will continue as usual. It should be possible however to try to coordinate it with normal clinic appointments to reduce travelling. Information about this will be sent out once that phase of the research starts, which will not be for a year or so.

Thank you all very much for your continued support - we could not do it without you

New Financial Administrator

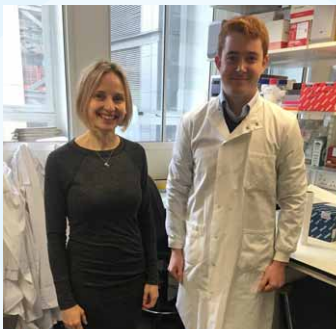
In the last financial year, Caring Matters Now achieved £169,000 in donations. This is a growth of £93,000 from donations received last year. The majority of funding (£101,000) came from individuals. Other key fundraising events were the Caring Matters Now PhD Research Post campaign and the Charity Dinner Dance. The charity also received grants from Children In Need and Jeans4Genes. It is absolutely amazing that a charity of our size is receiving such huge donations. With this increase in funds, the charity has to continue to ensure that all our finances are managed



efficiently. Therefore the CMN trustees decided to invest a very small proportion of these funds to employ a part-time financial administrator. Lisa Sly has qualifications in Bookkeeping and Accounts and has been managing accounts for a number of businesses over the years. Lisa has also been helping Lucy to manage our finances unpaid for a number of months and she supports Caring Matters Now away from the office too, by raising funds for the charity throughout the year. Lisa's husband has also been supporting Caring Matters Now in recent months by taking on fundraising cycling challenges for our charity. Therefore, there was no better person to take on this role.

By Val Unsworth,
Chair of Trustees

Introducing William Baird



My name is William Baird and I am very pleased to be starting a PhD project entitled '*Gene Therapy For Congenital Melanocytic Naevi*' with Dr Veronica Kinsler and Prof. Steve Hart. This is a completely new area of study for me, but it is one I find very interesting, and I am looking forward to starting in October.

I am 23 years old and I grew up in Enfield, North London. From an early age I enjoyed science and so when it got to my GCSEs and A-levels I chose a science heavy curriculum. Following my A-levels I decided to study Molecular Genetics at King's College London, I then went on to do a Master's in Genetics of Human Disease at UCL. For the next year I volunteered at UCL until I was recommended to apply for this incredibly interesting and important PhD project.

I am very grateful to Caring Matters Now for funding this project, and I will produce both a mid-term report and a final report to the charity about my progress. Any results we get will be published in medical journals and disseminated to other professionals at conferences.

Developments to our Board of Trustees

I am really pleased to inform you that we have recently made some positive changes to our board of trustees. **Ian Chance** has been on the board of trustees for the past 3 years and is now taking on the responsibility of CMN treasurer. I am really thrilled Ian is able to take on the responsibility, as he has a depth of financial knowledge within his employment work. I would like to publically thank Ian for his ongoing support to the work of Caring Matters Now.



The charity has also appointed 2 new CMN trustees, **Bronagh Cleland** and **Robert Jackson**. Bronagh lives in Ireland with her husband Adam and their 4 young children.



Bronagh's youngest little boy has CMN and the family have been actively involved in the work of Caring Matters Now for the past 3 years. Bronagh is our Ireland support contact and organises the support gatherings in Dublin. Bronagh and

Adam also support our fundraising efforts and in 2014 they both attended our charity dinner dance in London along with 8 friends. As a charity we want to ensure every corner of the UK is covered with an excellent support structure. Therefore, we invited Bronagh to join the board of trustees as we work together to develop support and awareness across Ireland.

Robert Jackson lives in East Sussex with his wife Diane and two grown up children, Katy and Danny. Katy has CMN and the family have been involved in the work of Caring



Matters Now for many years. The whole family took part in the CMN sky dive in March 2014 and they also attended the CMN charity dinner dance in September 2014. Rob has expressed a desire to be more actively involved in the work of Caring Matters Now, especially in helping the charity to develop corporate support. Rob & Diane run a financial business, so their knowledge of the 'corporate world' will help the charity to gain more support from big organisations. The CMN trustees believe Rob will be a great addition to the team, as he takes on the responsibility of gaining corporate partnerships for the charity.

CMN London Marathon 2016

We would firstly like to say a massive thank you to everyone that registered their interest in running the 2016 London Marathon for Caring Matters Now. It is always so encouraging to know we have individuals who are prepared to take on such big challenges for our charity, thank you.

Caring Matters Now is only allocated one place every five years! So this is a unique opportunity for us.



We placed all the names in the hat (bucket) on Saturday 31st October and the lucky winner, **Nathan Bevan** was selected to represent Caring Matters Now. Congratulations!

My Story: Nathan Bevan

I found out about Caring Matters Now after a friend got in touch having seen another person with birthmarks as noticeable as my own on a TV clip on the internet.

I looked on the net and to my surprise there it was. I had only ever seen a

newspaper cutting back when I was 16 years old of someone just like me, other than that I had never heard of, or met anyone like myself before.

At 35 years old I just assumed that my birthmark was so rare that I'd never meet another person like me. It was then that I looked up Caring Matters Now. It was such a shock to realise how

many others there were; just as special as me, who all spoke openly about something that they were so proud of. I felt assured that I wasn't mad and it was possible to love myself as much as I did; despite being so obviously different.



The difference between my skin and others was quite noticeable like I say...

I was born in Cambridge, in 1978 with CMN Syndrome.

Back in those days there wasn't much information available about CMN. Removal was thought to be the best option, so the consultants at Addenbrookes tried to remove the areas

that they thought would be exposed to the sun in later years.

My back is the main area covered by my CMN as well as my right arm down to the hand, my neck, the back of my head, the right side of my chest and the rest of my body and face had some smaller areas (but still of considerable size) and also other small spots all over.

By the age of 8 years old I had numerous operations to replace the skin on my right arm with skin from my stomach.

At 3 years old a tumour the size of a golf ball was taken from my back just below my right shoulder blade. Since then, I have undergone more surgery to remove further growths, fatty lumps or strange spots. The surgeons have got most of the tumour, but I don't think that it's ever really gone.

I've been lucky to be seen at least every year of my life by my consultants.

I've had times in life, as a child mainly, when others have not been so kind because of my spots, but, strangely I found those types of people always ended up wanting to be a friend of mine! Strange really!

As I've grown into my skin most think it really suits me, it's faded a lot but still has all it's colour to me. Some say they don't notice it but I prefer it when people do to be honest. It reminds me of the fight that I

shall never forget.

But, unfortunately at the age of 35 my fight stepped up a gear.

For a month or so I was suffering visual problems, with what I, and the GP thought were just migraines. In mid 2013, I suffered a seizure after biking home from work. I was found to have two stage IV melanoma mets in the optical area of my brain. These brain tumours grow quick. The brilliant neurosurgeon whipped them out and I was on my way to recovery in no time at all.

There was no primary cancer found so we had no idea if it was going to come back or not. Loved ones and friends made a fuss but it was like I had been prepared for this moment. I smiled the whole way through.

Don't get me wrong, it wasn't easy, the rest of this world isn't aware of how tough CMN can make a person. After this came a lot of changes.

I had to change my job, although I had been well and able throughout it all, and to prove this I had to see counsellors for the first time in my life. They were all very shocked with my positive mental attitude! I also saw some doctors who pretty much told me my days were numbered???

This was the risk of being so different yet it was being so different that would give me the strength to know it's just a part of my life and not the end. But it does make me wonder how things would be without all of

the removals I've had over the years.

I have continued to work whilst going through 3 monthly check ups, which include MRI scans, CT scans, dermatology and oncology check-ups.

After such a shock diagnosis and hearing about another person out there, I felt it was time to seek others like myself.

In March 2015 my partner Julie and I went along to the London CMN Support Day before attending the CMN adults gathering.

We were able to talk to a few parents and giggle with the young ones affected by CMN. It took my breath away to know that feeling in me is out there, I could feel it in the air and see it in the smiles.....confidence!

We then made our way to the adults gathering. I had never been so nervous in my life! I was worried that I was going to have more in common with the children than the adults! I wasn't sure if my feelings and emotions would be the same as the other adults I would soon be meeting. Julie and I sat down and had a drink before we ventured on.....

Admittedly I had two drinks to Julie's one. I was so overwhelmed with the anticipation that I was shaking!!!

Then we met the group of adults with CMN, and not to my surprise we all looked

very normal, well, as normal as we could look until I got my top off!

I found the beer to taste like water and I had to wet my whistle far too often to keep on top of all things that I'd been needing to say for over 3 decades. My mouth couldn't keep up, my ears were trying their hardest to help my brain take in and process all the information coming from people just like myself. The information and personal experiences shared within the group were so helpful to hear and it was strange to be hearing stories which I could so easily relate to. To say the time we spent together was overwhelming is an understatement!

What lovely people I met on that day! I can't wait to do it all again, and I advise anyone seeking comfort to do all you can to come along to the next support event arranged for 2016.

It's strange really because I always thought that if I had met someone with the same condition as me, I'd never leave them alone! However, I now feel after finding Caring Matters Now, and meeting people like me who are confident and full of life, I wouldn't want to take any of the valuable time away that we spend teaching the rest of the world how to be happy within their own skin!

Caring Matters Now International Support Weekend

Caring Matters Now trustees have invited various CMN patient support group leaders from around the world to come together and strengthen the relations we have already established with one another. The aim of the weekend is to give our guests an insight into the work of Caring Matters Now, including an insight into Dr Kinsler's CMN research, as we all endeavor to support those affected by CMN.

The Caring Matters Now International Support Group Weekend will be taking place from Friday 11th March – Sunday 13th March 2016.

This is a really exciting opportunity for Caring Matters Now and we are really looking forward to welcoming our guests to the UK.

Teens Big Day Out

Caring Matters Now is organising a Big Day Out for all our CMN members aged 12yrs to 17yrs at Warner Bros. Studios in London. The day will include a tour around the Harry Potter Studios. Caring Matters Now will be funding the Teens Big Day Out for all those attending. If you are aged between 12-17yrs and affected by CMN, you are welcome to come along and meet other young people of similar age to you. The

tour will start at 10am, followed by lunch and the day will conclude at 3pm.

This is a ticketed event - to book your

place, please email us at info@caringmattersnow.co.uk before Friday 15th January 2016.

Please check out

the website for more details

[http://www.caringmattersnow.co.uk/
support/support-events/](http://www.caringmattersnow.co.uk/support/support-events/)



Conferences in 2015

To raise awareness of Congenital Melanocytic Naevi and Caring Matters Now, it is always good to attend specific conferences for our target groups, such as, dermatology nurses, doctors and midwives.

The 2015 conferences we attended were:

British Dermatology Nursing Group



Caring Matters Now attended the BDNG

conference in June. The conference was fairly quiet but we found the nurses to be very receptive to what we are trying to do and were very willing to take literature.



British Association of Dermatology

This is an important conference for us to be present at as Dr Kinsler is in attendance

Children in Need

Training

As part of our Children in Need grant, Lucy & I attended a training day in Manchester.

The 'Your Difference' session explained more about the way in which BBC Children in Need works with projects to understand the differences they are making for children and young people.



and is often a guest speaker. This heightens the profile of the condition and our support group as a key funding source for CMN research, which Dr Kinsler speaks about often at this conference. It also allows us to build relationships with other charities and patient support groups for those with similar conditions and who are also trying to achieve the same goals as us.



Royal College of Midwives

This is the first year we have been to this conference and it was well worth the investment. The midwives were so willing to listen to what we had to say, take literature and learn more about the condition that they one day could find themselves facing. A very positive and encouraging event.

During the training we worked through concepts and principles of self-evaluation, outcomes and impact; the available strategies and tools for collecting information on outcomes, and how to use the information collected for learning, as well as for reporting to the BBC Children in Need.

It was hugely beneficial and well worth the time and travel to attend.

By Jodi Whitehouse

Media Coverage

We again received great coverage in the lead up to Children in Need.

In connection with our grant, we were asked if Caring Matters Now would be willing to feature on 'North West Tonight' during the build up programme to the main Children in Need Appeal Show on the 13th November! We were excited about this opportunity to raise awareness of Congenital Melanocytic Naevi and to raise the profile of Caring Matters Now. So



to facilitate this request, we brought forward our Liverpool Support Day as the

BBC wanted to be able to film an event supported by Children in Need and also interview some family members on how the

support events benefit them.

It was fantastic coverage and we would like to say a huge thank you to all those who attended the event, were willing to be interviewed and all the volunteers who made the event possible!

By Jodi Whitehouse

20th Anniversary Celebrations

2017 is going to be a huge momentous year for Caring Matters Now.....We will be celebrating our 20th anniversary.

Keep your eyes peeled for ways in which we will be marking this huge occasion for our small charity.

For now, we would like to inform you of the main event happening to mark our 20th year celebrations; The CMN Charity Dinner

Dance, planned for 3rd June 2017 at The Hilton Hotel in



Liverpool..... the home of Caring Matters Now.

After the huge success of the 2014 Dinner Dance we are very much looking forward to this being the best ever! Check out the video and photos of the last amazing event.



<http://www.caringmattersnow.co.uk/cm-n-charity-dinner-dance/>

2016 Dates for Your Diary

MEET THE SPECIALIST DAY

When? Friday 11th March, 12pm - 3pm **Where?** Great Ormond Street Hospital
What? Dr Kinsler will be presenting her latest research work, followed by Q&A session

CMN ADULTS GATHERING

When? Friday 11th March, 7.30pm **Where?** The Blue Door Restaurant, London
What? A meal for all our adults members affected by CMN

LONDON SUPPORT GATHERING

When? Saturday 12th March, 12pm - 4pm **Where?** The Crypt on the Green, Clerkenwell
What? A support day for all those affected by CMN and their families, with Dr Kinsler attending

FARNHAM REGIONAL SUPPORT GATHERING

When? Saturday 21st May **Where?** Venue to be confirmed.
What? A local gathering of CMN members - an opportunity to chat and develop friendships

BRIDLINGTON REGIONAL SUPPORT GATHERING

When? Sunday 29th May **Where?** Beach Chalet 13, Bridlington South Beach
What? A local gathering of CMN members - an opportunity to chat and develop friendships

DUBLIN SUPPORT DAY

When? Saturday 11th June, 12pm - 4pm **Where?** Malahide Castle and Gardens
What? A support day for all those affected by CMN and their families, with Dr Kinsler attending

GLASGOW REGIONAL SUPPORT GATHERING

When? Saturday 13th August **Where?** Venue to be confirmed.
What? A local gathering of CMN members - an opportunity to chat and develop friendships


TEENS BIG DAY OUT




When? Saturday 10th September **Where?** Warner Bros. Studios, London - The Harry Potter Tour
What? A social gathering for all those affected by CMN aged 12yrs - 17yrs

LIVERPOOL SUPPORT DAY

When? Saturday 19th November **Where?** Bridge Chapel Centre, Liverpool
What? A support day for all those affected by CMN and their families, with Dr Kinsler attending.

TAKE A LOOK AT THE WEBSITE FOR MORE DETAILS
<http://www.caringmattersnow.co.uk/support/support-events/>

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