

INSPIRE

NEWS FROM

CARING MATTERS NOW

Issue 02 - AUTUMN 2019



HOW DO YOU C ME NOW?



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Photographic
Exhibition Review

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2020 Caring
Matters Now
Conference



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 fund CMN research

MEET THE BOARD OF TRUSTEES



The board consists of 7 trustees who are either parents of children affected by CMN or have CMN themselves, therefore having a great desire and passion to ensure the charity are achieving all 3 aims.

- Val Unsworth (*Chair*)
- Ian Chance (*Treasurer*)
- Rob Jackson
- Bronagh Cleland
- Anne McIntyre
- Lucy Hardwidge
- Jodi Whitehouse

Caring Matters Now has 3 members of staff, who all have specific areas of responsibility.



Jodi Whitehouse
Chief Executive Officer



Lucy Hardwidge
Support & Communications Officer



Lisa Sly
Finance & Office Administrator

WELCOME



Welcome to the 2nd edition of your Caring Matters Now magazine! **'INSPIRE'**

Wow, what a year it has been... with the hugely successful 'HOW DO YOU CME NOW?' awareness campaign, our first ever CMN residential support conference, the growth of our Support Contacts team, major media coverage, and the CMN research going from strength to strength, we can safely say Caring Matters Now is thriving!

It is with huge thanks to the CMN trustees, staff, volunteers and charity members for making the past 12 months such a memorable time for our charity.

I am very excited to share with you all lots of exciting updates and developments... so grab a cuppa, sit back and enjoy reading through the 2nd edition of **'INSPIRE'**.

Jodi Whitehouse

Jodi Whitehouse
Caring Matters Now Founder & Chief Executive

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CARING MATTERS NOW



Support Contacts



The CMN volunteer support contacts are key to fulfilling our first and most important aim of supporting those affected by CMN. Each support contact is carefully selected to be able to provide you with personalised support. All our support contacts are either parents of a child affected by CMN or have CMN themselves, and therefore having personal experience and knowledge to best support you.

Over the past 12 months, our support contact team has grown and therefore, we have more support contacts placed in many regions across the UK. This enables all our members to receive face-to-face support from an individual who lives locally to you.

Details of your local support contact can be found on our website:

www.caringmattersnow.co.uk/support/support-contacts/



Regional Gatherings

The CMN volunteer support contacts organise annual regional gatherings; an opportunity for you to meet up with local families and individuals affected by CMN.

Regional Gatherings take place at various venues, such as a local park, a café, a soft-play centre, the beach, the zoo, etc. The events are low-key and relaxed, giving you the opportunity to chat with your CMN support contact and other families and individuals affected by CMN. All regional gathering details can be found on our website.

www.caringmattersnow.co.uk/support/support-events/



With special thanks to Children in Need

Children in Need currently fund all our 2019-20 support events. We are so grateful for their continued support.



Caring Matters Now Support Conference 2019

In July we held our first residential support conference at Liddington PGL Conference Centre with 112 attendees. The crammed-packed 3-day programme catered for all ages, including fun outdoor pursuit activities for the children and teens, off-site activities for our adult members, psycho-social presentations and workshops for parents, adults and teens affected by CMN, plus research presentations including Q&A session with Dr Veronica Kinsler and her research team.

The overall feedback received from attendees has been positive and therefore, we are currently planning the 2020 support conference. We do hope even more families

and individuals will be able to attend next year's event. Booking details can be found in this publication or on the Caring Matters Now website.

With special thanks to Appearance Collective, Centre for Appearance Research, YP Face IT and the CMN research team for presenting at the 2019 support conference.



Comments from attendees:

- “ It has been really good for my daughter to connect more with others with CMN. They now have a WhatsApp group together! ”
- “ This event is so important for children before they hit teens. ”
- “ Attending the conference has made my child more confident to show their CMN in public. ”
- “ My child is more confident to talk about their CMN and explaining what it is to other children who might be looking. ”
- “ It was an amazing mix of fun, informative medical sessions and supportive discussion with families facing the same challenges. It also gives us, as a family, a quality couple of days together away from our normal environment. ”
- “ Chatting to adults with CMN was very eye-opening and discussing approaches to issues with other parents was useful. The research update from the medical professionals was especially interesting and informative. ”
- “ Dr Kinsler's talk was very informative and the workshops with the other teenagers were really good. ”

- “ I have learned techniques to deal with people who stare and ask questions about my condition. ”
- “ I am so glad I attended the 2019 CMN conference. I would say it has changed my life in a very positive way. I have a group of new friends who I am now in regular contact with and hope to meet with new people in future. I fully understand the cause of CMN and am up to date with the latest research and information. Thank you so much Caring Matters Now for putting this together and I

would love to attend any future events. ”

- “ The Conference was a great experience and was loved by all that attended. So many people were helped by attending the conference in different ways - confidence, support, reducing isolation, building connections. It would be amazing for this to happen again for all attendees to continue to build the bonds they formed at the conference. And also be able to build new connections with new people who were unable to attend this year. ”

2020 CARING MATTERS NOW CONFERENCE

After the hugely successful **2019 CMN Conference**, we are very excited to invite all our members to the **2020 Caring Matters Now Conference**, taking place 26th-28th June 2020 at the Liddington PGL Conference Centre. Our weekend conference is going to be cram-packed full of activities which will cater for everyone!

We have planned specific activities for our adult members, teens, children and parents, including lots of fun outdoor pursuit activities; psycho-social presentations and workshops; CMN research presentations including Q&A session with the CMN research team - and much more!

This weekend conference is not to be missed and therefore we want to help all our members attend. We are offering an early bird promotion by covering the cost for each person affected by CMN to attend the conference. We hope this support will enable more members and families to attend.



Costs

£150 per person (age 4+)

Family of 4 or greater:

£125 per person (age 4+)

Early Bird Offer

Book before **1st January 2020** to receive your **FREE** place for the individual affected by CMN.

Accommodation

The accommodation consists of family rooms of multi-bedded bunk beds.

Booking & Deposits

Please complete the booking form available on our website.

We require a £35 deposit for each individual when you book. Full balance must be paid 8 weeks prior to the weekend conference.

A detailed conference schedule will be made available early 2020.

PERSONAL STORY

Hear Stacey's story and his hopes for the future

Hi, I'm Stacey and I was born with a large bathing trunk nevus and multiple satellites all over my face and body. Despite being different to other kids I had a really good childhood and I owe so much of this to my parents. Mum and dad never treated me any different. We went on holidays and did all the normal things a family would do and when asked the question they would simply say "They are his birthmarks",

"He was born that way". The more normal they made it seem the less interested people became and people just accepted me for who I was. Because I was happy my parents had always said a firm NO to the idea of me having any surgery to remove any birthmarks for which I am eternally grateful. We would visit dermatology once a year to get checked over but that was it.

Around the age of 18 I started to get really good at golf. My dad was a keen sportsman and he always encouraged me to try all sports, but this game was different. It was the one I had a passion for and what I wanted



to do as my career. I worked as hard as I could and in 1994 became a member of the Professional Golfers Association. Since then I have coached thousands of golfers from complete beginner to elite level. My job is very rewarding and people often remind me how lucky I am to do something that I enjoy so I intend to carry on coaching for as long as I can.

So, the years have passed, and I have my own family now and one of the questions I always asked myself was what would happen if I had children. Would they have the same skin as me? What would happen if they did? In 2008 my daughter Lucy was born, and she has completely normal skin. I probably should have researched it but even with myself I'd never really bothered to try and find out about my marks; it was just who I am.

That all changed in 2019 when out of the blue I started to receive text messages and calls about an exhibition in London with people who had the same skin as me. This is when I heard the name CMN for the first



time. They were on BBC, Sky, all the social media outlets. I'd never seen anybody else like me before so to see them in an exhibition was mind blowing. I just had to go and see for myself. I visited the 'HOW DO YOU **C** **M** **E** **N**OW?' exhibition and met so

many wonderful people. It was very emotional and as soon as I left, I called my parents to arrange a date for them to visit. We returned on the final day and shared stories with other families and made contacts and I became a member of Caring Matters Now.

The Caring Matters Now Conference in the summer of 2019 was another defining

moment for me. I got to spend time with other adults and children with CMN and their

families. We attended workshops with doctors, received the latest updates on research and developments and most importantly just chat about our experiences. I

have made a new group of friends that really are now friends for life.

Attending the exhibition and being part of Caring Matters Now has had such a positive impact on my life. 2019 is a year I will never forget.

Stacey

"The more normal they made it seem the less interested people became and people just accepted me for who I was."

Fabulous Fundraisers: Stok Kangri Challenge

In June this year, three phenomenal men took on the toughest Caring Matters Now charity challenge to date; Stok Kangri Summit Challenge, reaching 6,114 metres above sea water – which is 219 metres

HIGHER than Mount Kilimanjaro!

Nick, Norman and Phil signed up to take on this ultimate challenge to raise awareness of CMN and vital funds for Caring Matters Now.

This challenge became our 5th continent in our hugely ambitious aim to complete 7 challenges on 7 continents. To date, teams of Caring Matters Now members and supporters have completed challenges in Africa, Europe, South America and Australasia. Now was the time to take on Asia!

With all their might, Nick, Norman and Phil took on the Stok Kangri Challenge. The 3



brave men managed to make it to base camp reaching 4,900m above sea level on day 10, with their hopes pinned on summiting the 6,120m height over the following 2 days. However, after what was a very tough and dangerous summit attempt, heavy snow and a significant avalanche risk, Nick, Norman & Phil were forced to turn back at 5300m.

The disappointment felt by the team was huge, but the safety of the team was far more important than attempting to reach the summit.

Astonishingly, the 3 men have raised a phenomenal **£13,364.15** with funds still coming in! We are so thankful to Nick, Norman and Phil for their sheer determination to complete what was an extremely tough challenge, and for the huge amount of funds they have raised for our charity.

To read more about this challenge go to: www.caringmattersnow.co.uk/charitychallenge2019/blog/

Get involved! Sign up to a Caring Matters Now team challenge in 2020.

LONDON TO PARIS

CYCLING CHALLENGE: JULY 2020

More details can be found on our website or by emailing: info@caringmattersnow.co.uk



SEPTEMBER 2020

More details can be found on our website or by emailing:

info@caringmattersnow.co.uk

Stok Kangri final blog post: Our Challenge is Over – written by Nick

As I opened my tent at 0100 hours ready to set off for the summit of Stok Kangri my heart sank. It had clearly been snowing continuously overnight and there was a thick layer of snow on the ground. It was still snowing heavily with no sign of letting up.

We all met up in the mess tent, everyone geared up and ready to go despite the weather. At 0200, Joe our team leader broke the news that I had been dreading. The further snow had made our summit attempt impossible. The risk of avalanche on our route was no longer an acceptable risk. We had to cross several snow covered passes a glacier and the final ridge, 1200 metres of climb in total, all of which was now covered in fresh loose snow and there was significant evidence of avalanche activity. Phil, Norm and I were and still remain pretty gutted, we were all well acclimatised, motivated and ready to go, so to be stopped in our tracks by some unseasonably freak weather seemed so desperately unfair. Unfortunately though our window had closed and our challenge was over.

Good leaders sometimes have to make tough decisions based on the information they have available. This was definitely the right call, by Joe Johnstone who is an experienced mountain leader who has been exceptional throughout as has Hannah our team Doctor. As painful as it is to accept that we could not complete the push to the summit, quite frankly had we gone ahead there was a very real chance

we may have lost one or all of our team.

We regrouped later on the morning and the decision was made that there was no point in us remaining at Base Camp. Every other group had either left already or were in the process of packing up. The snow continued to fall and there was a real danger of us getting snowed in at base camp.

Around 11am we began what should have been a 6-7hour hike off the mountain back to Stok Village. As a group despite the weather conditions.....we did it in 5!! No one has summited Stok Kangri so far this season it remains an elusive goal!!

The day we were meant to summit the weather was so bad all flights in and out of Leh were cancelled. It is the middle of June and according to President Trump there is no such thing as global warmingReally Mr President ?!!

Phil, Norm and I just wanted to say a massive thank you to all of you who have supported us. Regardless of how things ended up, with your amazing support we have raised a great deal of money for a fantastic charity, met some amazing people and had an adventure along the way.

Finally just a word about my two climbing buddies, both Phil and Norman have been a pleasure to be with, great fun, highly motivated and resolute to achieve our goal despite the worst weather the Himalayas could throw at us.

Gents....thanks and respect !!!



TREASURER'S FINANCE REPORT

In the first half of the current financial year (2019/20), Caring Matters Now has received donations and other income totalling an amazing **£164,670** from a variety of sources, including;

- **£100,000** from our very generous individual benefactors
- **£1,000** from the sale of our exciting new merchandise
- **£25,000** from regular monthly donations, such as; Just Giving, Standing Orders and Payroll Giving.
- **£6,400** from our 2019 charity challenge: Stok Kangri Summit Trek
- **£34,000** from generous grants that the charity has been awarded, including; Children in Need, Wray Foundation and other benefactors.

The charity spends its money very carefully and always in accordance with relevant charity rules and legislation to support its 3 clear charitable aims; to support those affected by CMN, to fund CMN research and, to raise awareness about CMN. I have set out some of the costs to the charity below:

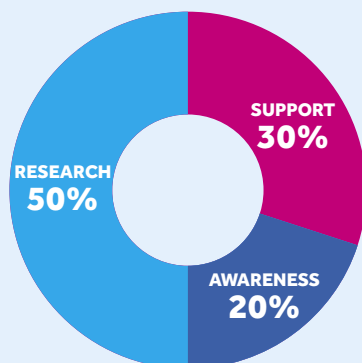
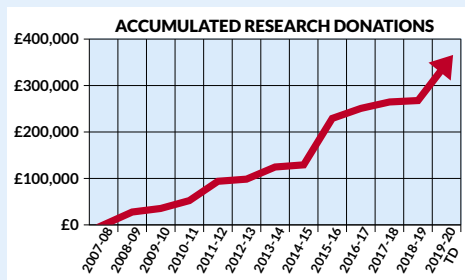
Support

Among other important support projects and initiatives, the charity has committed **£15,000** to help fund the hugely successful Caring Matters Now Annual Support Conference.

Research

The charity has awarded **£80,000** so far in this financial year to Prof. Kinsler and her team at GOSH/UCL for research into CMN. In addition, a further sum of **£80,000** will be handed to GOSH/UCL at the end of October 2019, as part of our ongoing funding

commitment to Prof. Kinsler and her team.



Awareness

The charity has allocated **£600** to printing our informative CMN newsletters, leaflets, booklets and flyers, and incurred website and social media costs of **£1,000**. In addition, the charity has provided **£9,500** in funds towards our CMN international development projects.

The charity clearly wouldn't be able to achieve any of its aims or support any of its amazing CMN events or projects without the very generous donations and grants it receives.

On behalf of the CMN extended family, consisting of our CEO Jodi, the Board of Trustees, our all of our wonderful staff and volunteers, I would like to say a huge **THANK YOU** for your continued support.

Ian Chance
Treasurer

RESEARCH UPDATE – by Dr Veronica Kinsler

This year has been as busy as ever in CMN research!

We would like to thank the patients and families who have contributed to CMN research this year. We could not make the advances we do without your willingness and selflessness in helping us with samples. It is absolutely integral to success of the research, and with the samples we are able to really understand CMN in a way we could not otherwise. Thank you so much.

Dr William Baird was awarded his PhD in December 2018, after his PhD studentship was funded by Caring Matters Now. William contributed very important work to the research project into therapies for CMN, and has now gone on to a new career.

Building on this work, and thanks to a phenomenal grant through Caring Matters Now (£400,000 over a 5-year period, 2019-2024), we were able to employ a senior post-doctoral research scientist, **Dr Dale Bryant** from March 2019. Dale already has lots of experience in biomedical research, and is a fantastic addition to our team. He is working full time, and only on treatments for CMN, looking at lots of different approaches including how to deliver treatments into skin in general. He is making excellent progress, and we will report back on this annually to Caring Matters Now.

Dr Maanasa Polubothu, who is a doctor and a scientist (we call this a clinical academic), has continued to work on her PhD on CMN. This research was “pump-primed” by Caring Matters Now – in other words you paid her

salary for the first 6 months to get enough data to apply for other grants – and then she and the CMN project was funded by the Newlife foundation <https://newlifecharity.co.uk>, and later by the GOSH/ICH Biomedical Research Centre <https://www.gosh.nhs.uk/our-research/nih-great-ormond-street-hospital-brc>. Without your initial funding we



could not have obtained these competitive grants for Maanasa. She has just finished her PhD into various aspects of CMN, and has been awarded numerous prizes during the period of her research, including most recently a poster award at the European Society of

Dermatological Research. Her work into CMN has led to important papers being published – particularly work on CMN genes, CMN natural lightening, and a new predisposing gene for CMN (*see website for summaries*).

Dr Sara Barberan, a talented post-doctoral research scientist joined our team in March 2019, thanks to a grant from the Livingstone Skin Research Centre in ICH. She has been working on new aspects of the genetics of CMN, and has travelled to Spain this year to attend the patient support group conference Asonevus for an update.

Good news for us this year is that we are moving our research lab to the **Crick Institute in London**. We will remain part of GOSH and UCL, but have the opportunity to work in one of the most amazing scientific environments in the world. This will greatly benefit the input into our research and help us to progress in the best way possible.

HOW DO YOU **CME** NOW

Earlier this year Caring Matters Now fell into the global media spotlight as a result of our hugely successful CMN awareness campaign 'HOW DO YOU **CME** NOW?'

The project began 3 years ago when the Caring Matters Now board of trustees set out on a mission to raise global awareness of CMN by celebrating the lives and beauty of those affected by CMN.

We began working with the world-renowned photographer Brock Elbank to create a series of positive portrait images featuring some of the most inspiring children and adults affected by CMN from around the world, representing 13 countries on 5 continents. We wanted to give a clear message to the world – to love the skin you are in!

It took 18 months to produce the series and following this, we secured a gallery space situated in the world-renowned Oxo Tower building in central London to exhibit the images. In the build-up to launching the series

of images we worked very hard at trying to catch the eye of national media, with the hope that we could raise the profile of the exhibition. Well, we can most certainly say we totally exceeded all our expectations and even our dreams in what was achieved through this awareness campaign....

The press coverage launched on Monday 11th March, and amazingly we were featured on BBC Breakfast, Sky News, Channel 5 News, ITV News, LBC Radio, Radio 5 Live and BBC Radio 1. Following the initial UK exposure, the coverage started reaching international levels, with the charity receiving press enquiries from media outlets in Germany, France, Norway, Russia, Taiwan, South America, and the United States. The global media coverage was phenomenal!





Alongside the media coverage, we gained major exposure across the capital with our exhibition posters placed in high footfall locations throughout London, including featuring on a huge digital billboard overlooking Waterloo Bridge. The billboard featured the exhibition posters for 2 whole weeks!

On Wednesday 13th March 2019, the gallery@oxo doors opened for the first time as we held our special exhibition launch event. Those in attendance were the inspirational photographed participants and their families, Brock Elbank and his family, the charity board of trustees and special guests who have supported us in this 3-year project.

Then the gallery doors opened to the general public on Thursday 14th March. We welcomed over 8,000 visitors to the gallery over the 10-day period! The response from the public was phenomenal, with the charity receiving emails and social media messages from individuals worldwide. The exhibition has inspired so many to reach out to us!

The HOW DO YOU **CME NOW?** awareness campaign well and truly raised global positive awareness of CMN and has phenomenally changed the general public's perception of beauty.

Overall the 'HOW DO YOU **CME NOW?**' campaign was an extremely positive experience for all involved.

The phenomenal impact of our 'HOW DO YOU **CME** NOW?' campaign!

During the exhibition campaign, Caring Matters Now worked in partnership with Dr Veronica Kinsler and Dr Saskia Sanderson to produce statistical data surveys allowing us to measure the psychosocial impact the campaign had on all those who engaged with it. The data gained has been very encouraging and enlightening, proving the 'HOW DO YOU **CME** NOW?' campaign had an overall positive impact; positively changing the perception of beauty, both for those affected by CMN and the general public! We are in the process of writing up our findings, which we hope will be published in a medical journal over the coming months.

For now, here are some of our findings...

65.31%

of people strongly agreed that the exhibition made them feel more appreciative of their unique skin, and as the majority of people at the exhibition did not have CMN, the positive impact of the exhibition isn't just confined to people with CMN but can be extrapolated to the general public and their individual differences in appearance.

33.34%

Over one third of the photographed participants (**33.34%**) always or usually considered what they would wear in relation to their CMN before the exhibition.

After the exhibition, not a single photographed participant said they would always consider what to wear in regard to their CMN.

58.33%

of the photographed participants felt not so confident/somewhat confident in a crowded place before the event, with only **41.77%** feeling very or extremely confident. After the exhibition, not a single participant said they were not so confident in a crowded place, instead, **83.34%** said they felt very or extremely confident in a crowded place now.

28.57%

Prior to the exhibition, only **14.29%** of parents whose children were photographed strongly agreed that their child was content and happy with their skin, with **42.86%** neither agreeing nor disagreeing.

After the exhibition, the 'strongly agree' category doubled to **28.57%**. Not a single parent was impartial, with the rest of the parents agreeing that their child was content and happy in their skin after the exhibition.

92.86%

Not a single photographed participant felt like the photoshoot was a negative experience, **92.86%** said it was a very positive experience for them.

84%

of people agreed that the exhibition made them feel more accepting of their looks, which helps validate the positive theme of change towards more self-confidence.

90.61%

The majority agreed that the exhibition made them feel more understanding (**90.61%**), sympathetic (**85.93%**), accepting (**85.64%**), and that people with visible differences are beautiful (**92.86%**).

98%

The exhibition was extremely well received by the public and was highly valued by **98%** of people that visited the gallery.

SOCIAL MEDIA



MARCH:
75,000 engagements



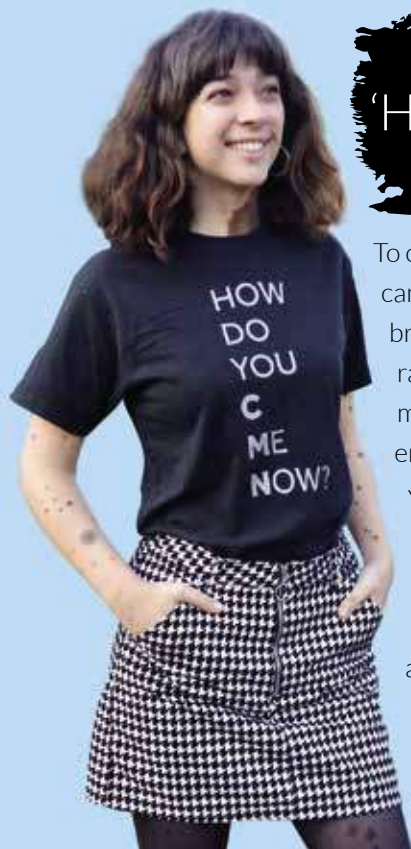
MARCH:
1,700 new followers
90,000 impressions



MARCH:
78,000 engagements
on website

The Caring Matters Now board of trustees would like to say a massive thank you to everyone who has been involved in this project over the past 3 years; the incredible and inspiring 30 photographed participants, the charity representatives who volunteered their time to welcome visitors to the gallery, the team who worked tirelessly behind the scenes by responding to press requests and email enquiries, the individuals who shared their personal stories within the media coverage, all those who visited the exhibition over the 12 days, to Dr Veronica Kinsler and Dr Saskia Sanderson for supporting our data analysis, and finally to Brock Elbank for his dedication and support in helping us raise global awareness of CMN.

THANK YOU to you all!



Buy your 'HOW DO YOU **CME** NOW?' t-shirt **today!**

To celebrate the huge success of our global awareness campaign **#howdoyouCMeNow**, we have produced branded clothing for all ages. We want to continue raising positive awareness of CMN, giving a clear message to the world; to love the skin you are in by embracing your visible difference.

You can support this campaign by purchasing a **#howdoyouCMeNow** tee and wearing it with pride.

www.caringmattersnow.co.uk/our-shop/clothing/

Why not take a photo of yourself in your new tee and post it on social media to continue raising positive awareness of CMN. Remember to tag the charity into your social media posts and use the hashtag **#howdoyouCMeNow**



Christmas is coming... CHRISTMAS CAMPAIGN 2019

Instead of buying unwanted gifts such as socks or sweets, hankies or hand lotion, why not donate the gift amount to **Caring Matters Now?**

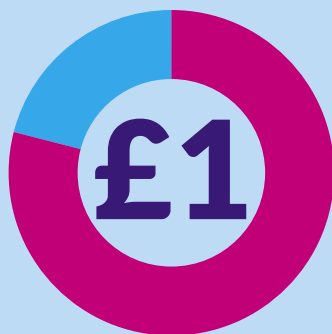
In return you will receive a Christmas gift voucher for the amount you donate, which you can then send on to your family member or friend.

www.caringmattersnow.co.uk/caring-matters-now-christmas-gift/

Become a CMN Hero

Become a CMN Hero in 2020 by giving a monthly donation to Caring Matters Now!

To sustain the support we offer, the awareness we raise and the research we fund, Caring Matters Now must raise a minimum of **£100,000 every year**. The CMN trustees are keen to increase our monthly giving to help us reach our annual fundraising target. This form of giving provides the charity with sustainable regular income and enables the trustees to manage how funds are spent in a more strategic way.



■ **79p** of every **£1** you raise goes on our charitable objectives - support, awareness and research.

■ **21p** is spent on development, governance and work to increase funds



£10 a month donation will pay for a child to attend the CMN confidence building weekend



£8 a month donation will pay for the publication of 200 CMN medical booklets to distribute to doctors across the UK



£40 a month will buy a full investigation of the genetics of a patient with melanoma

Why not consider giving a small donation each month as a new year resolution for 2020!

For more information, email info@caringmattersnow.co.uk

Join in with us by holding your own

COFFEE & CAKE MORNING

Friday 15th May & Saturday 16th May 2020

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/coffee-cake-morning-2020

JESSICA MA AWARD

In December 2014, one of our founding trustees Jessica Ma sadly 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.

Caring Matters Now established the **Jessica Ma Award** to publicly acknowledge and remember Jessica's outstanding and unique contribution to our charity. The prestigious Jessica Ma Award is for an individual or group who have gone above and beyond in raising funds for Caring Matters Now. All those who completed the Fundraising Event Registration Form on our website throughout 2018 were in with a chance of being selected!

We are pleased to announce the winner of the 2018 Jessica Ma Award is **Mark & Francine Melia**. Jessica's husband, Peter and children,



Jasper & Pascale said *"The amount of money and the number of events and fundraising activities they have organized is so inspirational to us. Thank you for all the effort and congratulations. Keep up the good work!"*

On receiving their award, Mark & Francine sent the following message:

"Thank you so much for this wonderful award - we are really touched that we were selected to receive it from the family of Jessica Ma.

We have been inspired to take part in fundraising because our daughter, Sofia, was born with CMN in 2017, but also from reading personal stories

on the website and through the support we have received from the charity to date, such as the Support Day.

Jodi kindly met us in Liverpool 10 days after Sofia was born and we were so grateful for the support she gave us then and that she still gives us. We are also grateful for being provided with the information to see Dr Kinsler at GOSH and to support the amazing research work that is going on. We want to be able to support this work, along with the support the charity provides, by trying to raise as much money as possible.

Last year, we were able to raise money through lots of different ways - my husband performed at a charity Beer Festival, I did a 50mile bike ride, and both our employers raised money through the coffee and cake morning. Our amazing friends took part in lots of events too; Gung-Ho 5k, the 50 mile bike ride, Tough Mudder, a sponsored walk and Sofia's childminders organised a sponsored toddler walk too.

We are so overwhelmed and encouraged by the support we have been given from our friends and family and we will be forever grateful. We hope to raise more money this year and already have three events lined up. The amount of money everyone connected to the charity collectively raised last year was brilliant and we are so happy that we could contribute to it."

Congratulation to our 2018 Runners Up:



Emma and Gareth Spray – with a special mention to their friend **Dave Chapman**.

Jessica's husband, Peter and children, Jasper

& Pascale said "It's wonderful to see all the different ways they have been fundraising. From cycling to dance to family fun days. It shows us all that anyone can use their skills and talents to fund raise for CMN."

CMN YOUTH

teenage@caringmattersnow.co.uk

'Hi everyone! I hope you all had an amazing summer!

It was great to see so many of you at the CMN conference in July and get to know you all better. I'm sure you will agree, it was a great couple of days spending time with to each other and taking part in all the activities on offer across the weekend. It would be great if more of our teens could join us at the 2020 conference... the more the merrier.

Along with attending the 2020 CMN conference, we have another opportunity to get together next year... by signing up to the first ever CMN teens fundraising challenge; climbing the rooftop of the O2 Arena in London! This will be great experience for all who sign up, as well as an opportunity to raise funds for the charity. Have a look at the details below and sign up today!

Finally, this section of the **INSPIRE** magazine is for you! If you want to share your story, experience or any news items, do get in touch with me by emailing teenager@caringmattersnow.co.uk

Thanks guys,

Katie

TEENS SUPPORT CONTACT

In this section of the CMN magazine **INSPIRE**, you will find all the interesting stuff for our youth! We want these pages to be used in bringing together our youth community. This section is for you guys, so keep in touch and share your stories, experiences and news!

You can contact our **Youth Support Contact**, Katie by emailing teenage@caringmattersnow.co.uk



**Climb London's
superstar attraction**

2020

Teens Fundraising Challenge

SIGN UP TODAY!

We are seeking a team of teens to climb
the rooftop of the O2 Arena!

Saturday 13th June 2020

Fundraising aim: £300

Booking deposit: £39

To book your place please email
info@caringmattersnow.co.uk

**Watch this space for
some exciting news coming soon...**

You will have the opportunity to become a **CMN Ambassador!** This scheme will give you a great head start in gaining unique opportunities and experiences; making you stand out from all your peers and becoming an attractive candidate for job opportunities and university places. **Launching in 2020!**

Meet a Member

Scarlett is a mature, self-assured and friendly 13-year-old, currently living in a small community within the Cotswolds. Scarlett is passionate about the Arts, a talented actress and dancer who has recently been signed to a London talent agency. What sets Scarlett apart from her peers is her CMN, which covers the majority of her back and part of her stomach, as well as small CMN marks covering the rest of her body. Scarlett states, *"My CMN doesn't and won't hold me back. I think having the visible difference makes me stand out more and people look at me more whilst competing."*

On the rare occasion when people comment or stare, only then Scarlett remembers she is visibly different. This has in the past made her subject to unkind words. Scarlett believes when people whisper and are not upfront it is harder to cope with, commenting, *"Little children just ask and that makes things a little easier to deal with."*



"My CMN doesn't and won't hold me back. I think having the visible difference makes me stand out more and people look at me more whilst competing."

Scarlett's advice to other teens with CMN is, *"Everyone will look at you, that's never going to stop. Just smile at them and they will smile back. It makes you feel better in yourself. Don't hide away your CMN. Girls, start wearing bikinis on holiday when you are young, so when you are older it will be easy to wear what you want when you want. Keep pushing yourself and eventually you will be proud of your CMN."*

Scarlett featured in the 'how do you C Me Now?' exhibition series, and also featured in the press coverage, being interviewed on Sky News. Scarlett says, *"I feel happy to be getting these opportunities that other people don't have. I take having CMN as a positive and not a negative and I would say to others with CMN "Be confident, be you, love the skin you're in!"*

You can watch Scarlett's Sky News interview on our website:

**[www.caringmattersnow.co.uk/
amazing-press-coverage/](http://www.caringmattersnow.co.uk/amazing-press-coverage/)**

THANK YOU FOR ALL YOU DO!

SPECIAL RECOGNITION

Caring Matters Now would like to congratulate **Dr Kinsler** on becoming the **Professor of Paediatric Dermatology and Dermatogenetics** at Great Ormond St Hospital for Children and the UCL Institute of Child Health. Prof. Kinsler truly deserves this prestigious title after her years of dedication to the CMN research and the CMN clinic at GOSH... not to mention her unmeasurable support towards the work of our charity.

This is great recognition for the CMN research and will continue to raise awareness of CMN worldwide.

We have found the cause... now it's time to find the cure!



caring matters now

We couldn't do what we do without your continued support.

Caring Matters Now relies entirely on the generous support and fundraising of our members, friends and families to allow us to inform and support those affected. The funds so kindly donated make a huge difference to the lives of those affected by CMN syndrome.

If you know someone who you think may like to support the work that we do, then why not give them your copy of this magazine so they can see what we do and why.

Share our online donation page:

www.justgiving.com/caringmattersnow

If you would like more copies please email us:

info@caringmattersnow.co.uk

If you would like further information about how you can support the work of **Caring Matters Now** or have questions, feel free to contact us:

Our address has changed to:

✉ **Caring Matters Now** | PO Box 184 | St Ives | PE27 9DU

@ info@caringmattersnow.co.uk 🌐 www.caringmattersnow.co.uk

Registered Charity No: 1120988