



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

WINTER 2017

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Happy New Year from the Caring Matters Now Trustees

What a year we have just left behind! The past 12 months have been an amazing time for our charity, as we celebrated our 20th anniversary in style. We held many celebratory fundraising events, such as the 20th Anniversary Ball, which raised over **£35,000** towards the CMN research. We also organised more support events than in years past and attended more medical conferences to raise awareness of CMN.

The past

As I look back over the past 20 years, I am overwhelmed by the support received to enable our charity to continually grow each year. Thank you to everyone for making Caring Matters Now what it is today; a charity that has a passion to support everyone affected by Congenital Melanocytic Naevi.

The future

As we look forward to the next 20 years of Caring Matters Now, I would like to ask you to consider helping us make 2018 the biggest year yet! Our board of trustees, are passionate about ensuring the charity continues to offer excellent support to all those affected by CMN, to increase the funds raised to further advance the CMN research, and to raise global positive awareness of CMN. To achieve all three goals, we need **ALL** our members to partner with us!



You really can make a difference in 2018!

Currently, our charity has very few monthly donors and this is something the CMN trustees want to change! You don't have to do a bungee jump, run a marathon dressed as a chicken or sit in a bath of baked beans to give funds to Caring Matters Now! You can simply make a monthly donation directly from your bank account. This form of giving is the most helpful in enabling the charity to carefully plan how we fund our work more strategically. To sign up to our monthly giving, please complete the form enclosed with this newsletter, or email us at info@caringmattersnow.co.uk and we can assist you in setting up your monthly donation.

Thank you for your continual support!

Jodi Whitehouse & the CMN Trustees

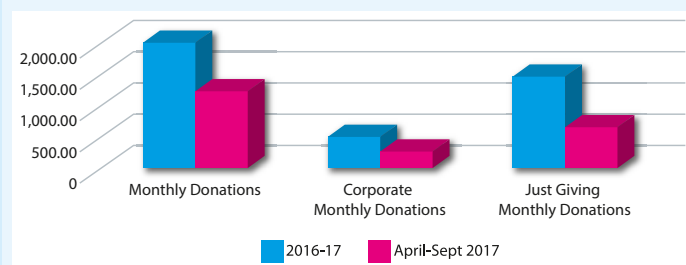


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CMN Hero - Monthly Giving & Payroll Giving

The bar chart below shows the total monthly donations received by the charity in 2016-17 (**blue bar**) against the donations



received between April and September in this financial year (**pink bar**). We have split this three ways to show; monthly donations, monthly corporate donations and monthly Just Giving donations.

We are currently focused on promoting all types of monthly giving and we hope to see an increase in these types of donations before the end of this financial year (2017-18). Please help us by inviting your friends and family to consider monthly giving as it can be simple to set up and tax effective (*see further details on the **Give-As-You-Earn** system below*).

Being a Hero is easier than you think!

You don't have to do a bungee jump, run a marathon dressed as a chicken or sit in a bath of baked beans to be a hero for charity. You can simply make a monthly pledge to **Caring Matters**

Now directly from your bank account or through **Charities Aid Foundation (CAF) 'Give As You Earn'**.

To become a CMN Charity Hero and pledge to make a monthly donation, please email info@caringmattersnow.co.uk or complete the form enclosed. If you want to give to **Caring Matters Now** on a regular basis, (CAF) Give As You Earn is a great option. Your donation is taken from your pre-tax salary,



meaning that part of your donation comes from money that would have otherwise gone to HMRC. Donating this way allows you to give more to **Caring Matters Now** and to ensure the charity receives regular financial support.

For example making a £20 donation to charity:

	As a 40% taxpayer:	As a 25% taxpayer:
Total donated to charity	£20	£20
You pay	£12	£16
The taxman pays	£8	£4

It's quite simple...

By signing up to donate through **CAF 'Give As You Earn'**, **Caring Matters Now** will benefit from a regular income and reduced administration and fundraising costs. You will benefit by paying less tax and knowing you are a charity hero without doing anything more than filling out a form.

For further information, see: www.cafonline.org

FOR MORE INFORMATION ON HOW YOU CAN BE A CMN HERO VISIT OUR WEBSITE
www.caringmattersnow.co.uk/help-us-make-difference-donating-monthly-caring-matters-now/

2018 Fundraising Events



As a result of all your fundraising efforts, Dr Kinsler and her team are making headway on research into the causes and treatments of Congenital Melanocytic Naevi Syndrome.

Caring Matters Now provides funding for specific research projects and a dedicated team of researchers who work alongside Dr Kinsler at The Institute of Child Health and Great Ormond Street Hospital. Our funding kick-starts many of the CMN research projects. Without such funding, the CMN research team would not be able to secure external medical grants to further develop the CMN research.

It is imperative that we continue to provide the funding Dr Kinsler and her team needs.

Not only do we need to fund CMN research, we also need funding to provide:

- The dedicated CMN support events taking place throughout the year, across the UK
- The information and support literature
- Attendance at medical conferences to raise the profile of CMN

To keep this charity running, provide support, and fund research we must raise a minimum of **£100,000** every year! To raise such funds, we need each family to give a minimum of **£211.00** a year. Achievable? This equates to just **£17.60** per month! Or **£4.40** a week.

There are many ways you can get involved and raise vital funds for **Caring Matters Now** and the pioneering research programme at The Institute of Child Health and Great Ormond Street Hospital.



Coffee & Cake Morning

Why not organise a CMN Coffee & Cake morning in 2018?

The dates are **Friday 22nd June to Sunday 24th June 2018**. Choose which date suits you and stick it in your diary!

This is a great opportunity to get together with friends, family and colleagues to raise funds for Caring Matters Now, whether at home, school, or your place of work; there are many possibilities. www.caringmattersnow.co.uk/coffee-cake-morning-weekend/

See what Fay said about her own coffee morning:

My friends and I got together to arrange our own CMN Coffee Morning. We decorated the garden with bunting, had a crafts table, put out toys for the children, organised a name the teddy & number of sweets in the jar and people donated gifts for the raffle! It was so busy, we had lots and lots of support from everyone that came and lots of cake donations. We raised **£350!**



Hadrian's Wall Trek Challenge

Make a new year's resolution to get fit and at the same time, raise funds for Caring Matters Now.



Fancy trekking 25 miles along Hadrian's Wall? One wall, one epic adventure in just one weekend! The trek takes you from Lanercost Priory to Brocolitia in an easterly direction, encompassing some breathtaking views and fascinating ruins.

The most remarkable Roman monument in the country, now a UNESCO World Heritage Site, Hadrian's Wall cuts through Northumberland National Park and attracts trekkers from far and wide. The challenging walks, filled with a stunning backdrop

and fascinating history make this an amazing weekend challenge.

Get a group of friends together, make a weekend of it! Just please get involved!

To follow in the footsteps of the Roman legions simply register at

www.caringmattersnow.co.uk/hadrians-wall-trek-challenge/

2019 CMN Charity Challenge – Stok Kangri

Part of the CMN 7 Challenges Across 7 Continents



Details coming soon!

Metro Safety 6 in 6 Charity Bike Ride

Ian Simcott



The team before the start of the arduous 509 mile journey



The tired but happy team at the end of the ride in Trafalgar Square

metroSAFETY

Celebrating 25 years of
making compliance simple.

As part of my company's 25th Anniversary year, we set ourselves a challenge of raising, £20,000 for 4 good causes. We work in safety, so we chose Children's Burns Trust and Mesothelioma UK as our first two causes. I was lucky enough to put forward Caring Matters Now and have it accepted as the next charity along with Macmillan Cancer Support. The main fundraising event we decided upon was to cycle through 6 countries in 6 days, covering a total distance of 500 miles.

Easy right?

10 brave souls made up of both competent and 'developing' cyclists and with a combined age that exceeded the planned mileage, set off on 21st September from Saarbrücken, Germany. We cycled through France, Luxembourg, Belgium and Holland. Some countries proved extremely accommodating for cyclist, others seemed intent to turn us into road kill. I'll leave you to decide which they were. We finished the ride late on 26th September arriving at Trafalgar Square. We were more than a little saddle sore, but totally exhilarated at our achievement.

It would be fair to say that we experienced a number of 'amusing' incidents over the course of the 6 days – some of which cannot be repeated for fear of litigation. The most bizarre was Day 5 when we thought we had plenty of time to get to Dunkirk for our 'evacuation' back to Blighty. We got to Dunkirk with 90 minutes to spare, or so we thought. Unlike Calais, Dunkirk port is over an hours ride from Dunkirk. As you need to check in 60 minutes before this left us with a bit of a problem. The solution was to send our 2 strongest riders with all our passports on ahead, while the rest of us peddled as fast as we could. The second group duly arrived at the port to find no trace of our flying squad. Unfortunately, our 2 'leaders' had gotten completely lost (bearing in mind they are carrying our passports) and had taken a wrong turn into a migrant camp. Needless to say the boys were a little concerned and beat a hasty retreat, and as it turns out - the wrong way up a

motorway! They finally arrived with 3 mins to spare and we were luckily all waved through to the ferry.

We were on the bikes at around 7.15am every day and usually not off them before 6.45 in the evening, so some very long days. We were self navigating as we went, and therefore had some very interesting decisions to take vis a vis closed roads – often we rode through a number of construction sites! For the geeks among you, we racked up some interesting stats over the 6 days; over 18000 additional calories burned, 45 hours of active ride time, over 17000 ft climbed and over 509 miles ridden and 5 falls – mostly because someone forgot to unclip! One thing's for sure, it was one of the most memorable events I've done and I loved being part of this fundraising team. To date we have raised around **£14,000** and have a few more events in our sights.

Corporate Charity Challenges

CH>RITY
CH>ALLENGE

Caring Matters Now is working in partnership with **Charity Challenge** to offer companies a unique

opportunity to improve company success, whilst demonstrating great Corporate Social Responsibility. Whatever your profession, improving the dynamics of your staff will have a big impact on the success of your business. Caring Matters Now is offering companies a once-in-a-life time experience for employees through CMN Challenges.



Take a look at the testimonial of Rick Parry, former CEO of Liverpool Football Club on Corporate Partnerships

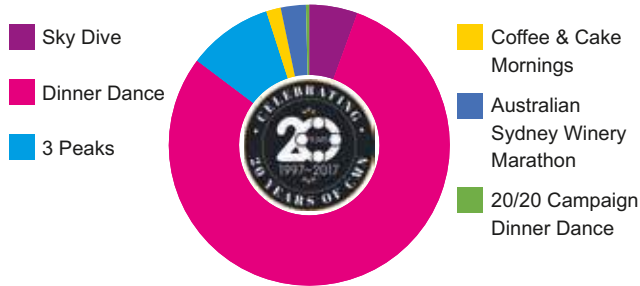
www.caringmattersnow.co.uk/get-involved/our-partners/partnerships/

Please do email lucyh@caringmattersnow.co.uk if you are interested in introducing your company to our corporate partnership programme.

Success of 2017 Fundraising

The chart below provides a breakdown of the amazing amounts raised through the Caring Matters Now 20th anniversary events:

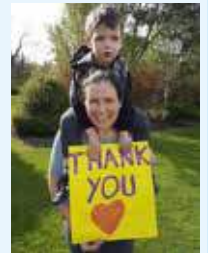
20th Anniversary Events



The total raised from the above fundraising events was **over £65,400**.

WOW! Thank you to each and everyone of you for getting involved, whether by participating in a CMN organised event or taking on your own challenge, organising your own event or making a donation...

THANK YOU, THANK YOU, THANK YOU!



2017 Jessica Ma Award Winner & Runner Up

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 that completed the Fundraising Event Registration Form on our website throughout 2017 were in with a chance of being selected!



We are pleased to announce the winner of the **2017 Jessica Ma Award** is **Sheila MacKenzie**. Jessica's husband Peter, and her children Jasper & Pascale said "We are delighted to announce Sheila MacKenzie as the winner of the 2017 Jessica Ma Award for her continued fundraising efforts and for her brave 20th Anniversary Skydive for CMN!"

Sheila said "Thank you so much for this wonderful award. To have the names of Caring Matters Now and Jessica Ma on an award means so much to me. Jessica was one of the most inspirational people I had the pleasure of knowing and this leaves me quite emotional. Her legacy lives on through both her lovely family and the charity. I've also been thinking today of the strength of last year's winners and their daughter Holly. Their lives have touched so many of us and encouraged us all to do anything, no matter how small.

I first met Jodi in Bristol in 2003 when Colin, Eva and I attended a family day when Eva was only 2 months old. We were so grateful for the support at that happy event. And here we are today at this exciting stage of the charity and Dr Kinsler's work. I know how much any money raised is crucial for its progress

and the future of our loved ones. As far as the fund raising is concerned, I've always played it safe; coffee mornings, selling crafts, cajoling people to dip into their pockets etc and left the physical challenges to others! This year I was able to step it up a bit as I didn't have to climb a mountain or cycle the length of Britain. All I had to do was jump out of a plane, attached to a parachute and another human being. Easy!

As I held my breath for the tricky bit and then floated for the rest, I had time to think. How fortunate we are to have each other and those who guide us at CMN. How wonderful to see the support and encouragement reach our family members. And how fantastic to see the creativity of those who keep the charity so healthy. I love to read about what people do whether big or small. It all helps. Eva makes crafts to sell at a festival each year and the comments of those who buy are wonderful and enormously encouraging.

Can I take this chance to thank each of you for everything you do for my family and here's to a new year and new horizons.
Sheila x"

This year's **2017 Jessica Ma Award** runner up is **Victoria Hamilton**. Peter, Jasper & Pascale said "We are very pleased to present the 2017 Jessica Ma runners up place to Victoria



Hamilton for her efforts in successfully swimming the channel and raising a significant amount for CMN".

Victoria said "I am surprised and delighted that Peter, Jasper and Pascale chose me as the runner up for the Jessica Ma Award. I feel honoured to receive it. Thank you so much."

Read Victoria's story on the website

www.caringmattersnow.co.uk/category/fundraising-stories/

Congratulations to you both and thank you for challenging yourselves to support Caring Matters Now and all those affected by Congenital Melanocytic Naevi.

Adult Support

Jodi Whitehouse

Over the past couple of years, the CMN trustees have wanted to develop our adult support for those adults affected by Congenital Melanocytic Naevi. We have made a start on developing this area by holding an annual adult gathering, which includes Dr Kinsler attending to present her work. This also provides a great opportunity for all the adults affected to enjoy some social time together in a relaxed environment and chat openly about their stories and experiences. We have been able to gain some insight and information into what we need to be providing as a support group and what is needed for our adults with CMN.

We now want to take some of the knowledge we have and further develop our adult support, but to do this we need a dedicated adult support contact.

The idea of the role is to involve this dedicated CMN adult support contact into talking and developing relations with our adult members to establish what they would like in terms of

support. They will be the main contact person for our adult members to get in touch with when they need to be listened to. They will also be the main point of contact for when we organise adult events, such as the adult gathering.

The adult support contact would be a part of the volunteer regional support contact team.

They would also develop the policies and procedures we currently have in place and keep this updated based on how this area of the support group develops.

I am delighted to introduce Gemma to the role. Gemma is a young adult with CMN who is keen to assist us in developing this area of support and is looking forward to meeting and getting to know more of our adult members. Please feel free to email gemma@caringmattersnow.co.uk, introducing yourself and maybe providing some suggestions on what it is that you would like to see offered to adults with CMN.

Welcome to the team Gemma.

Personal Story

Gemma Whyatt

My name is Gemma, I'm 22, grew up in Cambridge but now living and studying in Brighton. I like travelling, music and hope to graduate as a doctor in a few year's time. But if you meet me, you might notice something a bit different about me; I was born with CMN, in other words brown birthmarks of varying sizes all over my body. The main area is like an 'inverse t-shirt', covering the top part of my back and chest, half of my neck and the back of my scalp and ear. The rest of my body is covered in smaller marks. I like to joke that I'm a Dalmatian in disguise, but it has taken a while to get to the stage where I'm comfortable like that.



Growing up, although I was mostly a happy child I believed for a long time that I was simply from a different species. A lot of my early childhood was spent in and out of hospital; dermabrasion, tissue expanders, skin grafts... at times I felt like a human pin cushion and have been left with scars from cosmetic operations that are not routinely carried out on small children any more. Entering adolescence was especially hard for me. I stopped doing gymnastics and trampolining which I'd loved, partly out of reluctance to wear a leotard. I started wearing scarves and long sleeves even on warm days to cover my body, and god forbid any of my friends tried to invite me to the swimming pool. It was hard and I didn't know anyone else with the condition. Through Caring Matters Now I was put in touch with other people like me, which helped to reduce the feeling of isolation. I became

more confident in general and by the time I reached sixth form decided that I was going on a beach holiday to the south of

Spain with my friends. Stepping out in a bikini seemed far more terrifying than it should have done, but actually, it was fine! Barely anyone even batted an eyelid and I ended up having a great time. Since then, I've enjoyed travelling a lot, and sometimes in the hot weather when I'm wearing shorts and t-shirts, people will even approach me to compliment the uniqueness of my skin or offer to buy me a drink! Of course I get my fair share of stares and ignorant comments too, but more and more I'm growing to appreciate the skin I am in.

This year, Jodi asked if I would consider becoming the Caring Matters Now adult support contact. I have attended the most recent adult support events and found it useful to meet with other adults affected by CMN, to share stories, and glean from the experiences of others. I know Caring Matters Now would like to develop the support offered to adults affected by CMN over the next few years, so I hope I can give help and advice in this respect. At the next adult support event, I would like to chat with those attending about possible ways in which we can develop the support offered to our adult members. Furthermore, if any of the Caring Matters Now adult members would like to get in touch and chat, you can contact me at gemma@caringmattersnow.co.uk. I'm looking forward to taking on this new volunteering role and I'm excited for what the future holds.

CMN Exhibition Update

Jodi Whitehouse

The exhibition is in full swing now! We have been overwhelmed with the big response from all those whom so kindly submitted their application to participate in this exciting project.

Brock Elbank has selected 26 individuals to be photographed for the CMN exhibition series. The 26 participants represent many countries across the globe, including Australia, America, Poland, Norway, Spain, France, Switzerland, Italy and the UK of course! The majority of participants have been photographed with the remaining few to be photographed before the end of January 2018. Once all participants have been photographed, the 26 images will be produced in preparation for the exhibition which we plan to launch Spring 2018.

The aim of the exhibition series, is to create a series of stunning and positive images featuring individuals who are affected by Congenital Melanocytic Naevi. The series of images will give a clear message to the world; to love the skin you are in! We want the public to consider their perceptions and views of individuals living with a visual difference. Our aim is the general public will consider the beauty of the individual because of their CMN and not in spite of their CMN.

This is a huge project for our small charity and one we are working very hard to get right. So far all those that have participated have fed back how uplifting and positive the whole experience has been.

Launch details to come!



Research Update

Dr Veronica Kinsler

Please request a printed copy for this section:

info@caringmattersnow.co.uk

2018 Support Events

Support Days

We aim for our CMN support days to be welcoming and very beneficial for all who attend. We ensure all support days are informal, relaxed and child friendly with plenty to do, allowing time for chatting to others affected by CMN and developing friendships with one another. Dr Kinsler or a member of her research team attends all our support days and gives an update on the CMN research.

Come and join us:

LOCATION	VENUE	DATE	TIME
LONDON	Hackney House, 25 – 17 Curtain Road, EC2A 3LT	Sat. 03.03.2018	12pm – 4pm
LIVERPOOL	Long Lane Church, 8-12 Long Lane, Garston, Liverpool L19 6PF	Sat. 12.05.2018	12pm – 4pm
DUBLIN	Malahide Castle, Malahide Demesne, Malahide, Co. Dublin, Ireland	Sat. 23.06.2018	12pm – 4pm

Regional Gatherings

The CMN Regional Gatherings are organised by our Regional Support Contacts. These days are always great fun and full of activities with plenty to do! A great opportunity to meet other CMN members who live locally to you and develop friendships with one another. **Come along and meet others in your local area:**

LOCATION	VENUE	DATE	TIME
South West	Bristol Zoo, Clifton, Bristol, BS8 3HA	Sat. 05.05.2018	11pm – 3pm
South East	Brighton Seafront (exact venue TBC)!	Sat. 09.06.2018	12pm – 3pm
East Anglia	High Lodge Thetford Forest, IP27 0AF	Sun 17.06.2018	11pm – 3pm
North East	Guillemot Chalet, Princess Mary Promenade, Bridlington, YO15 3LG	Sun 22.07.2018	12pm – 3pm
Scotland	<i>To be confirmed</i>		
Northern Ireland	<i>To be confirmed</i>		

Adults Gathering

We welcome all adults affected by CMN to our Adult Gathering. There will be a presentation by Dr Veronica Kinsler followed by a Q&A session. Caring Matters Now will be providing lunch for all attendees, giving everyone an opportunity to chat openly and share stories/experiences in a relaxed and informal environment. You are welcome to bring a family member or friend along with you.

LOCATION	VENUE	DATE	TIME
LONDON	The Wesley Hotel, 81-103 Euston Street, London NW1 2EZ	Sat. 06.10.2018	11am – 3pm

Teens Big Day Out



This is a great team building and social gathering for all those affected by CMN aged 11yrs – 17yrs.

Situated on the south bank of the River Thames opposite Chelsea, **Go Ape Battersea** takes a new twist on the classic Tree Top Adventure. Incorporating some of the park's taller trees, the city experience includes knee-knocking crossings that are double the height of most Go Ape adventures, and many are twice as long, making them extra wobbly and challenging.

High Ropes, Low Ropes whatever takes your fancy, but be there!

And once you've completed the challenge, you can chill out and chat over pizza and a drink (*alcoholic only for those 18yrs or over!*)

LOCATION	VENUE	DATE	TIME
LONDON	Go Ape, Battersea Park, London, SW11 4NJ	Sat. 13.10.2018	11am – 3pm

Full details of all our support events are on the website
www.caringmattersnow.co.uk/support/support-events/



We would like to say a huge 'thank you' to Silicon Valley Community Fund for funding all of our 2017/18 Support Events.

✉ **Caring Matters Now** | PO Box 732 | Cambridge | CB1 0QF

☎ 07786 458883 @ info@caringmattersnow.co.uk 🌐 www.caringmattersnow.co.uk

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