



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

SUMMER 2017

VOLUME 1 • ISSUE 21

Raising Positive Awareness of CMN on a Global Scale!

Caring Matters Now charity is working closely with the world-renowned photographer Brock Elbank www.instagram.com/mrelbank, who is best known for his recent series 'Freckles' which appeared in media outlets worldwide. As part of this, Brock photographed Alejandra Garcia from Barcelona who has CMN (Congenital Melanocytic Naevus) and felt compelled to reach out to raise awareness of the condition.

Our aim is to create a series of stunning and positive images featuring individuals who are affected by CMN. This series of images will give a clear message to the world; to love the skin you are in!

Caring Matters Now and Brock Elbank are in the process of seeking 24 individuals to participate in this very exciting project. The series will include a wide range of different people with contrasting looks, all ages, both male and female.

Please take a look at the website for more details and the full criteria www.caringmattersnow.co.uk/raising-positive-awareness-cmn-global-scale/

If you require any further clarification, please do not hesitate to contact Jodi Whitehouse (info@caringmattersnow.co.uk).



Caring Matters Now 20th Anniversary Celebratory Ball

On Saturday 3rd June we held our 20th Anniversary Celebratory Ball at the Hilton Hotel in Liverpool, the birthplace of Caring Matters Now. The CMN trustees welcomed 220 guests to our special celebration, including Caring Matters Now members, long-term supporters, corporate sponsors and the CMN research team.

On arrival a gospel choir consisting of 50 singers greeted the guests. The amazing and uplifting sound that came from the gospel choir set the tone for the evening. The 220 guests enjoyed a 3-course dinner whilst being entertained by a number of performances from various bands, solo singers and dance acts. All the performances were outstanding and the whole evening, from beginning to end, felt like a musical masterpiece.

During the evening there were a number of speeches from Jodi Whitehouse, Dr Kinsler and Val Unsworth; each person spoke about all that has been achieved over the past 20 years within

continued overleaf



IN THIS ISSUE:

- | | |
|------------------------------|---|
| 1 Raising Positive Awareness | 4 20th Anniversary Fundraising Challenges |
| 1 20th Anniversary Ball | 5 Yorkshire 3 Peak Challenge |
| 2 Research Report | 6 Remembering Holly |
| 3 Financial Report 2016-17 | 7 CMN Activity Weekend |
| 3 Being a Hero | 8 Support Events |



Caring Matters Now and the CMN research. Dr Kinsler urged guests to support Caring Matters Now by donating funds to further advance the CMN research and in response the guests were phenomenally generous. Through the tombola, online silent auction, live auction and many fun games that took place throughout the evening, a staggering amount of funds were raised to further advance the CMN research.....

£33,242.50

This huge amount of money will pay for a dedicated CMN research nurse to help further advance the research, as well as supporting those receiving medical care within the CMN clinic at Great Ormond Street Hospital.

The Caring Matters Now trustees are absolutely overwhelmed by the generosity and kindness shown by all those that



supported our 20th Anniversary Celebratory Ball. Thank you to everyone who donated prizes, auction items, sought sponsorship, donated funds or attended the event. We do very much appreciate all your support!

Here's to the next 20 years!



Research Report by Dr. Kinsler

Please request a printed copy for this section:

info@caringmattersnow.co.uk

Charity Financial Report 2016-17

Income

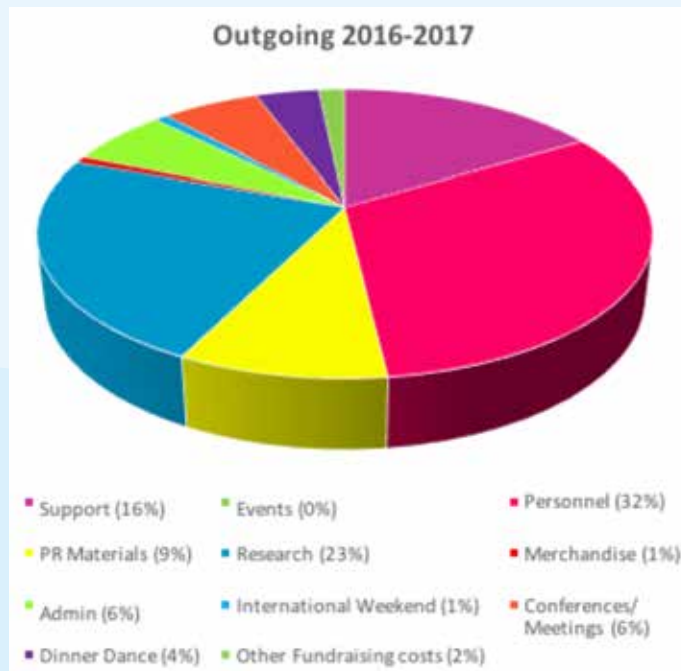
In the financial year 2016-17 the charity received a total income of £110,391, with donations and charity fundraising events making up the majority (51%). We have seen a significant increase in corporate/school donations during this period, raising 20% of our income. The 20th anniversary ball ticket sales have already raised 17% of our income during this period, with many more donations to be included in the 2017-2018 financial year.

Expenditure

In the same period, the total outgoings for the charity were £90,769.94. In 2015/16 we paid an exceptional amount to research specifically for the PhD post. Due to the success in securing external grants, this has relieved the pressure on Caring Matters Now to fund research and allowed us to seek

personnel to further develop the charity.

Since 2007 the charity's total donation paid to GOSH for research and to support both CNM research and the dedicated CMN clinic has been an amazing £250,679!!!



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 donation to **Caring Matters Now** directly from your pay through **Charities Aid Foundation (CAF) 'Give As You Earn'**.



A flexible tax-effective way to give money to Caring Matters Now

If you want to give to **Caring Matters Now** on a regular basis, payroll giving 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 Superhero visit our website: www.caringmattersnow.co.uk/help-us-make-difference-donating-monthly-caring-matters-now/.

CMN 20th Anniversary - Fundraising Challenges 2017

There is still time to be a part of the Caring Matters Now
20th anniversary fundraising challenges!

Coffee and Cake Morning



Everyone can take part in our fundraising campaign 2017! You can organise a CMN Coffee & Cake morning on a date that suits you. This is a fun and easy way for all of us to get involved and help raise funds for Caring Matters Now, regardless of where you live in the UK. Taking part will be an opportunity to get together with friends and family for a great cause, whether at home, school, or your workplace; there are many possibilities.

www.caringmattersnow.co.uk/coffeecake-morning-weekend-2017/.

Tandem Sky Dive

There is still time to book your place! If you know anyone aged 16yrs or older wanting a challenge, then maybe you could encourage them to take part in the Caring Matters Now 2017 Tandem Sky Dive! Caring Matters Now and Click & Jump have teamed up to offer a tandem day at BPS Langar Airfield, Nottingham, on Saturday 2nd September 2017 to celebrate the charity's 20th anniversary.

Check it out and encourage as many people as possible to sign up! It's a great day out for all!

www.caringmattersnow.co.uk/raise-money-cmn-completing-tandemskydive-2017.



20/20 Campaign



If all this sounds too energetic then there is another way to support our 20th anniversary celebrations! Why not join our 20/20 campaign. Simply make a monthly donation of £20 to represent our 20 year anniversary in 2017.

Monthly donations by direct debit give us a predictable income so we can commit to doing more as a charity. If you are a current UK tax payer, we are able to claim gift aid on your monthly donation, which is an extra 25%.

Find out more

www.caringmattersnow.co.uk/help-us-make-difference-donating-monthly-caring-matters-now/.

Yorkshire 3 Peak Challenge

The Yorkshire 3 Peak Challenge (Y3PC) began with an early 7am start on a cloudy Saturday morning on 20th May in the car park to the Golden Lion pub, Horton-in-Ribblesdale in the heart of the Yorkshire Dales.

The Y3PC organisers (www.purechallenge.co.uk) had set up a registration tent in the car park and this is where I met up with some of the other CMN fundraisers - Val, Joe, Jess, Fiona, Emma, Gareth, Steve, Shelley, Frances and Kate.

We each had a very heavy backpack, stuffed with waterproof clothing, energy bars and drinks, to see us through the 25 mile circular challenge which included climbing the 3 highest peaks of the Yorkshire Dales; Pen-y-Ghent, Whernside and Ingleborough.

The climb to the first peak, Pen-y-Ghent (694m), set the scene for pretty much the whole 25-mile challenge; incredibly pleasant in parts but also scary and both, mentally and physically challenging! We reached the first peak at 9am and although initially shrouded in cloud, there was a moment when the clouds parted to reveal the stunning Yorkshire dales below! Only 2 Peaks to go!

The trek down Pen-y-Ghent, through Horton Moor, took us through some simply stunning scenery. In total the Y3PC had over 600 people taking part and the various people I met on the way each had their own personal story for doing the challenge - and each was inspirational!

The 13-mile trek to the 2nd Peak, Whernside (736m), seemed like it would simply go on forever but it was soooooo good to reach the first refreshment tent at the amazingly scenic Ribblesdale Viaduct in the Ribblesdale Valley at midday. After a few energy bars and some water, just as the muscles in our legs were beginning to stiffen up, we gathered our things to begin the ascent of the Whernside Peak. In the distance we could see a long line of

trekkers ahead of us, looking like ants marching in single file! The weather had remained bright with some welcomed cooler cloud and no sign of rain, but that began to change as we made our ascent up Whernside. Despite a gentle winding climb, in parts by a railway line and some rivers, the weather began to

change for the worse and heavy rain fell on us as we reached the Whernside summit at 2.30pm.

The rain somehow found a way to bypass my waterproofs and I was soaked through! This was the most mentally challenging part for me personally and I just wanted to move on quickly to dry off somewhere. The descent was treacherous as it was an almost vertical climb down a rocky route and many people were slipping (including me) due to a combination of mud and smooth rock. However we somehow all supported each other through this and as we reached the bottom of the peak the weather improved and the sun re-appeared whilst we trekked to the next refreshment tent at Chapel-le-Dale, arriving at about 4pm.

We stopped briefly at Chapel, in a busy pub garden, for a very welcomed hot tea and more (rather unpleasant) energy boosting snacks before we embarked on the final leg of the challenge towards the 3rd Peak, Ingleborough (723m).

This ascent had its moments too, as a gentle trek turned into a near vertical climb up a rocky cliff that again needed some team encouragement and motivation for all of us!

At 6pm we reached the summit of Ingleborough and this felt like a huge achievement despite the

numb feet, aching joints and physical exhaustion - we had finally made it! Val was first in our group to touch the Monument at the top of the peak and there were huge smiles all round and a real sense of achievement!



continued overleaf

There were some amazing views from Ingleborough summit over the Yorkshire Dales towards Morecombe Bay and the Lake District - simply stunning!

Then the realisation dawned on us that reaching the final peak was far from the end of the adventure as we had to climb down and trek another 6 miles to the finish point - where we started in Horton-in Ribblesdale!

It is safe to say that this final leg of the challenge seemed to go on

forever and at every brow of every hill I was expecting to see the Golden Lion pub, the finish line, and a cold pint!

We reached the Golden Lion at about 8pm, just over 12 hours after we started, and we each received a certificate and a finisher's medal! But at that moment it was the cold pint of lager that was the most satisfying thing!

We all agreed that the Y3PC had been a physically and

mentally challenging endurance event but it was through some fantastic teamwork and support that we all got through some of the darker moments - and it was clear that everyone was on such a high!

It is simply amazing so say that the CMN team raised an incredible **£5,289.20**.

On behalf of all of those that completed the Y3PC for CMN we would like to thank you for your very generous donations - and if you

didn't get the opportunity to donate and would like to then please visit our team page www.justgiving.com/teams/CMN3Peaks.

I look forward to the 2018 CMN challenge!

Ian Chance



Remembering Holly

Wow, 20 years of Caring Matters Now, who'd have thought that the seeds sown all those years ago would have grown into such a strong and beneficial entity. Co-incidentally, it would have been our Holly's 18th birthday this year so what a better way to celebrate than to join in with the CMN coffee and cake weekend and see what we can do to help the cause.

Sometimes you cannot anticipate how wonderful people can be and, yet again, the generosity, both financially and in terms of human spirit, came to the fore. Yes, the usual friends and family who always step up to the mark when asked for help, supported our CMN coffee and cake morning. Most of our friends and family know our history and Holly's part in it. However, the tremendous support from those who knew nothing (or little) of Holly was stunning, both on the day itself and leading up to and after the event. People came out of the woodwork to make cakes and donate funds, even if they were not able to come on the day.

The day itself couldn't have been more perfect as far as weather and turnout was concerned. In fact, people were having such a good time they didn't want to leave - thank goodness we had enough cakes, scones and sausage rolls to keep them all happy! Our youngest daughter Meg and her lovely friends helped out. What a happy, thoughtful bunch they all are and to think that if we hadn't gone through what we did with Holly, Meg might not have been part of our lives today. Martin's eldest daughter, Anna, paid a surprise visit with her boyfriend from London and everyone contributed to the great

atmosphere - to be honest, it was more like an all day party and to be totally truthful it had turned into a cakes and wine event by early evening!



People, unsurprisingly, were very generous before and on the day and even now, two weeks later, we are still receiving donations that we need to forward on. What a lovely day it was to remember Holly and to contribute towards such a wonderful cause run by such a great team of dedicated people. We will obviously never forget Holly but equally we will never forget the support from Caring Matters Now and the tremendous strides that have been made over the last 20 years.

**Martin, Jackie,
Meg and Anna Thirkettle**



CMN Activity Weekend – What a success!



Well, what a fantastic CMN Activity Weekend we had this year! The sun shone, the location by the sea was wonderful and everyone had fun, fun, fun!

All those that attended the activity weekend had the opportunity to take part in abseiling, mountain biking, keel boat sailing, and flying down a zip wire... to name just a few of the activities!

We spent the evenings on the beach, kids having fun in the

water and the grown ups chilling with a drink on the waters edge.

A wonderful opportunity to get to know one another, develop friendships, share stories and experiences and have a fun filled family weekend!

But don't take out word for it; this is what Jamie & Georgia had to say:



I liked PGL because there was plenty to do and it was hard to be bored. The staff are friendly and they know their way around the sites. I made new friends during my experience at PGL. The activity that I liked the most was the rifle shooting because I almost hit the bullseye two times in a row. I also enjoyed the sailing because it was a first time for me. The food was very tasty and there were lots of options. I would like to go again and I would recommend it to other people with CMN because you get to try new things and have fun doing it!

Jamie Burton



I loved P.G.L because all the activities help you get over fears like a fear of heights. My favourite activity was the giant swing because when they pull you up it is so thrilling to go high into the air. I made lots of friends. It is easy to make friends at P.G.L. because everyone is so nice. You are supposed to go around without your mum and dad, which is good. The food is excellent too!

By Georgia c.Burton.

Details of our next CMN Activity Weekend will be on the website later this year. Keep your eyes peeled

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

CMN Support Events

CMN 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 the research team attends all our support days and gives an update on the CMN research.

Come and join us:

LOCATION	VENUE	DATE	TIME
GLASGOW	Cambuslang, Glasgow, G72 7JY	Sat. 02.09.2017	1pm – 4pm

Dates for the 2018 support days will be detailed on the website in November 2017. Keep your eyes peeled

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

Teens Big Day Out:

This will be a great opportunity to get together and develop friendships with other teens affected by CMN in a relaxed and social setting.

Open to all those affected by CMN aged 11yrs – 17yrs, plus one accompanying parent/career (or accompanying friend if you are aged 17yrs).

Caring Matters Now will cover the cost of the Hint Hunt escape rooms plus lunch.

HintHunt (www.hinthunt.co.uk) You get 60 minutes to climb a mountain of puzzles and mysteries in a tiny room. The goal is simple yet challenging: get out in time! Else ... you could be trapped inside forever!



LOCATION	VENUE	DATE	TIME
LONDON	HintHunt 72-76 Eversholt Street, London, NW1 1BY	Saturday 16.09.2017	11am – 3.30pm

CMN Regional Gatherings (No attendance from Dr Kinsler at these events):

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
EAST ANGLIA (TBC)	POSTPONED UNTIL FURTHER NOTICE	

Dates for the 2018 regional gatherings will be detailed on the website in November 2017. Keep your eyes peeled

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

Adults with CMN Social Gathering:

We welcome all adults with CMN to our Adult Gathering. There will be a presentation by Dr 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
LONDON	The Wesley Hotel, 81-103 Euston Street, London NW1 2EZ	TBC

Dates for the 2018 adults with CMN gathering will be detailed on the website in November 2017.

Keep your eyes peeled www.caringmattersnow.co.uk/support/support-events/.

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



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

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

Registered Charity No: 1120988