

January 2015

£50,000 Target Reached! THANK YOU

Inside This Issue

1. £50,000 Target Reached!
2. How the Money Will Be Spent
2. Research
3. Fundraising – Make a Difference!
4. National CMN Coffee & Cake Morning
4. Become a CMN Champion
5. Success of 2014 Fundraising
5. Financial Review 2013/14
6. Financial History
6. Ethan's Story
7. Success in Raising Awareness
8. CMN Support Events

Wow! We have been astounded at the support we have received since launching our £50,000 campaign to fund a PhD Fellowship post at Great Ormond Street Hospital/Institute of Child Health in London. We are delighted to report that we have reached our target, faster than anticipated and have had the great pleasure of handing over a cheque for **£50,000** to Dr Kinsler!

Recruitment for this post will commence shortly and we hope to have news of the newly appointed member of the CMN Research team in the July newsletter.

This has been achieved through many different activities such as the CMN Dinner Dance, a very successful marathon run which raised over £10,000 and all of you taking on challenges of your own, runs, bike rides, coffee mornings, fun days, not to mention the ice bucket challenges and text donate initiative.




Sheila (regional support contact for CMN) and her daughter Eva Mackenzie presenting the cheque to Dr Kinsler at Great Ormond Street Hospital.

If you want to support the work of Dr Kinsler and the NEW Great Ormond Street/CMN Fellowship with future research projects into life-saving treatments in Congenital Melanocytic Naevi, you can do so by text donating to Caring Matters Now and make a difference today.

TEXT - CMNR15 £5 to 70070

How the Money Will Be Spent

Caring Matters Now PhD Fellowship 2015



This new post at Great Ormond Street Hospital/Institute of Child Health in London is the first Fellowship to be endowed by Caring Matters Now, and is a major advance in funding ongoing research into CMN.

The post will be a full time position for three years for a PhD student, who will be supervised by Dr Kinsler, and starting in the first half of 2015. This will be the first project dedicated to looking at possible therapies for CMN, and the commitment and generosity of Caring Matters Now has been essential in getting this important research off the ground.

The partnership between the patient support group and the doctors/researchers continues to be a very powerful force in achieving results. The Fellow will report results back to Caring Matters Now on an annual basis, and present his or her results to the family day meetings, as well as to national and international conferences, to maximise the audience for the results.

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

Email: ICH.CMN@ucl.ac.uk



To view the whole of this section of the newsletter, please email us at info@caringmattersnow.co.uk for a hard copy. Thank you

*Thank you all very much
for your continued
participation in the
research projects and in
the fundraising – we could
not do it without you.*

Help Make a Difference!

With your help we really can make a difference to the lives of those affected by CMN and NCM.

Our annual fundraising target is set at £100,000 and this is achievable! Appealing to the general public to raise funds for rare disorders such as CMN is always a challenge, but a challenge not unmanageable for such a worthy cause, I think you would agree?

We rely almost entirely on the financial contributions from our members, their friends and families to raise the money we need.

To make it a little easier for all to help, we have broken this down to make it more manageable for everyone; All we need, to reach our annual fundraising target of £100,000 is for each family to give **£268.00** a year; Achievable? This equates to just **£22.40 per month** Or **£5.60 a week!**

Monthly Direct Debit

The simplest way to help is to set up a monthly direct debit. This can be from as little as £2 a month. For details email Lucy, lucyh@caringmattersnow.co.uk.

Workplace Charity of the Year

Approach your workplace and nominate Caring Matters Now as 'charity of the year' packs available soon on the website.

Payroll/Salary Giving

This is a very easy, tax effective way to donate to charities, so it costs you less to give more. This enables you to give to CMN straight from your gross pay, before tax is deducted. More information visit <http://www.payrollgivingcentre.com/employees.htm>

Pennies from Heaven

Employees sign up once and from then on every salary is rounded down to the nearest pound with the pennies being donated to charity. Visit <http://www.penniesfromheaven.co.uk/overview/overview.html>

Easyfundraising

Shop online, you can make a donation to the CMN support group through no extra cost! Set up is so easy <http://www.easyfundraising.org.uk/how-it-works/>

Book a Skydive

The exhilaration of a sky dive is even better when it's done to raise money for charity... raise funds for Caring Matters Now <http://clickandjump.co.uk/>

Challenge yourself!

A marathon! A triathlon! A Bike ride! Whatever takes your fancy Do It for CMN <http://www.doitforcharity.com/caringmattersnow.aspx>

There are so many ways raising funds can be achieved; take a look at the website for more ideas <http://www.caringmattersnow.co.uk/get-involved/how-you-can-help/>

Whatever you decide to do, run, trek, swim, bake, please register your challenge or event at <http://www.caringmattersnow.co.uk/get-involved/register-fundraising-event/>



National CMN Coffee & Cake Morning

Friday 12th & Saturday 13th June 2015



Well done to all those that took part in the National CMN Coffee & Cake Morning in 2014. It proved a huge success raising over £6,000.

This years' event will be on; Friday 12th and Saturday 13th June 2015, so put the 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 help raise funds for Caring Matters Now.

Taking part will be an opportunity to get together with friends and family, or colleagues if you hold one at work! Maybe 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.

To make it easy for you, we have produced small flyers, which you can use to invite your family and friends. These can be downloaded and printed from the website <http://www.caringmattersnow.co.uk/cmnm-charity-coffee-morning-12th-13th-june-2015/> We also have CMN posters, balloons and collection boxes which you can use on the day.

Don't forget to register your event email info@caringmattersnow.co.uk

Please get involved. Use this event to become a CMN Champion!



Become a CMN Champion!

'CMN Champions' is an awards programme for those who **commit to giving** and **campaign to the cause** of Caring Matters Now. Individuals, schools and work places can become CMN Champions by supporting Caring Matters Now throughout the year. Visit the website for more information.

Join the best and become a CMN Champion! Whatever your event, sign up now! <http://www.caringmattersnow.co.uk/fundraising/champions/>



Success of 2014 Fundraising

2014 has been an epic year for fundraising and we would like to say a massive thank you to you all for doing your bit! But we must not rest on our laurels!

We have seen an increase in corporate support, schools fundraising and so many more individuals getting involved in one way or another.

We would like to say a special thank you to the McCrossan Family, who so sadly lost their beautiful daughter Holly earlier this year, but who continue to support this charity and have continued to fundraise for Caring Matters Now and the research programme, even through the total devastation of their loss. Thank you.

Thanks also to everyone involved in hosting a wonderful CMN Charity Dinner Dance at the Intercontinental Hotel in London on 20th September.

The support we received from small corporates for this event was remarkable and the event could not have happened without such generosity.

Big thank you also goes to Brendon Cole for giving up his last Saturday night before the start of Strictly Come Dancing to be with us! Amazing!

It was a truly remarkable night and we are astounded at the amount raised: £20,700

Check out our website <http://www.caringmattersnow.co.uk/cm-n-charity-dinner-dance/> for the video and all the amazing sponsors who made this night possible.

Thank you to everyone involved in making this one for the joyous memory box!



Financial Review 2013/14

So, as you know, Caring Matters Now is funded entirely by donations from individuals, groups and some grant giving trusts. The charity receives no Government funding.

The Annual Report and Accounts reviews performance for the past financial year is available to view on the website <http://www.caringmattersnow.co.uk/about-us/annual-report/>. The financial year is from 1st April 2013 to 31st March 2014.

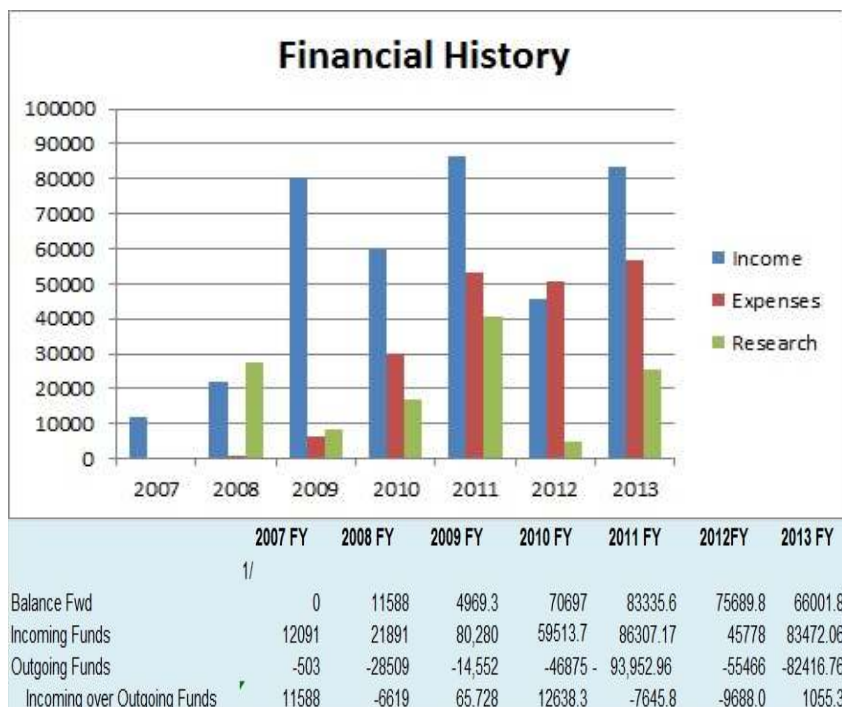
We are delighted to report that we achieved an income of over £83K of which £76K were donations in 2013. The majority (£48K) came from individuals. Other key events were the SKY Sports, Dancing with the Stars, CMN Sky Dive, 24 Peaks Challenge, Crabtree & Evelyn Events and Corporate/School fundraising events.

In 2013, we donated £26K on research at GOSH while £29K was spent on support campaigns (Support Days, Activity Weekend, Newsletters, Support Packs).



Financial History

Here is an insight into our financial history since becoming registered in 2007.



2011 we peaked in donations due to the CMN Charity Challenge; Mt Kilimanjaro and then in 2013 with again the CMN Charity Challenge; 24 Peaks as well as other events as mentioned above.

Looking at the financial history and the income over expenses you will see year on year and that we peaked in 2010 with a net cash flow of £12,638, this then dipped over the following two years 2011 and 2012 with development projects such as the website, redesign and print of materials, new merchandise, introducing the activity weekend and developing the support days with the introduction of London (which increased costs). In addition we had the employment of a development officer/administrator.

But we are now seeing the fruits of our labour and our net cash flow is increasing again.

Ethan's Story



On the 25th June 2012, our son Ethan was born and it was one of the happiest days our lives. Ethan was born with what only could be described as a birthmark/mole, which covered about 35% of his body, including the side of his face, his neck and shoulders.

When Ethan was born at York Hospital, the midwives and doctors had not seen anything like Ethan's condition before and we were referred to a dermatologist, Professor Newton-Bishop in Leeds. We were then referred to Dr Veronica Kinsler at Great Ormond Street Hospital in London and it was then that Ethan was diagnosed with Congenital Melanocytic Naevi (CMN). It was a great relief to be finally given some answers as to why our son was born with such an unusual skin condition.

Ethan was also under the care of Dr Thopte, a pediatrician at York hospital. Dr Thopte checked on Ethan's development regularly to make sure he was doing everything he was supposed to be.

Ethan has now been discharged from York hospital as Dr Thopte has no concerns and is happy with Ethan's progress.

On Ethan's 1st birthday, we took him for an MRI scan to check his brain and spinal cord for abnormalities, which can cause neurological problems.

Thankfully Ethan's results came back all clear and both my partner Tom and I were over the moon. Yet we feel sad that some families do not get the same results as Ethan. It was after Ethan's MRI scan that Dr Veronica Kinsler told us about this amazing charity called "CARING MATTERS NOW" which helps families who are affected by the same condition as Ethan's. Last year, we attended our first Caring Matters Now support day in Liverpool. We were, at first nervous to attend the support day, however we enjoyed it thoroughly and the day gave us so much more confidence. The support day allowed us to discuss our worries and concerns and as a result, left the feeling of isolation behind us.

Inspired by the support day, in 2014 we then decided to raise money for Caring Matters Now by holding various fundraising events such as a Golf Charity Event and 3 Yorkshire Peaks Challenge. Close friends and family also wanted to get involved, which included one of our friends doing a Sponsored Dance Competition and two other friends competing in a charity 10K run. As a result of holding the fundraising events, we have been able to spread more awareness about CMN,

and more people have wanted to support Caring Matters Now. The support we have received has been so overwhelming.

Ethan is now 2 years old and he's such a confident, handsome and happy little boy who loves to be outdoors and play golf with his daddy. Ethan now attends nursery and has made lots of friends. As parents we are so proud of Ethan.

Our special boy!

Success in Raising Awareness!

Wow... where do I begin? This year we have seen a huge rise in CMN awareness across the UK. Amazingly, we have been featured on three mainstream national Television channels; Sky News, ITV and BBC.

In July our charity featured on Sky News and ITV 'This Morning' as a result of Caring Matters Now hosting the visit of a very special little boy from Columbia. Didier, who featured in the channel 4 'Turtle Boy' documentary in 2011, had 6 full days experiencing the sights of London, meeting children affected by CMN for the very first time, taking part in the CMN research at Great Ormond Street Hospital and being featured on national television. The coverage we received on Sky News and ITV 'This Morning' was excellent. Both interviews explained what CMN is, the importance of CMN research and how Caring Matters Now supports those affected by CMN. Along with Didier and Jodi, Dr Kinsler was interviewed about her CMN research work on Sky News. As a result, our Caring Matters Now website received over 3,000 hits in the 24 hours after the interviews were aired.



Later on this year, we received a telephone call from BBC Children in Need asking if they could feature Caring Matters Now on BBC The One Show. We were thrilled to be asked to be featured on The One Show, as the TV programme has over 5 million viewers each evening.

The crew and presenter, Alex Jones, came along to our Liverpool Support Day in November and interviewed our CMN members, including Holly's parents Jon and Donna McCrossan. The editorial team produced an excellent feature, which highlighted the need for CMN support and research.

I would like to take this opportunity to say a huge thank you to Jon and Donna McCrossan for sharing Holly's story on The One Show.



Jessica Ma



It is with great sadness that we have to tell you our dear friend and committed trustee, Jessica Ma passed away on Sunday 7th December, after a long and very courageous battle with cancer.

She has been the most amazing friend and trustee to Caring Matters Now since we became a registered charity in 2007. Jessica's gifts and skills drove the charity forward and we wouldn't be where we are today without her.

Jessica is going to be missed by us all. We send our love and thoughts to her family.

CMN Support Events



Adults with CMN

London - Adults Only

Date: Sat 14th March 2015

Time: 4pm to 6pm

Venue: The Betsey Trotwood, 56 Farringdon Rd, Clerkenwell, London, EC1R 3BL

CMN Support Days

London

Date: Sat 14th March 2015

Time: 12pm to 4pm

Venue: Crypt on the Green, Clerkenwell Close, London, EC1R 0EA

Glasgow

Date: Sat 15th August 2015

Time: 1pm to 5pm

Venue: St Brides RC Church, 21 Greenlees Road, G72 8JB

Liverpool

Date: Sat 7th November 2015

Time: 1pm - 5pm

Venue: Bridge Chapel Centre, Heath Road, Liverpool, L19 4XR

CMN Gatherings (formerly Chat & Play Days)

South Devon

Date: Sat 2nd May 2015

Time: 12pm – 3pm

Venue: Woodlands Leisure Park, Blackawton, Totnes, TQ9 7DQ

Bridlington

Date: Sat 23rd May 2015

Time: 12pm – 3pm

Venue: South Beach Chalets, Princess Mary Promenade, YO15 3LG

Dublin

Date: Sat 5th June 2015

Time: 11am – 2pm

Venue: Tallaght Adventure World, Unit 1, Whitestown Business Park, Tallaght, Dublin 24

Brighton

Date: Sat 27th June 2015

Time: 12pm – 3pm

Venue: Details on the website

CMN Activity Weekend

Booking is now open for the 2015 activity weekend. Please book as soon as possible.

When: 24th – 25th July 2015

Where: Caythorpe Court PGL, Lincolnshire.

Price: Adult or Child with CMN

FOC

Adult & Child 7 years old or over

£99.00

Child 4 to 6 doing activities

£75.00

Child 4 to 6 accommodation and meals only

£30.00

Child 3 years or under

FOC



Check out the videos of previous weekends on the website

www.caringmattersnow.co.uk/support/supportevents/

Don't miss out book today! <http://www.caringmattersnow.co.uk/2015-activity-weekend/>