



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 2016

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20th Anniversary Celebrations!

Join in and help us celebrate this momentous occasion.

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

Oh how things have come on in 20 years! At the age of 16 years old Jodi and her family were asked to provide support to other families affected by Congenital Melanocytic Naevi. This request from Dr Atherton at Great Ormond Street Hospital prompted the first support day to take place in Liverpool all those years ago!

Fast-forward the clock 20 years on and today Caring Matters Now supports over 450 families worldwide affected by CMN, have a team of 12 volunteer regional support contacts, a board of trustees and three employed members of staff. We host 12 support events across the UK each year, and have raised a phenomenal amount of funds of which £230,000 has been given to CMN research.

With the money provided we have increased our support, raised awareness of Congenital Melanocytic Naevi and the profile of Caring Matters Now across the UK, and through funding the CMN research we have found the cause of CMN!

To celebrate the past 20 years of Caring Matters Now we are organizing some memorable events throughout 2017.

The first of these events will be a 20th Anniversary Celebratory

Ball on Saturday 3rd June 2017 at the Hilton Hotel in Liverpool.... the birthplace of Caring Matters Now! We would like as many of our members and supporters as possible to join us for a night of celebration! Tickets on sale NOW! <http://www.caringmattersnow.co.uk/cmnmn-20th-anniversary-celebratory-ball/>

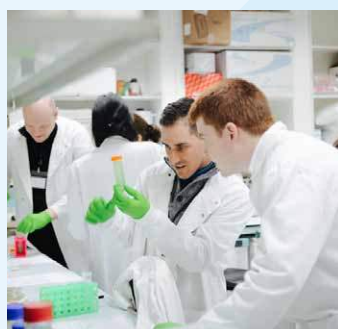


So, invite all your friends and family, the more the merrier!

If you fancy celebrating in a more extreme style, then join our 20th Anniversary CMN Skydive Team! After a successful CMN skydive in 2014, which raised a staggering £14,000, we have teamed up with Click and Jump again to offer you a tandem skydive day at BPS Langar Airfield, near Nottingham on 2nd September 2017. So, why not join in the fun and do something amazing to celebrate our charity's 20th anniversary.

<http://www.caringmattersnow.co.uk/raise-money-cmn-completing-tandem-skydive-2017/>

Let's all join in the celebrations and make 2017 our best year yet!



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Caring Matters Now International Developments



In March 2016 Caring Matters Now hosted our first International Support Group Conference in London. Thirteen CMN support groups were represented from across 5 continents. During the 3-day conference our guests gained an insight into the work of Caring Matters Now by visiting the CMN research laboratory at the Institute of Child Health and participating in some research of their own, as well as, hearing of the latest research findings and ongoing work from Dr Kinsler and her CMN research team. Our guests also received support training and copies of Caring Matters Now support materials to distribute in their own countries. In addition our guests had the opportunity to attend the London Support Day where they met many of the Caring Matters Now members and families. The weekend was a very special time for all.

Due to the success of the Caring Matters Now International Support Group Conference, we as a charity have decided to further develop our International relations by establishing the

Caring Matters Now International Partnership Scheme. We have invited all existing international CMN support groups and individuals who would like to start or further develop support in their own countries to partner with Caring Matters Now. As a charity, we would like to encourage our international friends to continue in offering excellent support, medical information and up-to-date research findings to those affected by CMN in each country.

As Caring Matters Now International Partners, the groups / individuals, will:

- receive updated Caring Matters Now support materials when created
- have access to Caring Matters Now medical literature
- receive an update on UK research every 6 months
- receive links to all new CMN research papers when published
- have an opportunity to financially support the CMN research taking place at the Institute of Child Health, London
- be invited to future Caring Matters Now International Partnership Conferences

We hope that through this partnership scheme, the support materials, medical information and research findings Caring Matters Now endeavors to provide for all those affected by CMN in the UK, will now be accessible globally.



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

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

London Marathon

We had three amazing runners who took part in the 2016 London Marathon in support of our charity.

Nathan Bevan was the lucky winner of CMN silver bond place ballot and Justin Smith got lucky in the ballot along with Rachel Hutchison.

All three runners did amazingly well, raising over £4,470.00 between them.

Nathan ran in support of our charity as an adult with CMN (you may have seen his story in the last newsletter), Justin ran in memory of his beautiful niece Holly, who sadly passed away of complications associated with CMN and Rachel ran in support of her Nephew, Elijah who has CMN.

I am sure you will all join us in congratulating them all on completing the full 26 miles in remarkable times.



**LONDON
MARATHON**

2016

Elijah - Hannah Cree's Story

Elijah was born on 2nd May 2014, after a healthy, normal pregnancy.

We were "ready for this," we'd planned Elijah, and we'd "had a baby already"- we were "going to really enjoy it this time!"

Elijah was born with a 10/12 cm black mark on his scalp, and a deep cut on his scalp as well. He looked like he had had a difficult time. The midwives said he must have cut his head on my pelvis on the way out and that the mark was bruising. This didn't sit with me, but I thought 'they knew better,' the paediatrics gave him a once over the next day before he went home and were happy there was nothing sinister.

And then the everyday began. Elijah was a terrible baby. He cried every time he was awake, the health visitor spent a lot of time with us and said he was an extremely irritable baby. This started to put strain on Adam and I, and in hindsight poor Ari'Ela took a bit of a back seat.

I only admitted to it a year later, but I had really struggled in these early days with the feeling that Elijah wasn't "perfect." His mark was so obvious, and everywhere we went people looked and asked questions "Will he grow hair?", "Is it sore?" All questions that I had no answer to.

Diagnosis

We went to the paediatrician in August, up until now we knew this was a birthmark and the only problem was that it cut very easily. I still remember the moment that the consultant walked out of the room after telling us that this was a condition called Melanosis, asking about limb movement, explaining that there was a risk of cancer, brain and spinal tumours, learning disability and mental health problems. Adam and I looked at each other in disbelief. It must have been around this time that we met with Dr Alderdice who is our dermatologist, he told us that Melanosis was an old term and told us about CMN, and about Dr Kinsler and Caring Matters Now. We now had somewhere to go for information!

We were referred then for a brain MRI and we would try that as soon as possible without anaesthetic- just using the bottle and swaddle technique.

This didn't work. The machine was too noisy and Elijah kept

waking up so rather than cause him distress, we came back when he was 6 months old and he went under anaesthetic. Then came more anxiety as we waited for the MRI results, which eventually came back as being clear.

Caring Matters Now

It was the day after Elijah's MRI that the BBC One Show featured the CMN, we told all of our friends and family to watch it. There were some difficult stories shown, including that of little Holly - Adam and I felt teary, the future was unpredictable. It was that night that we contacted Caring Matters Now, explaining how isolated we felt in Northern Ireland and asking them what the prospects would be, "Do children with CMN live a happy and healthy life?"

I was then put in contact with our regional support contact Bronagh Cleland who had shared similar

experiences with her little boy Ryan. It was so refreshing to meet someone who knew what they were talking about!

Adam and I are Christian and Adam has experienced healing of both epilepsy and of dyslexia. We believed our kids would be well, we never thought it would 'happen to us,' you never do.

It was the uncertainty of the condition and the rarity of it that made us so fearful. Up until we were put into contact with Caring Matters Now nobody seemed to know a lot about the condition, it seemed to us that either he would have cancer now, or that he would in the future. We would see posts on social media about children who had died due to complications associated with the condition and I found myself looking at the kids thinking "I need to remember this moment incase something happens to Elijah." It was unhealthy thinking, but it felt rational at the time.

GOSH

Great Ormond Street was a turning point for us. Adam and I hadn't spoken to each other much about our worries and we finally sat down to chat over a Pizza Express before our appointment, having just found the hospital. It was a strange feeling- is our child really sick? Why are we at Great Ormond?

continued overleaf >



(We've only ever seen this on the TV!) I asked Adam what he was believing for at our appointment- he was hoping we would be told this was the least threatening type of CMN, I thought he was naive and unprepared for the worst. I had resolved myself to know that God was good and sovereign no matter what, but whilst we are usually an optimistic couple we were feeling fearful.

Dr Kinsler was so comfortable with CMN, she didn't feed into the fear, infact she took one look at Elijah and said "Well, he's doing well isn't he?" She went on to say that his was one of the least threatening types.

We've had no complications with Elijah so far, other than his head cutting- Adam asked about sports in the future, would Elijah be able to play hockey or rugby? Dr Kinsler reassured us not to limit anything for Elijah unless we found that something led to lots of cuts and then we might want to adjust it! We came home feeling like Elijah was finally ours, we felt in control, and we realised we probably hadn't bonded with him out of fear of losing him.



Because the condition is so rare, we have been given a lot of different information along the way. Things we had just taken in as truth i.e. a link with learning disabilities like autism. It was the misinformation that fed the fear. When you are faced with a rare condition like this, you take in every single word a health professional says as you're searching for knowledge and security. Having met Dr Kinsler we feel so much more equipped- we know we have the best knowledge, we are now the experts with other doctors and dermatologists at Elijah's appointments and we have been fortunate enough to be surrounded by medical professionals who have been honest enough to say they "don't know" and are willing to learn from us!

I've been really honest in this write up, maybe you can relate to us or maybe you're experience has been totally different. I am a realist, but I also have a faith that our God is so much bigger than what we face. We're stronger than before



and all the fear has been redeemed for good- with opportunities to fundraise and to raise awareness.

I hope that we can give hope to people faced with similar situations, that you will get through this, that as a parent of a child with a rare disease you ARE the expert and to stay in the moment as all that fear does is rob you.

We feel very much that we have regained control and we are out the other side, but we wouldn't be there without Caring Matters Now! Elijah knows he has "special skin" and we will continue to encourage him to be confident and comfortable in his own skin. As I say this, Elijah is developing more and more satellite Naevi week in and week out and we do worry about other kids and school in the future, but we know we have Caring Matters Now to help us at every step!

How Hannah has helped Caring Matters Now!

When Bronagh mentioned the Belfast marathon to me as a fundraiser I thought that I would organise a few relay teams and I most definitely wouldn't be part of them!



I have never been athletic in anyway and so I watched in awe as Bronagh and my sister partook in the marathon last year!

As I started to mention to people that we were getting teams together the numbers just kept going up and up of people wanting to take part!! Our family and friends offered to join in without needing persuasion, friends were asking their friends and family and 12 of my mother-in-law's colleagues from SSE all jumped on board!! As the excitement built I decided that I would attempt a leg too! In the end we had 54 people running for Caring Matters Now. We later heard of another 10 who had separately chosen Caring Matters Now as their marathon charity!

Among those running were three other families affected by CMN, Adam and Bronagh Cleland, Robert and Sinead McGlone and Gareth and Jasmine Bleakley. We all set out to get sponsors.

We had a reserve list at the ready and it was put to great use right up to the morning of the marathon!! The stress was worth it as each team completed the marathon in great time, a few injuries later, after months of training.

We are so thankful to Product Earth Solutions designing and sponsoring Caring Matters Now t-shirts for every runner! We heard so many people say that they saw the t-shirts all around Belfast on the day!! We hope that this itself raised awareness and the status of the charity in Belfast this year!

It was Elijah's 2nd birthday on the same day, this felt like a milestone! At the start of our CMN journey we weren't sure what life would look like for Elijah when he was 2! So we had a party after the marathon



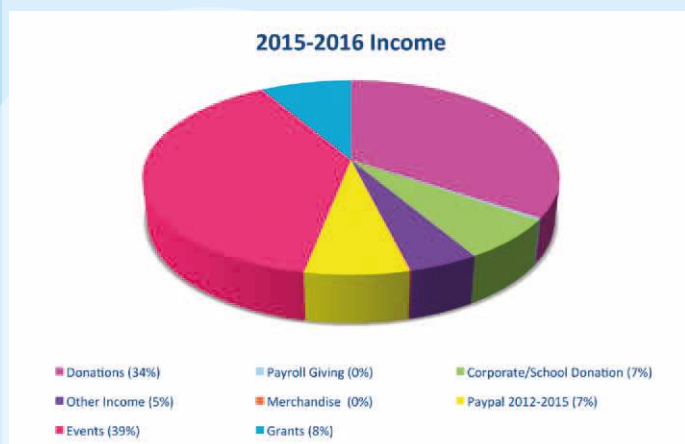
for him and our friends and family who had ran with or supported us that day! Aware that people are always being asked to give money to charities left, right and centre, we organised a raffle to give back to those who have shown so much love and support to us! The raffle prizes were incredible thanks again to generous friends, family and work places- it included VIP tickets to Elton John in December kindly donated by SSE and tickets to Ireland v Canada rugby match donated by Bronagh Cleland's dad! We are so thankful!

So far we have raised over £5000 with donations still coming in! I am delighted that 64 people have touched the people around them with knowledge, awareness and real life stories of those affected by CMN.

Charity Financial Report 2015-16

Income

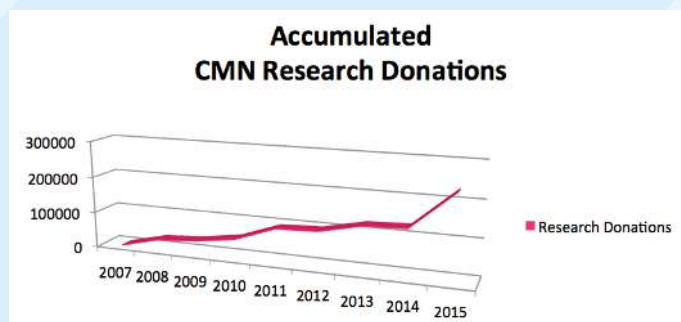
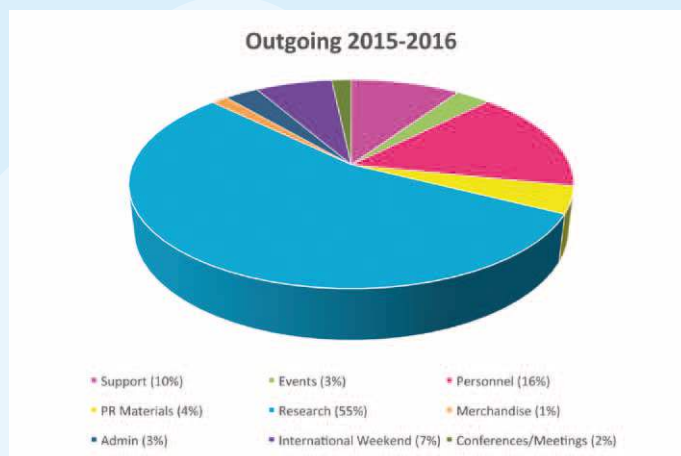
In the financial year 2015-16 the charity received a total income of £119,179, with donations and charity fundraising events making up the vast majority (73%), followed by grant income (8%), corporate/school donations (7%), PayPal receipts (7%), and payroll giving (less than 1% at £379.00).



Expenditure

In the same period, the total outgoings for the charity were £184,269. Since 2007 the charity's expenses have steadily risen each year, primarily due to the growing size and complexity of the charity. The charity's largest outgoings are always the funds paid for research to GOSH to support both CMN research and the dedicated CMN clinic, and the last financial year was no exception. The charity paid out a whopping £101,057 (55%) for research, making the total research donations since 2007 an incredible £230,078!

Other expenditure included; salaries (16%), support events (10%), international events (7%), PR materials (4%) and general administrative costs.



For further information please see the Annual Report for 2015-16 which is available on the CMN website:

<http://www.caringmattersnow.co.uk/about-us/annual-report/>

CMN Support Days

Funded by Children in Need

Over the past three years, Caring Matters Now has received funding from Children in Need to support the work of our charity.

We use the funds to hold support events across the UK to reach as many families affected by CMN as possible.

These events have a very positive impact on those that attend and Jasmine and Michelle tell you how.

Jasmine – A daughter's perspective

Hello my name is Jasmine and I'm nine years old. I have a large CMN birthmark on my right cheek which went all the way up to my eye and covered half my nose. I have had six surgeries to reduce my birthmark. The first one was when I was a tiny baby, only nine months old and the last one was in April last year.

After my surgery last year, I was really scared to go outside and I hid under my Mummy and Daddy's bed, as I thought people would stare at me and say horrible things about how I looked.

At my school I am the only child with a large birthmark on my face. Sometimes other children are mean to me about my birthmark and bully me at school or at the activity day camp I go to during some of the school holidays. They call me "ugly" or "Scarface". This makes me feel really sad but I think 'What's the worst that can happen?'.

When I go to the CMN London support day I am able to meet other children with the same type of birthmark that I have. I can chat to them and I can tell them about my surgery and what it is like. I like to share my experience with others because it helps them and that makes me feel happy and good about myself.

At the last London support day I prepared a speech. It was a little bit scary, because I spoke in front of a large crowd of 100 people but I wanted to do it so I had courage and I felt really happy because I was able to share my experiences with others and help them.

When I go to the support days, every year there's something different to do. I like helping my Mummy on the registration desk and there are arts and crafts and children's entertainers. It's lots of fun and I get to meet lots of other children with the same type of birthmark as me. It makes me realise that I'm not the only person like this, lots of other children are going through what I am and it's good to be able to speak to them about it and discuss my feelings with them.

At the London support day last year I spoke to a little girl of about 7 to 8 and she told me how she was feeling as she was about to have surgery like me. I helped explain to her that she would be put to sleep and she wouldn't feel a thing. The girl felt a lot better after I spoke to her and she was less scared about her surgery and that made me feel really happy that I was able to help her.

**Thank you,
love from Jasmine**

Michelle – A mother's perspective

Our daughter Jasmine who is nine was born with a large CMN, which covered nearly all her right cheek and half her nose and went up very close to her eye. Her CMN was a surprise to us when she was born, as the pregnancy scans cannot pick up on this condition. As soon as she was born, we were filled with an overwhelming sense of love for her and a desire to protect her. We were sad that she would have to go through surgeries and be left with a scar and we wished that we could go through the surgery for her, instead of her having to do so herself.

We saw a lot of different consultants and specialists, none of whom knew much about the condition or those who did, were not comfortable treating Jasmine, as they had not dealt with a CMN in the same position as she had and they were worried about the potential consequences of performing surgery on her.

We asked to be referred to Great Ormond Street Hospital as we felt that they must have specialists there who would have come across and be able to deal with Jasmine's condition. We were very lucky to find Mr Bulstrode, Jasmine's plastic surgeon who has performed six surgeries on her now to great effect. He

told us that if she did not have surgery, her CMN would be a blight on her life because of its size and position on her face. Jasmine had her first surgery when she was only nine months old and she had her last one in April 2015.

As Jasmine has grown up we've been very conscious to try and make her as confident and resilient as we possibly can. She is a beautiful, intelligent, sociable child with a caring heart and a great sense of humour. When Jasmine was a small baby we did some research on the Internet and we found the birthmark support group, however many of the people at the group

had other types of birthmarks therefore we didn't feel that that organisation was appropriate for Jasmine or our family.

We then found the Caring Matters Now support group on the internet and we travelled up from London to Cambridge for a support day there. Jasmine was only about two years old and my son was only a few months old. We were immediately made to feel welcome and we suddenly felt as if we had come home and we had found an extended family who completely understood everything that we were going through, without us even needing to explain it. Jasmine and her younger brother, who does not have CMN, have always both been extremely comfortable at the support days. They are good fun for the



children with CMN and their siblings. It also gives the parents an opportunity to speak to other parents who are going through similar situations. They are also attended by Dr Kinsler who carries out the research into the condition at Great Ormond Street Hospital and for many parents it is the first time that they are able to get detailed medical answers to their questions from an expert who understands the rare medical condition and its effects and also information about treatment and hopefully one day a possible cure.

When Jasmine had her sixth surgery at Easter last year, for two days afterwards she hid under our bed and refused to leave the house. This was so unlike Jasmine who is very confident, sociable and bubbly and it was very upsetting and difficult to deal with. It took a long time for me to persuade her to walk just to the sweet shop at the end of the road and we had to rebuild her confidence step-by-step very gradually.

That's why we were absolutely thrilled when at the London support day last year, Jasmine voluntarily decided with an older girl that she met there on the day for the first time that they wanted to give a speech having only half

an hour beforehand to prepare. The girls formed a deep bond of friendship and they gave the most inspirational heart-warming talk to a crowd of 100 people. We were incredibly proud of her and she was able to speak confidently and articulately to a large crowd of people, many of whom she did not know, because she spoke from experience and from the heart. There was not a dry eye in the house and it was such a good thing for her to do on a personal level as she felt that she was helping others by discussing how she feels when people make comments about the way she looks and about how she deals with it. She was able to give other children and their parents coping strategies for when the children are bullied or are lacking in confidence about their appearance, which was really admirable and we were and

continue to be incredibly proud of her every day. This really helped to rebuild her confidence.

Jasmine really looks forward to going to the support days as there is a real sense of community there and as she gets older she enjoys helping out at the support days. Last year she was on the registration desk with me and she also gets very excited about coming out with us to choose and buy some of the raffle prizes which we donate each year. She is also a keen fundraiser at school and does cake and sweet sales to raise money for the charity. Jasmine wants to be a paediatric plastic surgeon like her surgeon Mr Bulstrode and she reads medical books religiously.

Because CMN is such a rare and specific condition, it's so important for families with children suffering from this condition to be able to get together so that the children realise that they are not alone and to build their confidence about having a

visible difference in a society that is so image conscious. It is also an environment in which the parents can speak openly and freely about how they are feeling in dealing or in some cases not dealing so well with the situation and to get the emotional and medical help

and support that they need in a safe, supportive, caring and non-judgmental environment. The support days are informative, positive and upbeat and something the families and their children look forward to each year.

It is through the support days that we have become more involved in the charity. We got so much from them that we wanted to give something back and help support other families in the way that we were supported when we joined the charity initially. I'm now the London regional support contact and my husband is a trustee and treasurer of the charity. We have no doubt that when Jodi retires in many years to come as CEO, Jasmine will be the first one knocking on her door to volunteer to be her successor.



Upcoming Events

LIVERPOOL SUPPORT DAY

When? Saturday 09th July **Where?** Bridge Chapel Centre, Liverpool, L19 4XR

What? A support day for all those affected by CMN and their families, with Dr Kinsler attending.

GLASGOW REGIONAL GATHERING

When? Saturday 20th August **Where?** Airspace Playsport, Stewartfield Way, East Kilbride, G74 4GT

What? A local gathering of CMN members - an opportunity to chat and develop friendships

TEENS BIG DAY OUT

When? Saturday 10th September **Where?** Warner Bros. Studios, London - The Harry Potter Tour

What? A social gathering for all those affected by CMN aged 12yrs - 17yrs

This is a pre-bookable ticket event!

EAST ANGLIA REGIONAL GATHERING

When? Sunday 11th September **Where?** Bewilderwood, Horning Road, Hoveton, Norfolk, NR12 8JW

What? A local gathering of CMN members - an opportunity to chat and develop friendships

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