



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

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High Hopes for 20th Anniversary Celebrations

Caring Matters Now are delighted to announce their 20th Anniversary Celebratory Ball

Caring Matters Now is holding a prestigious 20th Anniversary Celebratory Ball at the Hilton Hotel in Liverpool on Saturday 3rd June 2017.

The Caring Matters Now Trustees would like all our members to join us in celebrating the success of Caring Matters Now over the past 20 years. We feel this is not only time to look back and celebrate the past 20 years, but also look ahead and be excited for what the future holds.

The success of the last 20 years could not have been achieved without the support of all our members, their families and friends.

During the evening, which will consist of a champagne drinks reception, 3-course evening meal and drinks, a charity auction and finishing off with a live band and dancing, we hope to raise much-needed funds.

Our goal is to raise £32,500 at this event, the amount needed to fund a Rare Disease Research/



Clinic nurse at Great Ormond Street Hospital. The nurse will be an important support to the CMN research team in Great Ormond Street, who are leading research on treatment that aims to stop CMN from being a potentially fatal condition.

We really do hope that you can join us and support this momentous occasion; we can guarantee you a fantastic evening.

If you are in a position to support this event beyond attending - such as donating an auction item, encouraging your work place to purchase a corporate table or even a corporate sponsorship package - I would be delighted to hear from you.

Your personal contacts are key to us raising the funds needed to support the pioneering research into treatments for CMN. Please do email me directly if you think you can help: jodi@caringmattersnow.co.uk.

You can book your tickets via the Caring Matters Now website <http://www.caringmattersnow.co.uk/cmn-20th-anniversary-celebratory-ball/>



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My Story

by Val Unsworth, mum of Jodi Whitehouse (Unsworth)

The grief began with the words "It's a girl!" gasp emergency (we mustn't let the mother see her child yet) door flies open in rush about 8 people I just lie there numb no emotions no joy just have the knowledge that all is not well oh god I want Joe where is he please get him chaos in the room only 2 people are calm - the Doctor methodically stitching me up and me - the mother of this newly-born abnormal child but what is this abnormality????

Forty-five minutes later through my wild thoughts, "Mrs Unsworth....you can hold your baby now but she has a slight birthmark, nothing to worry about ... here she is... what are you going to call her?"



Jodi Ann Unsworth

Born at
Liverpool
Women's Hospital

6th September 1980

We named her **JODI ANN** – a longed-for firstborn child. A beautiful child. A child who looked the image of her father - my husband Joe. But an abnormal child. A child with a rare skin abnormality. A number of hours after her birth we discovered that this "slight birthmark" covered 80% of her body. The largest mark was on her trunk and was very dark and hairy. The skin on her back looked like a severe burn as it was sore and weeping; we were told it might never heal. I found it very distressing that for months I had to apply dressings to Jodi's back, all the time wondering if I would have to do it for the rest of her life.

At two weeks old we took Jodi for a second opinion, only to be told "she may live for a few days or until she is 70". At that

moment Joe and I realised that doctors were as much in the dark as we were. Nobody knew the name of this abnormality or whether there was anyone else in the world who had it. For almost a year we struggled along; I shed countless tears.

Diary entry 16th August 1981

My beautiful abnormal daughter is now nearly a year old – in 21 days we will be 'celebrating' a year of grief ... Why me? Why is life so hard on people? Why is there so much suffering in life?

LIFE What is it all about? My life consists of a great many tedious things – nappies; dusting; washing; ironing; cooking - the list is endless ... But the worst aspect of my life is the deep

and never ending grief at having an abnormal child! Everywhere I turn the 'abnormality' stares me in the face.

"Oh God, please cure my daughter – may she no longer be abnormal but normal. Please God, cure her."

Two days after Jodi's first birthday, another night of many tears disappeared into my past ... but what had my tears achieved? Why did I weep for so long, well into the middle of the dark September night?



6th September 1980

First Birthday

At first, my tears were tears of grief – like so many tears I had shed before. They were pouring down my face as thoughts whizzed through my head ... my firstborn child is abnormal ... my poor daughter will have to cope with this abnormality for the rest of her life ... how will she face endless hospital visits and frequent operations ... how will she survive at school when other children mock her ... will she ever get married with such an abnormality ... and why, why do I feel so responsible?

Then my tears turned into tears of self-pity ... Why me? Why did I have to have an abnormal child? Why has God allowed this to happen to me ... me of all people?

Why should our lives be so radically changed? Why has God singled us out to have grief and sorrow as a constant fact of our life? Why has she got this abnormality when I never drank, smoked or took medication of any sort during pregnancy and other women all around me do all three and have normal children? Why has this tragedy happened to us?

And so the tears continued to flow....

1981 - 1997

For Joe and I the first fifteen years of Jodi's life were years of isolation and uncertainty, as so little was known about this rare abnormality. We also had to cope with medics seeming unsure what to do and a strong sense of Jodi being a 'guinea pig' whilst she endured 30 plus operations. Throughout these long, difficult and lonely years, our faith sustained and kept us as we clung to the God we love and who we knew had knit her together:

"For you formed my inward parts; you knitted me together in my mother's womb. I praise you, for I am fearfully and wonderfully made.... My frame was not hidden from you, when I was being made in secret... Your eyes saw my unformed substance; in your book were written, every one of them, the days that were formed for me when as yet there was none of them."

Psalm 139 verses 12-16

During Jodi's early years, in the midst of my many tears, these words brought great comfort to me even though I could not understand why God would choose to create her this way. I



knew that our God was a loving God – not a cruel God – and so deep down I did believe He not only had a good and wonderful plan for Jodi, but also a far greater purpose in mind beyond ourselves.

In 1995, when Jodi was 15, we met Dr. Atherton for the first time. Little did we realise that this was the start of God's wider plan unfolding. At a consultation in 1997, Dr. Atherton asked Jodi if, with our help, she would consider starting a support group for those affected by **Congenital Melanocytic Nevus**. Without even pausing for thought, Jodi instantly said yes!



Caring Matters Now

Founded 1997

THE YEARS THAT FOLLOWED:

"A picture paints a thousand words."



SO WHAT DO WE HAVE TO CELEBRATE?

In those dark early years of Jodi's life I had so many questions but today, as I look back down the past 20 years, not only have I been given many answers to my endless questions, I also have SO much to celebrate:

 What I saw as a tragedy for many years has proven to be an amazing blessing from God.
He certainly had a plan and a purpose!

 The opportunity and awesome privilege of establishing Caring Matters Now, which today supports families not just in the UK, but also across the world!

 The phenomenal amount of money raised for Caring Matters Now, which funds the dedicated and tireless research of Dr. Kinsler and her team.

As I reflect on the years since Jodi was born, I am so thankful that no other family needs to face CMN alone. I am also overwhelmed as I never dreamt that in my lifetime the cause of CMN would be discovered - let alone the possibility of a cure! Yet in 2017 this is the incredible reality!



CMN 20th Anniversary - Fundraising

Yorkshire 3 Peak Challenge – 20th May 2017

Val Unsworth, fellow founder of Caring Matters Now (Jodi's Mum), wanted to do something special to celebrate our charity's 20th anniversary in 2017. So, to mark this memorable event, Val is participating in the Yorkshire 3 Peak Challenge on 20th May 2017 to raise funds for the charity.

Would you like to join her on this epic challenge? The Next CMN Challenge Team! Take a look www.caringmattersnow.co.uk/yorkshire-3-peak-challenge



CMN Coffee and Cake Morning 23rd – 25th June 2017



Join in! Everyone can be a part of the fundraising in 2017! Organise a CMN Coffee & Cake morning. The dates are the weekend of Friday 23rd June to Sunday 25th June 2017 so put these dates in your diary now! Choose a date that suits you!

This is a fun and easy way for all of us, regardless of where we are in the UK, to get involved and help raise funds for Caring Matters Now.

Taking part will be an opportunity to get together with friends and family for a great cause, whether at home, school, or your place of work; there are many possibilities. www.caringmattersnow.co.uk/coffee-cake-morning-weekend-2017/



Tandem Sky Dive – 2nd September 2017

After a very successful event in 2014, Caring Matters Now and Click & Jump have teamed up to offer you a tandem day at BPS Langar Airfield, Nottingham, on Saturday 2nd September 2017 to celebrate the charity's 20th anniversary.

Check it out and sign up! Bring along your friends and family for support...it's a great day out for all! www.caringmattersnow.co.uk/raise-money-cmn-completing-tandem-skydive-2017



Fundraising Challenges 2017

20th Anniversary Celebratory Ball – 3rd June 2017



Caring Matters Now is holding a prestigious 20th Anniversary Celebratory Ball at the Hilton Hotel in Liverpool on Saturday 3rd June 2017. The aim of the event is to celebrate the huge success of the last 20 years and to raise funds to support the work of Caring Matters Now, including the CMN research at Great Ormond Street Hospital.

We would love you and all our members and supporters to join us in celebrating this momentous occasion. You can book your tickets to our celebratory ball on our website. This event promises to be one not to be missed!

www.caringmattersnow.co.uk/cmn-20th-anniversary-celebratory-ball/

Australian Challenge – 16th July 2017



We are teaming up with Nevus Support Australia to form a CMN team to take on the Winery Marathon in Sydney Australia on Sunday 16th July 2017. This is our 4th challenge in reaching our aim to complete 7 challenges on 7 continents. We already have two runners signed up to the Winery Marathon in support of Caring Matters Now.

If you are based in Australia or know people that are and would like to join the team (or would like an excuse to visit Australia), sign up **NOW!**

www.caringmattersnow.co.uk/support-next-7-challenges-7-continents-event-australia-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/

JESSICA MA AWARD 2016

WINNER & RUNNER UPS

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.

Jessica was passionate about Caring Matters Now and the trustees feel her loss immensely. Jessica left a lasting legacy and we will forever be indebted to her.

The Caring Matters Now trustees wanted to publicly acknowledge and remember Jessica's outstanding and unique contribution to our charity.



So, with the consent of Jessica's family we started the search in 2016 for a winner of the prestigious 'Jessica Ma Award'. This award is for an individual or group who have gone above and beyond in raising funds for Caring Matters Now.

So, for all those that completed the fundraising event registration on our website throughout 2016, you were all in with a chance of being selected!

The winners are:

Jon and Donna McCrossan

Peter, Jasper and Pascale decided the winning award very much deserved to be presented to Jon & Donna McCrossan.

This is what they said:

"For the outstanding amount of money raised and the ongoing efforts and numerous fundraising opportunities during a very challenging time for their family. We would like to award the inaugural Jessica Ma Award to Jon and Donna McCrossan."

Jon and Donna commented: "Thank you so so much, we feel very privileged to not only be considered but to actually win this beautiful award in honour of another inspirational



person and we accept it - with pride - on behalf of Team Holly, as we cannot do what we do without our fabulous family, friends and supporters.

We are very lucky to be surrounded by such a wonderful supportive community.

We do our fundraising in remembrance of our daughter Holly, who sadly lost her life to complications of CMN and to help raise much needed awareness of the condition and to support the ongoing research into finding a cure. Together, we will get there!"

#goteamholly



And the Runners Up Prizes go to:

Isabelle Armstrong

"Isabelle Armstrong. The bravery and effort of someone only 7 years old is an inspiration to all of us. Keep up the good work and thanks to your mom for all the support!"

Isabelle & her family commented: "We started fundraising for Caring Matters Now in 2014 as a way to show our immense appreciation for the information and support we received from the charity at a time when we were left feeling helpless."



Isabelle has grown in confidence over the last couple of years and is always thinking up new ideas to raise funds for Dr Kinsler and her team to enable them to continue with their amazing research and to ensure the charity continues to grow so that other families are able to find the support that they need.

Isabelle was super excited when we told her she was a runner up for the 2016 Jessica Ma Award.

This could not have been achieved without the continued support of our family and friends - thank you."

Hannah Cree

"Hannah Cree. For her ongoing efforts in fundraising and for bringing in an amazing amount of donations by organising & running the Belfast Marathon relay."

Hannah commented: "I am both overwhelmed and so thankful to have been awarded runner up for the Jessica Ma Award!

Caring Matters Now equipped us with the knowledge and confidence we needed for life with CMN, they lifted our chins up and inspired us with the ground breaking research they are partaking. It is an honour to have been raising awareness and funds for this charity, thank you."



Huge congratulations and a very big thank you to you all!

Thank you all for your continued support in 2016. We could not do what we do without your dedicated support and amazing fundraising!

We are making huge strides in the CMN research and are able to provide the much needed support and friendship to all those affected by CMN. We want



to be able to continue; we want to develop the support further and strive to make a difference! We will continue to fund research until we get the treatments needed for all those affected by CMN!

Please help us to make 2017 a year to remember.....

Wishing you all a happy and prosperous 2017.

Research Report by Dr. Kinsler

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

Thank you

It's back! The fun filled CMN Activity Weekend!

7th – 9th July 2017

All age groups welcome. Come and join the fun!

PGL Centre: Osmington Bay
Arrival Date: Friday 7th July 2017
Arrival Time: 15.30 onwards
Departure Date: Sunday 9th July 2017
Departure Time: 18.00
Board Basis: Full Board

For more information or to confirm your place please visit the website
[www.caringmattersnow.co.uk/
family-activity-weekend-2017/](http://www.caringmattersnow.co.uk/family-activity-weekend-2017/)



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 attends all our support days and gives an update on the CMN research. **Come and join us:**

LOCATION	VENUE	DATE	TIME
LONDON	Islington Upper Street Venue 277A Upper St, Islington, London, N1 2TZ	Sat. 11.03.2017	12pm – 4pm
LIVERPOOL	Bridge Chapel Centre, Heath Road, Liverpool L19 4XR	Sat. 06.05.2017	1pm – 5pm
GLASGOW	TBC	08.2017 (tbc)	TBC

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
N. IRELAND (Belfast)	W5, The Odyssey, 2 Queens Quay, Belfast BT3 9QQ	Sat. 28.01.2017
SOUTH EAST (Guildford)	Wildwood Adventure, Peacock Wood, Lido Rd, Stoke Park, Guildford GU1 1HB	Sat. 20.05.2017
SOUTH WEST (Bristol)	Bristol Zoo, Bristol Zoo Gardens, Clifton, Bristol, BS8 3HA	Sat. 17.06.2017
NORTH EAST (Bridlington)	Chalet 35, Bridlington South Beach, Princess Mary Promenade, Bridlington, YO15 3LG	Sat. 10.06.2017
EAST ANGLIA (TBC)	TBC	Sun. 10.09.2017

Adults with CMN Social Gathering

We welcome all adults with 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
LONDON	The Wesley Hotel, 81-103 Euston Street, London NW1 2EZ	Sat. 11.02.2017

Teens Big Day Out

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
LONDON	72-76 Eversholt Street, London, NW1 1BY	Saturday 16.09.2017

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

