

Dr Kinsler wins Award!

July 2015

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Dr Veronica Kinsler wins the coveted Great Ormond Street Hospital 2015 Child and Family Award

This award is given to a very special individual or team nominated by a patient, parent or carer, who is a great team member and is always welcoming, helpful and expert.

There were over 200 nominations received in this category and Dr Kinsler received more than 50 nominations, a record number. The panel, which was chaired by the Chief Executive and included staff and a parent representative, noted that many of the nominations spoke about the research Dr Kinsler is doing into CMN which provides patients and parents with reassurance that they are being treated by a world class specialist, and provides hope that there may be improved treatments – even a cure – in the future. The nominations also talked about Dr Kinsler as a person – her care and compassion, the respect she shows to families, and the personal dedication she demonstrates. The panel felt that Dr Kinsler was a very worthy winner of this year's Child and Family Award.

A message from Dr Kinsler:

To all the children and families who nominated me for the GOSH child and family award, I am overwhelmed by your nominations for this award. I cannot tell you adequately how much it means to me that you feel I am looking after you well, and that you can see that I am trying my best for you even when I can't yet offer you treatments for this disease. Occasionally in Medicine there are true partnerships between patient groups and individual doctors, which are in fact largely based on mutual trust built up over many years, and as a result are often a highly successful and productive way to tackle disease. This is one such pairing, and this award is such a boost to me to know that overall we are proceeding in the right direction in this long haul, life's work project of sorting out CMN.

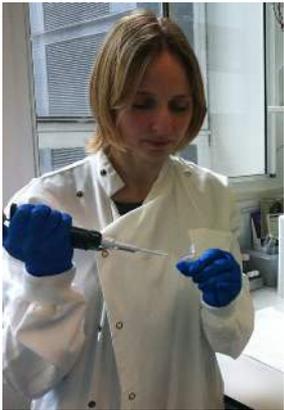
With many thanks to you all

Veronica Kinsler

Fay also had a message for Dr Kinsler on behalf of her and all patients with CMN:

"I am so pleased that you won this award, you really deserve it. You do so much for children like me and do so much more than you need to. What you do has helped us to understand CMN and we would not know what we know today without you. Thank you for being so kind, caring and for everything that you do. You make living with CMN so much easier, thank you."

We are absolutely overjoyed to hear that Dr Kinsler has won this award. Jodi & Lucy would like to thank all those who voted.



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

Email: ICH.CMN@ucl.ac.uk

As you might remember mutations in the gene *NRAS* are responsible for 80% of cases of CMN. It is now possible to have this gene tested for on the NHS within Great Ormond Street Hospital. So all patients who come to clinic can ask to have it tested for, and we will be offering it. This test involves a small skin biopsy, which is similar to having a blood test done, and we usually get the results within a few weeks.

This test can't be done on the day of your clinic appointment unless we know in advance, so if you already know you would like the test done you can contact Caring Matters Now funded database manager Mrs Lorraine Rowe on l.rowe@ucl.ac.uk and we can organize it. Lorraine works only on a Wednesday morning so don't worry if the reply takes a little while. If no mutation is found in the *NRAS* gene we will then ask for consent to look for new genes which cause CMN (without taking another biopsy). Identifying other genes helps us to understand how *NRAS* is having its effects, as it identifies common pathways leading from each gene, which is very useful going forward looking for treatments that might help with CMN.

We are nearing completion on experiments on the new gene we have found in families which does not directly cause CMN but seems to make it more likely to happen in some families. This is what our research assistant Lara Al Olabi, half-funded by Caring Matters Now, has been working on in her 6 months a year on CMN. This is very important research as it has major implications for melanoma in people without CMN as well, which is not only useful but allows us to have our research noticed by a wider scientific community. The results of this study are not yet published but we hope will be published in 2015. Much more work will be done on this gene for which we have received funding from the Wellcome Trust. This funding pays for all of my salary for the next 4 years, and that of a post-doctoral research assistant, Dr Anna Thomas. All this work is directly relevant to CMN.

Next month we are recruiting a PhD student to take up the 3-year Caring Matters Now Fellowship. The student will start in October, and will be working on a treatment study in the laboratory, jointly supervised by myself and Prof Steve Hart in the gene therapy research department. This will only be in the laboratory, not in patients. This is a first opportunity for us to look for ways of treating the problem of CMN at its source. As part of this study we will be hoping that some CMN patients would give us a skin sample (little skin biopsy, similar to having a blood test) so that we can grow some of their CMN cells in the lab. This will be completely optional and part of the research, not part of normal medical care which will continue as usual. It should be possible however to try to coordinate it with normal clinic appointments to reduce travelling. Information about this will be sent out once it starts.

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

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, text donate to Caring Matters Now and make a difference today.

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

TEXT - CMNR15 £5 to 70070

Three Inspiring Volcano Challengers



We have three inspiring and rather crazy dads taking on the ultimate challenge for Caring Matters Now.....Conquering the Avenue of Volcanoes in Ecuador!

Joe Unsworth, Dad of Jodi, founder and CEO of Caring Matters Now, Nick Atter, Dad of James (8yrs) with CMN and Phil, Dad of Callum (14yrs) with CMN have all committed themselves to the ultimate challenge in a bid to raise awareness and much needed funds for their children and all those affected by CMN.

This really is the craziest challenge to date!

- **Higher than Mt Kilimanjaro**
- **Trekking at high altitude in the Ecuadorian Andes**
- **Climbing Cotopaxi, the world's highest active volcano**
- **Finale is the glacier summit using crampons & ropes**

This challenge not only requires fitness and strength of mind, but a massive amount of hard work, time, dedication and a huge financial commitment beforehand. These three dads really are giving it their all and we would like all our CMN members to get behind them.

These guys are giving so much for all of us affected by CMN, please show your support, visit their team page; www.justgiving.com/teams/CMNVolcanoVenture



CMN Adult Gathering - by Alkin Emirali

By the time you get to your mid-forties many of your monumental 'first time experiences' are way behind you, but there I was on my way to attend my first ever 'adults with CMN gathering'. This would be my first time meeting anybody else with CMN.

I came across the term 'congenital melanocytic naevi' six years ago, and only because my partner and I were expecting a baby and I wanted to find out if this 'thing' I had would be passed on to our baby-to-be.

So, what was it like at the gathering? Well I felt very, very welcome but also a little self-conscious. I guess I'm used to being the only freak in the room. Having CMN poses very few problems for me, but all of a sudden I'm amongst people who apparently share the same 'condition' as me. It's like being in a room full of mirrors; you can't escape the fact that is literally, in my case, as plain as my face.

The other thing that made me self-conscious was the uniqueness of different people's CMN. There were some people there who you wouldn't know had CMN, their clothes hid their marks. There were others who were more visibly marked. So here's the thing; I've had a lifetime to get comfortable with the way I look but it does not follow as a direct consequence that I'm instantly comfortable with other people's differences.

So what did I take away from this gathering? It was great to meet other people who were confident and comfortable in their own skin and I was disarmed by the openness and honesty of virtual strangers, but perhaps I discovered something more profound.

I certainly haven't allowed the way I look to hold me back, quite the reverse. The way I look has informed the way I think and act in many positive ways, but I did learn that having excellent ways to navigate one's way in the world is not the same as confronting who you are. I'm glad to say that in my mid-forties I have more growing and learning to do and I'm thankful to Caring Matters Now for being the trigger for that.



Alkin & his family

Meet our Regional Support Contacts

Here we introduce the CMN Regional Support Contacts who are carefully selected to provide our CMN members with dedicated personal support. They are all in some way affected by CMN, so have the personal experience and knowledge to give informative advice.

**Don't feel alone;
Get in touch with
your local support
contact.**

Regional Support Contacts:

- Provide a listening ear by telephone, email or face to face contact
- Provide information in the form of booklets, leaflets etc
- Support you in your fundraising efforts
- Connect you with other families local to you who are affected by CMN or NCM



Scotland
Anne MacIntyre
0141 646 1069

anne@caringmattersnow.co.uk

I became involved with Caring Matters Now in 2001 when my daughter Erin was born with CMN. We attended the Liverpool family day when Erin was only two months old. This was where we met Jodi and became part of the support group. I found the group to be a great support through the difficult times, and it was then that I decided to give something initially becoming a regional contact for Scotland offering help and support to families in the local area. A while later I agreed to become a trustee of the charity and joined the board in 2007.



Scotland Highlands
Jenny Deschenes
01397 712181

jenny@caringmattersnow.co.uk

My name is Jenny; I was born and brought up on the island of Whalsay in Shetland. We live in beautiful Lochaber in the West Highlands. Our daughter Mia was born in 2006 with a large CMN covering her back, she also had 3 on her scalp and she has numerous satellites. Finding Caring Matters Now and having their support was a significant benefit to me in learning to cope and understand Mia's condition. I hope in turn that I can provide support and help now in my role as a Caring Matters Now regional support contact.



Ireland
Bronagh Cleland
00353861905853

bronagh@caringmattersnow.co.uk

My name is Bronagh; I live in Malahide Co. Dublin, Ireland with my husband Adam and our four children. We contacted Caring Matters Now last May when our youngest son Ryan was a week old. We visited the CMN clinic in Great Ormond Street Hospital last July and were relieved to learn of the research that is being undertaken. We then attended the charity dinner in London last September and shortly afterwards I took on the role as regional support contact for Ireland. I am keen to support other families in my role & fundraise for the charity.



North East
Nick and Rosinha Gollop
01262 601944
nick@caringmattersnow.co.uk

Our daughter Amy was born 12 years ago with a bathing trunk CMN. Caring Matters Now was a great support to our family, particularly during those early years, and we have made good friends with other families belonging to the charity. We feel Amy has benefited by getting to know positive role models, such as Jodi, and by developing friendships with children her own age with CMN. This has contributed to Amy having a successful and enjoyable first year at secondary school and why we want to be able to help other families.



**North Wales, North West
England**
Jodi Whitehouse
0151 281 2820
jodi@caringmattersnow.co.uk

I am the original founder of Caring Matters Now. I have CMN & therefore understand the impact living with CMN can have on an individual. Caring Matters Now has grown from strength to strength over the years and I see it as a real blessing and privilege to be a part of the charity. I have met some amazing people who are involved in Caring Matters Now & I strive to provide the support needed by all affected by CMN.



Wales & South West
Sheila Mackenzie
01752 772415
sheila@caringmattersnow.co.uk

Hi, my name is Sheila MacKenzie, CMN support for SW England & Wales. I have been associated with the charity since 2003 when my daughter Eva was born to my husband Colin and I. Eva has a bathing trunk CMN and satellites. We have greatly valued the hugely supportive membership. We all have one aim, to do the best for our family members who have CMN. I am here to listen, discuss, coordinate and hopefully be a friendly support.



South & Central

Susanna Hoar

01483 579647

susanna@caringmattersnow.co.uk

My youngest, Elspeth, was born in 2005. She has a bathing trunk naevus on her back and many satellite naevi. Elspeth was 4 at our first family support day and was delighted to see others with "special Elspie marks". We have received invaluable support and she has gained special friendships and confidence through attending family days and activity weekends. As a Regional Support Contact I hope to offer other families the support that we have so greatly benefited from ourselves.



South East

Catherine Brown

01273 203285

catherine@caringmattersnow.co.uk

I am mother to daughter Luca who is 13 and has CMN. We live in Brighton 5 minutes from the sea. We discovered the group when Luca was 3 and the group and that first family fun day had a huge impact on our lives. It gave us all strength in the feeling of solidarity with other families facing similar issues. I became more involved as we had benefitted so much from the group and wanted other families to too.



London

Michelle Chance

0208 852 1110

michelle@caringmattersnow.co.uk

My name is Michelle and I have a nine year old daughter Jasmin who was born with a large CMN on her right cheek. Jasmin has had six operations at GOSH (serial excision and two skin grafts.) Jasmin is confident and sociable and her whole family is exceptionally proud of how resilient she is and how she copes with her condition. I became involved with the charity about five years ago, initially attending the family days. In 2011 I became the regional support contact for the London and Middlesex regions.



East Anglia

Lucy Hardwidge

07786 458883 / 01954 719612

lucyh@caringmattersnow.co.uk

I have been involved with Caring Matters Now since the birth of my daughter Fay in 2005. Fay was born with a large bathing trunk CMN. We first learned of the charity through Dr Atherton at GOSH and we travelled from Cambridge to Liverpool to attend our first support day. It had such a huge impact on our family we instantly wanted to be involved. In my role as regional support contact I want to be able to support others as we have been supported by members of Caring Matters Now. I am also contracted as the Charity Development Officer and now oversee the charity on a day to day basis working closely with Jodi and the trustees.



Midlands

Julie White

01636 611 361

ulie@caringmattersnow.co.uk

Hi my name is Julie and I am your regional coordinator for the East Midlands. I am a working mum of 4 children; Luke who is now 15 was born with a facial CMN. After experiencing a roller coaster of emotions when Luke was born and wondering what the future held for him, I felt it would be really beneficial to link up with other local CMN members. I felt the role was important to support other families with children affected by CMN, something I would have benefitted immensely from. Luke is now a very successful 15 year old. My role also enables me to show how inspirational our children are and their bright future through the experiences I can share of Luke.



NCM Support - UK Wide

Hayleigh Crowe

hayleigh@caringmattersnow.co.uk

My name is Hayleigh Crowe. I'm married and have four children. We recently moved to Cornwall. Before the children I worked in the pharmaceutical industry but after having my eldest daughter Anna-Grace I became a full time carer as Anna-Grace was born with CMN with many neurological complications. She has had numerous brain and spinal surgeries and needs full time care. Being there to help support and listen to families with such needs can make a huge difference.



International

Simone Costa Araujo

020 8998 0484

simone@caringmattersnow.co.uk

My name is Simone Araujo, Mummy of 5 year old Mateus. Mateus was born with a large CMN on his back and small satellites all around. We got to know about this amazing group through Dr Kinsler when my child was about six months old. My husband and I try to get involved as much as we can mostly on London events - that's how we got to know and became friendly with most families in the group. We hosted Didier and his mother Luz when they came to the UK and we loved having them stay with us. That was when Jodi and Lucy realised, that I could be of some help if I became an International Contact and I was just thrilled to be asked to do such an honoured role and help more people from around the world.



Teenage Support

Katie Arends

teenage@caringmattersnow.co.uk

I was born with CMN covering both my arms and also the top of my chest and back. As a teenager, I found it extremely useful meeting and talking to others with the same condition at family days. I want to be able to offer support and advice for others with the condition and be able to share my experiences, to show that having CMN makes you the person you are.

CMN Bridlington Family Beach Day With Nick and Rosinha Gollop

‘Oh what a lovely day, the day we went to Bridlington’

...and so it turned out to be! The families came, the food was eaten, the sand sparkled, the sea was freezing but best of all the sun came out.

All week the Gollop family watched the weather forecast. A Beach Day in the rain just would not work. The little beach chalet might hold twelve people if we sat on each other's knees but we were expecting at least thirty for the day.

The night before the weather promised at least to be dry and we were able to take over the beach hut that evening in order to prepare (thank you Bridlington Town Council!).

How much can you get in a beach hut? Buckets and spades, beach balls and bats, chairs and tables, all made their way down to the beach, not forgetting the CMN balloons to decorate the chalet. Early next morning, the Gollop children set off in advance to place the balloons strategically to show our visiting families where to find us.

It was grey and windy and the balloons soon got tangled up but in usual Gollop optimistic fashion, the children set out the chairs and the Gollop parents arrived with food to feed an army. Gradually the sun came out and our first family arrived. Then more came and the party began. Old friends, new friends, babies, toddlers, teenagers, parents, grannies and granddads, CMN families and other visitors (including Rosinha's Brazilian and Polish guests with a handy electric barbecue); we packed the space and invaded next door territory, what a gathering.

As always, this was a time for the adults to talk and share experiences, hopes and fears and of course a time for the children to just enjoy themselves. Sand and water, what more do you want? Football on the beach, sandcastles and paddling; an English seaside day with enough sun to be thankful for.

Same time next year? We have already booked a larger chalet with a bit more play space. Hope to see you all again!

Sue Gollop
(Granny Sue)

CMN Brighton Gathering With Catherine Brown

We were very lucky with the weather, it was a real scorcher all morning. We met at a lovely cafe next to a park with a paddling pool right on the beach in Brighton. We were a total of 5 families, with families coming to join us throughout the morning.

The children had huge milkshakes and ran off to the park and later the beach to be buried in the stones by one of the Dads and most of the parents stayed and drank a posh tea or two and chatted about CMN and about life in general.

It was nice to meet in an informal, small group. Easy to talk to each other, relaxed. I think we would all be happy to do it again now the children have met and got on with each other and of course welcome more members.

See reports of the other CMN events on our website
www.caringmattersnow.co.uk/support/support-events/



My Daughter Sophie

By Ginny Bridger



Sometimes when I read the CMN newsletter I am left feeling heartbroken at what some families have had to endure with their children who have been born with CMN. Part of me is very glad I was so ignorant of this condition when my daughter was born because for us it has been a much easier experience and I hope the following will help others to feel positive about bringing up a child with CMN.

Sophie was born in June 2000 with a large hairy CMN covering the left side of her face and skull and with several satellites elsewhere on her body and legs. At the time it appeared that not much was known about CMN and we were referred to several medical people before we ended up at Frenchay Hospital in Bristol when Sophie was just a few weeks old. The sole topic of the consultation was how the mark should be removed and we listened with horror to a description of curettage before it was decided that the best course of action would be for Sophie to undergo laser treatment. So, at nine weeks old we left our daughter lying on a sheet of bubble wrap being prepared for surgery and waited. After what seemed like hours we were asked to go to the recovery room. As we approached we could hear Sophie screaming her disapproval about the whole procedure and we were so focussed on calming her and ourselves that we didn't really take in what she had gone through. She and I stayed in the high dependency unit for 24 hours as Sophie was on a morphine drip and, after four days we were allowed to go home.

Her skin was raw and required frequent dressing changes. I wasn't able to do this alone so the practice nurse at my local surgery did it for me. I don't know who was more shaken by the experience – her or me! However, when Sophie had healed we were able to see that the mark had lightened considerably and were persuaded to go through another couple of laser treatments. Each time we had battles with ourselves as to whether we should be putting Sophie through what we considered to be cosmetic procedures.

When Sophie was 4 we insisted that there should be no more laser treatments. It was never going to get rid of the coarse hair that was part of her CMN and, for a girl; we thought that would be more distressing than pigment or scars. The plastic surgeons turned to excision and suture and two skin grafts and Sophie went through 12 operations in as many years. I became quite adept at dressing changes and would pop Sophie on to the kitchen table to change the dressings after her skin grafts! She always took the procedures in her stride and the day after one operation she was rehearsing for the school play! She has never made a fuss about what the doctors and nurses put her through (although she gets very anxious about 'that cold cream' on the back of her hand)! She is now waiting for a date for the last operation and is happy with her appearance and confident about showing her scars.

The staff at Frenchay made the hospital visits as easy as they could and going 'for a sleepover at Frenchay' has been an annual treat!

It seems strange now that we knew so little about CMN but for us it was a case of 'ignorance is bliss', as we never realised that a CMN could be anything more than a cosmetic problem. Sophie never had an MRI and we were never anxious about how she would develop because it never occurred to us that there might be a problem.

As it has turned out she is a bright and confident girl. She has thrived at sport and is playing rugby at national level. She enjoys school and is fully involved in all aspects of school life. She has a beautiful face and a kind personality. She is completely relaxed about her face and has no fears about being photographed with her hair pulled back from her face. She has never been bullied and answers all questions about her condition in a calm and confident way. She has never seen herself as being unfortunate and has always been positive about her treatments. She says that being instantly recognisable is an advantage as rugby selectors never forget her! We are extremely proud of her.



Grant Success

It is with great excitement we announce that Caring Matters Now has been successful in receiving a whopping **£10,000** from Children in Need.

The grant will fund all our support days in 2015. This is AMAZING news as the grant will help increase the profile of our charity, as well as funding our work!

We are so grateful to Children in Need for accepting our grant application and awarding us this sum of money. We would like to encourage our members to support the work of Children in Need <http://www.bbc.co.uk/programmes/b008dk4b>

The Jessica Ma Award 2016

In December 2014 one of our founding trustees Jessica Ma 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.

Due to Jessica's wise and tireless work in managing the charity's finances over the years, Caring Matters Now has been able to grow from strength to strength and continually meet our 3 main aims to; support those affected by CMN, fund CMN research and raise awareness of CMN. Jessica's expertise in finance and business were invaluable to the board of trustees. However, her contribution went way beyond this!

In September 2014 the CMN trustees met for our Annual Strategy Meeting and you've guessed it, Jessica was there despite at this point being very weak within herself. Jessica brought to our board of trustees many things; she was a clear thinker, a problem solver, she was known to respond rather than to react. Jessica was wise and discerning, she was willing to have potentially difficult and hard conversations enabling the charity to function to its best ability.

Jessica was passionate about Caring Matters Now and the trustees feel her loss immensely. Just a few days before Jessica died, Jodi received a phone call from her, and in true Jessica style, she had called "to sign off". Well Jessica may have signed off but her immeasurable contribution to our charity lives on! Jessica left a lasting legacy and we will forever be indebted to her. Jessica will be sorely missed and will never be forgotten within Caring Matters Now.

The Caring Matters Now trustees want to publicly acknowledge and remember Jessica's outstanding and unique contribution to our charity. In 2016 we will be presenting the Jessica Ma Award to an individual or group who have gone above and beyond in raising funds for Caring Matters Now.

Throughout 2016, five finalists will be selected by the CMN trustees and from those five finalists, Jessica's husband Peter and two children, Jasper and Pascale, will choose a winner who will be presented with the Jessica Ma Award 2016.

CMN Charity Dinner Dance

We would like your thoughts.....

After the success of the first ever CMN charity dinner dance last year we are now considering the options of holding another in September 2016. Before proceeding with any plans, we would really appreciate it if you could spend a few minutes completing the survey by following this link <https://www.surveymonkey.com/s/XFJZFX5>. Thank you for your participation and support!

