

January 2010

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## HAPPY NEW YEAR FROM ALL AT CARING MATTERS NOW SUPPORT GROUP

wellcome trust



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If you have not already heard, we received wonderful news during the back half of 2009. Dr. Kinsler was awarded a grant by the Wellcome Trust to fund CMN research until August 2012. The Wellcome trust is a UK charity organisation that funds innovative biomedical research to support the brightest scientists with the best ideas. The grants awarded are hotly contested with many more applicants than grants given out. Being selected a recipient of the grant is a huge achievement and a direct result of Dr. Kinsler's continuing commitment and dedication to CMN research. The grant will effectively fund Dr. Kinsler's salary and provide extra money for research equipment and expenses which has been scarce to date.

This is a great opportunity to really advance the research already begun and help raise the profile of CMN in the medical community. The successful grant application would not have been possible without the legacy research compiled by Dr. Atherton (Dr. Kinsler's predecessor at GOSH) and funding supplied by the Caring Matters Now Support Group from June 2006. That initial funding allowed the research to get established and produced the promising early results by Dr. Kinsler which led to this successful application.

**Dr. Kinsler would like to thank everyone involved in the fund-raising over the last ten years for their amazing efforts. Everyone involved should feel extremely proud of what they have achieved.**

## Funding – What Next?



### NEW MATERIAL AVAILABLE

We have age-specific parent support packs, age-specific teachers guides, new look CMN medical information booklet, CMN leaflet (good for raising awareness at events) and fundraising packs available.

Please email either Lucy at [lucyh@caringmattersnow.co.uk](mailto:lucyh@caringmattersnow.co.uk) or Jodi at

[jodi@caringmattersnow.co.uk](mailto:jodi@caringmattersnow.co.uk) to receive any of the materials.

Also available to download [www.caringmattersnow.co.uk](http://www.caringmattersnow.co.uk)

We are all so grateful to Dr. Kinsler for her on-going efforts and fantastic achievement in obtaining this grant but our members need to know that the fundraising does not stop here! While the Wellcome Trust grant certainly does relieve fundraising pressure on our charity, we want to capitalise on the momentum that has been achieved to date and continue to raise money for CMN. There are two important reasons why: firstly, we know funds will be required well beyond 2012 (for at least ten years) but winning additional grants in the future is rather uncertain. Secondly, we need to continue to raise awareness of CMN and provide the required support to all our members. These aims remain fundamental to Caring Matters Now and with more funds, we could do more. We want to be in a position where we can really expand our reach with new projects – have more family day locations, improve publicity, and refine the support material available to all those affected by CMN. Such projects will require investment.

The great news is that we are well on track to achieving and surpassing our annual fundraising target of £30,000 by April. Well done, everyone! Let's keep up the pace and together, we can really make a difference in the CMN community.

## Fundraising Story – Sue Gollop

Hi to you all,

I am Amy's Granny Sue and chair of our local University of the Third Age here in Bridlington. Our U3A band, the U3Mix, with the help of a local pub, organised a Party Night for Amy to raise funds for CMN. Quite by chance we learned that the grandson of the leader of the band also has a birthmark-the family did not know anything about any support group.

Tickets sold out in no time-there was only room for 70 but I know that more squeezed in somehow. We oldies had a really swinging night-with all the grandchildren in attendance selling raffle tickets. Who could refuse them? Amy's mum Rosinha made wonderful Brazilian cakes for the interval refreshments. The Landlord ran a quiz and we did a 'Play your cards right' for the children. After paying £1 each for supper, we raised £285. Thanks to the U3A and to the lovely pub hosts Tom and Louise.

We are now looking forward to our next fundraising event. Amy's great Aunt Rosie, a professional artist, has donated a beautiful picture for us to raffle. So far we have raised nearly £200 by selling raffle tickets when she opened her studios to visitors over two weekends (part of the local artists' Open Studios annual event). We will now have one more raffle opportunity at our next U3A meeting in November.



Sue Gollop, the band and her grand-daughter Amy



Great Aunt Rosie's picture which raised a superb £250, Fantastic.

## Fundraising Story – Claire Byfleet



Send pictures of your event to [lucyh@caringmattersnow.co.uk](mailto:lucyh@caringmattersnow.co.uk) and we can feature them in future newsletters

We first heard about Caring Matters Now through the interview that Jodie Unsworth & Dr. Kinsler did on This Morning and since watching the program we have been in contact with the charity & they have really helped us by showing us that we are not the only ones in a sometimes difficult situation. It also helped when we attended the Cambridge family day as we were able to draw on other peoples experience for support.

Speaking to all of these people & hearing about the work that the charity does inspired us to take part in the research that Dr. Kinsler is doing, but also more importantly made us realise that this research has to be paid for – this is why we decided to hold a charity Salsa night to raise funds for the research.

We were donated the hall and the services of the salsa instructor and a few of our friends phoned around & managed to secure some fantastic raffle prizes as well as producing the tickets & posters for the event. We sold tickets for £10 pounds each – with friends and family helping us to sell them, advertising in local pubs & our local news paper, as well as selling raffle tickets for £5 a strip.

Everybody had a great time and we managed to raise £3645.24!

## Caring Matters Now and Jeans for Genes



Caring Matters Now was one of ten charities this past year to benefit from the 2009 Jeans for Genes campaign. Our support group was given a £4000 grant in December towards the maintenance of the patient registry at Great Ormond Street Hospital. This registry is one of the largest of its kind in the world and contains information from patients all around the UK. The data is used for research studies to determine the specific gene that causes the CMN disorder. Making sure the registry is kept up to date with all information gathered from patients is essential to progressing this important work and we are extremely grateful for this grant.

As part of the lead up to Jeans for Genes Day, both trustees Lucy Hardwidge and Jessica Ma participated in the school speaker program and led school assemblies in their local communities.

Jessica said, "Participating in the Jeans for Genes school speaker program was a great experience. It was a unique platform to talk to pupils about what it is like to have a genetic disorder and a fantastic opportunity to specifically raise awareness about CMN. I was able to confidently explain both the health and social challenges of CMN in an easy –to-understand and fun way for the school children. It felt good to motivate the kids to raise money for children's genetic disorders and moreover, to promote a better understanding and acceptance of differences in others. "

**Mark your calendars!**  
**Jeans for Genes day in**  
**2010 will be on Friday,**  
**October 1<sup>st</sup>.**

## My Story – Barry Illingworth




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Hi, my name is Barry Illingworth, father of Shelley Oakes.

Shelley is a twin. She and her brother Mark were born on the 30<sup>th</sup> June 1974 at the Queen Victoria Hospital, South Africa.

Although it is 35 years ago, I vividly remember my wife Marion and myself driving down to the Hospital at 5.30am on a Sunday morning with me telling her "I'll be taking you home you know! It's only stomach ache you've got!" (because she had been eating fruit the night before). It is a good job I'm not in the medical profession because Mark and Shelley were born only a couple of hours after our arrival about 7.30am. They were 5 weeks premature - Shelley only 2lb 12oz and Mark slightly bigger 4lb oz and they were put straight in incubators. Being so early I was still trying to find a cup of coffee when they were born so hadn't a clue that it had happened! I remember the ward sister grabbing me and asking if I had seen the babies my answer being "what babies!?" She also told me that before I go home the doctors wanted to speak to me. When I saw one of the doctors, he asked if I had seen them (obviously "No"! he then told me the reason why he wanted to see me was because the little girl had been born with a large mark on her back which they were not sure what it was but they would have a better idea later in the day after some tests. On returning in the afternoon, they explained that at first they were worried that the mark on Shelley's back might be Spina Bifida but the good news was that it wasn't and that it was a large birthmark with other various marks (now I believe called Satellites and the condition is called CMN).

The doctor then told me they wanted to keep an eye on it. As Shelley got bigger they recommended removal as soon as possible.

Anyway first things first! Mark, the biggest was home in 3 weeks, but Shelley was kept in an incubator for 2 1/2 months until she got to the 5lbs mark - they said she had to be before she could come home and because she was quite a sickly baby they felt even sure about their decision.

Over the next few months I remember we took her back to the hospital numerous times before she had her first operation which was when she was only 9 months old! Poor child! - and I suppose to a much lesser extent poor parents! I cannot count or remember how many operations Shelley had over the following years but I do recall her last major operation in South Africa was when she was 15/16 years old. She has had more operations since being in the UK and has to see a dermatologist every six months for check ups. I believe they take photos of her every so often for confirmation of change and if any new-found moles appear.

Shelley was and is a very brave girl. Memories, and I suppose some nightmares come to mind of her many stays in hospital sometimes even over Christmas and summer holidays (her stays in hospital were sometimes days and sometimes months) but after many down times she and ourselves just got on with it.

I remember twice going to see her after an operation finding the bed she should have been in empty and being told she was in Intensive Care being a very sick






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*We have often discussed if we were wrong making Shelley have the operations, putting her through all the pain that went with them and missing a big chunk of her childhood*

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*At her schools her mates and the other pupils never seemed to see or bother about her birthmarks*

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girl and much later being told both times we nearly lost her! Shelley received her hospital medical records several years ago from the hospital she was treated at (Johannesburg General) and subsequently found out it was due to anaesthetic reaction problems and not because of her birthmarks that she took those sudden turns for the worse.

I also remember Shelley, as a toddler rubbing her back against anything hard with a corner (including brick walls!) even drawing blood just to get some relief from the itching. Many times we were being woken up during the night with her crying because she was in such discomfort in her cot not being able to scratch her back – I rubbed it for a while to ease it then myself trying to get back to sleep for work the next morning. We made it priority that every morning and every night we would lather her back in cream in order to relieve some of the painful itch. And, as parents, we insist and ask if she still does!

I think of the times when dressing the wounds – sometimes they were infected not only the places where they had taken the birthmark off but from where they shaved the skin (skin grafts) from to do the plastic surgery – these sometimes took weeks to heal. Shelley after surgery was always in terrific pain because of the wounds but she was a little hard nut who fought through it (despite always being a petite little thing).

She had quite a few different surgeons who did the operations and everyone commented what a brave girl she was. She had been in and out of the hospital that many times that later on taking her in it was like a “Welcome Home Shelley!” from

regular doctors, nurses and even the cleaning staff. Everybody knew Shelley and some of the cleaners use to tell her “this is Shelley’s hospital” which always put a smile on her face – she bonded with so many staff!

We have often discussed if we were wrong making Shelley have the operations, putting her through all the pain that went with them and missing a big chunk of her childhood but remember in those days, right or wrong, most doctors said birthmarks should be removed due to the risk of getting malignant melanoma. Shelley now says at 35 she is pleased it was done especially the large one on her back.

We were lucky with Shelley that she was a type of kid that sailed through life nothing seemed to phase her. At her schools her mates and the other pupils never seemed to see or bother about her birthmarks because it didn’t matter what was going on – Shelley was Shelley!

Shelley never bothered about wearing a swimming costume or the like for PT and I never remember her coming home telling us that someone from school or outside had said something to upset her. In fact looking back she loved school and school loved her because she was a top grade student and got top grade in the subjects she took.

Maybe we were lucky living abroad in the 1970/80s, we had the beautiful weather and Shelley knew no different wearing shorts etc. I can remember once or twice getting my back up with people staring but to be honest even on the beach, it was not really a regular occurrence – it is human nature for people to look! BUT maybe again it was Shelley not being



self conscious about the marks from the operations and her smaller birthmarks, which won the day! I am aware that when Shelley developed into adulthood she might have become a bit more aware and conscious of her scars but she says she would rather deal with those scars than the birthmark.

I hope my story helps other parents who perhaps have not long started this journey but I can only give you my reassurance that “things are not that bad” – whether you make the decision for your child to

keep the birthmark or have it removed – the fact is, regardless it will be an upsetting episode at times but more often than not, we are all the same and life is life with or without the CMN! Just ask Shelley! She has always worked hard, has plenty of friends and is happily married with a child of her own.

Times have moved on and you and your child have more information and certainly more support from the medical profession and groups like Caring Matters Now - making it, I hope, that little bit easier!



## A Big Sister's Perspective – Georgia-Louise

My name is Georgia-Louise Brown and for 9 ½ years now I have grown up with a younger brother who has a CMN, his is situated mostly on his back. During that time we have had a few ups and downs like most kids but generally I have put up with him. As he has grown up we have had the usual arguing you expect from a boy as well as the “long discussions” we have about his back.

A few years ago we had a special garden room built so that my brother can play outside-but-inside (if you get what I mean). This took a couple of months to build and my brother was very into helping the builder to complete it but I think he was very sad when the work finished-he enjoyed it too much!

Inside the garden room we have a ping-pong table, a football table and what is to be our trampoline next year. He spends as much time as he can outside in the sunshine, often “forgetting” to wear his hat or put sunscreen on, so we have to keep an eye on him a lot of the time.

In the Christmas holidays 2003 and September 2006 we went on holiday to a villa in Spain. We spent as much of the time swimming early in the morning and early evening and at the beach in the evening. He had as much, or even more fun, as I did. He enjoyed those holidays like a normal boy and sets an example for other CMN diagnosed children.

He has had to put up with some bullying at school, which I used to help him with when I was at the same school, but I am at Senior School now and even though he is now in year 5, the same children still bully him. He talks to me about it when we are at home together and I try to help him with it. He had some counselling at GOSH to help him with it but that ended when the Psychologist moved to another hospital.

It is not easy for him, but mum and I help him as much as we can. He is a very happy, annoying little brother, who loves Pokémon and irritating me!!

## CMN Research at Great Ormond Street Hospital for Children, London - Veronica Kinsler



I would like to give everyone the CMN research email which I check on a regular basis: [CMN@ich.ucl.ac.uk](mailto:CMN@ich.ucl.ac.uk). This is for any questions about the research. If you have questions about appointments with the hospital it is still best to contact the Dermatology secretaries at GOSH directly. It would be very helpful to me if everyone already involved in the research could send me their email address with their child's name in the email so that I know who it belongs to. This would allow me to contact you occasionally if I need to check something in the data.

Research at GOSH is going very well. The big news which most of you will have heard is that thanks to the money you all raised to keep the research going from June 2006 – June 2009 I was able to get a big grant from the Wellcome Trust for the next 3 years. This is just for CMN research and has made a big difference to the type of work I am able to do.

The CMN genetics project is in its most exciting phase – it took 3 years to collect the samples from all of you who are taking part and from the control families, and now we are doing all the tests. The first results of the genetic tests are being posted to families involved during January, although many of you will have had them already at clinic appointments. These first results have been very useful and have led to a new study (see below). The next phase of the genetic tests (which will be done on the same samples) is starting in January and we should have the results by the Summer of 2010.

The CMN Registry which collects long-term data on people and families with CMNs has been relaunched in the last 6 months. Anyone who has been seen at GOSH at least once is eligible to take part. Thanks to everyone who has sent back consent form to say they are happy to continue filling in a questionnaire once a year. The real power of this database is in the numbers of people who take part. Anyone who has not filled in a consent form but would still like to take part please send it back, or email me to send you another. Anyone who did not receive a form in the first place please let me know. With all the new regulations in research we will no longer be allowed to send out questionnaires to anyone who has not filled in the consent form.

Two new studies are starting soon at GOSH, probably in March. One of those has a direct connection with the genetics study and I am therefore hoping to recruit initially 15 families from the genetics study to take part in that new study as well. The children involved have to be between the ages of 1 and 6. It involves only a single blood test. Information about it will be sent out from about March onwards. If this study shows up what I think it might it will then be extended to include 100 families. No extra appointments will be needed for this as I will rearrange those as necessary.

The other study starting around March or April will be open to anyone attending GOSH appointments and does not involve blood tests or extra appointments. Information about this study will again be sent out around March. We need 50-100 families for that study.

### NEW FUNDRAISING PACK AVAILABLE

Request a fundraising pack and join in the fun of raising money for a very worthwhile cause.

Please email either Lucy at [lucyh@caringmattersnow.co.uk](mailto:lucyh@caringmattersnow.co.uk) or Jodi at

[jodi@caringmattersnow.co.uk](mailto:jodi@caringmattersnow.co.uk) to receive a pack. Also available to download

[www.caringmattersnow.co.uk](http://www.caringmattersnow.co.uk)

Many thanks for everyone's continued support – the research could not happen if you families did not participate.



As you know the ultimate aim of this research is to find out as much as we can about CMNs so that we or other people may be able to develop better treatments, and better ways of working out which people need what sort of investigations or appointments. At the moment we know a lot more about the condition than we did 10 years ago, but it is still frustrating not to be able to give families more accurate information about their particular child, and not to be able to offer good and safe treatments. This will take many years to achieve but this sort of research should help to move us in that direction.

## CMN Family Day Review – Lucy Hardwidge

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

**Date:** Saturday 21<sup>st</sup> November 2009

The Liverpool family day was a fantastic success, our best yet! Thank you to everyone who attended. We had 15 families turn up, 4 of which were new families, a great encouragement for the CMN Trustees.

A big thank you to Veronica who also attended and spent the day running around talking to **all** the families and getting them to sign up to the research programme. We also had Mark Beckworth with us from the USA Nevus Outreach, which was a great opportunity to learn about what is happening over in the States and to present the enormous amount of work we have achieved over the past 2 years here in the UK. He reported how much he and his daughter enjoyed the day.

This was the launch event for all of our new CMN Material (available to download from the CMN website or contact Lucy H or Jodi for copies) – parent's guides (age specific), fundraising packs, teachers guides, new look CMN booklet, CMN leaflet and we also had CMN Christmas cards for sale!

The professional photographer did a wonderful job of capturing the fun we had on the day.

## 2010 FAMILY DAYS

**Date:** Sat 6<sup>th</sup> March **Time:** 1pm - 5pm **Location:** Bristol  
**Venue:** Counterslip Baptist Church, 648-652 Wells Road, BS14 9HT

**Date:** Sat 17<sup>th</sup> April **Time:** 1pm - 5pm **Location:** Cambridge  
**Venue:** The Hub, High Street, Cambourne, Cambridge, CB3 6GW

**Date:** Sat 26<sup>th</sup> June **Time:** 1pm - 5pm **Location:** London  
**Venue:** Covent Garden Dragon Hall Trust, 17 Stukeley Street, WC2B 5LT

**Date:** Sat 21<sup>st</sup> August **Time:** 1pm - 5pm **Location:** Glasgow  
**Venue:** TBC – check website for details

**Date:** Sat 25<sup>th</sup> September **Time:** 1pm - 5pm **Location:** Birmingham  
**Venue:** TBC – check website for details

**Date:** Sat 20<sup>th</sup> November **Time:** 1pm - 5pm **Location:** Liverpool  
**Venue:** Bridge Chapel Centre, Heath Road, Liverpool, L19 4XR

All family days will include:

- Light buffet and refreshments
- Children's crafts and activities
- Presentation from Dr V Kinsler and CMN trustees

Can you please inform Jodi if you are planning on attending any of the family days by calling 0845 458 1023 or email

[jodi@caringsmattersnow.co.uk](mailto:jodi@caringsmattersnow.co.uk)