



January 2013

NEW YEAR, NEW CHALLENGE!

Are you up for it?

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Join the team of 2013 on the ultimate challenge;

24 Peaks in aid of Caring Matters Now - 14-16th June 2013



This exciting challenge will have you trekking up and down 24 peaks in the Lake District in a mere 24hrs of trekking. The Lake District is home to some of the most rugged and challenging mountains in Britain giving it, its reputation as one of the best natural adventure play grounds in the U.K. This is a challenging trek both mentally and physically with long days of trekking, but with stunning views of the Lake District and a fantastic sense of achievement when you complete the trek.

Visit the website for a full description of the challenge ahead, including the itinerary, q&as, kit list, fact file and notes on how the challenge is funded. You can even book your place on the challenge.

<http://www.charitychallenge.com/expedition1.html?id=1697>



This is all part of the Charity's ultimate aim of 7 Challenges across 7 Continents. We want to be the first charity to achieve the unthinkable and you can be a part of this, check out our goal <http://www.caringmattersnow.co.uk/7-challenges-across-7-continents/>

Sign up now for the next challenge.

Family Activity Weekend

Friday 26th – Sunday 28th July 2013

Thanks again for a wonderful weekend. Josh was feeling very shy and out of his depth prior, but this weekend has brought him out of himself and he is much more confident with school etc. I believe that the activity weekend does more than meets the eye; the difference in Josh is great

Turner Family

We thoroughly enjoyed yet another fun-filled, action packed weekend at PGL this year and the feedback suggested we run the CMN Activity Weekend annually. So that's what we are doing; 26th to 28th July 2013 at Caythorpe Court situated close to Sherwood Forest in Lincolnshire.

£119 per person. This price includes: Food, accommodation, activities and evening entertainment. Under 3yrs go FREE and 4-6yrs get £24 reduction.

Book by 15th February 2013 and Caring Matters Now will subsidise those with CMN. **That's one FREE place per family! So be quick.**

This is what the Hoar Family thought of the weekend:

"We arrived at Boreatton Park not really sure what to expect. We had never done a PGL weekend before and while we try and make a CMN family day each year we didn't really feel we knew anyone that well. But we needn't have worried. We were made to feel so welcome by the lovely Unsworths and soon got chatting to other families.

We will all remember the activities; the big swing was our favourite; Mum actually managed the abseiling; William proved to be a bit of a natural at archery; we saw a swimming pool full of children with CMN; our room was covered in wet clothes and soggy shoes after raft building; the children danced to Jessie J at the disco. Our days were planned and there was a perfect mix of down time and activities. The PGL leaders were so encouraging and helpful.

As adults we will remember meeting new friends, sharing and listening to others' stories and feeling very much supported and no longer alone with your thoughts and worries.

Most importantly of all we have given Elspeth time to start building friendships which we hope in time will be a real source of comfort and strength. As she and a new friend walked out of the food hall I heard them laughing "Did you see those brownies were staring at us and we just stared right back." As a mother, I try and meet her needs but there is nothing like her having someone who just knows and really understands what it is like.

Not surprisingly we would encourage all CMN families to come along to the next one – even the 5 hour journey there and back won't put us off!! Thank you CMN!"

Check out the PGL website:

<http://www.pgl.co.uk>

These last two family activity events have had such a positive impact on our family it was great to meet other families who have a child with CMN and share experiences.

The activity weekend also gave Maddie the opportunity to make friendships and relate to other children with CMN.

Being with others with CMN is really positive for our children

Valleekanthan Family

CONFIRM YOUR PLACE NOW! Complete the enclosed booking form & return it by **15th February** with a non-refundable cheque deposit (made payable to Caring Matters Now) of £30 per person to: **CMN, PO Box 732, Cambridge, CB1 0QF.**



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

Email: ICH.CMN@ucl.ac.uk (please note changed recently)

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

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

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Neurological Complications in CMN

As you will know CMN can be associated with neurological or brain problems in a minority of people. These brain problems are very variable, and lots of different types of things have been described in different people. Briefly, these are the things that have been found:

The most common finding is melanosis (a bit like moles) in the substance of the brain. This is usually found on MRI scan, and only around 50% have any symptoms of this. When the melanosis does give symptoms directly, this is usually fits which are usually in the temporal lobe (temporal lobe epilepsy). However, the other symptom that is associated with seeing melanosis on the scan, but does not seem to be directly caused by the melanosis, is developmental delay. In other words, the melanosis we can see on scan seems to be a sort of marker for abnormal brain development, rather than being the actual cause. This is currently being investigated in more detail.

Everything else is much rarer, and when these things are present they are usually from birth or soon afterwards, so if children have not been scanned by the age of 2 years old, and are entirely well, they would be very unlikely to have any of these. These rare things include

- Brain tumours (not melanoma), usually benign, but usually need to be removed
- Hydrocephalus (too much fluid in the brain) – this is caused by melanosis in the coverings of the brain and spine, which is not always visible on scan. Hydrocephalus always needs treatment with a special operation to shunt the fluid out of the brain and into the abdomen.
- Malformations of the brain.

Melanoma can occur in the brain. This is rare but can occur at any age.

Dedicated Neurological Support

As a support group we want ALL our CMN families to get the specialist support they need and access to all the information available.

We understand that those with Neurological complications may need more specialist support or an understanding listening ear of someone that knows. So, through Dr Kinsler we were introduced to Hayleigh Crowe.

Hayleigh, as you will read below, has a daughter with NCM (Neurocutaneous Melanosis) in addition to other neurological complications and so understands the involvement of caring for a child with Neurological needs.

Hayleigh has offered to be a dedicated support contact for families affected by NCM.

Caring Matters Now are truly grateful and we very much look forward to working with Hayleigh in developing the support strategy for our NCM families.

Hayleigh can be contacted at hayleigh@caringmattersnow.co.uk

My Story – Hayleigh Crowe



Wes and I had only been married for 9 months when we found out I was pregnant. We were overjoyed at the thought of having a little one; it was like the icing on the cake. Anna-Grace was born in the small hours of 23rd March 2004. When Anna was born the midwife's wrapped her in a towel and briefly handed her to me saying 'Her face is clear'. I didn't have a clue what they were talking about. All I wanted to do was hold my beautiful baby. But this was not to happen! Anna needed oxygen, they said she was not well, that she had a large birthmark & needed to go to NICU (Giant naevi covering top half of body). It was all then a bit of a blur. I needed attention so had to wait in the room whilst Wes went with Anna. When I finally got to NICU I could at last see my little one.

She looked so fragile in the incubator & I longed to hold her. The doctor's had very little knowledge of Anna's condition & were using the internet to get more information; it was scary to think that they didn't know what was wrong. They said she will need an MRI scan to see if her brain was affected!

There was no room to stay on NICU so I had to stay upstairs on the maternity ward. I longed to be near her. As soon as it was light we rushed down to see Anna & there was a room full of doctors & nurses. They said she had a couple of seizures in the night, so they were going to bring her MRI forward. Anna was put on medication for epilepsy.

Every day we stayed, the doctors brought us more devastating news.



The MRI scan results showed that Anna had melanin pigments on her brain. They said that she would need to be transferred for more specialist treatment. They found out that Dr Atherton at G.O.S.H. was doing research into the condition so we opted to go there.

After two weeks on NICU at Kettering Hospital we went via ambulance to GOSH. It was a relief to get some answers to our now multiple questions. A couple of nights into Anna's stay I noticed she was not herself. She wasn't feeding well & she had a strange cry. I just felt something wasn't right. The Sister on the ward measured Anna's head and it had swollen slightly. It was quite late in the evening by this time & we were sent down to the Neurosurgery ward for an emergency brain tap. This confirmed Anna's brain was swelling with fluid & she needed to have an emergency shunt operation. We felt like we had been run over! Exhaustion & anxiety were at their foremost. We had three Neurosurgeons around Anna's bed explaining what needed to be done & that Anna had developed Hydrocephalus a complication from her Neurocutaneous Melanocytic Naevus. They operated the next morning. The Neurosurgeon has been magnificent. It felt like an eternity waiting during the surgery. Anna was transferred to the Neurosurgery ward from then on.

Anna had another MRI scan & again the results were not good. I always

remember the consultants asking us to leave Anna in her room & come into the parent room. They told us that the scan showed some tumours on Anna's spinal syrinx. They believed them to be malignant & due to the complexities of them untreatable. After all Anna had been through I was stunned. I couldn't take it in. The tumours were so rare they had never been seen inside a human body before. Yet again another completely rare condition!! I remember thinking she can't go now after all she has been through. Going back into her room & looking at my beautiful baby was heart-breaking, I just hugged & hugged her.

The neurosurgeon removed the tumours & sent them to histology when Anna was 2.5 months old. It was a very long & complex operation as the tumours were attached to the spinal cord. After the operation Anna had to lay flat & wear a specially made spinal jacket for quite a few months to keep her spine straight. We still have the jacket in the loft & will show her it one day. She wasn't a fan of it at the time as it was made from padded plastic & it wasn't the most comfortable thing to wear but was necessary.

We at last had some GOOD news; Anna's tumours were Benign so the future seemed brighter once again. Our Anna-Grace was such a little fighter that after a week in HDU she recovered well.

But just a week later Anna got very

Anna had developed Hydrocephalus a complication from her Neurocutaneous Melanocytic Naevus



sick & deteriorated very suddenly. Unfortunately the shunt had got infected in the brain & she needed to have strong Intrathecal Antibiotics to stop the brain fluid infection. It was so very scary seeing all these wires & tubes coming from Anna's brain with strong drugs being administered this way. I was scared to pick her up, she looked so vulnerable. The nurses were amazing, nothing seemed to faze them. They could see my hesitation so they helped me to support Anna & encouraged me to feed her as usual. It was a bit tricky but we managed it together somehow. When she was in my arms she would look up at me & I could see she was comforted. I just wanted to run away with her & wrap her up in cotton wool. I felt so helpless seeing my baby going through so much in her little life. After 2 weeks of Antibiotics Anna had her 2nd shunt inserted. It was a relief to have all the wires & tubes out of her brain. She looked so little laying there with her head all bandaged up.

We had been in hospital for over two & half months by now & didn't want to leave Anna's side. But the nurses could see that we needed to go out & get some air so they encouraged us to go out with some friends that had come to see us. We went rather reluctantly & I remember it seemed so strange going out & seeing everyone getting on with their lives. It was like we were in some kind of vacuum & life was on hold.

We were finally discharged to go

home when Anna was 3 months old. Although we were thrilled to at last go home & start our new life as a family, it was a very scary prospect. Anna had such complex needs & now we were on our own! Our family were a great support but they all lived far away. We had the most supportive friends & their kindness we will never forget. We soon gained confidence & it was great to start family life at home. Controlling Anna's seizures was a challenge when she was a baby due to the weight fluctuations & she would have around 30 to 40 mild seizures a day. We are fortunate that Anna has an excellent Neurologist who managed to control the seizures well with medication & since then she only has the odd breakthrough seizure every now & then.

Anna has always shown such determination & strength. We were told she would never walk & would have severe learning difficulties but Anna had her own ideas! She taught herself to sit up unaided at 9 months which considering all she had been through was amazing. Around this time Anna sadly had developed Intra-spinal cysts where the spinal tumours had been. This was drained at GOSH. Anna had to lay flat for 24 hours after the operation, which when she was younger wasn't such a mission but Anna had now learnt to sit up & was very pleased with herself, so I spent the whole night trying to lay her down!! Anna has another condition called Dandy Walker Variant which really

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affects her balance. But Anna didn't let this get in her way, just like everything else that she had to face she worked around it & just got on with a constant smile on her face.

The next few months Anna made good progress she taught herself to stand not like most children by holding on to something but by going to the middle of the room & with real effort & determination she would patiently try to stand up. When we tried to help she didn't want it. Eventually she mastered it & was so pleased with her achievement. She started to walk at 18 months old. But due to all her conditions, she would take a few wobbly steps & then would fall to her knees. Then she would just pick herself up again & try once more, every-time with a smile on her face. Due to all the brain conditions Anna's speech was very delayed. We knew she could understand everything we said & most times we could understand what she wanted but sometimes we couldn't & you could see the frustration on her face. After speech therapy she can now communicate very well although for strangers I have to interpret at times. It is a joy listening to her speak & hear her cheeky sense of humour coming out.

When Anna was 2.5 years old she developed yet another condition. She was diagnosed with Progressive Syringomyelia, which is again a condition affecting her spine. We noticed Anna's mobility was getting

less & less & she had started to get severe headaches, she would hold her head & cry. Her Neurosurgeon performed a Forum Magnum Decompression at GOSH which involved taking away some off her brain-stem & neck so the fluid could move more freely & not build up. I was heavily pregnant with Kaede our other daughter at the time. Unfortunately over time the fluid still kept increasing so Anna had to have a Syringo-Peritoneal shunt inserted the month before her 4th birthday. It was very scary Anna having two shunts. The later one can be more unstable than the 1st due to where it is. This proved to be the case as a year later the shunt blocked in the stomach & had to be revised at GOSH. Since then the shunt has managed to keep the syrinx in the spinal area from getting bigger but sadly due to all the damage to her spine caused by these conditions Anna lost her mobility & spent the next few years crawling around. She could no longer sit unaided & needed full care for all her needs. Despite this Anna remains a very determined & happy young lady & has such a zest for life. She is such an inspiration. I am constantly in awe of the way she accepts what has happened to her & gets on with life with a great sense of humour & joy.

It was around this time that we met Dr Kinsler when she took over from Dr Atherton. We were so delighted to have Dr Kinsler on board and her research, skills & support have been



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excellent. She has proved to be a tremendous & constant support to us throughout for which we will never forget.

Anna is a very beautiful 8 year old girl now and like most 8 year old girls she is becoming more aware of her appearance. We have always encouraged her to be proud of her special skin & although she is a lot more conscious of her appearance we hope this will continue.

This year has been extremely difficult. Sadly Anna's mobility has reduced & she can now no longer crawl, she has developed Spinal Melanosis. It was thought to be malignant so she had to have a spinal biopsy to determine the nature of the melanosis. Specialist tests were performed by Dr Kinsler and the results were to take around 6-8 weeks. Waiting seemed an eternity. As the biopsy was from Anna's spinal cord it was quite a procedure so Anna took a few weeks to recover. When she was starting to feel better she would smile up at me & say 'I'm happy, I'm getting better now Mummy', it broke my heart but I would smile & say 'Yes my darling'. Every day I put on a brave face for the children. We started to film the children everyday so

we had memories, it was so very painful!

At the start of the summer holidays I got a phone call from Dr Kinsler, the results were back & it was the best news ever. The spinal melanosis was Benign. Never, had this been the case before. When I put the phone down I literally fell to the floor in tears of relief. Kaede & Luca came in worried and all I could manage to say was 'Mummy is so happy'. I couldn't wait to tell Wes the news & the tears of joy were evident on his & everyone else faces when they were told. We know things are still not great for Anna at the moment but having that news was amazing. As the melanosis is covering the whole of Anna's spinal cord it cannot be removed but we hope some treatment will be available to stop it growing.

Life has certainly been a roller-coaster but through it all Anna has shown incredible strength, determination & a real zest for life. She has melted so many hearts & touched the lives of those that have met her. There are few people in life that can reach people like Anna can. She truly is a very special little girl and she brings so much joy, I love her so very much.

CMN Support Days (formerly known as Family Days)

CMN support days are held in London, Liverpool and Scotland each year. The days include a light buffet, children's crafts and activities and a presentation from Dr Kinsler and CMN trustees

London – Sat 16th March 2013 at 12pm – 4pm, Seven Dials Club, 42 Earlham Street, London, WC2H 9LA

Glasgow - Sat 10th August 2013 at 1pm - 5pm, St Brides RC Church, 21 Greenlees Road, G72 8JB

Liverpool - Sat 9th November 2013 at 1pm - 5pm, Bridge Chapel Centre, Heath Road, Liverpool, L19 4XR

Chat & Play Days

CMN Chat & Play Days are family fun days arranged by the dedicated Regional Support Contact for CMN giving an opportunity to get together with others and chat and play in a relaxed atmosphere. The day will include a light buffet, children's crafts and entertainment and brief charity update.

Bristol and Beyond – Sat 18th May 2013 at 1pm – 5pm, Nailsea Methodist Church, 72 Silver Street, Nailsea, North Somerset, BS48 2DS

BECOME A CMN CHAMPION

Can you, your school, your place of work become a CMN Champion in 2013?

Will you **commit to giving** and **campaign to the cause** of Caring Matters Now?

'CMN champions' is an awards programme for those who **commit to giving** and **campaign to the cause** of Caring Matters Now. Individuals, schools and work places can become CMN Champions by supporting Caring Matters Now throughout 2013. There are a number of awards that can be gained; Bronze Award, Silver Award and Gold Award. The award presented, will depend on how much support individuals give to the charity during 2013. The award criteria is as follows:

Bronze – awarded for:

- Organising a fundraising event – amount raised up to £1000
- Raising awareness of Caring Matters Now in the local media (see CMN media guidelines pack)

Silver – awarded for:

- Giving 6 or more direct donations throughout 2013
- Organising a fundraising event – amount raised £1000 to £5000
- Raising awareness of Caring Matters Now through national media (see CMN media guidelines pack)



Gold – awarded for:

- Setting up a monthly standing order throughout 2013 (12 direct donations)
- Organising a fundraising event – amount raised over £5000

There will also be special awards, which will be given:

- Mini Champion – for CMN children (primary aged) for any the above
- Challenge Champion – anyone who participates in a Charity Challenge

All of our champions will receive, a bronze, silver or gold 'Champions' pin-badge and certificate. Our CMN champions will also be listed on the CMN website and in the CMN newsletters. We will also publish fundraising stories on our website.

SCHOOL CHAMPIONS

Inserted into this newsletter is a small flyer which you can give to your school. How great would it be if your school became a CMN Champion! Not only will your school be raising funds towards our work, but also lots of awareness will be raised about the charity and the CMN condition. Please encourage your school to support Caring Matters Now.

WORK CHAMPIONS

Can your place of work become a CMN Champion by support Caring Matters Now throughout 2013? This campaign has the potential to raise lots of awareness and lots of funds for our charity. Please encourage your work place to support Caring Matters Now and download the information flyer for workplaces from our website.

To register in becoming a CMN Champion please visit our website or email champion@caringmattersnow.co.uk

Hair today, Gone tomorrow!

Huge thanks to Harvey Treby who cut his golden locks off raising a fantastic **£1033** for Caring Matters Now. Well done Harvey!

Read Harvey's story on the website

<http://www.caringmattersnow.co.uk/harvey-cuts-hair-cmn/>



Well done and huge thanks to Fay's cousin James who completely shaved off all of his hair in front of a large audience at his local golf club raising over **£1400** for Caring Matters Now.

Read the local newspaper report <http://www.cambridge-news.co.uk/Huntingdon-St-Ives-St-Neots/Generous-James-has-a-good-hair-day-for-charity-07112012.htm>

Check out the inspirational fundraising stories on the website
<http://www.caringmattersnow.co.uk/category/fundraising-stories/>

Thank You Steve



Steve Clarke has been on the board of trustees since 2007, when Caring Matters Now first registered with the Charity Commission. He has been a fantastic support and an integral part of the successful development of Caring Matters Now over the years. His willingness and motivation, particularly with the financial aspect of the charity, has been a real blessing and allowed us to develop so much in such a short period of time.

Steve has recently decided to step down from the board of trustees. He believes that the charity has a good structure and a stable team now with Jodi at the helm and Veronica being financially funded. Now is a new phase of development and so Steve feels it is a good time to look for a reinvigoration on the trustees' team.

We are very grateful to Steve for all his help and support over the years.

I am sure this 'thank you' not only comes from the board of trustees, but from all the CMN members too.

Financial Update 2011/2012

We are pleased to report that over £80K was raised and from that we donated over £40K to support Dr. Kinsler's research work at GOSH.

We need to continue to raise funds as our support network is growing in numbers and reach. Our presence at International Conferences such as Nevus Outreach in the USA and International Expert Meeting <http://cmnexperts.org/> is integral to helping develop our support services worldwide.

It is important to continue holding family days across the UK, to produce the bi-annual newsletters and the support materials.

The benefits of attending the activity weekend are already present in those that come along. We want to be able to continue these weekends and besides the Jeans for Genes grant, we make a contribution and subsidise the weekend for those who really benefit from attending.

Admin is growing in complexity as the charity grows and expands its support services and to continue to grow we need to fund both Jodi and Lucy, the equivalent of one full time person.

Please keep up the great work.

We solely rely on the financial support of our members, their families and friends to do what we do.

