



December 2007

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LIVERPOOL FAMILY DAY REVIEW



Venue: Liverpool Marriott Hotel South

Date: Sunday 16th September 2007

Review: The family day was very well attended, with 18 families, Dr Atherton (CMN skin specialist) and the CMN team.



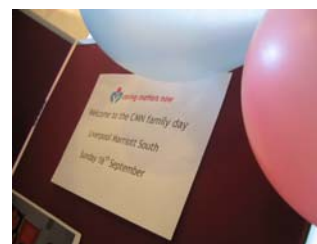
At the Liverpool family day there was lots going on... craft activities, toys, bouncy castle, light buffet, refreshments and raffles. Plus, the Marriott Hotel allowed the families to enjoy the experience of the hotel's airplane simulator!

The CMN team gave a short presentation on the support group's progress over the past 6 months and Dr Atherton gave an up-date on the latest medical research findings.

Children from the support group organised a 'name the teddy' competition and also sold handmade crafts, to raise money for the CMN medical research. The CMN team organised a raffle, in which the funds raised also went towards the CMN medical research.

18 families attended, including many families travelling far distances. Four families attended for the first time and they were able to meet and develop friendships with other CMN members.

Thank you too all those who attended, enabling the day to be a great success!



FEBRUARY 2008

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UPCOMING FAMILY DAYS

Date: Saturday 23rd February 2008

Time: 1pm - 5pm

Location: Cambridgeshire

Venue: The Hub Community Centre, High Street, Great Cambourne, Cambridgeshire. http://www.theaa.com/maps/map_results.jsp just at the junction with Sackville Way

Accommodation nearby: The Cambridge Belfry Hotel is situated within a 2 minute walk of the community centre. Visit the website: www.ghotels.co.uk

Light buffet will be provided.

Children's crafts and activities.

Dr Atherton and/or Dr Kinsler will be present.

Can members inform us if they are attending by calling Jodi on 07812467809 or email jodi.unsworth@googlemail.com



Date: Saturday 7th June 2008

Time: 1pm - 5pm

Location: Bristol

Venue: TBC



Date: Saturday 13th September 2008

Time: 1pm - 5pm

Location: Glasgow

Venue: Saint Brides RC Church, 21 Greenlees Rd, Cambuslang, Glasgow G72 8JP – www.saintbrides.com



Date: Saturday 29th November 2008

Time: 1pm - 5pm

Location: Liverpool

Venue: Bridge Chapel Centre, Heath Road, Liverpool, L19 4XR – www.bridgechapel.com



CMN REGIONAL SUPPORT CONTACTS

The Caring Matters Now Support Group wants to ensure that all members are receiving support in many different ways. Support is given through, CMN family days, CMN newsletters, CMN email up-dates and CMN website information. The CMN team would like to offer a more personal form of support through regional support contacts. We have 8 regional contacts in places at present.

You are more than welcome to get in touch with your regional contact at anytime. Your regional contact is there to offer one-to-one support through phone calls, emails and visits. The CMN team hopes that friendships will be developed and CMN members will receive personal support at any time it's needed.

The Caring Matters Now Support Group wants to ensure that all members are receiving support in many different ways.

Support area: Scotland Contact: Anne MacIntyre Contact number: 0141 646 1069 Contact email address: anne@macintyre1150.fslife.co.uk	Support area: North Wales Contact: Judy Sealey Contact number:01244 815 997 Contact email address: judy.sealey@dsl.pipex.com
Support area: North West England Contact: Jodi Unsworth Contact number: 0151 281 2820 Contact email address: jodi.unsworth@googlemail.com	Support area: South Wales Contact: Lynne Davies Contact number:01656 870 511 Contact email address: Andrew3davies@btinternet.com
Support Area: North Midlands Contact: Julie White Contact number: 01636 611 361 Contact email address: andrew@awhite46.orangehome.co.uk	Support area: South West Contact: Lucy Clarke Contact number: 01386 831 994 Contact email address: lucyandstephen@btinternet.com
Support area: South Contact: Hannah Woods Contact number: 01837 871282 Contact email address: hanex20@aol.com	Support area: East Anglia & South East Contact: Lucy Hardwidge Contact number: 01954 719612 Contact email address: lucy.hardwidge@btinternet.com

Your regional contact is there to offer one-to-one support through phone calls, emails and visits

Each regional support contact is a member of the CMN support group. All contacts are parents of children with CMN or those who suffer with CMN. All 8 contacts cover the majority of the United Kingdom. However, there are a few areas that could do with a support contact. If you would like to be a regional support contact for your home town/region then please do contact the CMN team at caringmattersnow@googlemail.com or by calling Lucy Clarke on 01386 831 994.

THE STORY OF RHYS

By Lynne Davies



Rhys was born with CMN, which at the time we knew nothing about, and it absolutely scared us to death

Hello, my name is Lynne Davies, I have a son called Rhys, and he is 10yrs old and has CMN. Until 6 weeks ago we had never met anyone else with this condition.

We met Jodi Unsworth in Liverpool, and many other lovely people who had children with this condition; we also met the children, which was amazing for Rhys and myself, as Rhys has never met another person like him.

Rhys's father Andrew found this meeting very inspiring, and we are all so glad we attended.

After we returned home, I was asked to write a story about Rhys, and this is my story!

Rhys was born with CMN, which at the time we knew nothing about, and it absolutely scared us to death. We thought he would never grow up and have a normal life, and at the time we didn't even know what was going to happen to him medically or how this condition would affect him.

Where I live, the hospital didn't have a clue what it was, and at the time I just wanted answers. My experience in hospital was not at all good, I felt so alone and frightened. Having since met other parents in Liverpool, I realised we were all treated the same, which in this day and age is quite disgusting. There was no support at all; we were all left to just accept and to get on with it, which some of us found very hard especially myself.

We were sent to London, to meet Dr Atherton and only then did we learn what his condition was. We realised that he was going to be ok, as we had all different thoughts about what Dr Atherton was going to tell us. We found out so much in just one visit, the visit brought some answers to us, which we both so needed at that time.

We then met with our local plastic surgeon, who at first just didn't know quite what to do with Rhys, as he had never seen such a large CMN before. Rhys's largest mole covers from the top of his head down to the middle of his back, and also covering his shoulders. Our local plastic surgeon said it was too big to treat. However, when we met Dr Atherton he had already suggested to me about tissue expansion, which I passed onto our local plastic surgeon, he told me he would give it a go, and as the hospital was much closer to me than London, I thought it would be much better for us all if we had the treatment done locally.

Rhys had his first tissue expander put in when he was about six months old. It was put in the lower part of his back, with the port, which is used to fill the expander under his arm. Things seemed to be ok, until it came to filling the expander.

I had to take Rhys every week for them to fill the expander. As Rhys was so young, and this was something that hadn't been done before, the nurses were very nervous, and very unknowing about this procedure. Things did go wrong with the treatment, but I don't blame the nurses as they were lovely to me and Rhys.

The tissue expander was punctured and had to be removed. To puncture the expander is so easy, as you only have to be slightly out of the port and it



The operations lasted over two years, and I would be a liar to say it wasn't hard, it was the hardest thing I have ever done in my life.

would puncture the expander, or even just have a shaky hand, and when your nervous this cant be helped! Every time this happened it meant Rhys would go through two operations, one to take it out, then and another operation to put another tissue expander back in.

Rhys had at least 7 expanders, and only 2 were successful. One of the expanders was filled by the plastic surgeon with a large syringe, which seemed to make such a difference. He didn't have to fuss around changing the small 10ml syringes. I think the punctures that did occur was because of the small syringes that were used in the past.

The other tissue expander was actually filled on the operating table, as Rhys got to a stage were he wouldn't tolerate it no more. I am convinced that if the plastic surgeon had filled them himself, things would have been so different.

The operations lasted over two years, and I would be a liar to say it wasn't hard, it was the hardest thing I have ever done in my life.

Things were not made easy as Rhys developed extremely severe eczema, all over his body, his face being the worst. The medical staff thought it was because of stress. This was awful for Rhys as he was 'wet wrapped' twice a day, and hospitalised a lot because of his eczema. It was very distressing for Rhys and me, in fact it was a nightmare I will never forget.

Now Rhys is nearly 11yrs old, we have got his eczema under control, but it still affects him, however it is a part of life now, he has had no more tissue expanders, as I think me nor Rhys could take no more, mentally or physically, and when people see his back they think it is great, but for what Rhys and myself went through and of course it affects all the family in ways, as I have a daughter as well, who I didn't seem to have any time for, so if I am asked was it worth it? In my experience I would say no, as I think in the beginning I just wanted to get rid of it all no matter what, I think it was just down to the fact I didn't accept his condition and would have done anything just for him not to have it.

As Rhys has grown, I now realise this is part of him, and it is what makes him, and his vibrant personality. Rhys has never had a problem with it, he accepts his condition, and that he is a little different, but that is what makes him so special to us all, and who meets him.

Rhys is now in his last year in junior school, he knows that sun cream and his hat are the most important things, but other wise he lives a naughty and quite normal life, and fair play to him, all that he has been through doesn't stop him doing anything, he is so confident in himself I hope he has always got this enthusiasm to live his life with the courage and pure determination he has shown so far, we are so proud of him.

FUNDRAISING IDEAS

The key aims of the formation of Caring matters now as a charitable trust is to provide support and advice to families and those affected by CMN, and raise funds to into the research for understanding as to the causes and potential treatments.

We have made a commitment to sponsor Dr Kinsella at Great Ormond Street to conduct specific medical research into CMN. We need to raise funding every year of approximately £20,000 to continue this research and every little effort helps.

Jodi and the team of trustees have set up some ways to help you contribute to this excellent cause.

Just giving – a regular direct debit which can start from as little as £2 per month

<http://www.easyfundraising.org.uk/> - If you shop on the internet with virtually any company from ebay and Amazon to Tesco and Next any purchase you make can contribute to Caring matters now without costing you a penny.

But the best way of raising funds is to get involved and organise an event yourself! – In every case you will be amazed how many of your family and friends want to support and help you it is just having the idea and getting going is the hard part.

The list that follows is not exhaustive but is designed to stimulate your imagination.

- Promises auction – approach friends to commit
- Babysitting evening or Taxi journey, add this to local companies donating hampers or gifts and then run an auction in a local club function room
- Fashion Show – maybe at school
- Concert / Play / Musical Evening
- Trivia Quiz - Pop / Sport / General Knowledge / etc.
- Fete / Raffle /Car Boot Sale
- Sponsored sports event
- Sponsored Haircut
- Five / seven a side football / rugby / hockey / etc.
- Sponsored Walk or Run (Great North Run, London Marathon)
- Approach the company that you work for to sponsor Caring Matters Now as their chosen charity for the year.

The list is endless and we have not yet mentioned the "Thon" family, MaraTHON, WalkaTHON, SlimaTHON.



Erin raised £20 from her cake stall



Lucy & Anthony Hardwidge raised £3,700 by completing the Great North Run in 2hrs and 25 minutes

The Way Ahead

Once you have chosen your event there are many areas that you must cover to make it a success.

The keyword is PLANNING - allow plenty of time to look at the various aspects of the challenge that lies before you.

- Discuss with friends, colleagues, and management how easily the event can be organised.
- Do we have the people to make all parts of the project run smoothly?
- Will the event cost us anything to get off the ground?
- Arrange a date.
- What resources (people transport venue tickets) do we need?
- How do we publicise the event? Flyers leaflets advert?
- What can go wrong? Weather, venue.
- Can we get a celebrity? (There are generally tame celeb's in your local area, or people who may give their time)



Publicising the event

Your event must be well publicised if it is to be a success.

At work: Work notice boards, Company magazine, Word of mouth, Mums on the school run, children/toddler groups.

At home: Leaflets to families, Leaflets to local suppliers, Announced on local radio, Advertisement in local paper, Notices placed in public places in the community, for example, surgeries, libraries, local shops.

The media

If you are able to get the support of your local Radio and TV station your event's profile is taken onto another level. You will find it invaluable when approaching people in the local business community. If they think that they might be able to get some good (and cheap) local PR, they are more likely to help.

The person to get in touch with in the local paper is the news editor. If you know a reporter use the personal contact as this always works better than the cold contact. Find out the paper's deadlines for copy and photographs. They must always know:

- What the event is
- Who is involved?
- Why the event is taking place
- When, where and what time?
- Contact name for further information

Handy hints when seeking sponsors

- Set your sponsorship target - aim high! Most Big companies have a CSR – Corporate Social Responsibility team who have a fund to support 'local' events. – Don't be afraid to ask the local Bank or building society Supermarket or employer.



- E.g. Nationwide Building society donated £100 to a recent charity event for CMN in the midlands when asked to provide an oversized cheque!!
- Seek help from your friends - network, friends of friends - you will collect more than you thought possible, but you need to work at it.
- Start your sponsorship early - well in advance of the event.
- When you approach people for sponsorship, ask them if they would mind giving you the money NOW - offer a receipt (we can provide you with a book if you need it).
- It is easier to give money back should you have to pull out of the event, as opposed to trying to collect after the event - people lose interest quickly, and often find excuses for not giving you the money.
- Always maintain a record of your sponsors and ensure that your list reflects those who have paid and those who have *still* to give you their contribution.
- If you belong to a club or association, get them involved either as a sponsor, by organising a fundraising event, or by 'matching' the funds you raise.
- Ask local companies or firms to sponsor you in return for wearing their logo on your T-shirt.
- Think about organising small events, a coffee morning, disco, jumble sale or a car boot sale - whatever you feel comfortable with.

Remember - The only limit is your imagination!

Here are some examples of what people have done:

Helen Douglas held an Aloe Vera Party, invited all her friends and family and raised £200

Susy Hallewell is organising a children's Christmas party, with Santa as the star guest. Money will be raised from ticket sales and selling photos with Santa

Charlotte Davenport sold cakes on a stall at her school and raised £65

SPECIAL THANK YOU

A special thank you goes to Julie White who sadly lost her father earlier this year. Rather than flowers the family asked for donations to Caring Matters Now.

A sincere thank you to Annie Sly and Eric Law (Annie is great Aunt to Fay Hardwidge), who sadly lost their mother, Rose Law, and again the family, chose for donations to be made to Caring Matters Now.

From all at Caring Matters Now we would like to send you and your families our gratitude and sympathies for your loss.

MERCHANDISE

T-SHIRTS

Caring Matters Now T Shirts are now available in children's and adults sizes, in white with the CMN logo on the left hand side.



Children's sizes from ages 3/4, to 11/12 cost £5

Adult sizes from XS to XXL cost £8

These will be available at the Family days but if you can't wait until then, post and packing will be charged at £1.99. For more information:

Email: judy.sealey@dsl.pipex.com

Phone: 07944 846878

Write: The Bridge Chapel Centre, Heath Road, Liverpool, L19 4XR

TROLLEY TOKENS

Also at Family Days we will be selling Trolley Tokens embossed with the CMN logo.

Use these instead of a pound coin and you'll never be stuck for a trolley again. They come complete with a clip to attach to your key ring or handbag.



RECYCLING APPEAL

We hope to soon to have envelopes to recycle mobile phones and printer cartridges, to raise funds for CMN.

So if you get a new mobile for Christmas or are putting new cartridges in your printer at home or at work, hang on to the old ones until we get this scheme fully operational.

Watch this space for further details.

CMN RESEARCH AT GREAT ORMOND STREET HOSPITAL FOR CHILDREN, LONDON

Caring Matters Now

Bridge Chapel Centre
Heath Road
Garston
Liverpool
L19 4XR

Tel: 0151 281 9716
Fax: 0151 281 9717
Email: jodi.unsworth@googlemail.com

Dr. David Atherton, Consultant Paediatric Dermatologist at Great Ormond Street Hospital for Children (GOSH) has been involved in research into CMNs for the last 20 years. Dr. Veronica Kinsler has been involved in this research since 1998. Since June 2006 Caring Matters Now patient support group has funded Dr. Kinsler (who works part-time because of family commitments) to do a research degree into CMNs. This allows Dr. Kinsler to dedicate all 20 hours a week to the research.

The research is currently focusing on why a particular person develops a CMN. The more patients and families we can see, talk to, and enrol in the studies the better. Larger studies will give more meaningful results. As a result we will see any patient

with a large or multiple or problematic CMN in our dedicated clinic at GOSH, but this requires a referral from your GP to Dr. Atherton.

The results of our research are reported annually to Jodi Unsworth and the Committee of Caring Matters Now. We also update patients involved in the research when we see them in the clinic, and formally at the end of the study. Once results are ready for publication in medical journals they will be posted on the website.

Dr. Kinsler and Dr. Atherton would like to thank everyone involved in Caring Matters Now for funding this important research, and everyone involved in the studies for taking the time to contribute.



We're on the web!

See us at
www.caringmattersnow.co.uk

FROM ALL THE TEAM AT CARING
MATTERS NOW

MERRY CHRISTMAS

