

June 2008

THANK YOU DR ATHERTON

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In 2000 Dr David Atherton asked me to support CMN patients throughout the UK and due to his support I established the Caring Matters Now Support Group. Dr Atherton was, and has always been, the driving force behind my decision to establish and coordinate the Caring Matters Now Support Group. For many years Dr Atherton has single-handedly ran the CMN clinic at Great Ormond Street Hospital.

Dr Atherton's work has not only given hundreds of CMN patients' expert medical advice and treatments, but also given CMN patients and their families peace of mind about the skin condition and a hope for the future. Dr Atherton has also raised tremendous awareness of CMN's throughout the medical field.

Dr Atherton is sad to be leaving a work he has a real passion for....

I regret to inform you that after many years of dedication to the CMN clinic, Dr Atherton is retiring this year. Dr Atherton is sad to be leaving a work he has a real passion for, but he has a peace of mind, that DR Veronica Kinsler can take his work forward, as the CMN support group funds her medical research into the skin condition.

I would like to take this opportunity to thank Dr Atherton, on behalf of all the CMN members, for his dedication and support to all CMN patients. Dr Atherton has set a solid foundation to the CMN clinic and CMN medical research. Without his caring and compassionate nature, the CMN support group would never have been established and CMN sufferers would never have had expert medical advice and treatments.

THANK YOU DR ATHERTON FOR ALL YOUR TIME, ENERGY, ADVICE AND COMMITMENT TO THE CMN CLINIC AND THE CMN SUPPORT GROUP.



Thank you for all your support...

- Liverpool Marriott Hotel South for funding the CMN newsletter and the Liverpool Family day.
- ITV's This Morning for raising awareness of CMN.
- CBA Design and Print for re-branding the CMN Support Group and producing the CMN booklet, posters and stationery



ITV's THIS MORNING

Fern Britain and Eamon Holmes talk to Jodi and Veronica about CMN

One Wednesday 9th May, Jodi Unsworth and Dr Veronica Kinsler had a lovely day out at the ITV studios in London. Jodi and Veronica were asked to appear on 'This Morning' with Fern Britain and Eamon Holmes to be interviewed for 10 minutes about CMN.

The interview went really well and as a result, thirteen new CMN sufferers have joined the support group. Jodi has also received many emails from viewers offering support, including 'Woman' magazine offering to interview Jodi about CMN. The interview will appear in the health section of the magazine in the coming weeks.

Fern Britain and Eamon Holmes were really friendly and at the end of the interview Fern Britain commented on how the interview could have gone on a lot longer. Fern and Eamon were very interested in the CMN skin condition and the support group, so all in all the interview was a success.

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MY STORY

By David Franklin



I would have my swimming trunks on even though it didn't cover my right leg and my back where my CMN is.

My name is David Franklin I am 41 years of age. Until recently I thought I was the only person to have a CMN and I probably would of until now if it wasn't for my mum phoning me and telling me she had just watched This Morning and seen a young girl on the programme with what I had. At first I found it hard to believe that there was someone the same as me so that evening I looked up the 'This Morning' website and saw Jodi. I then went on to the Caring Matters Now website and I was in total shock that there was even a name for my condition let alone there where other people who had the condition. I decided to email Jodi, not really knowing what to say and to be honest, I was feeling scared because I have kept my CMN to myself and I never discuss it. However, here I was e-mailing a total stranger. Anyway, Jodi emailed me back and I felt able to tell her some of the things that happened to me so far in my life... good and bad happy and sad. We both felt that it would be a good idea to share some of my experiences with family and friends and people that have the same condition.

I can't really recall the first time I noticed that I was different to everyone else. We used to have family holidays when I was younger and my brother and I, who is two years older than me, would splash around in the sea without a care. I would have my swimming trunks on even though it didn't cover my right leg and my back where my CMN is. I think it was about 9 years

old when things started with my friends calling me names and when I played for the school football teams and the other team would stand and stare at my leg. That's when I started to get conscious of my CMN.

The day I remember the most was when I went to the local swimming pool. I was the first to arrive and it was a hot day so I thought I would get into the pool and wait for my friends. The pool was really busy because it was such a hot day. After ten minutes the lifeguard came over and asked me to leave the pool.

He told me I was frightening the other people in the pool and he didn't want what I had spreading in the water. I went home upset and to this day I don't think I've told my mum about that day.

Bless my mum... I am sure she blames herself for my CMN but it's not her fault its just one of those things. My mum tried everything for me when I was younger, including countless trips to Oxford hospital, but I used to get fed up with being referred to as the boy with the moles. At times I used to feel like a freak show, as all these doctors stood around poking and prodding me and nothing ever seemed to work.

I still got on with my life and had loads of friends and I used to always be out and about. My late teens were a bit of a blur, as I discovered the pub and I had money to go and watch Chelsea. At the age of 22 I meet a lady that

In summary I've had a great life so far and my CMN hasn't stopped me from doing anything that I've wanted to do.

would later become my wife. I remember the day in my flat when I told her about my CMN. It was a very hard day and I thought when she knew she would dump me but here I am 20 years later married with two daughters aged 18 and 13. I did worry before both my daughters were born that they would have a CMN but they didn't

and neither of them have ever questioned my CMN. I feel so proud of them both, as they are so caring and so excepting of other people and that we are all different. In summary I've had a great life so far and my CMN hasn't stopped me from doing anything that I've wanted to do.

CMN RESEARCH AT GREAT ORMOND STREET HOSPITAL FOR CHILDREN

By Veronica Kinsler



The CMN research at GOSH is going really well, thanks to the continued willingness of patients and families to participate in the studies. We have finished analysing the 19 years of the CMN Registry. This is the data we have been collecting at GOSH on pregnancy, parental skin characteristics, and changes in the CMN over time. The results have been submitted to the British Journal of Dermatology as 2 papers and should be published during 2008. We have also finished analysing the 16 year study of MRI scans for CMNs. This has been accepted by the same journal and will be published shortly. These 3 papers have greatly improved the data we have on the risk of complications in CMNs, which patients need scans, and how often patients should be seen. I have been asked to go to the European Society of Paediatric Dermatology meeting and will be presenting this data, so the results of the research are getting well publicized.

We have recruited 75 patients and their parents to the genetics study, and have just received the green light from the ethics committee to start collecting blood samples from people (children or adults) with CMNs who are not currently seen at GOSH. This would involve coming to GOSH for a one-off appointment of about an hour. This new phase should start within the next 6 months and we will automatically send an invitation to anyone for whom we have a current address on the CMN Registry, or anyone who has ever been a patient at GOSH but isn't any longer.

We are also beginning the study into the spontaneous lightening seen in some CMNs. This will only be for babies (under 1) and they will be monitored for 2 years. We hope to recruit 20 babies within the next year. If we can work out why some CMNs lighten a lot we may be able to work out how to make it happen.



CMN FAMILY DAY REVIEW

Venue: The Hub Community Centre, Cambourne, Cambridge

Date: Saturday 23rd February 2008

Review: The family day was very well attended, with many new families, Dr Veronica Kinsler and the CMN team.

The Cambridge family day was the first dedicated CMN fun day to be held in the south and it was a great success. There were many new faces, providing a great opportunity to meet and chat with new families.

There was a lot going on... easter egg hunt, craft activities, toys, bouncy castles (with slide!), light buffet, refreshments, raffles, and CMN medical information and support group up-date presentation.

We also had the help of a professional photographer on the day who took some great shots, which will be used on promotional material and the new look CMN Booklet.

The CMN team gave a short presentation on the support group's progress over the past 12 months and Dr Kinsler gave an up-date on the latest medical research findings.

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

UPCOMING FAMILY DAYS

Date: Saturday 7th June 2008

Time: 1pm - 5pm

Venue: Counterslip Baptist Church, 648-652 Wells Road, Bristol, BS14 9HT

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

Date: Saturday 13th September 2008

Time: 1pm - 5pm

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

Date: Saturday 29th November 2008

Time: 1pm - 5pm

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



JUNE 2008						
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15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30					

CMN REGIONAL SUPPORT CONTACTS

The Caring Matters Now support group want 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 10 regional contacts in places at present.

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Judy



Jodi



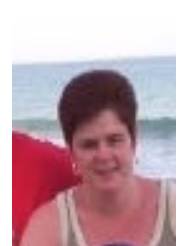
Lucy C



Lucy H



Jessica



Lynne

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

Support area: Scotland
Contact: Anne MacIntyre
Contact number: 0141 646 1069
Contact email address:
anne@macintyre1150.fslife.co.uk

Support area: North West England
Contact: Jodi Unsworth
Contact number: 0151 281 2820
Contact email address:
jodi.unsworth@googlemail.com

Support Area: North Midlands
Contact: Julie White
Contact number: 01636 611 361
Contact email address:
andrew@awhite46.orangehome.co.uk

Support area: South
Contact: Hannah Woods
Contact number: 01837 871282
Contact email address:
hanex20@aol.com

Support area: Thames Valley, Surrey & Hampshire
Contact: Karen Millen
Contact number: 01494 870173
Contact email address:
hanex20@aol.com

Support area: North Wales
Contact: Judy Sealey
Contact number: 01244 815 997
Contact email address:
judy.sealey@dsl.pipex.com

Support area: South Wales
Contact: Lynne Davies
Contact number: 01656 870 511
Contact email address:
Andrew3d Davies@btinternet.com

Support area: South West
Contact: Lucy Clarke
Contact number: 01386 831 994
Contact email address:
lucyandstephen@btinternet.com

Support area: East Anglia & South Midlands
Contact: Lucy Hardwidge
Contact number: 01954 719612
Contact email address:
lucy.hardwidge@btinternet.com

Support area: London & Kent
Contact: Jessica Ma
Contact number: 01732 760 029
Contact email address:
ppottierjma@aol.com

Each regional support contact is a member of the CMN support group. All CMN. All 10 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 Jodi Unsworth on 01512812820.

Help the CMN support group raise £30,000 for the CMN research

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 Kinsler at Great Ormond Street to conduct specific medical research into CMN. We need to raise funding every year of approximately £30,000 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.

Steve Clarke has produced some supporting sponsor forms flyers and thank you notes etc to help publicise your event.

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.



Sponsors and contributors

Lifeshall steel services
Matthew and Vanessa Thomas
Rupert and Laurie Bell
Stephen and Sarah Adkinson
Vale Golf Club
CPRE Railway
West Midlands Motor Park
Mike and Maria Outfield

Clifford
Colwood Wildlife Park
Lego Land
Jocelyn, Philippa and friends
Phil and Kerry Bullas
Nicky and Ashlee Mayhew
Neil and Katrina Cockerton
Margaret Thompson





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.

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.
- 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.

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

We're on the web!

See us at
www.caringmattersnow.co.uk