



Media Toolkit

This media toolkit is designed to help you contact your local media about your fundraising event.

Sharing your family story in the media is a wonderful way of raising awareness about CMN Syndrome as well as increasing your fundraising total.

The toolkit contains:

- a template press release
- a step by step guide to contacting your local media
- key messages to help you talk about the syndrome, Caring Matters Now and your fundraising

Please contact us on 07786 458883 if you have any questions about the process.

Be aware of national independent journalists that will offer to write your story for national womens magazines or newspapers and will get you a fee payable on the article being published. They have been known, in some cases to adapt the stories and attach an eye catching (but negative) title. If you are at all concerned please feel free to call us and we will endeavour to help all we can.

Good luck and we hope to be reading about your family soon.

Best wishes,

Lucy Hardwidge
Caring Matters Now

PRESS RELEASE FOR A FUNDRAISING EVENT

[Insert date]

[Insert town] [man/ woman] organising a fundraising event, inspired by their [son/ daughter's/ niece's] rare syndrome

A [man/ woman] from [insert town] is preparing to organise a [quiz night/ charity ball/ etc] to raise money for research into their [son's/ daughter's/niece's] rare condition.

[Fundraiser's name] from [area] is [mum/ dad/ uncle] to [child's age and name] who has Congenital melanocytic naevus (CMN) Syndrome, the association of brown/black moles present at birth, neurological problems including brain tumours and an increased risk of malignant melanoma (skin cancer).

The syndrome is thought to affect just 1 in 10,000 babies born in the UK and many families can struggle for months or even years to get a diagnosis.

[Fundraiser's name] is organising a fundraising event for Caring Matters Now, the only UK dedicated support group for people affected by the condition. [He/ she] says it's important to find out what causes CMN syndrome in order to develop future treatments.

"When [child's name] was born, nobody could tell us what this huge dark mark on [his/ her] skin was. We didn't know what the best course of action was; if we should try to have it removed or not. We weren't just worried about how it could affect [his/ her] health, we were also concerned how it would affect [him/ her] socially. People can be very hurtful, even when they don't mean to be, which is why we want to raise awareness about CMN syndrome as well as money for research."

"This is going to be a challenge as I have not done anything like this before" [fundraiser's name] says "but I will be inspired every step of the way by [child's name]".

To find out more about CMN syndrome visit www.caringmattersnow.co.uk. To make a donation to [fundraiser's name] visit www.justgiving.com/xxxxxxx

- Ends -

For more information or to arrange an interview please contact [fundraiser's name] on [fundraiser's phone number]

PRESS RELEASE FOR CHARITY CHALLENGE TEAM

[Insert date]

[Insert town] [man/ woman] preparing for [Name of Challenge], inspired by their [son/ daughter's/ niece's] rare syndrome

A [man/ woman] from [insert town] is taking on the challenge of their life to raise money for research into their [son's/ daughter's/niece's] rare skin condition.

[Fundraiser's name] from [area] is [mum/ dad/ uncle] to [child's age and name] who has Congenital Melanocytic Naevus (CMN) syndrome an association of brown or black moles present at birth, neurological problems including brain tumours, characteristic facial features, and an increased risk of malignant melanoma.

The syndrome is thought to affect just 1 in 10,000 babies born in the UK and many families can struggle for months or even years to get a diagnosis.

[Fundraiser's name] is participating in [Name the challenge] for Caring Matters Now, the only UK dedicated support group for people affected by the condition. [He/ she] says it's important to find out what causes CMN syndrome in order to develop future treatments.

"When [child's name] was born, nobody really knew what this huge dark mark on [his/ her] skin was. We didn't know what the best course of action would be; whether to have it removed or not, what the long term implications would be. The worries were not just how it could affect [his/ her] health, there we also concerns about how it would affect [him/ her] socially. People can be very hurtful, even when they don't mean to be, which is why the charity Caring Matters Now with the help of members, their family and friends want to raise awareness about CMN syndrome as well as money for pioneering research being carried out at the Institute of Child Health."

[Fundraiser's name] is one of [No.] fundraisers attempting the mental and physical challenge in the Lake District between 14-16 June and wants to raise at least [insert amount] towards the charity's £XXXX target.

"This is going to be the toughest thing I've ever done" [fundraiser's name] says "but I will be inspired every step of the way by [child's name]".

To find out more about CMN syndrome visit www.caringmattersnow.co.uk. To make a donation to [fundraiser's name] visit www.justgiving.com/xxxxxxx

- Ends -

For more information or to arrange an interview please contact [fundraiser's name] on [fundraiser's phone number]

Caring Matters Now

Contacting your local media

Here is a step by step guide to contacting your local media about your event/challenge. Sending them a press release is inviting them to talk to you and print/ broadcast details about your family, so please make sure you are happy for that to happen.

- Make sure you have filled in the template press release with the relevant personal details. The quote provided is just an example so change it to reflect your family's experience. But please avoid any negative comments on the level of support or information you had from an individual or hospital
- Add in any other details that you think are newsworthy:
 - Has your son or daughter been through a particularly difficult event because of their CMN?
 - Have they had a large number of operations or missed a considerable amount of school?

It doesn't have to be a negative experience but be brief and aim to keep the press release to just one page

- Identify the media in your local area, including newspapers, radio stations and television news programmes. Before you approach them, bear in mind that newspapers may want to come to take a photograph, radio may want to do a live or recorded interview and TV will want to film you, so only choose the ones you would be happy to talk to
- Copy your press release into the body of an email. Don't attach it as a document as this can send messages into recipients' spam folders. You can use the headline of the press release as the title of your message
- Send your press release to the newsdesk. You can find contact details for the media on the internet. You can send the release at any time, but radio and TV may not contact you until much closer to the event/challenge
- If you haven't been called by the media by two weeks prior to your event and you feel confident to do so, you can call the newsdesk. Tell them you sent them a press release about your fundraising event/challenge to raise money for research into your child's rare condition, [your event is in/you leave for your challenge in] two weeks' time and would they like to talk to them. They may well ask you to send your press release again as they see hundreds every day
- Your personal story is what the journalist wants to talk about in an interview. As well as raising awareness about CMN syndrome, your story may inspire readers/ viewers/ listeners to donate towards your fundraising. Read through the key messages in this pack which will help you if you're not sure how to describe CMN syndrome or Caring Matters Now
- Make sure you know the URL of your fundraising page so that you can mention it in your interview or ask that it is included in a newspaper article

Caring Matters Now

Key messages

These are the key messages. They will help you talk about the event/challenge, charity and the condition with confidence.

The charity

Caring Matters Now is the only UK dedicated charity that supports people affected by Congenital Melanocytic Naevus Syndrome (CMN syndrome), a rare disorder affecting the skin and brain.

The condition

CMN syndrome is an association of birthmarks which can cover up to 80% of the body and can affect the brain and spinal cord.

CMN syndrome affects 1 in 10,000 babies born in the UK.

The reasons behind the fundraising

An event

I have not organised a fundraising event before, but I wanted to do something to support Caring Matters Now.

By organising this event I hope to raise £X towards the charity's annual target of £45,000, which is used towards the cost of research into the causes and treatments of CMN syndrome.

A challenge

There are [No.] of us taking on the challenge of [Name of Challenge] and we hope to raise a total of [£XXXX] towards the cost of research into the causes and treatments of CMN syndrome.

By climbing [Name of Challenge], I hope to raise at least [£XX] towards the charity's target of [£XXXX].

URLs

To support me, please visit my fundraising page at www.justgiving.com/myname

To find out more about CMN syndrome visit www.caringmattersnow.co.uk