



**Caring  
Matters  
Now**

# **DATA PROTECTION POLICY**

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**CARING MATTERS NOW  
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UK Registered Charity No: 1120988

# **The Caring Matters Now Support Group Data Protection Policy**

## **Our Mission**

Caring Matters Now is the only dedicated UK charity to provide information and support for those affected by Congenital Melanocytic Naevus. The charity has three main aims:

To support those affected by CMN  
To raise awareness about CMN  
To raise funds for the CMN research

Caring Matters Now holds support events across the UK to allow families to come together to share stories and experiences and for the children to bond with others that share the same condition. The charity also has developed a wide range of support material for parents of children with CMN.

Caring Matters Now also raises awareness about CMN, especially within the medical field and aims to raises £100,000 per year, which supports the CMN research at Great Ormond Street Hospital.

## **Contact Information**

### **Chairperson and Trustee**

Mrs Valerie Unsworth

### **CEO and Trustee**

Mrs Jodi Whitehouse

### **Charity Development Officer and Trustee**

Mrs Lucy Hardwidge

### **Treasurer and Trustee**

Ian Chance

### **Regional Support Contact and Trustee**

Mrs Anne McIntyre

### **Trustee Responsible for Corporate Developments**

Robert Jackson

### **Regional Support Contact and Trustee**

Bronagh Cleland



## Data Protection Policy

At Caring Matters Now we are committed to protecting all personal information and being transparent about what we do with it. We are committed to using all personal information in accordance with all applicable laws concerning the protection of personal information and not to do anything with information that wouldn't be reasonably expectable.

This Privacy Policy explains:

- how Caring Matters Now may obtain your personal information
- what information we collect
- how we will use that information
- who we share your information with
- your choices regarding your information we hold

If you have any questions about this Data Protection Policy, please contact our Data Protection Compliance Officer at Caring Matters Now, emailing [info@caringmattersnow.co.uk](mailto:info@caringmattersnow.co.uk), or telephone 07786 458883.

## How do we obtain your personal information?

We collect information in the following ways:

- **When you give it to us directly**

You may give us your information in order to register as a member, sign up for one of our events, when you contact us to ask about our activities, to tell us your story, order products and services from us, seek assistance, make a donation to us, fundraise on our behalf, or otherwise give us personal information.

Sometimes when you support us, your information is collected or processed by an organisation working for us, for example, a data processing company. Where they are doing it purely on behalf of Caring Matters Now, we will be responsible for your information at all times.

- **When you give permission to other parties to share it with us**

Your information may be shared with us by independent event organisers, for example the London Marathon or fundraising sites like Just Giving or Virgin Money Giving. These independent third parties will only do so when you have indicated that you wish to support Caring Matters Now with your consent.

You should check their Privacy Policy when you provide your information to understand fully how they will process your information. We may also obtain information about you from a family member or a friend who contacts us on your behalf or if a fundraiser passes on your details to us.

- **When your information is available publicly or from other external sources**

We may combine information that we already have about you with information available publicly or information available from external sources in order to gain a better understanding of you and to improve our fundraising methods, products and services. Such information could be for example, socio-demographic and lifestyle information and information about previous donations you have made.

The information we get from other external sources may depend on your privacy settings or the responses you give, so you should regularly check them. For example, you may have provided permission for a company or other organisation to share your data with third parties including charities. This could be when you buy a product or service, register for an online competition or sign up with a comparison site.

Depending on your settings or the privacy policies for social media and messaging services like Facebook, WhatsApp or Twitter, you might give us permission to access information from those accounts or services.

We may also obtain information about you where it is publicly available and found in places such as Companies House, Land Registry website and information that is published in articles and newspapers.

## **What information do we collect?**

Personal information is any information that can be used to identify you. For example, it can include information such as your name, date of birth, email address, postal address, telephone number and credit/debit card details, as well as information relating to your health or personal circumstances.

Data protection law recognises that certain categories of personal information are more sensitive. This is known as sensitive personal information and covers health information, racial or ethnic origin, religious beliefs or other beliefs or a similar nature, political opinion and trade union membership. We would only collect sensitive personal information where there is a clear need to do so such as health issues relating to Congenital Melanocytic Naevus. Before collecting any sensitive personal information about you we will make it clear to you what information we are collecting and the purposes for collecting such.

## **How do we use your information?**

How we use your information would largely depend on why you are providing it. We may use your information in the ways set out below.

- We use your personal information to give you the information, support, services, or products you ask for.
- We use your information to gain a full understanding of your situation so we can develop and offer you the best possible personalised services.
- We use your information to keep a record of your relationship with us and for internal administrative purposes (such as our accounting and records), and to let you know about changes to our services or policies. We use your personal information look into, and respond to, complaints, legal claims or other issues.
- We use your personal information to claim Gift Aid on your donations.
- We use personal data to carry out statistical analysis and research in order to help us to understand how we are performing and how we can improve our services and meet the needs of people that require our help.
- We may also use your personal information for other purposes which we specifically notify you about and, where appropriate, obtain your consent.

## **Who do we share your information with?**

We will not sell your details to any third parties, but we may sometimes share your information with our trusted service providers who are authorised to act on our behalf, associated organisations who work on our behalf, or whom we work with in partnership to deliver and improve services for people affected by CMN. This includes organisations who fundraise on our behalf.

When we collect your personal information, we use strict procedures and security features to prevent unauthorised access. However, no data transmission over the Internet is 100% secure. As a result, while we try to protect your personal information, Caring Matters Now cannot guarantee the security of any information you transmit to us and you do so at your own risk.

## **Accessing and updating your personal information**

You can request access to any information we hold about you by contacting our Data Protection Compliance Officer at Caring Matters Now by emailing [info@caringmattersnow.co.uk](mailto:info@caringmattersnow.co.uk), or telephone 0808 808 00 00. Equally, please let us know of any changes to your personal information.

You can also let us know if you would no longer like to receive fundraising communications from us or if you would prefer us not to profile you for the purposes of targeting or tailoring our fundraising efforts, by emailing [fundraising@macmillan.org.uk](mailto:fundraising@macmillan.org.uk) or calling us on 07786 458883.