



# CdLS Foundation UK & Ireland

The Cornelia de Lange Syndrome Charity Reg. No. 1054033

*"The CdLS Foundation UK & Ireland is a family support organisation which exists to ensure early and accurate diagnosis of CdLS throughout the world, promoting research, and enabling individuals, families, friends and professionals make informed decisions and plan for the affected person's present and future."*

## Privacy & Data Protection Policy

### Introduction

The CdLS Foundation UK & Ireland ("we") promises to respect any personal data you share with us, or that we get from other organisations and keep it safe. We aim to be clear when we collect your data and not do anything you wouldn't reasonably expect.

Developing a better understanding of our families and donors through their personal data allows us make better decisions, fundraise more efficiently and, ultimately, helps us to reach the goal of our mission statement. We have made improvements to this policy to make it more understandable to our people.

In May 2018, we will be moving to be an 'opt-in only' communication policy. This means that we will only send marketing communications to those that have explicitly stated that they are happy for us to do so via their preferred channel(s) (email, SMS, phone or post).

Our marketing communications include information about research, Awareness Day or other campaigns and events, as well as our magazine "Reaching Out.". If you would like to receive such communications but have not opted in please contact us on 01375 376439 or [info@cdls.org.uk](mailto:info@cdls.org.uk)

### Where we collect information about you from

We collect information in the following ways:

- When you give it to us DIRECTLY

You may give us your information in order to register on our database, sign up for one of our events, tell us your story, make a donation, join us as a volunteer or communicate with us. Sometimes when you support us, your information is collected by an organisation working for us (e.g. a professional fundraising agency), but we are responsible for your data at all times.

- When you give it to us INDIRECTLY

Your information may be shared with us by independent event organisers, for example the London Marathon or fundraising sites like Just Giving or BT MyDonate. These independent third parties will only do so when you have indicated that you wish to support The CdLS Foundation UK & Ireland and with your consent. You should check their Privacy Policy when you provide your information to understand fully how they will process your data.

- When you give permission to OTHER ORGANISATIONS to share or it is available publicly

We may combine information you provide to us with information available from external sources in order to gain a better understanding of our supporters to improve our fundraising methods and services.

The information we get from other organisations may depend on your privacy settings or the responses you give, so you should regularly check them. This information comes from the following sources:

#### Third party organisations

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.

#### Social Media

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

#### Information available publicly

This may include information found in places such as Companies House and information that has been published in articles/newspapers.



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## When we collect it as you use our Website or Apps

Like most websites, we may use "cookies" to help us make our site - and the way you use it - better. Cookies mean that a website may remember you. They're small text files that sites transfer to your computer (or phone or tablet). They make interacting with a website faster and easier - for example by automatically filling your name and address in text fields.

In addition, the type of device you're using to access our website or apps and the settings on that device may provide us with information about your device, including what type of device it is, what specific device you have, what operating system you're using, what your device settings are, and why a crash has happened. Your device manufacturer or operating system provider will have more details about what information your device makes available to us.

The cookies we currently use store temporary information to enable site functionality. They are automatically deleted when you close your browser and do **not** collect personal information. You may refuse to accept cookies by activating the setting on your browser which allows you to refuse the setting of cookies. Unless you have adjusted your browser setting so that it will refuse cookies, our system will issue cookies when you log on to our Website.

## Links from our Website

Our website contains links to other websites. Please note that we have no control of websites outside the [www.cdls.org.uk](http://www.cdls.org.uk) domain.

If you provide information to a website to which we link, we are not responsible for its protection and privacy.

Always be wary when submitting data to websites. Read the site's data protection and privacy policies fully.

## What personal data we collect and how we use it

The type and quantity of information we collect and how we use it depends on why you are providing it.

### Supporters

If you support us, for example make a donation, volunteer, register to fundraise, sign up for or pay an event, we may collect:

- Your name
- Your contact details
- Your date of birth
- Your bank or credit card details.

Where it is appropriate we may also ask for:

- Information relating to your health (for example if you are taking part in a high risk event)
- Why you have decided to donate to us. We will never make this question mandatory, and only want to know the answer if you are comfortable telling us.

We will mainly use your data to:

- Provide you with the services or information you asked for
- Administer your donation or support your fundraising, including processing gift aid
- Keep a record of your relationship with us
- Ensure we know how you prefer to be contacted
- Understand how we can improve our services, events or information.

If you enter your details onto one of our online forms, and you don't 'send' or 'submit' the form, we may contact you to see if we can help with any problems you may be experiencing with the form or our websites.

We may also use your personal information to detect and reduce fraud and credit risk.

### Direct Marketing

With your consent, we will contact you to let you know about the progress we are making, upcoming events, other news and to ask for donations or other support. Occasionally, we may include information from partner



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organisations or organisations who support us in these communications. We make it easy for you to tell us how you want us to communicate, in a way that suits you. Our forms have clear marketing preference questions and we include information on how to opt out when we send you marketing. If you don't want to hear from us, that's fine. Just let us know when you provide your data or contact us on 01375 376439 or [info@cdls.org.uk](mailto:info@cdls.org.uk)

We do not sell or share personal details to third parties for the purposes of marketing. But, if we run an event in partnership with another named organisation your details may need to be shared. We will be very clear what will happen to your data when you register.

## **Sharing your story**

Some people choose to tell us about their experiences with CdLS to help further our work. They may take on a role as an ambassador or spokesperson, attend our events or sit on our committees. This may include them sharing sensitive information related to their health and family life in addition to their biographical and contact information.

We use some of the information provided, including gender, ethnicity or the genotype/phenotype of CdLS people have experience with, to target opportunities to get involved. We will also monitor the types of people who are involved to ensure that the views we hear are representative of all people affected by CdLS.

If we have the explicit and informed consent of the individuals, or their parent or guardian if they are under 18, this information may be made public by us at events, in materials promoting our campaigning and fundraising work, or in documents such as our annual report.

## **Support for individuals affected by CdLS**

We run services to provide support to individuals and their families affected by CdLS, and collect personal data in order to provide those services.

We may collect sensitive personal data about the health of a CdLS person when you speak, email or send an online message to us. We will use this information to answer your questions and give advice, guidance or refer you to our specialists. We will also use it for training, quality monitoring or evaluating the services we provide.

We may also collect and retain your information if you send feedback about our services or make a complaint.

## **Children's data**

We collect and manage information about children, and aim to manage it in a way which is appropriate to the age of the child. Information is often collected when children attend our events or fundraise for us.

Where possible and appropriate we will seek consent from a parent or guardian before collecting information about children. Our events have specific rules about whether children can participate, and we'll make sure advertising for those events is age appropriate.

## **How we keep your data safe and who has access**

We ensure that there are appropriate technical controls in place to protect your personal details. For example our online forms are always encrypted and our network is protected and routinely monitored.

We undertake regular reviews of who has access to information that we hold to ensure that your information is only accessible by appropriately trained staff, Trustees, Regional Volunteers and contractors.

We do not use external companies to collect or process personal data on our behalf.

We may need to disclose your details if required to the police, regulatory bodies or legal advisors.

We will only ever share your data in other circumstances if we have your explicit and informed consent.

## **Keeping your information up to date**

We do not use publicly available sources to keep your records up to date. We are wholly reliant on you informing us of any change of details.



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We really appreciate it if you let us know if your contact details change.

## **Your right to know what information we keep about you, make changes or ask us to stop using your data**

You have a right to ask us to stop processing your personal data, and if it's not necessary for the purpose you provided it to us for (e.g. processing your donation or registering you for an event) we will do so. Contact us on 01375 376439 or [info@cdls.org.uk](mailto:info@cdls.org.uk) if you have any concerns.

You have a right to ask for a copy of the information we hold about you, although we may charge £5 to cover the costs involved. If there are any discrepancies in the information we provide, please let us know and we will correct them.

If you want to access your information, send a description of the information you want to see and proof of your identity by post to the CdLS Foundation UK & Ireland, 6 Vale Close, Harpenden, Hertfordshire AL5 3LX. We do not accept these requests by email so we can ensure that we only provide personal data to the right person. If you have any questions please send these to [info@cdls.org.uk](mailto:info@cdls.org.uk), and for further information see the [Information Commissioner's guidance here](#).

## **Changes to this policy**

We may change this Privacy Policy from time to time. If we make any significant changes in the way we treat your personal information we will make this clear on the CdLS Foundation UK & Ireland Website, our Facebook page or by contacting you directly.

If you have any questions, comments or suggestions, please let us know by contacting the CdLS Foundation UK & Ireland, 6 Vale Close, Harpenden, Hertfordshire AL5 3LX or email [info@cdls.org.uk](mailto:info@cdls.org.uk)

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