

Interim Privacy Notice

Introduction

Children's Liver Disease Foundation (CLDF) ("we") promises to respect any personal data you share with us, or that we receive 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 supporters through their personal data allows us to make better decisions, target our services more efficiently and, ultimately, helps us take action against the effects of childhood liver disease by providing information, emotional support, research funds and a voice for all affected.

Our marketing communications include updates around our work, how to access our services and how to support us and get involved. If you would like to receive such communications but do not currently do so, or would like to change the way you hear from us, please complete our short form online at childliverdisease.org/keep-in-touch or call us on 0121 212 3839.

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 sign up to our services, book on to an event, tell us your story, make a donation, participate in fundraising activities, purchase an item in our shop or communicate with us.

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 Virgin Money Giving. These independent third parties will only do so when you have indicated that you wish to support Children's Liver Disease Foundation (CLDF). You should check their Privacy Notice when you provide your information to understand fully how they will process your data.

When we collect it as you use our WEBSITES OR APPS

Like most websites, we use "cookies" to help us make our site – and the way you use it – better. Cookies mean that a website will 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. There are more details in our [Cookie Policy](http://childliverdisease.org/privacy-policy/cookie-policy/) (childliverdisease.org/privacy-policy/cookie-policy/).

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.

We do not receive any personal information from use of our My Liver App, only statistics such as number of downloads etc.

Our Yellow Alert app only collects personal information that is passed to us if Yellow Alert packs are ordered.

CLDF websites and social media accounts may contain links to other websites. When you click on one of those links you are accessing a website that is not owned, operated or controlled by us or any of our affiliates. The operator of such a site may have its own Privacy Notice, which we encourage you to read carefully. The notice will govern the collection and use of your data on that site.

What is personal data?

Personal data is information that can be used to help identify an individual, such as a name, address, phone number or e-mail address.

What personal data we collect and how we use it

We will only ever collect the information we need – including data that will be useful to help improve our service. 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 or access our services - for example contact a member of our support team, request an information pack, make a donation, volunteer, register to fundraise, sign up for an event or buy something from our shop - we will usually collect the following information:

- Your/your child's name
- Your contact details (address, email address, telephone number(s))
- Your bank or credit card details (if any transaction is involved)

Where it is appropriate/necessary we may also ask for:

- Information relating to your/your child's health (for example if you are taking part in an event or accessing support services)
- Your/your child's date of birth
- Your/your child's ethnicity
- 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, products 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, products or information.

Direct Marketing

We will contact you to let you know about our support services, fundraising activities and general updates on our work. We make it easy for you to tell us how you want us to communicate with you in a way that suits you. All our online forms contain clear contact preference questions and anything we post or email to you includes information on how you can change your contact preferences/opt out at any time. If you don't want to hear from us, that's fine. Just let us know when you provide your data or contact us by any of the following methods:

- Fill in a short form at childliverdisease.org/keep-in-touch
- Call us on 0121 212 3839
- Write to us at –
FREEPOST RTLB-TTXZ-KLZB, Children's Liver Disease Foundation, 36 Great Charles Street Queensway, Birmingham B3 3JY

You may directly consent to us contacting you, or we may have a legitimate interest to do so.

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 liver disease to help further our work. They may take on a role as an ambassador or volunteer, attend our events/events on our behalf, or allow us to share their story in the press and media. This may include them sharing sensitive information related to their health and life, as well as their contact information.

If we have the explicit and informed consent of the individuals, or their parent/guardian if they are under 18, this information (eg. Talk Tell Transform films) may be made public by us at events, in materials promoting our campaigning and fundraising work, or in documents such as our Impact Report. We may also include this information in applications for funding.

Support for individuals affected by Liver Disease

Our services provide support to individuals and families affected by liver disease and collect personal data in order to efficiently provide those services.

Our Support team may collect sensitive personal data about your health or the health of your child when you speak, email or send an instant message to them (eg. Facebook). They will use this information to answer your questions and give advice or guidance.

We will only share your details in exceptional circumstances or where legally required, for example where a child reports abuse, or someone reports serious self-harm or a serious intention of harming someone else.

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

Children's Data

We will always seek consent from a parent/guardian before collecting information about children under the age of 16. This includes when a young person under 16 gives us their contact preferences and tells us they want to hear from us. Children under 13 cannot sign up to receive

information from us. However, our Young People's team may contact children age 11 and over through their parent(s), or directly with the parent's consent to make contact.

Our fundraising events have specific rules about whether children can participate and we make sure advertising for those events makes this clear and is age appropriate.

When registering to use Hive (our secure online community for young people age 13 and over with liver disease) we will ask for the user's name, email address, date of birth, liver condition, hospital treatment centre and their parent's name and email address. We ask for this information as a means of protecting the young people accessing the site and so that we contact the parents of those aged 13-16 to gain their consent for their child to use Hive. The user's email address may be used to contact them about new features and updates to Hive, administrative issues and changes to the site.

We will never make children's details available to third parties, other than when necessary as explained in other areas of this Privacy Notice.

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 network is protected and routinely monitored.

We restrict access to information that we hold about you or your child to ensure that it is only accessible by appropriately trained staff and volunteers who need to know the relevant information.

On occasions, we use external companies to process your details (name and address) on our behalf, for example to assist us with large bulk mailings such as Liver Life magazine. We do comprehensive checks on these companies before we work with them and put a confidentiality agreement in place. Any personal information sent to external companies is always transferred in a secure manner and password protected. Password information is then provided separately. Such companies comply with all relevant laws applicable to the collection, storage, use and/or processing of personal data. They also maintain the confidentiality of all details processed on CLDF's behalf and have systems adequate to ensure their security. Any details provided are only used for the purpose for which they are supplied (eg. to fulfil the mailing) and upon completion of the work all details are deleted and nothing is stored (in any format).

When we run residential events (eg. our national conference and family weekend), we may pass your/your child's name and/or age to a third party such as a hotel or crèche provider, in order for them to reserve rooms/places for you/your child.

If you take part in a challenge event (eg. London Marathon) for CLDF we will provide the event organiser with your name and any other details they require in order to enter you for the event.

We may need to disclose your details if required by the police, regulatory bodies or legal advisors in the case of child protection or criminal activity.

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

Keeping your information up to date

We really appreciate it if you let us know when your contact details change. We will never use publicly available sources to keep your records up to date – you have a right to choose what information you provide to us and you don't have to update your details if you don't want to.

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

You have a right to the following:-

- To ask us to stop processing your personal data and, if it's not necessary for the purpose you provided it to us (e.g. processing your donation or registering you for an event), we will do so.
- To ask for a copy of the personal information we hold about you. We will provide this information within one month of receipt of the request. For complex or numerous requests this period may be extended by up to a further two months. If this is the case we will inform you within one month of receipt of the request as to why the extension is necessary. A fee may be charged for excessive or repetitive requests or further copies of the same information.
- To ask us to delete/remove all information we hold about you. In some circumstances we can refuse to carry out this request – eg. if we require your data in order to fulfil a legal obligation (eg. Gift Aid) or if the data is processed to exercise the right of freedom of expression and information (eg. safeguarding or complaints). If this is the case we will advise you as to why we cannot comply with your request.
- To block/suppress the processing of your personal data. In these circumstances we are permitted to store your data but stop any further processing/use of it.

If you would like to access the personal information we hold about you, write to us at Children's Liver Disease Foundation, 36 Great Charles Street, Birmingham B3 3JY enclosing proof of your identity and a description of the information you would like to see. We do not accept these requests by email in order to ensure that we only provide personal data to the correct person. If there are any discrepancies in the information we provide, please let us know and we will correct them. We will make any changes requested within one month of receipt of the request. For complex rectification requests this period may be extended by up to a further two months.

If you have any questions please call us on 0121 212 3839 or e-mail them to info@childliverdisease.org. For further information see the [Information Commissioner's guidance \(www.ico.org.uk/for-the-public/personal-information/\)](http://www.ico.org.uk/for-the-public/personal-information/).

If you have any concerns about the way Children's Liver Disease Foundation handles your personal information you also have the right to make a complaint to the Information Commissioner's Officer (ICO) by calling the ICO helpline on 0303 123 1113.

Changes to this notice

We may change this Privacy Notice from time to time. This is an interim Privacy Notice which will be replaced with a fully revised and updated Privacy Notice as soon as possible.

If you have any questions, comments or suggestions, please let us know by writing to Children's Liver Disease Foundation, 36 Great Charles Street, Birmingham B3 3JY, or send an email to info@childliverdisease.org.