**Draft Privacy Notice – Children’s Heartbeat Trust**

Children’s Heartbeat Trust has been working since 1984 to provide practical, emotional and financial support to children and young people living with heart disease and their families.

If you would like to chat to us about how we use your personal information, please contact;

Sarah Quinlan

Chief Executive Officer

Children’s Heartbeat Trust

Howard Building

Twin Spire Centre

155 Northumberland Street

Belfast BT13 2JF

Tel: 028 9031 2228

sarah@childrensheartbeattrust.org

**We can ensure that:**

We are only collecting essential personal data, in order for us to carry out tasks related to our service. This will include sensitive data relating to children.

Children’s Heartbeat Trust is the 'data controller' – and we will be completely open and transparent about how we use your data.

We will never sell your personal data to third parties, ever.

We only keep your data for personal information for as long as we need it.

* Service User or Family of a Service User – up to seven years or for as long as we are regularly working with a family, by agreement.
* Campaigner, donor or fundraiser – only has long as necessary
* Gift Aid – Up to six years, in compliance with HMRC regulations
* Volunteer – Up to seven years.

You can opt out of receiving communications from us at any time.

You can request to access, change, or delete your information at any time.

To safely store your information, we on occasion us Third Parties (i.e. use their services to complete a task) we will ensure your data is safely stored and disposed of after use. Third party services include:

* E-Tapestry – our CRM system used to track donations, service users and volunteers;
* Survey Monkey – a tool to help us run surveys and evaluate services;
* Mailchimp – a service that helps us send out emails to all our volunteers, families, supporters and patrons.

We will protect your personal data by:

1. Keeping it only for as long as necessary
2. Disposing of it once these time limits have passed
3. Restricting access to this information to only those who need to use it
4. Ensuring our security is up to date.
5. Keeping a clean desk policy
6. Acting upon any requests to view, change, or delete your information, within 30 days.

If you are unhappy with how we've handled your personal information, or a complaint you've made in respect of this, you have the right to contact the Information Commissioner's Office.

**USERS OF OUR SERVICE AND FAMILIES**

Your information, or that of your child will be sent on to Children’s Heartbeat Trust, with your permission, by your nurse. We will only accept contacts that have permission from the parent/guardian to share this information with us.

The data we collect on users of our service is the following:

* Parent Name
* Parent Telephone
* Parent Email
* Parent Address
* Service User Name
* Service User Address
* Service User brief Medical Information

This information is stored on Excel and E-Tapestry and used to help provide a service to the child and their family.

**FUNDRAISERS AND DONORS**

If you host or take part in a fundraiser on behalf of the Children’s Heartbeat Trust we may collect some information relating to your donation, to help better understand how to improve our fundraising in the future, as well as comply with some laws – especially Gift Aid.

**MARKETING**

We will not add you to our mailing list without explicit consent. At any point you can unsubscribe from the mailing list by using the links at the bottom of emails. Alternatively, you can contact Children’s Heartbeat Trust directly to ask for this information to be removed.

**VOLUNTEERS**

In order to arrange events and activities, we will hold a small amount of detail on volunteers, including: Name, Address, Email, Phone Number and interests. We promise to never share this data with other volunteers or third parties without your permission.

**YOUR RIGHTS**

You have the right to:

* Ask us for the data we hold on you – and be provided with that information
* Ask to amend, update or alter any inaccurate information we hold about you
* Withdraw your consent for us to use your information, unless specified by law
* Ask us to delete your information entirely, unless specified by law
* Make a complaint or ask any other question in relation to your information

If you would like to do any of the above, or find out more about your rights – please contact Children’s Heartbeat Trust at:

Sarah Quinlan

Chief Executive Officer

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Belfast BT13 2JF

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You can also contact the Information Commissioner’s Office if you have any query about how we are handling your data, at [www.ico.org.uk](http://www.ico.org.uk).