

# ECHO (Evelina Children's Heart Organisation) Website Privacy Policy

## **ECHO (Evelina Children's Heart Organisation) Website Privacy Notice**

Last updated June 2022.

This policy describes the information/data gathering and dissemination practices of ECHO, for the website [www.echo-uk.org](http://www.echo-uk.org) (the "Site"). ECHO is committed to protecting your privacy online. ECHO will not release any personally identifiable information to a third party such as your name, address, e-mail address, phone number or health information except as described in this policy. If users have questions or concerns regarding this policy, they should first contact ECHO: [hello@echo-uk.org](mailto:hello@echo-uk.org) or telephone us at 020 7998 4710.

### **What Information We Collect and Why**

As described below, we collect personal information from members and other visitors primarily so that we can enable them to access ECHO support services, donate money, apply to volunteer or attend ECHO events. But also so that we may enhance our services to our website visitors, make each visit as pleasant and helpful as possible, and track trends and statistics.

We request certain personal information (such as name, address, e-mail, telephone number and health information) in the following sections of our website:

- Join ECHO/ECHO Teens
- Access support: specifically cardiac family support service and bereavement support
- Donate to ECHO
- Request fundraising materials
- Register to attend events
- Register to advertise your event
- Tell us how your event went
- Apply to volunteer
- Submit a volunteer report
- Share your personal story
- Ask an expert
- Sign up for updates
- Purchase items via our online shop

### **Collection of Health Data**

Within the 'Join ECHO' member application form we request data regarding specific heart conditions of ECHO members. This information is requested so that we can provide bespoke support to our member families, connecting them with others who have experience of similar health conditions as well as

enabling us to provide occasional specialist support. Health data is stored within the ECHO member database which is for use by ECHO staff only. No health data is ever shared with any third party, including hospital staff, and is purely for ECHO use. This data is stored within the ECHO database until such time as a member may request to no longer retain ECHO membership, at which point this data profile will be deleted from the database.

### **The legal basis for processing**

In providing you with ECHO's services, or to meet any of the purposes listed above, we will process your personal data under Article 6 (1)(b) of the UK General Data Protection Regulations, on the legal basis that processing is necessary for the provision of our services, or in order to take steps at your request prior to entering into a support arrangement with us.

In addition, we may process your personal data on the following legal bases;

- Consent: where you give your consent for the processing - Article 6 (1) (a);
- Legal obligation: the processing is necessary for compliance with a legal obligation - Article 6 (1)(c);
- Vital interests: the processing is necessary to protect someone's life - Article 6 (1) (d);
- Legitimate interests: the processing is necessary for an organisation's legitimate interests or the legitimate interests of a third-party - Article 6 (1) (f). In such cases, the legitimate interest of the processor will be balanced against the rights and freedoms of the data subject to ensure no detriment is caused to the latter.
- Child/Adult Safeguarding concern: where safety is of paramount concern and must override the confidentiality of all information pertinent to protection. ECHO Charity is obliged to report to Social Care or The Police any individual thought to be at risk.

When processing special category (health) data, we do so in accordance with Article 9 (2)(a) GDPR with your explicit consent for the processing for the purposes specified above.

In addition, we may process special category data on the following legal bases;

- Vital interests of the Data Subject - Article 9 (2) (c)

### **How long will we keep your data?**

We will retain your data indefinitely in order to answer any queries you may have in the future. You have the right to request at any time that your data is deleted (see below).

### **Data Subject's Legal Rights (an individual's legal rights if ECHO is holding your personal data):**

Your rights are, where applicable:

- The right to be informed about processing of your personal data;
- The right to have your personal data corrected if it is inaccurate and to have incomplete personal data completed;

- The right to object to processing of your personal data;
- The right to restrict processing of your personal data;
- The right to have your personal data erased (the “right to be forgotten”);
- The right to request access to your personal data and information about how we process it;
- The right to move, copy or transfer your personal data (“data portability”); and
- Rights in relation to automated decision-making including profiling

You may exercise these rights by contacting us using the details given at the top of this Notice. You are not required to pay any charge for exercising your rights. If you make a request, we have one month to respond to you.

### **Additional data collected:**

The Site may further collect non-personally identifiable information, such as type of browser, operating system, domain name, or IP address. Web servers automatically identify your computer by its IP address. When you visit pages on our Site, our servers may log your IP address. We do not link IP addresses to any personally identifiable information. Your IP Address is used to gather broad demographic information only.

To process all online donations we use a third party - the Charities Aid Foundation (CAF), [view their privacy policy here](#).

To send updates via email we use a third party - Campaign Monitor, [view their privacy policy here](#).

For our online shop we use a third party - PayPal, [view their privacy policy here](#).

### **Cookies**

Cookies are routinely used. We use ‘persistent’ and ‘non-persistent’ cookies on our Site to provide you with the best presentation of the information currently available. ‘Persistent’ cookies store text, which is available to us when you return to our Site. ‘Non-persistent’ cookies are temporary information, which is eliminated once you close your Internet browser and/or shut down your computer. Only our Site has access to the information in our cookies. This information about the user enables us to track and personalize the Site to enhance your experience. For instance, by setting a cookie on our Site, we can provide you with storage of items in your shopping cart or save the contents of projects created with our Tile Configurator between visits.

These cookies can in no way be used by us or anyone else to get data from your hard drive, obtain your e-mail address or access sensitive information about you as an individual. Cookies must meet strict specifications to ensure that they are not used to compromise security.

If a user rejects the cookie, the user may still use our Site although we will be unable to provide the user with the personalized experience we can offer using the cookie data. If you have any questions about our use of cookies, please send an e-mail to [hello@echo-uk.org](mailto:hello@echo-uk.org) or telephone us at 020 7998 4710.

### **Security**

ECHO has security measures in place to provide protection against the loss, misuse and alteration of the information under our control. Strong precautions are taken to protect the information of the users of our Site.

Your information is encrypted and is protected utilizing the industry standard Secure Sockets Layer (SSL) encryption software. While on a secure page, most web browsers will indicate the encrypted nature of your data in some readily identifiable fashion (e.g., the lock icon on the bottom of Web browsers Netscape Navigator and Microsoft Internet Explorer becoming locked, as opposed to unlocked, or open, when you are just 'surfing').

While we use SSL encryption to protect sensitive information online, we also protect user information offline. All of the information of our Site's users, including the sensitive information mentioned above, is maintained in a restricted section in our offices. Only those of our employees who need the information to perform a specific job (for example, our account or customer service representatives) are granted access to personally identifiable information. Furthermore, our employees are kept up-to-date on our security and privacy practices.

Unfortunately, no data transmission over the Internet can be guaranteed to be 100% secure. As a result, while we strive to protect your personal information, ECHO cannot warrant or ensure the security of any information you transmit to us, and you do so at your own risk. Once we receive your transmission, we make commercially reasonable efforts to ensure its security on our systems.

If you have any questions about the security at our Site, you can send an e-mail [hello@echo-uk.org](mailto:hello@echo-uk.org) or telephone us at 020 7998 4710.

## **Links**

Our Site contains links to other sites. While we enforce our privacy policy with respect to information gathered on our Site, we are not responsible for any information you provide to other websites you may access through links on our Site.

## **Consent**

By using our Site, you consent to the foregoing collection and use of information by ECHO. This policy may change from time to time, so please check back periodically.

## **Choice/Opt-Out**

Our Site provides users the opportunity to opt-out of receiving communications from us. To remove your information from our database so that you will not receive future communications please contact:

Email: [hello@echo-uk.org](mailto:hello@echo-uk.org)

Tel: 020 7998 4710.

## **How to make a complaint or contact ECHO**

If you would like to make a complaint about the way ECHO processes personal data, or report a concern regarding your own personal data please contact the Data Controller: Samantha Johnson, CEO  
[samantha@echo-uk.org](mailto:samantha@echo-uk.org)

If you have any questions about this privacy statement, the practices of this site, or your dealings with this site, you can contact:

ECHO  
Canterbury House  
1 Royal Street  
London  
SE1 7LL

Email: [hello@echo-uk.org](mailto:hello@echo-uk.org)

Tel: 020 7998 4710.