Empowering children, young people and families living with Usher syndrome

Privacy Notice v2.0

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1.0 Introduction

1.1 Usher Kids UK is a registered charity. It exists to empower children, young people and their families living with Usher syndrome in the UK.

1.2 We take the safety of your personal information very seriously and this policy explains how we keep your information safe and secure. Our full contact details can be found in section 6.

2.0 Scope

2.1 This privacy notice applies to all Usher Kids UK staff and volunteers involved in processing personal data and provides information to any interested parties about the way we process personal data.

2.2 Sections of this policy may be made available separately to interested parties.

2.3 Where we collect personal data directly from individuals or families, we provide this privacy information at the point of first meaningful contact.

3.0 Families and Professionals in the Sector

3.1 Why we need your information

In order to support members of our community and continue to deliver and improve services available to people with Usher syndrome, we need to process personal information and, in some cases, sensitive information, of those families and professionals who subscribe to our services, submit enquiries and/or attend our events.

Information captured is used to manage subscription records and facilitate your involvement in the events and activities for which you have registered.

We may use personal information, including photos and videos, to communicate with funders, produce publicity and evaluation materials, create support/training materials and post content on our website or on social media.

3.2 What information do we capture?

Subscription: When you ask to join the mailing list (either through our website, email, social media or face-to-face), we collect your name, email and information about the nature of your interest in our services.

Events and services: When you register for an event or service, we typically capture your contact details including name, address, email address and telephone numbers and the name and date of birth of the child(ren) attending the event/service.

You may share other information with us within your enquiry or correspondence, and we may capture details of any accessibility needs you or your child may have. If you are attending an event we may ask if you or your child have any specific food allergies or preferences and other questions which will help with the smooth and safe running of the event.

If your child is attending an event where we, or the event partners, act in loco parentis, we will ask you for additional information of their health conditions, diagnoses, wellbeing and support needs, which data protection legislation classifies as sensitive.

You may also choose to share details of your/your child or young person, or another individual's, health condition or personal circumstances which data protection legislation classifies as sensitive.

We do not knowingly send communications to children, but we may have their details on file if a parent or care giver has sought information from us and we may contact a young person via their mobile phone number (for example, while at residential camp) with their parents' prior knowledge.

We capture photographs, video footage, and feedback quotes and stories from individuals. Where people can be identified, information about the use of the data is clearly shared at the time of data capture, alongside information about how to remove consent. Where children can be identified, written consent will always be sought before storing and using data.

3.3 The legal reason for processing your information and how long we keep it

We process your personal data on the basis of legitimate interests. We process your sensitive data on the basis of explicit consent, vital interests and health or social care. We use your information to support you safely and to continue to run our services. We consider that the use of your information is proportionate and does not unduly interfere with your interests, rights or freedoms. Where photographs and videos of children are used, we process this on the basis of consent.

We retain your records for a maximum of 10 years from your last contact with us or, in the case of families, until your youngest child with Usher syndrome has reached the age of 25. We will then request consent if we wish to continue to process this information. When disposing of your information we do this by securely deleting the files and removing from electronic storage, in line with requirements.

3.4 How we obtain the information

Typically, personal data relating to subscription and events will come directly from you, or your representative, and this may be via phone, email, website, social media or where we met you in person at an event.

With your permission, your details may also be passed to us from other not-for-profit and third-party organisations.

3.5 How your information is stored

Your information is securely stored, electronically, in an encrypted file with access only given to authorised and named individuals within the charity. It is managed within Europe. When disposing of your information we will do this by deleting the files and removing them from electronic storage.

3.6 With whom we share your information

When assisting at or attending events we may need to share contact details with venues, organisers, service providers and other volunteers.

We may share images, film or quotes with third-parties, such as funders, or on our website or social media

4.0 Donors, Fundraisers and Funders

4.1 Why we need your information

In order to support our community and continue to improve services available to people with Usher syndrome, we need to process personal information and, in some cases, sensitive information.

Information captured is used to manage communication records and keep accurate financial records in relation to donations and gifts.

We also maintain a record of correspondence or enquiries that you make with us.

We may contact donors, supporters and funders about our charitable work, fundraising activities, and opportunities to support Usher Kids UK. We do this on the basis of our legitimate interests as a charity, or - where required by law or guidance - your consent. You can opt out of receiving fundraising or marketing communications from us at any time by using the contact details in section 6.

4.2 What information do we capture?

We typically capture your contact details including name, address, email address and telephone numbers.

Where donations or payments are made, for which we are very grateful, full details of the donation are needed; this will include details of the donation including amount and source, bank or card details, if given, and any gift aid declarations that you may give.

4.3 The legal reason for processing your information and how long we keep it

We process your information on the basis of legitimate interests. We use your information to continue to run our services. We consider that the use of your information is proportionate and does not unduly interfere with your interests, rights or freedoms.

If you make a one-off or regular donation or award to us, we are legally obliged to keep tax records and we keep our financial records for 10 years from the last interaction with you. Where you are a subscriber or supporter, we retain your records for 10 years from last contact with us or, in the case of families, until your youngest child with Usher syndrome has reached the age of 25.

4.4 How we obtain the information

Typically, personal data relating to fundraising will come directly from you, or your representative, and this may be via phone, email, website, social media, or through one of the numerous online donation sites, such as JustGiving, or where we met you in person at an event.

With your permission, your details may also be passed to us from other not-for-profit and third-party organisations.

In relation to corporate supporters and trusts, we may have your details passed to us by colleagues or third parties who believe you may have an interest in supporting us. We may also identify companies and corporate individuals whose details are in the public domain, for example on the Internet or on social media platforms.

4.5 How your information is stored

Your information is securely stored, electronically, in an encrypted file with access only given to authorised and named individuals within the charity. It is managed within Europe. When disposing of your information we will do this by deleting the files and removing from electronic storage.

4.6 With whom we share your information

Your donor and funding details will be kept within the charity, accessed by staff and the Board of Trustees. We will be required on occasion to share information with HM Revenue and Customs to facilitate financial processes and Gift Aid claims. We may also need to share information with our professional advisors such as our accountants.

5.0 Volunteers, Staff and Job Applicants

5.1 Why we need your information

We use applicant's details contained from your application, correspondences and interviews with us to allow us to manage the recruitment process. We may use a third-party recruitment site, such as CharityJobs, to store this data.

We need information from volunteers and staff to keep our community safe and the charity running ethically, such as DBS checks, medical needs, emergency contact details and Trustee declarations of interest.

We need other information from staff to ensure the smooth running of the charity, for example their bank details if they are paid members of staff and their phone number for volunteers attending events.

5.2 What information do we capture?

For applications, we typically capture your contact details including name, date of birth, address, email address and telephone number as well as other specific information such as employment history, work eligibility and referee details.

For paid staff, additional information will be captured during onboarding, including bank and HMRC details, vetting information and medical and support needs. Where staff require a DBS certificate, we may use a third-party to assist us.

For volunteer onboarding, information needed for specific events will be collected, including name and contact details, emergency contacts, medical and support needs, and DBS checks when required.

For Trustees, name and contact details will be collected, alongside date of appointment and termination and any conflicts of interest, which will be maintained as a register. Trustees may also be asked to provide declarations regarding criminal activity and bankruptcy and may be subject to further vetting. Required information will be shared with the Charity Commission and charity documents.

We may use personal information of volunteers and staff, including photos and videos, to communicate with funders, produce publicity and evaluation materials, create support/training materials and post content on our website or on social media.

5.3 The legal reason for processing your information and how long we keep it

We process your information on the basis of legitimate interests. For employees, we process your information in order to perform the employment contract and to comply with a legal obligation (HMRC tax duties). We use your information to continue to run our services safely and with due regard for good governance. In the case of paid staff, we process your information on the basis that it is necessary to perform our contract with you. We consider that the use of your information is proportionate and does not unduly interfere with your interests, rights or freedoms.

We retain your records for a maximum of 10 years from last contact with us and will then request consent if we wish to continue to hold this information. When disposing of your information we will do this by deleting the files and removing from electronic storage.

5.4 How we obtain the information

Typically, your personal information will come directly from you. In the case of job applicants, further information may be provided by given referees.

Volunteer onboarding may be undertaken by a partner organisation, who will pass your information to us, with your knowledge. DBS information will be obtained through a third-party service provider.

5.5 How your information is stored

Your information is securely stored, electronically, in an encrypted file with access only given to authorised and named individuals within the charity.

5.6 With whom we share your information

We will share information if we are named as a referee by you in the future.

With your consent, we will share details with third-parties as part of the vetting process.

For employees, we share your information with third-party payroll providers, pension providers and the HMRC.

When assisting at or attending events we may need to share contact details and other data with venues, organisers and other staff/volunteers.

We may share images, film or quotes with third-parties, such as funders, or on our website or social media.

We may share personal information with the charity commission or on our website within charity documents.

6.0 Your Rights

You have rights over your personal information which are:

- With some exceptions designed to protect the rights of others, you have the right to a copy of the personal information that we hold about you. We may make a reasonable charge for additional copies of that data beyond the first copy, based on our administrative costs. Where the data is data that you have given to us, you have the right to receive your copy of it in a common electronic format, and to provide copies of it to other people if you wish.
- You have the right to have the personal information we hold about you corrected if it is factually inaccurate.
- In some circumstances, you have the right to have personal information that we hold about you erased ("the right to be forgotten"). This right is not generally available where we still have a valid legal reason to keep the data (for example, for security reasons or because we are obliged to do so by law).
- You have the right to require us to stop using your personal information to send you marketing information.
- You also have the right in some circumstances to request that temporary restrictions are placed on how we process your personal information, for example if you contest its accuracy or where we are processing it on the basis of our legitimate interest and you contest our assessment that our interest overrides your rights.
- If we are processing your personal information on the basis of your consent, you have the right to withdraw that consent at any time, in which case we will stop that processing unless we have another legal basis on which to continue.

If you want to exercise your rights in respect of your personal information, the best way to do so is to contact us by email on info@usherkidsuk.org or to write to us at 16 Heathfield Avenue, Stockport SK4 4QJ. In order to protect your privacy, we may ask you to prove your identity before we take any steps in response to such a request.

If you have any concerns about how your personal information is being used, we encourage you to contact us first so that we can respond to and address your concern as quickly as possible. You have the right to make a complaint at any time to the Information Commissioner's Office (ICO) if you are unhappy about the way your personal information is being used by Usher Kids UK – please refer to the ICO website for further information about this (www.ico.org.uk). We would, however, appreciate the chance to answer your concerns before you approach the ICO and so, if you are happy to do so, please contact us at info@usherkidsuk.org

7.0 Monitoring Compliance

7.1 This policy is reviewed every year by the CEO. Members of the team or other external experts may be consulted, and the Board of Trustees will ratify the policy prior to dissemination.

7.2 A Record of Processing Activities (ROPA) is kept updated and reviewed annually by the CEO.

8.0 Document Review History

Version no.	Type of Change: Major, minor, none or taken out of use	Date	Author of change	Description of change
1.0	Major	May 2025	Emma King	Reformatting to new policy template and complete review of content
2.0	Minor	June 2026	Emma King	Soft opt-in; internal complaints process; first contact information provided

Executive approval is subject to the understanding that the policy owner has followed the organisation process for policy ratification.

Please contact the policy owner should you require this policy in an alternative format.