



Privacy Policy

Alpha 1 Awareness UK promises to respect any personal data you share with us and keep it safe. We aim to be clear about when we collect your data, what we collect, and how we use that data.

As of May 2018, Alpha-1 Awareness UK will have an 'opt-in' communication policy, meaning we will only send direct communications, such as newsletters, information materials and emails, to those people that have explicitly stated that they are happy for us to do so. By allowing us to contact you via your preferred method (post, email, or phone), you must agree to have read and understand this Privacy Policy.

Our communications include updates about the charity, including information days, events, and how to support us or get involved. If you are an existing member of our charity and would like to receive such communications but have not opted in, please contact us at <http://www.alpha1.uk/contact-us/> or info@alpha1.uk.

How we collect your information

We collect information from you in the following ways:

When you give it to us DIRECTLY

You may give us your information directly when you sign up to receive our newsletter and information materials, contact us to organize 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 third parties and independent event organisers, for example the London Marathon or fundraising sites like Just Giving. These independent third parties will only do so when you have indicated that you wish to support Alpha-1 Awareness UK and you have given them your consent to contact us. You should check their Privacy Policy when you provide your information to understand fully how they will process your data.

When your details are passed on to us by third parties, we will email our Privacy Policy to you directly via the details that have been provided to us. If we do not hear from you acknowledging receipt of the policy within 21 working days, we will make a second attempt to contact you and send you the policy. If we still do not hear from you within 21 working days of the second attempt, we will remove your personal contact information passed to us by the third party organization. We may still store non-identifiable information on the event, for example, but will remove any personal contact details passed along to us.

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.

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 Alpha-1 Awareness UK website 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 policy, which we encourage you to read carefully. The policy 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, or any medical information such as Alpha-1 Antitrypsin Deficiency diagnosis.

What personal data we collect and how we use it

We will only collect the minimal amount of information we need from you to help you use our services and direct you the appropriate resources. 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 by contacting a member of our team, requesting an information pack, making a donation, registering to fundraise, or buy something from our shop - we will usually collect the following information:

- Your/your child's name
- Your preferred contact details (address, email address, telephone number(s))
- Your bank or credit card details (if any transaction is involved)
- Your relationship to Alpha-1 Antitrypsin Deficiency

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

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.

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

Direct Marketing

We do not sell or share personal details to third parties for the purposes of marketing. With your consent, we will contact you with newsletters 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 www.alpha1.uk/contact-us
- Email us at info@alpha1.uk
- Write to us by post at

Alpha-1 Awareness UK
PO Box 8294
Bakewell
DE45 9BF

Sharing your story

Some people choose to tell us about their experiences with Alpha-1 Antitrypsin Deficiency to help further our work. They may take on a role as a volunteer, attend 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 you choose to do this, we will only share your information if we have received your explicit and informed consent, or that of your parent/guardian if you are under 18.

Children's Data

We will always seek consent from a parent/guardian before collecting information about children under the age of 18. This includes when a young person under 18 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 Alfie Support team for children may contact children age 11 and over through their parent(s), or directly with the parent's consent to make contact.

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

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. In line with best practices as outlined by the UK Data Service, we store your data for 10 years after the point of acceptance of this Privacy Policy. For example, if you accept this Privacy Policy multiple times (through using our shop or sharing your data with us), we will keep your data for 10 years from the most recent acceptance. After this period, we will remove your contact information such as address, email, etc., and archive your record in case you wish to revisit the charity as well as for our own records. For more information, please see our Data Confidentiality Policy.

We restrict access to information that we hold about you or your child to ensure that it is only accessible approved Board members who need to know the relevant information.

If you take part in a challenge event (e.g. London Marathon) for Alpha-1 Awareness UK, 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. If you need to update your contact information, please contact us at info@alpha1.uk or www.alpha1.uk/contact-us.

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 – e.g. if we require your data in order to fulfil a legal obligation (e.g. Gift Aid) or if the data is processed to exercise the right of freedom of expression and information (e.g. 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 Alpha-1 Awareness UK, PO Box 8294, Bakewell, DE45 9BF, 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 e-mail them to info@alpha1.uk. For further information see the [Information Commissioner's guidance](#).

Changes to this policy

We may change this Privacy Policy from time to time. This policy was last updated on 29 October 2017. If we make any significant changes in the way we treat your personal information we will make this clear on the Alpha-1 Awareness UK website or by contacting you directly.

If you have any questions, comments or suggestions, please let us know by writing to Alpha-1 Awareness UK, PO Box 8294, Bakewell, DE45 9BF, or send an email to info@alpha1.uk.

Version History

Version 1.2 – 1st March 2018

Version 1.1 – 29th October 2017