

Our privacy policy – How we use your personal information

We're sending you this privacy policy to help you understand how we collect, store and use your personal information. **This is for information only – you do not have to take any action in response to this information.**

1. Introduction

We collect and use your personal information in order to help us to work towards our aim of providing effective support to Hereditary Angioedema (HAE) patients and their family members living in the UK and promoting good practice in the diagnosis and treatment of HAE.

We are committed, as data controller, to protecting your personal information. This statement tells you more about why we collect your personal information and how we use it.

2. Personal information that we collect

The types of personal information that we may collect and use include:

- Your full name, home address and contact details
- Your date of birth
- Your sex/gender
- Your marital (or relationship) status
- Information about your health

3. Where does your personal information come from?

The personal information that we hold about you is provided by you when you choose to volunteer with us.

4. What do we do with your personal information?

The legal basis for us using most of your personal information is to enable us to carry out the charitable objects of HAE UK, which are to:

- provide effective support for patients and their family members
- promote good practice in the diagnosis and treatment of HAE
- promote research into new treatments and a cure
- seek to improve the quality of life of those affected by HAE
- facilitate access to the best available treatment for patients going forward

We have a legitimate interest in using your personal information to help us obtain these aims.

We collect certain special categories of personal information about you (in particular, information about your health) with your express consent.

5. Sharing your personal information with other parties

Your personal information is not shared with any third parties, other than as necessary to carry out the purposes at 4 above. Currently, your personal information is only shared with the provider of computer servers on which your data is stored but note that we may also share personal information with regulatory authorities where we are required by law to share personal information.

Your personal information may be shared outside the European Economic Area (EEA) (for example, if computer servers used by our providers are located or backed up in a country outside the EEA). Under data protection legislation, we can allow your personal information to be transferred outside the EEA if:

- (a) the country to which your personal information is being transferred has been confirmed by the European Commission to provide adequate protection for personal information; or
- (b) the entity that is holding your personal information has entered into a written contract which requires it to provide all protections to your personal information required by data protection legislation.

In the event that the UK is no longer part of the EEA, references in this section to the "EEA" should be taken to mean the EEA and the UK.

Further information about transfers of personal data outside the EEA can be obtained by contacting us at the address below.

6. How long do we keep your personal information for?

We will keep your personal information for so long as you are a member of HAE UK but we will retain it for a reasonable period thereafter in order to stay in touch with you as an alumni of HAE UK.

7. Accessing and updating your personal information

Data protection legislation gives individuals the following rights in relation to personal information held about them:

- individuals can ask what personal information is held about them and be provided with a copy;
- if personal information held about an individual is incorrect, he or she can ask for it to be corrected;
- individuals can ask for personal information about them to be deleted or for processing of that personal information to cease in certain circumstances, for example, where that information is no longer needed;
- individuals can request that certain types of personal information held about them is sent to them, or another organisation, in a format that can be read by computer; and
- individuals can withdraw their consent to how their personal information is being processed, where that processing is based on their consent.

Exercising these rights is subject to certain restrictions under data protection legislation. For further information about these rights, you should write to: support@haeuk.org

8. Complaints

If you are unhappy at any stage with how we are using your personal information, you have the right to lodge a complaint with The Information Commissioner's Office (www.ico.org.uk).

9. Changes to our privacy policy

This statement is subject to regular review and may be updated from time to time. We will tell you if we make any changes to how we use your personal information.

10. Contact us

If you have any questions about how your personal information is used, please feel free to contact us at the following address: support@haeuk.org

May 2018