Haemochromatosis UK
Privacy Policy for Genetic Testing and Counselling Services
(September 2024)

1. Who we are

Haemochromatosis UK ("**HUK**", "**us**", "**we**", "**our**") is a charity registered in England and Wales with charity no. 1001307 and SCO41701. We are a Company Limited by Guarantee No. 2541361. We are the controller responsible for the personal information processing set out in this policy.

2. Important information

We respect your privacy and are committed to protecting your personal information. In this privacy policy, we provide you with information on how and why we collect, store, use and otherwise process your personal information when you participate in our genetic testing service ("**Testing Service**") and our genetic counselling service ("**Counselling Service**").

When we refer to personal information, we mean information that relates to you, whether it directly identifies you (e.g., your name or email address), indirectly allows us to identify you (e.g., in combination with other data), or is associated with this identifying data (e.g., any test results, family history etc.).

If you have any questions about this privacy policy, including any questions on how you may exercise your privacy rights, please contact us at privacy@huk.org.uk.

3. What personal information we process and why

We have set out below a description of the personal information we process, the purposes for which we process it, and which of the legal bases we rely on to do so.

Purpose/Activity	**Type of data**	**Lawful basis for processing including basis of legitimate interest**
To conduct the Testing Service	Name, address, email address, telephone number, year of birth, biological sex ("**Identity and Contact Data**") Family history of genetic haemochromatosis and existing health issues, including details of alcohol consumption ("**Health-related information**")	Necessary to fulfil our contract with you to conduct the genetic test and deliver the test results to you (Art. 6(1)(b) GDPR) Necessary for the purposes of medical diagnosis (Art. 9(2)(h) GDPR)
To conduct medical research in order to improve the health and care of others and help inform our	The results of your genetic test, which will be generated by one of our third-party pathology laboratory partners ("**Laboratories**") using the	Consent (Arts. 6(1)(a) and 9(2)(a) GDPR)

advocacy of NHS policymakers and our elected representatives.	sample you provide ("**Genetic test results**"), in pseudonymised form	
To conduct the Counselling Service, where you choose to participate	Identity and Contact Data Health-related information	Necessary to fulfil our contract with you to provide the genetic counselling service (Art. 6(1)(b) GDPR) Necessary for the purposes of the provision of health or social care or treatment (Art. 9(2)(h) GDPR)
To comply with our statutory obligation to inform your GP or doctor's surgery of your test results	Identity and Contact Data Genetic test results	Compliance with a legal obligation (Art. 6(1)(c) Necessary for the purposes of medical diagnosis and the provision of health or social care or treatment (Art. 9(2)(h) GDPR)

Where we rely on your consent, you have the right to withdraw your consent at any time by contacting us as set out below. We do not carry out any automated decision-making, including profiling.

4. Who we share your personal information with

We may share your personal information with the following parties:

- Our Laboratories, who may be located within or outside the UK (e.g., in the USA).
- Our internal staff and nurses conducting the Counselling Service, where you choose to participate.
- Internal and external parties, as otherwise required by law, including to comply with a subpoena or similar legal process or request, or when we believe in good faith that disclosure is legally required or to protect or rights and interests

5. Security of your personal information

We take the security of your personal information seriously, and have put in place appropriate security measures, internal policies and controls aimed at preventing your information from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed.

6. Transfer of your personal information

The Testing Service is mainly conducted on our behalf by Laboratories based in the UK. However, there may be situations where the Testing Service is conducted by a Laboratory based in the U.S., e.g., where the Laboratories based in the UK are facing capacity issues. Where we use Laboratories based in the U.S., we may transfer personal information to them using appropriate safeguards, such as under the UK Extension to the EU-US Data Privacy Framework, or the UK Information Commissioner's Office ("ICO") international data transfer agreement (IDTA) or addendum to the European Commission's standard contractual clauses, as appropriate. For more information, please contact us using the contact details below.

7. For how long do we keep your personal information

We will only retain your personal information for as long as reasonably necessary to fulfil the purposes we collected it for, and/or for the purposes of satisfying any legal, regulatory, tax, accounting or reporting requirements. We may retain your personal information for a longer period in the event of a complaint, to protect us against legal claims, or otherwise comply with our legal obligations.

8. Changes to this privacy policy and your duty to inform us of changes

We keep our privacy policy under regular review and regularly make changes to it. It is important that the personal information we hold about you is accurate and current. Please keep us informed if your personal information changes during your relationship with us by emailing privacy@huk.org.uk or by updating your information in your Account.

9. Privacy rights

You have the following rights under data protection laws in relation to your personal information, which may be subject to applicable limitations and restrictions and where relevant conditions are met:

- Request access to your personal information (commonly known as a "data subject access request"). This enables you to receive a copy of the personal information we hold about you and certain details about our processing of your personal information.
- Request correction of the personal information that we hold about you. This enables you to have any incomplete or inaccurate information we hold about you corrected.
- Request erasure of your personal information. This enables you to ask us to delete or remove information in certain circumstances.
- Object to processing of your personal information.
- Request restriction of processing of your personal information. This enables you to ask us to suspend or limit the processing of your information in certain circumstances
- Request the transfer of your personal information to you or to a third party. Where relevant conditions are met, we will provide to you, or a third party you have chosen, your information in a structured, commonly used, machine-readable format.
- Withdraw consent at any time where we are relying on your consent to process your personal information. However, this will not affect the lawfulness of any processing carried out before you withdrew your consent. If you withdraw your consent, we may not be able to provide our services to you. We will advise you if this is the case at the time you withdraw your consent.

If you would like to exercise any of these rights, please contact us at privacy@huk.org.uk. We may need to request specific information from you to help us confirm your identity and ensure your right to access your personal information (or to exercise any of your other rights). This is a security measure to ensure that personal information is not disclosed to any person who has no right to receive it. We may also contact you to ask you for further information in relation to your request to speed up our response.

If you have concerns about our processing of your personal data, you have right to make a complaint at any time to the ICO, the UK supervisory authority for data protection issues (www.ico.org.uk). We would, however, appreciate the chance to deal with your concerns before you approach any supervisory authority, so please contact us in the first instance.

10. Contact us

If you have any questions about this privacy policy or our privacy practices, including any requests to exercise your rights, please contact us at privacy@huk.org.uk.

Last updated: 6th September 2024.