

TERMS & CONDITIONS FOR GENETIC TESTING SERVICES – May 2021

OVERVIEW

This is a summary of the services provided :

- We are Haemochromatosis UK ('HUK'), a charity registered with the Charity Commission (reference 1001307) whose registered address is Henrith Business Centre, 3 Enterprise Way, Pinchbeck, Lincolnshire, PE11 3YR
- We provide genetic testing services on a non-refundable basis for testing people resident in the UK, who are already registered with a NHS General Practitioner, who are aged 18 years or older, who have given their consent to be genetically tested.
- We will provide genetic testing for c2828y and h63d variants of Type 1 Genetic Haemochromatosis only.
- We will provide the outcome of the genetic testing results to the person being tested and their NHS General Practitioner.
- Unless requested not to before a genetic test is ordered, we will use the anonymised genetic testing results to further our medical research into genetic haemochromatosis, to help others at risk or affected by the condition. We will always do so in accordance with our charity's policies, including our Data Protection and Privacy Policy (see <https://www.haemochromatosis.org.uk/our-policies>)
- We will provide the genetic testing services in accordance with this Agreement.

0. DEFINITIONS

The definitions which apply to these Terms and Conditions are set out below.

'HUK' means Haemochromatosis UK, a charity registered with the Charity Commission (reference 1001307) whose registered address is Henrith Business Centre, 3 Enterprise Way, Pinchbeck, Lincolnshire, PE11 3YR

'Client' means the person requesting Services from HUK and for whom HUK has agreed to provide the Services;

'Agreement' has the meaning given in clause 1.2;

'Applicable Law' means the laws, regulations, judgments, binding on the relevant party, as amended from time to time;

'Client' means the person requesting Services from HUK and for whom HUK has agreed to provide the Services;

'controller', 'data subject', 'personal data', 'process' and 'processor' have the meanings given to those terms in Data Protection Laws;

'Data Protection Laws' means the UK Data Protection Act 2018, and any other Applicable Law having effect in the United Kingdom concerning privacy or the use of personal data;

'data subject' and 'personal data' have the meaning given to those terms in Data Protection Laws;

'Health Authority' means (i) a department of the UK government or of a devolved administration, (ii) an executive agency of such department, or (iii) a body exercising statutory functions in relation to public health in the UK or any part of the UK;

'Laboratory' means a pathology laboratory which meets UKAS medical laboratory accreditation standard (ISO 15189) and implement the guidelines of the Royal College of Pathologists for the retention and storage of pathological records and specimens;

'Order' has the meaning given in clause 1.2;

'Personal Data' has the meaning given to that term in Data Protection Laws;

'Protected Data' means personal data provided to HUK by the Client;

'Public Health Programme' means a programme administered by a Health Authority to monitor or analyse health data

for the purpose of public health or for statistical, scientific or research purposes in the public interest;

'Sample' means a sample provided by the Client to HUK for Testing;

'Services' means the services to be provided under this Agreement;

'Test' means a laboratory test to be carried out by HUK on a Sample, and **'Testing'** means the process of conducting that Test and reporting the results;

'UKAS' means the United Kingdom Accreditation Service, or any successor to it.

- 0.1 References to the singular include the plural and vice versa. Clause headings and paragraph headings are for ease of reference only and are not part of these Terms and Conditions for the purpose of construction.
- 0.2 Words following the terms 'including', 'include', 'in particular', 'for example' or any similar expression shall be construed as illustrative and shall not limit the sense of the words, preceding those terms.

1 THE SERVICES

- 1.1 These Terms and Conditions will apply to any genetic testing services that HUK provides to the Client. These Terms and Conditions apply to the exclusion of any other terms presented by the Client or implied by custom or course of dealing.
- 1.2 By submitting a request for genetic testing services provided by HUK (an **'Order'**), the Client offers to purchase those services on these Terms and Conditions. A contract between HUK and the Client for the provision of services incorporating these Terms and Conditions (an **'Agreement'**) takes effect when HUK confirms acceptance of the Client's Order in writing or begins performing the Services (whichever occurs first).
- 1.3 HUK will provide the Services under the Agreement:
 - 1.3.1 in accordance with Good Industry Practice;
 - 1.3.2 in accordance with the UKAS medical laboratory accreditation standard (ISO 15189); and
 - 1.3.3 using suitably skilled and experienced staff.
- 1.4 HUK will use reasonable efforts to achieve the Test turn-around times quoted on its website, but does not warrant that it will achieve those times in the case of any particular Sample.
- 1.5 If the Client provides a Sample which HUK or its Laboratory consider unsuitable for Testing or the Laboratory is unable to conduct the Testing then HUK may decline to carry out the Testing under the Agreement and will be entitled to arrange disposal of the Sample.
- 1.6 HUK will destroy or dispose of a Sample after completing the Testing.

2 PRICE AND PAYMENT TERMS

- 2.1 The fees payable by the Client for the Services will be the most recent price confirmed by HUK to the Client on its website in writing prior to the Client submitting its Order.
- 2.2 As at the date of these Terms and Conditions many of HUK's services are VAT exempt. All of HUK's prices are stated inclusive of VAT where applicable and where VAT is chargeable on the Services the Client will pay it at the applicable rate.
- 2.3 All Orders are non-refundable.

3 CONFIDENTIALITY

- 3.1 HUK agrees that it will hold and maintain the confidence of:
 - 3.1.1 all information of a confidential nature which is received by HUK from the Client in connection with the Services; and
 - 3.1.2 all Test results and other information of a confidential nature issued by HUK to the Client in connection with the Services, and, save with the Client's consent or as otherwise permitted under this Agreement, will not disclose such information other than to the Client and their General Practitioner, professional staff, independent consultants and/or persons to whom it has delegated the performance of the Services and who require the information for such purpose.

- 3.2 The restrictions in clause 3.1 will not apply to information which: (i) was in HUK's possession prior to disclosure by the Client; or (ii) is now or hereafter comes into the public domain other than by default of HUK; or (iii) was lawfully received by HUK from a third party acting in good faith having a right of further disclosure; or (iv) is required by law to be disclosed by HUK; or (v) which is required by a regulatory or accreditation body to be disclosed to it for the purpose of regulating or accrediting HUK or its Laboratory.

4 CLIENT RESPONSIBILITIES

- 4.1 The Client will provide HUK with any information reasonably necessary for performing the Services, including by ensuring that the Order contains sufficient information regarding the Sample, the relevant patient, and the persons to whom the Test results are to be reported, and will ensure that any information the Client provides to HUK in connection with the Services is accurate and complete.
- 4.2 The Client undertakes that genetic testing Services will not be provided to any person under 18 years of age or any person who has not consented to providing a Sample for the purposes of genetic testing.

5 LIABILITY

- 5.1 Nothing in the Agreement will limit or exclude liability for death or personal injury caused by negligence or any other liability that cannot be limited or excluded under Applicable Law.
- 5.2 In these Terms and Conditions 'liability' means any liability whether in contract, tort (including negligence), misrepresentation, breach of statutory duty or otherwise, which arises in connection with the Services or under or in connection with any Agreement.
- 5.3 The liability of HUK and the Client will each be limited to £100 in total. This limit applies per Agreement and in aggregate for all Agreements made in a calendar year.
- 5.4 Neither HUK nor the Client will have any liability for:
- 5.4.1 loss of reputation or goodwill; or
 - 5.4.2 indirect, special or consequential loss.
- 5.5 HUK will have no liability for any delay or failure in performance of the Services arising from the Client's delay or failure in performing its obligations under clause 4 (Client Responsibilities).
- 5.6 All of the warranties which HUK gives in relation to the Services are expressly set out in these Terms and Conditions. All other warranties, whether implied or express, are excluded from the Agreement where it is lawful to exclude them.

6 FORCE MAJEURE

If the performance of any obligation under the Agreement (except for an obligation to pay) is prevented, restricted or interfered with by reason of circumstances beyond the reasonable control of that party obliged to perform it (a '**Force Majeure Event**'), the party so affected will be excused from any resulting failure or delay in performance, and the time for performance will be extended by an amount of time equal to the duration of the Force Majeure Event. The party so affected will use reasonable endeavours to mitigate the effect of the Force Majeure Event on its performance of its obligations. If the Force Majeure Event delays or prevents performance of a party's obligations for more than three months, either party may terminate the agreement on written notice to the other.

7 DATA PROCESSOR AND DATA CONTROLLER

- 7.1 When HUK processes Protected Data on behalf of the Client in providing the Services the parties agree that HUK will be the data controller and the data processor.
- 7.2 The Client will comply with the Data Protection Laws in relation to the Protected Data, and ensure that all instructions given by it to HUK in respect of Protected Data will at all times be in accordance with Data Protection Laws.
- 7.3 The Client agrees that HUK may transfer Protected Data to countries outside the United Kingdom for the purpose of providing the Services, provided all transfers by HUK of Protected Data to such recipients are in

accordance with such safeguards or other mechanism(s) for transfers of personal data as may be permitted under Data Protection Laws from time to time. The Client agrees that HUK may implement such safeguards by entering into standard data protection clauses authorised under the Data Protection Laws, which HUK may do as agent on behalf of the Client.

- 7.4 In relation to the processing of the Protected Data, HUK will implement and maintain, at its cost and expense, appropriate technical and organisational measures to ensure for the Protected Data a level of security appropriate to the risks presented by the processing, taking into account the state of the art, the cost of implementation and the nature, scope, context and purpose of the processing of the Protected Data as well as the risk of varying likelihood and severity of the rights and freedoms of natural persons.

10 USING THIRD-PARTY LABORATORIES

- 10.1 By accepting these Terms and Conditions the Client authorises HUK to appoint a suitably qualified Laboratory to process a Sample for the Services.
- 10.2 HUK will ensure that all persons authorised to process Protected Data are subject to a binding obligation to keep the Protected Data confidential.

11 DELETION OR RETURN OF PROTECTED DATA AND COPIES

- 11.1 HUK will, at the Client's written request, delete Protected Data belonging to the Client.

12 PROTECTED DATA THAT HUK PROCESSES AS A DATA CONTROLLER

- 12.1 HUK may process Protected Data as data controller.
In particular HUK may:
- 12.1.1 retain and submit Protected Data to a Health Authority in the United Kingdom for the purposes of a Public Health Programme operated by that Health Authority, or to regulator for the purpose of complying with regulatory obligations; and
- 12.1.2 retain and process Protected Data in its laboratory records in order to meet the requirements of the UKAS medical laboratory accreditation standard (ISO 15189) and implement the guidelines of the Royal College of Pathologists for the retention and storage of pathological records and specimens.
- 12.3 When HUK processes personal data on its own behalf as data controller, it will do so in accordance with the obligations of data controllers under Data Protection Laws and with the applicable terms of the Agreement.

13 GENERAL

- 13.1 HUK may amend these Terms and Conditions by publishing it on our website. Such amendments will only apply to an Order submitted after the date of the update, and the Client will be deemed to accept those amendments by submitting an Order after that date.
- 13.2 Except as set out in clause 17.1, any amendments to this Agreement will not be effective unless in writing and signed by an authorised signatory on behalf of each of the parties. The terms of this Agreement may be varied by agreement of the parties but without the consent of any third party whether or not the rights of such third party are affected by such variation. The Client will not unreasonably withhold, delay or condition its agreement to any variation to this Agreement requested by HUK in order to ensure the Services and HUK can comply with any change in Applicable Laws.
- 13.3 Rights and waiver
All rights granted to either of the parties will be cumulative and not exhaustive of any rights and remedies provided by law. The failure of either party to enforce (or delay in enforcing) at any time for any period any one or more of the terms of this Agreement will not be a waiver of such term or of the right of such party at any time subsequently to enforce all the terms of this Agreement.
- 13.4 Severability
If any provision of this Agreement is or becomes invalid, illegal or unenforceable in any respect under any law, the validity, legality and enforceability of the remaining provisions will not be in any way affected.

13.5 Assignment

HUK may assign or sub-contract the performance of this Agreement (in whole or in part) or any one or more of the Tests to be performed hereunder to suitably accredited laboratories.

13.7 Notices

All notices given under this Agreement will be in writing and will be delivered by hand or sent by prepaid first class post or by prepaid first class recorded delivery or by email transmission. All notices will be delivered at or sent, in the case of HUK, to Henrith Business Centre, 3 Enterprise Way, Pinchbeck, Lincolnshire PE11 3YR. A notice sent by post will be deemed to be served at 9.00 am on the second business day following the date of posting.

13.8 Entire agreement

The Agreement is set out in the Order and these Terms and Conditions, which together set out the entire contract between the Client and HUK relating to their subject matter. In the event of a conflict between the Order and these Terms and Conditions, the Terms and Conditions will take priority. Each party acknowledges that it has not entered into the Agreement in reliance on, and will have no remedies in respect of, any representation or warranty that is not expressly set out in the Agreement except in the case of fraudulent misrepresentation.

13.9 Third parties

The Agreement is not intended to create any rights for, nor be enforceable by, any third party except as set out in clause 5.

13.10 Governing law

The Agreement and any dispute arising out of or in connection with it (including non-contractual disputes and claims) will be governed by and construed in accordance with English law and each of the parties submits to the exclusive jurisdiction of the English Courts.

Dated : 1st May 2021