TERMS AND CONDITIONS FOR GENETIC TESTING SERVICES - SEPTEMBER 2024

OVERVIEW

This is a summary of the services provided:

- *Haemochromatosis UK ("HUK") is a charity registered with the Charity Commission (charity number 1001307) whose registered address is Haemochromatosis UK, The Flaxmill, Flaxmill Lane, Pinchbeck, Lincolnshire PE11 3YP.*
- *We provide genetic testing services on a non-refundable basis for people resident in the UK, who are registered with a General Practitioner, who are aged 18 years or older and who have given their consent to be genetically tested.*
- *We will provide genetic testing services for c2828y, h63d and (optionally) s65c variants of Type 1 Genetic Haemochromatosis only.*
- *We will provide the outcome of the genetic testing results to the person being tested and his or her General Practitioner.*
- *Unless requested not to do so before a genetic test is ordered, we will use the pseudonymised genetic testing results for the purpose of medical research into genetic haemochromatosis, to help others at risk or affected by the condition. We will always do so in accordance with our policies, including our Data Protection and Privacy Policy and our Genetic Testing and Counselling Services Privacy Policy (see https://www.haemochromatosis.org.uk/our-policies).*
- *We will provide the genetic testing services in accordance with this Agreement.*
- *We reserve the right to update these Terms and Conditions from time to time by posting the updated version on our website.*

1. DEFINITIONS AND INTERPRETATION

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

"Agreement"	*has the meaning given in clause 2.2;*
"Applicable Law"	*means the laws, regulations and 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;*
"Counselling Service"	*has the meaning given to it in clause 2.7;*
"Controller"	*has the meaning given to it in Data Protection Laws;*
"Data Protection Laws"	*means the UK Data Protection Act 2018, as amended, and any other Applicable Law having effect in the United Kingdom concerning privacy or the use of personal data;*
"Fees"	*has the meaning given to it in clause 3.1;*
"General Practitioner"	*means a general practitioner who is registered on the GP Register of the General Medical Council;*
"Genetic Testing Services"	*means genetic testing for c2828y, h63d and (optionally) S65C variants of Type 1 Genetic Haemochromatosis, or such other genetic biomarkers related to genetic haemochromatosis conditions as may be confirmed by HUK in writing;*

"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;*
"HUK"	*means Haemochromatosis UK, a charity registered with the Charity Commission (charity number 1001307) whose registered address is Haemochromatosis UK, The Flaxmill, Flaxmill Lane, Pinchbeck, Lincolnshire PE11 3YP;*
"Laboratory"	*means HUK's third party pathology laboratory partner which is permitted to perform the Testing under Applicable Law;*
"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;*
"Order"	*has the meaning given in clause 2.2;*
"Personal Data"	*has the meaning given to it under Data Protection Laws;*
"Process"	*has the meaning given to it under Data Protection Laws;*
"Processor"	*has the meaning given to it under Data Protection Laws;*
"Protected Data"	*means the 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 Genetic Testing Services and, where applicable, the Counselling Services to be provided under the applicable Agreement;*
"Terms and Conditions"	*means these terms and conditions for genetic testing services;*
"Test"	*means a laboratory test to be carried out on a Sample;*
"Testing"	*means the process of conducting a Test and reporting the results; and*
"UKAS"	*means the United Kingdom Accreditation Service, or any successor to it.*

1.1 References to the singular includes 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.

1.2 Words following the terms "including", "include", "in particular", "for example" or any similar expression will be
construed as illustrative and will not limit the sense of the words preceding those terms.

1.3 "or" will be interpreted in the inclusive sense ("and/or").

2 THE SERVICES

2.1 These Terms and Conditions will apply to the 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.

2.2 By submitting a request for Genetic Testing Services provided by HUK (an "Order"), the Client offers to purchase (where applicable) and receive those Services on these Terms and Conditions. A contract between HUK and the Client for the provision of Services for a given Order incorporating these Terms and Conditions (an "Agreement") takes effect when HUK confirms acceptance of the Client's Order

in writing or otherwise requests the Client to provide a Sample for the Genetic Testing Services (whichever occurs first).

2.3 *HUK will provide the Services under the Agreement:*

2.3.1 *using all reasonable skill and care;*

2.3.2 *using suitably skilled and experienced staff; and*

2.3.3 *with respect to the Genetic Testing Services, in accordance with (i) ISO 15189 and (ii) UKAS accreditation requirements (or equivalent standards as may apply in other jurisdictions).*

2.4 *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.*

2.5 *If the Client provides a Sample which HUK or its Laboratory considers unsuitable for Testing, or if the Laboratory is otherwise unable to conduct the Testing using such Sample, then HUK may decline to carry out the Testing under the Agreement and will destroy or dispose of the Sample.*

2.6 *HUK or the Laboratory will destroy or dispose of any Samples remaining after completing the Testing or pursuant to clause 2.5 in accordance with HUK's or the Laboratory's internal procedures.*

2.7 *In connection with any Genetic Testing Services, HUK may make subsequent online counselling/support services available to the Client at its discretion ("Counselling Services"). HUK reserves the right to withdraw such Counselling Services, or decline to provide additional Counselling Services, at any time.*

3 PRICE AND PAYMENT TERMS

3.1 *Subject to clause 3.3, the fees payable by the Client for the Services will be the most recent price confirmed in writing by HUK to the Client on its website prior to the Client submitting its Order ("Fees"). HUK must be in full receipt of payment prior to delivery of any Service to the Client.*

3.2 *Fees must be paid via online card payment or, where agreed in writing, bank transfer and paid in advance prior to delivery of the Services (unless otherwise agreed by HUK in writing). The Client will pay interest on any sum due under an Agreement at a rate of four percent (4%) a year above the Bank of England's base rate from time to time calculated on a daily basis from when the overdue sum became due, until it is paid.*

3.3 *HUK may, at its sole discretion, provide certain Services free of charge. Services provided free of charge will still be subject to these Terms and Conditions under an applicable Agreement.*

3.4 *As at the date of these Terms and Conditions, the Services are VAT zero-rated or are VAT exempt. To the extent that VAT becomes chargeable on the Services, the Client will pay it at the applicable rate in addition to the Fees.*

3.5 *All Orders are non-refundable. Subject to clause 3.3, HUK will be under no obligation to perform the Services prior to receiving the Fees for such Services in full.*

4 LINKS TO OTHER WEBSITES AND INFORMATION

4.1 *Any information on this website, or printed materials provided to the Client by HUK are provided on an "as is" basis for educational and information purposes only and are not a substitute for personal, medical or genetic advice. The Client should consult his or her General Practitioner or other healthcare provider in all matters relating to genetic diagnosis, management and health. HUK makes no representations or warranties of any kind with respect to its website or printed materials or their contents and disclaims all such representations or warranties to the fullest extent permitted by Applicable Law. The Client agrees that HUK will not be liable for any loss or damages the Client or any third party may suffer in connection with any information on this website, or printed materials*

provided to Client by HUK.

5 *CONFIDENTIALITY*

5.1 *Each party agrees that it will hold and maintain the confidence of all information of a confidential nature which is received by such party from the other party in connection with the Services without the other party's prior written consent. With respect to Test results and other information of a confidential nature relating to the Client, HUK will not disclose such information other than to the Client and his or her General Practitioner, professional staff, independent consultants or persons to whom it has delegated the performance of the Services and who require the information for such purpose.*

5.2 *The restrictions in clause 5.1 will not apply to information which:*

5.2.1 *is in the receiving party's possession prior to disclosure by the disclosing party;*

5.2.2 *now or hereafter comes into the public domain other than by default of the receiving party;*

5.2.3 *was lawfully received by the receiving party from a third party acting in good faith having a right of further disclosure;*

5.2.4 *is required by law to be disclosed by the receiving party; or*

5.2.5 *is required by a regulatory or accreditation body to be disclosed to it for the purpose of regulating or accrediting HUK or its Laboratory.*

6 *CLIENT RESPONSIBILITIES*

6.1 *The Client undertakes to comply with all instructions provided regarding the taking, storage and transport of Sample. The Client will provide HUK with all necessary information, materials or Samples requested by HUK to perform 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. Failure to do so may result in a delay in providing Test results or inaccuracies in Test reports which may affect the evidential value of the Test result and in such circumstances HUK will not be liable for any such delay or inaccuracy. For clarity, HUK will not be liable for any failure to provide accurate, complete or other form of Test result due to insufficient or poor quality Samples.*

6.2 *The Client acknowledges that any information provided to the Client by HUK is provided for educational and information purposes only and is not a substitute for personal, medical or genetic advice. Client undertakes to consult his or her General Practitioner or other healthcare provider in all matters relating to genetic diagnosis, management or health.*

6.3 *The Client acknowledges that any Counselling Services made available to the Client by HUK in accordance with clause 2.7 are to be used at the Client's discretion and should not replace personal, medical or genetic advice or treatment from the Client's General Practitioner or other healthcare providers.*

6.4 *The online Counselling Service uses online video conference technology, which is a secure and encrypted web platform. Client acknowledges that HUK cannot guarantee its Counselling Service will be uninterrupted or error free, that defects will be corrected, or the server that makes it available are free of viruses or bugs. Client acknowledges that it is the Client's responsibility to implement sufficient procedures and virus checks (including anti-virus and other security checks) when using such Counselling Services.*

6.5 *HUK will provide the Genetic Testing Services in accordance with the standards set out in clause 2.3 but does not represent, guarantee or warrant that any particular Test result will be achieved or*

reproduced. The Client acknowledges that all tests have limitations and by accepting these Terms and Conditions, Client accepts these limitations.

6.6 *The Client will only provide Samples that are either the Client's own, or from someone who has consented to providing a Sample for the purpose of Genetic Testing Services and for whom the Client is a legally authorised representative.*

6.7 *The Client undertakes that Services will not be provided to any person:*

6.7.1 not registered with a General Practitioner;

6.7.2 who is not a resident of the United Kingdom; or

6.7.3 subject to clause 6.8, under 18 years of age.

6.8 *Services may be provided, at HUK's discretion, to any person 16 or 17 years of age, provided HUK is satisfied that the person can provide free consent in accordance with Applicable Law.*

6.9 *The Client acknowledges that HUK has complete discretion to determine the eligibility of Clients for the Services using its own internal processes. HUK reserves the right to refuse provision of Services to the Client.*

6.10 *The Client acknowledges that, unless requested not to before placing an Order, HUK will use pseudonymised genetic testing results for research purposes. HUK will use do so in accordance with HUK policies, including the Data Protection and Privacy Policy and Genetic Testing and Counselling Services Privacy Policy.*

7 LIABILITY

7.1 *Nothing in this 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.*

7.2 *Except in the case of death or personal injury caused by negligence or any other Liability that cannot be limited or excluded under Applicable Law, Liability of HUK under any Agreement will be limited to the Fees payable by the Client or, if no Fees are payable under such Contract pursuant to clause 3.3, forty-nine pounds (£49).*

7.3 *HUK will have no Liability for:*

7.3.1 loss of reputation or goodwill; or

7.3.2 any indirect, special or consequential losses.

7.4 *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 these Terms and Conditions.*

7.5 *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 to the extent permitted by Applicable Law.*

8 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.

9 GENERAL

9.1 *HUK may amend these Terms and Conditions by publishing them on our website. Such amendments will only apply to Orders submitted after the date of the update, and the Client will be deemed to accept those amendments by submitting any Order after that date.*

9.2 *Except as set out in clause 9.1, any amendments to an Agreement will not be effective unless in writing and signed by an authorised signatory on behalf of each of the parties. The terms of any 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 an Agreement requested by HUK in order to ensure the Services and HUK can comply with any change in Applicable Laws.*

9.3 *Survival*

The provisions of clauses 1, 3 (with respect to any payment obligations accrued prior to the effective date of termination), 4, 5, 7, 8, and 9 will survive any termination of these Terms and Conditions.

9.4 *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 an 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 such Agreement.

9.5 *Severability*

If any provision of an 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.

9.6 *Assignment*

HUK may assign or sub-contract any of its rights or obligations under an Agreement (in whole or in part) to a third party or third parties at any time including, for clarity, subcontracting the performance of Tests to suitably accredited Laboratories.

9.7 *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 to HUK will be delivered at or sent to Haemochromatosis UK, The Flaxmill, Flaxmill Lane, Pinchbeck, Lincolnshire PE11 3YP, or such other details as may be notified to Client from time to time, and all notices to Client will be delivered at or sent to the details included in the Client's relevant Order. Any notice will be deemed to be received: (i) if delivered by hand, at the time the notice is left at the proper address (ii) if sent by post, at 12.00pm on the second business day following the date of posting, (iii) if sent by recorded delivery, at the time of delivery (as confirmed by the delivery receipt) or (iv) if sent by email, at the time of transmission.

9.8 *Entire agreement*

The Agreement (including the Order and these Terms and Conditions) sets out the entire agreement between the Client and HUK relating to its 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 an 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.

9.9 *Third parties*

The Agreement does not give rise to any third party rights under the Contracts (Rights of Third Parties) Act 1999.

9.10 *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: 6th September 2024