## Please complete using BLACK ink - form will be scanned in lab

# REQUEST and RECORD OF DISCUSSIONS regarding TESTING AND STORAGE OF GENETIC MATERIAL



Genetics Laboratory, South East Scotland Genetic Service, CGEM Building, Western General Hospital, Edinburgh, EH4 2XU

PATIENT DETAILS (printed label preferred)  Sex M / F	REFERRER DETAILS Name:
	Report to:
Required: Name, date of birth, CHI or 1 <sup>st</sup> line home address and postcode	☐ Email report to:(Lab preference) Other contact details:
I have discussed genomic/ genetic testing with my health professional and I understand that:	DISEASE / CONDITION
<ol> <li>Family implications The results of my test may have implications for other members of my family. I acknowledge that my results may sometimes be used to inform the appropriate health care of others. This could be done in discussion with me, or in such a way that I am not personally identified in this process.</li> <li>Uncertainty The results of my test may reveal genetic variation whose significance</li> </ol>	TESTS REQUESTED (SPECIFY GENE / VARIANT IF KNOWN)
is not yet known. Deciding whether such variation is significant may require sharing of information about me including (inter)national comparisons with variation in others. I acknowledge that interpretation of my results may change over time as such evidence is gathered.	CLINICAL DETAILS
3) Unexpected information The results of my test may reveal a chance of a disease in the future, and nothing to do with why I am having this test. These may be found by chance, whilst focussing on the reason for my test, and I may then need further tests to understand their significance. If these additional findings are to be looked	Discussed with Clinical Genetics? Y / N If yes, name Clinical Genetics contact:
for, I will be given more information about this.	SAMPLE DETAILS
4) <b>DNA storage</b> Normal laboratory practice is to store the DNA extracted from my	Taken by: Name (print)
sample even after the current testing is complete. My sample might be used as a 'quality control' for other testing, for example, that of family members.	Date taken:// Signature
<ul><li>5) <i>Data storage</i> Data from my genetic test will be stored to allow for possible future interpretations.</li></ul>	High risk (see over) Y / N □ URGENT (phone lab to discuss)
6) <b>Health records</b> Results from my genomic test and my test report will be part of my	☐ Blood in Potassium EDTA (KE)
Patient Health Record.	All DNA tests including microarray and QF-PCR  □ Blood in Lithium Heparin
Note of other specific issues discussed (e.g. referral to particular research programmes, insurance):	Cell culture-based tests – G-banded karyotyping
*I gave to gavetic as gavenic investigations for	☐ DNA, mouthwash, tissue etc. ( <i>Please state</i> ):
*I agree to genetic or genomic investigations for	Arrange for immediate transport to the laboratory by van service or first class post. If sending later blood specimens should be refrigerated. (DO NOT FREEZE)
Patient/Parent Signature DATE/	LAB USE ONLY
Discussion undertaken by:	
(Clinician's name, designation and signature)	

\*Insert e.g. to investigate the cause of my child's developmental delay/ family history of cancer/ heart disease etc.

#### Send samples to:

Genetics Laboratory
South East Scotland Genetic Service
CGEM Building
Western General Hospital
Crewe Road
Edinburgh
EH4 2XU

Arrange for immediate transport to the laboratory (van service or first class post). If this is not available, blood specimens should be refrigerated. **(DO NOT FREEZE)** 

## Summary of blood samples required for routine tests

Cytogenetic tests (other than microarray):

Blood in a Lithium Heparin tube - volume 1ml (babies) or 2ml (children and adults).

Molecular Genetic (DNA) tests or microarray:

Blood in an EDTA (KE) tube - volume 1ml (babies), 3ml (children and adults).

For both Cytogenetic and either microarray or other DNA tests TWO samples are required: Blood in a Lithium Heparin tube - volume 1ml (babies) or 2ml (children and adults) and Blood in an EDTA (KE) tube - volume 1ml (babies), 3ml (children and adults).

Consult our website (see below) for information about other sample types and specific requirements for certain tests.

It is your responsibility to ensure that samples are packaged to comply with the European Agreement concerning the International Carriage of Dangerous Goods by Road (ADR 2019) at <a href="https://www.unece.org/trans/danger/publi/adr/adr/2019/19contentse.html">https://www.unece.org/trans/danger/publi/adr/adr/2019/19contentse.html</a>

ADR 2019 requires that this sample (unless subject to exceptions outlined in "infection control" below) is labelled:

#### **EXEMPT HUMAN SPECIMEN**

-----Fold along this line and place into specimen bag sleeve with delivery address showing------

## **Infection Control**

Both laboratories handle samples in accordance with procedures outlined in the National Infection Prevention and Control Manual: http://www.nipcm.hps.scot.nhs.uk/

The Cytogenetics Laboratory cannot accept samples from patients who have or are suspected of having Group 3 or 4 pathogens. The DNA laboratory is however able to extract DNA from these samples which must be labelled with a 'Danger of Infection' sticker.

Samples from individuals with a confirmed or suspected diagnosis of CJD are not extracted by the Molecular Genetics laboratory. DNA from such samples will be tested after extraction by the CJD Unit. Samples should be sent to Molecular Genetics, labelled with a 'Danger of Infection' sticker, with the CJD status clearly indicated on the form.

#### Information for users of genetic tests

The South East Scotland Genetic Service Cytogenetics and Molecular Genetics (DNA) Laboratories website should be consulted first for full details of tests available and sample requirements. This can be found at:

## https://services.nhslothian.scot/geneticservice/

If the information there does not answer your question, please contact the appropriate section directly:

Clinical Genetics (clinical enquiries only)

Tel 0131 537 1116

Molecular Genetics (DNA) Lab Email loth.edinburghdna2@nhs.scot Tel 0131 537 1116/1280

Cytogenetics Lab Email loth.wghcytogenetics@nhs.scot Tel 0131 537 1183

Incomplete or illegible forms, or use of incorrect blood tubes, will cause delay or rejection of samples.

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