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

NHS Lothian

PATIENT DETAILS (*printed label preferred*) Sex M / F

Required: Name, date of birth, CHI or 1st line home address and postcode

I have discussed genomic/ genetic testing with my health professional and I understand that:

1) ***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.
2) ***Uncertainty*** The results of my test *may* reveal genetic variation whose significance 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.
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 for, I will be given more information about this.
4) ***DNA storage*** Normal laboratory practice is to store the DNA extracted from my 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.
5) ***Data storage*** Data from my genetic test will be stored to allow for possible future interpretations.
6) ***Health records*** Results from my genomic test and my test report will be part of my Patient Health Record.

Note of other specific issues discussed (*e.g. referral to particular research programmes, insurance*):

.....

***I agree to genetic or genomic investigations for** .....

.....

Patient/Parent Signature ..... **DATE** .../.../.....

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.*

REFERRER DETAILS

Name:

Report to:

☐ Email report to:.....
(Lab preference)

Other contact details:

DISEASE / CONDITION

TESTS REQUESTED **(SPECIFY GENE / VARIANT IF KNOWN)**

CLINICAL DETAILS

Discussed with Clinical Genetics? Y / N

If yes, name Clinical Genetics contact: .....

SAMPLE DETAILS

Taken by: Name (print) .....

Date taken: ...../...../..... Signature

High risk (*see over*) Y / N ☐ URGENT (*phone lab to discuss*)

☐ Blood in Potassium EDTA (KE)
All DNA tests including microarray and QF-PCR

☐ Blood in Lithium Heparin
Cell culture-based tests – G-banded karyotyping

☐ DNA, mouthwash, tissue etc. (*Please state*):

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)**

LAB USE ONLY

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

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
https://www.unece.org/trans/danger/publi/adr/adr2019/19contentse.html
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:

http://tinyurl.com/Edinburghgenelab

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 edinburgh.dna@nhslothian.scot.nhs.uk	Tel 0131 537 1116/1280
Cytogenetics Lab	Email wgh.cytogenetics@nhslothian.scot.nhs.uk	Tel 0131 537 1940

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