



MRC Prion Unit at UCL, Institute of Prion Diseases  
Courtauld Building, 33 Cleveland Street  
London W1W 7FF  
tel: 020 7679 5147 email: [j.collinge@prion.ucl.ac.uk](mailto:j.collinge@prion.ucl.ac.uk)



National Prion Clinic  
Courtauld Building, 33 Cleveland Street, London W1W 7FF  
tel: 020 7679 5142 / 020 7679 5036  
fax: 020 70619899 email: [help.prion@uclh.nhs.uk](mailto:help.prion@uclh.nhs.uk)

Director: John Collinge CBE, FRS

## Using your sample for research

After diagnostic tests have been done your sample (or your child or relatives' sample) could, with your consent, be kept for use in research studies into prion and other brain diseases. Such research is of great value in understanding the causes of prion and other brain diseases. It is because of previous donations of samples for research that diagnostic tests for conditions have been developed. We hope that future research will help develop tests and treatments for many such brain diseases.

If you agree to donate your sample for research it could be used in studies that are being or will be performed into the causes of and possible treatments for prion and brain diseases, which may include genetic studies. These studies could be within our department or in other units. All research projects are approved by a Research Ethics Committee before any samples are used. Your sample would be used anonymously and any research results that are published would not identify you in any way. You can request full details of our research projects from us at the address below or look at our [website: www.nationalprionclinic.org](http://www.nationalprionclinic.org)

We are studying which genes or proteins are involved in prion diseases and related disorders and how these genes can affect the type and patterns of these diseases. This will help to determine how many people could be at risk of prion disease and related disorders. It is not yet known what effect some of these genes or proteins have on diseases and so we do not inform participants of individual results. Such research could ultimately lead to tests and treatments for disease being developed commercially for clinical use which would benefit future patients. Those donating samples would not benefit financially from such development. Samples such as these are a very useful way of studying brain disease and so your sample could be kept indefinitely and be used for future studies in the same area, which will always have approval from a research ethics committee.

It is entirely up to you whether you agree to the sample you give being used for research and neither the diagnostic tests nor your medical care will be affected by your decision about research. You can change your mind about taking part in this research at any time and ask that your sample be disposed of. **Please ask your doctor any further questions you may have.**

### Information relating to research samples

In order to use your sample for research we need to keep some data about you on our research database, including your name, details of your illness and the result of the diagnostic tests. This information is stored on a confidential, secure database in the MRC Prion Unit at UCL. Professor Collinge is responsible for security and access to the database. Only scientists and doctors directly involved in relevant research with ethical approval are allowed access to data. To increase confidentiality, your sample will not have your name on it, or information that could reveal your identity. Under the Data Protection Act 2018 you are entitled to ask what information is on the database about you and also to request the information is removed. You should understand that while it will not be possible to remove your individual data from previously analysed and reported results, your sample will not be used in any further analyses. Requests for access to your information should be referred to: [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)



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## Clinical request

### Request for prion blood test (Direct Detection Assay)

**Blood test for prion infection**  
Please provide at least 2 x EDTA 5ml tubes for assay of the abnormal prion protein associated with variant Creutzfeldt-Jakob Disease (called the Direct Detection Assay). Whilst we will attempt to return results at the earliest opportunity, clinicians should allow up to four weeks for results. More details can be found by visiting [www.nationalprionclinic.org](http://www.nationalprionclinic.org)

<b>Patient label or details</b>
Name.....
Address.....
.....
DoB..... Hosp no.....
<b>Lab use only</b>
Sample ID.....
Received: date ..... / ..... / ..... Time.....

All fields must be completed before sample(s) can be processed and accompanied by details of clinical information.  
Please also send contact details for return of results.

**Clinical details**

**Detection of abnormal prion protein in blood (Direct Detection Assay)**

Signed..... Date.....

Name (PRINT)..... Job Title.....

Consultant (in charge)\* ..... Hospital.....

\*to whom results will be addressed



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## Research into prion disease and related disorders

I agree that in addition to the clinical tests my blood sample may be used for research into these diseases and their genetic associations. I understand that this research (which may involve the improvement of clinical diagnostic blood tests) will not necessarily provide information that will be of direct benefit to me. A relative, carer or nominated consultee can sign this form if the patient is unable to take their own decisions and if they do not believe that the patient would have objected to taking part in this research.

**Please tick box to indicate agreement to each part:**

- I have read and understood the information sheet (v2.0, 08/10/18) and have had the chance to ask questions about it.
- I understand that donating my sample for research use is voluntary and that I can withdraw my permission at any time, without having to give a reason and this will not affect my medical care in any way or my legal rights..
- I agree that my sample is a gift and can be used for research into prion and related diseases including genetic analysis and other tests.
- I understand that the results of such research will not be available to me on an individual basis and that any published results will not identify me.
- I agree that relevant sections of my medical records can be looked at by senior responsible individuals from the MRC Prion Unit at UCL, Institute of Prion Diseases (IoPD) and the clinical staff at the National Prion Clinic. I understand this would only be done if it was relevant to the sample or associated data being used in research and also that my confidentiality will be respected.
- I agree that information about me that is relevant to the research may be held on a secure confidential database that is kept in accordance with the Data Protection Act 2018, as amended. I understand that UCL is the Data Controller of my personal data and that I can request to see what information is held about me or to have it removed. Requests for access should be referred to: data-protection@ucl.ac.uk or through the National Prion Clinic.
- I understand that the sample I give for research could be used in the development of diagnostic tests and treatments with academic or commercial collaborators in the UK or worldwide. I understand that neither I, nor my legatees will benefit financially in this case.
- I understand that decisions about future use of my donated sample and data generated will be made by Prof Collinge and that my sample may be used in future studies in the UK or worldwide and that my identity will not be revealed. After the research has been completed, if the sample is not retained, the IoPD will arrange lawful and respectful disposal of the sample(s).

I consent to the use of my sample for research and have read the information overleaf relating to this **or** The patient cannot give consent for themselves.

I do not believe s/he would object to the sample being kept for research use

Signature.....Relationship to patient.....

Name (PRINT).....Date.....

Person taking consent.....Signature.....

Position.....Date.....

**Statement of interpreter (if used)**

I have interpreted the information given to the patient to the best of my ability and in a way which I believe s/he can understand

Signed.....Date.....

Name (PRINT).....Contact details.....