

Who may use my stored DNA?

Only you, or someone with power of attorney for your affairs, will be able to request your DNA sample to be tested during your lifetime. You will have the opportunity to discuss the pros and cons of testing before making any decisions. In the event of your death, your relatives may be able to request testing, if it is relevant for their care. If you would like us to destroy your DNA sample at any point you can write to the NI Regional Genetics service requesting this.

What happens next?

If you wish to have your DNA stored, let your doctor or nurse know. You will need to sign a consent form, and give a blood sample.

Please let your family know that you have DNA stored at the Genetics Laboratory Belfast City Hospital.

Your doctor or nurse may also refer you to the Clinical Genetics department to discuss your family history and genetic testing.

Please remember that no genetic testing will be carried out using your stored DNA until you, or a relative, have been referred to the Clinical Genetics department and a full clinical assessment of your family history has been made.

Further Information

If you have any further questions about DNA storage, please contact:

Northern Ireland Regional Genetics Service
A Floor, Belfast City Hospital
Lisburn Road, Belfast,
BT9 7AB
Telephone: 02895 048022

E-mail:

GenomicAssociate@belfasttrust.hscni.net

Scan here for our website:



<https://belfasttrust.hscni.net/service/laboratory-services/clinical-genetics/>

You may also find the following websites helpful:

Genetic Alliance
<https://geneticalliance.org.uk/>
Cancer Research
www.cancerresearchuk.org
Macmillan
www.macmillan.org.uk
Action Cancer
www.actioncancer.org

Northern Ireland Regional Genetics Service

Information leaflet for individuals with an illnesses which may have a hereditary basis

DNA Storage Saving your DNA For the future



Why have I been given this leaflet?

You have been given this leaflet because you have been diagnosed with a condition which might have an underlying genetic cause, and your doctor has suggested referring you to the Clinical Genetics department.

Who do we offer DNA storage to?

DNA storage is usually offered to individuals who have a condition which may have a hereditary cause.

DNA storage is particularly valuable if a full clinical assessment of your family history is not possible straight away. This might be because you are unwell, in the midst of treatments, or due to waiting lists.

Having DNA stored means that a sample is available for genetic testing, if and when the time is right. Even if no genetic testing is required at present, having stored DNA may allow you and family members to benefit from future advances in genetic testing.

Some individuals may also choose to store DNA if they don't want to have genetic testing at the moment, but they might reconsider at some point in the future, either for their own information, or to inform their relatives.

Your DNA may be stored indefinitely, but please be aware that the quality of DNA can deteriorate over time, which may affect testing.

What is DNA Storage?

DNA is the substance that contains the genetic instructions which make up your genes – these instructions tell our body how to develop and function. You inherit your genes from your parents, and pass them onto your children. DNA can be extracted, usually from a blood sample, and stored in the lab for many years.

Stored DNA can be used for genetic testing. Genetic testing involves looking at DNA for changes that may explain why someone develops an illness. If changes are found, this may have implications for your health, or your family members.

Where will my DNA be stored?

Your DNA sample will be stored in the Genetics Laboratory at Belfast City Hospital.

What is required for DNA storage?

A small sample of blood is taken by your doctor or nurse. This is sent to the Genetics Laboratory in Belfast. They extract DNA from your blood and keep it frozen in safe storage. If receiving chemotherapy, ideally a blood sample should be taken prior to starting treatment, or four weeks after your treatment has finished. This is because the drugs given in chemotherapy can affect the amount of DNA that can be obtained from a blood sample.

A sample of saliva could also be given if a blood sample is not possible. However, a saliva sample *may* limit the testing that is possible. Your doctor or nurse can request the kit for collecting a saliva sample from the Belfast genetics laboratory.