

Genetic Tests and the NHS service

An expert team from the UKGTN will then check whether providing the test as an NHS service is likely to be of benefit to patients. If the test is approved the recommendation is then passed to the national Genetics Commissioning Advisory Group who may request that your local health commissioners consider providing the funding for the test.

More Information about this can be found on the UKGTN web site <http://www.ukgt.nhs.uk/dossier.html>

How you can have your say about the service

Action:

You can contact patient support groups for a particular condition or the Genetic Interest Group an umbrella organisation for all people affected by genetic disorders, who can help with general questions about genetics. Support groups can approach the UKGTN about the need for a specific test.

Useful websites:

Genetic Interest Group (GIG), www.gig.org.uk 020 7704 3141
Contact a Family, www.cafamily.org.uk

Contact Information

UK Genetic Testing Network
c/o Bexley Care Trust
Specialised Services
221 Erith Road
Bexleyheath
Kent DA7 6HZ
Tel: 020-8298-6111
Fax: 020-8298-6244
E-mail: ukgtn@bexley.nhs.uk
Web: www.ukgt.nhs.uk



UKGTN: UK Genetic Testing Network A guide to genetic testing in the NHS

This leaflet gives information about the purpose of the UKGTN and how it works. Further information can be found at www.ukgt.nhs.uk.

What is the UKGTN?

The UKGTN brings together all the people involved in providing genetic tests for inherited disorders. These include the laboratory staff that carry out the testing, the geneticists (doctors trained in genetics), the commissioners who arrange the contracts for the services and provide the funds, and the patient support groups.

Why was it established?

The UKGTN was established in 2003 to ensure that people across the UK can have the same level of genetic services, to ensure that the services are of high quality, to check that new genetic tests put forward for acceptance into the UKGTN listing are effective, and to influence the way the NHS arranges genetic services.

Accessing genetic tests

About genetic tests

People request genetic testing for different reasons:

- To confirm a diagnosis of a genetic disorder
- The test may reveal a susceptibility to certain disorders (e.g. cancer or heart disease) and allow targeted surveillance or risk-reducing options to be offered.
- People with a known genetic disorder in the family can be tested to see whether they have inherited the same disorder or not
- In some cases a prenatal genetic test may be performed during pregnancy, to see whether the unborn baby has a genetic disorder, suspected on the basis of clinical information or family history.

To find out if a test is available through the NHS

You can check if the condition is on the UKGTN online database www.ukgtn.nhs.uk (the list known as the NHS Directory of Molecular Genetic Testing) or you can contact your GP requesting information on testing services for a particular condition.

To arrange a test

There are a variety of ways in which this may take place. The list below is not definitive but offers a guide to the likely way in which a genetic test will be arranged for you by a health professional. Support and counselling are offered through the regional genetics centres.

1. Your GP may refer you to a specialist health professional, in relation to the disorder affecting you or your family,

2. Your GP may refer you directly to your local regional genetics centre to see a genetic health professional who will be able to advise you about genetic testing.
3. You may already be under the care of a health professional, other than your GP and they, if required, may send a sample directly to your local regional genetics centre.

What will be tested

- A blood sample is normally taken for testing
- A strict range of requirements have to be checked before testing is offered

Obtaining the results

Results will be provided either directly through the regional genetics centre or through the health professional who requested the test. The health professional responsible for your care should discuss the various options available following the test results. Where it will be helpful, counselling from specialist genetic counsellors is offered.

Genetic Tests and the NHS service

How are tests accepted on to the UKGTN

Researchers are finding more about the genes involved in particular conditions. These advances can sometimes lead to new tests being developed. However, it is very important that all tests are thoroughly checked to ensure that they are of high-quality. The method used by the UKGTN is called the Gene Dossier process.

A Gene Dossier form is completed by the laboratory and specialist who wishes to provide a new test. The testing methods have to meet the quality standards of the NHS.