



**The Leeds
Teaching Hospitals**
NHS Trust

Yorkshire Regional Genetics Service

Genetic Testing

Information for patients



Yorkshire Regional
Genetics Service

The condition you have may be due to a change in a gene (portion of inherited material). We are able to offer a test to look for changes in the genes associated with your condition. This leaflet has some further information about genetic testing.

How may finding a gene change help me?

- To confirm your diagnosis.
- To provide further information about the condition and whether you need to have more tests.
- It may or may not affect any treatment.

How may finding a significant gene change in me help my relatives?

- This can help to work out the inheritance pattern of the condition and therefore, the risks to different members of the family.
- It can then lead to a gene test being available for your relatives if they wish to know whether they have inherited the condition.
- Depending on the gene and the condition, we may not offer gene testing to children until they are old enough to make the decision themselves.

- It may provide more options for when you are planning a family and in pregnancy. These can be discussed further with the genetics team.

Do you sometimes find uncertain gene results?

- **YES.** We all have changes in our genes as part of normal variation in the general population and most of these do not have any health implications.
- It may not be clear whether these types of gene changes are causing your condition or not.
- We cannot test family members for these types of changes.

Could there be any unexpected results from gene testing?

- **YES.** Sometimes, we find gene changes that may have other health implications. Your doctor can discuss these further with you.

How long will it take to get my results?

- Genetic testing takes some months to complete. If you do not receive a result within 6 months, please contact the doctor who arranged the test.
- If a gene change is identified, you may be offered a referral to the clinical genetics team to discuss the implications for yourself and your family.
- Once a specific gene change is known in the family, any testing in relatives is much quicker.

What do I need to do to have a genetic test?

- A routine blood sample is required to do the testing, which your doctor will arrange.
- Genetic material (DNA) from this sample will be stored in the NHS genetics laboratory.
- Results and samples may be used for counselling other family members in relation to this condition.

Who should I contact if I have questions about this?

- Please contact the doctor who arranged your genetic test.



Yorkshire Regional Genetics Service

Department of Clinical Genetics
Level 3, Chapel Allerton Hospital,
Chapeltown Road,
Leeds LS7 4SA