What does this involve?

At the first appointment you will be asked for more information about your family. This helps to find out whether there is a genetic condition in the family. It also helps to find out which genetic condition it may be. It means you can be given information about your risk of having a child with a genetic condition. You will also be given information about choices available to you, and helped to make decisions about what you want to do.

This process is called Genetic Counselling, and can be carried out by doctors and Genetic Counsellors. The Genetic Counsellors have a good understanding of religious and cultural issues. They can also speak several languages including Urdu, Hindi, Punjabi, and Gujarati, Mirpuri and Hindko.

This discussion is confidential, and not shared with other members of your family unless you give permission.

What could I be offered?

In some families the gene change responsible for the genetic condition may have been identified. Testing can then be offered to see if you and your partner are carriers of the gene change. This is called 'carrier testing'. However, arranging tests can take some time, longer if the gene change is not already identified. Therefore, the best time to do this is before you become pregnant.

If both partners are identified as carriers then the child can be tested to see if they have inherited the genetic condition. Testing can be done during the pregnancy or soon after birth. This allows the management of the condition to be started as early as possible.

Where can I get more information?

If there is a child with these sorts of health problems in your family and you would like more information, please talk to your GP.

Produced by: Yorkshire Regional Genetics Service
Printed by: The Leeds Teaching Hospitals NHS Trust Print Unit • WRU1300

Publication date 03/2013 Review date 03/2015

Airedale, Wharfedale and Craven
Bradford Districts
Bradford City
CCGs working together
NHS

Every Baby Matters

Inherited Conditions

Is there anything running in my family which could affect my pregnancy or my children?

YORKSHIRE NHS
Regional Genetics Service

BRADFORD
working in partnership

Could there be a disease or condition running in my family?

Some diseases or conditions run in the family. You may already know that there is an inherited, or genetic, condition within your family.

You may have noticed clues which can suggest that there is a disease or condition running in your family.

- Several children affected with the same illness
- Deafness and / or blindness in a child
- A child who is having problems with his or her development, e.g. speech difficulty or delay in sitting or walking.
- A child who is seen regularly at the hospital, or by a hospital team such as the Metabolic Outreach Team
- A child on a special diet
- A child with many health problems
- Several miscarriages or stillbirths

Even if a child with these clues is a distant relative this may be very important for you and your children. Please remember that not all health problems are inherited or run in the family.

What causes conditions to run in families?

Genes. We have 2 copies of every gene, one from our mother and one from our father. Genes are the instructions for our body. They make us the way we are, for example our eye colour or hair colour. Sometimes a change can occur in a gene. This can change the instruction and cause health problems. These health problems are then said to be part of a genetic condition.

But my partner and I are both healthy.

Both parents can be healthy, but still be at risk of having a child with a genetic condition.

This is because, in some conditions, you need a gene change in both copies of the gene before you have any problems. If you have one copy of the gene with the change and one healthy copy, you are said to be a "carrier" for that condition. Carriers do not usually have any health problems. They are not aware that they are carriers for a genetic condition. Often the only clue is that there are children in the family with health problems.

If both parents have a gene change in the same gene they are said to be carriers for the same genetic condition. They are at risk of having a child with that genetic condition. This is because any child they have may inherit one copy of the gene with the change from each parent. The child will have a gene change in both copies of their gene, and develop the genetic condition.

This pattern of inheritance is called autosomal recessive inheritance. It is only one example of a pattern of inheritance. There are other patterns of inheritance too, and these are also important.

What should I do if I think I may be at risk of having a child with a genetic condition?

First of all, see your GP and talk through the health problems within your family. They may be able to reassure you that the health problems within your family are not a sign of a genetic condition. Your GP may be able to offer 'carrier' testing to you and your partner for certain common conditions, e.g. Thalassaemia.

If your GP feels there may be a genetic condition running in the family they may suggest a referral to the Genetics clinic at the hospital.