

Frequently Asked Questions about Genetic Testing

You are going to speak to a health professional about genetic testing. What do you need to know? Here is a list of questions which may help you find the answers that you need. They have been developed with the help of patients and families that have been through a similar experience. Although the questions are quite general it is important to remember that every situation is unique, and not all the questions may be relevant to your particular situation. In addition you might have some questions that are not on this list that you want to ask. Write them down and take them with you to your appointment so that you don't forget.

Remember, you do not have to take a genetic test, it is your choice. You should only go ahead with genetic testing when you feel sure that it is the right decision for you and your family.

A. Information about the Condition

Why have I *or* my child been referred to see a genetics specialist?
Why do I *or* my child have this condition?
Can you tell me about the condition I *or* my child is being tested for?
How common is this condition?
What might it be like to live with this condition?
Is there any treatment for this condition?
If so, is it expensive and will I have to pay?
Is everybody with this condition affected by it in the same way?
How is the condition passed from one generation to the next?
If I have another child what is the risk that they will have the condition?
Where can I find more information about the condition?

B. Information about the Test

What will actually happen when I *or* my child takes the test?
Do other members of my family need to be tested?
What will the test results tell me?
Are there any risks in taking the test?
Does it hurt?
How accurate is the test result?
Will I definitely get a test result?
How long will it take to get the test results?
How will I receive the test results?
Is the test going to cost me anything?
Do I *or* my child have to take a genetic test or are there other ways of finding out the information I want to know?
Who will the test results be given to?

C. Other Things to Think About

Will the results of the test affect other members of my family? If so, should I discuss the test with them first?
How might the results of the test affect me and my family emotionally?

Who should I tell about the test results (e.g. family members, work colleagues, teachers)?

Will the results affect my insurance?

Will you be giving me written information that goes over what we have been discussing?

(You might want to ask for this if this is not standard procedure).

Who will be the one to explain the results to my child and/or relatives?

Is there any written information that you can give me, which will help explain the situation to my child and/or relatives?

Are there any support services or patient organisations I can contact?

What other health professionals should I get in contact with?

If I think of anything else I would like to ask, can I contact you again? If so, how?

More information can be obtained from your local regional genetics centre (www.gig.org.uk/services.htm) or from these addresses:

The Genetic Interest Group

Unit 4D, Leroy House,
436 Essex Rd.,
London, N1 3QP
Telephone: 0207704 3141
Email: mail@gig.org.uk

Antenatal Results and Choices (ARC)

73 Charlotte St.,
London,
W1T 4PN
Tel: 020 7631 0285
Email: info@arc-uk.org
Web: www.arc-uk.org

Orphanet

Free-access website providing information on rare diseases and orphan drugs, and links to support groups across Europe.

Web: www.orpha.net

EuroGentest

Free-access website providing information about genetic testing and links to support groups across Europe..

Web: www.eurogentest.org

This information was developed with the help of patients and families from across Europe who all have first hand experience of living with a genetic condition. We are immensely grateful for their contribution to this work and their continued efforts on the Eurogentest project.

January 2007

This work was supported by EuroGentest, an EU-FP6 supported NoE contract number 512148