

relevant to any health concern. Third, even if you do know the results, the ABI has confirmed that insurers will only consider results of tests done as part of a clinical diagnostic process and approved by the Government's Genetics and Insurance Committee. It is most unlikely that the committee would approve using research tests. You should not let worries about insurance put you off from helping with research if you wish to.

Seen in clinic by.....

For more information:

If you need more advice about any aspect of Genetics & Insurance, you are welcome to contact:

ABI website -

www.abi.org.uk/public/consumer/codes/disclosure.asp

ABI helpline - 020 7216 7455

Genetic Interest Group - an organisation that works to support people with genetic disorders -
Website: www.gig.org.uk
Telephone: 020 7704 3141

Clinical Genetics Departments

Northern Scotland (main base Aberdeen)

Tel: 01224 552120 Fax: 01224 559390

(Aberdeenshire, Moray, Highland, Western & Northern Isles)

Tayside (main base Dundee)

Tel: 01382 632035 Fax: 01382 645731

(Perth & Kinross, Angus, North East Fife)

South East Scotland (main base Edinburgh)

Tel: 0131 651 1012 Fax: 0131 651 1013

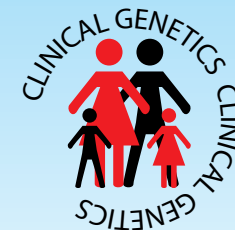
(Borders, Lothian, South West Fife)

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(Glasgow, Argyll & Bute, Ayrshire, Dumfries & Galloway, Stirling, Lanarkshire, Falkirk)

Genetics and Insurance



General Information

Our thanks go to Andrew Read (Professor of Human Genetics at Manchester University) for his suggestions on this leaflet which was written by Clinical Genetics, Guys Hospital. Updated by Genetic Interest Group Scotland. Last updated March 2003.

Introduction

For some types of insurance it is necessary to provide medical information, including genetic information, to the insurers in order for them to set up your policy and work out your premiums. This leaflet outlines answers to questions you may be asking about how genetic tests could affect your insurance.

Do I have to tell the insurance company about a hereditary (genetic) disease that runs in my family?

If it is requested on your insurance application form, then you must give the insurers any information about current or previous illness amongst family members. However, you only need to answer the questions that are on the form.

Will the insurance company ask me to have a genetic test?

No. The Association of British Insurers (ABI) has a Code of Practice on Genetic Testing that states that people seeking insurance must not be asked to have a genetic test in order to get insurance.

If one of my relatives has a genetic test, do I have to tell the insurance company?

No. Relative's genetic test results cannot be counted in the decision to offer you insurance. However, you do need to include all details about any illnesses that run in your family if the application form requests that information.

I have already had a genetic test? Do I have to tell my insurance company the results of this test?

British insurers have agreed to a 5 year moratorium, introduced in October 2001, which states that you can apply for a total of up to £500,000 of life insurance and up to £300,000 of certain types of health insurance (critical illness, income protection or long-term care insurance) without having to tell your insurers the result of previous genetic tests. Above these amounts you need to tell the insurer the result of a genetic test when answering the insurer's questions. These questions only apply to genetic tests that are approved by the Government's Genetics and Insurance Committee (GAIC) as being relevant to the type of insurance you want. An up-to-date list of approved genetic tests can be obtained from the Genetics and Insurance Committee website: www.doh.gov.uk/genetics/gaic/index.htm.

Do I have to tell my insurers about any genetic tests that I have in the future?

No - not for existing policies. But it is important to tell insurers all of the relevant information that is asked for when you apply for new insurance. If you need to claim later on, insurers can withhold payment if they believe you deliberately failed to inform them of relevant medical information in your original application.

What happens if I have a genetic test and the result is negative, which means I have not inherited a genetic disease that runs in my family?

You may tell an insurance company about a negative test result if you wish. Many insurance companies take this into account when working out your policy. This may vary with different companies.

What will insurance companies do with my genetics result?

Your genetic information is private, and insurers are required to adhere to data protection legislation and ABI rules. Any genetic information about you is securely locked away and only brought out by the staff that need to use it in order to prepare your policy. Any genetic information that you provide is confidential, and will not be shared with any other insurance company unless you agree to it. The genetic information is destroyed when it is no longer relevant, so you don't need to worry about it being passed onto other agencies.

Can insurance companies really interpret my genetic test results properly?

Insurance companies employ staff and medical experts who are trained in the interpretation of medical information and test results. If you believe that your results have been interpreted incorrectly, you should contact the insurance company to ask for a reassessment.

I have been asked to take part in a genetics research project. Could this affect my current or future insurance?

No. The Association of British Insurers has officially stated that their members would not be interested in any test results produced by research projects. First, no research will affect any policy you have already taken out. Second, only tests where you know the results could, even in principle, affect any future insurance. With many research projects participants are not told their test results, because these are not