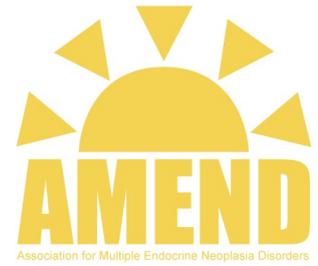




**Genetic Alliance UK**  
Supporting. Campaigning. Uniting.

Approved by:



## Genetic conditions and insurance

### What you need to know and what you need to tell



## About this booklet

This information booklet has been produced to provide accessible and impartial information for people with and at risk of genetic conditions who wish to access insurance. Accessing appropriate insurance is a significant problem for many people affected by genetic conditions. Genetic Alliance UK regularly receives helpline calls and emails from people affected by genetic conditions. Often, people are finding it difficult or impossible to access appropriate or affordable insurance cover or people are uncertain about their rights and obligations in relation to disclosing details of genetic risks or family medical history. The information in this booklet is designed to answer such questions.

The information contained in this booklet is for general purposes and guidance only, is not necessarily comprehensive and does not purport to give professional or legal advice. The information relates to circumstances prevailing at the date of its original publication and may not have been updated to reflect subsequent developments. While all efforts have been made to ensure the accuracy of the content of this booklet, Genetic Alliance UK cannot be held responsible for any information contained in it and in particular not for the details of any quoted insurance policy or product. Genetic Alliance UK urges all individuals to obtain a suitable insurance policy or product through an independent financial advisor (IFA) or insurance broker and to read and understand the policy details before committing to buying it.

## About Genetic Alliance UK

Genetic Alliance UK is the national charity of over 150 patient organisations supporting all those affected by genetic conditions. Our aim is to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them. We are well-placed to provide patient and family-focussed information.

To download a copy of this document, please use the following link:

[www.geneticalliance.org.uk/insurance.htm](http://www.geneticalliance.org.uk/insurance.htm)

Published by:	Genetic Alliance UK Unit 4D, Leroy House 436 Essex Road London N1 3QP
Telephone:	+44 (0)20 7704 3141
Fax:	+44 (0)20 7359 1447
Email:	<a href="mailto:contactus@geneticalliance.org.uk">contactus@geneticalliance.org.uk</a>
Website:	<a href="http://www.geneticalliance.org.uk">www.geneticalliance.org.uk</a>
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# Introduction

Genetic Alliance UK has produced this booklet to provide accurate and impartial information that is easily accessible for people with and at risk of genetic conditions who wish to access insurance.

This booklet provides information on genetic testing and insurance, all information is applicable to financial products that are affected by the Concordat and Moratorium on genetic testing and insurance (see page 10 for explanation).

There are three financial products that are affected by the Concordat and Moratorium on genetic testing and insurance:

## Life insurance

Life insurance is designed to pay a lump sum to provide financial support to your partner or family if you die.

## Income protection insurance

Income protection insurance pays you a monthly income if you are too ill to work or suffer from an injury for a prolonged period.

## Critical illness insurance

Critical illness insurance typically pays out a lump sum if you either die or are diagnosed with a critical illness that meets the insurance company's policy definition. Each insurer only covers the critical illnesses defined in their policy and no other.



# Family Medical History

Family medical history (sometimes called 'family history') is a record of health information about a person and his or her close relatives (blood relatives). Family medical history can identify people with a higher-than-usual chance of having some disorders.

## What information do I have to disclose about my family medical history?

You may be asked to disclose information to the insurance company about what you know of your family's medical history.

This includes:

- **Current** or **previous** illness amongst family members.
- Whether a genetic condition runs in the family.
- Whether any deaths in the family are due to a genetic or inherited condition.

## Who counts as 'family' according to insurance companies?

Insurance companies most often ask for the family medical history of your immediate/first degree family members (parents and siblings). However, a complete record of family medical history may also include; children, brothers and sisters, parents, aunts and uncles, nieces and nephews, grandparents, and cousins.

## Do I need to tell the insurance company if a genetic condition runs in the family?

**Yes.** If your insurance company asks you, details of any genetic conditions that run in your family must be disclosed.

## Can insurance companies ask me for family members' predictive genetic test results?

**No.** Under the Concordat and Moratorium (see page 10 for explanation) insurance companies are not allowed to ask you for family members' **predictive** genetic test results\*. (see page 6 for an explanation of what a predictive genetic test is and bottom of page for \*).



**Remember...** you only have to answer what is asked for by the insurance company, or requested on the application form. Answering all questions truthfully will prevent any chances of your policy becoming void.

### What insurance companies ARE allowed to ask...

- If a genetic condition runs in your family.
- Your family medical history.

### What insurance companies are NOT allowed to ask...

- Your predictive genetic test results\*.
- Family members' predictive genetic test results.

\* Unless you are seeking to obtain life insurance cover of more than £500,000 and have taken the predictive genetic test

# Genetic Testing

Insurance companies may ask you questions about genetic test results to allow them to produce an insurance policy. A genetic test looks for gene mutations (DNA changes) associated with genetic conditions. There are two types of genetic tests:

## Predictive genetic test

If a particular genetic condition runs in your family, but you show no signs or symptoms of the condition, a predictive genetic test predicts your future risk of developing the condition. This may be for a gene that is suspected of causing a late onset condition or for a gene that is suspected of causing a high incidence of a common condition in your family.

A **positive test result** (sometimes called 'adverse' test result) means that the gene mutation has been found and you will either develop the condition, or are likely to develop the condition.

A **negative test result** (sometimes called 'normal' test result) means the gene mutation has not been found.

## Diagnostic genetic test

If you are showing signs or symptoms of a particular genetic condition, a diagnostic genetic test confirms or rules out whether you have the condition.

A **positive test result** (sometimes called 'adverse' test result) means that the gene mutation causing the condition has been found. The result confirms your diagnosis of the condition.

A **negative test result** (sometimes called 'normal' test result) means the gene mutation associated with the condition has not been found.

If you want more information about genetic tests and genetic testing, Genetic Alliance UK has freely available information. Full contact details are on the back page of this booklet.

## When do I need to disclose a predictive genetic test result?

You need only disclose a predictive genetic test result to an insurance company if you are obtaining life insurance cover for over £500,000 and have taken the test for Huntington's disease.

According to the Concordat and Moratorium (see page 10 for explanation), insurance companies may only ask you for certain predictive genetic test results that have been approved by an independent government committee.

No predictive genetic test has been approved for critical illness insurance and income protection insurance at the time of publishing this booklet.

## Can insurance companies ask me to take any genetic tests?

**No.** The Association of British Insurers (ABI) and UK Government have a Concordat and Moratorium that states that people who are seeking insurance will not be asked or put under any pressure to take a genetic test to obtain insurance cover.

## When should I disclose my predictive genetic test results?

Key: No, don't disclose **X** Yes, do disclose **✓**

Test	Predictive genetic test	Diagnostic genetic test
Life insurance of less than £500,000	<b>X</b>	<b>✓</b>
Life insurance of more than £500,000	<b>X</b>	<b>✓</b>
Life insurance of more than £500,000 for Huntington's disease	<b>✓</b>	<b>✓</b>
Critical illness insurance	<b>X</b>	<b>✓</b>
Income protection insurance	<b>X</b>	<b>✓</b>

## What if I take a diagnostic or predictive genetic test and the test result is negative?

You may wish to tell an insurance company about negative diagnostic or predictive genetic test results; many insurance companies will take into account the result of such a voluntarily disclosed genetic test and may remove any loadings or special terms applied to your premium based on your family medical history.

**Remember...** you only have to answer what is asked for by the insurance company, or requested on the application form. Answering all questions truthfully will prevent any chances of your policy becoming void.

## Do I need to tell the insurance company of any genetic tests taken after the insurance policy starts?

**No.** You do not have to disclose any genetic test results taken after the cover has started, for as long as that cover is in force and not altered.

**Remember...** if you have disclosed a predictive genetic test result that does not need to be disclosed, insurance companies will ignore it.

### What insurance companies ARE allowed to ask you for...

- Diagnostic genetic test results.
- Predictive genetic test results if you have taken the test for Huntington's disease AND applying for more than £500,000 for life insurance cover.

### What insurance companies are NOT allowed to ask you for...

- Your predictive genetic test results\*.
- Predictive genetic test results for critical illness cover and income protection cover.
- Family members' predictive genetic test results.

\* Unless you are seeking to obtain life insurance cover of more than £500,000 and have taken the predictive genetic test for Huntington's disease.

# Genetic Conditions

## Existing medical conditions

### Symptomatic

Persons who show signs or symptoms of a disease, disorder or condition.

### Asymptomatic

Persons who carry a disease, disorder or condition, but who do not show any signs or symptoms.

### What information am I expected to disclose to insurance companies about my condition?

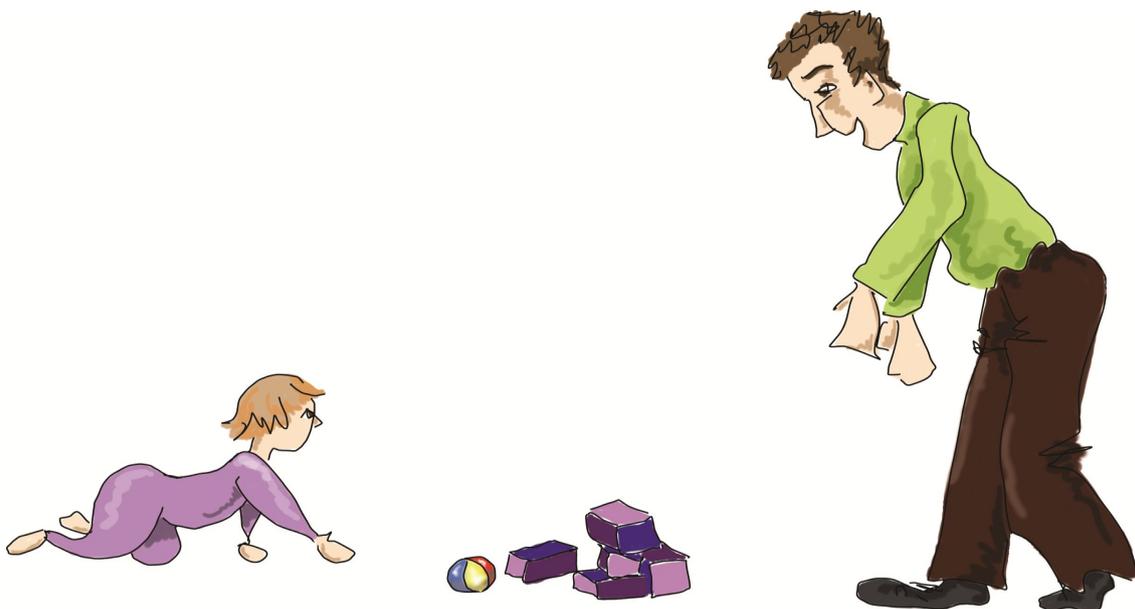
You will normally be asked about your current health, previous health problems and any major health problems in your family.

### What if the insurance company has not heard of my condition?

Insurance companies need to understand your condition so they can assess your application. If your condition is not common, the insurance underwriter may want to find out more information from you or your doctors. An insurance company may also consult with their Chief Medical Officer (a qualified medical professional) or other qualified experts. Information from your GP or hospital doctor may also be requested to better understand the risk (see page 13 for explanation). The insurance company will always ask for your permission to contact your GP or hospital doctor.

### What if I don't know a lot about my condition?

You will need to disclose that you have a condition and may be asked about treatment, consultations etc, issues you will know about. The insurance company may request a report from your GP or hospital doctor to find out a bit more about your condition. Insurance companies employ medical doctors to help them with unusual and difficult cases, sometimes they investigate the condition and may ask medical experts for input.



## Risk of future medical conditions

### What if you have not taken a predictive genetic test and are asymptomatic?

If other members of your family have been diagnosed with a disease but you have not experienced any signs or symptoms, you must disclose any medical history about yourself and family members if asked by an insurance company.

### What if you have taken a predictive genetic test and are asymptomatic?

If you have taken a predictive genetic test and the test result is 'positive', but you are asymptomatic and all other tests are normal, then you do not currently have the disease. You do not need to disclose the result of this predictive genetic test to the insurance company, with the exception of a predictive genetic test for Huntington's disease for life insurance cover over £500,000.



### Remember...

- You only have to answer what is asked for by the insurance company, or requested on the application form. Answering all questions truthfully will prevent any chances of your policy becoming void.
- You must be honest about your diagnosis and the likely progression of you condition.

# Concordat and Moratorium

The UK government and insurance industry have worked together after recognising the concerns around the potential use of genetic data by insurance companies. The Concordat and Moratorium protects the interest of both customer and insurer, by preserving customer access to insurance and insurance companies' right of equal access to information about risk.

## Concordat

Preserves the principle that unless otherwise agreed, insurance companies should have access to all relevant information to enable them to price risk fairly in the interest of all their customers.

## Moratorium

Allows patients who have taken a predictive genetic test to obtain significant levels of insurance cover without disclosing the results of that predictive genetic test. This is with the exception of a predictive genetic test for Huntington's disease for life insurance over £500,000.

*"The Concordat and Moratorium on the use of predictive genetic test results works well for consumers. It means people can insure themselves and their families, even if they have had an adverse result from a predictive genetic test. The Concordat and Moratorium has proved effective since its introduction in 2001 and has now been extended to 2017."*

*- Nick Starling, Association of British Insurers Director of General Insurance and Health.*

## What happens if the Concordat and Moratorium ends?

The Concordat and Moratorium has proved effective since its introduction in 2001. It is on-going at present until 2017, following its review in 2011. The next review will be in 2014. The Concordat and Moratorium has a three year review cycle, if any changes were to be made there would be time for you to address them.

Genetic Alliance UK is monitoring the Concordat and Moratorium and will do all it can to ensure that if any changes are made they will not damage or disadvantage those who have existing policies.



# Treatment

## Should I tell the insurance company if I am receiving treatment for a condition?

Explaining current treatment is essential, it shows that the condition is treatable, it may alter your prognosis and maintain your health. The insurance company may ask for a letter from your GP or a hospital doctor for further information of the treatment and its effectiveness.

## Should I tell the insurance company if I start receiving treatment after the insurance cover starts?

Unless your insurance company specifically requests that you advise them about treatment, after you have taken insurance cover, you do not have to tell the insurance company about any treatment you are taking. However, if you later start a new policy, you will have to disclose the treatment you have had to the insurance company.



## What if I am a carrier of a genetic condition?

Being a carrier of a genetic condition but showing no symptoms does not need to be disclosed to the insurance company. This is effectively the same situation as taking a predictive genetic test. However you must disclose all relevant medical history.

### Helpful information...

Receiving treatment may affect the price of the premium in a positive way, remember if treatment is effective, insurance companies may take this into account when calculating your premium.

# Privacy and Rejection

## Will my information be shared with other insurance companies?

When insurance companies are dealing with sensitive, personal and medical information they have to protect it in line with the law (the Data Protection Act 1998) and with the Concordat and Moratorium.

- Any information you provide is securely locked away, and electronic information is kept with secure access and is password protected, the information is only accessed by staff that need it to use it in order to prepare your policy.
- Any genetic information you provide is confidential and your genetic and personal information is destroyed when it is no longer relevant.
- There are companies called reinsurance companies. Reinsurance is insurance purchased by other insurance companies to share some of the risk your insurer takes on. Reinsurance companies are allowed to have access to the information, but it will only be used with the same protection as the insurer and will not be used in connection with the business of any other insurance company.

## Why was I rejected?

There are a number of reasons you may be rejected (not offered a policy) or have a high premium. Some of these include:

- Disclosures about health – height, weight, smoking, drinking.
- Occupation, dangerous hobbies, sports and activities.
- Family medical history.
- Pre-existing medical conditions.

## If I am rejected insurance cover by a particular insurance company, will this affect future attempts?

Some insurance companies may ask if you have been refused insurance or special terms applied elsewhere, if so you must tell them.

This is so the insurance company can process your application correctly and fairly, and to prevent any chances of your policy becoming void.

Remember... you only have to answer what is asked for by the insurance company, or requested on the application form. Answering all questions truthfully will prevent any chances of your policy becoming void.

### Helpful information...

- Insurance companies are aware that a prognosis can change so a decision made in the past would not automatically be used. A new application will be looked at afresh.
- If your application has been rejected or if your premium is increased, you are entitled to know the reasons for these. You can request a written explanation from the insurance company.

# Requesting Information From Your GP or Doctor

## Why do insurance companies need medical information from my GP or hospital doctor?

Insurance companies may request medical information from your GP or hospital doctor to better understand your condition in order to accurately price the additional risk from any health problems you disclose.

## What questions will the insurance company ask my GP or hospital doctor?

With your fully informed consent, insurance companies will usually send your GP or hospital doctor a 'General Practitioners Report' (GPR) which they will be required to complete. General questions typically involve:

- Current health – are you receiving any medical care, medication, treatments.
- Sickness record – have you taken days off work due to ill health.
- Past health – have you had any hospital admissions, treatments, illnesses.
- Predictive genetic test results – must be disclosed only in the case of Huntington's disease cases for life insurance policies over £500,000.

## Can I ask my medical geneticist to explain or does the insurance company only ask my GP or hospital doctor?

There is nothing to stop you from sending information to the insurance company from your medical geneticist. This may be helpful if you have a rare disease or condition which you feel the insurance company may not be familiar with.



## What you are entitled to...

- If a GP or hospital doctor report is requested, you will be asked for your fully informed consent, and there may be a question asking if you want to see a copy of the report before the GP sends it to the insurance company. The insurance company will tell the GP or hospital doctor if you do want to see a copy of the report first.
- You are entitled to talk with your GP or hospital doctor before medical reports are sent to the insurance company.
- You are entitled to know what information your GP or hospital doctor has provided to the insurance company.

## Concerns

Can insurance companies really interpret my genetic test results?

**Yes.** The interpretation will be carried out by a nominated senior insurance company staff member. They will refer to qualified medical experts for guidance whenever it is needed.

What if I think the insurance company has made a mistake?

If you feel you have been treated unfairly over something to do with your genetic risk or genetic condition first contact your insurance company, who will try to sort it out.

If this does not resolve the situation, the insurance company will give you in writing, contact details for the free arbitration service that will look at all underwriting complaints, including decisions, under the Concordat and Moratorium.

**IDRS** - The consumer redress, independent complaints review and ombudsman specialist.

Telephone: 020 7520 3800

Website: [www.idrs.ltd.uk](http://www.idrs.ltd.uk)

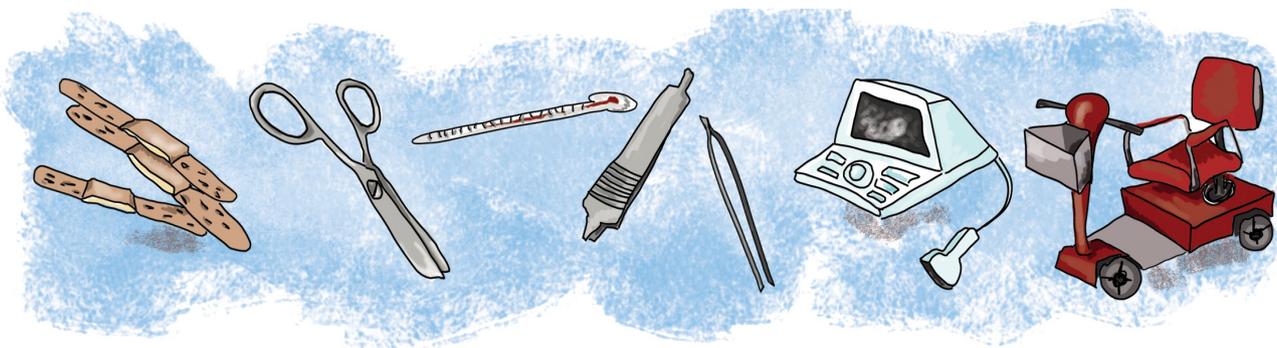
Email: [info@idrs.ltd.uk](mailto:info@idrs.ltd.uk)

Alternatively, you can make a complaint to the [Financial Ombudsman Service](#)

Telephone: 0800 023 4567

Website: [www.financial-ombudsman.org.uk](http://www.financial-ombudsman.org.uk)

Email: [complaint.info@financial-ombudsman.org.uk](mailto:complaint.info@financial-ombudsman.org.uk)



# Summary

## Do...

- Explain your condition, be truthful.
- Let the insurance company know if you are receiving treatment for a condition.
- Tell the insurance company of a predictive genetic test result if it is in your favour.
- Disclose diagnostic genetic test results if you are asked to do so.
- Ask the insurance company for the reason for any increase in the quoted premium or rejection in writing.
- Talk with your GP or hospital doctor before hospital medical reports are sent to the insurance company.

## Don't...

- Purposely leave out any information which is asked for as it may affect and void your policy should you or a family member need to claim, even if your claim arises from a different condition.
- You do not need to provide the results of a predictive genetic test\*.
- You do not have to disclose family members' predictive genetic test results.

\* Unless you are seeking to obtain life insurance cover of more than £500,000 and have taken the predictive genetic test for Huntington's disease.

Remember... you only have to answer what is asked for by the insurance company, or requested on the application form. Answering all questions truthfully will prevent any chances of your policy becoming void.

## Recommendations...

- Shop around with different insurance companies for a secure and better deal.
- Do not just look at price comparison websites or major insurance companies.
- If you are not confident about finding the right insurance policy, seek help from an independent financial advisor (IFA) or insurance broker who is regulated by the Financial Services Authority. They will approach different insurance companies on your behalf to find you insurance. Useful contacts are listed on the back page of this booklet.
- Find insurance companies with a specialist interest in dealing with people who have medical conditions, these can be found on the internet or through an independent financial advisor (IFA) or insurance broker.
- Always read and check the terms and conditions of the policy before accepting.
- The cheapest cover may not be the best cover - know what you are buying.

## Useful Contacts

### Genetic Alliance UK

The national alliance of over 150 patient organisations supporting all those affected by genetic disorders. Working to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them. This booklet is part of a range of information produced by Genetic Alliance UK and are available on the website, including information about genetic tests and genetic testing.

Telephone: 020 7704 3141

Website: [www.geneticalliance.org.uk](http://www.geneticalliance.org.uk)

### Unbiased.co.uk

If you are considering purchasing one of the financial products described in this leaflet, it is highly recommended that you seek financial advice from an Independent Financial Advisor (IFA) or an who is regulated by the Financial Services Authority. Unbiased.co.uk is a free consumer resource for people looking for legal and financial advice run by an Independent not-for-profit body.

Website: [www.unbiased.co.uk](http://www.unbiased.co.uk)

### The Association of British Insurers (ABI)

The ABI is the voice of insurance, representing the general insurance, investment and long-term savings industry. To find out more about the Concordat and Moratorium, insurance companies' approach to genetics and other general information about insurance, contact the ABI.

Telephone: 020 7600 3333

Website: [www.abi.org.uk](http://www.abi.org.uk)

### British Insurance Brokers' Association (BIBA)

BIBA is the UK 's leading general insurance intermediary organisation representing the interests of insurance brokers, intermediaries and their customers. Insurance brokers are regulated by the Financial Services Authority. An insurance broker's prime purpose is to help customers find suitable cost effective insurance protection. BIBA offers a 'Find a Broker' helpline and directory.

Telephone: 0870 950 1790

Website: [www.biba.org.uk](http://www.biba.org.uk)

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