



# GENETIC INFORMATION AND LIFE INSURANCE PRODUCTS

*in Australia*

MAY 2003

**Genetic information which includes a family medical history and the results of predictive genetic tests may have implications for your options for insurance cover such as life, disability, trauma, business and insurance relating to bank loans. Predictive genetic testing refers to testing in a person who currently does not have symptoms or signs of disease, but may be at increased risk due to their family history. Predictive genetic testing is currently available for a limited number of inherited conditions.**

## Concerning insurance

The Investment and Financial Services Association Ltd (IFSA), an organisation representing most insurance companies in Australia, has a policy on genetic testing and life, disability and trauma insurance. Under this policy, you will not be required to undergo a predictive genetic test in order to obtain insurance or to renew a policy.

IFSA's policy is explained in an 8-page fact sheet 'Life Insurance and Genetic Testing in Australia'. It is available from IFSA through its website ([www.ifsa.com.au](http://www.ifsa.com.au)) or by telephone (02 9299 3022).

Policy applications usually require a disclosure of any known genetic information. This information, depending on the condition involved, may or may not lead to higher (non-standard) insurance premiums, a reduced period of coverage, an exclusion for one or more medical conditions, offer of an alternate insurance product, deferral or denial of an offer to insure you.

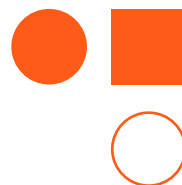
Costs of insurance, and the ability to obtain insurance cover, may vary between different companies depending on your risk. You may wish to make applications to a range of companies **at the same time**. An insurance broker or agent may be helpful in this process.

Insurance for a limited amount may be available with your superannuation plan. This is called "group insurance" and therefore not subject to health information, including family history and genetic testing results. However, if you require insurance for a higher amount, the application will require disclosure of this information.

Insurance policies offered by Life Insurance companies in Australia are "guaranteed renewable" so that you only have to apply for the cover once and are not subject to providing any other information for the period of cover. Under law, in the time between your application for this type of policy, and it being approved and accepted, you are required to inform the insurance company of anything that may impact on their offer of insurance. Once this type of policy has been issued you are no longer obliged to inform the company of any changes in circumstances, such as the result of a predictive test. Nevertheless, if a predictive genetic test result indicates you are at lower risk than estimated based on your family history alone, you may wish to inform your insurance company so that your policy can be reassessed with this new information.

However, insurance policies that are offered by General Insurance companies covering "sickness and accidents" are renewable during the time of cover of the policy. At every renewal period, you will be required to disclose any information that you **now have**, including any change in genetic information (family medical history or predictive genetic test results). With these policies, each renewal period is like making a new application.

Under the Insurance Contracts Act 1984, a person applying for insurance has a duty "to disclose to the insurer every matter that you know, or could reasonably be expected to know, that is relevant to the insurer's decision...". Some will ask for more details than others. You are obliged to provide answers to the questions asked honestly and to the best of your knowledge.



**Please read and consider carefully the following information. Involve your GP, specialist or geneticist if necessary in negotiations with the insurance company and document your screening and prevention strategies, where applicable.**

**1. Where you have not yet had a blood sample taken for a predictive genetic test:**

You may wish to investigate your insurance options before considering predictive genetic testing. Securing a policy may take several weeks or more.

Some companies ask whether you have sought advice or counselling about your health or future health. This question would include attending **genetic counselling** to discuss your risk based on your family medical history but where you did not have a sample taken for a predictive genetic test.

While this may highlight your concerns about a family history, you are already required to provide to the potential insurer **what you know** about the health of your parents, brothers and sisters (first-degree relatives).

In fact, sometimes the genetic counselling can clarify that a person's family history does not indicate that they are at potentially high risk for a certain condition and this can be helpful when applying for insurance.

**2. Where you have already given a sample for a predictive genetic test and:**

*(a) Your sample has not yet been analysed by the laboratory:*

As with all types of medical treatment, a person can withdraw their consent to a procedure at any time. You can withdraw your consent to the sample being analysed at any time prior to the laboratory starting the process.

In this situation, you can expect to have to disclose to a potential insurer the fact that you gave a sample for a predictive genetic test but that you have withdrawn from the testing process and do not have a result. It is unclear how this will impact on your insurance application. However the insurance companies are bound, under IFSA's genetic testing policy, to respect your right "not to know" your predictive genetic test result (see #6 *Dealing with insurance companies*).

Sometimes a person will give a sample for analysis to be done in the future. This is called "DNA banking". If a person provides a sample for DNA banking they have not yet undergone a genetic test.

*(b) The laboratory has analysed your sample and you are waiting for your result:*

If you have provided a sample for testing and the laboratory has analysed the sample, it is assumed that you have undertaken a predictive genetic test. You can expect to

have to disclose to your potential insurer the fact that you have had a predictive genetic test.

In this situation your insurance company may wait for your result to be available before proceeding with the application.

*(c) The laboratory has analysed your sample but you have chosen not to have your result:*

There may be a number of reasons why you would choose not to have your predictive genetic test result. For example, a person may have a test only for the benefit of other family members but will not want to know their own result.

If you have chosen not to receive your results, your obligation to disclose to the insurance company that you have had a test is not clear. However the insurance companies are bound, under IFSA's genetic testing policy, to respect your right "not to know" your predictive genetic test result (see #6 *Dealing with insurance companies*).

### 3. Where you have received your predictive genetic test result before securing insurance cover:

The insurance company will require that you make available the results of any genetic test results.

### 4. Where a relative has had a predictive genetic test and the test result is known to you:

When applying for insurance, you are required to disclose any *health* information that **you know**, about yourself, parents, brothers and sisters, which is relevant to an assessment of your risk. This would include past and present health problems and predictive genetic test results but would not include providing personally identifying information like your relatives' names.

You will also generally be asked to provide written consent to your potential insurer for your doctor to provide any information about you known from *your* medical record. If there is information about a relative's genetic test result in your medical record, your doctor may be obliged to disclose the test result information. In your consent you may request that your doctor does not disclose any personally identifying information about your relatives.

### 5. Research Projects

**You do not have to disclose to your potential insurer that you have participated in a research project except in the following circumstances:**

**(a) The research protocol states that during, or at the completion of the research project, you will receive your personal test result:**

You can expect to have to disclose the fact that you have participated in the research. If you have the result, you can also expect to have to disclose it.

**(b) The research protocol states that you will not be given your personal test result, but you will be informed if the family test result might be important to your future health, and given the opportunity to investigate your options further through a clinical service:**

You do not have to declare your participation in the research project until you are informed that the research has provided information that may be important to your future health. Once you have received this information, you are now aware of a matter that the insurer may consider relevant, and you can expect to have to disclose this information in your application for a policy or a renewal.

If you choose to undergo a further predictive genetic test in a clinical setting, you can expect to have to disclose your test results to a potential insurer if you are applying for or renewing a policy.

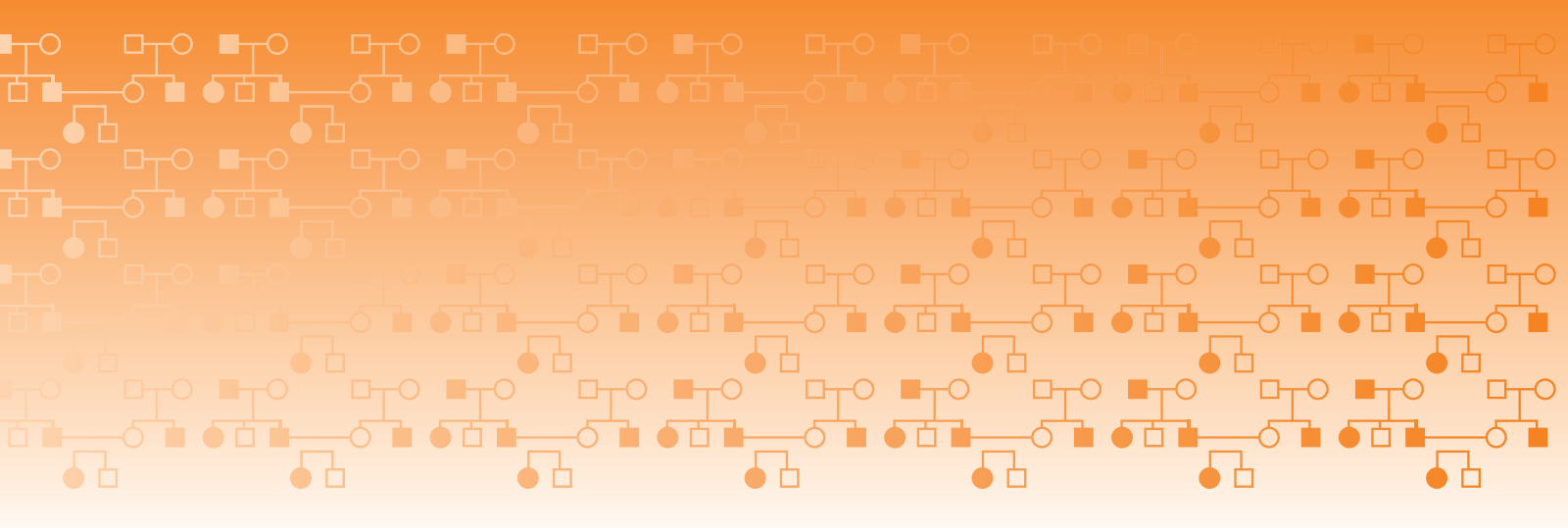
### 6. Dealing with insurance companies

Find out if the insurance company you are dealing with is a member of IFSA and therefore bound by the IFSA policy. If the company is not a member of IFSA, inquire about their policy regarding genetic testing.

If advised by an agent/broker that an insurance offer may be declined, deferred, offered at non-standard rates or impacted on the basis of a particular genetic test result, check that this advice has been received from the company's underwriter in writing and request a copy.

You can discuss the insurance company's decision with your genetics specialist who may be able to explain to you the reasons for the decision, and if necessary can discuss the decision with the company's Chief Underwriter or Chief Medical Officer.

If experiencing difficulties with your insurance company over your application or renewal, follow the Internal Disputes Resolution process each company has documented in their product disclosure brochure – this is the brochure that contains the application form.



Produced by:

The Centre for Genetics Education  
PO Box 317  
St Leonards NSW 1590

Tel: (02) 9926 7324

Internet: [www.genetics.com.au](http://www.genetics.com.au)

With the assistance of

Ms Fiona Richards, Senior Social Worker, Dept  
of Clinical Genetics, The Children's Hospital at  
Westmead and Ms Jennifer Blackwell, Executive  
Officer, NSW Genetics Service

May 2003

