

## POSITION STATEMENT

### *Use of Genetic Information by Life Insurers in Australia*

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*This document provides factual information and outlines the official position of the Australian Mitochondrial Disease Foundation (AMDF) on the use of genetic information by life insurers in Australia.*

#### **Genetic Discrimination in Life Insurance**

Genetic discrimination refers to “differential treatment of asymptomatic individuals or their relatives on the basis of their actual or presumed genetic characteristics”. The premise of this is that it is unfair to discriminate against people based on their genetic makeup, as this is out of their control. In the context of life insurance, genetic discrimination is where asymptomatic people are refused coverage or are required to pay larger premiums due to possible health risks determined by predictive genetic testing.

#### **Australia**

Under current legislation, consumers have a duty to disclose all relevant information to life insurers and life insurers are permitted to use consumers’ genetic information. Additionally, life insurers who are members of the Financial Services Council (FSC) are obligated to require genetic information from consumers under a mandatory self-regulatory regime. Consumers are required to disclose genetic information only if they are aware of it. Therefore, consumers are not required to disclose such information if they have participated in clinical research anonymously. Recently, life insurers have also been obligated to question whether consumers are considering genetic testing. They are prohibited however from requesting consumers to undertake genetic testing. A consumer’s genetic information can only be used to assess risk associated to them and not that of their family members.

#### **United Kingdom**

In the UK, there is a moratorium on the use of genetic information by life insurers, with the exception of a predictive genetic testing for Huntington’s disease where the claim exceeds \$50,000. Insurers are prohibited from using direct-to-consumer genetic test results or results arising from clinical research. Consumers are allowed to provide genetic information to disprove they are at risk of an inherited condition.

## Canada

Under legislation, life insurers are prohibited from requiring genetic information from consumers and requesting individuals to undergo genetic testing. Insurers are permitted to use family history information. Genetic discrimination may be a criminal offence. However, such Canadian legislation's constitutionality is under scrutiny.

## Parliamentary Inquiry Report into the Life Insurance Industry (March 2018)

The Parliamentary Joint Committee on Corporations and Financial Services in Australia conducted an inquiry into the life insurance industry in March 2018 and refers to use of genetic information. The committee recommends that a minimum 5-year moratorium on the use of genetic information by life insurers be put in place via reform of the FSC's self-regulatory regime, except in cases where consumers are disproving their risk of an inherited condition. The report also detailed recommendation for future legislative change, if the Australian Government and the FSC cannot agree on and abide by a revised co-regulatory regime.

You can read the full Parliamentary Inquiry Report [here](#). See Chapter 9, pages 137 – 156, for relevant details.

## AMDF's Position

AMDF believes that permitted use of genetic information by life insurers in Australia may lead people to forego potentially life-saving genetic testing or participating in clinical research due to fears of genetic discrimination. Additionally, AMDF finds that there is insufficient legislative protection for consumers against genetic discrimination.

AMDF supports the committee's recommendation for a moratorium and reform of the current self-regulatory regime of the FSC, and calls upon the Australian Government to implement these recommendations as a matter of urgency.

AMDF also calls upon the government to implement the committee's recommendation to review the moratorium after a 5-year period and subsequently pass legislation that will permanently ban the use of genetic information by Australian life insurers. AMDF believes that such a ban will protect consumers and also benefit genetic research, which is integral to finding treatments, diagnostic methods, prevention strategies and cures for genetic diseases, such as mitochondrial disease (mito).

For further information regarding AMDF's position please contact Rebecca Davis at [rebecca.davis@amdf.org.au](mailto:rebecca.davis@amdf.org.au) or on (02) 8033 4113.