



**FOR IMMEDIATE RELEASE**

## **Human Genetics Society of Australasia welcomes Government announcement to ban genetic discrimination in life insurance**

The Human Genetics Society of Australasia (HGSA) welcomes the Australian Government's announcement that it will legislate to ban the use of genetic testing in life insurance underwriting.

The phrase 'Genetic testing will not affect your ability to get life insurance' is one genetic health professionals have been wanting to be able to say to people for years. Until now, life insurance companies were able to use the result of an individual's genetic test to decline cover or increase insurance premiums. Every person must be told this when considering a genetic test, and it has historically been a deterrent to people having testing that could otherwise empower them to make important health and life decisions.

Once the announced legislation has been passed, Australians will be able to access genetic testing without the fear of compromising their access to insurance.

The HGSA is the peak body representing scientists, researchers, clinical geneticists, and genetic counsellors working in the field of human genetics in Australia and Aotearoa, New Zealand. HGSA members also include policy makers and educators. The HGSA seeks to ensure that all people have equitable access to excellence in genetic healthcare across their lifespan.

The Government's announcement will dramatically assist with removing barriers to genetic testing and supports the HGSA's vision and mission.

Dr Jane Tiller, and Professor Paul Lacaze from Monash University, have worked tirelessly on this issue for many years. Dr Tiller said "I have been working on this issue since 2016, with many colleagues working on this issue for decades before that. This announcement marks a significant move towards consumer protection and preventive health outcomes."

Dr Jane Tiller is a genetic counsellor, lawyer and public health researcher, and a member of the HGSA. The HGSA congratulates Dr Tiller on the work she has undertaken and the leadership she has demonstrated to create a positive change for Australian people and the field of human genetics.

CEO of HGSA Julia Mansour also welcomes the announcement and the hard work of Dr Tiller and Professor Lacaze, "What Jane has done is shine a light on this issue to drive change. Jane's work in this area has been immense. She undertook systematic and methodical research to identify the extent of the genetic discrimination problem. She also educated the rest of the HGSA membership on the issue to ensure that patients were appropriately informed about the decisions they were making about genetic testing."

Dr Tiller has been tireless in her advocacy, presenting at Parliamentary inquiries, that resulted in a moratorium on the use of genetic test results for life insurance purposes from 2019 for policies up to \$500,000.



While this was an excellent first step, it was undertaken in a self-regulated industry and participation by insurers was voluntary and not enforceable.

Dr Tiller continued her work to get to the heart of the matter and demonstrated that even with the moratorium in place, people were still being refused insurance. Many patients held fears about having genetic testing because of the potential impact on their access to life insurance and, in some cases, their concerns about the impact for other family members.

This is an issue that many felt powerless around, but Dr Tiller's determination, passion and commitment, alongside so many others, has made a real difference, and is especially important as genetic testing is becoming more broadly integrated into health care and medicine. The HGSA will continue to advocate with government to ensure the final legislation includes a total ban on the use of genetic testing for life insurance underwriting (including trauma, disability and income protection insurance), without caps or exceptions.

The HGSA acknowledges that while this is a fantastic outcome for Australians, our colleagues in Aotearoa, New Zealand are still working to achieve similar legislative reform and we hope to support them through this process.

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