SENATE LEGAL AND CONSTITUTIONAL COMMITTEE
INQUIRY INTO THE PRIVACY ACT 1988

Australian Medical Association

Answer to Question taken on notice

On 20 May 2005 Senator Stott Despoja asked of the AMA:

"Are current privacy laws sufficient in relation to newborn screening and testings, specifically Guthrie cards?

I am just wondering what the 'AMA's view is on current consent and privacy provisions in relation to Guthrie cards, newborn screening cards or whatever you call them, depending on what state you are in."

The AMA's response

The AMA has no specific policy on privacy and Guthrie or other newborn screening tests. We are able to provide our comment on the impact of patient privacy to secondary purpose use and disclosure of such tests, for example disclosure to and use by insurance companies.

Guthrie card tests have been around for approximately 40 years. Their purpose was to test primarily for phenylketonuria, hypothyroidism, cystic fibrosis and galactosemia to allow for early and correct treatment. These congenital and genetic diseases are person specific and their misuse pose perhaps only a theoretic risk of invasion of the privacy of other family members.

However, with the expansion of medical genetic testing breaches of others' privacy is now a practical reality. The structure of the *Privacy Act 1988* that permits the use and disclosure of personal (and sensitive) information with the consent of the individual has large potential for the invasion of the privacy of family members, and of others who are presumed to be blood family members.

Consent by an individual to undergo and/or reveal test results can impact on other family members who might be presumed, or are wrongly presumed, to have the same genetic makeup.

There are strong arguments to support the stand that individuals should not be asked to consent to the provision of their genetic information.

Insurance companies already have access to family histories which allow them to put people into broad risk categories. Allowing insurance companies to classify people into even finer categories defeats the purpose of the risk sharing nature of insurance.

Importantly, the potential for genetic information to be used for secondary purposes might influence people to decide not to be tested when it would be to their medical benefit to do so. To ensure that people will get the medical benefit of this type of testing it is necessary to ensure that the insurance industry is not able to use the information for its secondary purposes.

There is a fear that if individuals are required to provide genetic information in order to obtain insurance cover that the information could be misused to the disadvantage of family members.

Wrong assumptions can easily be made about blood relationships. For example, while two siblings might have the same mother, their paternity might not be known. Invasion of others' privacy can occur if an individual is required to undergo DNA testing to prove separate paternity from a family member with a history of a congenital disease.

We trust that these comments are of assistance to the Committee.

Pamela Burton
Legal Counsel

Dr Margaret Chirgwin
Director, Department of Public Health and Ethics

Federal AMA
6 June 2005