



23 May 2005

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ENQUIRIES

Ms Sophie Power
Committee Secretary
Senate Legal and Constitutional Committee
Department of the Senate
Parliament House
Canberra ACT 2600

By Email (Sophie.Power@aph.gov.au)

Dear Ms Power

Inquiry into the *Privacy Act 1988* (Cth) – Question taken on notice

I refer to a question received on notice at the public hearing of the Legal and Constitutional References Committee on 22 April 2005 (Melbourne) in relation to the Inquiry into the *Privacy Act 1988* (Cth).

The question on notice came from Senator Stott Despoja and concerned genetic information and complaints or cases involving genetic discrimination in Victoria.

The Law Institute of Victoria (*LIV*) has consulted both the Office of the Victorian Privacy Commissioner (*VPC*) and Health Services Commissioner and concludes that:

- there are no known or reported cases relating to complaints about the handling of genetic information in Victoria; and
- a number of general inquiries relating to the issue of genetic information have been received by the VPC.

Accordingly, the LIV suggests that there needs to be greater public education and awareness of the privacy laws.

During our consultation with the VPC, we were directed to the New Zealand case of *Auckland Healthcare Service Limited* (Case 99HDC09011).

In this case, the New Zealand Health and Disability Commissioner (*Commissioner*) had to determine whether there had been a breach of consent in relation to the collection of genetic information.

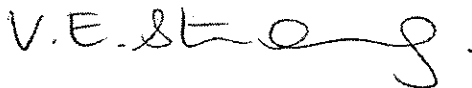
In summary, the Commissioner found that Auckland Healthcare Service adhered to the requirements of consent in collecting the information. The Commissioner also found that there was confusion as to how this information was to be handled, the reasoning behind holding on to it for such a period of time and what was required by the healthcare provider.

While the Auckland Healthcare Service Limited case is not an Australian case, we suggest that similar problems exist in Australia surrounding genetic information. The above case may have been avoided if there was appropriate education and awareness of the legal issues. In particular, how genetic information should be handled, how technology is being used and its purpose. Legal-education kits, such as the Privacy Kit for Diabetes Educators, assist health professionals in the area of diabetes.

Accordingly, the LIV recommends that there is a need for national uniformity in the way in which health information is handled and further public consultation relating to development of new and emerging technologies.

Thank you for the opportunity to provide further comment on this issue.

Yours sincerely

A handwritten signature in black ink, appearing to read "V.E. Strong". The signature is written in a cursive style with a long, sweeping tail on the final letter.

Victoria Strong
President
Law Institute of Victoria