

[REDACTED]
15/04/2008 11:04 AM

To
cc
bcc

Subject Fw: SUBMISSION: Disclosure of Genetic Information
[No Protective Marking]

UNCLASSIFIED



"Leah Lonsdale"
[REDACTED]

14/04/2008 04:27 PM

To [REDACTED]
cc

Subject SUBMISSION: Disclosure of Genetic Information [No
Protective Marking]

Cheryl Cooke
NHMRC
Email: [REDACTED]

14 April 2008

Dear Cheryl,

RE: Disclosure of Genetic Information to a patient's genetic relatives under Section 95AA of the *Privacy Act 1988 (Cth)*: guidelines for health practitioners in the private sector, Consultation Draft 11 February 2008

Thank you for the opportunity to review and comment on this document.

The Genetic Support Network of Victoria (GSNV) is an umbrella organisation which encompasses some 130 genetic support and self-help groups in Victoria and Australia. GSNV has circulated the document widely amongst its membership, encouraging our member groups to review the document and make their own submissions reflecting their unique lived experiences.

Having discussed the draft with several people and group representatives from the GSNV Network, I also submit that:

THE FAMILY BE PROVIDED WITH INFORMATION ABOUT INTERIM SUPPORT/COUNSELLING, IF DESIRED (page 38; 3.3.2)

An individual receiving an unexpected letter "out of the blue" about a genetic condition could become quite distressed about the letter and the possibility of having a genetic condition. It can sometimes take weeks or even months

between the time of making an appointment and attending (where they would receive genetic counselling).

SUBMISSION: interim counselling and support is available for the "window period" between receiving the letter and attending a first appointment (where genetic counselling is available/offered). This could take the form of telephone counselling, peer support, a contact person named on the letter, or a combination of these.

WHERE CONFIDENTIALITY HAS BEEN BREACHED, ADVISE FAMILY MEMBERS THAT THIS IS AN EXTRAORDINARY SITUATION

(page 39; section 3.3.2)

Should family members become aware that they had been contacted without consent of the first individual, trust in that health practitioner by the family may be eroded. This may have ramifications for the family member's healthcare.

To help foster good relationship between the individual and health professional, I submit that the ***family member be advised that confidentiality has been breached due to an extraordinary circumstance, the process for breaching confidentiality and why it was needed,*** Otherwise the family member contacted by letter may be concerned that their own confidentiality may not be respected by the health professional.

PEER SUPPORT FOR PEOPLE GIVEN INFORMATION ABOUT A HERITABLE (GENETIC) CONDITION OR CARRIER STATUS (page 41; section 3.3.5)

The role of genetic support groups is gaining increasing recognition nationally and internationally. As one example, *Genetics in Family Medicine - the Australian Handbook for General Practitioners* states that:

"In addition to support from the GP, Genetics Services and professional counselling, referral to support organisations can be beneficial and, in some cases, necessary for the wellbeing of the patient and/or their family".

"Support groups can be an important source of peer support and empowerment, practical information and advice about living with a genetic condition. Families can benefit from contact with other people in similar situations, regardless of their level of coping or need for support."

"Genetic support groups can be state, national or international, allowing families to appreciate that they are not alone in the challenges they may face living with a particular genetic condition."

To meet this necessary need, I submit that people should be informed about genetic support services in their state/territory.

A list of support agencies are attached (see attachment 1).

Thank you for considering this submission. Please feel free to contact me on [REDACTED]
[REDACTED] or email [REDACTED] if you require further information.

Yours sincerely

Leah Lonsdale
GSNV Coordinator

Leah Lonsdale
Coordinator
Genetic Support Network of Victoria

...Overcoming Genetic Challenges...

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Attachment 1 Genetic_Support_The Australian Handbook for General Practitioners.pdf

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