

To whom it may concern,

I would like to make a submission regarding the draft guidelines for health practitioners in the private sector under the *Privacy Act 1988* (Cth) s 95AA (*Disclosure of genetic information to a patient's genetic relatives*).

Having considered the draft guidelines it is apparent peer support for people given information about a heritable (genetic) condition or carrier status has been inadvertently omitted.

The Commonwealth and medical profession recognises the important role of genetic support networks and peer support for families affected by genetic conditions, which is why genetic support networks are funded across Australia. The *Genetics in Family Medicine – The Australian Handbook for General Practitioners* (refer attached file “*Genetics in Family Medicine_ The Australian Handbook for General Practitioners_Support 2008.pdf*”), highlights this by stating:

“The importance and value in referring to genetics support groups

- *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.*
- *All people who live with a genetic condition (either personally or in their family) should have access to appropriate, up-to-date and accurate information. Additionally, they should have available the necessary support to assist them to manage the challenges to their health and wellbeing and to enable them to reach their full potential.*
- *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.*
- *Genetics 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.”*

Genetic support groups are invaluable for people affected by genetic conditions; whether they have the condition, a predisposition to a genetic condition or are a carrier of a genetic condition. Peer support groups give affected people a place to give and receive both emotional and practical support as well as to exchange information. They provide a vehicle where affected people can share medical

information, get confirmation that their feelings are "normal," educate others, or just let off steam (refer M Randall, *Support Groups: What they are and What They Do*, [2003] GeneticHealth.com).

People with genetic health conditions often become "experts," in that they know a great deal about the medical, social, and emotional aspects of having a particular disease. They may want to connect with others who they can talk to from an "I've been there too" perspective. The importance of these peer experts increase as the number of people affected by the genetic condition decreases; a significant consideration with many genetic conditions.

It is also clear from the article by Kristine K Barlow-Stewart and Clara L Gaff, *Working in partnership with support services in the era of the "new genetics"* (2003) 178 MJA 515, that peer support is one of four vital pillars required to meet the needs of people affected by genetic conditions (refer attached). Without peer support, the full needs of the effected person have not been met, which arguably may constitute a failure to fulfil a health professional's duty of care.

I therefore propose the draft guidelines includes, within it's process, a requirement that information on genetic peer support networks and supports groups as detailed in the Australian Handbook for General Practitioners are provided to the affected person, in addition to a statement on the value of peer support.

Please contact me if you require any additional information.


Sincerely,

Tony

Tony Briffa JP

President, AISSGA

P.O. Box 1089
Altona Meadows VIC 3028
Australia



CAUTION - This message may contain privileged and confidential information intended only for the use of the addressee named above. If you are not the intended recipient of this message, or this message was sent in confidence, you are hereby notified that any use, dissemination, distribution or reproduction of this message is prohibited. If you have received this message in error, please notify Anthony Briffa at tony.briffa@briffa.org immediately.
