27 February 2009

Ms Vesna Cvjeticanin
Director
Evidence Translation Section
National Health and Medical Research Council

Dear Ms Cvjeticanin,

Re: Use and Disclosure of Genetic Information to a Patient’s Genetic Relatives Under s 95AA of the Privacy Act 1988 (Cth) – Guidelines for Health Practitioners in the Private Sector

Thank you for the opportunity to provide feedback on the revised draft NHMRC s95AA Guidelines which have been circulated for targeted stakeholder consultation.

I have reviewed the most recent version of the guidelines and am pleased to advise that the concerns that I had raised in my previous submissions have now been satisfactorily addressed (concerning the scope of the guidelines and related liability issues and how the guidelines should deal with the issue of deliberate non-disclosure by the relevant health practitioner, notwithstanding that grounds for disclosure have been established). I believe the current guidelines are well-balanced and are in appropriate terms for their purpose, and will, in practice, be extremely useful as a guide for practitioners.

I do have a few minor comments and suggestions in respect of the current draft:

Page 12 – bottom of page, in the box ‘Potential benefits of not disclosing’ – I would query the terms of the second dot point –‘potential disruption to patient/doctor relationship’. Shouldn’t this be expressed in terms that a benefit of not disclosing is to avoid such disruption?

Page 26 – Scenario 4 under heading ‘points for consideration’ – first dot point. I would suggest that you avoid the term ‘carrier’ in connection with the condition of Huntington’s disease. The reason for this is that this term often merely indicates the
capacity to pass on a condition in circumstances where the carrier is unaffected, whereas in the case of Huntington's disease, because of its autosomally dominant means of transmission, a genetic test that identifies a person with the mutation is in fact a pre-symptomatic diagnosis, given the virtual inevitability of that person progressing to develop the condition.

Page 31 - Scenario 9 – query whether there may also be cultural considerations around the issue of disease which may account for the indigenous woman’s desire for this information not to be communicated to her family members. If this is the case, reference to respect for cultural considerations could be added to the second dot point under 'points for consideration', under the heading 'What factors weigh against disclosure'.

Thank you again for the opportunity to have input. Please let me know if any of the above requires clarification.

Yours faithfully,

Margaret

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