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Please respond to
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Dear Vesna,

Thank you for inviting MND Australia to comment on the draft guidelines. I have read the guidelines in detail and commend NHMRC on developing these comprehensive guidelines for practitioners in private practice.

The guidelines appear to provide adequate protection for the patient and ample opportunities for them to consider the implications of not informing relatives of their genetic condition. The process for informing relatives also appears to ensure protection and opportunities for support to assist them to proceed with genetic testing or not.

I am concerned however that access to genetic counselling and support is not always readily available and waiting lists are often very long. This leads to unnecessary stress and worry for families waiting for genetic testing.

Private practitioners would need to ensure that genetic counselling is immediately available when informing relatives without the patients permission to reduce stress and further conflict within the family.

One aspect that could be included in the guidelines is the inclusion of providing information to patients regarding disease specific associations.

Associations such as MND Australia are able to provide further disease specific information and support to enable them to make an informed decision regarding disclosure to relatives. See link below re information on predictive testing for people living with MND:

<http://www.alsmndalliance.org/resources/testing.html>

This information should also be available to the families when the nature of the genetic abnormality is divulged to ensure optimal support at this time especially if access to a genetic counsellor is delayed.

I am unclear what guidelines exist for practitioners in the public sector - and whether the guidelines they are required to follow are similar.

Kind regards

Carol

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National MND Conference to be hosted by MND NSW on 23 June 2009 in
Sydney -
email conference@mndnsw.asn.au for further details

"A world free from the impact of MND"