

CMO

From: Mary Holt

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**Conference/Seminar on the Ethical and Social issues Surrounding a
Diagnostic Test for CJD**

Issue

1. In September 2001, you suggested the need for a conference/seminar as a forum to discuss the ethical and social issues that may arise should a diagnostic test for CJD become available.
2. This paper sets out proposals to take arrangements for this conference/seminar forward and requests your agreement to proceed as outlined.

Background

3. Papers written by Dr Nicky Connor and Mr Peter Jones were sent to you which you may recall, suggesting possible topics for a seminar.
4. The CJD Policy Team suggests that these issues would best be debated within a National event.
5. We plan to go ahead with the organisation of an event and it is timely that there is a parallel strand of activity in preparation led by the Blood Borne Viruses – Public Health Unit. This involves the establishment of the MSBT subgroup to consider the preparatory work required prior to the introduction of a blood screening test for CJD. There are similar significant ethical issues surrounding both these areas of work and benefits derived could be usefully shared. The MSBT vCJD Subgroup will meet on 17 February 2003.
6. The MSBT vCJD Subgroup will :

- (i) Prepare for the introduction of a blood screening test for vCJD, bearing in mind the criticism of the NBS for apparently not preparing for the introduction of a screening test for HCV
- (ii) Look at research in progress in relation to diagnostic tests and
- (iii) Examine the CPHL role in evaluating any tests, now and in the future, and the impact of the European IVD Directive
- (iv) Consider the ethical issues arising from the need to acquire samples for test development and evaluation

Conference/Seminar

7. The proposed seminar will focus on the ethical and social issues associated with both screening and diagnostic tests for CJD and the intention is to take this work forward within a forum of relevant stakeholders, in particular, those representing the consumer. Topics will include:
 - (i) Implications for public health in reducing risk of transmission and for the NHS in terms of potential disadvantage through loss of blood donors
 - (ii) Looking at the background information on tests currently in development and on therapeutic developments
 - (iii) Discussion of practical arrangements such as who should be offered the test and how should it be delivered
 - (iv) Examination of the implications of a test for an individual
8. Our initial discussions have led us to the conclusion that an event for around a hundred delegates would be the right size to ensure the capacity to ensure that the appropriate interests could be represented without the disadvantage of being too large.
9. A number of Central London venues are being considered for possible dates in Summer 2003
10. Two potential Chairs have been suggested to us:
 - (1) Professor Alastair Campbell, Professor of Ethics in Medicine, Centre for Ethics in Medicine, University of Bristol who is Vice Chair of the Retained Organs Commission and was a member of the DH Surrogacy Review Team in 1997.
 - (2) Professor Robin Gill, Professor of Modern Theology, University of Kent at Canterbury who is a leading Anglican theologian and prolific author whose publications include A Textbook of Christian Ethics, Moral Leadership in a Post-modern Age and Euthanasia and the Churches. He is a member of a number of MRC committees including the Stem Cell Banking Steering Committee.

Do you agree or would you like to suggest other individuals?

- (i) Are you content for the CJD Policy Team to continue with the planning process for this event?
- (ii) Would you like to be involved as a key speaker or to introduce the event on behalf of the Department or would you like to suggest another senior figure?

11. If you are content for the CJD Policy Team to continue, we will proceed to convene a small steering group to assist us to plan the event and with the delegate list.

Mary Holt
CJD Policy Team

GRO-C