

NOTES OF A MEETING HELD AT THE ROYAL COLLEGE OF PHYSICIANS OF
EDINBURGH ON 9TH MAY 1996 TO DISCUSS THE POSSIBLE IMPLICATIONS
OF A LIKELY NEW VARIANT OF CREUTZFELD-JACOB DISEASE FOR UK
TRANSFUSION SERVICES

The meeting was organised by Dr Angela Robinson and Professor John Cash following reports from the CJD surveillance unit in Edinburgh of a new variant of CJD disease, possibly related to BSE. Dr James Ironside of the CJD surveillance unit was present.

Attendees	Dr Angela Robinson	Dr Jack Gillon
	Professor John Cash	Dr Virge James Dr Philip Mortimer
	Dr John Barbara	Dr Philip Minor
	Mr Martin Bruce	Dr Philip Mortimer
	Dr Brian Dow	Dr Terry Snape
	Dr Peter Flanagan	Professor Richard Tedder
	Dr Eddie Follett	Dr Bill Wagstaff
	Dr Peter Foster	Dr Pen Lee Yap

The initial part of the meeting comprised a presentation by Dr Ironside on the 10 reported cases of variant CJD and an outline of our current understanding of prion disease. The details of the newly identified variant are contained in the Lancet volume 347 pages 921-925 (1996). This was followed by a question and answer session. It was apparent that information in relation to the natural history of BSE and its potential transmissibility by blood, especially in the context of transfusion, is very limited. This was seen as a major concern and it was felt that urgent action should be taken to correct this deficiency. The absence of information severely restricts our ability to provide definitive reassurance that the new variant form of CJD does not pose a threat to the Blood supply.

→ 4 more in the wings + 1 in France.

The group then considered the possible implications for Transfusion services of the identification of the variant form of CJD. It was agreed that the possibility that this disease could be transmitted by transfusion of blood and its products could not be excluded on the basis of currently available information. It was also agreed that until further evidence was available it should be assumed that the newly described syndrome is a new disease and that it was inappropriate to assume that this will behave in a manner analogous to classical CJD. In view of this it was decided to consider the mechanisms whereby the potential impact of the variant on the safety of the Blood supply could be minimised.

The following points were agreed by the group.

1. **UK Transfusion services should take urgent action to ensure that current European Directives in this area are followed, in particular that direct questioning of donors in relation to a family history of CJD disease should now be instituted.**

Action: SAC on donors to formulate recommendations by which direct questioning of donors can be implemented, to include consideration of staff briefing, definition of family members, counselling of excluded donors and allied issues. These will be forwarded to the Chairman of the UKBTS/NIBSC executive for his endorsement prior to implementation.

(? Gimpark) Direct antecedents

- Parents, children + siblings

2. It was agreed that it was inappropriate to consider extending current donor selection guidelines beyond the regulatory requirements until the position became clearer.

We don't know anything about infectivity by

Work on assumption it can transmit

*transfusion /
highly
cont.*

3. It was agreed that action should be taken to improve our current knowledge in relation to the potential for CJD to be transmitted by blood transfusion, and that knowledge would need to be acquired in relation to both the classical and variant form of the disease.

*Is it a potential threat to the blood supply or not? - Weybridge.
Try & define the extent of the risk. (Ray Bradley - explain)*

Action: SACTTI will develop a series of questions relating to the natural history and transmissibility of BSE in cattle that will assist improving our understanding of the potential hazard to the blood supply. These will be forwarded to the DoH via MSBT. The absence of specific information in this area was seen to be a particular concern and it was felt that the DoH should recognise the importance of this type of information being obtained.

*1. Strain
What's passed
? vs. cut
transmission*

*injecting
BSE can
brain into
muscle via
to other countries
Knowledge poor
particularly in the
of transmissibility*

Action: Dr Eddie Follett undertook to identify any blood samples that may be available from the reported 10 cases of the variant. These should be stored in anticipation of the development of possible screening tests.

4. It was agreed that it is essential to ensure that accurate information is obtained to identify whether identified CJD patients have ever donated blood, and that this would require information to be provided to Transfusion Services to enable interrogation of donor databases.

Action: Dr Angela Robinson to raise this issue at MSBT.

5. It was agreed that there is a need to consider what action should be taken when a new case of CJD is identified in a current, or lapsed, donor, and that the feasibility of introducing a form of lookback being instituted to assist in identifying the transmissibility of this agent by blood needs to be assessed. The group recognised that the transmission characteristics of the classical and variant forms may differ. It was felt important that information should be accumulated on both forms of the disease.

Action: This will require careful consideration involving relevant experts to enable recommendations to be developed for submission to MSBT.

6. It was agreed that there is a requirement to investigate systematically whether reported cases of CJD have received transfusions of blood or blood products. This may require the initiation of carefully structured case control studies.

Action: An active collaboration with the CJD surveillance unit will need to be developed.

7. It was agreed that there is a need to consider the position that plasma fractionators should take following notification by Blood Centres of donors who have been rejected on the basis of CJD related exclusions. It was noted that the level of BSE in the UK is significantly higher within the UK than in other countries and that it may thus be appropriate to be pro-active in this area.

Action: Dr Terry Snape to raise this issue at the MSBT.

8. It was agreed to consider the feasibility of introducing measures to reduce the impact of donor notifications to plasma fractionators, in particular the implications of quarantining of source plasma or changes in the management of plasma from different pool sources.

Action: BPL and PFC will review the current position, possibly in the context of the CPMP Biotechnology Group.

9. The possibility and potential benefits of reconsidering quarantining of frozen blood components was considered.

Action: It was agreed that further information on the natural history of variant CJD would be required before this aspect could be properly assessed.

Peter Flanagan 12th April 1996.

need a briefing for SEAC Prof. John Pattison
Infectious studies
+ a search by Philip Hunter.

? if significant PTH risk.
? Leuco-depletion could be a means of
preventing transf. transmission if infective agent carried
in lymphocytes.