TMER MEETING
MONDAY 12TH SEPTEMBER 2005

CJD SURVEILLANCE UNIT, EDINBURGH

Present: Professor R Will
Dr C Llewelyn
Ms M Malfroy
Miss J Mackenzie

Apologies: Dr P Hewitt

1. **vCJD donor notification and possible further lookback: update from CJD IP meeting on 7th Sept 05.**

The reverse TMER donor notification exercise was initiated by UKBS on 20th July 2005 to inform 110 donors considered at risk by the CIP. These donors, who donated to 3 vCJD cases, have all been traced. These donors are being contacted and asked not to donate blood, organs or tissue. The CIP has also considered whether to notify other recipients who received blood from these donors. It has been decided to notify the recipients of 7 donors who gave blood to 2 vCJD cases, provided that there is evidence in the medical record that the blood component was transfused to that recipient. A decision about notification of the recipients who received blood from the 103 who gave blood to the liver transplant case has been delayed until more information is available from further risk assessment work.

2. **Confirmation of diagnosis of vCJD**

Dr Hewitt wished to clarify the role of tonsil biopsy in the diagnostic criteria, in relation to the Irish case who had a positive tonsil biopsy The tonsil biopsy is currently included in the diagnostic criteria and, along with relevant clinical features, a positive tonsil biopsy result can be used to classify a case as "probable" vCJD. Brain biopsy is still required to enable a classification of "confirmed" vCJD. Tonsil biopsy is not recommended as a routine investigation. If, hypothetically, tonsil tissue on a deceased recipient was positive, one would still need to look at the clinical features before deciding this

could be a case of "probable" vCJD. In relation to diagnostic criteria, Professor Will reported on a recent EEG finding in an Italian case of vCJD. The current diagnostic criteria for vCJD excludes cases where the EEG is typical for CJD (triphasic periodic complexes). Normally after a diagnosis of vCJD is made it is unusual to have further tests such as EEG repeated. However experience from some other countries is different and in the Italian case, serial EEGs were done after the diagnosis of vCJD was made. Towards the end of the patient's illness the EEG became typical (as seen in sporadic CJD). The Japanese also experienced this with their case. It may be that a footnote will be added to the diagnostic criteria indicating that in the late stages of the illness periodic complexes may be seen on EEG. **(Please note the above information is confidential).**

3. **Problems with wording of recent press release on reverse TMER**

Charlotte Llewelyn reported that a recent update containing information on the reverse TMER notification exercise circulated internally to all staff within the NBS (using wording approved by DH and the CIP included the sentence "To date there have been only four possible cases of vCJD being transmitted by blood." This is misleading taken out of context of the reverse TMER, and PEH had corrected the wording on a different document which was used to produce the briefing. The four cases comprise the index case, in which donor and recipient both had vCJD, and the three vCJD cases whose donors are currently being traced and notified (see 1. above) Professor Will thought this may have arisen because of a risk assessment undertaken by Peter Bennett where he suggests that vCJD infection the latter three cases could have been transmitted from their blood transfusion rather than from BSE-contaminated food. However since all the donors for 2 of the cases are still alive more than 10 years after transfusion to the vCJD case without appearing on the NCJDSU register, it becomes increasingly unlikely that this is the case.

4. **Deceased recipients – update**

Approval has been received from the Department of Health to start requesting notes and any tissue samples on the deceased recipients of vCJD blood. A letter was sent out to all the hospitals of these deceased recipients on 5th September. So far, there has been word from 2 hospitals that the notes have been destroyed and from a further 2 hospitals asking for

consent from the next of kin before releasing the notes. In an additional 2 cases the notes have already arrived at the CJD Unit. In relation to the issue of consent, Professor Will is reluctant to start getting in touch with the relatives of these individuals at this stage. An alternative will be to ask the Department of Health if they could provide a letter of authorisation for us to have access to the notes. Professor Will will contact Department of Health to request this.

ACTION: RGW

When we have obtained GP details for these individuals, a letter will also be sent out to the GPs requesting GP notes. Copies of both these letters should be sent to Dr Hewitt for information.

ACTION: JM

5. **Paper for Vox Sanguinis**

A 3rd version, updated by Dr Hewitt, was circulated before the meeting. A decision had to be made whether the paper would just concentrate on vCJD cases (main and reverse results) or whether to include the case-control data also. After discussion the following was decided:

- update on direct vCJD
- inclusion of reverse vCJD data
- data on sporadic and familial, direct and reverse

It was decided not to include vCJD control data as the controls we currently have data on are hospital controls which are not ideal as this may introduce bias. There have been 3 other methods of recruiting variant controls since then. These are GP controls (3 controls to one vCJD case), NATCEN (one off collection of control data) and relative nominated controls. Jan Mackenzie will send further vCJD control data from GP or relative nominated controls to Charlotte.

ACTION: JM

It was decided that the next step would be for Jan Mackenzie to update the figures in the text, the tables and add a couple of new figures. Charlotte Llewelyn could then check these figures with her data.Note: some of the sporadic cases have been reclassified as familial on further investigation. JM to send updated disc to CL to amned TMER database.

ACTION: JM/CL

Professor Will can then write the discussion.

ACTION: RGW

6. ANY OTHER BUSINESS

- Because we are now sharing information with the HPA and CIP, it is important that we all use the unique TMER id nos as assigned by CL on the TMER database to identify vCJD cases, reverse donors, recipients respectively . The data is kept by Charlotte Llewelyn as 3 distinct groups with their own unique id numbers. However each group has an id numbering system of 1 onwards so there is the potential for 3 people (one from each group) to have the same id number. As such, it is important to distinguish whether we are discussing cases, recipients or donors in correspondence between the different organisations. As such the id number should be quoted as follows: eg TMER106 (for cases), D106 (for donors) or R106 (for recipients). In a couple of instances there will be a case who falls into more than one group and in such cases both identifiers should be used, eg TMER463 (R63) It may also be useful to add the initials in any email correspondence for clarification (this currently occurs in correspondence with Kate Soldan).

  Professor Will will write to Kate Soldan, and Helen Janceck at Dept of Health and copy to Pat Hewitt, Charlotte Llewelyn and Moira Malfroy.

  ACTION: RGW

- Professor Will reported that Dr Azra Ghani has written a paper on the effect of blood transfusion on predictions of numbers of vCJD cases. When this paper has been accepted, Professor Will will circulate.

  ACTION: RGW

- We are now notifiying all blood centres of newly identified vCJD cases. It has been suggested that we should send details of all previous vCJD cases to all blood centres. Professor Will has written to Professor L Davies on this matter and a reply is awaited. Professor Will will write again to remind her.

  ACTION: RGW

- Funding – funding is secure until 2007 and we will not need to do anything about this until next year.

- Professor Will felt it would be useful to have information on the French vCJD blood donors as they are carrying out a similar study to the TMER and it may be useful to set up a meeting between them and us. Professor Will will speak to Dr J-P Brandel in the first instance.

ACTION: RGW

7. **NEXT MEETING**

The next meeting will be planned for early next year (February 2006). Dawn Mills to liaise with all over dates.