# SACTTI meeting

## Wednesday 21st January 1998

### CJD Issues

**1. Notification of blood donors who subsequently developed CJD.**

Kate Soldan ... ensure system works in office

The Departments of Health have asked Dr. Bob Will (National CJD Surveillance Unit) to notify the relevant National Medical Director of the Blood Transfusion Service of all variant CJD cases. The National Medical Directors should then ensure that the necessary action is taken with respect to any plasma which may have been included in fractionated blood products. This instruction relates only to variant CJD cases, and is necessary because of the need to withdraw plasma products.

need a Procedural Protocol can we have for notification S.O.P. in my office for authorship copy subject to Pat Hewitt.

The individual UK Transfusion Services are setting up protocols for action to be taken on notification of a vCJD case. Currently, the CJD Surveillance Unit is also notifying suspect vCJD cases, and these are being logged in the same manner, but no action is taken with respect to notification of the fractionator until the case becomes "probable" or "confirmed". Currently, notification from the National CJD Surveillance Centre may come in the form of a letter, a fax, or a telephone call. It would be of considerable advantage if the UK Transfusion Services could agree a preferred method of notification, possibly with a common notification form, that the National CJD Surveillance Unit could use in such cases.

2. Cases of classical CJD are not currently notified, since there is no requirement to take any action with respect to any blood products manufactured from the plasma from such donors. The donors are, however, included in the Transfusion Medicine Epidemiology Review, but are blinded to the Transfusion Services by the inclusion of control subjects. One database has been created to contain the information relating to the Transfusion Medicine Epidemiology Review (TMER) which summarises the information provided from the National CJD Surveillance Unit and the information on the fate of any donations made by such individuals. The information on recipients will be fed back to the National CJD Surveillance Unit, as proposed in the original ethical committee proposal.

As there is currently no collation of the information relating to donations from vCJD cases, it has been proposed that the database set up for the TMER could be utilised to collate the UK data on vCJD donors and the fate of their donations. Would SACTTI support the advisability of having

collation of the information within the UK Blood Transfusion Services? It does not seem sensible that the only central point where this information is held is outside the Transfusion Services (at the CJD Surveillance Unit).

## 3. Investigation of transfusion history in confirmed CJD cases

The joint submission by the National CJD Surveillance Unit and the UK Blood Transfusion Services to the Ethics Committee of the Lothian Health Board proposed a two way limited CJD look-back study. The two arms of the study were as follows:

3.1. Notification of a case of CJD to the National Surveillance Unit would trigger an investigation of the donation record relating to the CJD case, identification of the recipients of the blood components, and notification of that information back to the CJD Surveillance Unit. This arm of the study is well under way.

3.2. The second arm was the reverse. This related to CJD cases with a history of blood transfusion, notification of the patient details to the Transfusion Services, and identification of the relevant donor records, with transmission of donor identifiers to the CJD Surveillance Unit. This arm of the study has not been pursued.

Initially, it was felt that the forward arm of the study would be the easier to implement, and the more likely to produce results (i.e. the identification of named recipients). This was on the basis of the HCV look-back programme, where hospitals were able to identify names of recipients with relative ease, through hospital blood transfusion laboratory records, although further information required from medical records was much more problematical.

When the full data from the CJD Surveillance Unit was received within the Transfusion Services, it was clear that much of it related to donations and transfusions given in the 1970s and 1980s. The forward arm of the study has confirmed what has been already apparent from the HCV look-back, but information prior to the mid 1980s is difficult to retrieve either at the Transfusion Centre or the Hospitals. Nevertheless, the availability of computerised transfusion laboratory records from the mid 1980s, and the retention in many areas of well documented manual records within the laboratories have enabled a large proportion of information to be retrieved.

The situation with regard to recipients of blood transfusions is much more problematical. There is no doubt that, with computerised laboratory records, it is a relatively simple task to retrieve transfusion information. For information pre-dating computer records, most hospital transfusion laboratories would either have a card index system, filed alphabetically by recipient name, or would hold the relevant information in their laboratory cross-match and day book records. I have spoken to a small number of

our local hospital laboratories, and have ascertained that the information should be available, for at least 11 years and in many cases back to the late 1970s. Although it is a relatively time consuming procedure, most hospitals would have only a single number of recipients (and probably none or one), which would make the work manageable.

Could SACTTI please advise whether the reverse arm of the study should now proceed, and if so how this is best approached with the hospitals?

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