CJD INCIDENTS PANEL

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Date DRAFT

Dear Dr

Incident reference PI 07.

CJD type: Confirmed Variant CJD.

Reported procedure: Appendicectomy

Thank you for your attending the Panel sub-group meeting that discussed this incident on 21st April 2004. The CJD Incidents Panel have agreed the following advice that given in the sub group meeting.

Incident background

This incident involved an appendicectomy carried out the index patient in 1995. The patient died of confirmed variant CJD in 1998.

The abdominal set of instruments used for the appendicectomy has been identified and traced.

The Trust involved were advised by the Department of Health (prior to the establishment of the CJD Incidents Panel) to hold a list of the next ten patients who were operated on with the implicated set of instruments.

You have sought Panel advice on the following questions:

- Should the patients who were subsequently operated on with the instrument set in question be contacted?
- Should the National Blood Service be informed of the incident, without contacting the patients concerned, given considerable concerns about conveying information which might cause extreme anxiety over many years?

Panel Advice

The Panel commends the Trust on having an instrument tracking system in place that enabled the identification and withdrawal from use of the implicated instrument set (following around 80 decontamination and sterilisation cycles).

Should the patients who were subsequently operated on with the instrument set in question be contacted?

The CJD Incidents Panel advises on the basis that in variant CJD significant infectivity exists in the central nervous system, olfactory epithelium, eye and peripheral lymphoid tissue. Tissues of concern include the tonsil, appendix, lymph nodes, spleen, thymus, adrenal gland and rectum.

In order to protect public health, the **next 2 patients** exposed to the implicated tray of instruments used for the appendicectomy on the index patient should be informed of their possible exposure, and advised to take precautions to minimize the risk of onward transmission.

The patients should be advised not to donate blood or organs. They should also inform medical staff of their exposure should they undergo invasive medical procedures in the future.

Healthcare professionals who are carrying out invasive medical procedures will need to know about their patients' exposure status. The patients should be managed as 'at risk of CJD' as described in the ACDP Working Group on TSE's 2003 guidance 'Transmissible Spongiform Encephalopathies: safe working and the prevention of infection. Department of Health 2003'. This is available on line at http://www.advisorybodies.doh.gov.uk/acdp/tseguidance/Index.htm.

Staff directly involved in further invasive procedures on these patients should be aware of the recommended infection control precautions, and should ensure that preparations for any future medical procedures are undertaken in conjunction with the Infection Control Team and the Sterile Services Department.

Dental procedures are low risk, provided decontamination procedures are satisfactory. Dentists may be informed about their patients' 'at risk' status in case they refer them for more invasive procedures that could involve the trigeminal ganglia. Other doctors who care for the patient may need to be aware of the 'at risk' status to help them assess any clinical signs and symptoms.

The Panel is aware that providing this information to individuals requires careful consideration and preparation, including arrangements for counselling. The Department of Health has asked the Health Protection Agency (HPA) to support Trusts that are informing patients of their potential exposure. The HPA is developing a toolkit for this purpose. The HPA will also provide a gateway to expert support for local counsellors and clinicians. If you would like further information, please contact Dr Nicky Connor at the CJD Team at CDSC on GRO-C Ext GRO-C.

The remaining 8 patients on the list currently retained by the Trust, on the advice of the Department of Health, do not need to be informed. Please ensure that all information relevant to this incident is retained locally in case new evidence leads to a

re-evaluation of the risks of surgical transmission of CJD, or in case a research database of possibly exposed persons is established.

Should the National Blood Service be informed of the incident, without contacting the patients concerned?

Both the CJD Incidents Panel and the National Blood Service believe that it is ethically unsound to discard blood donated by 'at risk' patients without informing them.

Further information:

Please do not hesitate to contact me if you would like to discuss this further,

Yours sincerely,

Professor Don Jeffries

Acting Chairman, CJD Incidents Panel

Cc Dr