



To: Professor Liam Donaldson From: Alan Harvey
Date: 5 October 2001

cc: Dr Pat Troop
Dr Mary O'Mahony PH6
Mr Rob Beasley COMMs
Dr Ailsa Wight PH6.2A
Dr Vicki King PH6.6
Dr Philippa Edwards PH6.2B
Dr Nicky Connor PH6.2B
Mr Peter Jones PH6.2B
Miss Carole Fry NUR
Mr Charles Lister PH6.6
Dr Martin Donaghy SEHD
Dr Michael Simmons NAW
Dr Elizabeth Mitchell DHSSPS(NI)
Mr Phil Walker IPU
Ms Helen Wiggins HSD7

CJD INCIDENTS PANEL: CJD EXPERT SUPPORT FOR LOCAL INCIDENT TEAMS

Issue

- 1 Support for clinicians providing information and advice to patients who have been put at possible risk of CJD from medical interventions.

Individuals who must be contacted

- 2 The CJD Incident Panel provides advice on follow-up action to CJD incidents, including those involving blood donated by individuals who go on to develop CJD. You are aware the Panel has put together a framework of guidance document that will go out to consultation on 10 October (the subject of a separate submission).
- 3 You are also aware the Panel is proposing that those individuals identified as possibly at the most risk should be informed straightaway, in advance of the results of the consultation, in order to protect public health (the 'contactable' group). Ministers have accepted this. Contacting such individuals would therefore occur in advance of the conclusion of the consultation exercise. There are none currently identified as being in this group arising from surgical exposure. However the group does include certain individuals possibly exposed as a result of a potentially contaminated blood donation that has already been identified and on which Panel advice has been sought. Clearly the approach should involve the utmost sensitivity in handling. Mindful of this, the Panel is keen to ensure satisfactory counselling arrangements are in place for these and any 'contactable' individuals identified in future.

Proposed way ahead

- 4 Whilst the prime responsibility for informing patients will fall to the clinicians already involved in the patients' care and the local incident management team, these people may not have the depth of understanding of CJD that is required.
- 5 We therefore propose setting up a mechanism for supporting effective counselling by local teams through enlisting the co-operation of:-
 - i. the London Prion Unit who have provided assistance in the past, and have a vCJD counselling expertise;
 - ii. the National Creutzfeldt-Jakob Disease Surveillance Unit, who have similar experience and expertise;
 - iii. the PHLS, who through Noel Gill have been heavily involved in the Panel's work and the management of CJD Incidents.
- 6 We met haemophiliac and other patient groups last week to explain the proposed approach and they appear to accept the position (we are currently liaising over implementation detail). There is no doubt they would welcome having additional counselling arrangements put in place as described, as would the CJD Incidents Panel.

Recommendation

- 7 You are invited to agree the proposal described in paras 4 and 5. The drafts of the letters to take this forward are attached for your consideration.
- 8 The key elements of this submission were agreed with Pat Troop a little while ago.

Alan Harvey
CJD Team
Room 634B SKH