

POLICY - RESTRICTED

1. Dr Harvey PS/CMO
2. Miss Burnett PS/PS(L)

From: Charles Lister HEF(A)10  
Date: July 1994

cc: Ms O'Brien PS/M(H)  
Mr Hollebbon PS/PS(H)  
Mr Heppell HSSG  
Dr Metters DCMO  
Ms Christoperson ID  
Mr Bridges HEF(A)  
Dr Jones HEF(M)  
Dr Skinner HEF(M) 1  
Dr McGovern HEF(M) 1  
Mr Cunningham HEF(A) 8-11  
Mrs Gordon-Brown HEF(A) 10  
Ms Kinghorn ID  
Dr Skinner SO  
Ms Liz Jones WO  
Mr T Robinson DHSS NI  
Mr Eddy MAFF

**CREUTZFELDT-JAKOB DISEASE: 3RD ANNUAL REPORT OF THE UK SURVEILLANCE UNIT**

**Purpose**

1. This submission, which has been agreed with colleagues in HEF(M), alerts PS(L) to the contents of the forthcoming annual report of the CJD Surveillance Unit and presents options for publication. ✓ It also highlights concern over the presentation of results which could be misrepresented by the media and others as evidence of a link between CJD and the consumption of veal. ✓

**Recommendation**

2. PS(L) is invited to agree the recommendation at para 13. ✓

**Background**

3. The Unit, which is funded by DH and the Scottish Office, was set up in May 1990 to look for any clinical or epidemiological changes in CJD since the emergence of BSE. The Director is Dr R G Will, a consultant neurologist who is also deputy chairman of the Spongiform Encephalopathy Advisory Committee (SEAC). ✓

4. The epidemiological component of Dr Will's study looks at the incidence of CJD, its geographical distribution, and the occupational and dietary histories of CJD sufferers. ✓

5. The Unit has produced annual reports since 1992. These have been 'published' by placing a copy in the Commons library and announcing the results in an inspired PQ. In previous years, publication has been achieved prior to the Summer Recess. This year, with an increasing amount of data to be analysed, this has not proved possible. A first draft of the 1994 report is currently with officials.

6. Much of the 1994 report is unexceptional and confirms our existing knowledge of the epidemiology of CJD. The reported incidence of CJD fluctuates from year to year ; in 1993, for example, the incidence was lower than in 1992. We believe these fluctuations are due to random variations in the true incidence of the disease and changes in the rate of detection or reporting. There is no convincing evidence of a true increase in the incidence of CJD. There is no evidence of any change in geographical distribution of CJD since the advent of BSE nor is there any evidence for clusters of CJD (in space or time). Also there was no relationship between particular occupations (eg those involving exposure to cattle) and an increased risk of CJD. The problems arise in the case-control study on dietary exposure. x x

#### Problem

7. The main findings in the case-control study were statistically significant associations between consumption of veal or venison and the development of CJD (increased risks of 2-13X). There was also evidence of a dose-response relationship between dietary exposure and development of the disease. (Last year's findings showed an apparent association between eating black pudding and risk of CJD which was neither statistically significant nor biologically plausible - interestingly, this has not been replicated in this year's results.) <sup>repeated</sup> This year's findings show a number of associations but the strongest is for veal.

This is of considerable concern given recent developments. In particular Ministers will be particularly concerned about the European dimension given the recent troubles with the Germans.

9. DH doctors advise - and we understand Dr Wills agrees - that the association the study found between the developments of CJD and veal consumption cannot be regarded as demonstrating a causal relationship or give any reason to change the advice that eating beef and veal is safe. If PS(L) wishes to probe this further we think it best to explain the matter verbally. The problem is how to present the findings in this year's annual report in a way which avoids unnecessary public alarm and limits the scope for media scare stories.

#### Next Steps

10. The following action has been taken:

- we have written to Dr Will raising a number of questions about the findings and their presentation, and will be meeting him in early August to consider the draft report in more detail.

- SEAC will be asked to consider the significance of the dietary findings at their next meeting on 30 August and to agree a statement which can be quoted on publication of the annual report. The Chairman, Dr Tyrrell, has agreed to co-opt an expert medical epidemiologist onto the Committee for this item.

*For completeness PS(L) should know that*

11. SEAC are producing their own review of current knowledge and research on transmissible spongiform encephalopathies, particularly BSE and CJD. We hope that this can be finalised on 30 August, in which case it might be possible to publish in October. The SEAC review does not refer to the CJD Unit's latest findings on diet, which would not in any case be appropriate to this rather more broad-based survey. It is long and detailed,

and is unlikely to be read by many non-specialists.)

#### Publication of the CJD Report

12. PS(L) is invited to consider the following options for publication:

i. a DH publication issued in September with a DH press release containing SEAC's statement. An early publication date runs less risk of leaks and gives us control of timing. It could be accompanied by an informal press briefing given by officials. It breaks the practice over the past two years of publishing the report through Parliament, but we have made no undertaking to publish in this way.

ii. Option (i) with an HMSO publication. No advantages over Option (i) but would raise the profile of the report unnecessarily and would take longer to organise.

iii. publication through Parliament after recess with an inspired PQ containing SEAC's statement. This would continue the practice of the past two years and allow MPs an immediate opportunity to raise questions. However, it would mean extra delay and the risk, if the report were to leak, of accusations that the Government is suppressing unpalatable information.

iv. publication timed to coincide with the SEAC report. Due to the technical nature of the SEAC report, this option is unlikely to help presentationally with the general public and the media, although we could refer to it in the press statement/PQ reply. Even so, it will be of secondary importance compared with the statement SEAC will be asked to draw up on 30 August. The timing of the publication of the SEAC report will depend on how satisfied members are with the current draft. At the most optimistic, it could be published in October and could fit in with Option (iii). However, a delay beyond October would rule this option out

**Conclusion**

13. PS(L) is invited to select Option (i). This will enable us to publish as soon as we have the final report and SEAC's statement and to manage the presentation of the data in as controlled a way as possible. But PS(L) should not that it is possible that after the SEAC meeting Dr Will may decide that further work is needed prior to publication, and this might take us nearer to October.

14. If PS(L) would prefer to continue the practice of presenting the report to Parliament (Option (iii)) we recommend that to minimise delay this is done through the House of Lords immediately after recess. X

**Line To Take**

15. In case information about the CJD report leaks before the SEAC meeting, the following line to take is recommended:

"We have seen an early draft of this report which contains very provisional conclusions. Nothing in it changes our previous advice that beef and veal are safe to eat. However, we have asked the Government's expert advisory committee (SEAC), chaired by Dr Tyrrell to consider, the findings and advise on any possible public health implications.

**IF PRESSED**

"These are provisional findings from a very small study of patients and are of doubtful clinical significance. We are awaiting a final draft of the report which SEAC will consider prior to publication.

Charles Lister  
642B Skipton House  
Ext 25053