PS/Minister of State

Copy to: PS/Secretary of State
PS/Lord Lindsay
PS/US of S
PS/DoH
PS/AEFD
CMO
Mrs Munro
Director InD
Mr Major InD
Mr Warner

CREUTZFELDT-JAKOB (CJD) DISEASE IN YOUNG PEOPLE

1. This submission informs the Minister of letters to be published in this weekend's Lancet giving information about two cases of sporadic CJD in teenagers in the UK. One of these cases will be made public for the first time.

Background

2. Sporadic CJD normally occurs in people in their 50s and 60s, although it can occur more rarely in younger age groups. Until this year, the youngest case of sporadic CJD in the UK had been in a 34 year old. Other countries, however, have reported sporadic CJD in teenagers. Those we know about are:

- in the USA, a 16 year old in 1978;
- in France, a 19 year old in 1982;
- in Canada, a 14 year old of UK origin in 1988;
- in Poland, cases in people aged 19, 23 and 27 were identified in a retrospective study (published 1991), having been originally misdiagnosed with a viral encephalitis;
- Creutzfeldt's first patient in 1920 was aged 23.

3. The two UK cases (they are not in Scotland) of sporadic CJD in teenagers - the first in this country - will be reported in tomorrow's edition of the Lancet. The cases are:

- a 16 year old female, born in the UK of Turkish-Cypriot parents. She is still alive, CJD having been confirmed by a brain biopsy. This case has not previously been made public;
4. The CJD Unit are also investigating a confirmed case of CJD in a 29 year old.
   The patient is still alive, and the diagnosis has again been confirmed by brain biopsy. This case is not yet public. There is also a probable case of CJD in a 38 year old woman - which is still young for CJD - which has attracted media attention.

Consideration of the Cases by the Spongiform Encephalopathy Advisory Committee (SEAC)

5. The SEAC have considered the two cases and have agreed the following statement, which DH will issue in response to media enquiries:

   "We note that two cases of CJD have been diagnosed in adolescents in the UK. It is not possible to draw any conclusions from this, as confirmed cases of CJD have been found in the same age group in other countries. In addition, the two cases had no exposure to risk factors for CJD and no contact with BSE. It is essential, however, to study the patients in great detail and consider whether there are any implications for the cause or management of the disease."

InD are content with the proposed response.

Conclusion

6. The Minister is invited to note the publication of these case reports in The Lancet and the line agreed by the SEAC.

J T BROWN
27 October 1995

PHPU1
Room 16
AH
Ext 2192