

(214)

Ref: CJD6jul

Ms McDonagh ID From: Dr H Pickles

Med ISD/3

Date: 6 July 1990

Copy: Mr Murray
Dr Harper
Mr Noterman

CREUTZFELDT JAKOB (CJD) UNDERDIAGNOSIS

You asked for comment for News at One on today's Lancet article that claims CJD is widely underdiagnosed. They quote from Dr G R Roberts (not a medical doctor) of St Mary's. I have seen the evidence he submitted to the select committee.

The points to make are.

- (1) None of this is directly relevant to BSE.
- (2) On the question of whether classical CJD is being adequately diagnosed, and the number of cases that are occurring, refer people to Dr Will's evidence to the select committee. CMO has also stated he believes Dr Robert's calculations are incorrect. Basically Dr Roberts has extrapolated from biased data and assumed that those demented cases that come to postmortem are typical of all cases. Dr Will points this out and also refers to careful analysis of postmortems of people diagnosed as Alzheimers and that only one in 925 patients were actually CJD. His belief, from his own experience of surveying CJD in the early 1980's, is that the true incidence of CJD is not far off 30 to 40 cases a year.
- (3) There is also the matter of whether the spectrum of "prion disease" is wider than that recognised at present. This could very well be the case and is something we, with the MRC, are happy to encourage research in. It would be a mistake to alter the definition of CJD just because this new technique is available. The surveillance that is being done needs to compare CJD rates with those that occurred before. CJD should be a good enough marker of "prion disease" for detecting any changes, say in the unlikely event BSE is a hazard for man.
- (4) You could suggest the media make direct approaches to $\mbox{Dr Will}$ for comment.

I will be putting a note up later today to bring everyone up to date on developments in CJD/BSE.

Hilary Pickles
Room 414

EH