

National Creutzfeldt-Jakob Disease Surveillance Unit

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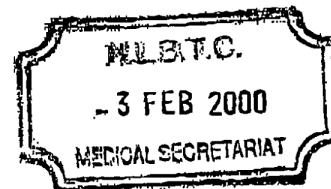
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1st February 2000

Dr Ailsa Wight
Department of Health
Skipton House
80 London Road
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Dear Ailsa

Re: Lookback study in CJD

In view of the developments in relation to the ethical review of the look back study in CJD and the recommendation from MSBT regarding potential blood donors I wrote to the local ethics committee to renew approval for this study. I am now enclosing a letter from the chairman of the Lothian Medicine Research Sub Committee in which Dr Starkey has refused my request to renew ethical approval for this study. The details of the reasoning for this are included in Dr Starkey's letter.

As you may recall I was very uneasy about the ethical situation in relation to this national study when approval had only been given by local ethics committee. I contacted Dr Metters about this and I believe that a decision was made within the department of health that it was ethically appropriate for the study to continue under the original conditions.

The situation is now very difficult. I believe that the lookback study in CJD addresses an issue of major public health importance and I personally feel it would be irresponsible to discontinue this study because of the absence of local ethical approval. I would therefore seek your advice on how to proceed with this issue and whether it would be possible for the department of health to provide ethical approval for this national study.

With kind regards

Yours sincerely

GRO-C

R G Will
Professor of Clinical Neurology

c.c Dr Pat Hewitt National Blood Authority