72/6
20

National Creutzfeldt-Jakob Disease Surveillance Unit

Please reply to: Western General Hospital, Crewe Road, EDINBURGH EH4 2XU

Clinical Office:
(Department of Clinical Neurosciences)
Tel: 0131 537 2128
Fax: 0131 343 1404
Professor RG Will, Consultant Neurologist GRO-C
Dr R Knight, Consultant Neurologist GRO-C
Dr MA Macleod, Research Fellow GRO-C
Ms. K Estibeiro, Molecular Geneticist GRO-C
Miss JM Mackenzie, Study Co-ordinator GRO-C

Neuropathology Laboratory:
(Department of Pathology)
Tel: 0131 537 1980
Fax: 0131 343 1404
Dr JE Bell, Consultant Neuropathologist (GRO-C)
Dr JW Ironside, Consultant Neuropathologist (GRO-C)
Mrs L McCardle, Chief MLSO (GRO-C

Dr McGovern — By fax
Dr Wight

Grateful for advice & draft reply asap.
GRO-C
5/3

2nd March 1999

R 8/3

Dr Jeremy Metters
Deputy Chief Medical Officer
Department of Health
Richmond House
79 Whitehall
London SW1A 2NS

Dear Dr Metters

I am enclosing an information sheet on blood and Creutzfeldt-Jakob disease which we intend to supply to the relatives of all cases and controls in whom we seek information in the course of the study of CJD. This text has been approved by the S.A.C. on Transfusion Transmitted Infection.

The decision was made at the meeting at the Scottish Blood Transfusion Service that we should not seek informed consent from the relatives of patients or controls for permission to forward information to the Blood Transfusion Service. The reason, as I understand it, was pragmatic in view of the public health importance of the TMER in CJD and new variant CJD. I have been uneasy about this since the meeting and feel that we really must let the relatives of patients and controls know that we are informing the Blood Transfusion Service. I would also be most grateful if you could confirm that the Department of Health have concluded that this is the best ethical way to proceed. My understanding is that the ethics of the whole TMER study were approved in such a way.

cc Mr Jones

Thank you for your help.

Kind regards
Yours sincerely

(I think this has happened with HIV testing).

Could you please liaise with HSD to provide a reply - one way of reconciling concerns could be to add a rider to the statement saying that if however you do not want your details forwarded please let the CJDSU doctors know, & they would be happy to discuss further.
GRO-C 8/3

GRO-C

R G Will
Professor of Clinical Neurology

copy : Dr P Hewitt, Lead Consultant in Transfusion Microbiology

Enc