From the Rt Hon Dawn Primarolo MP
Minister of State

DH Department of Health

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Bridget Prentice
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28 JAN 2009

Dear Bridget,

Creutzfeldt-Jakob disease (CJD) Post Mortem Study.

I am writing to seek your assistance with an important research study we wish to carry out to test human tissue obtained from post mortems for variant Creutzfeldt-Jakob Disease (vCJD).

This study will help us gain a better understanding of how many people in the population might be infected with vCJD, but are not yet showing symptoms. This information is critical for effective cost-benefit analysis of potential new risk management measures to prevent person to person transmission of the disease through medical interventions. This has become even more of a priority following recent media reports of a possible new case of vCJD in a person with a genetic make-up that is different from previous vCJD patients.

We also expect new testing technologies to appear on the market in the next year or so which could be used to screen blood donations for vCJD. However these are likely to be very expensive as well as presenting various other drawbacks. A more complete understanding of the reservoir of potential infection in the population will therefore be highly desirable to help inform our decision on whether to introduce them.

The Government's independent expert advisory committee the Spongiform Encephalopathy Advisory Committee (SEAC) have advised that the best way of obtaining sufficient samples for the study is with the participation of coroners. Following many months of unsuccessful negotiation with the coroners at official level, the Chief Medical Officer wrote to the Coroners Advisory Group (CAG) on 9 September 2008 (copy attached) proposing a methodology for the study, which would minimise the role of coroners or their officers. The letter also offered to pay for a temporary worker in participating coroners' jurisdictions to undertake the additional work and agreed that no post mortem should be delayed because of the study. Nevertheless, much to our disappointment, the CAG and the Coroners' Society have continued to refuse to endorse coroners' involvement.

Officials are currently developing a pilot for an alternative study methodology using NHS bereavement services in the role originally envisaged for coroners. It is hoped that this pilot can begin in April 2009. However, it is unlikely that this methodology, unlike that involving coroners, will be able to deliver sufficient quantities of tissue (ideally 100,000 samples) in a meaningful timeframe.

If would therefore be extremely helpful if coroners would participate in the study as well, on the basis laid out in the Chief Medical Officer's letter of 9 September. Initially we are simply seeking a small number of coroners to agree to take part in the pilot study, with a view to rolling out more widely if the pilot is successful.

There are powers in s45C(3)(b) of the Public Health (Control of Disease) Act 1984, provided by s129 of the Health and Social Care Act 2008, which enable the appropriate Minister to make regulations "for the purpose of preventing, protecting against, controlling or providing a public health response to the incidence or spread of infection" to confer on "... persons functions in relation to the monitoring of public health risks". DH solicitors have advised that it would be possible for us, using this power, to make regulations to require coroners to participate in the study. However, I would of course much prefer it if we could work with the coroners by co-operation rather than having to seek your agreement to making such regulations.

I should stress that your officials have been very helpful throughout, and the difficulty lies entirely with the coroners. I do hope you will be able to bring your influence to bear in persuading them to participate in this study.

Yours ever,

GRO-C

DAWN PRIMAROLO