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NHS
National
Services
Scotland

Our ref:imf04ldavies

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PRIVATE & CONFIDENTAIL

Professor Lyndsey Davies CBE
Chair of MSBT/Regional Director of Public Health East Midlands
Government Office East Midlands
The Belgrave Centre
Stanley Place
Nottingham
NG1 5GG

Dear Lyndsey,

Re. Variant CJD Notifications to UK Blood Services

We spoke at the SHOT launch meeting at the Royal College of Physicians a month or so ago with regard to the current arrangements for vCJD notifications in the UK. Since that time I have had a number of discussions with individuals and there has not been, I have to say, much enthusiasm for arranging a meeting to revise the current arrangements agreed at a meeting with Jeremy Metters in 1997. However, I do have a number of residual concerns about the present arrangements, which I believe do need some review and upgrading in the light of the two recent cases associated with blood transfusion. It seems to me that this has now gone beyond the initial aims of surveillance and research and is now clearly a public health / Health Protection issue. The areas that I believe need revision are as follows (but may not be a complete list).

1. I believe that *all* cases of vCJD wherever they occur in the UK should be notified to all the four UK blood services. At present, cases are only notified to those blood services where the patient has a history of residence. The chance of missing a potential vCJD donor is probably small but are almost certainly not zero and this has been a residual concern to me since the original arrangements were put in place around 1997.

2. At present the notification process is covered under two different parts with the primary notification being dealt with under the protection of public health. However the reverse TMR is carried out as a research study under ethical committee approval. I think given these recent two cases, which provides

prima facie evidence of transfusion association, it would be better if we had a single coherent approach based on health protection principles.

3. In the light of the case in the Lancet earlier this month I believe we need to review the approach taken with those blood donors, who remain healthy, whose blood was transfused into patients who later developed vCJD. This seems now to be especially important given the possibility of occult "carrier" states in M/V prion heterozygotes, as suggested by the second case. My understanding is that these donors have been notified to the CJD Surveillance Unit. In Scotland we have taken these donors off service but have not as yet told them. I am not sure whether donors elsewhere in the UK are still being used as donors. I know that three or four years ago this was the case.

I fully accept that reviewing these issues and the whole process does not necessarily require a meeting but I do think that these points need to be considered so that we have the whole process as tight as possible.

With kind regards

Yours sincerely

GRO-C

Professor Ian M Franklin
National Medical & Scientific Director SNBTS

Cc. Prof. R Will, Dr P Hewitt, Dr A Robinson, Dr R Jones, Dr M McClelland, Dr A Keel