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Subject: URGENT: vCJD & BLOOD TRANSFUSIONS - HANDLING ENQUIRIES FROM THE PUBLIC

Pat

The publicity this week about the 22 vCJD-implicated blood transfusion recipients has generated a small number of calls today - two to the Department, two to the CJD Support Network - from people asking if they are one of the 22 (in practice there are 10 as 12 of the 22 have died - all from causes other than vCJD). We would welcome your urgent guidance on handling these calls, in particular how we should deal with a caller who turns out to be one of the 10.

Neither of the two callers who came through to me today were on the list, and I took the decision (after discussion with colleagues here and NBS) to give them this information. Having been asked a direct question, our conclusion was that we could not refuse an answer (NBS get identical calls from time to time and deal with them in the same way). The CJD Support Network told their callers to contact their doctor.

There is no indication that we are going to get a lot of these calls but, were this to happen, our thinking is that these would be best handled by NBS. From initial discussions they are reluctant to take this on as it's outside their direct area of responsibility. However, as NBS are the only ones (apart from the CJDSU) who have access to the information, it's hard to see who would be more appropriate. Are you happy for me to press NBS to do this?

This leaves the question of what we do if, by chance, we get an enquiry from someone who *is* on the list, in particular:

(i) who should provide the information?

(ii) what public health advice should the patient be given?

(i) the best person to give the information is probably a patient's GP. NBS have made the point at Incidents Panel meetings that they are not equipped to do this and, given that the patient is likely to need ongoing support, it seems right that the GP should be involved from the start (this chimes in with the Incidents Panel's recommendations). Whoever is handling

the enquiry (NBS?) would therefore need to obtain the name of the patient's GP and make the necessary contact so that the patient can be informed. In these circumstances, CJDSU may also be willing to provide back-up support to the GP.

If you are content with this approach, should we be providing advice now to GPs explaining this process, bearing in mind that the chances of an enquiry from one of the 10 recipients is extremely remote?

(ii) if the Panel's recommendations for a contactable group are accepted, the 10 transfusion recipients would be told that they should not donate blood or tissues and that special precautions might be needed if they have surgery. At present, if one of the 10 turns up as a blood donor, they would be contacted by NBS and told that they should not donate blood or tissues but NBS would not mention surgery. I would welcome your views on what public health advice should be given if a patient is informed that they have received vCJD implicated blood as a result of contact initiated by them. This is difficult without pre-empting decisions on implementation of the Panel's recommendations.

Charles