PEH/EJ

12th October 1999 13 OCT 1999

Professor R Will
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Crewe Road
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EH4 2XU

cc: Dr McGovern. Dr Wright.

Copy: Mr Jones
We need to include NBA on our gp.
GRO-C 18/10

Dear Bob,

Re: **Recipients of blood donations from individuals who themselves later develop nvCJD**

I know this has been an area of concern for some time. I am writing to report the outcome of a meeting held at the Department of Health last week, between the NBA and the Department. Also present were the legal advisers of both the NBA and the Department of Health.

The purpose of the meeting was to discuss the recommendation from MSBT that donations from individuals who had received blood from donors who later developed nvCJD should not enter the blood supply. A number of consequences will arise from this recommendation and a meeting was held to ensure that all parties fully understood the implications of adopting the MSBT recommendation.

We have already determined that it is possible for the NBA to "pre-register" individuals on the donor database, and then to flag such entries. The consequence of this action would be that the individual could present as a blood donor, give a blood donation (since the flagging would be invisible to the blood donor clinic staff), but the donation would be discarded and not enter the blood supply. Once this had happened, the donor would be contacted and informed at a face to face interview, that the blood could not be used. The reasons for the decision would be given at that point. It was agreed that the issue could not be addressed when the individual first presented at the donor session, since this is such a sensitive area it would require experienced and well informed staff who were able to deal with the consequences of passing this information to the individual concerned. The task would therefore fall to the staff who currently counsel donors on the basis of positive microbiology tests, who are experienced in breaking bad news and in dealing with the issues that follow. The Department of Health is in agreement with this proposed action.

No, not going ahead till we have met [illegible]

I have informed the relevant staff within the NBA of the action which is being taken. The names of the recipients who have so far been identified, and who are in an age range which would make them eligible to be blood donors, will be passed to the minimum number of individuals required in order to ensure that the information is included on the databases and there is security in the system for discarding any blood. (The NBA currently has three Zonal databases, so entries would need to be made on all three of these). We have asked the Department of Health to address the issue of similar actions in Scotland, Wales and Northern Ireland.

It would also be necessary for us to share this information, since there is no guarantee that individuals will remain in the country in which they lived at the time they received their blood transfusions. The Department of Health has promised to address this with the relevant Health Departments.

I have been asked to prepare a procedure for the handling of individuals who may present as donors in future, and who would be excluded because of receiving blood from an individual who later developed nvCJD. Clearly, this will be a difficult counselling challenge and we will ensure that we have uniform information and documentation at all sites within the NBS. I will, however, need some input from you on this. We are also very anxious to ensure that, once individuals had been informed of their situation, they can be referred with the minimum of delay to a specialist unit where they can then be given further advice. Again, this is an area in which I will need your help and advice, since clearly we would wish to direct these individuals to units with particular interests in nvCJD.

The majority of recipients so far identified are too old to become blood donors. There are wider issues, in that any of the individuals so far identified as recipients of blood from donors who later developed nvCJD could themselves become tissue donors in the future. There is no one database covering all the tissue banks within the UK. Tissue banks within the UK blood services could be covered, but much tissue is donated outside the blood transfusion services and this presents a much larger problem. The Department of Health is planning to include this problem in the discussions which will be taking place at the expert group advising on the issues relating to identification of patients who have possibly been exposed to surgical instruments used on individuals who later developed nvCJD. We have not been asked, at this stage, to therefore take any action except in respect of those (currently few) individuals who would be eligible to attend as blood donors.

I am planning to draft a procedure. I could then forward it to you for comments. I hope you think that this is a reasonable way forward, but please let me know if you have any points that you wish to make at this stage. You may think that we should arrange to meet to discuss the various issues, and I would welcome your comments on this.

With best wishes,

Yours sincerely,

GRO-C

pp. Dr P Hewitt
Lead Consultant in Transfusion Microbiology

cc: Mr Charles Lister, Department of Health