

7th April 1997



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Dear Maurice

I am enclosing a copy of a submission made to the Department of Health for a national registry of transfusion acquired hepatitis C infections and of other HCV infections with a known date of acquisition to be funded from specially reserved research monies related to HCV infection. I am pleased to say that at the last MSBT meeting it was announced that the funding for the national registry had now been approved. However, during the meeting there was a plea that could the registry also involve Scotland, Northern Ireland and Wales such that it became a UK registry and not solely reserved, as it is at present, to the NBA database in collaboration with the PHLS CDSC.

At present the NBS database includes all the data accumulated from the LBF3 forms returned from blood centres on all the identified and so far followed up HCV positive recipients. We are about to advertise for an HCV registry co-ordinator and obviously if this co-ordinator has to co-ordinate inputting data from the whole of the UK we may have to re-look at the budgetary allocation made for travel expenses etc. I would be grateful if, after discussion with your colleagues who have been more intimately involved in collecting the HCV Lookback data, whether you would wish to join in this national HCV registry, or in what way you would prefer to collaborate.

The MSBT certainly expressed a view that they would like it to be a UK wide national registry but the logistics may make this difficult, equally the way the initial data has been collected may also make it rather difficult. Dr Mary Ramsey of the CDSC/PHLS will be directly communicating with her counterparts throughout the UK on similar lines to see what can be achieved nationally. It has taken over 12 months to get agreement for funding for this registry and I am anxious now to go ahead and advertise, as the longer it is left the more difficult it will be to collect the missing data that is out in the blood centres, so I would appreciate an early response as to what your view is on trying to make this a UK wide registry.

Best wishes.

Yours sincerely

GRO-C

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