Note of A Meeting held on Tuesday, 24 January 1995 between the Officers of UKHCDO, Dr A Rejman and Officials of The Department of Health

1. Hepatitis

The meeting began with an account of the DOH initiative on hepatitis C infection in blood transfusion and the recent Epinet publication entitled "Hepatitis C and Blood Transfusion". It was acknowledged that DOH would not be offering ex-gratia payments for hepatitis C infection, however caused, and it was agreed that widespread litigation in the haemophilia community would be unhelpful and probably largely unsuccessful.

The Officers of UKHCDO explained that guidelines for the treatment of hepatitis C in haemophilia were being drawn up and it was likely that interferon prescription would increase rapidly now that the drug was licensed for this indication. Funding for hepatitis C management including interferon treatment was discussed and DOH stated that no ring-fenced extra money would be available for this purpose. It was suggested that it should be easier, in the current climate, to negotiate funding for hepatitis care, including interferon, because of the recently granted product licences and the effect of national publicity. The officials encouraged the use of contracts in which purchasers agreed to pay for concentrates and interferon or other drugs prescribed in the care of people with haemophilia.

2. Factor Concentrates

The discussion opened with an account of the value of prophylaxis, especially in childhood and the importance of safety, especially in those without evidence of infection. The UKHCDO group emphasised the perceived safety of recombinant factor VIII and noted that material free of any plasma products would soon be available. There was a discussion on parvovirus and the difficulty in inactivating the virus in plasma derived concentrates.

It was explained that overall factor VIII usage was bound to continue to rise and that recombinant factor VIII concentrate was likely to be used in significant quantities in the future, especially if the price fell. The implications for producers of plasma derived concentrates were discussed with particular emphasis on the national plasma resource and its costing.

DOH repeated the view that the funding for factor concentrates would be determined by negotiations between purchasers and providers and it was noted that earmarked AIDS funding has now disappeared although the money is still available within the system. It was acknowledged that very expensive inhibitor patients would have to be treated according to clinical indications in an emergency and that purchasers might wish to reinsure their risk by forming consortia. The issue of expensive immune tolerance induction regimens was discussed and it was suggested that in these cases individual applications should be made to the relevant purchasers.

It was thought that an appeal to DOH might be possible if agreement could not be reached but no commitment was made by DOH to provide any additional top sliced funding.

Conclusion

DOH listened sympathetically to the points made by UKHCDO on the future needs of people with haemophilia but made no commitment to take any action. UKHCDO was encouraged to use cost/volume contracts rather than block contracts for all aspects of haemophilia care. The meeting provided an opportunity for UKHCDO to explain the need for more resources for proper haemophilia care and to inform DOH of the actual and potential consequences of any failure to fund the service.

It was agreed that an annual meeting of the two groups would be valuable

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Chairman, UKHCDO