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## MEETING OF HAEMOPHILIA REFERENCE CENTRE DIRECTORS 19.9.83

I invited myself to the above meeting to hear the latest on AIDS!

Salient points were:

1. read out a letter which he has prepared for the Haemophilia Society to send to its members (ie an up-date on his earlier letters). I haven't got a copy of the letter but it sounded reasonable and, hopefully, will not create any new problems.
  2. The relatives of the haemophiliac who died of AIDS in Bristol have taken legal advice and are keen to sue the manufacturers (Alpha and Immuno) of the commercial FVIII concentrate which he received in 1981. If they go ahead, this could put the cat amongst the pigeons. Is it worth mentioning at this stage to ID and SOL C?
  3. (who is coordinating the AIDS surveillance in haemophiliacs) is unable to cope, without additional funding, with the necessary follow-up of other recipients of the batches of FVIII which were used in the 2 haemophiliacs with AIDS. I think this is an instance in which the Department should come up with some money. I have alerted to the fact that an approach to OCS will probably be made by
  4. will take upon himself the reporting of all cases of AIDS or suspect AIDS occurring in haemophiliacs to CDSC unless the reporting doctor withholds authorisation for him to do so. (The Bristol case who died of AIDS was known to but because it didn't fulfil all the criteria for AIDS, he did not report it to CDSC. From now on, he will do so unless the reporting doctor specifically refuses permission.)
- Incidentally, it transpires that some of the commercial FVIII concentrate from the batches administered to the Bristol case, found their way to hospitals which are not haemophilia centres. This is undesirable, both from the point of view of patient care, but also because these patients and the treatment they receive do not get included in the national statistics on the use of FVIII which provide so much valuable information (a copy of the 1982 annual returns was made available at the meeting and is attached). I took the opportunity to mention to Directors that further consideration is to be given to rationalising the purchase of blood products and that this was to be considered by the Advisory Committee on the NBTS. I promised that the Directors would be given an opportunity to comment on any proposals to change the present system of FVIII purchase and distribution. (It is clear that this is a fertile ground for almost wilful misunderstanding on their part!).
5. The total usage of FVIII for 1982 was 75m i.u. (1m i.u. has been added since the returns were compiled). Only next year and subsequently may it be possible to discern any downward trend in usage because of AIDS. In other words, if AIDS hadn't happened, it looks as if we are on course for the 100m i.u. projected for the mid 1980s! Directors were convinced that Regions would not come up with the plasma for this target - or anything

approaching it. They urged (naturally) some central funding to increase plasma supplies. Would there be any harm (I know it would probably be no good) in putting up a bid for this in the next PESC round? If we start early enough, we may reach the top of the list in 1990!

6. I discussed genetically engineered FVIII - still about 10 years off, is the guess.

MED SEB

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3. Matters arising from the Minutes

All matters arising would be dealt with as items on the Agenda.

4. Discussion document on the designation of Centres

\_\_\_\_\_ said that a start had been made in drafting a new document but was not yet finalised. He understood that the Haemophilia Society had now modified their views on decentralization of haemophilia treatment; the Society realised the distinct advantages of centralised treatment, especially when problems like AIDS arose.

\_\_\_\_\_ suggested that the new draft document should be sent to the Reference Centre Directors for their comments before the February meeting and should be discussed in detail at that meeting. This was agreed. It was also agreed that the new discussion document should be mentioned at the October meeting of all Haemophilia Centre Directors.

5. Annual Returns for 1982

\_\_\_\_\_ presented the documents which he and Miss Spooner had drawn up giving the provisional statistics available from the 1982 Annual Returns. There was some discussion regarding details in the report. It was requested that some more detailed analyses should be made regarding the materials used to treat the von Willebrand's disease patients and it was agreed that \_\_\_\_\_ would give these details to the Reference Centre Directors at the February meeting. Reference Centre Directors agreed that the preliminary report on the 1982 statistics should be presented to the Haemophilia Centre Directors at their meeting on 17th October.