c.c. DR. E. BIDWELL)
DR. D. ELLIS) FOR INFORMATION.
MR. L. VALLET)

Wd'AM/PP

28th February 1977.

Dr. C.R. Rizza,
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Dear Charles,

I am replying to your letter of 17th February 1977 about working parties.

The list I suggest, in order of priority is:-

(1) Incidence of haemophilia in U.K. First because everything else follows from this and I conclude from listening to the experts that the answer is not certain. Exact terms of reference would be necessary. The working party should be told what is meant by haemophilia in this context (A, B & von W) and where the cut-off point is to be taken. The method of testing for AHF should also be defined. (At times one is told that there are about 3000 haemophiliacs in U.K., at others that there are about 3000 severe haemophiliacs; thinking is not exact).

(2) Incidence of factor VIII antibodies. Second because their presence is potentially dangerous to the patient and leads to the use of large amounts of factor VIII in one form or another.

(3) Cause and prevention of development of factor VIII antibodies and their treatment. Third because it follows from (2) and because treatment is pragmatic and uncertain. (I have altered the title).

(4) Home treatment of haemophilia and staffing of haemophilia centre. These are inter-related and would be more effectively studied by the same group.

(5) Incidence of hepatitis in haemophilia. I put this last because the sensitivity of tests used to screen donors is now very good (a third generation test is obligatory in U.S.A. and recommended in U.K. (here we rarely make anything obligatory nor, as is sometimes unkindly said about the German attitude to things, do we say "anything which is not obligatory, is forbidden".) All products in U.K. and U.S.A. are tested by RIA. Among the other reasons for putting this subject last is that any worthwhile survey, now, of hepatitis is going to be very expensive, in man hours (needed for follow up, interviewing, correspondence), in laboratory tests (e.g. liver function tests, the value of which in subclinical cases is often debatable, unless several different tests are done at fairly close intervals and all other causes of positive results in such tests are considered and eliminated; hepatitis tests should also be mentioned here) and lastly, it is now suggested in the States that

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most cases of hepatitis in patients given blood products are neither hepatitis A nor hepatitis B. I think it would be worth waiting till the non-A non-B disease is confirmed and defined.

I imagine most centres routinely test their registered patients for HBsAg and anti-HBs. If it could be arranged without great expense for all registered patients at a given number of centres to be tested for antigen and antibody by agreed simple but sensitive tests, some information of value might be gathered. One would have to decide whether one was going to test certain categories of patients (e.g. a group based on severity) or take in all registered patients. But such an exercise could quickly fan out into a big affair unless kept under tight control.

Craske is planning a survey to compare in certain centres the numbers of cases of hepatitis after certain different preparations of concentrate. Perhaps he should be encouraged to constitute himself as a working party and the proposal should be left at that.

If a cheap reliable test for A and anti-A hepatitis became available and one were found which would distinguish the so-called non-A non-B hepatitis, then I think this question should be re-examined.

I think it is possible that hepatitis may have attracted undeserved attention.

(6) Prophylactic treatment, I assume of haemophilia A. I think this should be left out because I see little possibility of reaching the 50 iu target in the form of concentrate which is now talked about for ordinary treatment including home treatment. Presumably even more would be needed for prophylactic treatment. A break through in Bovine factor VIII would quickly change the picture, of course.

I have just seen from the minutes of the Directors Meeting in January last that Rainsford reported that prophylactic treatment with factor IX was no more expensive than on demand treatment. Perhaps there is therefore something to be said for this working party if its term of reference were very closely defined.

(7) I also see from the minutes that one Working Party suggested was to study standardisation of reagents. I would have thought this came in the province of NIBSC and should not be "fathered" by the Directors meeting.

Kind regards,

Yours sincerely,

GRO-C

W. d'A. Maycock.

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