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With Compliments

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JDC/EP

14th March 1985

Dr M E Abrams
Department of Health and Social Security
Hannibal House
Elephant and Castle
LONDON, SE1 6BY

Dear Dr Abrams

E A G A

I left the meeting on the 13th March a little concerned. I felt there was much more work that could have been done and sufficient time to do it. I was also concerned that I have previous commitments on the dates of the next two meetings (22nd April and 29th May) and thus will not be present to contribute to what I suspect will be important meetings.

Had the meeting gone on after lunch I would have made the following points:-

(a) It is, in my view, essential that the Group responsible for the HTLV-III antibody screening kit evaluation exercise must include the Western Blot technique for examining those samples proven positive by the kits. Such a development not only permits valuable comparison with evaluations taking place in other countries but will give us critical information with regard to the techniques required for Reference facilities - a feature of considerable importance not only to the Transfusion Services but all those concerned with the safety of health care workers.

(b) I would like to see the last sentence of item 11 (EAGA(2)3) incorporated into the recommendations of EAGA.

(c) I was interested and pleased to note at the 13th March meeting that the EAGA agreed that HTLV-III antibody testing should be introduced simultaneously in the UK Transfusion Services. How will this responsible decision be implemented unless there is additional central funding made available? I believe that the EAGA should recommend the provision of additional central funds for the implementation of this programme and that following the release of these funds a "D-Day" is agreed and announced. Without such planning and provision the recommendation is not credible.

(d) I would be most grateful if you would let me have the names of the ad hoc panel which is being set up to supervise the evaluation of the diagnostic kits (Item 5 EAGA(2)4).

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(e) The last sentence of item (7) (EAGA(2)4) deserves comment. The Danish programme has increased the counselling requirement only to the extent of those who are HTLV-III antibody positive. I would suggest that this increased workload needs to be set against the potential gains in terms of public health, health care workers' safety and protection of patients being transfused with blood and blood products. I take the view that these gains outweigh the problem of the increased counselling workload.

(f) I was unhappy with item (13) (EAGA(2)4). I have always believed that one of the important aspects of transfusion practice, for instance in the context of syphilis testing, is to be quite certain that the sample tested actually comes from the donor in question. It is therefore essential to recall the donor to obtain a second sample for local verification and reference work. I have seen too many examples of laboratory/transcription errors to let the comments in this paper pass and believe, particularly in the circumstances of HTLV-III A/B testing, that this matter should be subject to a formal recommendation by the EAGA.

(g) I was unhappy with item (15) (EAGA(2)4). The point raised by Dr McClelland is of fundamental importance and whilst the use of false positive donors/donations may have to be left to local judgement I believe it should be discussed very carefully by the EAGA and a formal recommendation made. At the same time the EAGA will need to consider whether those designated as "false" positives should be subject to similar counselling as those with "true" positives with the associated passage of this information to the GP/dentist etc. On balance I would advise that they are taken off the donor panel, but not subject to the precautionary counselling advised for "true" positives. However, I would recommend that they are followed up (HTLV-III A/B tested etc.) at 6-monthly intervals.

(h) Item (3) (EAGA(2)6): I'm not sure that all Directors of the BTS would agree that they are not in a position to counsel every donor found "truly" HTLV-III A/B positive. Indeed I would suggest that many would take the view that it was their responsibility (a view which I share). I do not believe that Item (7) - last para - is entirely satisfactory. The BTS is responsible for the Care and Selection of Donors and referral, if necessary and with the agreement of the GP, should be to a doctor who is interested, committed to and experienced in caring for such people. This, in my opinion, is an unavoidable responsibility of the BTS.

(i) I note that in item 1.2 (EAGA(2)8) there is a proposal that asymptomatic HTLV-III A/B individuals should have a regular medical evaluation and follow-up (see (g) above). Item 2.1 raises the question of pregnant staff - a very interesting and important matter. I can report that one Haemophilia Director has insisted

that his pregnant Centre Nursing Officer is given "sick leave" on the grounds that all his patients (although fit and well) are 'high risk'. The EAGA needs to consider this matter carefully.

(j) It was unfortunate that the EAGA did not have a copy of Dr Gunson's draft paper (Item 2 EAGA(2)10). This should be made available (as should the note of the second meeting of the Testing Group).

(k) Whilst I agree that the donors should be given advance warning of the introduction of HTLV-III A/B testing I am strongly opposed to the concept that the donor should indicate by questionnaire what should be done with the information. This proposal, in my opinion, is operationally unacceptable and impracticable. This information is confidential and should be subject, if appropriate, to caring, personal and professional counselling.

(l) It follows that I am totally opposed to all the substance contained in item (5) (EAGA(2)10).

(m) I support the recent US decision that even after the introduction of full HTLV-III A/B testing the BTS should not knowingly accept donors from the high risk groups.

(n) The sentiments contained in the last para, item (10) (EAGA(2)10) are of interest and would have my support. It is for these reasons that I believe it is important that we (BTS) take the responsibility to ensure follow-up of asymptomatic HTLV-III A/B positive ("true" and "false") donors (see below).

(o) There are many mine fields in this area but from a Transfusion Service point of view it would be our experience - from HBs-Ag testing - that a very large number of GPs do not "welcome" the information of positivity in their patients supplied by the BTS. Many, as a consequence, are not sufficiently sympathetic to the plight of the donor who has been labelled as a "leper" by the BTS (item (16) EAGA(2)10). Similar considerations apply in certain hospital departments and with certain dentists. It has been our experience that these difficulties have only been resolved by the efforts of the BTS doctors who have successfully liaised with certain clinical colleagues so that comprehensive care, which the donor enjoyed before the BTS labelled him/her as HBs-Ag positive, is maintained. I take the view that as doctors in the BTS this activity is our duty, if it is required. This view is shared by an increasing number of BTS doctors and must apply to HTLV-III A/B positive donors.

I apologise for writing at such length but I'm sure you will appreciate that many of the views I have expressed are strongly held and in the light of events I am concerned that they will not be presented to

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the EAGA. In the circumstances I have felt it appropriate to copy this letter to Harold Gunson and Brian McClelland.

Perhaps I may be permitted one last point. If it has been decided that the UK Transfusion Services will introduce HTLV-III A/B testing simultaneously then we will soon need to have an approximate expected date for the completion of the kit evaluation and thus "D-Day". This will, in turn, sharpen our thoughts with regard to the planning of when donor counselling systems have to be up and ready to receive their first donors. The sooner this detailed planning commences the better for, based on the experience of Dr Pinching's group, there will be a requirement for training.

Kindest regards,

Yours sincerely

John D Cash

Copy to:
Dr H H Gunson
Dr D B L McClelland