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~~1.~~ 2. Dr Reid
~~2.~~ 1. Dr Scott (1) 2 applications for bringing S10 into similar position @ DHSS 2 finalise Press Office - this must be considered.
3. Mr Macpherson
~~4.~~ 4. Mr Davies 3/5 (2) We may need to cancel a regular meeting ourselves to coordinate how matters are progressing.
5. Mrs Neep (for file) (3) A paper for either Policy Group or Policy Board may need to be considered soon – for information if nothing else.

Copy to Dr Young } no enclosures
Dr Bell }

(4) The USA figures are quite terrifying – if my arithmetic is correct USA can expect 15-30,000 new cases per year. If Gallo is correct & the conversion to symptoms for HTLV III + is 3% per annum.

30/4

EXPERT ADVISORY GROUP ON AIDS
22 APRIL 1985

GRO-C 26/4

Please find attached the agenda and papers for the above meeting which I attended. Due, I think, to the postal strike I did not get a copy of the papers until the meeting. As usual the agenda was long and controversial, surprisingly since the latter two-thirds of the meeting were concerned with papers from the Sub Groups. At least we broke for lunch which gave a welcome breather.

Item 1 - Apologies

There were a large number of apologies (including Dr Cash) although many like Dr McClelland had come straight to the meeting from Atlanta.

Item 2 - Announcements

Dr Abrams announced that this was his last appearance as Chairman (he is going to be a DCMO) and Dr Harris would probably be taking the chair from him. Dr Ower has taken Dr Oliver's post as SPMO in charge of the Infectious Disease Group. Dr Abrams thanked people for their comments on the annexes to the draft CMO's letter and said that he hoped the final version would be out shortly (? when). He said that Dr Ower would be chairing the Sub Group on "advice to clinicians" ie surgeons and dentists. The Royal College of Surgeons would be represented by Prof Dudley, the Faculty of Anaesthetists by Dr Lumley and the dentists by Prof Shovelton.

Dr Abrams then asked for a report on the Atlanta meeting.

Dr Sibellas said that the three day meeting had consisted of a daily plenary session after which it had broken up into virology/immunology, clinical and epidemiological sessions. Not everybody had been at all the sessions and she invited others to report on the sessions they had attended.

Prof Bloom said that the session on testing had been included at the end of a day and there had been, therefore, an unsatisfactorily rushed session on the reliability of testing. He mentioned particularly one paper which described 10 haemophiliacs who were HTLV III antibody positive and whose wives were antibody negative. However the virus was isolated from the blood of four of the wives. This was worrying in relation to "false negatives". (Others suggested, however, that these four might have been in the pre-antibody viraemic stage.) In general he took away from the meeting (a) that there was a rapidly increasing problem from AIDS in the States. Dr Gallo estimated that 500,000 to 1,000,000

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would be infected by the virus by the end of 1986. (b) There was little new to report on scientific work but one or two new problems had arisen related to the spread of the virus in the United States.

Dr McClelland said that 125 cases of AIDS had occurred in the United States traced to fresh blood products. Forty six of these cases were investigated and donors found to be in the risk groups. Most were HTLV III antibody positive. The virus was isolated from 22 out of 26 of these recipients. It had been found that the incubation period of transfusion associated AIDS was 3-4 years or longer. Therefore there was likely to be a general increase of cases from this source over the next year or two. It seemed that the voluntary deferral system is working well in the United States and that there had been very little evidence of spread since this had been introduced.

Several blood banks had started screening in New York. All banks were introducing screening. None were informing donors of the results.

The test kits seemed to indicate (?) 0.2-0.3% repeatable. Seventy per cent positive on confirmation. There was no data on comparison of test kits - informally he had had reports of a considerable degree of inconsistency in the tests. Most centres accept a repeat positive test as the sole confirmation. It is also accepted now that anyone who is antibody positive carries the virus and therefore must be considered infective.

Further research is being carried out:

(i) Several centres are trying to isolate the virus from donations;

(ii) 200,000 donor samples are being screened with follow-up of recipients.

Dr McClelland felt that parallel work should be being done in the United Kingdom.

Dr Smithies said that all the blood banks informed donors that testing was taking place and offered them the alternatives of withdrawing or giving their blood to research rather than donating. Talking to blood transfusion Directors, she had gathered that there was more variation in testing than had been officially reported - possibly 8% false positives. The Commissioner of Health for New York was setting up a valuation of test kits. No decision had been made over counselling of positive patients.

Dr Mortimer (PHLS) said that he too had gained the impression that the Americans have a very big problem indeed ie 1,000,000 cases infected. There was more emphasis in the United States on changing the life styles of homosexuals and drug abusers, particularly by peer advice. The "side shows" at the meeting bore pretty tough advice for gay men. This is justified - in some areas up to 50% of the homosexual community had been found to be HTLV III antibody positive.

As far as tests were concerned the virologists thought the commercial kits were reasonably good (not the transfusion centres). However it was too early to judge yet. Their real "gap" is the lack of a convenient confirmatory test. Another difficulty was the likelihood of seronegative infective states such as occur in hepatitis B, and the lack of an antigen test.

From Dr Gallo's laboratory greater variations had been found in viruses within the one laboratory than between different laboratories, confirming the view that the viruses HTLV III, LAV and ARV were all the same. Otherwise there had been no new virological discoveries.

Prof Bloom mentioned two other points :

(i) that the accession rate of symptoms in serologically positive people appeared to be 2-3% per year;

(ii) there were a number of fatalities reported among people with AIDS related disease and not the full CDC AIDS picture. Were we missing some pathology by restricting our surveillance to people with full AIDS?

Dr Pinching agreed that there is now a clear need to move towards more broadly based definitions. "AIDS Related Complex" was a hotch-potch of conditions meaning different things to different people. To some the prodromal condition, to others PGL. New criteria were needed.

One compelling picture of the conference had been the elegant documentation of the neurological disorder. This was a progressive dementia without focal signs and occurred in a very high percentage of AIDS patients (? 50%) and also in some with AIDS Related Complex. It was caused by direct infection of brain cells with HTLV III. Here was fully documented evidence of an effect of the virus on T4 cells producing neurological signs without immunosuppression. This may occur in some patients without AIDS or ARC.

Paediatric AIDS was now thought to be transmitted by the intra-uterine route rather than intra-natally. This had been shown by a study on a lady who had had a Caesarian section. HTLV III was present in the thymus and other tissues of the foetus.

Treatment of AIDS - evaluation of treatment had not been very satisfactory. Six anti virals had been found to stop viral replication in vitro:

Suramin
HPA 23
Alpha interferon
Ansomycin
Ribovirin

It was thought that they act against reverse transcriptase. Unfortunately HPA 23 is toxic and causes thrombocytopaenia. Its clinical benefit was not well established; suramin likewise.

Reports on immunology re-emphasised T4 cells as the virus target. However it seems that macrophages may be affected as well.

On the social side in the United States behaviour modification is being taken rigorously by the high risk groups (most of them know someone who has died of AIDS). In contrast in this country the risks do not appear great enough and there is, for example, less reduction in numbers of sexual partners among homosexuals.

There were some useful presentations on the cost implications of AIDS. National statistics were not perhaps relevant to the UK but there was a report from one county in San Francisco where the system of health care is very much closer to our own and from which analogies could be taken.

In reply to a question Dr Pinching said that drug therapy had not been evaluated sufficiently for use in cases of needle stick injury. However there was one study reported of 500 needle stick injuries without seroconversion after 11 months.

Dr Galbraith said that the emphasis on heterosexual transmission of AIDS which also came top on the list of risk factors at a WHO meeting held at Atlanta at the same time, seemed exaggerated. There were several good papers on epidemiology but no clear evidence for female to male transmission.
There was however evidence both in Haitians and Africans of multiple heterosexual activity and the likelihood of the use of contaminated syringes.

Other interesting points raised were:

(a) the re-affirmation of multiple homosexual partners, passive anal intercourse and rectal trauma as special risk factors;

(b) homosexuals who are HTLV III antibody positive are more likely to get Kaposi's sarcoma if they use nitrates. (One study);

(c) the intravenous drug abusers are a much larger risk group than it has appeared so far since many belong to other risk groups. It is estimated by some that 25% of American AIDS cases are in intravenous drug abusers;

(d) one study indicates that it is the mixing bowl for the drugs, and not the syringes and needles, which transmits the virus ie issuing intravenous drug abusers with syringes may not even help at all;

(e) there is good evidence of intra-uterine spread of virus during pregnancy. One study indicated that pregnancy in infected women precipitates clinical symptom.

Criticism about definitions of AIDS were level but the general feeling was that the CDC definition had worked well and should not be abandoned but rather added to. Several other countries were developing reporting systems for HTLV III antibody.

Dr Pinching commented that male to female heterosexual spread seemed to be on the increase but not female/male.

Dr Sibellas said that the Americans had been very generous with information about their AIDS experience. She was impressed by the differences between San Francisco where homosexuality was the clear prime risk factor as opposed to New York where intravenous drug abuse held a far more significant place in the causation of the disease.

The cost of the 9,000 cases of AIDS in the United States, including loss of earnings but excluding out patient treatment, was estimated at $5.6 billion - a lesson to us for the need for prevention (if we needed one!).

She quoted Dr Brandt who said that the voluntary reporting system of AIDS was important but nevertheless some states had made reporting of AIDS mandatory. He also stressed the need for scientific evidence to be well sorted out before such issues are discussed in front of the general public.

Item 3 - Minutes of Last Meeting

No comments.

Item 4 - AIDS and the Media, and Health Education, Prevention

The Chairman emphasised the need for increased efforts to educate the gay community. Prof Adler said that it had been demonstrated that the most effective way was for the effort to be seen to come within the gay community. It was therefore better to fund bodies like the Terrence Higgins Trust rather than the Health Education Council.

Dr Pinching supported this view but also the need to get at other groups notably the intravenous drug abusers and the people involved in their care. On the broader issue of the media he said that up to now journalism had been very bad indeed. One factor was their desire to find new angles on the AIDS story. Dr Pinching suggested that it was dangerous to leave the press to their own devices and that the profession should be taking a more active role in directing them towards new and different aspects of the disease.

Mrs Cunningham from the DHSS Press Office said that the journalist would always make a "good story" whatever facts they were given. Editors instructed them to pursue a particular line irrespective of professional advice. The Press Office had already done a great deal in giving out background information. The best approach was to give as much good information as possible and hope for the best.

Prof Adler suggested that there should be organised regular briefings and updatings for the press at regular intervals, say every two to three months. Mrs Cunningham said that this was in effect done but there were difficulties in arranging timings for meetings of this sort. In the west Midlands the regional public relations officer was a member of the local AIDS advisory group. This had proved useful.

After further discussion Dr Abrams summarised the views of the Group as follows:

(i) Gay groups must be encouraged to educate themselves.

(ii) There must be more general education of the public.

(iii) More emphasis should be placed on the education of drug abusers.

(iv) Open access to testing in the future may result in modification of risk group behaviour.

(v) There should be regular briefing of journalists.

(vi) Consideration should be given to including a gay individual "of stature" on one of the EAGA Sub Groups.

Item 5 - Screening Test Sub Group

Dr Smithies spoke to the report EAGA(3)2. She stressed:

(i) the importance of the availability of screening tests outside BTS (para 8);

(ii) the importance (in para 9) of blood transfusion Directors devising an agreed procedure for all centres to follow when informing donors.

The Chairman then went through the paper page by page. Prof Zuckerman took issue over item 7 which, he said, excluded the use of the Western Blot test which had been agreed at the previous meeting. This resulted in a prolonged wrangle with Dr Tedder over the pros and cons of the Western Blot test. Finally Dr Mortimer managed to produce a form of words (which I missed) and which will appear in the minutes and this satisfied everyone.

Paragraph 8 stimulated a lengthy discussion. Dr Bloom promoted the view that access to testing, preferably through the GP, must be available before screening is introduced by the blood transfusion service; either that or some system for testing and not informing the patient of the result.

Dr Pinching appreciated the need to protect the Blood Transfusion Service but said that the matter must be kept in perspective. Tests should not be asked for until proper counselling was available for those found to be positive. At the moment people who are found to be antibody positive are being told without adequate counselling facilities. Very many more will be thrown up when screening becomes more generally available.

Other representatives of the Blood Transfusion Services supported open testing (without going through GPs) since the tests which would be available via the Blood Transfusion Service would equally be "open".

Prof Adler repeated his view that there is no argument for screening except to protect the Blood Transfusion Service. It is not scientifically honest to suggest screening since it alters nothing in the way of advice or treatment. Behaviour should be modified for all risk groups, antibody positive or negative.

The matter remained unsolved. Dr Abrams included that there was still time to argue the problem since the tests were not likely to be evaluated for some time (eight weeks at least .....).

On paragraph 9 it was agreed that:

(i) prospective donors must be told in general terms that testing would take place and should be given the chance to withdraw from donating;

(ii) donors with a confirmed positive test must be informed of the result;

(iii) paragraph 9 should be discussed among all BTS Directors.

Paragraph 10 was accepted. As far as paragraph 11 was concerned it was agreed that the only circumstances in which a donor would be informed was when the confirmatory test is positive. There was considerable discussion about the rest of the paragraph and it was decided to refer it back to the Antibody Testing Group for reconsideration.

Item 6 - Counselling Sub Group

This was only touched upon briefly at the end of the meeting. What appeared to be emerging was (a) that health care staff who were HTLV III antibody positive could be allowed to continue working except in particular areas eg surgery and renal dialysis units. (However this aspect will be re-examined by the new Clinical Sub Group.) (b) There is no need for the screening of renal dialysis staff (or indeed any other health care staff) at the present time.

GRO-C

DR R G COVELL
25 April 1985

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Encs