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CONFIDENTIALMinutes of AIDS Information and Advisory Group, 31.5.85.

Seminar Room, University Dept. of Medicine, Glasgow Royal Infirmary.

<u>Chairman</u>	Dr.C.D. Forbes.	
<u>Present</u>	Dr.A. Burnett	Dr.T.W. McFarlane
	Dr.G.D.D. Lowe	Dr.D. Kennedy
	Sister D. Campbell	Dr. J. Emslie
	Mr. E. Galloway	Dr.R.J.Crawford
	Dr.E. Follett	Dr.T.S.Wilson

Secretary Dr.Lowe took the minutes in the absence of the Secretary, Dr. J.M. Hunter.

1) Apologies were received from Drs. Hunter, Somerville, Covell and Professor Timbury

2) HTLV-III Antibody testing

Dr.Follett reported that the Regional Reference Laboratory uses the Abbott kit at present, confirmed by immunofluorescence testing. If I.F. testing does not confirm, the sample is sent to Dr. Tedder in London. Of Glasgow patients tested to date, haemophiliac patients treated with commercial factor VIII concentrate have the largest number of positive tests: all seroconverted between 1981 and 1983.

Increasing antibody titres in this group suggest the possibility of continued production, a unique viral situation. HTLV-I antibody testing may also be performed elsewhere in this group. The prevalence of HTLV-III antibody testing appears very low at present amongst GUM patients and drug addicts in the West of Scotland.

3) Reports from Atlanta AIDS meeting

Dr.Emslie reported on the general management and problems of AIDS and HTLV-III infected patients in the U.S.A. Hospital experience in

areas with large numbers of patients (e.g. San Francisco) had shown that it was undesirable to segregate patients in "leper colonies", that it was practical to manage patients in general wards (perhaps localised in one wing), and that hospital staff had accepted this. Psychological problems including depression and suicide attempts were common amongst persons in the community who believed themselves at risk. Many patients with AIDS were abandoned by family, friends and lovers, especially when they became depressed or when their mental function deteriorated. Support groups, e.g. provision of "buddies" to talk with, were valuable (such groups already exist in U.K., e.g. Terence Higgins Trust). Many babies with HTLV-III infection were abandoned by their mothers.

Estimates of the number of patients with HTLV-III antibodies who progressed to clinical symptoms of AIDS varied from 4-20%, with a similar percentage perhaps progressing to ARC or progressive lymphadenopathy syndrome. All such estimates are based on selected populations of homosexuals attending clinics. It was inappropriate at present to extrapolate such experience to the U.K. general population, or to haemophiliacs.

Dr.Kennedy reported that the drug suramin, reported in Atlanta as of possible benefit, was available from West Germany. Dr.Crawford reported that cytomegalovirus immunoglobulin was available from the B.T.S.

Dr.Emslie distributed American literature for public information from the Atlanta meeting. This led to discussion of the progress of local dissemination of information in the West of Scotland. Dr.Wilson reported that Dr. Hunter's information booklet for homosexuals was now available. Following general discussion, it was agreed that further education of general practitioners, as well as the public, was needed. Dr.Wilson agreed to arrange distribution of Dr. Hunter's leaflet to G.P.'s. It was also agreed that symposia for G.P.'s should be held in

each of the five Glasgow districts, probably in the usual Wednesday afternoon half-day release programme. It was pointed out that the prison service was also a priority for education, given their prevalence of homosexuality and drug abuse. Dr. Forbes would contact Clyde Action concerning a radio programme on information for the general public about AIDS. This could be followed by a non-recorded 'phone-in-service, for which some of the group volunteered. It was suggested that the preferred practice was a 'phone number available for one day only. Sister Campbell pointed out that many people felt inhibited when talking to doctors (although it need not be indicated that a telephone counsellor was a doctor).

#### 4) Clinical problems

Dr. Kennedy has one current patient with progressive problems from immunosuppression. He had a useful visit to Dr. Pinching's unit in London, where large experience had suggested that (a) HTLV-III infection may affect the brain, causing progressive encephalopathy and psychiatric symptoms; and (b) lung function tests (CO transfer) had given early prediction of *Pneumocystis carinii* pneumonia (before their availability was curtailed). Dr. Kennedy has indentified a clinical psychologist in Glasgow who may be available for counselling people at risk of HTLV-III infection.

Dr. Lowe reported that 16% of West of Scotland haemophiliacs were HTLV-III antibody positive; the lowest incidence amongst reported haemophilia centres. None had clinical symptoms, although some lymphopenia had been observed. These patients are being closely followed. Following discussions with Dr. Kennedy, a flexible policy would be pursued for such patients should they require hospital admission. Admission to the Royal Infirmary might be favoured by need for regular clotting factor replacement or other facilities best provided in the Royal; while external bleeding, vomiting or diarrhoea,

or major infective problems might indicate admission to Ruchill. Sister Campbell suggested it would be useful for staff of the relevant wards in the Royal Infirmary and Ruchill to meet.

#### 5) Blood transfusion

Dr. Crawford reported that the national HTLV-III test evaluation was progressing. The second generation of heat treated factor VIII concentrate is now being evaluated clinically. Heat-treated factor IX concentrate is still under development and not yet released for clinical evaluation. The aim is to test all blood donations at major regional BTS centres, with the particular aim of protecting the higher-risk pooled products, rather than low risk single donor products. Efforts to educate clinicians to reduce single-unit "top-ups" should continue. Arrangements to counsel blood donors found to be HTLV-III antibody positive should be made.

#### 6) Dental care

Dr. Macfarlane reported that his meeting with the C.A.M.O. and dental specialists from the Royal Infirmary and Yorkhill had taken place: the latter had agreed to provide dental care of HTLV-III antibody positive haemophiliacs in their respective hospitals. Ruchill patients would have care provided by the Northern Area consultant oral surgeon and his colleagues while other at-risk patients would be treated at the Dental Hospital (at which however some departments were more enthusiastic than others). The B.D.A. had published a leading article in the B.D.J. on AIDS but as yet has no national policy. It was reported that dentists in the U.S.A. had expressed concern that they may be at risk.

#### 7) Laboratory investigation

Dr. Burnett suggested that when current uncertainties about provision of new safety cabinets and other equipment had been settled, that the situation might normalise. Dr. Wilson reported that such

facilities would probably be confined to major hospitals. It was reported that Dr. Fallon had agreed to provide haematological and biochemical tests on HTLV-III antibody positive patients. There was some uncertainty as to where cross-matching of blood for such persons would be provided.

8) Information exchange

i) DHSS letter concerning compensation for health care personnel acquiring virus infection in the course of their work. Dr. Forbes asked the position as regards the S.H.H.D. and whether their circulars included HTLV-III infection. Dr. Wilson agreed to write to the S.H.H.D. concerning this and to inform the group of the position.

ii) Scottish Medical Journal - draft editorial on transfusion-associated AIDS.

iii) MMWR - latest report on AIDS in U.S.A.

9) Nursing care

Dr. Crawford commended the Atlanta nursing care guidelines as a model of clarity. Sister Campbell reported that more concern was now being shown by nurses occasionally involved - in, for example, casualty departments, - compared to nursing staff regularly involved with high risk groups (such as haemophiliacs). Dr. Kennedy reported concern among midwives delivering high-risk mothers, and nurses working with drug addicts.

Forthcoming meetings

- 1) Royal College of Physicians & Surgeons of Glasgow - June 1985
- 2) Meeting on AIDS in Africa (Brussels, November 22-23).
- 3) Royal College of Pathologists meeting on AIDS (London, November 22-23 also).

Date of next meeting

It was agreed that a date in September would be circulated, however Dr. Forbes would convene a meeting before then should developments warrant it.