HIV INFECTED BLOOD/TISSUE RECIPIENTS
NOTE OF MEETING 21.2.92

Present

DH	Mr Scofield	CDSC	Dr Evans
	Mr Thompson		Dr J Mortimer
	Dr Rejman		
	Mrs James	NBTS	Dr Gunson
	Ms Staniland		
	Mr Burrage		

Proposed scheme

DH said that a submission was currently with SofS seeking agreement to an outline scheme. DH outlined their current thinking. The intention was to pay as soon as possible a first batch of cases which had already been validated. There would be benefits financially in making as many of the payments as possible in the current financial year. Payments would be made probably by the Department without a handling organisation, in view of difficulties involved in extending the remit of the Macfarlane Trust. The submission to Ministers registered the complexity of this group, and recommended that where status of donation could not be firmly established, cases should be considered on the balance of possibilities.

A draft application form was tabled for comments. The form would

- be signed by a medical "sponsor" (more than one medical practitioner may be needed to provide information in respect of the transfusion and the HIV status),
- include patient's consent to disclosure of information to the Department and the Panel.
- be issued under cover of a letter to all NHS consultants, copied to RGMs, and RTC Directors.

Patients who approached the Department direct would be asked to seek the support of a medical "sponsor".

A unit would need to be set up, probably in the Department, to screen applications; anything contentious would be referred to the Panel. The Department would write a procedure for consideration by the Panel. (It was expected that Chairman of the Panel and Solicitors of potential beneficiaries would be contacted during week commencing 24 February.) It would be for the Panel to decide what further information they required, eg PCR testing and what weight to put on information about eg lifestyles in individual cases. DH asked NBTS and CDSC what information was available to them to assist in the validation process.

AIDS Unit comments

People tested anonymously or being treated in private clinics would need to be catered for.

There could be difficulties for those without a medical practitioner to confirm their HIV positive status. The Department would need to acknowledge the right of an individual patient to self apply.

National AIDS Helpline could help and would need to be briefed.

AIDS Unit expressed unease at:-

- proposal for in house screening of applications, which could be perceived as a conflict of interest.

- the "quasis" for drug dependency and homosexuals in the application form.

Information available from NBTS

Pre 1985 library samples of donations in RTCs would be very rare. RTCs hold stored samples for last 2-3 years, and may have stored samples post 1985.

NBTS hold the donation number of all HIV positive donations, full records of the positive donations held at RTCs.

All HIV positive donors who could be traced (about 90%), have been informed of their HIV positivity, and told not to donate again.

NBTS would be in a position to find the donation number from the hospital and trace back to the donor. Where a donor moves from one RTC to another a transfer note should be held to enable the donor to be traced. Difficulties could arise where perhaps as many as 30 units used in one transfusion would need to be traced.

During 1987, Dr Tim Wallington, Bristol RTC undertook a look back study, and was able to trace recipients from only one third of the seropositive donors due to resistance from consultants and ethical committees. Clinical opinion about the potential benefits of early diagnosis of HIV was now changing and this together with the potential for payments to the patients concerned should lead to greater cooperation.

Dr Gunson raised the question of funding the additional work that providing information for validation of claims would create.

Information available from CDSC

CDSC's validated cases were those where it had been confirmed that blood had been received from an HIV positive donor. CDSC did not have either the name of the individual recipient or donor.

Subject to legal advice, CDSC may be able to write to consultants of patients with reports on the CDSC database, enclosing the questionnaire/literature on the scheme. This would provide a back up to the proposed DH letter to all NHS consultants.

Again, subject to legal advice, CDSC may be able to give to DH an indication on a report after consulting NBTS about the donation.

CDSC said that there would be a problem where the risk had not been identified - some people genuinely did not know how they became HIV positive.

CDSC might be able, subject to legal advice, to check an application in confidence before it went to the panel. CDSC would be able to say, in a particular case, whether they were aware of the case and had followed it up, and if so whether the follow up had established transfusion using HIV positive blood. If it was a new case, CDSC would ask for a report from the consultant.

Both CDSC and NBTS objectives are not to spoil either the donor base or the voluntary reporting system.

Other points

The draft application form implied that the transfusion/ transplant would need to have taken place between 1979 and 1985 to qualify.

The draft application form should include a question "first positive test known".

Tissue to be defined as in CMO letter of 26 April 1990.

Where a payment is made, care would need to be taken that there is no implication of negligence on the part of the health authority.

Further action

Dr Rejman to draft a note on procedure.