MEETING WITH THE HAEMOPHILIA SOCIETY - 3 30 PM WEDNESDAY 21 OCTOBER 1981

Those Attending:

The Revd Alan Tanner - Chairman of the Society
K R Polton MBE - Honorary Secretary
J L Prothero - Chairman, European Advisory Board
K Milne - Chairman, Blood Products Sub-Committee
D G Watters - Co-ordinator (full-time official of the Society)

DHSS Official

S. Godfrey (HS1A)

Background

Haemophilia is an inherited condition where there is a life-long deficiency in the clotting factor in the blood. There are about 5,000 haemophiliacs in the UK, of whom about 2,000 are "severe" haemophiliacs.

The Haemophilia Society

The Society is a voluntary organisation of and for haemophiliacs. Its aims are set out at Annex A. It is supported entirely by its own fund-raising and contributes substantial sums towards research. It has established a network of local groups and works closely with most, if not all, Haemophilia Reference Centres in NHS hospitals. It has done much to increase understanding of haemophilia, particularly among health and personal social service professionals. The Society produces a range of excellent booklets for parents, health visitors, potential employers etc, and represents an excellent example of constructive collaboration between the voluntary and statutory sectors.

Agenda

The Society wishes to discuss:-

a. the supply of Factor VIII and self-sufficiency in blood products; and

b. prescription charges.

a. The Supply of Factor VIII to Meet Projected Demands Over the Next Few Years and the Achievement of Self-Sufficiency in Blood Products, Including the Position As it Affects Commercial Products. As MS(H) knows, about one-third of the Factor VIII used in the NHS is produced by the Blood Products Laboratory at Elstree. Supplies are supplemented by the less concentrated cryoprecipitate manufactured by Regional Blood Transfusion Centres, but the remainder of Factor VIII used in the NHS is purchased commercially at a cost of about £3m. Minister will wish to reassure the Society of the Government's support for the principle of self-sufficiency in blood products, and to report that planning has already begun for the redevelopment of the Blood Products Laboratory. Although the capacity of the new Laboratory has yet to be decided and will be influenced by health authorities' ability to provide the plasma for fractionation, we hope that the Laboratory when fully commissioned in the mid-1980s, will enable the NHS to become self-sufficient.* MS(H) will also wish to mention that in the interim, the short-term upgrading programme currently being carried out at the Laboratory will enable it to double its Factor VIII output to 30 million international units by the end of 1982; indeed there are indications that increasing yields might mean that the Laboratory's output increases to 40 million units a year.

[* possibly in conjunction with the Scottish plant at Liberton.]

Plasma Supply

A working group of the Advisory Committee on the National Blood Transfusion Service has recently prepared a detailed report which indicated that over 400,000 kilograms of plasma would be required to enable the NHS to achieve self-sufficiency in blood products based on estimates obtained from Haemophilia Centre Directors about the demand for Factor VIII which is expected to rise from 60 million international units at present to 100 million international units by 1985. MS(H) might point out to the Society that this represents more than three times the current level of plasma supply and collection on this scale has considerable financial implications for health authorities. Whilst self-sufficiency will offer considerable savings in imported blood products, it is important not to lose sight of the cost of plasma collection, and health authorities will be consulted shortly about the amount of plasma they might supply to the redeveloped Laboratory.

Effect on Commercial Products

BPL's Factor VIII compares favourably to any produced commercially and is suitable for most cases of haemophilia. Clearly if health authorities devote substantial sums to the production of plasma for the Laboratory, they will look to their clinicians to use the BPL product. It is thought that the Society is concerned that clinicians might be prevented from bying commercial products. MS(H) might assure the Society's representatives that we recognise that there will always be cases where for medical reasons a particular commercial product might be required.

Packaging and Presentation

The Society may complain that BPL's product compares very poorly with its commercial counterparts in its packaging and overall presentation. The patient on BPL Factor VIII has to obtain syringes etc separately from his Haemophilia Centre. Commercial Factor VIII often comes as a total package, including the wherewithal for administering the drug. Some companies provide special insulated boxes for transporting Factor VIII until supplies can be stored in a fridge. MS(H) will wish to emphasise the importance of devoting BPL's necessarily limited resources to the product itself. However, the Department is always prepared to consider suggestions about how to improve the product from the consumer's point of view, and the Society could be invited to send its suggestions to officials.

b. Prescription Charges

This is a very difficult area. Most haemophiliacs on home therapy receive supplies free of charge from their Haemophilia Centre. At each visit they account for their usage of the Factor VIII supplied which enables the clinician to maintain a close watch on the pattern of bleeds etc. /NB MS(H) will wish to be aware that there is now some doubt whether supplies of commercial Factor VIII should be provided free or by means of a hospital prescription costing £1. This is being investigated by officials but MS(H) will not wish to mention this to the Society/. Some haemophiliacs, particularly those who live a considerable distance from their Centre, occasionally obtain prescriptions from their general practitioners in the normal way. When they do, however, they have to pay the standard prescription charge. The Society has campaigned long and hard for haemophilia to be added to the list of diseases which attract exemption from prescription charges.

MS(H) is aware of the arguments for and against extending the current list of conditions which are exempted from prescription charges. Ministers have a great deal of sympathy for those people who suffer from any of the <u>many</u> differing individual conditions that are <u>not</u> included in the list of specified medical conditions. Many requests for exemption have been put forward from sufferers from cystic fibrosis, glaucoma, emphysema, multiple sclerosis, schizophrenia, as well as haemophilia. MS(H) will wish to tell the Society that Ministers have very carefully considered the position but, reluctantly, came to the conclusion that an approach to the medical profession in an attempt to agree extension of the list should <u>not</u> be made because any approach would have to include a number of conditions and the cost could be considerable.

The Haemophilia Society was told in May 1980 that there was little prospect of haemophiliacs becoming automatically exempt from prescription charges on medical grounds. The Society is well aware of the existing measures (eg pre-payment certificates, exemption on grounds of low income) designed to assist patients with prescription charges.