SofS MEETING WITH HAEMOPHILIA SOCIETY – 12 NOVEMBER 1991

Present: SofS
Dr Rejman
Mr Canavan
Mr Burrage
Mr GRO-A

<u>Haemophilia Society</u>
Reverend A Tanner – Chairman
Mr Watters – Secretary

The Society welcomed the opportunity to discuss with Secretary of State its concerns about the provision of haemophilia treatment and care. The Society was concerned to preserve in the post Reform NHS and improve on the facilities currently available to haemophiliacs. Haemophilia was a lifelong disorder with no cure, and early treatment could provide its sufferers with the opportunity to lead normal lives. Special facilities were available at reference centres which provided comprehensive care, and patients built up relationships with the reference centres which they often travelled long distances to visit. The Society was concerned to preserve this element of patient choice.

The Society welcomed the Reforms, but a survey of health authorities undertaken by the Society, which had been supplied to the Department in July had indicated areas of concern, particularly:-

- reference centres might not be sufficiently funded and patients might be forced to sever links with centres; the key point was that the money should follow the patient, not the other way round;
- transfer of responsibility for purchasing haemophilia care, hitherto a regional specialty *, to DHAs would lead to a tendency for treatment and care to be provided in local haematology departments, where the expertise and experience may not be available;
- extra contractual referral might be seen by DHAs as the way to provide services which were not available in the district, which would detract from continuity of patient care and would not allow reference centres to offer the comprehensive range of services they currently provide. There would also be problems funding the ECRs.

The Society had circulated copies of "The Essentials of Haemophilia" to Health Authorities and hoped they would aim to provide the level of service described in it. The Society had considered asking for central funding for haemophilia services but recognised this would run counter to the Reforms.

Secretary of State thanked the Society, and referring to the unique provision for haemophilia treatment and care, said that it would be necessary to find a way of ensuring that comprehensive care would continue through the DHAs as purchasers contracting for the services. SofS said that it would be helpful if the guidance contained in circular HC(76)4 was reissued, recouched to reflect purchaser/provider arrangements; the circular would need to remind districts of the need for access to comprehensive services, whether provided at a single centre or as a package at two centres. There were a number of difficult issues, including self referral, which would need to be considered. SofS reminded the Society that medical audit, which the haemophilia centre directors were currently working on for haemophilia treatment and care, would provide a powerful means of ensuring quality of care for small patient groups.

SofS invited the Society to join with the Department in redrafting the circular, which would also require input from the professional haemophilia treaters. The Society said that they would be happy to work with the Department, and were anxious to see guidance issued to ensure that arrangements were in place in good time for April 1992.

* This is not correct, since there is at present no regional funding.

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