Appendix 51
DÍOSPOIREACHTAÍ PARLAIMINTE
PARLIAMENTARY DEBATES

DÁIL ÉIREANN

TUAIRISC OIFIGIÚIL—Neamhcheartaithe
(ONOFICIAL REPORT—Unrevised)

Wednesday, 20 November 1985

Order of Business
Anglo-Irish Agreement 1985: Motion (resumed)
Dáil Éireann Debates: 20 November 1985
Mr. B. Desmond: I will have to be made known so that we will not have the ludicrous position whereby every health board and voluntary hospital in the country will be coming here to see the Minister for Health to see if he is a competent person to be made which are sanctioned without money being provided.

Dr. Ormonde: Did the joint review committee do it? The Department and the Minister in 1983 take place?

Mr. B. Desmond: I do not know but I will find out.

Dr. McCarthy: The Minister does not know?

Mr. B. Desmond: I am being honest and I said that I will find out. The Deputy is a former member of the country so I would not presume to suggest that he did not attend the meetings. I will also write to the Deputies regarding the joint review.

Deputy Ormonde rose.

Mr. B. Desmond: I propose to take Questions Nos. 8 and 21 together. Eight cases of AIDS have been diagnosed in Ireland to date, seven among homosexual or bisexual men and one haemophiliac.

Five have died, one has gone abroad and one is under care. The groups most at risk of developing the disease are the bisexual or homosexual men, intravenous drug abusers, people who have received transfusions or blood products from an infected source and sexual partners of AIDS patients or AIDS suspects. There is no evidence that this condition is in anyway compromising the sexual contact with others presents a risk of infection.

Dr. Ormonde: We accept that but the purpose of questions is to get information which, unfortunately, we are not getting.

Mr. B. Desmond: In relation to the statement which the Minister made regarding the streamlining of procedures for appointing consultants, is he aware that there is an application before Comhairle na nOspidéal for a 15th cardiologist for the city of Dublin while the rest of the country have only three.

Mr. B. Desmond: I have endeavoured to give as much detailed information as possible. For example, I have encouraged direct contact between the Deputy Chief Medical Officer of the Department of Health and the media. I have asked him to speak to the groups and to the media in a professional capacity about the various aspects of this disease and he does so very competently. We are lucky in terms of written information, but that is being remedied. This matter has been the subject of considerable public misconceptions and fears. Nevertheless, eight cases have been diagnosed so far.

Dr. Ormonde: There is growing public concern about this condition. I questioned the Minister’s predecessor in 1971 about four years ago and the Minister is not aware. It is time that a more effective means of communication is set up by the International Centre for the control of AIDS in Atlanta in the United States. Does the Minister have any statistics to show the importance of AIDS cases? We have the same situation in this country since a certain percentage of those serological positive cases may develop the disease. Has the Minister any statistics in relation to the AIDS related complex which is now causing considerable concern internationally since there is a high rate of transmission by a heterosexual contact?

Mr. B. Desmond: Our dependence on the WHO questionnaire, as the Department knows, is very complex. I am reasonably satisfied with the discussions I have had in the Department that the directors of community care have made satisfactory arrangements. I am satisfied that there is a sufficient degree of alertness and that we do not need to be too preoccupied with the Atlanta report. I will write to the Deputy to give him the serological data and other relevant matters. I made a public statement about the incidence of positive reports and I do...
Mr. Taylor: Would the Minister clarify the separation regarding blood given by donors for transfusion to others? What type of testing is carried out on such blood to ascertain the presence of AIDS? Does the Minister regard the testing being done as satisfactory? Would he specify if testing is done for serological analysis and is he aware that it takes three months to ascertain if anti-bodies are developing? He referred to deep freezing of blood. Would he agree that this destroys the essential red cells and therefore is not suitable for transfusion except in limited cases?

Mr. B. Desmond: It is of critical importance that suspects in any circumstances should present themselves to the National Blood Transfusion Service and try to avoid themselves of the automatic testing which the service now carries out on donors. The testing can be done separately. I have made substantial additional resources available to the transfusion service, and major precautions are being taken in this matter. The board has been asked to consider the possibility of using heat treatment to blood products since January and I am assured that the deficiencies referred to by the Deputy are being looked at in the process. We are not now importing any blood because there was a substantial risk of infection from certain imported blood. All our blood resources are now being filled by domestic suppliers. Great precautions have been taken in the last four or five months under new chairmanship; an excellent board member has been appointed chairman of the transfusion service and our service is now a match for any transfusion service in the world, including the UK and Northern Ireland.

Mr. Taylor: Are we using the antibodies test?

Mr. B. Desmond: All blood donors are tested for the HIV virus. A number of representations have been made by individuals who wish to give blood to their relatives that is not acceptable. The precautions now in force are very extensive. We spent money in 1985 on in this and the Government has made more money available.

Dr. McCarthy: I wish to ask a supplementary on Question No. 21.

An Ceann Comhairle: The Deputy may ask one brief question and the Minister may give one brief reply.

Dr. McCarthy: The Minister said he would supply me with figures. Have the Department got those figures or will it take a long time to provide them? I am asking of people who are serologically positive to the virus. In other countries, that is probably the best yardstick they can get. In the United States they found one million people who are HTLV-3 positive. In the UK the figure is 10,000 and in France, 40,000.

An Ceann Comhairle: The Deputy has asked the question and he should let the Minister answer.

Dr. McCarthy: Can the Minister give us the incidence of serologically positive cases among those who suffer from thalassemia?

An Ceann Comhairle: If the Minister has a short answer would he give it?

Mr. J. Leonard: I have been waiting to ask a supplementary.

An Ceann Comhairle: I know that. It is ridiculous.

Mr. B. Desmond: I will forward the information to the Deputy.

Dr. McCarthy: Have the Department got the information?

Mr. B. Desmond: We have got it.

Small Island Farmers Health Contributions.

Mr. D. Gallagher asked the Minister for Health if he will exempt small farmers living on islands who are not medical cardholders from liability towards the payment of health contributions.

Mr. B. Desmond: I would not consider it equitable to exempt small farmers living on islands simply because of their occupation and residency while still requiring persons in similar or indeed poorer financial circumstances to pay health contributions.

Dr. O'Hanlon: Would the Minister arrange to have the names of small farmers, not alone those living on islands, who are not eligible for health contributions because they hold general medical service cards, sent to the Revenue Commissioners so that those people will not be getting demand notices? It is a serious problem for many farmers who are not eligible for health contributions.

Mr. B. Desmond: I will supply the information to the Revenue Commissioners.

Mr. J. Leonard: I have a question on the Order Paper for a long time and I have not been able to get a reply. I should like to raise it on the Adjournment.

An Ceann Comhairle: I will get in touch with the Deputy.

Medicine Costs.

Mr. J. Leonard asked the Minister for Health if he will make a statement on the action he proposes to take following the GMS report on the increasing cost of medicines in 1984.

Mr. J. Leonard: I wish to raise the subject matter of Question No. 10 on the Adjournment but I thought that in order to seek permission to do so I would first have to ask a supplementary question.

An Ceann Comhairle: That is not necessary. The Chair will communicate with the Deputy.

Section 31 Orders.

Dr. O'Hanlon asked the Minister for Health if he has issued section 31
[Mr. B. Desmond] and higher specialist activities in the major teaching hospitals and in the major urban areas.

Tests for AIDS.

33. Mr. Taylor asked the Minister for Health the tests, if any, for AIDS which are applied to blood donated through the Blood Transfusion Service.

Minister for Health (Mr. B. Desmond): All blood donated through the Blood Transfusion Service is currently being screened for anti-bodies to the AIDS virus using the Wellcome anti-HTLV III test. This has been established as the most reliable test for AIDS anti-bodies following an evaluation which has been carried out on the available tests. If a blood sample is found to be positive, it is subjected to a second test, and if the sample is again found to be positive, a confirmatory test is carried out at the virus reference laboratory at UCD.

Offaly Hospitals.

35. Mr. Connolly asked the Minister for Health if he will approve the planning brief for the psychiatric day hospitals in Tullamore and Birr, County Offaly.

Minister for Health (Mr. B. Desmond): The planning brief for the psychiatric day hospitals in Tullamore and Birr, County Offaly, was approved on 6 September 1985.

Beaumont (Dublin) Hospital.

36. Dr. O'Connell asked the Minister for Health the reasons for the present delay in the opening of Beaumont Hospital and when it is expected the hospital will open.

Minister for Health (Mr. B. Desmond): The present delay in opening Beaumont Hospital arises from difficulties which arose with the consultant medical staff of St. Laurence's and Jervis Street Hospitals relating to the provision of facilities for the treatment of private patients. I have put certain proposals to the Irish Medical Organisation with a view to overcoming the present difficulties and I am very hopeful that an agreement can be reached which will enable Beaumont Hospital to be commissioned as soon as possible.

County Mayo Home for Handicapped.

37. Mr. Callan asked the Minister for Health if his intentions in relation to the extra finance and staff needed to open the home for the handicapped at Swinford, County Mayo, and the stage the negotiations with the Western Health Board in relation to staffing have reached.

Minister for Health (Mr. B. Desmond): Officials of my Department met with the chief executive officer of the Western Health Board on 6 November to discuss the commissioning of Aras Airtraic, Swinford. My Department is awaiting the submission of further details requested at the meeting. I will consider the question of the allocation of resources to the project when full details are available to me. The Deputy is aware, however, that there is an embargo on the recruitment of additional staff for the health services at present.

Female Sterilisation.

38. Proinsias de Rósa asked the Minister for Health if he has yet completed the examination of the situation regarding the availability of female sterilisation if he will outline his findings; and if, in view of the established demand for such a service, he will ensure that facilities for female sterilisation are made available at least one public hospital in each health board area.

Minister for Health (Mr. B. Desmond): My Department have recently completed a survey on the availability of female sterilisation throughout the country which indicates that the procedure is available in most health board areas. I am currently examining the information obtained from this survey to see if there is a need for providing this service on a more widespread basis. I will be in a position to communicate with the Deputy as promised as soon as I have completed my examination.

County Tipperary Hospital Appointment.

39. Dr. McCarthy asked the Minister for Health the reason his Department have not yet sanctioned the appointment of a second obstetrician-gynaecologist for St. Joseph's Hospital, Clonmel, County Tipperary, and when this appointment will be made.

Minister for Health (Mr. B. Desmond): The saniton of consultant posts lies with Comhairle na nOspidéal. However, before proposals are submitted to Comhairle na nOspidéal (the statutory body responsible for the regulation of the numbers and type of consultant appointments), my Department examine the funding implications.

In respect of a second obstetrician gynaecologist post for St. Joseph's Hospital, Clonmel, the South-Eastern Health Board have indicated that ten support staff for this consultant at an annual cost of approximately £100,000 are needed. The Department cannot provide the board with any additional resources but they have indicated to the health board that redepolyment of existing resources might be considered as a means of funding if in the board's view the proposal merits sufficient priority.

Services for Mentally Handicapped.

40. Mr. B. Ahern asked the Minister for Health when he intends to allocate funds for the provision of staff in the many new buildings provided for the mentally handicapped but un-opened for some years due to lack of staff.

Minister for Health (Mr. B. Desmond): Since I became Minister for Health I have provided the equivalent of £7,300 million in full year costs to facilitate the commissioning of new services for people with a mental handicap, in different locations around the country including almost £70,000,000 in the current year.

I appreciate that there are still units for people with a mental handicap awaiting commissioning. I will continue to look sympathetically at the needs of mentally handicapped people and their families in the light of any further resources which may be made available to the health services overall.

Availability of Medical Drug.

41. Mr. Kirke asked the Minister for Health the reason cyclosporin used to prevent rejection after heart transplant is not available on the GMS prescription.

Minister for Health (Mr. B. Desmond): An application to have cyclosporin admitted to the GMS was rejected by my Department on the grounds that, because of the special characteristics of the drug, it was more appropriate to have it supplied through hospitals. I understand that arrangements have been made by health boards to have the drug supplied to medical card patients free of charge. The question of admitting the drug to the GMS proper is under examination again within my Department. I assure the Deputy that it is the intention to have the drug made available free of charge to medical card patients in the most appropriate manner possible.

Anti-Smoking Campaign.

42. Mr. B. Ahern asked the Minister for Health if he accepts that the anti-smoking campaign run by the Health Advisory Bureau has been ineffective and if, so, what action he proposes to take.

Minister for Health (Mr. B. Desmond): I do not accept that the no smoking campaign launched by the Health Education Bureau is ineffective. Research carried out for the bureau indicated that 89 per
Appendix 52
COUNCIL OF EUROPE (PARTIAL AGREEMENT)
PUBLIC HEALTH COMMITTEE

ACQUIRED IMMUNE DEFICIENCY SYNDROME

The United Kingdom note on Acquired Immune Deficiency Syndrome in accordance with item 7 of Appendix C to CD-P-SP(83)14.

UK Liaison Section
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September 1983

01-407 5522 Ext 7148
ACQUIRED IMMUNE DEFICIENCY SYNDROME

NOTE FOR OCTOBER 1983 MEETING OF COUNCIL OF EUROPE (PARTIAL AGREEMENT)
PUBLIC HEALTH COMMITTEE: CURRENT UK POSITION

In September 1982 a surveillance scheme to monitor Kaposi's sarcoma and opportunistic infections in the United Kingdom was set up by the Communicable Disease Surveillance Centre (CDSC) in collaboration with the Communicable Diseases (Scotland) Unit (CD(S)U). The objectives of the surveillance scheme are:

1. to detect AIDS in the United Kingdom and to monitor trends in its incidence;
2. to describe the basic epidemiology of the condition;
3. to provide information for those undertaking research in AIDS.

For their purposes, the Communicable Disease Surveillance Centre has adopted, from the USA Centers for Disease Control, the following definition as the criterion for acceptance of a genuine case of AIDS:

"...for the limited purposes of epidemiological surveillance a case of acquired immune deficiency syndrome is defined as one in which a person has a reliably diagnosed disease that is at least moderately indicative of an underlying cellular immune deficiency (such as an opportunistic infection, or Kaposi's sarcoma in a person aged less than 60 years) but who, at the same time, has had no known underlying cause of cellular immune deficiency or any other cause of reduced resistance reported to be associated with that disease."

The so-called "extended lymphadenopathy syndrome" characterised by unexplained lymphadenopathy in two or more extrangular sites for more than three months with fever, malaise, night sweats, weight loss and hepatosplenomegaly, is not included in the definition because of the current doubts about its implications.

To date (19 August 1983), 15 cases of acquired immune deficiency syndrome have been reported to the Communicable Disease Surveillance Centre. All the patients were white men. There were 7 cases of Kaposi's sarcoma without pneumocystis, 5 cases of pneumocystis pneumonia without Kaposi's sarcoma, and 3 cases of other opportunistic infections. The other infections reported were toxoplasmosis and cytomegalovirus in 2 patients and the third has oesophageal candidiasis. Patients ranged in age from 20 to 45. The youngest patient had haemophilia A. There have been 5 deaths, 2 from Kaposi's sarcoma and 3 from pneumocystis pneumonia, all in homosexual patients aged between 35 and 45. Of the 15 patients, 13 were homosexual, one of whom was a drug abuser; 11 of these reported from London, one from Bristol and one from Oxford. The haemophiliac patient was from Wales, and had received Factor VIII imported from the United States; a patient from Lancashire did not come within the known risk groups; 8 patients are thought to have had sexual contact with Americans. Two of the homosexual men reported had had sexual contact with each other. No cases have been reported in laboratory staff or others working in other areas of health care.
...th regard to blood donation in the UK, a leaflet is being disseminated through the National Blood Transfusion Service seeking to discourage potential donors in high-risk groups from giving blood until more is known about what causes AIDS.

Regarding blood products from the USA, as Member States are aware, in March this year the US Food and Drug Administration initiated new Regulations for the collection of plasma, designed to exclude donors from high-risk groups. Although future supplies of Factor VIII both for export and for use in America will be manufactured from plasma collected in accordance with these Regulations, there is still a quantity of stock, some already in the UK and more in America awaiting shipment here, which has been made from "pre-March" plasma. The FDA has recently decided not to ban the use of similar stocks intended for the USA market because to do so would cause a crisis of supply. The same considerations apply to the UK supply position.

So far as Hepatitis Vaccine is concerned the one vaccine which is licensed to be used in the UK is imported from the USA. This vaccine is treated by approved inactivation methods and we have no evidence that it carries any risk of transmitting AIDS. As Member States will be aware, a recent review of the safety of Hepatitis Vaccine by a WHO Expert Group has also failed to find any such evidence.
AIDS, Haemophilia and the Government

SUMMARY

The Irish Haemophilia Society is a voluntary body founded in 1968 to represent the needs of Haemophiliacs in Ireland.

Of the 1500 Haemophiliacs in Ireland, 15 have been infected with the human immune deficiency virus (HIV), 9 have developed AIDS and 4 have died. The infection with HIV was a direct result of medical treatment. This treatment was administered in order to keep people with haemophilia healthy but has exposed them to a potentially fatal illness. The implications are proving devastating to both the people involved and their families who have already faced extraordinary difficulties on account of their haemophilia alone.

We are asking the Government to help restore the quality of life of people with haemophilia and HIV infection by providing recompense to them. We propose that the Government provide life insurance, access to mortgage protection insurance and special ex-gratia payments. Alternatively, a special Trust Fund should be set up to deal with these requirements.

In addition, we are asking for an extension of certain benefits to seropositive Haemophiliacs in order to assist them in maintaining an acceptable level of health and therefore keep them at home and out of acute hospital beds.

The society looks for an understanding response from the Government to help relieve the distress of those affected. This request is urgent; HIV infection has already placed an intolerable pressure on the lives of many of the infected families, who are a limited, clearly defined group, who by any standards deserve compassionate treatment.
SUBMISSION TO THE GOVERNMENT

THE IRISH HAEOMOPHILIA SOCIETY

The Irish Haemophilia Society is the national body which represents the interests of all those with haemophilia and related blood disorders in the Republic of Ireland. The Society was founded in 1968. The Society seeks to maintain a direct contact with Haemophiliacs, and works with the medical profession to promote research into and information on Haemophilia.

WHAT IS HAEOMOPHILIA?

Haemophilia is an inherited blood disorder which affected 1 in 20,000 males born in Ireland. About 1 in 100 males are severely affected. It is potentially life-threatening, since all people with haemophilia do not have sufficient amounts of clotting agents like Factor VIII or Factor IX in their blood.

Commercially obtained concentrates would be caused by using Factor VIII or Factor IX concentrates made from human plasma. Before the advent of home therapy in 1978, people had to present to hospital but then treatment could be continued at home for many weeks.

The development of Factor VIII and Factor IX concentrates meant that patients could be given treatment at home, with a single injection. Until then, haemophiliacs would have been hospitalised at a major economic cost, home therapy allowed people with haemophilia to cope, to maintain contact with their peers, becoming productive members of society with normal life expectancy.

PROBLEMS WITH HAEOMOPHILIA

Blood products used to treat haemophilia in Ireland are manufactured from two sources:

1) Commercially obtained clotting factor concentrates made from blood from paid donors abroad.

2) Factor VIII concentrates made from blood from voluntary donors in Ireland, collected by the Blood Transfusion Service Board, and fractionated commercially.

The price of 1,000,000 doses of human plasma to produce each batch of concentrates clotting factor concentrates. Initial infection of only one donor may contaminate the entire product. The past two years has resulted in most haemophiliacs being exposed to the hepatitis C virus.

Concentrates obtained from abroad have been primarily associated with contamination, but material from both sources may have been contaminated by hepatitis C virus.

FINANCIAL BURDEN

It is impossible to obtain life insurance or mortgage protection insurance to protect homes and families.

Domestic needs: HIV infection can result in rapid weight loss, profuse sweating, diarrhoea and anorexia. Extra heating and lighting are necessary in order to keep warm and to fight infection. There is also increased laundry costs and additional expenses incurred in travelling to hospital.

SOCIAL BURDEN

Families have been stigmatised in their neighbourhood. Pupils are excluded from the playground.

At work — people have been dismissed, or not offered jobs, when their mobility status, or even the fact that they have haemophilia, has been known.

In hospitals — incidents have occurred where HIV positive haemophiliacs have been stigmatised due to hysteria regarding AIDS.

Due to the fear associated with AIDS, many, regardless of their antibody status, have had to publicly deny their blood disorder, and subsequently are a double lie.

Since 1985 all Factor VIII has been heat treated to prevent infection, and all individual donors have been tested.

Commercially obtained concentrates, from the plasma of paid donors, were first suspected of carrying the HIV virus in 1982. Despite this, concentrates produced from Irish volunteer donors were not available until 1986, and by March 1988 we are still not totally self-sufficient; imported concentrates are still being used.

Of the 296 Haemophiliacs registered in Ireland,

- 268 have been tested for exposure to HIV.
- 196 have been infected with HIV (40%).
- 9 have developed "full blown" AIDS.
- 4 have died.
- 70% of severe Haemophilia A patients have been infected.

Medical evidence suggests that large numbers of those who are HIV antibody positive will go on to develop AIDS.

LIVING WITH HAEOMOPHILIA AND AIDS

The implications of HIV infection upon the haemophilic patient have been devastating. Haemophilia is already a potentially life-threatening disorder. HIV and AIDS are placing an intolerable pressure upon family life.
FAMILY BURDEN

Social relationships with wives and girlfriends carry the risk of infection.

It is very important that children avoid the risk of the child being infected at the same time as the mother. The normal process of forming steady relationships and marriage is inhibited because of the risk of infection to the partner.

Low earnings, insufficient benefits, and the inability to secure health insurance and financial aid in a situation of serious financial distress following the death of the breadwinner, widow, and dependent children are left to rely upon social services alone, often with considerable stress to the family. Because of their primary source, many haemophiliacs have been rendered ill and are more vulnerable in these present circumstances.

PERSONAL BURDEN

The sero-positive haemophiliac has to cope with:

Anger and bitterness at the cause of his SEROPOSITIVE status — no medical treatment.

Fear of developing "full blown" AIDS and the fear of any symptoms which can be construed as such.

Fear of infecting his wife or girlfriend.

Fear of losing his job or livelihood.

Burdens of not being able to share his joys with friends due to the danger or being ostracised.

THE NEED FOR GOVERNMENT ACTION

- Medical treatment for haemophiliacs is provided by the Government through the Haemophilia Treatment Centres.
- Their HIV antibody positive status is a result of their medical treatment, which was intended to keep them healthy.
- The number of haemophiliacs who have been exposed to HIV infection is limited. As at present, this is 126. Due to safer concentrates available since 1986, this number is unlikely to increase substantially.
- Those who are HIV positive are easily identifiable through their haemophilia treatment centres.

THIS TASK IS URGENT. The Government must be aware of the strengths left within the haemophilia community and the degree of anger felt by their present status.

RECOMPENSE

The society considers that the needs of haemophiliacs who have been infected with HIV are as follows:

1. THE INSURANCE

1.1. It is proposed that the government should do the following:

Provide and pay for life insurance policies for anyone who is seropositive or becomes seropositive in the future. (The amount of this policy should be ten times the mean banked average wage.)

1.2. Supplement any existing life insurance policy in force for that individual, to the amount equivalent to the above.

1.3. Pay, in the event of death, a lump sum equivalent to the above.

1.4. The above benefit should apply to any haemophiliac, 21 years old or over.

1.5. Any of the above benefits payable on death, should be paid through the executors to the dependants.

1.6. The above benefits should be paid to the dependants of any haemophiliac who has already died or AIDS caused by this illness.

2. MORTGAGE PROTECTION INSURANCE

Proposals in this area are necessary because seropositive haemophiliacs cannot obtain mortgage protection insurance.

2.1. Haemophiliacs who are house owners, and who have existing adequate valid mortgage protection policies should require no special assistance in this area.

2.2. Haemophiliacs who are house owners who have not or have not an existing mortgage protection policy need:

2.2.1. The outstanding balance on the mortgage to be paid off by the government in the event of their death.

2.2.2. The government to arrange for the provision of a special mortgage protection policy to cover the amount of the outstanding loan on the house, and policy premium to be paid for by the haemophiliac at the normal commercial rates.

2.2.3. Haemophiliacs who do not currently own a home but who intend to purchase a house in the future should be covered under 2.2.1. or 2.2.2 up to a maximum of the current amount of the average cost of a house in their own county of residence.
GENERAL BENEFITS

5.1. The aims of these benefits are to keep the Haemophiliacs as healthy as possible, to alleviate hardship, and to keep the Haemophiliacs in the community and out of an acute hospital bed as much as possible, within the bounds of good medical practice. The benefits should be in two categories and should apply to haemophiliacs in these categories.

5.2. CATEGORY 1: SEROPOSITIVE HAEMOPHILIACS -- WELL

5.2.1 Free telephone rental and an allowance to partly cover use of the telephone.

5.2.2 Free travel on road and rail.

The purpose of these 2 benefits would be to facilitate frequent contact with, and visits to the Treatment Centre and convalescing services. Frequent medical checks, reassurance and sympathy should help the Haemophiliac to stay in the community.

5.3. CATEGORY 2: SEROPOSITIVE HAEMOPHILIACS -- UNWELL AND THOSE WITH FULLY BLOODY AIDS

5.3.1 APPROPRIATE CASH SUM TO SUPPLEMENT DIET

It is strongly advised that seropositive haemophiliacs should maintain their general dietary status to help counteract weight and fluid losses. Certain high protein and high calorie drinks are available on medical order, but it is essential that further supplementing or the diet is necessary to allow for a greater intake of high protein foods. It should also be noted that the dietary needs of unwell haemophiliacs may be totally different from their haemophilia, as well needs may have to be prepared for them at considerable extra cost.

5.3.2. FULL ALLOWANCE

Adequate heating is necessary because symptoms involve weight loss and inactivity due to illness, lead to loss of body heat.

5.3.3. FREE ELECTRICITY ALLOWANCE

Electricity usage will increase in order to cope with extra cooking, heating, washing and drying of clothes. Incasim due to night sweats.

5.3.4. FREE TELEVISION LICENCE FOR BLACK & WHITE SET

Television may provide a much needed source of entertainment and distraction, as the sick and possibly inactive haemophiliac.
5.3.5. **AVAILABILITY OF A HOME HELP TO THE HAEOMPHILAC**

The provision of a home help to help with domestic tasks would allow the wife or next of kin to concentrate more fully on looking after the Haemophiliac, or would allow the Haemophiliac living alone to cope better with domestic tasks if unwell.

5.3.6. **Travel Expenses** in the form of vouchers, or petrol expenses, for the next of kin to accompany the Haemophiliac to the Treatment Centre or Counselling service, or to visit him in hospital.

This is necessary because in many cases the patient is not well enough to travel to hospital alone and should be accompanied by his wife or next of kin. Secondly, it is recommended that the Haemophiliac should be counselled together with the next of kin in order to help them to cope with any problems together and offer each other support.

5.3.7. **Any Appropriate Additional Services** which are available such as meals on wheels or visits by Public Health Nurses.

The majority of these services are currently available to people as need requires. We ask that the services be extended to seropositive Haemophiliacs.

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**GLOSSARY**

1. Haemophiliac: as stated in this document is one who has seroconverted and is HIV positive.

2. Any monetary awards or cash sums referred to in this document may be appropriately index-linked to inflation or C.P.I.

3. The Government, in the context of this document, refers to the Department of Health, Social Welfare and/or any of its agents.
Appendix 54
Haemophilia and HIV/AIDS

1. HAEMOPHILIA

1.1 Haemophilia is a bleeding disorder which results in the blood of the haemophiliac not clotting in the normal way. "Normal" blood contains 13 different factors (No. 1-13) which work together to form clotting. If any of these are missing, the blood will not clot properly and bleeding will continue for a much longer period than is normal.

The clotting factors most commonly missing are Factors 8 and 9.

There are two different types of haemophilia - Haemophilia A, where Factor 8 is missing and Haemophilia B, where Factor 9 is missing. Haemophilia A is the more common of the two.

1.2 Haemophilia is an hereditary disorder, passed from the mother to her sons. A woman can carry the characteristic for haemophilia without being affected herself and, on average, half of her sons will be haemophiliacs.

2. Treatment of Haemophilia

2.1 Treatment for haemophilia consists of replacing the missing Factors, 8 and 9. The objective of the replacement therapy is to allow normal clot formation to occur and thus haemorrhage is prevented. Without replacement therapy haemophiliacs suffer life-threatening haemorrhages and other clinical sequelae, such as joint deformities. The results of not having replacement therapy - whatever the quality of such therapy - indicates that the benefits of such therapy would outweigh any risks and the availability of replacement therapy has greatly improved life expectancy and quality of life for haemophiliacs.

2.2 Prior to 1964, the only available form of replacement therapy was fresh whole blood or plasma. This was largely unsuccessful because the required level of the missing factor could not be achieved in the circulation because of volume overload and the fact that these factors have only a short half-life in the circulation. The discovery in 1967 that plasma could be processed to produce a Factor 8 rich product call cryoprecipitate was the major milestone in Haemophilia A treatment. This product was the first successful replacement therapy in Haemophilia A and by 1969 - one year after it was discovered - the Blood Transfusion Service Board (BTSB) was producing it on a large scale.

2.3 Cryoprecipitate is a derivative of blood and was produced by the BTSB from the domestic blood donations - no imported blood donations were ever used for its production.

2.4 The following is the sequence of events relating to the availability of the BTSB home-produced cryoprecipitate, the availability of commercially produced Factor 8, the popular and widespread use of the commercial products and the availability of heat treated and "home produced" Factor 8 by the BTSB.
1968:

A Medical Advisory Panel, representative of various organisations concerned with haemophilia, was established with Dr. J.P. O'Riordan, the then Medical Director of the BTSE, as Chairman. The Advisory Panel set up the first Haemophilia Treatment Centre in the Meath Hospital and at Harcourt Street Hospital. Two bodies were established to work towards improving the quality of life for people with haemophilia - The Haemophilia Society and The National Co-ordinating Committee.

The Treatment Centre was later moved to St. James' Hospital in Dublin (1977) where it was hoped that better facilities for Haemophiliacs would be provided. At that time too, Regional Centres were set up in Cork, Limerick and Galway so the need to co-ordinate the services on a national basis became important.

The committee became recognised by the Department of Health, as its advisory body in all matters relating to comprehensive care for Haemophiliacs.

1971 & 1972

The number of people with Haemophilia A (registered) in this country was as follows: 69 (severe), 13 (moderate), 11 (mild). The number of people with Haemophilia B was: 20 (severe), 5 (moderate), 2 (mild). The BTSE was issuing 11,000 donor units of cryoprecipitate (Factor 8) and 735 units of a Factor 9 concentrate (PFPB) which was by then becoming available and the BTSE was able to produce this product from the supernate plasma residual after extraction of cryoprecipitate.

The BTSE was, in fact, supplying the countries Factor 8 and Factor 9 requirements from domestic donors - there was no need to use imported donations.

1973

Commercially produced Factor 8 concentrates (manufactured by Cutter U.S.A.) were available for the first time. This was administered by the haemophiliac by way of needle/jab and was - and still is - the most convenient form of replacement therapy. In 1973, the BTSE was meeting this Country's needs with our own FACTORY. Home treatment was initiated also in 1973 using cryoprecipitate (Factor 8) prepared by the BTSE - this was not as convenient as the commercial Factor 8 as it had to be administered by way of a shot where the haemophiliac had to lie down during the administration for about a half hour.
1974

In 1974, Travemol also introduced commercial Factor 8. At that time, a decision was taken by the National Haemophilia Co-ordinating Committee (NHCC) to provide commercial concentrates as

- these were more concentrated than the BTSB products;

- they had certain clinical advantages, particularly, for covering major surgical procedures, and

- were more suitable for the home treatment of haemophiliacs (needle/jab rather than "Set" as indicated).

The treatment physicians on the NHCC supported fully the use of the commercial concentrates but the BTSB members of the NHCC did not and reiterated the policy of the BTSB that the home-produced cryoprecipitate should be used as the standard treatment for haemophiliacs for the reasons that

- imported products could not be guaranteed absolutely for their safety (hepatitis B and other viral agents) as the blood-base was derived from dubious sources e.g. drug addicts in the U.S.A.;

- it was morally wrong to use products which were manufactured from the blood of donors in developing countries, and

- the general commercial principle of importing human blood products when there was a self-sufficiency of domestic product.

This decision by the NHCC in 1974 is crucial and central to considerations of liability. The membership of the NHCC is

- the BTSB,

- the Medical Directors of the Treatment Centres in Dublin, Cork, Limerick and Galway,

- the Irish Haemophilia Society, and

- others (Dept. of Education, Dental Surgeons, Nursing, FDVR).

The push to use the commercial products came largely from the treatment physicians and the Society and while the BTSB members sought to have BTSB policy in relation to the use of cryoprecipitate endorsed, they could not intervene in what is fundamentally a doctor-patient relationship.
1974 (contd.)

In view of the NHCC recommendations and the growing availability of commercial concentrates, the BTSB considered the development of home-produced product but did not proceed as:

- the production of commercial concentrates requires a large-scale manufacturing process which would not be economical for a population of the size of Ireland (a £15-£20 million investment would have been required at that time to produce £300,000 worth of final product).

- they also necessitated the collection of much greater volumes of raw plasma as the process results in a significant loss of activity units of Factor 8 as compared to cryoprecipitate.

1974-1976

The BTSB developed a small pool of freeze-dried cryoprecipitate for home use and commenced the manufacture of cryoprecipitate in a more convenient form for clinical use.

1977

All along the BTSB consistently advocated the principle of National self-sufficiency and met this requirement through the availability of cryoprecipitate. It was a matter for the clinician to recommend a particular form of treatment and in 1977 the BTSB members on the NHCC won the concession that where practical (i.e. in hospital mainly), BTSB products should have priority over commercial products. The clinicians continued to recommend the use of the commercial concentrates for home use.

1980

Towards furthering their policy of self-sufficiency, the BTSB requested the Minister for Health for approval to begin the development of a more commercial form of Factor 8 (which is the present freeze dried cryoprecipitate). The Department of Health approved of this request and it was at this point that a start was made at becoming self-sufficient and non-reliance on commercial products, well in advance of the AIDS problem.

1981

In line with its role as central distribution/purchaser, the BTSB, on the instructions of the Directors of the Treatment Centres, purchased concentrates from three commercial companies - Armour, Immuno, and Travenol. At
this stage, the volume of work undertaken by the BTSB in relation to self-sufficiency was being advanced favourably and by 1980, at the request of the HRCC, the BTSB became the central purchasing and distribution body for the commercial supplies of intermediate and concentrated Factor 8 and Factor 9 products. BTSB products were available on request.

It was in 1983 that the AIDS Syndrome was first described.

1983

In January 1983, it was reported in the U.S.A. that seven Haemophiliacs had developed AIDS and a possible connection with blood products was reported. There was general concern about AIDS and its relationship with the infusion of blood products.

The BTSB moved swiftly to protect the blood supply at this stage, even though there was no test available for the antibody to the virus and the screening donated blood. Following a Council of Europe Recommendation (June 1983) that compulsary ability of self-exclusion from donating blood under which persons in identified high-risk groups could refrain from donating.

Ireland was the first Country in Europe to implement this recommendation.

1984

The possible causative viral agent for AIDS (HTLV-III) was discovered and the BTSB stepped up its national self-sufficiency programme for Factor 8.

In December 1984, the BTSB began stocking heat-treated Factor 8 and all non heat-treated product was withdrawn and returned to the suppliers.

1985

The BTSB entered a contract with a commercial fractionation company to process fresh source plasma of Irish origin for production of Factor 8 concentrate. It was estimated that 12,000 litres of plasma would be required to yield the required units of Factor 8. Three factors emerged which prevented the immediate attainment of full self-sufficiency. The factors were:

- the introduction of heat-treatment of the product, which adversely affects the yield;

- the cessation of use of cryoprecipitate which could not be heat-treated, and

- the poor yield achieved by the commercial fractionation of our plasma.
These factors resulted in a delay of about 2 years until self-sufficiency was achieved, but even during the process, information was given to the Department verbally that the Haemophilia Society members of the NHCC did not wish to use BTSB products.

Testing of the Antibody to the HIV (AIDS) virus begins in the USA (1985) in June 1985 and it extended to Europe in October of that year. BTSB tests began routine testing of all blood donations, but required that additional testing sites be available at BTHD Clinics throughout the country. Heat treatment is introduced for blood products to inactivate any possible virus. As mentioned blood products which had been issued prior to the introduction of heat treatment were withdrawn by the BTSB.

Over 3,000,000 units of Factor 8, heat treated, was produced for the BTSH. By April of 1987, the BTSH had sufficient supplies of Factor 8 to meet the full estimated national requirement of this product. Ireland is one of only 4 countries which are self sufficient - the others being Finland, Norway and the Netherlands.

1988

Since June 1988 there are ample supplies of Factor 8 prepared from Irish sourced plasma to meet requirements. Commercial imported concentrates continue to be recommended and demanded, however.

3. Summary of precaution to protect blood supply

(i) a policy of excluding orthodox high risk groups (June 1985). Ireland was the first European country to introduce this policy.

(ii) the BTSB always advocated the use of home-produced cryoprecipitate before and during the AIDS problem.

(iii) testing blood donations for antibodies to the virus commenced in 1985 as soon as a test became available. As a result, Ireland has not had a case of donation-related case of HIV on AIDS.

(iv) heat-treated products only were used from 1985 again as soon as it was shown heat treatment kills that virus and non heat-treated products were withdrawn and

(iv) self-sufficiency in heat-treated convenient Factor 8 was achieved in 1987. Movement towards this commenced in 1980 but prior to that, Ireland was self-sufficient in cryoprecipitate. Only 3 other companies are self-sufficient (Norway, Finland and the Netherlands).

In the light of the above, Ireland acted to protect the blood supply as the first priority in relation to AIDS and acted at all times to introduce newly discovered measures towards this end.
4. Licensing of Factor 8 and Factor 9

The commercial Factor 8 (Travenol, Immuno, Armour) always required a Product Authorization, as these go through a process which entails the addition of chemicals etc. PA's were granted for the products by the Department of Health on the advice of the NDAB.

The "old" cryoprecipitate (1978-1987) did not need a PA as this was simply a derivative of blood plasma. Factor 9 did not need a P.A., for this reason alone.

The Factor 8 concentrate, which has made Ireland, self-sufficient, requires a P.A.

5. Haemophilia and HIV infection/AIDS

5.1 The Irish Haemophilia Society have sought compensation from the Irish Government for haemophiliacs and for their dependants who have suffered HIV infection. To date (11 April, 1989)

- 112 haemophiliacs have tested positive.
- 10 have developed full blown AIDS and
- 6 have died.

5.2 The Society allege that the infection resulted from treatment received by haemophiliacs from:-

- commercially obtained Factor 8 and
- concentrates (Factors 8 and 9) made from blood from Irish donors and collected in America

The Society state that two persons were infected from Factor 9 (home produced) and the remainder from Factor 8. The reference to Factor 9 is of concern, although the question of treatment with Factor 8, and perhaps lifestyle, would have to be explored in relation to the 2 cases.

5.3 Profile of HIV Positive Haemophiliacs

In order to provide a profile of the HIV positive haemophiliacs population the Irish Haemophilia Society has supplied the following information compiled from a recent confidential survey:

- No of surveys despatched - 70
- No. returned - 58
- Adults (> 16 years) - 43
- Children (< 16 years) - 15
The following information is compiled from the adults survey returns:

1. **Age distribution**

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<td>31-40</td>
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<td>41-50</td>
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2. **Marital Status**

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<td>Single</td>
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4. **Benefits**

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6. **Accommodation**

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<td>Live with Parents</td>
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<td>Council/Corporation</td>
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<tr>
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7. **Mortgages**

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8. **Life Insurance**

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homosexuals, bisexuals and their families - over half of the I.V. drug abusers affected have families and 53 babies born to these couples have tested positive;

- by dealing with one group in a special way, for what is an extremely sensitive condition, would have the effect of stigmatising other groups of sufferers and of generating feelings of guilt and discrimination against these groups;

- if special arrangements, such as the establishment of a Trust Fund were made for one group, they would have to be made for all AIDS sufferers and their dependants, and this would be difficult to contain, numerically and financially (there are 900 HIV+ persons in Ireland at present);

- in relation to AIDS it is the responsibility of the Minister to provide health services for all persons suffering from the disease who require them, equitably and pragmatically and this responsibility has to be implemented uniformly and effectively in the light of the needs of all such persons;

- it is not appropriate to base decisions on criteria such as the existence of "finite numbers" in a particular group as the possible source of infection (through treatment) and exclude other sufferers on the basis of their numbers and the possible source of their infection (through lifestyle) and

- the treatment provided for Haemophiliacs was and still is the standard treatment for their condition and was assessed for safety and efficacy, and administered on the basis of the state of the Act at the time (this is a crucial consideration given the precedent which would be created of a litigation conscious Society for other forms of medical treatment, if it were conceded that one particular form of treatment was singled out as a basis for special compensation arrangements).

7.3 In addition, the information in sections 2 and 3 of this memorandum shows that all possible measures were taken as soon as they possibly could, to protect the blood supply from infection and the taking of these measures - and other measures outlined - underline the case for not departing on special schemes for infected haemophiliacs.

7.4 There is also the consideration that because of their condition many haemophiliacs could not get adequate insurance/mortgage protection cover in any event and the onset of HIV was not necessarily the sole obstacle to the availability of such services.

7.5 It is known that at least one haemophiliac was a homosexual and some may have been using drugs intravenously and while it is accepted that there is a prima facie link between the infection and their treatment, other possible sources of infection could not be overlooked.
Working Group to review the Accessibility to Health Services for AIDS Sufferers

Towards evaluating the problems, if any, which all AIDS sufferers have in access to health services in the most equitable and pragmatic way possible, the Minister established a Working Group under the Chairmanship of Mr. Terry Leyden, T.D., Minister of State to enquire urgently into the accessibility of services to AIDS sufferers generally. The Group consists of representatives of the Irish Haemophiliac Society, Dept. of Health, the health boards, the Virus Reference Laboratory, U.C.D., and the Drugs Treatment and Advisory Centre, Dublin. The Group has commenced its work and has met with relevant organisations and persons to enable it to evaluate any difficulties which might exist in access to services generally for AIDS sufferers as follows:

- the Eastern Health Board,
- the AIDS Action Alliance,
- Dr. O. Carey G.P. to the Dublin Prisons,
- the C.S.S.C. (Pr. Lavelle),
- St. James's Hospital,
- Cork AIDS Alliance,
- Ana Liffey Project,
- Drug Treatment Centre, Trinity Court,
- Dublin Dental Hospital (Dr. D. Shanley),

and on 17 April, 1989 with

- the Dept. of Justice,
- the Dept. of Social Welfare and
- Dr. S. O'Hickey, Department of Health, Chief Dental Adviser.

In the light of the Group's report, the Minister proposes to bring the matter to Government.

Possible Local Implications

The Society and others (some newspapers, public representatives have stated that the State has a moral, if not legal obligation to compensate haemophiliacs who have contracted HIV from Factors 8 and 9 "through no fault of their own". As indicated in Sections 2 and 3, however, despite the advice of the ETSB, the HESC (which includes the IHSE) and the Treatment Centre Directors pressed for the availability of the more convenient imported commercial factor 8 and this in itself, shows that persons outside the State agencies were to the forefront in recommending this particular form of Factor 8 treatment.
There is a thin dividing line between acceptance of responsibility on a moral and a legal basis and in the context it would not be appropriate for the State to take decisions on moral grounds, particularly where other related issues and precedents would inevitably arise.

In the U.K., for instance, the Government there accepted that I had a moral responsibility to provide especially for infected haemophiliacs but subsequently, 100 haemophiliacs have initiate legal proceedings against the U.K. Government, health authorities etc. and the decision of the Government there is seen as not being helpful in establishing a defence.

10. Legal Proceedings in Ireland

Legal proceedings have been served (6 April, 1989) by the Irish Haemophilia Society on:
- the Minister for Health;
- the NDAB;
- St. James's Hospital Board;
- the BTSB, and
- Prof. Ian Temperley, and
- the Attorney General.

The proceedings indicates that the case will revolve around negligence and breach of statutory duty in relation to the safety of the blood products in question.

11. Precedents Quoted in Support of Special Measures for Infected Haemophiliacs

11.1 Thalidomide

Thalidomide preparations were marketed in this country from May 1959 to January 1962 when they were withdrawn from sale by the manufacturers. They had come under suspicion in connection with the incidence of certain types of congenital deformities, mainly limb defects and, in severe cases, lack of limbs. The preparations on sale in this country were manufactured by Chemie Grunenthal of Germany and distributed by one firm.

In May 1970, it was confirmed that an offer of compensation by the German manufacturers of thalidomide applied to Irish children born with defects attributable to the drug. The compensation provided by the firm of Chemie Grunenthal was agreed out of Court and amounted to DM 100 million. The German Government added a further DM 50 million which, with accrued interest of DM 20 million, made a total fund equivalent to about £23 million. A law passed in Germany, which came into force in October 1972, provided for the administration of the fund (Stiftung "Hilfswerk fur Behinderte Kinder"). The German
compensation was in the form of a lump-sum ranging from DM 7,500 to DM 25,000 (from £1,250 to £4,200 approx) and monthly allowances for life ranging from DM 100 to DM 450 (from £17 to £75 approx). Although no undertaking was given by the German authorities at the time, the monthly allowances have been increased twice from 1st August 1976 (25%), from 1st January, 1980 (13%) and from 1st January 1985 (10%) and they now range from DM 55 to DM 699 per month.

In May, 1973 the Irish Government decided in principle that it should provide financial assistance in addition to the compensation available to Irish children from the Compensation Fund set up in the Federal Republic of Germany.

The Minister then appointed the Irish Thalidomide Medical Board to identify the number of Irish children affected by the Thalidomide Drug and report in each case the degree of disability and the care and treatment required. Between November, 1973 and April, 1974, when they reported to the Minister, the Board examined 112 children (5 cases had already been accepted as due to Thalidomide). The Board accepted that there were 34 Irish children affected. One of these, however, had already been accepted for compensation under the much more favourable settlement concluded with Distillers, who made and distributed the drug in Britain, because the mother took thalidomide while living in Britain.

In December, 1974 the Government decided to grant to each of the 33 Irish children affected by the Thalidomide Drug further financial assistance in the form of a lump-sum equivalent to four times the German lump-sum and a monthly allowance for life equivalent to the German monthly allowance. The lump-sums range from £5,000 to £16,667 and the monthly allowances, payable from 1st January, 1975, from £17 to £75 (a conversion rate of DM 6 t £1 was used).

On 9th January, 1975, when the Minister for Health met representatives of the parents to give them details of this decision, he indicated that the monthly allowances would be adjusted from time-to-time “linked with money values”. Other provisions were also made to the victims, such as the availability of medical cards.

It should be noted that

(i) all of the persons who were considered by the Irish Thalidomide Medical Board to have been damaged by Thalidomide were compensated, and

(ii) all of the persons would probably have been otherwise healthy had their mother not used Thalidomide during pregnancy.

11.2 Whooping Cough Vaccination

In response to calls from the Irish Association of Parents of Vaccine Damaged Children (1973-77), the Minister for Health established (1978) a three-man Expert Medical Group to assess i
persons in respect of whom it was alleged, had been damaged by
whooping cough vaccination, were in their opinion, so damaged.

93 persons were assessed by the Group out of which 16 were
considered on the balance of probabilities to have been vaccine
damaged.

Initially, the Government felt that the most practical was of
dealing with the 16 persons was to ensure that all relevant
health services were available to them but in November, 1982
decided to offer to each of the 16 persons an ex-gratia payment
of £10,000. To date, 13 persons have accepted the offer.

As with thalidomide —

(i) each person considered to have been damaged by the
vaccine was made the offer, and,

(ii) each person would otherwise have been healthy if the
vaccine had not been administered to him/her.

12. Options for consideration (if required)

12.1 Pressure on the Financial Services Sector (Insurance, Building
Societies, Banks)

In view of Government intervention to assist insurance companies
(PMPA, ICI) and Banks (AIB), in the past, there is a case for
Government to seek to involve these sectors in establishing, or
joining with the I.H.S. in establishing a Trust Fund for
haemophiliacs. The issues raised by the I.H.S. do not relate to
the areas of responsibility of the Minister for Health and if
necessary, either a joint approach by Government through the
Ministers for Health, Industry & Commerce and Finance or better
still, the Ministers for Industry & Commerce and Finance only to
the financial insurance indemnities to participate, would be
appropriate.

12.2 Contribution by Government towards the establishment of a Trust
Fund

The Government, through, the Minister for Health could
contribute a sum of £100,000 to the I.H.S. as seed money for a
Trust Fund for Haemophiliacs or to the AIDS Fund as seed money
for a Trust Fund for all AIDS Sufferers.

12.3 Review Group on Haemophiliacs/AIDS issue

A Group, chaired by a High Court Judge, could be established to
review the issue and to make recommendation to Government. The
Group would consist of representatives of:

- Dept. of Health.
- the BTSE.
- the I.H.S.
12.4 At E.C. level
Seek to have an E.C. recommendation, which Ireland would react to, made through the E.C. Council of Health Ministers. In this regard, the situation in the E.C. seems to be fluid at present.

13. Measures taken to date to assist infected Haemophiliacs in Ireland:

(i) By Dept. of Health to Society
- Grant of £5,000 in 1988 from National Lottery to Irish Haemophilia Society for support services.
- Further grant of £50,000 offered (February 1989) but no indication from Society to date of acceptance.

(ii) From Eastern Health Board (with approval of Department) to Society
- Previous grant of £12,000 increased this year to £30,000.

(iii) Other Support from the Department
- Funding in 1988 (£15,000) from the National Lottery for counselling services has been provided to St. James Hospital where the National Haemophilia Unit is located.

14. Recent decision of the Eastern Health Board support the position of the Minister for Health
The E.H.B. recently voted to support the position of the Minister for Health.

15. Position in other E.C. Member States
The position as in January 1989 is set out in the following - the Embassies of the E.C. Member States were asked (11 April, 1989) for the up-to-date position and this is awaited.

15.1 Special Schemes
(a) U.K. - Fund of £10 million which works out at about £8,500 Sterling per person.

(Note: Despite the D.H.S.S. initiative, 100 infected haemophiliacs are taking legal action in the U.K.)

(b) Denmark: Scheme of payments based on need.
(c) France: Announcement (8 April, 1989) that a compensation Fund for infected Haemophiliacs is to be established - no further details available yet.

15.2 No Special Measures in Other Member States although -

(a) West Germany have a general drugs-related injury scheme.

(b) Netherlands - have a private foundation which attempts to meet the financial needs of haemophiliacs.

15.3 The U.K. D.H.S.S. has informed the Department verbally that the decision (November 1987) to have a Trust Fund established for HIV infected Haemophiliacs was taken as a result of the intensive lobbying done by the U.K. Haemophilia Society on Members of parliament and the political parties there and the resultant discussions in the House of Commons.

Initially, the Secretary of State for Social Services decided not to make special provision for Haemophiliacs on the grounds that:-

- it would be difficult to contain in one group and

- it would be tantamount to an admission of liability in relation to the quality of the standard form of treatment given at the time.

This decision was revised on humanitarian grounds alone. The Secretary of State (John Moore) met the Society and was influenced, on a personal basis, by their spokespeople, some of whom were HIV positive. He decided to recommend to the Cabinet that the persons in question were in a unique position whose quality of life had already been compromised.

So far, no other AIDS Group have sought similar arrangements in the U.K. Neither have applications been received for compensation from other persons who may have suffered injury or loss as a result of medical treatment.

Litigation has however been initiated by 110 HIV positive haemophiliacs.

The Trust Fund called the MacFarlane Trust is administered by the Society and the D.H.S.S. and to date only £700,000 has been paid out, in small single payments or payments of £20 approx. per week. The administration of the Fund is a matter for the Trustees.

M Lyons

Minister

of Health

10 April, 1989.