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Briefhs.260

From: Dr R J Moore  
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**BRIEF FOR MEETING WITH THE HAEMOPHILIA SOCIETY ON 3 NOVEMBER 1987**

I attach a brief prepared in collaboration with Dr Smithies and Mr D MacKay of A3D. It takes no account of the reply given by the Prime Minister in the House on 27 October that she would discuss the matter with MS(H).

**GRO-C**

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*Prescription charges?  
Is severe disability  
premium?  
Package private policy?*

## BRIEF FOR MEETING WITH HAEMOPHILIA SOCIETY ON 3 NOVEMBER 1987

### Summary

The Haemophilia Society have mounted a campaign for compensation for their members who have become infected with the AIDS virus (HIV) from contaminated blood products. The campaign was launched in early October and the Government have not yet responded directly. Ministers reconsidered the issue before the campaign and decided that there was no justification for changing the line given to the Social Services Select Committee on AIDS in May 1987 that no special compensation arrangements would be made.

### Background

#### 1. The Haemophilia Society

The Society is a registered charity which represents the interests of all those with haemophilia. It seeks to maintain standards of medical care and works with the medical profession to share information with its members. The Society received Section 64 grants from the Department of £15,000 in 1984/85 £20,000 in 1985/86 and £8,500 approximately in 1986/87 to help in providing information on AIDS to their members. They have not applied for a grant in 1987/88. Their Patron is HRH The Duchess of Kent. Annex A gives an introduction to the Society and its work.

## 2. The Delegation

The delegation to meet Secretary of State will consist of:

The Rev Alan J Tanner	Chairman
Dr Peter Jones	Medical Adviser
Simon Taylor	Executive Committee Member
David Watters	General Secretary

Details are at Annex B

## 3. Haemophilia

Haemophilia is a group of hereditary blood disorders which affect over 7,000 individuals in the UK. Around 2,000 of these are severely affected. People with haemophilia lack essential agents which help their blood clot. There are two main forms of the disease, sufferers from Haemophilia A (the majority) lack the agent Factor VIII, sufferers from Haemophilia B lack Factor IX. Both groups suffer from bleeding episodes, most often into their joints, which if untreated can lead to severe arthritis crippling them. If this bleeding occurs into the brain it can cause premature death. Annex C describes what the disorder can mean to individuals.

## 4. Treatment for Haemophilia

Factor VIII and Factor IX is obtained from the blood of donors. Treatment with concentrates of these factors manufactured from blood enables haemophilia sufferers to lead normal lives and to enjoy a normal life expectancy. Since the mid 1970's because of technological progress in the production of the concentrates haemophiliacs have been able to treat themselves at home to control bleeding episodes or as a prophylactic. These

concentrates need to be injected intravenously - in children this will be done by the parents.

5. Supply of clotting concentrates (Factor VIII and IX)

In England and Wales Factor VIII and Factor IX are made by the Blood Products Laboratory at Elstree (part of CBLA, a special health authority) from the blood of voluntary donors to the blood transfusion service. Although we are self-sufficient in Factor IX, we have always been unable to match the demand for Factor VIII, consequently the extra requirement has been met by importing Factor VIII from commercial sources, mostly in the USA. To enable the increased demand for Factor VIII to be met by England and Wales nearly £60 million has been spent on a new Blood Products Laboratory at Elstree. This was opened in April 1987 and has already started trial production. It will produce up to 75% of our requirement in 1988 and enable us to be self sufficient in human derived blood products in 1989. [Annex D gives details of the new BPL]

[The development of a genetically engineered product is proceeding but its availability for clinical use is still some years away.]

6. Haemophilia and AIDS

It is now known that the AIDS virus HIV can be transmitted in blood products. Manufacturers of Factor VIII pool thousands of donations to make a batch of product. One infected donation can contaminate a whole batch. The danger of HIV transmission was not anticipated. Many haemophiliacs were infected in the period between the apparent advent of AIDS virus in the USA in the late

1970's and the discovery that the virus could be inactivated by heat treatment in late 1984. Most of the haemophiliacs were infected by imported Factor VIII because AIDS was more prevalent in the USA. However some have been infected by product made at Elstree.

Methods to test blood for antibodies to the AIDS virus were developed in 1985 and nowadays all blood products are made from tested donations and are also heat treated to inactivate any HIV which may be present. They are therefore considered to be safe.

7. Numbers of Haemophiliacs infected

The total number of haemophiliacs infected is not known exactly. We accept the Haemophilia Society estimate of 1,200. So far 57 have AIDS and 41 have died. The outlook for the rest is unknown but seems bleak.

8. The Campaign

The campaign was given a Press launch on 13 October. There will be a lobby of MP's on 5 November, all MP's have been sent campaign literature. So far over 170 pieces of Private Office correspondence on the issue have been received. More than 110 needing a Ministerial reply. Nearly all the quality newspapers have now carried articles or editorials supporting the campaign Annex E. The television programme 'First Tuesday' is expected to run the issue in December or January.

9. The Governments' Line

The Government's line has been that there has never been a general State scheme to compensate those who suffer adverse

effects from medical treatment. Compensation can only be awarded by the courts if negligence is proved. The full range of Social Security benefits are available to those haemophiliacs who qualify. Officials have helped the Haemophilia Society to prepare guidance for their members on claiming benefit.

This line has been held because of the logical difficulty of distinguishing the claim by haemophiliacs from the claim of others damaged in the course of their medical treatment. Compensating haemophiliacs would lead to pressure from other groups for similar compensation

#### 10. The Social Services Select Committee

The Government's line on compensation was presented to the Social Services Select Committee. In their report on 'Problems associated with AIDS' the Select Committee commented 'that calls for compensation for haemophiliacs ... and for special life insurance arrangements ... deserve careful consideration.' They acknowledged that demands for compensation raised many difficult issues. The detailed Committee comment is at Annex F

#### 11. Provision of Counselling Facilities

The Department recognised the extra social and medical problems which AIDS was causing haemophiliacs and provided additional funds to the 6 Haemophilia Reference Centres in England. This funding, totalling ~~£~~£650,000 since 1985, was specifically for the HIV counselling of haemophiliacs and their families. Support for counselling will continue.

## The Issues

The case presented by the Haemophilia Society is at Annex G.

### 1. Negligence

There has never been any suggestion from the Society or elsewhere that doctors or manufacturers were negligent. The Society have themselves obtained legal advice to the effect that on present known facts the prospect of the majority of claims succeeding is remote because of the difficulty of proving negligence and the difficulty of identifying the proper body or person to sue.

### 2. Line to Take

I am not aware that negligence has ever been suggested. This would be something for the courts to decide.

### 3. Government delay in achieving self sufficiency in Factor VIII

The Haemophilia Society have made the point in the past that if we had not been reliant on imported Factor VIII then many fewer haemophiliacs would have been infected with HIV. That is probably true. However, they further argue that it is due to Government inertia that nothing was done, until too late, to increase supplies of Factor VIII in England and Wales. David Owen promised in 1976 that we would be self sufficient in 1977. Now in 1987 we are still not self sufficient.

### 4. Line to Take

I am not of course responsible for David Owen's promises, however it is interesting to note that in 1976 our consumption of Factor



VIII was only 15 million units a year. As so often happens with health care, a successful treatment generates increased demands and today it is nearer 80 million units. Since 1976 production from Elstree has increased from 7 million units a year to 25 million units. Recognising the need in 1981 we agreed to build the new Blood Products Laboratory at Elstree to make us self sufficient. This was before the advent of AIDS. This project has been built using a fast-track contracting method to get it completed as quickly as possible. We had hoped it would be completed during last year but it has proved a very complex undertaking. Nevertheless we can look forward to substantial production during 1988 and self sufficiency in 1989. The final cost is close to £60 million so it represents a considerable commitment to haemophilia care.

5. Extra Benefit for Special Diets/Heating/Laundry

The Society are asking for a non means-tested benefit to assist with special dietary requirements, laundry and heating bills. They have calculated that these amount to £65.22 a week.

6. Line to Take

I appreciate that there are extra costs brought on by this illness. There are some provisions in the social security scheme to help to meet the extra costs of disability on a general basis for example Attendance Allowance and some of your members will qualify for these benefits. [The Supplementary Benefit Scheme does include additions for dietary, laundry and heating needs.] I hope that the advice which officials have given the Society about



benefits will help your members to qualify for their proper entitlement.

It would be very difficult, however, to justify the introduction of the type of benefit which the Society proposes within the social security system as other people, with similar extra costs, would be unable to qualify only because these arose from a different cause. The approach to the provision of these benefits has always been that entitlement is based on the effect of disability rather than its cause.

7. Help with life insurance or mortgage protection policies

The Society are asking for a fund to help with life insurance and to give mortgage protection.

8. Line to Take

It is sadly true that many people with serious illnesses are unable to get life insurance at affordable premiums. I cannot see how we can make exceptional arrangements for haemophiliacs.

9. A Fund for Recompense

The Society are asking for a special fund from which payments can be made in recognition of the social distress caused to haemophiliacs by HIV infection.

10. Line to Take

I have every sympathy for this courageous group who are coping with HIV infection as well as their haemophilia. We are already doing what we can to help.

We have provided funds totalling £650,000 to Haemophilia Reference

Centres so that they can give the specialist counselling support which is needed. We have helped people with haemophilia towards all the financial support from Social Security benefits to which they are entitled. Last but not least we have provided the splendid new factory at Elstree. ~~£~~<sup>¥</sup>60 million represents a considerable commitment to the care of haemophiliacs.

Although I do not believe further special financial measures can be justified, we will continue to show our sympathy in these practical ways.

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