HAEMOPHILIA AND AIDS
THE HIDDEN DISASTER

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AIDS, HAEMOPHILIA AND THE GOVERNMENT

A SUBMISSION from the
HAEMOPHILIA SOCIETY
calling for financial provision
for people with haemophilia
infected with the AIDS virus.

October 1987

AIDS, HAEMOPHILIA AND THE GOVERNMENT

SUMMARY

The Haemophilia Society is an independent charity founded to represent the needs of people with haemophilia and related disorders in the United Kingdom.

1200 people with haemophilia are now known to have been infected with the human immunodeficiency virus (HIV). The infection with HIV was a direct result of National Health Service treatment. This treatment was administered in order to keep people with haemophilia healthy but has in fact 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.

At Government's suggestion the Society has already explored the question of redress through the legal system and has been advised that claims for compensation as such are most unlikely to succeed because of the difficulty of proving negligence. In any case, the Society is advised that any solution which may be provided by the courts will not be available in the short term. However, the needs of families are immediate.

The Society is therefore looking to Government as the only available source of support, recognition and recompense.

The Government should provide a weekly benefit to help all infected people with haemophilia and HIV to live with AIDS, a fund in recognition of the disaster which has befallen them, an insurance scheme to protect the home, and provision for dependants.

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 HAEMOPHILIA SOCIETY

The Haemophilia Society is the national body which represents the interests of all those with haemophilia and related blood disorders in the U.K. The Society seeks to maintain standards of care around the country, and works with the medical profession in sharing research and information.

WHAT IS HAEMOPHILIA?

Haemophilia is an hereditary blood disorder which affects over 5,000 individuals in the U.K., of whom 2,000 are severely affected. It is potentially life threatening inasmuch as that people with haemophilia do not have sufficient amounts of the clotting agents factor VIII or factor IX in their blood.

Without treatment haemophilia results in an extremely severe and painful arthritis and subsequent crippling, or in premature death. Control of the disorder can only be achieved using blood product therapy. People with haemophilia are totally reliant on transfusions of factor VIII or factor IX made from human plasma. It is through these blood products that the Human Immunodeficiency Virus (HIV, the virus which causes AIDS) infected people with haemophilia.

Factor VIII and factor IX are completely absent in people with severe haemophilia. In this condition spontaneous bleeds can occur any time of the day or night, without warning. On average a person with severe haemophilia bleeds 35 times each year, but the range is wide. Children and young adults often experience bleeds which require daily treatment.

Before the advent of home-therapy in 1973 people had to attend hospital for their treatment and were confined to bed for many weeks.

The development of potent factor VIII and factor IX concentrates meant that patients could be given their treatment at home or work by simple injection.

Until the emergence of AIDS the treatment of haemophilia had been heralded as a major success story. Home-therapy allowed people with haemophilia to compete on an equal footing with their peers, becoming productive members of society with a normal life expectancy.

AIDS AND HAEMOPHILIA

It takes up to 30,000 donations of human plasma to produce each batch of clotting factor concentrate. Viral infection of only one donor may contaminate the entire product. Of the 1200 people exposed to HIV from within the haemophilia community, to date, 60 have been notified as having developed AIDS; 45 have died.

In other words of all people with haemophilia:

- Approximately 1 in 5 have been exposed to HIV. They therefore have developed antibodies to the virus and are susceptible to developing AIDS

- Of those exposed approximately 1 in 20 have died to date as a direct result of their treatment with contaminated blood products

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

- **People with haemophilia who have been exposed to HIV infection are a finite number**

- **They were infected whilst taking treatment which was intended to keep them healthy**

- **They are easily identifiable through their Haemophilia Treatment Centres**

- **Their HIV antibody positive status is a result of medical treatment from the N.H.S.**

Blood products are manufactured from two sources:-

(a) Commercially obtained clotting factor concentrates drawn from blood from paid donors abroad and bought and distributed by the N.H.S.

(b) Domestically obtained N.H.S. factor VIII or factor IX clotting factor concentrates from voluntary donations

Concentrate obtained from abroad has been particularly associated with contamination but material from both sources has been identified as being contaminated by the virus in the past. Since 1985 all individual donations have been tested and factor concentrates have been heat treated to prevent HIV infection.

Despite successive Government promises since the early 1970's, the U.K. is still not self-sufficient in blood products. In 1987 only 20% of the demand for factor VIII is being met by N.H.S. sources. If the U.K. had processed sufficient voluntary donated plasma into factor VIII and factor IX concentrate, the number of people infected would be substantially less because the use of heavily contaminated material from abroad would have been avoided.

LIVING WITH HAEMOPHILIA AND HIV

The implications of HIV infection upon the families of people with haemophilia have been devastating. Haemophilia is already a potentially life threatening disorder. HIV and AIDS are placing an intolerable pressure upon family life.

FINANCIAL BURDEN

- It is impossible to obtain endowment mortgages or life insurance to protect homes and families
- Domestic needs: Bedding and clothing allowances are required because of rapid weight loss, profuse sweating, diarrhoea and incontinence. Extra heating and bathing is necessary in order to keep clean, warm and to fight infection. There are also increased laundry costs and additional expenses travelling to hospital
- Dietary needs: A high quality diet is necessary to build up health
- Many people with haemophilia and infected with HIV are too ill to work resulting in loss of career and predicted earnings
- DHSS benefits presently available for those with haemophilia, do not cover the increased cost of living with HIV

SOCIAL BURDEN

- Prejudice exists in the playground
- At work - people have been dismissed, or not offered jobs, when their antibody status, or even the fact that they have haemophilia, has become known
- Families have been shunned in their neighbourhood
- People in rented accommodation have, on occasion, been evicted
- Due to the hysteria associated with AIDS and haemophilia many, regardless of their antibody status, have had to publicly deny their blood disorder, and subsequently live a double life

FAMILY BURDEN

- Sexual relationships with wives and girfriends carry the risk of infection
- 18 wives have already become HIV positive, indicating that the infection has been transmitted to them
- It is unwise to have children because of the risk of the child being infected in the womb or at the time of delivery
- The normal process of forming steady relationships and marriage is inhibited because of the risk of infecting the partner
- Loss of earnings, insufficient benefits, and the inability to secure life insurance is placing families in a situation of serious financial distress. Following the death of the breadwinner, widows and dependent children are left to rely upon social security benefits, often without the security of the family home. Because of their primary disorder, many people with haemophilia have been under-insured and are more vulnerable in the present circumstances

THE NEED FOR GOVERNMENT ACTION

The task for the Government is to find realistic and workable solutions to alleviate distress. This task is urgent. The Government will be aware of the strength of feeling within the haemophilia community and the degree of anger felt by families at their predicament, and of the ground swell of popular support within the country.

The House of Commons Social Services Committee recognised the nature of some of these dilemmas. Paragraph 163 of the Report states:

> "Calls for compensation for haemophiliacs and others who have become HIV positive as a consequence of infected blood transfusion and for special life insurance arrangements, the haemophiliacs deserve careful consideration."

To date requests to government for help have been answered with the suggestion that legal advice as to negligence be taken. As a result the Society sought such advice which suggested that such actions would be unlikely to succeed, and would not provide solutions in the short term.

The need is now, and the only way forward for people with haemophilia and their families is by immediate, positive and compassionate government action.

RECOMPENSE

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

1. A fund for help with insurance premiums for householders, so that the home is protected.

2. A weekly, non-means tested hardship allowance on death

   - for the widow until her death

   - for the children until they reach the age of 19

   - for elderly dependent parents until their death

3. A disability premium, to replace single payments, which is sufficiently high to cover the costs of coping with AIDS related problems. This would be back-dated to the presumed point of sero-conversion (i.e. 1982).

4. Although the pursuit of compensation through the courts is unlikely to be successful, we believe, in the light of the manner in which these people were infected, that the Government has a moral responsibility to provide some recompense. The Government should establish a fund from which payments will be made in recognition of the severe anxiety, distress, prejudice and discrimination suffered by people with haemophilia who have become infected with HIV as a result of treatment through the Health Service. This would be a solatium, although it would also help cope with the additional expenses incurred as a result of AIDS which have not been included in the weekly benefit.

The first requirement is necessary because people with haemophilia who have become infected are unable to obtain life insurance or mortgage endowment. The Society is asking the Government to underwrite a mortgage protection scheme to ensure that the family home is secure in the event of the death of the breadwinner. This scheme should be available to all affected so that individuals are not prevented from purchasing homes on a normal basis.

The second requirement should also be paid retrospectively where bereavement has already occurred. This allowance is necessary as a result of individuals inability to provide through life insurance or any other method for dependants. Alternatively this need may be met by means of a Government sponsored life insurance scheme providing a lump sum on death. The Society's advice is that the third requirement will cost between £65 - £75 per week. An example is set out in Appendix A.

The Society ask that in making payments to families strict anonymity is preserved.

The fourth requirement would recognise unquantifiable loss suffered. In this case that would include severe anxiety, distress, despair, prejudice and discrimination suffered by people with haemophilia who have been infected with HIV as a result of their NHS treatment. The Society ask that Government consider a form of solatium for patients with HIV infection as a result of their National Health Service treatment.

APPENDIX A

A weekly non-means tested benefit to assist with HIV costs on a daily basis should take into account:-

Special high protein, high energy diet using convenience foods and prescribable supplements (formulated by the Dietetics Department, Royal Victoria Infirmary, Newcastle upon Tyne)	£ 32.75	per week
Additional heating costs	£ 5.00 - £ 10.00	per week
Extra laundry costs - presuming one trip to the launderette each day and travel	£ 8.00 - £ 15.00	per week
Baths: 6 baths per week at 30p per bath	£ 1.80	per week
Travel to hospital etc. (average figure)	£ 10.00	per week
Prescription "season ticket" = £35.00 per annum	£ 0.67	per week
Extra clothing and bedding (averaged out over a year)	£ 7.00	per week
TOTAL	**£ 65.22**	

Peter Morgan
NEWS AT TEN

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Appendix 1

Chronology: Haemophilia and AIDS

end of 1973	First introduction to U.K. of Hemofil, from USA, because supplies of concentrate in UK were not sufficient
April 1974	Outbreak of Hepatitis B began among haemophiliacs
1974	Decision by UK Government to increase supplies of concentrate Factor VIII ("F8")
1975	Extra money allocated for the Blood Transfusion Service
20 August 1975	Mr. Prothero of the Society wrote to Dr. Owen, complaining of low supplies of F8 (and deterioration of standards at Haemophilia centres)
23 September 1975	Dr. Owen's reply, acknowledging that production of concentrates in the UK "falls far short of what is needed", and hoping that "in about a year we will be able to meet some 2/3rds of the present requirements". "Within 2 years we may be able to reach the target recommended to us by the Expert Group on the Treatment of Haemophilia".
1976	58 cases of hepatitis had been recorded
29 April 1976	The World Federation of the Haemophilia Congress met in London and was addressed by Mr. Owen. He said that "self-sufficiency of home-produced F8 we expect to be reached around the middle of 1977".
1976	Meeting between Dr. Owen and Mr. Tanner, Chairman of the Society.
18 October 1978	Mr. Poulton of the Society wrote to the then Minister of State Mr. Moyle (missing)
23 November 1978	Reply from Mr. Moyle. He acknowledged that despite increases of supply there was still insufficient F8. He pointed to the difficulty in balancing the requirements of the various components of the blood transfusion services. A report of a working party was being studied.
1978	Probably the first AIDS case arose in the U.S.A. (but was not recognised as such).
1979	Probably the first AIDS case arose in the UK (but was not recognised as such)
1981	The first officially-recognised cases

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by December 1982	Reports were received of patients apparently contracting AIDS from (eg) parents or spouses.
1983	Virus HTLV III was identified in the USA Virus LAV was identified in France (? same virus)
1983	First AIDS case in a haemophiliac was identified. UK Blood Transfusion Service asked high-risk Groups not to contribute blood.
September 1983	Meeting between Lord Glenarthur and Mr. Tanner. Details not known, but the meeting is referred to in a subsequent letter (12.12.1984)
by mid-1984	HTLV III and LAV were convincingly shown to be causative of AIDS.
Autumn 1984	Heat-treatment was shown to render the viruses inactive (although the process also made the concentrate 20% less active and more expensive). The National Haemophilia Foundation of USA advised heat-treatment.
by December 1984/ January 1985	Heat-treated supplies became available from the USA
December 1984	Heat-treatment was advocated in UK
7 December 1984	Second meeting between Lord Glenarthur and Mr. Tanner.
12 December 1984	Lord Glenarthur wrote to Mr. Tanner. The Blood Products Laboratory was to heat-treat from April 1985. The new production Unit at the B.P. Laboratory "is still on target for completion in January 1986". Tests for screening for HTLV III were to be conducted in pilot trials.
March 1985	Screening for AIDS viruses was begun in the USA.
October 1985	Screening of blood donors in UK was begun.
31 October 1985	National Haemophilia Foundation of USA resolved against having a "class-action", in the interests of privacy (etc).

<u>Notes</u>

1. As already mentioned in my Opinion, the sources are not always consistent, and the above facts relating to the progress of AIDS

Haemophilia
HW.

HAEMOPHILIA AND AIDS
CHRONOLOGY

End 1973	**First introduction of Factor VIII concentrates from the USA because supplies in the UK were inadequate.**
April 1974	**Outbreaks of Hepatitis B amongst people with haemophilia.**
1976	**58 cases of hepatitis had been reported.**
April 1976	**Government announced "self sufficiency of home produced Factor VIII expected to be reached by middle of 1977."**
Nov 1978	**Government admits insufficient supplies of UK factor VIII**
1978	**Probably first AIDS case in USA**
1981	**First officially recognised AIDS cases in USA and UK.**
1983	**HIV identified**
1983	**First AIDS case in haemophilia identified**
1984	**Heat treatment shown to inactivate HIV**
End 1984	**Heat treated supplies available from USA**
April 1985	**Heat treated supplies available from UK.**
1985	**Testing for HIV available, over 1,200 people with haemophilia found to be HIV+**