cc Mr R. Powell
Mr R. Golawski
Dr A Rejman
Mr M Arthur

GEB 16 ANNEX A
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Haemophiliacs (AIDS)

Motion made, and Question proposed, That this House do now adjourn.—*[Mr. Sackville.]*

Mr. Deputy Speaker (Sir Paul Dean): Before I call the hon. Member for Staffordshire, South (Mr. Cormack), I should draw the attention of the House to the fact that a case affecting haemophiliac AIDS victims is currently before the courts. Mr. Speaker has exercised the discretion given to him in relation to court cases which are sub judice in permiting this debate to go ahead, but I trust that hon. Members will seek to avoid as far as possible direct reference to the issues specifically before the courts.

11.52 pm

Mr. Patrick Cormack (Staffordshire, South): I am grateful to Mr. Speaker for exercising his discretion in that way and for allowing us to debate a matter which is of great importance, as illustrated by the fact that there are present tonight so many of my hon. Friends—I use the expression advisedly—in all parts of the House. I am also grateful for the fact that two Ministers from the Department of Health are present.

The words "special case" are probably more overworked than any others in the political vocabulary, but tonight we are considering a group who really merit that description. Their numbers are known, their problems are tragic, and Government have a real moral responsibility for their problems. Although nobody has the means of solving them, Government can remove the financial anxiety which adds immeasurably to the acute and continuing stress of dread illness that their agent, albeit unwittingly, created.

There are 5,000 haemophiliacs in this country; 1,200 of them, including 200 children, were infected with the HIV virus before the Health Department officially told doctors, in September 1985, to use only the heat-treated version of the blood clotting agent factor X, which had itself brought new life and hope to haemophiliacs. Of those 1,200, 163 developed full-blown AIDS, and 107 of them have already died.

We are dealing with a well-defined and inevitably sadly diminishing group of people. There will be no more victims, save perhaps for a few infected babies yet to be born. There will be no more victims because supplies of factor X are safe. However, for the 1,200 who are suffering now, that is small consolation because their supplies were not safe. Those supplies were obtained and administered through the National Health Service. No one can give back to those victims the hope of a normal life that was once theirs. No once can remove the uncertainty with which they and their families live from day to day—the uncertainty of when the bell will toll. If any group of people live in the shadow of death, they do. It is no wonder that their story has been described as the most tragic in the history of the NHS. Many of them carry the extra burden of financial hardship, or the even greater worry of not knowing how their dependants will fare after they have gone.

Many heart-rending cases have been brought to my attention. I received a letter today stating:

> "We have been married for 24 years and watched the treatment improve from plasma to factor X and factor 8. It led us to believe that the life expectancy of a haemophiliac was near normal. Because of this we chose to have a family. We now have three grandchildren. Once we learned of my husband's HIV status, our world was shattered. It has affected all of us very badly. We were never ashamed to tell anyone that he was a haemophiliac. Now we all suffer in silence."

The daughter of a constituent wrote:

> "I have watched his treatment improve over the years. Imagine our horror when we were told that he had the AIDS virus."

Another of my constituents simply said:

> "Money is nothing compared to human life but it can give a family the ability to choose how their life should go forward. Families may feel that they need to move house if hostility has been experienced in their neighbourhood. Many haemophiliacs have cars through the motability scheme—how can a family cope with suddenly being without transport? A family which has been living on State Benefit needs financial support when the husband or father is very ill and certainly when he dies. The hardest part to accept is that this should never have happened."

Hon. Members will have seen innumerable letters like that, many of which have been circulated by the Haemophilia Society. No one who has studied this sad saga can accuse the Government of callousness or indifference. Two years ago, partly due to pressure from hon. Members on both sides of the House, the Secretary of State for Social Services announced at the Dispatch Box that £10 million was to be placed in a trust fund to help haemophiliac AIDS victims. That gesture was appreciated and many families have cause to be grateful. However, the MacFarlane trust was not intended to provide compensation. It is a welfare fund to deal with specific needs at particular times. These people need proper recognition that they are the victims of the most ghastly and far-reaching of accidents.

The victims of accidents frequently sue those whom they hold responsible, but just as frequently the moral responsibility is accepted and an out-of-court settlement is made. That is not the same as saying that culpability is accepted. Those who suffered as a result of the Piper Alpha explosion, the Clapham train crash, or more recently, the sinking of the Marchioness just down the Thames from here benefited or are likely to benefit from out-of-court settlements. The Government should act in like manner towards these haemophiliac victims. Six hundred people have already begun court action, but the courts take time, and time is what they do not have. Moreover, some people have not even been able to begin proceedings because they do not qualify for legal aid and cannot contemplate a lengthy, costly struggle.

The problem is not unique to Britain. In other countries in which circumstances of infection have been very similar, Governments have accepted their moral responsibility and agreed to compensate. In Canada, where there are 950 victims, the Government have opened an extraordinary assistance programme, as they call it, under which compensation is to be paid in the same manner as it is paid to victims of natural disasters such as hurricanes and earthquakes. There are compensation schemes in operation in Germany, Denmark, Norway and France. In some countries, such as New Zealand, there are already fully developed no-fault compensation schemes from which all victims of medical mishap can benefit.

If the Government opt for an out-of-court settlement, they need not admit culpability. If the matter is dragged through the courts, it could mean sad consequences for haemophiliacs who are not infected. Although commercial pharmaceutical companies are not involved in any pending High Court case, plaintiffs and defendants have

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[Mr. Patrick Cormack]

reserved the right to call them to give evidence. It is not impossible that that could have the effect of stopping or slowing the supply of perfectly safe factor X.

No one has suggested that these tragic victims do not have a case. No one disputes how they were infected. No one suggests that they were in any way, as a result of personal carelessness or lifestyle, responsible for the cruel predicament in which they find themselves. Everyone expresses sympathy, but only the Minister can effectively translate that sympathy into action—and not merely by adding more money to a trust fund administering means-tested benefits. Two years ago, the Government said that compensation could not be awarded other than by the courts. The Government now say that they cannot make an out-of-court settlement because the matter is before the courts. That simply will not do.

I often remember the lovely story about the artist painting the model. When the lady says, "I hope that you will do me justice," the artist replies "Madam, it is not justice that you need—it is mercy." I am not asking for charity. I am not even demanding justice. I am asking the Government to accept their moral responsibility and to show mercy to a group of people who, more than any other single group I can think of, manifestly deserve it. I hope that we shall have a full and good answer from the Minister, but whatever he says, unless he agrees to our request, the campaign will go on and we shall not go away. *The Sunday Times* will continue its thundering, and we shall continue our thundering.

I am glad to see so many of my hon. Friends present on both sides of the House. I pay tribute to my hon. Friend the Member for Salisbury (Mr. Key), who has done a great deal in this matter. We shall fight until we win the battle, but I hope that, as there are so many other battles to fight, we shall not need to wage this one any further after today. I hope that my hon. Friend the Minister will give us the answer that we believe that he should.

12.2 am

Mr. Alfred Morris (Manchester, Wythenshawe): I am grateful to the hon. Member for Staffordshire, South (Mr. Cormack) for leaving time after that distinguished speech for me to make it clear that his very genuine concern is widely shared on both sides of both Houses of Parliament. In my role as an Opposition Front Bench Member, specialising in this field, I have had deeply moving correspondence from people with haemophilia and HIV in all parts of Britain. It is a dossier of despair, from which I have time to quote only from the letter of a constituent of mine, who writes:

> "While the MacFarlane Trust has been of help, a long-term solution it is not. It is wrong for us to have to depend on welfare handouts when the disease was contracted by no fault of our own.
>
> An out-of-court settlement should be made promptly, so that I and my fellow sufferers can enjoy some sort of reasonable lifestyle before we die."

The case for an out-of-court settlement is overwhelming. Many of the victims of this huge disaster in health care have already died. Many more know that they have little prospect of living to see a settlement in court, and they rightly insist that posthumous justice is no justice at all. Their case is self-evidently unique and in my view deserves the unique response that it has received in other countries. Opposition Members want to see a no-fault compensation scheme and we urge the Government to recognise that the plight of people with haemophilia and HIV argues unanswerably the need for such a scheme.

Another Thalidomide-style tragedy can and must be prevented. In that case, after years of campaigning, the Spiller's finally accepted that an out-of-court settlement was unavoidable. Why cannot the Government accept that the victims of this disaster are just as deserving? They have been dealt the cruellest possible hand. They have to live not only in a genetic disorder, but with HIV as well. They are doubly stricken and in double despair as they await the outcome of this most urgent all-party plea on their behalf.

12.4 am

Sir Michael McNair-Wilson (Newbury): I congratulate my hon. Friend the Member for Staffordshire, South (Mr. Cormack) on raising this case of the most tragic human misery of these haemophiliac victims.

I rise to speak because three of my constituents are haemophiliacs and HIV-positive as a result of using the blood product, factor 8, provided by the NHS for home treatment, and because their plight points up the weaknesses of the present compensation system, whereby negligence is the sole reason for offering compensation to victims of medical accidents, and then only after a long-drawn-out and costly process. As my hon. Friend has said, in these cases, time is the one substance in the shortest supply.

Over the weekend I met one of the haemophiliacs, a young man, with his wife and family. He told me of the psychological change that had come over him since 1985, when he was first advised he had the virus. He described how originally he was told that he had a one in 400 chance of contracting AIDS but subsequently has learned his chances are one in two, with a 75 per cent. chance of mortality in seven to 10 years. He is a man who will probably never know the joy of seeing his children grow up, for whom the future holds nothing, whose job promotion prospects are nil.

He is grateful for the £1,200 a year he gets from the McFarlane Trust. It helps to pay for the extras he needs, but his worry is about his family, and who will pay for the mortgage if he is no longer able to work, or is no longer with them. He can make no provision for his family. He is precluded from taking out a life insurance policy because of the virus. In other words, if the worst happens, he fears for his home and for his wife and children—yet there is nothing he can do to help them.

He suggested that, if the Government would underwrite a life insurance scheme, he would happily pay the premiums. It was a generous suggestion, and it would be better than nothing. But in conscience can any of us really accept that this young haemophiliac, and the others like him, who were supplied by the NHS with what they believed was a tested, pure, life-saving product only to find it contaminated with a deadly virus, should be expected to manage on means-tested McFarlane handouts, or be asked to wait for the result of litigation, which is at least 18 months away and may go against them? And if it does, what then? Do we walk away from them, and leave them with their tragedy?

The quality of their lives has been irreparably damaged —no-one denies that. They live with the ever-present fear of AIDS, knowing that over 100 have already died. Whatever compensation may be paid cannot restore what

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they have lost, but at least we can ease their worries for their families if anything happens to them; and we can do that by setting up a compensation fund for their families now, and with it, the promise of payments for those already in need or who have contracted AIDS. That is my urgent request to the Government tonight, and I make it on both moral and humanitarian grounds.

12.8 am

The Parliamentary Under-Secretary of State for Health (Mr. Roger Freeman): My hon. Friend the Member for Staffordshire, South (Mr. Cormack) has certainly done a great service to the House by raising the plight of some 1,200 haemophiliacs who have become infected with the AIDS virus as a result of treatment with infected blood products. My hon. Friend the Minister for Health, whose responsibility this subject is, has only just returned from Brussels. She particularly wanted to join the debate, because she shares with me and my right hon. and learned Friend the Secretary of State for Health a great concern about the plight of these haemophiliacs.

My hon. Friend has described a most moving story to the House. The record should show that, in addition to my hon. Friend the Member for Newbury (Sir M McNair-Wilson) and the right hon. Member for Manchester, Wythenshawe (Mr. Morris) also in the Chamber at this late hour are my predecessor, my hon. Friend the Member for Derbyshire, South (Mrs. Currie) my hon. Friends the Members for Rutland and Melton (Mr. Latham), for Salisbury (Mr. Key) who has made representations directly to my hon. Friend the Minister for Health, for Suffolk, Central (Mr. Lord) who has questioned the Prime Minister on this subject, for Meriden (Mr. Mills) and for Wyre Forest (Mr. Coombs), and the hon. Members for Linlithgow (Mr. Dalyell) and for East Lothian (Mr. Home Robertson). The level of attendance at this late hour is a sign of how seriously hon. Members take this subject.

All hon. Members would like to express their sympathy for those who are infected and for their families. It is particularly tragic that the coagulation products that were intended to revolutionise their lives have caused so much suffering. I appreciate the tremendous mental stresses under which those affected are living. I know that the six haemophilia reference centres provide specialist counselling. The Department provides financial support for those services, and since April 1985 we have provided nearly £1 million.

I am also conscious that the personal health problems for haemophiliacs with HIV may, in some cases, be compounded by the reactions of other people around them. The fear of AIDS has all too often led otherwise humane and sensitive people to prejudice and discrimination, which is completely unjustified. There is no scientific or ethical justification for discriminating against people who have the AIDS virus.

Clearly, too, there are financial worries for those who are infected with HIV. It is understandable that they should wish to live with dignity and make adequate provision for their families. Let me stress that the Government have already acted by setting up the Macfarlane Trust, to which my hon. Friend the Member for Staffordshire, South (Mr. Cormack) has referred. It is named after an eminent haematologist. We set up that trust with an initial £10 million. When that ex gratia payment was announced to the House in November 1987, my right hon. Friend the Secretary of State for Social Security, then Minister of Health, said that we had recognised the very special circumstances of the haemophiliacs with the AIDS virus.

The Haemophilia Society had put to us a powerful case that the position of haemophiliacs was wholly exceptional and should be treated as such. Their employment prospects and insurance status were already affected by the haemophilia itself. The treatment that led to their infection was designed to help them live as near normal lives as possible. The hereditary nature of haemophilia can and sometimes does, mean that more than one member of the same family may be affected. Providing the grant to set up the trust was a wholly exceptional measure which recognised those special circumstances.

Some commentators have been critical of what they see as the "means-tested" nature of the Macfarlane Trust—two of my hon. Friends referred to that. It is true that the trust deed limits the use of the fund to cases of "need", but positive criteria are not laid down and it is a matter for the trustees to allocate funds in the way which they consider best meets the needs of those who are eligible for help under the terms of the deed. I believe that the trustees carry out this task conscientiously and with sensitivity. They have been able to help a large number of people and make single payments for a wide variety of purposes arising from reasons of physical health and mental stress, including help with travel, accommodation and employment.

Regular payments help with the extra cost of living with HIV. In the period up to 31 October 1989, the trust has made over 1,800 single payments totalling nearly £1 million and implemented regular payments in more than 600 cases at a cost of nearly £1·2 million. Some have expressed fears that the £10 million may run out. We made it clear when we announced the £10 million grant that our mind would not be closed to representations that might be made at a later stage in relation to the amount available.

I would also remind hon. Members that the Government have made regulations to ensure that payments from the trust do not reduce any entitlement to income support, family credit and housing benefit.

Let me stress that the grant provided to the trust was not, and is not intended as, "compensation." The position in this country under successive Governments has been that there is no state scheme of "no fault" compensation for those injured by medical treatment.

The case for alternative means of compensating victims of medical accidents was carefully investigated by the Royal Commission on Civil Liability and Personal Injury, which reported in 1978. It came down against introducing a system of no-fault compensation. The arguments for and against have not fundamentally changed. No-fault compensation may overcome the perceived unfairness of treatment between those victims of medical accidents who are awarded damages after proving negligence and those who are not compensated because either they fail to prove negligence or because negligence was clearly not involved. However, such a scheme would, in its turn, create unfairness between those who are disabled by a medical accident, who would then be compensated, and those who are equally disabled as a result of the natural progression of their disease who would not normally fall to be compensated under a no-fault scheme.

I want to refer briefly to the court action but, Mr. Deputy Speaker, I shall be mindful of your ruling on the

[The Parliamentary Under-Secretary of State for Health]

matter. Some 600 haemophiliacs with the AIDS virus are pursuing compensation through the courts. The Department of Health, the Medicines Licensing Authority, which comprises the United Kingdom Health Ministers, and the Committee on Safety of Medicines, which gives advice to the licensing authority, are among the defendants. The legal advice which I have received is that it would be wrong of me to make any comments today which might prejudice the conduct or outcome of the case. Various allegations of negligence are made which we deny categorically. I am sure that the House will understand that I am unable at present to comment in more detail on these matters, as they are sub judice.

I should like to repeat the Government's sympathy for the plight of the haemophiliacs with HIV and their dependants. We have already expressed that in a tangible way with the £10 million ex gratia payment for the Macfarlane Trust. I should like to remind the House of what was said by my right hon. Friend the Secretary of State for Social Security when he was the Minister for Health. When announcing the grant, he said that our mind would not be closed to representations that might be made at a later stage.

Mr. Tam Dalyell (Linlithgow): Is this a question of precedent and the feeling of the Department's legal advisers that the Department might let itself in for many other payments if it were not to defend itself on this, or is it seen as a one-off problem?

Mr. Freeman: We believe strongly that there was no negligence on the part of the Department of Health. You, Mr. Speaker, have said that it would be wrong to go into the merits of the case before the courts. However, we categorically deny any negligence. An entirely separate issue—it has been put by my hon. Friend the Member for Staffordshire, South (Mr. Cormack)—is the consideration of the plight of those who have suffered this appalling affliction.

Mr. Alfred Morris: Is not the governing factor here that many of the victims cannot expect to live to see a settlement in court, and that posthumous justice is not justice? Is not that the special case that the Government need in order to concede the argument that the Minister has heard tonight from both sides of the House?

Mr. Freeman: The hon. Gentleman has made a very telling point, which was also made by my hon. Friend the Member for Staffordshire, South. Many of the victims have a short life expectancy and the matter is one of some urgency. We are seized of the significance of that argument.

I repeat the commitment given by my right hon. Friend the Secretary of State for Social Security when he was Minister for Health, which is that our minds are not closed to representations that might be made about the adequacy of the sums provided.

Mr. Cormack: Can the hon. Members who are in the Chamber now come to see my hon. Friends the Under-Secretary of State and the Minister for Health to discuss the matter in detail?

Mr. Freeman: I am sure that my hon. Friend the Minister for Health, who is responsible for these matters, will be pleased to see my hon. Friend the Member for Staffordshire, South and any or all the right hon. and hon. Members present. I will undertake to draw the record of this debate to the attention of my right hon. and learned Friend the Secretary of State and officials in the Department——

Mr. Cormack: And our right hon. Friend the Prime Minister?

Mr. Freeman: I would be delighted to convey to No. 10 Downing street a copy of the *Official Report*. We shall study with great care this important debate. It has been a matter of great concern and emotion for all of us—I speak not only for myself, but my ministerial colleagues. I can assure my hon. Friend the Member for Staffordshire, South that the matter will not rest with tonight's debate. We look forward to further discussions.

12.19 am

Mr. Dalyell: I believe that the Minister feels strongly about this issue, and his reply was totally sincere. However, a long time ago I was Parliamentary Private Secretary in the Department of Health and I wonder whether Ministers might be unduly influenced by the lawyers' difficulties and the matter to which I have referred —setting a precedent. Is there not an argument for saying that this is a one-off situation and there is an element of culpability, which the hon. Member for Staffordshire, South explained very well?

In these unique circumstances, the Government should not feel bound by the terrible shroud of legal precedent. This is something different, and all of us with experience of these matters know that these are not run-of-the-mill cases, but a one-off situation. Am I being told that this is not a one-off situation?

Question put and agreed to.

Adjourned accordingly at twenty minutes past Twelve o'clock.