Mr Harris

COMPENSATION FOR HAEMOPHILIACS

I regret the delay in replying to your minute of the 13 January. Some background information about the treatment of haemophilia may help to provide perspective to the question of whether or not haemophiliacs have a special case for compensation for the tragedy of having had the AIDS virus transmitted to them as a result of their treatment.

Background

There are estimated to be approximately 7,000 people in the UK with a variety of genetically determined coagulation disorders known collectively as haemophilia. All these disorders have different degrees of penetrance such that the severity of their disease can vary from those who never require treatment, others requiring treatment solely when major surgery or dental extraction takes place and yet others who generate major haemorrhages as a result of the slightest trauma and are now given treatment prophylactically each day to prevent such haemorrhages occuring.

The majority have haemophilia A where there is a deficiency of Factor VIII and this tends to include in its spectrum the most severely affected. The rest have haemophilia B which requires Factor IX or von Willebrands disease which requires Factor VIII. Women very rarely have haemophilia A or B and occasionally have von Willebrands disease.

Treatment

Some 30 years ago it was recognised that haemorrhage in haemophiliacs could be arrested by the infusion of plasma from normal donors. Since then refinement of treatment has occured as the knowledge about clotting factors has increased. Up to the early 1970's clotting factors from proteins precipitated when plasma is frozen were effectively used in the control of haemophilia (cryoprecipitate). However, whilst this was highly effective in arresting haemorrhages the procedure required hospital admission. Other limiting factors were that only limited volumes of plasma/cryoprecipitate were suitable for transfusion before the haemophiliac circulation became overloaded. It should be noted that cryoprecipitate was prepared from pools of plasma to which only a very limited number of donors had contributed.

By the early 1970's it was possible to prepare Factor VIII and IX concentrates from paid plasma donors recruited in both Africa and in the USA. To satisfy the demand pool sizes of up to 30,000 units of plasma were used to make the coagulation factors. These concentrates enabled haemophiliacs to be able to treat themselves and maintain a normal lifestyle.

Transmission of Infection through use of Coagulation Factors

In 1974 it was recognised in the UK that hepatitis was being transmitted through the use of commercial Factor VIII concentrates. This hepatitis known as non-A non-B has never had its causal agent identified. Non-A non-B hepatitis was originally associated with commercial concentrates but monitoring by Haemophilia Centre Directors has shown that now it has become almost equally prevalent amongst recipients of NHS concentrates. Infection with non-A non-B hepatitis may cause a transient illness which clears, but a chronic hepatitis may develop which may proceed to cirrhosis. Heat treatment of commercial concentrates has in the few studies published, failed to prevent transmission of the non-A non-B agent. However, the BPL Factor VIIIY and Factor IXA have not been found to transmit the non-A non-B agent. presumably due to the rigorous heat treatment given in their production.

Apart from non-A non-B hepatitis there are a number of viral infections which may be transmitted through unheated coagulation factors. It is not yet known whether these are responsive to heat treatment.

HIV Infection in Haemophiliacs

The table below shows the number of haemophiliacs known to have antibody to HIV.

Number of patients tested for Anti-HIV and number found positive (1986 Survey)

DIAGNOSIS	No. Tested	No. +	% +
Haemophilia A	2228	902	40.48
Haemophilia B	386	26	6.74
von Willebrand's Disease	327	9	2.75
TOTAL	2941	937	31.86

It will be seen from the table that only a third of haemophiliacs have been tested for HIV antibody. There are two major reasons for this incompleteness of data. One is that, as has been mentioned above, some haemophiliacs may nevery present themselves for treatment and have therefore not been offered antibody tests. The other reason is that there is some evidence that some Haemophiliac Centre Directors are unwilling to provide the Centre for collecting results of this survey with their own results. The reasons for this include the fear of loss of confidentiality for the patient (a very real and justified fear) and possibly the fear of litigation.

Although there is some evidence that the commercial heat treated Factor VIII concentrates initially transmitted HIV. since all plasma donations have been screened for HIV antibody followed by heat treatment, there has been no such evidence. The Haemophilia Centre Directors are undertaking a careful monitoring exercise of the

situation and are investigating any cases where seroconversion after use of the heat treated concentrates may have arisen.

Compensation

It seems likely that we have a finite number of haemophiliacs who have contracted HIV infection. Their position is pitiful and has attracted great sympathy in particular because of the perceived stigma of the disease which is associated with promiscuous sexual activity. The equally sad fact that a number of haemophiliacs will undoubtedly die of chronic hepatitis as a result of non-A non-B infection has not been recognised publicly.

Some patients are relieved of their symptoms (say of arthritis) by taking non-steroidal anti-inflammatory drugs which can and do cause death. I find it difficult to advocate that there are any special circumstances surrounding the care of haemophilia which makes their case for compensation greater than that of other patients who take medicines which kill them. That is, of course, provided the doctors caring for the patients have prescribed their treatment in a proper manner.

GRO-C

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