

24 APR 1987

Dear Mr [REDACTED],

I have recently received and read the latest Haemofacts leaflet, 'AIDS and compensation'.

This leaflet left me feeling very angry and distressed because it offers the HIV positive haemophiliac very little hope, when hope is psychologically vital. It also left me feeling that the people, including yourself, who run the society, have no idea of the consequences (physical, emotional and psychological) of being HIV positive.

The leaflet gives the impression that the society, as a whole, doesn't want legal action to be taken against any person or body. I believe your leading counsel has looked at this case purely from the legal angle, such as the difficulties of bringing such an action and not from the human angle.

The proper bodies to sue must be; —

- (i) The DHSS, 'because this is the appropriate government body. The government must bear the burden of the responsibility for failing to fulfil promises to make Britain self sufficient in factor VIII. I am referring to the Labour government at the time when Dr David Owen was Health Secretary. His promises failed miserably due to lack of funding and enthusiasm.
- (ii) The American Drug Companies, who supplied the NHS with factor VIII, which it knew to be at risk of contamination, with such things as Serum hepatitis, Australian Antigen hepatitis, hepatitis B and non A non B hepatitis, and more recently AIDS. These drug companies did not attempt to make a cleaner, more safe product until the AIDS virus had already affected a large number of the countries' haemophiliacs.

(2)

I believe the American suppliers knew of the dangers long before it all became public knowledge. Some factor VIII batches were recalled to the States after a known donor developed AIDS, others were not.

The blood donors were often the same, or same type of person that had contaminated earlier batches with hepatitis. Even with this knowledge, the drug companies did not try to attract new low risk donors. The very nature of the American methods of collecting plasma attracted all the known hepatitis carrying high risk groups, drug addicts, winos, homosexuals, and others such as tramps, social drop-outs, and illegal immigrants.

Their process of paying donors, and locating collecting stations in the run down areas of major cities, must bring into doubt the integrity of the drug companies. They admittedly must make a profit, but at what cost? And as suppliers to the public and health authorities, must surely have an obligation to supply safe materials, or at least as safe as possible.

In the past, when drug companies have made mistakes, which resulted in death or deformity, such as Thalidomide, the drug companies have paid out compensation. Surely this sets a precedent on which the case of the HIV positive haemophiliac should be based.

I believe you should publish more of your leading counsels findings. For I know, I am not alone in feeling isolated, bewildered and helpless, and very angry by the inactivity, lack of action, and constructive advice from the society on gaining compensation. It is at a time like this that the Haemophilia Society should do all it possibly can to help haemophiliacs to gain compensation for the suffering that being HIV positive brings. The knowledge of being HIV positive is indescribable and can not be measured, but I will try to enlighten you.

The nature of AIDS, means that once you have discovered that you are HIV positive, you have to keep it as secret as possible for many reasons, most of which should be obvious, but I shall try to list:-

Fear of losing your job.
Fear of losing friends.
Fear of attacks by neighbours.
Fear of the reaction of G.P.s.
Fear of the reaction of dentists.

And the worry that is caused to relatives, who may feel at risk, and fear losing a loved one.

It is for those reasons that haemophiliacs will not come forward and attempt to sue for compensation. Simply the fear of being found out that they have HIV antibodies and the public and social consequences that could occur, will stop all but a few taking action.

There is a case for the Society to act on behalf of all haemophiliacs corporately, if the Society decides to take it upon itself. I believe this is vital, because the infected haemophiliacs cannot come out into the open. You have a duty to these haemophiliacs, for the Society was set up to assist haemophiliacs, and at a time of crisis you can not distance the Society from its members. The haemofacts leaflet gives the impression that you are washing your hands of the whole affair except for minor actions. There are many examples where group actions have been taken, and won e.g. the Manchester Air disaster. And you cannot possibly say that individual cases are different, the facts are, HIV positive results have affected everybody in the same basic ways.

Fear of being found out, (stigma, loss of job etc)
Fear of premature death, (long protracted illness)
Fear of infecting the person you love, (guilt)
Fear of having children, (they and their mother may become infected)

I would lose my job and find it very difficult to find work elsewhere if the person with whom I work found out that I was haemophiliac and was HIV positive.

You begin to worry when you cut yourself, you may infect someone, (guilt).
You cannot kiss someone for your lip or mouth may be bleeding, (guilt).
You cannot make love to the person you love because you may infect them.
When you do you feel guilty. I worry that if I have a car accident