HAEMOPHILIA SOCIETY - AIDS CAMPAIGN - AGENCY BRIEF

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Background

Haemophilia is an inherited defect in the blood clotting mechanism in which a clotting factor, essential for coagulation, is absent or diminished. The most common bleeding episodes of severely affected people are into joints and muscles. Such haemorrhages are acutely painful, often spontaneous, and can lead to crippling. Even mildly affected people bleed excessively after surgery or injury. It is estimated that there are approximately 7,000 people with haemophilia in the United Kingdom, and that the condition affects 1 in 10,000 males.

In order to lead a reasonably normal life, people with haemophilia must receive regular injections of the missing clotting factors. The most effective form of treatment is factor VIII and IX concentrates which are derived from thousands of pooled blood donations. For many years the majority of concentrates have had to be imported from the United States, as the UK has been unable to manufacture sufficient quantities. If any of the blood donors is an AIDS carrier then the AIDS virus (HIV) may be transmitted in the donated blood.

All blood donations are now tested for HIV, and concentrates are heat-treated which is believed to kill the virus. However in the UK it is estimated that at least 1,000 people with haemophilia are now infected with HIV and 26 have AIDS - all through treatment received before the discovery of the heat-treatment process.

AIDS and Haemophilia

The UK has been reliant on imported blood products for many years, as a result of the UK Government's inability to produce sufficient home-produced material. Commercially produced material imported from the United States, has routinely been produced from pooled blood donations for which donors received payment. These donors included people from groups such as drug addicts and down-and-outs in American innte-city areas. In the mid-1970's it became clear that these products had a high risk of passing on hepatitis B to the patient. For this reason the Government announced in 1976 that it would seek to become self-sufficient in blood products by 1979. This has still not been achieved in spite of that expectation being confirmed by successive Ministers.

It became clear in 1983 that what had become known as AIDS, could be transmitted in a similar way to hepatitis B. When a test became available in 1984/5 it was indeed found that a large proportion of people with haemophilia in the UK, as well as in the United States, had been infected with the AIDS virus.

In the early stages of the AIDS epidemic, after homosexual men, people with haemophilia were initially the second largest affected group. They have now been overtaken by drug abusers, but continue to constitute the third largest risk group. While it is easy to view the subject retrospectively, and with all the wisdom that accrues the reality of the situation is that there has been at least token recognition across the years that American product was more susceptible to the transmission of viral infection. In spite of this, inadequate efforts were made to implement the commitment to UK self-sufficiency, until the effect of AIDS on haemophilia sufferers was clear.

All blood concentrates are now heat-treated, which is believed to destroy the virus, together with screening of all donors for the AIDS virus (HIV).

Legal Remedy

A limited number of legal actions have been started in the United States against commercial manufacturers of blood products. Those cases are not supported by the National Hemophilia Foundation (the US equivalent of the UK Haemophilia Society) as it is envisaged that this could bring about problems with the supply of concentrates in the United States. Indeed, the concern is that the manufacturers might withdraw from the production altogether. While it is the case that in the UK the Central Blood Laboratories Authority produce a considerable amount of concentrates under the National Health Service, this amounts to only (currently) 22% of the UK requirement. The NHS is in the process of commissioning a new plant at the Blood Products Laboratory, Elstree which will have the capacity to produce a substantial proportion of the UK requirement for blood products.

The Haemophilia Society has sought Counsel's Opinion on the possibility of taking action on behalf of all people with haemophilia who are HIV antibody positive. The indication is that those actions could not succeed in the majority of cases and the indication is that a "class" action would not be possible in the UK. It is, however, possible that a number of individual claims may have a valid case against a person or a body, dependant upon the personal circumstances involved. It is possible that a number of individual legal actions will take place in the near future. It is our opinion that, in the light of Counsel's Opinion, there is little chance of success in seeking a legal remedy against the Government and so it is considered more appropriate to mount a public campaign on this subject.

Campaign Objective

The Haemophilia Society is seeking to secure from the Government acknowledgement of the special needs of all people with haemophilia who are HIV positive in respect of the dramatic effects this has had on their lives. The effects may be divided into financial and non-financial effects. Direct financial costs to such people include inability to obtain life insurance; a consequent inability to secure endowment mortgages; costs related to special diet; heating; additional clothing costs: diet: not to mention the overall additional costs experienced by people who are gravely and terminally ill. Non-financial aspects include the inadvisability of having children; discrimination in employment: social discrimination by the general public; reduced life expectancy. The best example of the "non-financial aspect" is perhaps seen by viewing the situation of a 23 year old man with haemophilia A. In the normal course of events he would be contemplating marriage, seeking a mortgage with which to buy his home and settle down with a family. None of those are likely to materialize in the current climate of HIV infection since he would be unable to insure his mortgage, advised not to have children, and thereby place the likelihood of marriage in some jeopardy. The experience in other countries has been that haemophilia societies have opted for a weekly payment of benefit rather than lump-sum payment: such lump-sum payments do have an adverse effect on recipients in a number of ways and it <u>may be</u> the case that weekly payments are a more tangible objective to aim for.

We appreciate that other risk groups may wish to pursue their own claims but we consider that people with haemophilia have their own special case as a result of infection by vital treatment.

+ recipients of whole blood

Current Activity

The Society has had occasional meetings with health ministers, and is in correspondence with the DHSS on a wide range of issues including AIDS. A number of M.P.'s have, without encouragement from the Society, asked PQ's on issues relating to AIDS and haemophilia, and in particular a "no fault compensation scheme". Frank Dobson has been particularly vocal on this issue. Jack Ashley has also asked questions in the House and is currently in communication with the General Secretary of the Society. The Society prepared a brief in advance of the debate in the House of Commons on the 21 November, which was sent to all Party Health Spokesmen. The Society has also prepared and sent a Memorandum of Evidence to the House of Commons Social Services Committee which is currently examining AIDS. The Society has no well developed links with any particular M.P.'s or Peers, and would see this campaign as an opportunity of rectifying this situation. The Society has exceedingly good links with all the Haemophilia Centre Directors around the UK, many of whom are expert and eloquent advocates for people with haemophilia. It may be possible to obtain spokesmen through the Society - people with haemophilia - who would be prepared to talk about policy matters generally, but not in their own personal positions.

Requirements

It is for the agencies to propose how they consider best to achieve the above objective. However the Society considers that essential elements of the agency support to the Society would include: the co-ordination of M.P.'s and Peers; medical experts; support for the Society in the preparation of briefings for public spokesmen; support for the Society in presentations to the DHSS; assistance in informing the Society's membership of the progress and nature of the campaign; assistance and advice of the Society's relationship and use of the media in relation to the campaign. The Society recognizes that it is probably difficult to indicate any anticipated time-span that the campaign may cover, and although the campaign should seek to reach its objectives in the shortest possible time the Society recognizes that at this stage it is unrealistic to place a target date on this.

Simon Taylor
Executive Committee — 9 February 1987
As amended by David Watters — 13 February 1987

GRO-C

PJ given sight of a copy 17/2/87