THE HAEMOPHILIA SOCIETY

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11 December 1996

The Rt. Hon John Major
Prime Minister and First Lord of the Treasury
10 Downing Street
London
SW1H 2AA

Dear Prime Minister

Petition calling for Government support for people with haemophilia infected with hepatitis C through NHS treatment.

This petition calls on the Government to provide financial support for people with haemophilia infected with hepatitis C through contaminated blood products used as a part of their NHS treatment. It reflects the terrible disappointment and widespread concern among the haemophilia community at the way in which the Government has responded to the plight of the 3,100 people with haemophilia infected with the hepatitis C virus (HCV).

There is a great depth of feeling among the haemophilia community that they are being dealt with unjustly by the Government and are simply being forgotten and some left to die.

The Haemophilia Society and the Manor House Group - the special interest group within the Haemophilia Society of people with haemophilia and HCV - have widespread support among Members of Parliament. Over 270 MPs from all parties have signed an Early Day Motion in our support - yet still we are unable to obtain any financial help for those infected from the Government.

You showed compassion and understanding when you made a settlement to help people with haemophilia infected with HIV. That settlement was made because it was morally right for the Government to provide help. The same moral argument applies to people with haemophilia infected with hepatitis C virus. Like HIV it is a blood borne virus, like HIV it devastates lives and can kill, like HIV it was contracted by people with haemophilia through their NHS treatment before 1986.

Medical opinion states that it can take 20 - 30 years for HCV,to cause severe liver damage. However, many people with haemophilia have been infected for over 20 years, often repeatedly with many different genotypes of the hepatitis C virus. This has put them at even greater risk of developing liver damage, and more than 60 are thought to have died already as a result.

We accept that there are some differences between HIV and HCV. Nevertheless, the similarities between the two infections are strong and people with haemophilia infected with hepatitis C are suffering hardship and illness now; many have lost their jobs because of their HCV infection and are trying to make ends meet on benefits. We need action now. That is why we are handing in this petition today, and why we are holding a lobby of Parliament this afternoon.

It is for all of these reasons that we are now asking for you to become involved. We feel that the Government's current position is logically and morally indefensible. We hope that you will intervene personally to give the 3,100 people with haemophilia who are suffering the help that they need.

Yours sincerely

GRO-C

The Rev. Prebendary A J Tanner
Chairman of the Haemophilia Society

Richmond House 79 Whitehall London SW1A 2NS Telephone 0171 972 3000
From the Parliamentary Under Secretary of State

Rev. Prebendary Alan Tanner
Chairman
The Haemophilia Society
123 Westminster Bridge Road
London SE1 7HR

19 DEC 1996

Dear Rev Tanner,

Thank you for your letter of 11 December to the Prime Minister about the Government's decision not to give financial help to people who have been infected with hepatitis C through blood products. I have been asked to reply to the letter and petition.

I acknowledge the concerns of those who have signed the petition you presented, and of the MPs who have signed Early Day Motions in support of your request that the Government make financial support available to those who have tragically been infected with hepatitis C through blood products. I have explained the Government's reasons for concluding that it should not make such payments in my letter of 1 October, as well as during the debate in the House on the date of your letter, while stressing that I shall continue to listen to the arguments and look at other ways in which we can provide help.

The decision a few years ago to make payments to those infected with HIV through blood products was, as I have said, taken in the light of the assessment then of the very special nature of the disease, and of arguments that that payment would not lead to further similar claims. We are not convinced that hepatitis C falls into the same special category. At the time of the HIV settlement, it was believed that HIV would lead speedily to death and some haemophiliacs infected with HIV, especially children, were subject to some appalling examples of ostracism. Of course, we now know rather more about the effects of HIV, and there is a much greater public understanding of how relatively limited are the ways in which it can be passed on

If we were to provide payments on the basis of non-negligent harm in the case of those infected with hepatitis C, this would very quickly develop into a general no-fault compensation scheme, which would be both unworkable and unfair. I have also explained that all proposals for payments schemes involve the expenditure of substantial sums of public money. I have a duty to consider the effect of such a sizeable sum on other heath service expenditure. That duty has led me to conclude that funds that are available to the NHS, from whatever source, are best used in direct patient care.

I have made clear my deep sympathy for all those affected by this inadvertent tragedy. I have also confirmed that I share the Haemophilia Society's aim to see progress in work on hepatitis C As you know, my Department has made £1m available to aid research into hepatitis C, its natural history transmission and prevalence, and is giving grants to the Haemophilia Society, for projects concerning those infected with hepatitis C, as well as with those infected with HIV.

GRO-C

JOHN HORAM