Doc 4

19/03/96.

Ms C. A. Grayson.
GRO-C

Dear Mr Horam,

Re Haemophiliacs infected with hepatitis C.

Thank-you for your letter of the 12th March 1996 passed on by my M.P. Mr Jim Cousins.

I believe you will by now have received a further letter detailing more questions to which I am seeking answers.

Regarding your last letter and the information on hepatitis C tests. Your letter confirms that tests were not introduced into England until late summer 1991 despite the fact that other countries were prepared to use an early test as far back as late 1989. Although the early test may not have been completely accurate other countries were concerned enough to introduce the test and remove all blood supplies that might possibly have been contaminated. Our country did not do this. This fact was confirmed as you are probably aware by a director of the Blood Transfusion Service speaking on a Panorama documentary "Bad Blood." The director felt that if blood supplies that were thought to be infected were destroyed there would not be enough blood to meet the country's needs. People such as haemophiliacs who often require regular blood transfusions were put at risk of infection whereas other countries took the correct decision to destroy infected supplies thus preventing the spread of hepatitis C.

Surely where there was a risk of infection the Blood Transfusion Service should have taken all possible precautions even if it did mean destroying some blood which may not have been contaminated. Who are they to play God with other people lives? Who will now take the responsibility for those who are sick and dying and for those families who have lost a relative through hepatitis C.

Regarding Factor VIII blood products, you said 'they have been subjected to viral inactivation to destroy HIV, hep B and hep C since 1985'. May I draw your attention to the following article printed in Bulletin, the Haemophilia Society's newsletter. It is from the Manor House Group - (haemophiliacs infected with hepatitis C, a number of whom Mr Dorrell has already met.) Eminent hepatologists were campaigning for safer blood products long before 1985 and asking for measures to be taken to eliminate the risk of infections. I repeat my question why did this not happen until 1985?

It did not matter that there were no tests for hepatitis C until 1989. Had viral inactivation been introduced earlier, (in some countries it was introduced in 1979) then all viruses would have been destroyed at a much earlier date including hepatitis C, many people would not have been infected with either HIV or hepatitis C, and lives would have been saved.

Thank-you for verifying that quote, 'at the time of the HIV haemophilia settlement it was known that in some cases non A - non B hepatitis, as hepatitis C was then known could lead to serious liver disease and some deaths had already occurred in UK haemophilia patients.' Why was this information not available to haemophiliacs at the time they were asked to sign the 'no further proceedings' clause in the HIV ex-gratia payment settlement? Why were haemophiliacs specifically told that non-A non B was in fact a much milder form of hepatitis than A and B and 'nothing to worry about'. Why were some haemophiliacs not even told of the existence of non-A non B hepatitis, let alone the consequences of having the disease, haemophiliacs being such a high -risk group? Why indeed was I as a practising nursing sister caring for many 'high-risk' patients not told of the seriousness of non-A non-B? It would seem that this information was deliberately withheld from haemophiliacs and those people representing them in the HIV compensation claims.

In fact most haemophiliacs were not even tested for hepatitis C until around eighteen months ago, and then often without there knowledge most having given blood as part of routine cell count tests, and without any pre or post test counselling. It would seem a very cruel and calculated action that those haemophiliacs infected with HIV, quote 'were required to give an undertaking not to bring proceedings at any time against the Health Departments, health authorities or any other body involving any allegations about matters of policy or operational concerns concerning the spread of of HIV or hepatitis viruses through blood or blood products.'

This clause would seem to be invalid as haemophiliacs could not make an 'informed decision' whether or not to sign the clause without all the facts being made available to them. Haemophiliacs who were ill and dying, afraid and vulnerable were it would seem deliberately conned by the Government into signing the afore mentioned clause. That is detestable! As health advisors to the Government were well aware, and was a known hepatitis A was not seen by haemophiliacs to be a major problem. Almost every haemophiliac had already been exposed to hepatitis B, and many had developed the antibodies, so this was a known risk. What haemophiliacs did not know was that there was a far greater problem of hepatitis non- A non- B,(hepatitis C) which is now starting to kill off those haemophiliacs who have so far escaped death by AIDS. Who will take responsibility for the deception of haemophiliacs by the introduction of the hepatitis clause?

Finally in my last letter I mentioned my brother-in-law who died from AIDS. Perhaps you misunderstood my point. My mother-in-law did receive compensation from the Macfarlane Trust for Stephen which is held for her grandson when he becomes an adult. The point I was trying to make was that Stephen himself did not benefit from this ex-gratia payment as it was years in the coming. At the time Stephen most needed financial help to make his last months more comfortable there was none forthcoming. He was dead by the time the settlement was agreed. He died a painful death, his face bloated from Karposis Sarcoma, cancer to the mouth. His last few days were agony for him and his family, as he could not swallow anything, had gone blind and demented. My partner who is infected with HIV and now has hepatitis C witnessed this and is aware of his own poor prognosis. Will he have also died before any financial compensation is forthcoming for infection for hepatitis C. Will I myself succumb to these infections as other partners have, leaving children alone without either parents. What about the stress our twelve year old son has suffered for years in secret knowing of his father's HIV infection ~~illness~~? and now knowing his dad has yet another serious infection

With reference to the world market in blood, is it true as haemophiliacs believe it to be, that American companies have bought blood from Asia, Africa and the Middle East, for example Egypt, where one in seven of the population are infected with hepatitis C, this blood then being processed in America and sold on to Britain?. Why does this country still buys ~~By~~ from America and sell our own blood supplies on the European market when British blood products have always been considered safer than American blood products. Why are some haemophiliacs still prescribed American products when it is known they are a higher risk to the patient because of contaminants?. Is this country so gripped by profit and "market forces" that it becomes more important than saving lives.

I would also like an answer to the following question, whether in the case of haemophiliacs infected with HIV the American drug companies made any contribution to the ex-gratia payments settled by our Government. It was my understanding they did not. A recent article in the 'Times' stated that five American companies have contributed to the payouts made by Japan's Ministry of Health to Japanese haemophiliacs infected with HIV. I suggest that if no money was forthcoming from American companies to British haemophiliacs when the ex-gratia payments were made that our Government tackle these companies now. After all many haemophiliacs asked for compensation to be pursued with the American companies in the mid ~~early~~ eighties and were told help from these companies would never be forthcoming, Japan has proved our Government wrong. Japanese haemophiliacs have received a much better settlement than British haemophiliacs because the drug companies were pursued. Surely it would have been more beneficial for the Government if the American drug companies had helped to pay for the ex-gratia payments rather than the payouts being funded from the British treasury.

To return to the most recent infection of hepatitis C, I enclose once again a copy of the Haemophilia Society's request for finance ~~help~~ for all haemophiliacs infected with hepatitis C and ask the Government to take action now, not when its too late.

Yours sincerely