

27/09/2000

Carol Grayson

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Dear Jim,

Thank-you once again for supporting us in our fight to obtain recombinant synthetic factor VIII for all haemophiliacs.

As you are aware I have been fighting for a number of years now to persuade the Government to set up a public inquiry into how haemophiliacs came to be infected with HIV and hepatitis C, and other forms of hepatitis. Peter has a legal case with legal aid to pursue overturning the waiver, which would then allow us to fight a medical negligence case against the Dept Of Health and present all the vital information which was withheld from haemophiliacs in the original HIV "ex-gratia" settlement. I now have 19 boxes of evidence/ information to support haemophiliac's belief that the Government were allegedly negligent in importing blood products which were known to present a far higher risk of being contaminated with blood-borne viruses than British products. Fortunately for us this has been well-documented for several decades in scientific and medical journals. Haemophiliacs were deliberately put at a much greater health risk and not informed of this increased risk, the resulting viruses leaving hundreds dead and many others in very poor health.

I work in close contact with campaigners in Canada and Southern Ireland now. Both countries originally adopted the same stance as Britain but were forced through public opinion to hold public inquiries. Canada now has a criminal investigation in progress and some of the evidence is very relevant to Britain. We have been advised to contact our police, which we have done in order that they can share information internationally.

I find it appalling that the Government refuses to hold a public inquiry, as it is certainly not through lack of available evidence. Perhaps as highlighted yesterday with the leak of a memo advising ministers to steer clear of blaming the previous Conservative Government over the BSE crisis this same attitude has governed with HIV/hepatitis C. There are 83 known victims of CJD and I am pleased to say a report following the public inquiry on BSE out in October. However in one Newcastle hospital alone there have been 77 HIV/hepatitis C deaths to date yet still no public inquiry. There has been no official recognition of the second hepatitis C infection and I find it decidedly odd that the RVI Trust has never held a meeting with infected patients and their families to discuss their concerns over the hepatitis C infection. Usually when problems of this nature arise there is an inquiry and a meeting to bring those affected together for advice and support. I would be very grateful if you could inquire of Mr Fenwick why haemophiliacs have been denied such a meeting. I know this is the same all over the country which makes this lack of action highly suspicious, you may perhaps draw your own conclusions from this.

I would ask once again if you could set up a meeting for a small group of haemophiliacs organised by myself to meet with Mr Milburn to raise a number of issues. The co-infected have still NOT had a chance to talk with a health minister. I

have patiently written campaign letters on this subject for a number of years now and frankly can understand the recent "direct action" petrol protests to highlight the issue of high petrol prices. Apart from the help from yourself and your office staff for which I am very grateful despite always maintaining a peaceful correspondence and never having resorted to any "direct action" I have not received any satisfactory letters from Government nor a meeting.

One piece of news is that after years of challenging the Haemophilia Society I now here from a reliable source that we will be receiving a letter in which the Society will be including the word ALL in its campaign, as in campaigning for ALL haemophiliacs with hepatitis C (as it should have done from the beginning) and has also been shamed into renewing its recombinant campaign because of the safety issues Peter and others are raising!

I am working with two documentary- makers now who intend to produce a program on haemophiliacs highlighting the waiver and a history of the blood trade, also looking at what Governments have done in this country compared to Southern Ireland and Canada, perhaps this may shame the Government into action! The film-makers have a background in investigative journalism and have worked on both "Newsnight" and "Panorama" so I would expect a very professional approach. I look forward to hearing from you.

Kind Regards

GRO-C

Carol Grayson.