Sent to Mr Gutowski Blood Policy Unit ?
(DoH) H1M/16/2

H1M8?

26th April 2004

GRO-C

Tel GRO-C

RE MISINFORMATION FROM LORD WARNER AND MELANIE JOHNSON DEPARTMENT OF HEALTH

Dear Mr Gutowski,

I am writing with regard to our telephone conversation of 12th March 2004 with regard to the misinformation coming from the Department of Health in relation to the ex-gratia payment awarded by the Eire government to haemophiliacs infected with hepatitis C through blood and blood products. I also wish to make comment on our own government's proposed ex-gratia payment to haemophiliacs infected with hepatitis C through blood or blood products. My husband Peter is a haemophiliac infected with HIV, hepatitis B and C through his NHS plasma treatment, and was recently exposed to the blood of donor(s) who have since died from v CJD. GRO-A also a haemophiliac died of AIDS in 1986 as a result of his plasma treatment.

Firstly, my apologies, I intended to write to you sooner but my husband's condition has recently deteriorated even further, and my priority has been to care for my husband at home and now to ensure I spend as much time as possible supporting him whilst he is in hospital. Incidently my husband is now into his fourth year of treatment strike refusing human plasma on the grounds of safety, and also on moral grounds to protest against the continued use of paid ("blood for money") plasma donors used to provide plasma for treatment for adult haemophiliacs which is still imported from the U.S.

We are aware of continuing safety violations in the collection of U.S. plasma, including the acceptance of plasma from British students studying in the U.S. and selling their blood to help them through college despite a so-called ban on the use of donors from European countries with cases of BSE and v CJD. One English student wrote to me describing how he smoked cannabis prior to selling his blood but that wasn't picked up either. It rather makes a mockery of importing U.S. plasma, don't you think, especially with the history of gross safety violations with regard to the U.S. plasma companies.

Incidently, I am the lady responsible for setting up the initial contact with U.S. lawyers and setting up meetings in the UK to enable the lawyers to meet up with haemophiliacs to establish legal cases in the U.S. The process is going well with around 1,000 cases in total from European countries and more to follow. We are now in the discovery phase and our lawyers have got the judge they want who is familiar with haemophilia cases, the companies have so far failed to halt the proceedings. The lawyers are now seeking to examine shipment records which will link U.S. plasma treatment back to Europe and should help us to identify who exactly was buying in this unsafe treatment in the UK. We shall shortly be applying for access to any shipping records at this end and presumably the government will allow us access to these records as government continually claim that all the information is in the public domain. It is very important that we establish the names of those who licensed this unsafe treatment for import from around 1973. I have contacted my MP on this issue.

In a separate case I also look forward to testifying by phone to a judge in Arkansas in September with regard to issues related to the collection of prison plasma from Cummins Unit Arkansas. My husband has been informed that he was a recipient of this so-called "treatment", as shown when some of his plasma treatment batch numbers were traced back to prison donors in Arkansas and Florida.

To return to the situation in Eire I write to express my serious concern over the recent misinformation coming from Lord Warner and Melanie Johnson in relation to their so called "facts" with regard to the Eire settlement. I also note that the same type of misinformation is coming from Malcolm Chisholm, Health Minister, (Scotland), and that he may be recalled before the Health Committee by politicians to account for his comments. (See enclosed article Sunday Herald 14th March 2004).

I enclose an extract of Hansard, (comments from Lord Warner), and an extract from BBC Woman's Hour, (comments from Melanie Johnson), for your information. Politicians have over the years asked a number of questions in relation to why our government are not paying out on a parity with Eire in relation to our haemophilia hepatitis C settlement. Haemophiliacs are very angry that our government are not making it absolutely clear to fellow politicians and the public that the Eire hepatitis C settlement for haemophiliacs was the same as England, quote a "no-liability", "moral", "compassionate", "ex-gratia" payment which the Irish government made in recognition of "extraordinary suffering". These are the words of representatives of the Irish government, and the Irish lawyers, please see attached letters.

Our government claims that the Irish government accepted "wrongdoing" and uses the example of the pregnant women, anti-D cases (non-haemophilia) cases, as referred to in the Finlay Tribunal as opposed to the findings of the Lindsay report which dealt specifically with haemophiliacs. I enclose references from the book "A Case Of Bad Blood", written by my contacts Rosemary Daley and Paul Cunningham which detailed the events surrounding the Lindsay Tribunal, and you will see that no-one was held to account for the contamination of haemophiliacs, to repeat myself there was no acceptance of "legal liability" for wrongdoing. If you have any papers that state that the Irish government accepted quote "legal liability" please show these to fellow politicians that are asking questions on this issue and make this public to haemophilia campaigners. The Irish government certainly can't produce any such papers, I have already asked them. They are quite clear that their payment to haemophiliacs for hepatitis C infection was a "no-liability", "ex-gratia", "moral", "compassionate" payment. They have also stated to me by phone that anyone not on the ball with their facts on the Eire government settlement could easily be completely confused by the misleading statements coming from the Department of Health in England and the Health Minister in Scotland.

I have had a number of phone calls now with the government in Eire, namely the Blood Policy Division, and they are aware of the confused statements coming from our government. We sent them these statements which is why they have been so helpful in providing the correct facts in writing, addressed to me. With the help of the Irish government I will once more try to correct our government. First of all in legal terms the Irish government has definitely not accepted wrongdoing as it has not accepted "legal liability". Only a handful (around 8 haemophilia cases) had any possible links to receiving plasma from the anti-D women. As in England the vast majority of haemophiliacs were virally infected through imported U.S. plasma and the "extraordinary suffering" of ALL haemophiliacs infected with hepatitis C was recognised in financial terms BEFORE any tribunal of investigation was established. The outcome of any tribunals of investigation did not bring about payment to haemophiliacs as payment was established prior to these tribunals.

In fact infected haemophiliacs and infected partners were not the only ones to receive recognition and financial payment but also the bereaved, and uninfected wives/partners/carers etc. Please see enclosed letter given with the permission of my friend and campaign colleague, widow, GRO-A, who lost her haemophiliac husband to hepatitis C. This shows the categories of individuals who received payment for their "extraordinary suffering". Can you explain why this government is refusing to pay out to the same categories of individuals and why the forthcoming payment is only around a tenth of that paid to individual haemophiliacs and their families in Eire?

We have the ridiculous situation where a haemophiliac living and receiving plasma treatment in England received a one-off plasma treatment in Eire while on a visit to Eire, and because of this he has claimed the financial settlement under the Eire settlement. If he waited and claimed under the English /UK settlement he would only receive one tenth of the payment available through the scheme in Eire. This again highlights the discrimination that is occurring in England.

We also have the case of a family where there are cousins living in Eire and cousins living in England, all with haemophilia. Two cousins in Eire will receive upwards of £250,000, for hepatitis C infection, whilst the poor relation in England will receive at best £45,000. Yet, the crazy thing is all three haemophiliacs could have been infected through the identical U.S. plasma products used in both countries as the vast majority of haemophiliacs in Eire and England were infected not through home produced plasma products but through imported U.S. treatment. This again demonstrates discrimination and the need for the rest of the UK to have parity with the Eire settlement.

ECAS has now contacted myself and others with regard to seeking legal redress in Europe. We have submitted a number of petitions to the European Parliament and have instructed ECAS to seek any avenue to redress as we do not believe we will ever get truth and justice from this present government. A French lawyer has been looking into our cases, she will no doubt be only too aware of the international cover-up on haemophilia blood contamination especially with the criminal cases tried in France!

We are very concerned at the inclusion of an HIV and hepatitis legal waiver in the original HIV settlement and believe this infringes human rights. We have specifically asked for this to be investigated alongside other issues. We are aware that Eire reversed their version of the original waiver because of such concerns and made further payments for HIV infection as well as for hepatitis C infection.

My husband who is currently very ill in hospital has instructed me to request your department to send him information on the forthcoming proposed hepatitis C settlement so that we can study the details and pass them on to ECAS for their deliberation. Can you verify that you have now removed any legal waiver from the forthcoming hepatitis C settlement?

My fellow campaigners and I are still open to negotiate with the Department of Health before we take the matter further. We would require a meeting with Department of Health officials as a matter of urgency and of course an apology for the misinformation on the Eire settlement and a financial settlement on a parity with Eire, as well as a full and open public inquiry, and recombinant for all haemophiliacs as already established in Scotland and Wales, so that adult haemophiliacs in England do not to have to wait until April 2005.

Can you explain why the money for the hepatitis C settlement is not coming from the contingency fund? I understood that the HIV settlement was funded from the contingency fund. If the Department of Health was to treat the hepatitis C virus in the same way as HIV and use the contingency fund there would be more money available for a settlement on a parity with Eire and this would not be eating into NHS monies. Why aren't the Department of Health treating both viruses in the same way? The Department of Health used to use the excuse that there was discrimination against those with HIV and those with hepatitis C didn't suffer in the same way. Well, if you care to read the Living with Hepatitis C study carried out for the Haemophilia Society a few years ago, you will see that haemophiliacs with hepatitis C suffer discrimination in the same way as those haemophiliacs living with HIV/co-infected.

You should also be aware that haemophiliacs and their families have referred their concerns with regard to misinformation on the Eire settlement to the Parliamentary Ombudsman via our MPs.

I look forward to your reply which I understand should be forthcoming within 20 days. I still have not had any reply with regard to the internal investigation into Lord Owens' pulped files. In a letter from the Department of Health dated January 2001, I was promised a reply within 20 days. I am still waiting for a reply with regard to the outcome of that investigation, as no doubt is Lord Owen!

Yours sincerely
GRO-C
Carol Grayson (Haemophilia Action UK)

Cc John Reid
Jim Cousins
Lord Morris
Earl Howe
Lord Clement- Jones
Christine Graham (Scotland)
Press-various