

22nd November 2003

GRO-C

Tel GRO-C

UK HAEMOPHILIACS AND U.S. PRISON BLOOD – NEW EVIDENCE

Dear Jim,

Thank-you for your continued support and for your recent letter with regard to our demonstration at Westminster. Colette Wintle, whom you have met and her sister were also with me. I would be grateful if you could liaise with Sir Michael Spicer, her MP, with regard to this letter as Colette has also received U.S. plasma whilst living in Scotland and later when she moved to England.

I have now received a letter from Malcolm Chisholm's office declining to meet with myself and fellow campaigners and stating that they believe I have no new evidence. They also suggest I try to secure a meeting with Dr John Reid. Since receiving the letter from Mr Chisholm's office I have been presented with new evidence from America which I know neither Malcolm Chisholm nor Dr Reid have in their possession.

The Government line has always been that they refuse to hold a full and open public inquiry unless there is "new" evidence. I write to you enclosing a letter sent to Peter's QC, Stephen Grimes, which unfortunately arrived too late to be submitted to the High Court for his judicial review. It is from a documentary maker, Kelly Duda, who has investigated the past prison plasma trade, used as a source to supply plasma for haemophilia treatment products used in the UK. He is willing to come and give evidence in this country as an expert witness once the appropriate channels have been set up for a public inquiry into the mass contamination of the haemophilia community with HIV and hepatitis viruses. Kelly is currently assisting lawyers within the U.S. representing UK haemophiliacs, Canadian haemophilia campaigners, and lawyers from Japan.

Kelly has collected testimonies on film from both prisoners and professionals with regard to the alleged gross safety violations which occurred in the collection of prison plasma. He has also had access to relevant documents pertaining to plasma batch numbers supplied across Europe through the U.S. Freedom Of Information Act and has traced some of my husband's treatment back to Arkansas prison. I enclose his letter for your information and request that this is sent directly to Dr Reid and Mr Chisholm with an urgent request for a meeting with them, which has so far been denied me.

On the day I demonstrated at Westminster, I bumped into Karin Pappenheim, Haemophilia Society, who was about to attend a Department Of Health meeting, and asked her what evidence the national Haemophilia Society had presented to Government on the issue of U.S. prison plasma. She informed me that the Society had presented no evidence on prison plasma and that I was the person with information on this subject. Colette was a witness to this conversation. I wonder then why Mr Chisholm and Dr Reid have so far failed to meet with me as they cannot now claim to have seen all the evidence relating to the contamination of haemophiliacs.

I will repeat myself once again, and state that for years our national Haemophilia Society has received funding from the U.S. plasma companies named in Kelly's letter and to remind the Government that there is ongoing litigation in America (with UK cases) with regard to these companies. Please note that we have a collection of articles from the 1960s that were published in medical journals about the dangers of using prison plasma for coagulation products. I am very concerned about what was known in the UK in the 1970s when U.S. plasma was licensed for import.

It defies belief that the Department of Health could have sanctioned such products and that haematologists continued to use the U.S. treatment knowing the serious concerns about U.S. prison plasma voiced in medical journals. These products should not have been licensed on the grounds of safety. We demand to know why haemophiliacs weren't informed that their treatment was being sourced from prisons. Patients have an "absolute right" to decline treatment as stated by Justice Charles in court. In order for patients to make an "informed decision" on treatment, the "high risks" related to prison plasma, as described in old medical journals recently accessed from Newcastle Medical Library, should have been explained to patients prior to them taking this highly dangerous and controversial treatment.

It is not surprising that Dr David Owen who expressed his own concerns over U.S. plasma in the mid 1970s and put money aside for the UK to become self-sufficient in blood products should find that his papers when health minister have now been pulped, a move he described as "unprecedented". As you are aware I have copies of his letters accusing the Government of "gross maladministration," with regard to failing to carry out his parliamentary commitment once he left office. Lord Morris of Manchester and I were promised an investigation into this issue back in January after an investigation by the "Journal" newspaper. I have still not received a reply from the Department of Health on this issue!

I am sure you will be appalled at the contents of Kelly's letter and I believe that had you or a family member received blood collected in such appalling conditions you would want a public inquiry into this issue as a matter of urgency. I also enclose recent press from Canada where the information has now been passed on to the Royal Canadian Mounted Police.

I have already spoken to police here and will be sending Kelly's letter to them as well as to the General Medical Council, solicitors representing other haemophiliacs who received U.S. plasma, and the press. I have watched Kelly's documentary, which the RCMP describe as "disturbing". It is very important that this documentary is shown in the UK, particularly as the general population now receive U.S. plasma from paid donors, (because of the "theoretical" risk of vCJD from UK plasma), not just haemophiliacs, as in the past. If there is no public inquiry and lessons are not learnt, how can we be sure that similar practises are not going on now? Recent safety violations continue to be exposed, (I have some on film). Will we experience a similar cover-up to the past if things do go seriously wrong again?

I would also like to remind you that the local Primary Care Trust still refuse to provide Peter and other haemophiliacs over 16 with the safest treatment, recombinant, a synthetic alternative to plasma derived products, (see press article). It is disgusting that we have had to go to the High Court on this issue. Haemophiliacs find it astonishing that they are still expected to take human plasma with the knowledge haemophiliacs now have with regard to alleged safety violations in relation to human coagulation products past AND present. What is clear is that there is generally a great lack of compassion in the Health Service with regard to contaminated haemophiliacs and their need for the safest products. Post-code prescribing rules once again as there

are cases of haemophiliacs over 16 with viruses in other parts of the country being given recombinant. The ridiculous thing is that we sent these individuals our written argument to help them fight for recombinant, which they used, their PCT's saw sense, ours did not!

Thank-you once again for your help and I ask you to address this issue as a matter of urgency. A "no liability", financial assistance package for haemophiliacs infected with C through blood products is not enough, we demand an independent public inquiry, accountability, and the truth, which is long overdue!

Yours sincerely

GRO-C

Carol Grayson (Haemophilia Action UK)