Sat 1st March 2003

GRO-C

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Testing Haemophiliacs For Hepatitis C Without Their Knowledge Or Consent

Dear Inspector Bleasedale,

I am writing to you and your colleagues who visited me with regard to our concerns over haemophiliacs being tested for hepatitis C without their knowledge and permission against the rules of the General Medical Council as discussed in a recent phone call with yourself.

I intended to get this to you earlier but Pete has been quite ill and it has been a battle with the hospital over treatment. Despite the Department of Health recently announcing its decision to allow all haemophiliacs to be given recombinant, the safer synthetic treatment, what wasn't properly explained was that it is being phased in over 4 years by age and in reality Pete is unlikely to see recombinant for a couple of years.

This week Pete has been bleeding into his stomach and was turned away from hospital on the first day without Factor VIII treatment, as he won't take the human plasma for obvious reasons and remains on "treatment strike" and the hospital wouldn't fund the synthetic treatment. The second day they panicked as they didn't want a corpse on their hands and made it clear that they would only give him a "one – off" treatment of recombinant as Pete's condition could be life threatening, in order to give Pete an endoscopy. We have since found out that instead of giving Pete the third generation recombinant which they give to all children on safety grounds and which doesn't contain any human albumin they gave him a first generation product containing human albumin, so they breached his human rights anyway as he had clearly stated in writing that he wouldn't take human products! We have however now got legal aid to hopefully seek a judicial decision on treatment. The legal aid decision has gone from Newcastle (where it was initially sat on for several weeks on even though it is an urgent medical case) to Leeds then on to Brighton to the top man who has had to inform the Government as any legal case of this nature could be extremely costly for them. Our new solicitor is quite perplexed by the whole thing. Pete is so swollen now with fluid due to his hepatitis C, one consultant is now wanting to drain 15 to 20 litres of fluid off his stomach but can't until he can cover Pete with recombinant and so it goes on.

For your information I have enclosed my letter on testing without permission to the Department of Health, to health ministers Hazel Blears and Lord Hunt. (It is self-explanatory and deals with the related issues to save me repeating myself here.) The DOH was supposed to be giving me a reply within 20 days. I have just e-mailed the DOH and got the enclosed response. Questions are also being asked in parliament. I understand from Louella (Houldcroft) journalist at the Newcastle "Journal" that after the "Journal" ran a front page article the national Haemophilia Society rang the paper to say that they themselves had raised the issue of testing for hepatitis C without permission at a meeting with the Department of Health in 1999. The DOH apparently did nothing! The Haemophilia Society may have reported this but members were certainly not told about it in the Haemophilia Society magazine or asked if they had evidence to support this or to write to their MPs on the issue.

This issue is one that even the Government will have difficulty avoiding now because its been made public and some politicians are raising serious concerns. I understand that doctors testing without consent can face being struck off and may have to account for their actions in a criminal court according to the GMC booklet. Testing without permission appears to have happened all over England, Scotland, Wales and Eire. Some haemophiliacs have made initial complaints to the General Medical Council who are passing this back to local health authorities. The GMC only deal with complaints against individual doctors and seem to be saying that anything which involves a number of consultants will get passed over to the DOH. I have enclosed my letter to the GMC anyway. Other haemophiliacs all over the UK have sent in complaints.

I have permission from Colin Potts whom you met to pass on the following information. In his medical records which he accessed there is a letter dated 1991 stating that he tested positive for the hepatitis C virus a year earlier (presumably 1990) before he signed the hepatitis legal waiver in the HIV government settlement in 1991, yet when he asked for a copy of his first test result he was only sent results from December 1992 onwards, so where is this early result? He and his wife who always accompanies Colin to hospital appointments as I do with Pete recall that they were not told of his positive hepatitis C result until 1994, the same year Pete and I were told Pete's result. We recently requested a copy of Pete's first positive test result and we were sent a test report dated December 1992 (same date as Colin and another haemophiliac Simon) but I am not convinced this was Pete's first positive test. Dr Peter Jones's initials appear on the 1992 tests. We had no knowledge at the time blood was being tested for hepatitis C, no consent was ever sought.

I am sending you information from the GMC and we would be very grateful if you could check if there is anyway that we can proceed down this avenue with yourselves. The Scottish haemophiliacs have informed me that they have approached the police in Scotland for assistance with contamination issues and to complain about hepatitis C testing without permission. There is a meeting arranged for Wednesday 5th March in Stirling for haemophiliacs with Stephen Heath (Sorry, I am not sure of his rank). I spoke to him and I understand he is in communication with your office. I have explained that I have documents relating to a Glasgow hospital showing that they were using American factor VIII in 1980. I have letters between a man on holiday from New Zealand whose son, a haemophiliac had his first ever treatment of factor concentrates at Yorkhill Hospital in Glasgow as a child and became infected with both HIV and hepatitis C. This man Mr GRO-A came to visit me from New Zealand and I gave him information on accessing medical records and helped him obtain treatment information from Yorkhill Hospital (after he threatened legal action). The case was pretty clear cut so he also wrote to the American plasma company again threatening legal action and was offered a financial settlement from the company which included a silence clause, however he passed the papers on to me to use where I could as he knew some other haemophiliacs would probably have had the same treatment batch numbers but wouldn't get justice. The Scottish Executive has played down the use of American plasma as Scotland had always claimed to be selfsufficient in blood products (untrue) and did not include this in their whitewash of an inquiry.

I thank you once again for your assistance and hope that there may be a way we can at least proceed on the testing without permission issue. The doctors have covered up so much there must be some route to justice. I look forward to your reply.

Yours sin GRO-C

Carol Grayson and Peter Longstaff