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GRO-C

Tel: GRO-C

PATIENTS TESTED WITHOUT PERMISSION

-HAEMOPHILIACS DEMAND A PUBLIC INQUIRY

Dear Ms Blears and Lord Hunt,

First of all I wish to state that I am writing this letter on behalf of a number of haemophiliacs and their families, as many are too afraid to speak out.

As you are aware haemophilia patients have recently been accessing their medical records over the past few months with regard to U. S. litigation against major American plasma companies for contamination with HIV and hepatitis viruses. In the course of this procedure we are absolutely appalled to find that in the past there has been testing of haemophiliacs for the hepatitis C virus on a national scale WITHOUT the expressed permission of the patient, and WITHOUT any pre or post- test counselling being offered. In addition to this the results of these tests were withheld from the patient often for several years. This follows hot on the heels of the discovery that organs were taken from haemophiliacs who died from HIV and hepatitis C, (including my partner's brother) and that is now part of the NHS Retained Organs Commission inquiry. THE TESTING OF HAEMOPHILIACS FOR HEPATTIS C WITHOUT CONSENT IS A SCANDEL!

Haemophiliacs had long suspected that they had been tested without their knowledge years before they were told of their condition but until they accessed their notes we did not have the written evidence. Prior to accessing medical records my suspicions were highlighted during a discussion with a retired virologist who remembered the year he had carried out the first hepatitis C tests on haemophiliacs in Newcastle. If you care to ring the General Medical Council and ask for their leaflet on testing patients for HIV and hepatitis you will see that testing without permission is completely against guidelines and has been for many years and that inquiries should be held into such unprofessional behaviour. Doctors can of course be struck off the register for such actions!

Any pathetic excuse that the first HCV test was not accurate enough and therefore a reason for not disclosing results will not hold weight. The issue here is not the accuracy of the test but the failure to request permission. Haemophiliacs are not guinea pigs. This was not random anonymous testing, this was testing on official request forms on a named patient basis. We also have documentation of good practice where haemophiliacs were tested in 1991 according to guidelines.

It would have been very easy to test haemophiliacs without their consent or knowledge probably more so than other patient groups. Haemophiliacs are often asked to give blood to be checked for clotting levels or inhibitors. What is NOT allowed is for this blood to be used for another purpose such as HCV testing without the expressed permission of the patient, and this amounts to abuse of the patient.

I am very familiar with such procedures because of my own nursing background where part of my role was to offer HIV testing. I was involved in producing the first guidelines with regard to testing in relation to HIV in 1985 in order to protect the rights of the patient and these guidelines for doctors, nurses, etc became the accepted standard and practice to be applied also in relation to hepatitis C when a test became available in 1989. The hope was that health professionals had learnt from their mistakes in the past with regard to early HIV testing.

The standard procedure is that in the first instance a person must first be counselled as to whether or not they wish to be tested for HIV/hepatitis viruses. If they do want a test then the professional should explain the implications of testing (eg positive result, safe sex, problems with mortgage and insurance etc) and ensure the person gives permission. It is usual to put this in writing with the patients signature to say that they understand the procedure and have given their consent to test, and the professional signs to say that they have carried out the pre-test counselling procedure. The signatures protect both professional and patient. The patient is then told the result of the test and is offered counselling with regard to the result. If the result is positive then the professional may discuss further implications of the result and the patient is offered ongoing support, again this is noted in writing.

The fact that in many cases this procedure was never carried out has had far-reaching consequences for haemophiliacs. There are many considerations to be taken into account when a person has been infected with hepatitis C. Haemophiliacs have been denied the opportunity to make certain life choices with regard to their health such as taking precautions to ensure that they don't infect their wives or partners, stopping any alcohol intake, changing diet etc. Haemophiliacs were unable to consider any possible treatment for hepatitis C infection. What is truly shocking is that in some cases haemophiliacs have actually been diagnosed with serious conditions related to their hepatitis C infection and were not told of these for many years either. This testing without permission was so wide spread that it leads myself and many others to believe that there was a deliberate policy NOT to tell haemophiliacs of their condition and NOT to treat the condition.

Haemophiliacs have been extremely worried for some time that patients were being allowed to die from their hepatitis C and related conditions without any treatment or appropriate medical intervention. It is only very recently that patients are being offered treatment and only after patient groups like Haemophilia Action UK and the Manor House Group have put pressure on haemophilia centres and hospitals. In addition to this haemophiliacs have had to fight to be referred to specialist liver clinics, fight for biopsies and scans and fight to be referred for assessment for possible transplant. One liver specialist spoke to me of his utter frustration and deep concern that haemophiliac patients were being referred to him far too late for him to transplant (if they were being referred at all) and therefore died. Is this all part of the great NHS cost-cutting exercise? Is it that those who were infected with HIV and hepatitis C through their NHS treatment are being written off and are considered not worthy of transplantation?

I will give you one example of the case of a Newcastle haemophiliac who has given me permission to give his name which for your purpose is recorded on a

separate piece of paper but otherwise the gentleman wishes to maintain his confidentiality. Patient A accessed his medical records recently and discovered two letters dated 1991 in which it refers to his hepatitis C positive test result and the fact that he actually tested positive "last year" 1990. In 1991 he was admitted for a scan but presumed that this was in relation to his previous hepatitis B infection not knowing anything about hepatitis C at the time. One letter from a Consultant Physician to a Consultant Haematologist documents "persistently abnormal liver function tests for a number of years" and that the patient "has hepatomegaly consistent with hepatitis C related cirrhosis" and that "he ought to have a liver biopsy and scan". The patient was NOT told of his hepatitis C result until around 1994 and was told it was nothing to worry about for years even though he felt unwell and had a swollen abdomen. To this date he has not been told in person that he has cirrhosis, he found out from his records. He is now receiving treatment for hepatitis C but only after he went to his GP and insisted he be referred over to a co-infection doctor at another Newcastle hospital. In 1991 patient A like hundreds of other haemophiliacs signed a "hepatitis undertaking" known to haemophiliacs as the "waiver" as part of the HIV litigation not realising he had been infected with hepatitis C and tested a year previously!

THIS IS AN OUTRAGE!

My partner Mr Peter Longstaff was also one of those haemophiliacs who was not offered a hepatitis C test at the time he signed the hepatitis waiver or advised to consider testing by his haematologist (who in fact tested him without his knowledge, without his written consent and without pre and post test counselling). The solicitor acting for him with regard to the HIV litigation did not advise of a test either although the solicitor and doctor were in contact with each other. In 1991 when Peter signed the waiver he was unaware of the existence of such a test. He was tested without his permission and this information withheld for years until 1994. Even if it was felt that this test was not so accurate my partner would not have signed the waiver knowing that hepatitis C was a dangerous virus and that there was every possibility he would be infected.

I was with my partner when he was officially told he had hepatitis C in 1994, a further sample of his blood was taken in 1994 after the Consultant said in a matter of fact tone that he was going to test him for hepatitis C. He was not offered pre or post-test counselling in 1994 which I discussed with Peter at the time giving him the benefit of my experience with regard to the implications of testing.

When the hepatitis C result came back positive I consulted the original HIV solicitor in 1994 with regard to hepatitis C litigation. He informed me that he could not act for us because Peter had signed a hepatitis waiver. It was then that Peter and I realised the significance of the waiver and why haemophiliacs were told that if one person did not sign no-one would receive recompense. Haemophiliacs did not realise at the time that 99% of HIV positive haemophiliacs would test positive for hepatitis C and that the doctors, the solicitors and the Government knew this fact but the only people who didn't know when signing the waiver were the haemophiliacs!

Haemophiliacs were told by solicitors in 1991 that hepatitis C was "no big deal", "nothing to worry about" and "less of a problem than hepatitis A or B". What haemophiliacs didn't know then was that in the 69 boxes of HIV litigation which they weren't shown (and which we have since accessed) there was thousands of pages of research, medical journal articles, Government documents and expert advice on the dangers of the hepatitis C virus. Some experts considered at that time that hepatitis C

was a more dangerous virus than HIV and this has proved to be the case for some haemophiliacs.

The national Haemophilia Society who had access to many haematologists and other medical experts also told their members in 1991 that hepatitis C wasn't a problem and not to worry. This is documented in Haemophilia Society minutes. I have a letter from the Department of Health from the mid 1990s, which states that at the time of the signing of the waiver in 1991, Government knew that haemophiliacs had died from hepatitis C and others were seriously ill! I can come to no other conclusion from all the evidence in my possession that there has been a deliberate conspiracy of silence from many professionals in responsible positions which has involved withholding of vital information, a web of deceit and putting patients lives at risk. This has been maintained for many years and began with the introduction of imported American factor concentrates in 1973 when professionals knew that they were putting their patients at a greatly increased risk of becoming infected with hepatitis viruses by using this treatment from high-risk sources.

To refer back to medical records, when patients have tried to access their records they have discovered that records are missing even though haemophilia is a life-long condition requiring life-long treatment, and records are supposed to be maintained for 10 years after the patient's treatment has ended or death. One haemophiliac simply asking questions with regard to information on his condition was told by a consultant haematologist to "go to hell". An official written complaint was sent to the hospital. We have copies of written complaints from other haemophiliacs in our possession.

The state and content of medical records is a disgrace. Haemophiliacs on home treatment (factor concentrates) were told that in order to receive home treatment haemophiliacs must record the following for legal requirements.

1. The name of the product and company.
2. The batch number.
3. The date the product was used.
4. The expiry date of product.
5. The dosage used.
6. Site of bleed.

We find however that far from following their own rules health care professionals frequently failed to complete the documentation for legal requirements. Records are often illegible with sections not filled in and not signed, that is if they haven't gone missing.

Other patients' names appear in haemophiliacs medical records breaking the confidentiality of that person.

There are unprofessional, derogatory comments and judgemental statements written about patients, which are nothing to do with their treatment. There is also documentation, which is so factually incorrect and so perverse it is libellous. Attempts are made to discredit those who campaign and speak out even though that is a person's right in a democratic society. This is widespread across the country and we are receiving dozens of calls from angry haemophiliacs complaining about the content of their records and asking for advice or the name of a good lawyer.

I note that during a period when I had for years been expressing concern at what I identified as major symptoms of liver disease in my partner we were told not to worry with hepatitis C being completely down played. The records corresponding to that time record "this patient is entering the terminal phase of liver disease as a result of hepatitis C infection."

We demand that Government holds a full and open public inquiry into the contamination of haemophiliacs with HIV and hepatitis C and into the medical treatment of haemophilia patients. Haemophiliacs are currently seeking legal advice on treatment as they are alleging medical negligence and professional incompetence on a large scale. In many cases there is a complete breakdown of trust between doctors and patients. Patients are so distressed at their treatment at the hands of the NHS they are afraid to go to hospital and are in fact cancelling appointments. This cannot go on. What more evidence do you need? The Government promised that if new evidence came to light it would hold such an inquiry. Only a full and open public inquiry where mistakes are admitted and addressed will serve to give patients the confidence to return to their haemophilia centres to be treated. I require an urgent response to this letter.

Yours sincerely

Carol Grayson (Haemophilia Action UK)