Witness Name: GRO-B
Statement No: WITN1551001
Exhibits:0
Dated: NOVEMBER 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MR GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1965 and I live at GRO-B with my wife, GRO-B I am by occupation an Accountant and I work for GRO-B company.

2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. Method of Infection

3. I suffer from Haemophilia A, classed as severe. I was diagnosed with haemophilia whilst receiving medical treatment at the age of six months. I was the first family member identified with Haemophilia A.

4. I was treated from diagnosis at the Middlesex Haemophilia Centre until around 1979 under the care of Professor Stewart. From 1979 I was treated at St Thomas Hospital until around 2002. From 2002 until 2008 whilst living in GRO-B I was treated at the Royal Norfolk and Norwich Hospital. Since 2008 to date I have been treated at the Bristol Royal Infirmity.

5. I have not been treated with blood products for many years. I was initially treated with cryoprecipitate and later (although I am unsure as to precisely when) I was given Factor VIII products. In or around 1976 or 1977, it was identified that I had developed inhibitors and was in fact allergic to Factor VIII products. I have not been treated with Factor VIII since than time.

6. No advice had ever been given to my parents or myself about the risk of being exposed to infection from blood products.

7. I was told that I was infected with Hepatitis C by at the clinic of Dr Savidge at St Thomas Hospital sometime in the mid 1990s as I recall.

Discovery of Infection

8. In the mid 1990s, it hit the press that in addition to the risk to haemophiliacs of HIV through contaminated blood products, it had been identified that they were also contracting Hepatitis C. I received an appointment from St Thomas Hospital asking me to come in and get checked. A blood test was taken and I am pretty sure that I was told at that same appointment that I had tested positive for HCV. At the clinic I was simply advised 'Yep, you

got it. Don't worry too much as there are lots of new drugs coming. If you develop a problem with the liver in the meantime we will pop in a new one in'. I don't recall an in-depth conversation about the cause but I had been called in because of the contaminated blood risk. If you were tested positive at that time, it was pretty much 'a given' that the source of the infection was the blood you had been treated with.

9. The manner in which I was told was what I would describe as casual and flippant. The hospital did not give me any specific information about HCV and nothing about managing the infection and/or risk to others of infection. The source of the little knowledge I had was the press and the usual haemophilia literature. GRO-B was tested for (negative) HCV at a later time.

10. The news that I was infected was delivered to me without any sympathy. I was at that same appointment informed that they had identified that I had previously been infected with or had picked up that I had been vaccinated (for the purpose of overseas travel) against Hepatitis B. I was now immune.

11. I believe I should have been informed about the risk of Hepatitis C much sooner. As soon as they had any suspicion they should have told me/my parents so enabling a choice on treatment. In developing inhibitors sometime around 1976/1977, Factor VIII treatment was withdrawn in any case and my condition was managed with nothing more than pain killers since. Clearly the decision to stop using Factor VIII could have been made much earlier had the risks been shared. As a result I would not have been infected with Hepatitis C. They had the knowledge and the opportunity but chose not to disclose the risks. Instead they chose not to tell people. My own treatment clearly demonstrates there was an alternative.

Section 3. Other Infections

12. I am not aware of any other infection or risk of infection other than that of hepatitis as detailed above. However it is worth noting the decision to stop using Factor VIII was a consequence of developing inhibitors. Without that event, I would have continued to be treated with contaminated Factor VIII, so potentially exposing me to the HIV virus like so many of my friends at the time.

Section 4. Consent

13. I have no knowledge of being treated or tested without my knowledge or consent.

Section 5. Impact of the Infection

Physical Impact

14. My liver is severely damaged – I have liver cirrhosis. In the years prior to clearing the virus I suffered with terrible bouts of stomach pain as a result – the consequence of liver inflammation.

15. I have had three attempts at clearing the Hepatitis C infection. I was one of the first to take part in an interferon trial in or around 1997 that proved ineffectual and failed but there were not many side effects.

16. I had a second attempt when we moved to Norfolk and I was under the care of the Royal Norfolk and Norwich Hospital some time between 2004 and 2006. The treatment was horrendous. I was treated with interferon tablets and ribavirin injections I had to self inject for six months. The side effects included extreme tiredness, what I would describe as a chesty

smokers cough, weight loss and flu like symptoms. At the end of it all I was informed 'sorry it didn't work'. It was a long time before another attempt.

17. I started the third attempt at clearing with interferon and ribavirin in 2013 as my liver was by then severely damaged with cirrhosis. This treatment lasted for a full year with even worse side effects. It was described by those receiving the treatment as "poison" and made me very sick. I suffered from a complete loss of energy and again flu like symptoms. I still went to work throughout the entirety of my treatments. My employers were not aware of my Hepatitis C status. I spent my evenings and my weekends curled up on the sofa under a blanket. The cold would really get to me. I recall that GRO-B and I spent that Christmas with my grandmother. It was all I could do to get us there. I slept for the whole Christmas period. The third attempt at clearing was ultimately successful but my liver is 'shot'. I still suffer with the side effects of the clearing treatment to include fatigue and feeling the cold. My metabolism has been affected and I have gained weight I am unable to shift.

Mental Impact

18. The infection has had a huge impact on my family life. As stated, GRO-B had to be tested. The stress and strain placed upon GRO-B in having a husband with hepatitis C has been hard. We had to make the difficult decision not to start a family of our own. At that time there was no sign of a cure. Apart from the obvious cross infection issue, I did not know or believe for certain if I would be around to raise a family. This has been a big regret and sadness to us.

19. My parents died (young) in their sixties. I was their only child. I believe the worry and stress of my infection impacted upon their life span.

20. I have not disclosed to my employers my health status for fear of being stigmatised. I was open about my haemophilia when applying for jobs after

I finished university. Because AIDs had hit the press and haemophiliacs were associated as at risk, I received fewer interviews than my qualifications warranted. At that point I chose not to disclose my Hepatitis. Throughout my working career, I have had to omit my HCV from my applications in order to be accepted.

21. I found it impossible to get a NHS dentist to take me on as I was considered high risk and have been treated by hospitals since the early 1990s.

22. Having Hepatitis C has caused me financial difficulties. I cannot get life insurance; Obtaining a loan/mortgage has been most difficult as a consequence. Anything requiring a medical declaration has been problematical – for example I cannot get travel insurance either.

Section 6. Treatment/Care/Support

23. I do not recall being offered any psychological support or counselling.

Section 7. Financial Assistance

24. I am a Skipton Fund stage 2 recipient. I have had no problems at all with the process.

Section 8. Other Issues

25. At a very early stage I believe that there was knowledge about the possibility/risk of infection through blood. The consequences and impact of the various infections was not re-laid therefore it took away individuals choice.

Anonymity, disclosure and redaction

I do not want to give oral evidence and I am seeking anonymity and would like my Statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed... **GRO-B** ....

Dated 15. 11. 18