Witness Name: GRO-B
Statement No: WITN1352001
Exhibits: 0
Dated: JANUARY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on the GRO-B 1958 and I live at GRO-B GRO-B I am married with two sons.

2. This witness statement has been prepared without the benefit of access to my 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. How Infected

3. I have mild Haemophilia A. I am the first known haemophiliac in my family. I was diagnosed with haemophilia aged 14 years when I had a tooth removed after blood tests due to trouble I had when I was 7 years old. My younger brother was tested and confirmed to have haemophilia shortly thereafter.

4. I was treated at the Newcastle Haemophilia Centre at the Royal Victoria Infirmary under the care of Dr Peter Jones.

5. I am infected with Hepatitis C (HCV) as a result of being given contaminated blood products.

6. I was initially treated with cryoprecipitate and latterly with DDAVP. I believe that I was infected with HCV from Factor VIII (FVIII) in 1977 at aged 19 years. I was admitted to A&E at the Newcastle Royal Victoria Infirmary late at night with a badly injured thigh. As I was admitted outside of day time hours, the medical team did not have the benefit of my medical notes and gave me FVIII by mistake. I had not had FVIII up until then. I remember that night clearly as there were no beds available on the hospital ward and I waited in a side room until a bed became available. I was eventually put into the bed of someone who had just died. The bed was still warm. It was horrible and I can't forget it.

7. I have had many visits to hospital and treatment over the years. Because of the passage of time, my memory has faded. I may have had FVIII treatment after that occasion but I believe I contracted HCV when I was treated at hospital in 1977.

8. I was not given any information or advice beforehand about the risk of being exposed to infection from blood products. I took the doctors' word for it when I needed the treatment that I would be given the best treatment for me. After being treated with FVIII in 1977, my suspicions were aroused because of articles in the media. I recall asking my Consultant, Dr Jones, if he was one hundred percent sure that the FVIII treatment was safe. He replied "It is as safe as it can be and you need the treatment."

9. I continued to feel sceptical about the safety of my treatment throughout the best part of the 1980s and would suffer at home rather than go to the Haemophilia

Centre for treatment. Retrospectively I believe I was right to do so as I had friends with haemophilia that died from HIV/AIDs because they received a lot of FVIII treatment.

10. I found out I had HCV in or around GRO- 1993 after the death of my father. I received a letter from the hospital asking me to attend an appointment. I thought the appointment was a routine one. I was instead informed by Dr Jones that I had been tested for infection from blood taken at my previous appointment. His Clinical Nurse was present taking notes of the meeting. He told me that I had tested HIV negative but that 'unfortunately' I was HCV positive. I was not told prior to the appointment that I was going to be tested.

11. I was shocked to be told I had HCV. I said "How is that? You said I was getting safe treatment." Dr Jones said "Unfortunately we could not see this coming." At this I lost my head and accused him of lying to me. Dr Jones told me that they had done their best for me.

12. I believe that Dr Jones and his team knew I had HCV approximately two years before telling me. I do not have my medical notes and records but I instructed a solicitor to look into this matter some years ago and I was told that I was tested positive around two years before I was told. The solicitor dealing with the matter on my behalf back then also told me that my medical notes and records were incomplete and that some of the information was missing.

13. Very little information was given to me about HCV at my appointment with Dr Jones. There was no treatment available to me. Treatment options were not discussed for several months. I was handed a booklet to read about safe sex and hygiene. It was a bit late for me because by then I had a wife and two sons. Dr Jones informed me it was very unlikely to cross infect your partner with HCV through your sexual relationship. However, my younger brother who was also infected with HCV passed HCV to his wife that way.

14. In or around 1998, I underwent clearing treatment. It was unsuccessful. I had a second round of treatment around 15 years ago and the virus looks to have cleared.

Section 3. Other Infections.

15. I have been notified that I am at risk of vCJD having been treated with the same batch as somebody who had died from vCJD. As a result, I am left to wonder what else I might have been exposed to.

Section 4. Consent.

16. I was tested for HIV and HCV without my knowledge, consent and without being given adequate and full information. When I was called in for an appointment by Dr Jones in 1995, I had no idea that I had already been tested for HIV and HCV.

17. I was treated with FVIII without my consent in 1977 when I was first given the FVIII by the hospital when I had my thigh injury.

Section 5. Impact

18. Before being informed that I had HCV, I felt unwell. I had flu-like symptoms and felt tired and lethargic. When I found out that I had contracted HCV (formerly known as non-A, non-B Hepatitis) in 1977 I understood why I would have been feeling unwell and run down.

19. The clearing treatment I had in 1998 was awful. I had to self-administer Interferon injections three times a week over the course of a year, but with a review at 6 months. I would dread the injections. I would take the injection at night with paracetamol in order to try to sleep through the side effects. I suffered with the shakes, night sweats, aching arms and legs, the worst flu-like symptoms

imaginable and what felt like a hang over on top. I was sick and my hair fell out. I went into a deep depression. At five months I experienced unbearable stomach pains and was rushed to hospital with appendicitis.

20. At the beginning of the treatment I had a job on the lines at GRO-B fitting car doors. My job was quite physically demanding. My wife and I also ran our own GRO-B business. I ended up losing my job at GRO-B and our business. I was incapable of working. My wife tried her best by getting people in to cover but they took us for a ride and the business went bust.

21. My wife and I have been together since we were 15 and 16 years old respectively. Our children were just 14 and 10 years old when I was having treatment. The treatment sent me crazy. I was short tempered and had dramatic mood swings. My wife and I nearly split up at that time. My treatment was stopped at five months for two reasons; my severe depression and the emergency appendicitis.

22. Because of the mental impact upon me of the first clearing treatment, I had to have a psychological assessment and counselling before I could embark on further treatment. I believe the second round of treatment would have been around 15 years ago. I had counselling for about six months. I then had new treatment being a combination of Interferon and Ribavirin. The treatment reduced my viral load to zero but the antibodies are always there.

23. The side effects of the second treatment were less severe but I still had bad headaches and flu-like symptoms to include aching joints. I would also wake up during the night soaking wet to the extent that my wife needed to get out of bed and change the sheets, whilst I moved into the spare bedroom.

24. My heath has suffered. I have atrial fibrillation and have had a heart device fitted. I have high blood pressure and have had three strokes. I woke up on the morning of the first stroke (7 years ago) unable to move my left arm, leg or face.

I was rushed to hospital and my heart rate was through the roof. I have had constant lung infections (pneumonia). My eye sight is also affected.

25. Being infected with HCV has ruined my life and has adversely affected my wife and children. The impact of the stigma of being infected with HCV upon me and my family is palpable. We live in a close knit community. Our neighbours found out about my diagnosis through the children and stopped their children from playing with mine. My children were excluded from invitations to parties.

26. The blood thinning medication I was given to prevent me from further strokes was problematic as it caused severe nose bleeds that went on for days. A nurse at reception in A&E ran screaming from the area, ripping her apron off after I reminded her that I had HCV and that she needed gloves. She had started clearing up my blood and was yelling that I had not told her (when I had in fact just told the receptionist). It really knocked my confidence.

27. I am treated differently at the dentist because I have HCV. Around 12 years ago, my local dentist found out I had HCV and politely asked me to leave his practice. I am always last on the daily list of patients to be seen at the hospital dentist and am taken into a different room/theatre to everyone else. The dentist is garbed in a mask and a uniform that makes him look like he is expecting a nuclear explosion.

28. I do not tell anyone about my diagnosis if I can help it. I have not worked since 1998 when I had my first round of clearing treatment but I have never declared haemophilia or my HCV status to a prospective employer. If I had done so, I would not have been employed. For a long time, my wife and I were solely reliant upon Income Support. That was all we had. We had to borrow money from our friends and family. My mother in law helped us meet our mortgage repayments. We would otherwise have lost our family home. Eventually I received help from the comprehensive care system at the Haemophilia Centre. The Social Worker there assisted me in applying for Disability Living Allowance.

29. I continue to suffer with chronic fatigue, insomnia and nightmares. I am no longer able to drive because I cannot concentrate and I go into a dream like state. I am on anti-depressants and I see a counsellor which started recently.

Section 6. Treatment/Care/Support

30. I was not offered any counselling when I was first diagnosed with HCV. As stated at paragraph 22 above, I had counselling and a psychological assessment to ensure that I would be able to cope (mentally) with further clearing treatment. I have started seeing a counsellor again recently.

Section 7. Financial Assistance

31. I received the Stage 1 £20,000 Skipton Fund payment.

32. Within the past five years I have started receiving a monthly payment of £500 and from July 2018 a monthly payment of £1,500 to include a top up payment triggered by the special category mechanism. The Social Worker at the hospital informed me that I was entitled to a monthly payment and helped me with the application. At first I received a basic payment £500 until I became aware that depression fulfilled the top up criteria. I was at first turned down but was successful on appeal with the help of my Social Worker. The payments are now made through EIBSS.

Section 8. Other Issues

33. It took my previous solicitors six months to get hold of my medical records only for it to be revealed that a large proportion were missing

Anonymity, disclosure and redaction

34. I confirm that I wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry. I would not like to provide oral evidence to the Inquiry at the hearings.

Statement of Truth

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

Signed... GRO-B ....

Dated........ 30/1/19 ....