Witness Name: GRO-B
Statement No: WITN1130001
Exhibits: WITN1130002
Dated: MARCH 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 GRO-B 1960 and I live at GRO-B I am married with two children. I am by occupation a delivery driver working for GRO-B three days per week.

2. This witness statement has been prepared without the benefit of access to my full medical records. I have a limited number of GP notes and records and nothing more.

Section 2. How infected

3. I was given a blood transfusion which resulted in my contracting the Hepatitis C Virus (HCV) from contaminated blood following the birth of my daughter. My daughter (our second child) was born on GRO-B 1991 by emergency caesarean section at 28 weeks gestation. Something ruptured inside me, resulting in the hospital having to perform an emergency hysterectomy that

same day. I was in intensive care for a week. When I came round I was informed that I had been given 45 units of blood product.

4. The rupture and hysterectomy took place at the Clarendon Wing of Leeds General Infirmary. I believe my Consultant to have been Dr Vinyl.

5. As a direct result of the blood transfusion I contracted HCV. No information or advice was given to me beforehand about the risk of being exposed to infection. The operation was performed on an emergency basis and I knew nothing about the blood transfusion until I awoke from the operation.

6. I knew nothing of risk until very many months later at the end of 1991 or the beginning of 1992. My mother saw a Panorama programme which she recorded for me on Betamax. Through the programme I discovered that there was a window of time before September 1991 wherein the blood used for transfusions had not been tested for HIV/AIDS or non-A, non-B (NANB) hepatitis. I was concerned enough to go to my GP. My GP was quite rude and dismissive to me about the matter. I was told that I was being stupid, watching too much TV and to go away. I had to persist with my request and said that if he did not test me, I would go to the hospital for testing. He then relented and told me to make an appointment for testing with his nurse. I had the test a few days later and I had my daughter tested because she too had blood transfusions when she was born prematurely.

7. When my GP surgery called for me to come back to receive my test results, I knew the news was not going to be good news. I was told that I was NANB positive and referred to a Consultant Hepatologist at St James Hospital. I believe his name was Professor Lisophski. When I explained to Professor Lisophski that I had contracted hepatitis from a blood transfusion, he said 'you have your ears pierced, it could be that'. He also said 'I do not know what you are worrying about because it (HCV) does not do anything or have any life threatening impact on a sufferer for 20 years or so'. I was appalled. I had a three year old and a baby. I remember thinking that I would rather like to be around in 20 years time when my children are older.

8. My GP and my Consultant provided me with very little information and no advice in relation to managing the infection. I read about HCV myself so I knew I had to be very careful. Fortunately my daughter tested HCV negative. The worry I had about cross infecting my young children (if I accidentally cut my hand for example) created a great deal of stress and anxiety for me. My marriage to the father of my children broke down. I have since re-married.

9. It was later confirmed to me that I had contracted HCV as a direct result of the blood transfusion. I refer to **Exhibit WITN1130002** being an extract from my GP records in confirmation. Ironically, out of all the 45 units I received there was only 1 identified as being infected. I remember reading that somewhere amongst my hospital records whilst I was, on one occasion, waiting to see someone at an appointment. I am either very unlucky or very lucky.

Section 3. Other Infections

10. I did not receive any other infection than HCV.

Section 4. Consent

11. I have no reason to believe that I was tested without my knowledge or consent.

Section 5. Impact of the Infection

12. When I found out about the HCV, I was distraught. The worry about infecting my children has been terrible. The mental anguish for me has been worse than the physical affects. The mental anguish I have suffered has taken over my life.

13. In terms of physical impact, I have had three or four liver biopsies which were not nice to say the least.

14. I had Interferon treatment to try to clear the virus over a one year period from September 1995 to August 1996. My now husband, GRO-B gave me weekly infections into my stomach. I could not do them myself. It was very distressing for both of us. I was responding well to the treatment (despite chronic fatigue and nasty flu-like symptoms) and my PCR became negative. Unfortunately as soon as the treatment stopped the HCV came back.

15. I had no further treatment until 2009. There was nothing available to me until then thought likely to be successful. The second course (28 to 30 weeks) of clearing treatment commenced in June 2009 was a combined Pegylated Interferon and Ribavirin course. My husband GRO-B was again injecting me weekly and I was taking the tablets daily. I knew what was coming in terms of side effects but it was worse than the first treatment. Interferon is akin to a cancer drug. It kills the bad and the good in your body.

16. The side effects were horrendous. It has wiped my memory as I am no longer the person I was. I felt lousy, my hair fell out, I had severe nose bleeds, I couldn't eat resulting in me losing weight, I had no energy and was unable to go anywhere or do anything, It was like having the worst case of flu ever then multiplying it by 100. At that time I also needed treatment for a corneal ulcer.

17. My HCV PCR is now undetectable and is thought to have cleared. I am still very conscious about what has happened to me and I think 'don't have a drink, don't do this, don't do that'. It has taken over my life. I will never rid the virus from my body even though it is not active. It is still there as antibodies.

18. I have had lower back pain since 2017 and in December 2018 I had surgery to my left elbow for cubital tunnel syndrome. I believe this to be linked to HCV or the treatment. I have been left with chronic paroxysmal hemicrania (debilitating cluster headaches) which I never had before. No-one (none of the doctors) can tell me if the HCV has caused this or not.

19. Being diagnosed with HCV has had an affect on my medical care and support. I had weekly blood tests in an open plan/general hospital area.

There would be a skull and cross bone sign in yellow and black on my blood bag container. I noticed other patients looking on and occasionally nudging each other.

20. I remember having a tooth extraction at the Leeds Dental Hospital. The dental staff walked in with masks, gowns and gloves as if they were going to the moon. It made me feel awful, like I was unclean.

21. I could not tell anyone at work that I was ill because of the stigma attached. We had ATOS health carers and I told them why I was off work but my colleagues did not know anything about it. I feared that I would have been shunned. People were ignorant about HCV and it's stigma was similar to the AIDS stigma wherein people thought they could catch AIDS by sharing the same toilet seat or shaking your hand. It was not my fault that I was infected with HCV but I felt unclean. There is no other way to describe it. People with HCV are normally thought of as drug users or promiscuous so you get painted with the same brush. People think you are on drugs or sleeping around.

22. I have been married to GRO-B or over 20 years. My first marriage broke down through the stress of what had happened to me. I am not the same person as I was. Bringing up the children was hard. I missed out on so much and so did they because I was poorly.

Section 6. Treatment/care/support

23. I have not been offered any counselling or physiological support.

Section 7. Financial Assistance

24. I found out about the Skipton Fund myself, through internet research. No-one told me about the financial support available through the Skipton Fund. If I want to find out about something I look it up.

25. I received a Stage 1 payment in 2004. I received a monthly payment of £250 until it increased to £330. Last year, through EIBSS and the new additional special category payments, I submitted my application and it was initially rejected. I was successful on appeal on the grounds that I have suffered problems since the clearing treatment and because of my mental anguish.

Section 8. Other Issues

26. I class myself as lucky because I am still alive. I feel sorry for the people who are not around anymore. Their stories need to be heard.

27. I requested my hospital records last year but they said they could not find them. I made telephone contact with the records office (in case they were in my previous name). I was then told that there was a flood at the hospital and my records were destroyed.

Anonymity, disclosure and redaction

28. 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. I do not wish to give oral evidence.

Statement of Truth

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

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

28/3/2019

Dated