Witness Name: GRO-B Statement No: WITN1637001 Exhibits: 0 Dated: January 2019

#### INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B , will say as follows:-

#### Introduction

- 1. My full name is **GRO-B**. My date of birth is **GRO-B** 1974. I have a partner and we have been together for twenty-seven years. I have three children. Due to my disability, I am unable to work.
- 2. This witness statement has been prepared without the benefit of access to my full medical records.

#### How Infected

- 3. I was diagnosed with mild Haemophilia A at the age of 3 when had a tooth extracted at the dentist and my gum did not stop bleeding. I was treated with the Cryoprecipitate.
- I was treated at the GRO-B by Dr GRO-B. GRO-D
  GRO-D was the on-duty nurse who also regularly treated me whenever I was admitted.

- 5. When I was 4 years old I received Factor VIII concentrate. In addition to this, I was given a blood transfusion at the age of 7. I believe it was through one of these treatments that I became infected with Hepatitis C.
- 6. My parents were not informed about any of the risks related to being infected through the use of the blood products that I was given at the GRO-B GRO-B. The information which was given to my parents was inadequate. I do believe the risks associated with taking the infected blood products should have been provided to my parents prior to me being treated. Had my parents been informed they would have decided against treating me with the infected blood products.
- 7. I can confirm I was infected as a result of being given infected blood products.
- 8. I was informed I had been infected with Hepatitis C by GRO-D at the GRO-B This tragic information was passed on to me at an appointment which was arranged and sent to me via post. The only information given to me regarding the Hepatitis C during the appointment was that I could possibly infect others however the likelihood of this happening was very low.
- 9. The information given to me by <u>GRO-D</u> was not adequate as I was not advised as to how I could manage the Hepatitis C or the effects of the infection on my body, nor was I given satisfactory information regarding the nature of the infection. I believe all the information which was known at the time by the doctors concerning Hepatitis C and the infected blood products should have been explained to me, this is because I felt as though I had been left in the dark. The test results should have been communicated to me more sympathetically that they had been, as I was only a child and the experience of being informed was very traumatic as I was bewildered as to how having Hepatitis C would effect my life, in addition to how the lives of others would be effected and put at risk because I had been infected.

#### **Other Infections**

10.1 do believe I have also been infected with vCJD as a result of being given infected blood products.

#### <u>Consent</u>

11. I do believe I was tested without my knowledge and without my consent as I was not told I was having a blood test in order to decipher whether I had been infected with Hepatitis C. Furthermore, I was tested without being given any information regarding the nature of the blood tests. As a result, it is my firm belief that I have been continuously tested for the purpose of medical, pharmaceutical and experimental research.

#### <u>Impact</u>

- 12. The mental impact that being infected with Hepatitis C has had on me is catastrophic. I have suppressed so many ill feelings which I have towards the gross injustice that the use of these infected blood products has had on my life and the lives of others. The physical impact the Hepatitis C has had on me is momentous. For the majority of my life I felt as though I have absolutely no energy. I find it extremely difficult to leave my bed in the morning. The fatigue has caused a debilitating effect on my life.
- 13. As a result of the continuous fatigue, which is a result of being infected with Hepatitis C from being given infected blood products, I have developed muscle dystrophy as I cannot use my limbs frequently and vigorously enough to even reach their maximum potential. This has caused my muscles to suffer greatly. A further medical complication which I have developed as a result of the Hepatitis C infection is Stage 2 Liver Cirrhosis.
- 14. In 2009 I was offered the Interferon treatment; GRO-D explained that the course of Interferon was supposed to eradicate the Hepatitis C infection.
  My treatment on Interferon lasted nine months. During the nine month

3

Interferon treatment I lost all my hair, I also lost thirty-two kilograms in body weight, I looked very sick. However, after nine months of being treated with Interferon my body could no longer withstand the effects and Dr **GRO-B** made the decision to take me off of the Interferon treatment. Tests results show that the Interferon did not clear the Hepatitis C. However, in January 2018, I was offered the new Hepatitis C treatment. This treatment lasted twelve weeks and has successfully cleared me of Hepatitis C.

- 15.1 have never faced difficulty in accessing treatment for my Hepatitis C infection. However, I believe the Hepatitis C treatment that I received in January 2018 ought to have been made available to me considerably earlier. I was unaware that there was an alternative Hepatitis C treatment other than Interferon and that it has been available for a considerable amount of time. The only reason I was offered the Hepatitis C treatment was because I was due to have a hip operation and it was at this time that the doctor offered me the latest treatment. I should have been offered this treatment earlier as it could have prevented the damage which has occurred to my liver as a result of the Hepatitis C.
- 16. The anguish caused to me as a result of being unable to easily access medical care as a result of being an infected person with Hepatitis C is despicable. My teeth are extremely damaged as a result of the trouble I have had accessing dental care.
- 17. Having Hepatitis C has affected my personal life, as I was unable to reveal my infected status to my partner of twenty-seven years. My three children remain unaware that I am infected with Hepatitis C. However, I have only recently revealed to my partner that I had been infected with Hepatitis C. I have only ever had my mother and sister to discuss the infection with and the impact it has had on me. However, my mother has passed away, which left me with only my sister to speak to. Telling my partner however has been a great relief.
- 18. Nevertheless, the impact that having Hepatitis C has had on my family life is isolating. I have anxiety as a result of having Hepatitis C, because I am so

4

afraid of infecting my children and my partner. As a result of this I have lived apart from my family all my adult life. My children and partner live in one home and I live in another. The fear of my child using my toothbrush by mistake pains me; I just cannot take that risk as I know how devastating it is to live with Hepatitis C. I have also isolated myself socially, as I cannot create lasting friendships with people as there is always this infection that I have to keep a secret. As a result of the muscle dystrophy the Hepatitis C had caused, travelling alone is quite difficult, so overall having Hepatitis C has dissolved any hopes of me having a social life.

- 19. Having Hepatitis C affected my performance at school as I was always fatigued, so I missed many lessons and therefore was always catching up. I was also prevented from playing on any of the school sports teams as I did not have the energy to attend all the training days and therefore was unable to compete in the tournaments. The Hepatitis C has also affected my ability to work. I would have become a sports teacher or a football coach; however the fatigue and muscle dystrophy has hindered me from doing so. I have also been on disability allowance as a result, which in turn has affected me financially.
- 20. My infected status impacted my mother greatly, as she did not know how to give me the correct support throughout the years of my diagnosis. This had a crippling effect on her as she was constantly frustrated that she could not control the stress and pain the Hepatitis C was causing me.
- 21. The stigma of having Hepatitis C only affects me, and it is more of a mental effect, as previously explained it has prevented me from forming long lasting friendships. As I had not told my partner and children about my infected status I have protected them from the stigma that is associated with having Hepatitis C, although my partner is now aware, there has been no effect on her. I feel as though a great weight has been lifted off my shoulders as I can now speak to my partner about how I am feeling and the effect that having Hepatitis C has had on me.

## Treatment/Care/Support

- 22.1 have struggled greatly in my attempts to obtain dental care. However, before **GRO-D** retired, she helped me find a dentist who would treat me.
- 23.1 was never offered any counselling or psychological support. I would have accepted the help if it had been offered.

#### Financial assistance

- 24. I have received the Stage 1 and Stage 2 payments from the Skipton Fund.
- 25.1 currently receive payments of £1,500 per month from the Skipton Fund.
- 26. My eldest sister was in charge of the application process. My sister had to get a doctor at the hospital to fill parts of the application forms out for me.
- 27. The only precondition I faced was that I had to sign the waiver for the initial £20,000 from the Skipton Fund.

#### Other Issues

28.1 understand that Scotland were screening the Factor Concentrates they were giving to the haemophiliacs. I am confused and appalled as to why that was not done every where in the United Kingdom.

#### Anonymity, disclosure and redaction

29. I would like to apply for anonymity.

# Statement of Truth

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