Witness Name: GRO-B

Statement No. WITN1097001

Exhibits: 0

Dated: April 2020

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 and I was born on GRO-B I live

 at GRO-B I work for the GRO-B as

 a GRO-B at GRO-B
- 2. I was infected with Hepatitis C and Hepatitis B via contaminated Factor IX concentrates.
- 3. This witness statement has been prepared without the benefit of access to my medical records.

Section 2. How Infected.

- 4. I have severe Haemophilia B, which was diagnosed at birth for which I am treated with Factor IX concentrates. Due to the severity of my Haemophilia I required large quantities of Factor IX concentrates. I had my first bleed at 4½ months in my groin and was admitted to Guy's Hospital in London.
- 5. I was initially treated at Guy's Hospital until about 5 years old and then transferred to St. Thomas' Hospital (STH) in London under the care of Professor Savidge. I recall attending STH to be taught how to administer my Factor IX concentrates at home. I commenced home treated when I was around 14 years old.
- 6. My care was then moved to the Kent and Canterbury Hospital (KACH) under Dr. Mark Winter. Dr. Gillian Evans, Haemophilia Centre Director, took over my care following Dr. Winter's retirement. I am now also seen by Dr. Kim Elliott.
- 7. I was infected with Hepatitis C and Hepatitis B.
- 8. Neither my mother, who attended my appointments with me, nor I were given any warning or advice regarding the risk of infection from Factor IX concentrates. My mother knew I would have to have Factor IX concentrates for life because Haemophilia is hereditary. She was never informed where the concentrate came from and just assumed it was from the U.K.

9. I believe I was told I had been infected with Hepatitis C when I was aged 17 or 18 which would have been in or around 1994. I think Dr. Winter told me at a routine consultation. I do recall Dr. Winter telling me that everything was fine and that Hepatitis C was nothing to worry about. I am unsure as to what factual information he provided me with regarding Hepatitis C.

10. Following this, every time I attended KACH I was always told "your levels are fine" and I was led to believe that Hepatitis C was not really much to write home about. No one seemed to be unduly worried at KACH and therefore I was, understandably, unperturbed about being infected.

11. It was only relatively recently, as Hepatitis C gained press coverage, that I came to appreciate that I had been living with "a silent killer" for the last thirty odd years. I started finding out more about what having the virus actually meant and I started to appreciate the severity of Hepatitis C. Up until this time, I had always been led to believe that everything was fine.

12. I cannot recall being sat down and formally told that I had been infected with Hepatitis B. However, at some point I became immune to this virus and something was mentioned by the clinicians about my previous infection with Hepatitis B.

Section 3. Other Infections

13. At some point, although I cannot recall when, I was told that I had been put at risk of v CJD.

Section 4. Consent

- 14. I could well have been tested for various viruses without my consent. I don't think the medical professionals told my mother or me that I was being tested for Hepatitis C. As far as I am aware, the first time we found out that I had been tested for the virus was when we were told that I had the virus. At every visit blood was taken so can only surmise tests were made then without my knowledge.
- 15. I was treated with Factor IX concentrates without informed consent, by virtue of the fact that we were not advised of the possible risk of infection.
- 16. I am unsure as to whether I was used for the purposes of research without consent.

Section 5. Impact

17. I think that I am one of the lucky ones as, in the main, I have never really felt ill with my Hepatitis C. There was no mental crash for me in terms of finding out about my infection because I was led to believe, both initially and going forward, that my health had not been compromised. I also felt, and still feel, very relieved that I managed to dodge HIV.

18. I did go through one very difficult time in my younger years which involved a relationship breakdown, my Hepatitis C status and ultimately being treated like a leper. People, who I had wrongly classed as friends, were very cruel to me and I experienced some horrible stigma as a result of my infection. However, I don't really want to go into any further details about this painful time in my life.

19. I was offered Pegylated Interferon (PEGIFN) Treatment approximately 10 to 15 years ago. However, a GRO-B had undergone this treatment in 1996/97 and experienced terrible side effects and could not work so stopped after approximately 2 months. I think I was told that there was a 50% success rate by the clinicians and I thought "I am not doing that on the flip of a coin". Had the success rate been

20. GRO-B	
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something like 80% I would have, in all likelihood, commenced treatment.

21 GRO-B told me that GRO-B were running new trials for Hepatitis Ctreatments and this included one called Abacavir. I was advised that this treatment had a much higher success rate than previous treatments, which was somewhere in the region of 96%. It also came with the privilege of fewer, and less harsh, side effects than previous treatments. I was told that I was eligible for this treatment and following blood tests, a Fibroscan and Liver Function Tests (LFTs), commenced the same in or around GRO-B Within two months my viral load was undetectable but I finished the course, experiencing only mild flu like symptoms, to be declared clear of the virus in GRO-B

22. Immediately prior to commencing the treatment, I did go out with myparents for the alcoholic drinks over a period of 3 or 4 days, because I had been told that during the treatment I must abstain from alcohol. This must have affected my blood test results which were taken immediately prior to starting the treatment. The results were terrible, the figures have gone through the roof and this scared me. However, this was a good thing because I abstained from alcohol throughout the treatment and I now only drink in moderation at the weekend.

Section 6. Treatment/Care/Support

23. I don't believe that I have been treated less favourably, as a result of my infections, by clinicians, dentists or any other professionals.

24. I have never been offered any counselling or psychological support inconsequence of my infections. However, I had always been told that I was ok by medical professionals. Conversely, if I had always been told that I developed cirrhosis then I would certainly have hoped that counselling would have been offered. Another close relative has cirrhosis due to Factor IX bad blood and it is scary that this could happen to me in the future.

Section 7. Financial Assistance

25. I received the Stage 1 Payment of £20,000 from the Skipton fund (SF) about 5 years ago.

- 26. I was not aware that the SF offered grants.
- 27. I currently receive the Special Category Mechanism (SCM) Payment from EIBSS.

I also receive an annual Winter Fuel Payment of £500.

Section 8. Other Issues

- 28. I want to remain anonymous GRO-B However, Iam of the view that this is the biggest scandal to befall the NHS. I believe that the UK Government were complicit in obtaining infected blood and blood products from the USA, solely to save money, which were then used to treat thousands of innocent people in the UK leading to mass infection and in some cases, death. The UK Government then shamelessly attempted to cover this up.
- 29. It has taken years to get this far and to finally have an inquiry. It is therefore absolutely vital that this inquiry delivers answers, the truth and justice must prevail.
- 30. I don't blame Dr. Winter he was a very good doctor to me and I believe that he had my best interests at heart. However, I don't know what he did or did not know regarding the imported blood products and I do believe that if he did know he would have told me. He was a very caring doctor.
- 31. I want to be adequately compensated but I am acutely aware that this won't bring back loved ones or undo what has happened.

Anonymity

32. I want to apply for anonymity and I do not wish to give oral evidence to the Inquiry.

Statement of Truth

I believe that the facts stated in this witness statement to the best of my knowledge and memory, are true.

Signed... GRO-B

Date. 14 04 2020