Witness Name GRO-B Statement No: WITN1462001 Exhibits: WITN1462002 Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF GRO-B

GRO-B will say as follows:-

Section 1. Introduction

- 1. My name is
 GRO-B
 My date of birth is the
 GRO-B
 I live at
 GRO-B

 GRO-B
 with my wife
 GRO-B
 We

 have been married for
 GRO-B
 years and we have
 GRO-B
 GRO-B

 I currently work as a
 GRO-B
 GRO-B
 GRO-B
 GRO-B
- 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 exhibited to this statement in the medical chronology.

Section 2. How Infected

- From a young age I started to suffer from spontaneous nose bleeds. I was referred to the GRO-B in GRO-B by my GP for blood tests. I was later diagnosed with Von Willebrand's disease at the age o GRO-B
- 4. My main hospital was
 GRO-B
 and the treating

 doctor was
 GRO-B
 I believe I was initially treated with Cryoprecipitate

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when I was diagnosed and in the late **GRO-B** I believe I was treated with Factor VIII (FVIII). I was treated quite often at the hospital because of my spontaneous nose bleeds. I did not self-administer FVIII.

- 5. I would only require FVIII as and when I had a bleed. I was quite a sporty person at the time and I got knocks and injuries quite easily.
- 6. I was involved in a car accident in or about GRO-B and I believe I was given FVIII. I had GRO-B and GRO-B at the hospital and there is a possibility that I was treated with FVIII. At the time I was young and my parents took care of my medical needs. Further details about what treatment I was given are stated in the National Haemophilia Database which is exhibited at "WITN1462002".
- 7. I do not believe that any information or advice was provided to my parents beforehand about the risk of being exposed to infection from blood products. I do recall being given some general advice about the treatment I was having, but I was certainly not informed about any potential risks.
- 8. It was indicated by the doctors to my family that the blood products came from poor people who got paid to donate blood and that Cryoprecipitate came from single donors, rather than a group of people combined. However, nobody sat us down to explain that there was a potential risk in FVIII.
- 9. In GRO-B | had a pre-operation blood tests for an GRO-B surgery. The tests were done at the GRO-B
- 10. After I had the blood tests, I was telephoned by the hospital and asked to attend immediately. I had a meeting with Dr **GRO-D** this was the first time that I met Dr **GRO-D** He told me casually that I had Hepatitis C (Hep C). I was in a state of shock and I do not recall what information, if any was provided. I did not understand the impact of Hep C. My understanding was that I would have a few injections and I would clear the infection. I recall the doctor at the appointment was very brief; it lasted approximately 10 minutes. He simply said that it needs to be treated and that I should not get a solicitor, as the Skipton Fund would provide me with assistance. I got the impression that Dr

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GRO-D simply wanted to give me the diagnosis and get me out of his office. I was then referred to a nurse **GRO-B** who managed me from then onwards.

- 11.1 was seen by GRO-B once a month and she was a great help. In the first meeting which lasted approximately an hour, I believe she gave all the information that she knew about the infection. She told me of the next steps. I believe this was the first time that I was provided with adequate information about the infection and how to manage it. This was also the first time that I truly understood the implications of the infection and also they wanted me to administer the treatment myself. I was also informed that there was a low risk of transmission and I was told that I would need to have regular scans to the liver. This scared me.
- 12.1 believe that adequate information should be provided a lot earlier. There was a gap of approximately 4 weeks between my diagnosis and first appointment with **GRO-B** I believe that the doctor should have provided the information that **GRO-B** relayed to me. It was a very anxious 4 weeks for me due to the lack of information that I was given. I did try and research Hep C on the internet myself, but I did not find it very helpful. I did not tell my wife when I was diagnosed with the infection, because I did not know what to tell her and I did not want to worry her.
- 13. I believe that I should have been tested a lot earlier **GRO-B** because I believe that the doctors were aware that there was a risk of infection/s in the FVIII products and tests were being carried out prior to when I was diagnosed. I did confront Dr **GRO-D** at the first appointment in relation to how I contracted the infection and he believes it was through the FVIII treatments that I received in the **GRO-B**
- 14.1 am not happy that I found out about the infection by chance. I believe that if I did not have the pre-operation examination for myGRO-BI probably would not have known about the infection until it was too late.

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Section 3. Other Infections

- 15. When I was diagnosed with Hep C, I was also diagnosed with type 2 diabetes.
- 16.In the early **GRO-B** | received some information about potentially being exposed to vCJD. I have not received anything further in relation to this.

Section 4. Consent

- 17.1 believe that I was treated and tested without my knowledge or consent. I recall an incident in or about **GRO-B**when I attended the hospital after having a major nose bleed. The treating doctor sprayed something up my nose and as a result I sneezed. The blood from the sneeze went all over him, which made him very angry because he thought I contaminated him. This was when I was first told that I tested negative to HIV. I do not recall ever being told that I was going to be tested to HIV. I was very relieved that I tested negative because at that time it was very worrying because of how the media portrayed it.
- 18.1 also believe that I was tested for Hep B in the mid 1980s, and the test was negative. I did not know I was being tested for it at the time.
- 19.1 recall that I was asked to take part in a Hep C research trial in **GRO-B** I agreed to take part in the trial and I believe I was provided with adequate information about it. I recall having some blood taken for that purpose.

Section 5. Impact

- 20.1 do not believe that I had any major physical effects as a result of the Hep C. However, I do recall having heavy nose bleeds again, but I am not sure if this was as a result of the Hep C.
- 21. The infection has affected me mentally. I was initially shocked by the news and did not know what to think. I did not tell my wife as I did not know the severity of it and did not know what to tell her. When I saw **GRO-B** she did put my mind at ease, although I was still anxious about the future in relation to my family and my career.

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- 22.1 believe that the infection also affected my personality. I was always fun and outgoing, however, after I found out about the infection I became more withdrawn and private. I kept the infection very private as I did not know how people would react.
- 23.1 was offered Interferon and Ribavirin treatment in or about **GRO-B** which I accepted. The course was for 48 weeks. I completed the course and I was told that the treatment cleared the Hep C.
- 24. When I started the course of treatment, I experienced intermittent nose bleeds. I recall that I was away for work and as I was travelling I stopped for the night. My nose was bleeding continuously for approximately 5 hours. I also lost approximately 1½ stone in weight, but my appetite was still the same. During the treatment I recall that my gums started to bleed. I used to wake up in the mornings with a massive blood stain on my pillow. As a result the doctors changed the dosage of the treatment. When I completed the treatment my gums stopped bleeding.
- 25.1 was always tired and I tried to fight it off. I experienced some problems with my memory during the course of the treatment and I believe it has continued. I tried to work, however since it involved a lot of travelling and I was always exhausted I had to tell my employer what was happening and therefore took sick leave. I was on leave for approximately 14 months. As a result of taking sick leave, it affected my finances. I was only paid 3 months full salary, half the salary for the next 3 months and then I was paid statutory sick pay.
- 26.1 believe the infection and the treatment affected my life socially. I always had a very active social life.
- 27. When I returned back to work after 14 months my employers were making people redundant. Due to my symptoms as a result of the infection, I took the redundancy as I was unable to continue.

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- 28. Being infected with Hep C was very stressful for my wife. Friends and family would always ask her if I was okay and she did not know what to say other than I was not feeling well.
- 29. I believe that I am not the same person that I used to be prior to the diagnosis and treatment. Although I have cleared the Hep C, I am still very withdrawn and not as social as I used to be.
- 30.As a result of the infection, I told the doctor that I wanted to postpone the GRO-B because I was told that the recovery period was approximately 2 years. My priority was to have the Hep C treatment and clear the infection. As a result of not having GRO-B I believe my arthritis has deteriorated. I am unable to have the surgery now as my elderly parents rely on me for help as my father is currently in hospital. I will now have to wait until everything has settled before I consider having the surgery.
- 31. Overall, I was very lucky to have a supportive family when I was diagnosed with Hep C and when I had the treatment. My family helped me get through it.
- 32. We live in a very close knit town, where we know a lot of people. Due to the stigma attached to the infection and in order to prevent any prejudice and uncomfortable questions, and to protect ourselves, we decided to keep the infection to ourselves. I recall an incident that occurred in the **GRO-B**

GRO-B

GRO-B however, I found it extremely offensive. This was long before I was diagnosed with Hep C. I believe it was because of the way the media portrayed the infections.

Section 6. Treatment/Care/Support

33.1 believe I did not face any difficulties in accessing the treatment. It was offered soon after I was diagnosed, which I accepted.

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- 34.1 am not sure as to whether there were any other treatments available at the time.
- 35.1 recall that when I started my treatment someone came in to one of my appointments to assess my mental wellbeing. However, I was never offered any counselling.

Section 7. Financial Assistance

- 36.1 received two lump sum payments from the Skipton Fund. The first was a Stage 1 payment in the sum of £20,000. A few months later, I received a Stage 2 payment in the sum of £50,000. I believe I received both the payments in 2012.
- 37. Dr GRO-D informed me about the Skipton Fund when I was initially diagnosed.I believed he contacted the Fund and requested an application form for me.He also helped me complete the form. I had no difficulty with the application process.
- 38.After I received the two lump sum payments, I made an application for a monthly payment. I received approximately £1,500 a month in or about 2012.I now receive this payment from the EIBSS.
- 39.1 do not recall any preconditions imposed for any of the above applications.
- 40.1 think it is unfair that people based in Scotland get paid a lot more than we do in England. I believe that we should receive the same financial assistance as we have all been infected the same way.
- 41.1 would also prefer to be paid larger lump sums, rather than smaller regular payments. I believe that this could help many people to make use of the money and do whatever they were planning to do. I believe it would be more helpful.
- 42.1 feel lucky that I have been able to provide a reasonable standard of living for my family. I understand that many other people are not so lucky, and I believe that a large lump sum could prove to be of a great help for them.

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Section 8. Other Issues

43.1 have applied for my medical records from the hospital and after reviewing them, I do not believe I have received all my medical records.

Anonymity, disclosure and redaction

- 44. I confirm that I do wish to apply for anonymity.
- 45. I do not wish to give oral evidence.

Statement of Truth

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

GRO-В Signed...

Dated 21.2.19

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Medical Summary

(This summary is not intended to exhaustive but sets out key points in the records relevant to the statement)

Virology Results

23/04/2012 Newly diagnosed Hep C Positive

Significant Entries/Absent Entries

30/01/2012 From Dr **GRO-D** to **GRO-B** – "pre-operative advice concerning his haemophilia, he is due to have a ankle surgery....I note that he had a raised ALT when he had a liver function test in 2010. He was screened for Hepatitis B and HIV in the late 1980s and was negative he told me, however, Hep C test did only come in the early 1990s and on testing him today he had a positive result."

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