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Witness Name: **GRO-B**
Statement No: WITN2513001
Dated: 8th March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MR **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

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

1. Introduction

1. My name is Mr **GRO-B** My date of birth is **GRO-B**
and my address is known to the Inquiry. I am married to Mrs **GRO-B**
We have no children.

2. How Infected

1. I have Haemophilia A. I was infected with Hepatitis C through blood transfusions and contaminated blood products. I was treated with factor 8 products including Cryoprecipitate from early childhood and on into the **GRO-B** and **GRO-B** Throughout my childhood and up until **GRO-B** I was given these products at the **GRO-B** In **GRO-B**

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came to [GRO-B] as a student and commenced treatment at the [GRO-B]
[GRO-B] I was one of the first patients to trial the new
synthetic recombinant clotting products introduced by [GRO-B]
My [GRO-B] had Haemophilia and they remained in [GRO-B] when I
moved to [GRO-B] [GRO-B] became infected with HIV because they continued to
be treated with pooled blood products. [GRO-B]
in [GRO-B] and [GRO-B] They were both in their [GRO-B] when they died.

2. At no point prior to being given infected blood products was I advised of the risk of being exposed to infection from these products.
3. I was surprised to note that my medical chronology commences in 1991 because I was told during a routine clinic appointment in the middle of the 1980s that I had Hepatitis C. I was shocked when I received the diagnosis because I was not aware that I had been tested for the infection and I was told of the diagnosis at a routine clinic appointment at the [GRO-B]
[GRO-B] with no prior warning that this information was going to be shared with me. I was told that Hepatitis C would lead to cirrhosis of the liver, liver damage and I was at risk of getting cancer in the liver. I was given a life expectancy of 10 to 15 years. I was not married at this point and I believe that more support should have been put in place at the time I received the diagnosis and prognosis.
4. At the time of the diagnosis there was no cure or treatment for blood borne viruses. My medical notes as provided to me by [GRO-B]
[GRO-B] don't appear to be complete. My medical chronology records that I received my first treatment in [GRO-B] and that was with Interferon with Ribavirin. However, this was not the first treatment I received. I received three separate periods of treatment. The first treatment I received was Alpha Interferon alone. The second treatment I received was Alpha Interferon plus Ribavirin in [GRO-B] and the third treatment was in [GRO-B] namely Peginterferon and Ribavirin. Each period of treatment lasted approximately 12 to 18 months.

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5. The side effects I experienced during each period of treatment were horrific. The treatment involved injections one to three times each week and oral medication. Following each injection I suffered days of flu-like symptoms and fatigue. As the treatment process continued, the side effects I experienced got worse and worse. I became anaemic and required blood transfusions every week. I permanently lost all my hair. I was depressed and needing to take replacement thyroid hormone as my thyroid gland was permanently damaged by the treatment. The treatment also caused memory loss.
6. The last treatment I received in **GRO-B** caused such severe side effects I thought I was going to die and formed the view that I would not consent to any further treatment. The plan with each treatment was to achieve a cure but those three courses of treatment I received did not achieve this however they were the best and only treatment available at that time.
7. In **GRO-B** I commenced a new treatment following persuasion from my wife. The side effects of the new treatment were not as dramatic and following a period of treatment over 18 months, the treatment was successful. There was a delay of approximately 12 months before the treatment commenced because the treatment was expensive and there was a delay in receiving financial consent from the Health Board.
8. I was therefore cured of Hepatitis C in **GRO-B**. However, as a result of having the condition for so long, I have sustained long-term damage. I have significant cirrhosis of the liver and liver damage. It is in the top stage of damage. My liver is still predisposed to cancer and I have a risk of liver failure. I have on-going discomfort in the liver region and the damage to my liver means that the blood flow through my liver has been affected which causes bleeding blood vessels in my gullet. I, therefore, have to have an ultrasound of my liver every 6 months to review the progression of the damage and a MRI scan of my liver every two years. I also have to have an invasive gastroscopy every 18 months to investigate any bleeding blood vessels in my gullet. I therefore live with this "Sword of Damocles" over me all the time.

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9. It would have been nice to have the diagnosis sooner and the treatment that eventually cured me. I think I should have been prepared better to receive the information about my diagnosis since I was not even aware that I had been tested for blood borne viruses when I attended the clinic and received the news that I had been infected. I wish I had been provided with more information and support at that time.
10. I was made aware that I could infect other people and this is the reason my wife and I do not have any children.

3. Other infections

1. I do not believe that I have received any other infections as a result of being given infected blood products.

4. Consent

1. Since being diagnosed with Hepatitis C I have consented to all treatments that I have received. Prior to my diagnosis, I have no knowledge of any tests or treatments which were undertaken. I was tested for Hepatitis C without being given adequate or full information. I was not even aware that I had been tested for the virus.

5. Impact

1. The physical effects of being infected with Hepatitis C were that I suffered fatigue, depression and abdominal pains. When receiving treatment I also suffered with flu-like symptoms, depression and anaemia, requiring blood transfusions. I also suffered hair loss and poor memory.

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2. Despite having been cured of Hepatitis C I still have significant liver damage as a consequence of the virus. I have cirrhosis of the liver and I am still at high risk of developing liver cancer and liver failure. I continue to experience abdominal pain and have to have on-going investigations as I have described above to monitor my condition.
3. As I have already set out within my statement above, the treatments that I received above caused me significant side effects to the extent that I felt that I would die.
4. I faced the financial obstacle of accessing the last treatment I received which led to my cure. This was an expensive treatment and there was a delay of approximately one year before the Health Board approved the cost of the treatment. The delay in receiving the final treatment caused me great anxiety.
5. I have already explained the mental and physical effects the treatment had upon me. I still experience the physical effects to date due to the liver damage I have suffered. The mental effects are also prevalent in that I have found it difficult to review my medical chronology without experiencing distress. I was only able to read the chronology on the morning I prepared the statement.
6. The impact of the infection has been enormous upon my private and family life in that it has meant that my wife and I have not been able to have children. My wife underwent three, painful invasive course of In Vitro Fertilisation treatment to try to start our family. This was ultimately unsuccessful. This meant that my family life has been significantly curtailed because GRO-B
GRO-B from infected blood and I have not been able to have children.
7. My wife has been the only person supporting me through this process and therefore the impact upon my wife has been significant. It has been an emotional strain upon my wife and it has impacted upon her employment because she has had to arrange her work around transporting me to and from

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hospital appointments. I have not been able to take out life insurance due to my condition and this causes me great anxiety for the future if I was to die and leave my wife a widow.

8. At the time of [GRO-B] and [GRO-B] there was great stigma attached to such infection. Therefore other than my wife, no other persons are aware of my diagnosis. Keeping my diagnosis a secret has caused me great anxiety. [GRO-B] diagnosis was difficult for my parents. Following the [GRO-B] my mother retracted into her shell and always worried about me, therefore I did not inform her of my diagnosis. This has meant that I have had limited support. I have also felt 'survivor guilt' because [GRO-B] and I didn't.

6. Treatment/Care Support

1. As I have already explained above, at the time of my diagnosis I did not feel very well supported. There was also a delay in the granting of the approval of the financial cost involved in the last treatment I received.
2. I have been offered counselling but I declined as this was to be provided at the same Haemophilia Centre where I am treated.

7. Financial Assistance

1. Regarding financial assistance, I cannot recall the exact date that I received money from the Skipton fund. I was awarded the Stage 1 payment because I was Hepatitis C positive, and the Stage 2 payment due to the significant liver damage caused from being Hepatitis C. I also receive an annual payment from the Skipton Fund. However, it was not a straightforward process to apply for a payment from the fund; there were a lot of forms to complete and an appeal. The process took two to three years before I received the final payment. It was the scan in [GRO-B] confirming the extent of my liver damage that triggered the Stage 2 payment. The process was not kind or sympathetic

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and was also means tested. I felt that it was inadequate to someone given a life limiting diagnosis..

2. In addition, as I have already explained within my statement, I have not been able to take out life insurance because of my diagnosis.

8. Other Issues

1. I was part of the group class action in the early [GRO-B] taken against the manufacturers of the products. This led to an award of £5,000.
2. My medical records have a huge gap, where there appears to be no records between [GRO-B] and [GRO-B] when I was diagnosed with Hepatitis C in the middle of the [GRO-B]. There appear to be no records from [GRO-B] until early [GRO-B].

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Statement of Truth

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

Signed

GRO-B

Dated 2/3/19