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Witness Name: **GRO-B**
Statement No: WITN2422001
Exhibits: **WTN2422002**
Dated: 29th November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 29th November 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

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

1. Introduction
2. My name is **GRO-B** My date of birth and address are known to the Inquiry.
3. I live with my wife **GRO-B** **GRO-B** has two grown up children. I am known as 0% Haemophilic; this is considered the most severe type of Haemophilia.
4. As a result of contaminated blood I have HIV and Hepatitis C. I unable to work and have been out of employment since the early 1980s. I am constantly in and out of hospital which makes it almost impossible to work.

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2. How Infected

1. My brother was found to be a severe Haemophiliac when he was six months old when he bit his tongue and had a bleed.
2. As a result when I was born I was tested immediately and also found to be a Haemophilia carrier. My mother is a carrier of the Haemophilia gene; however it is GRO-B that suffers from the condition in our family.
3. As a child I was constantly in and out of hospital, I knew everyone there by first name as I was there so regularly. As a child I briefly attended Cardiff Royal Infirmary, I was under Dr Bloom there. From 1977 onwards, I started attending the Haemophilia Centre at the Heath Hospital I was also under Dr Bloom there who was then known as Professor Bloom.
4. Cryoprecipitate was what was originally given to Haemophiliacs like me. This was given to me in a bag which was connected to a drip and was slowly pushed through to enter into the blood stream. Having Cryoprecipate administered was quite a slow process and would find myself at the Haemophilia Centre in the Heath for hours when I had to have this.
5. I was also the carrier of an Inhibitor, some Haemophiliacs carry an inhibitor but it is rare. An inhibitor destroys any of the factor products that are given to you. So, when I was given Cryoprecipitate I would often have double doses given to me, this meant I would spend longer in the hospital and would require bed rest for weeks as my body would often reject the factor products such as Cryoprecipitate.

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6. Being a severe Haemophiliac impacted on my schooling. Any sort of bump from playing with my friends or even just walking about would cause an internal bleed. I would find myself going to school only twice a week if I felt well enough. The Local Authority provided me to have a tutor twice a week, she visited me at home at my mother's house. However I fell significantly behind as I had to miss so much school to have treatment for my Haemophilia. I feel like I spent half my childhood in the hospital!
7. I felt like I missed out a lot during my childhood, especially when it came to playing sports with friends, I couldn't have a kick about with my friends as again this would cause a bleed. Even sleeping awkwardly could cause a bleed whereas in the average person would get an ache or pain from this.
8. From looking at my Haemophilia database records I can see that all different kind of Factor VIII product was given to me between 1977- 1997.
9. However in the early 80s my body started to change and began to start accepting the blood products a lot better. I was told that my body had stopped producing the inhibitor which had led to me spending weeks in hospital receiving Cryoprecipitate or the factor VIII concentrates. All of a sudden I began to feel normal.
10. I can reflect on the early 1980s as a happy time, I was a young man who was enjoying life. It was not until my diagnosis of HIV in 1987 when I slipped into a deep depression and went off the rails.
11. In 1987, I also met Dr Desani who was Professor Bloom's number two so to speak.

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12. I know that it was Professor Bloom who had prescribed me the contaminated blood product. I was under only his care. There was Professor Bloom, two Sisters on the ward and a Registrar. It was Professor Bloom who called all the shots.
13. It would be a shot in the dark to state exactly when I was given the contaminated blood product. I am shown Exhibit WTN2422002 which are my Haemophilia database records that state I was given contaminated Factor VIII concentrate in 1984 and first tested positive for HIV on 15/7/1984, however I was not told until 1987. I feel completely violated that this was hidden from me for 3 years. I don't understand why this was hidden from me and I believe that Professor Bloom has a lot to answer for. As a 21 year old young man I was diagnosed with HIV, I honestly thought my world had ended.
14. That day in 1987 Professor Bloom told me I had HIV will stay with me forever. In the run up of being admitted to hospital, I had been on holidays to Majorca with family and some family friends when I had a terrible bleed. I had to come home early from my holiday, there was an ambulance parked on the runway ready to take me from the aeroplane to the Heath Hospital, I was in agony.
15. When I got to the Heath Hospital I was given Factor VIII and Pethadine. That weekend a registrar was looking after me and Professor Bloom came to see me first thing on the Monday morning. He pulled back the curtain around my bed and told his entourage of doctors and nurses to go away, he then said to me 'you have contracted AIDS anti-bodies'. I said to him immediately, 'what does that mean?' and he said 'you have got the virus'.
16. I was sat in my bed in complete shock. Professor Bloom's exact words to me were 'you're going to have to keep it all quiet and to yourself' as 'nobody knows'. I said to

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him I was going to call my mother and he just said not to, he then disappeared for the rest of the day. The information he gave to me then should have been given to me in 1984 when they knew, not three years later.

17. I rang my mam immediately. She came down to the hospital. Professor Bloom came in and I asked him how long I had to live. He stated that he 'cannot answer that question' and that it could be anywhere between eighteen months to two years.

18. I didn't have any counselling that year and it was never offered to me. There was such a stigma attached to the virus, it was like having leprosy, no one wanted to touch you. My mam told my aunties and that was all who knew about this. Professor Bloom did not explain what it meant to carry this virus, I found out what AIDS was through quite graphic adverts on the television. The television adverts put fright into people; they showed how it was passed through sex, needles and homosexuals. I felt so alone and that people would automatically assume I caught the virus through what was portrayed on the television.

19. In the years on from that, my friends from the hospital were all dying one by one. I kept thinking it has got to be me soon. The thing was I could not cope, I could not sleep.

20. It was not until the 1990s that I was diagnosed with Hepatitis C. I remember Dr Desani telling me this. During that period the AIDS virus had so much emphasis and controversy surrounding it that everyone was focussed on that.

21. Only during the 1990s and early 2000s did I worry about Hepatitis C as I knew how bad it could be. I always felt tired and lethargic, however I cannot pin point this to having HIV or Hepatitis C, it could be a combination of having both.

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22. I would see people I knew down the Haemophilia Centre in the 1990s and they would be yellow. I would often ask my wife if my eyes were going yellow. It was not until the 2000s when Dr Desani asked if I wanted to try the Interferon treatment. I was on it for around 3 months and it scarred me for life, especially the second round of it. It was very aggressive, almost like a chemotherapy treatment.

23. I had a fibre scan in the Heath around 2006/2007. I went to see the consultant and he told me my liver was very badly damaged and that I had cirrhosis. However, he told me, not all is lost as you can have a liver transplant.

24. About two years later I had another scan and after the worrying I had for two years about having a transplant I had the all clear. I didn't have cirrhosis.

3. Other infections

1. As I have previously stated. I was diagnosed with cirrhosis of the liver. However this came back false.

2. When I first met my wife in 1992/1993 I had pneumonia. Pneumonia was a side effect of AIDS. I am not sure why my medical notes refer to me contracting pneumonia for a second time as I don't remember this.

3. In 1998, I developed a lump on my right breast. The Consultant who diagnosed me said that this was a result of the drugs I was prescribed for my HIV. The consultant said it was a Bilateral Gynaecomastia- this meant it was a fatty lump and there was not a tumour there.

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4. The drugs I take for HIV have ruined my teeth. In total I would say I have had around eight teeth taken out as they were decaying from the HIV drugs.
5. I often get tooth abscess which can be painful.

4. Consent

1. It was never mentioned to me that I was at risk of catching a virus through the blood products we were being given in the Heath Hospital.
2. I was tested without my knowledge as I did not know that I was infected in 1984 and they had hidden it from me until 1987. All the testing they did on me was performed without my knowledge.. As a haemophilliac your bloods are constantly being taken, they would have tested me for these infections through checking my blood 'levels'.
3. The testing that was performed in 1984 would have been without my consent as I would have wanted to know if they were testing me. I never provided consent for any tests of this kind.
4. I wasn't given any information in relation to being tested and the first time I found I had been tested in 1984 and told in 1987 was through my Haemophilia Database records last month. I was completely taken a back that I had been tested then and they knew and had not told me.
5. From my own knowledge and understanding I was only receiving factor VIII concentrates. The blood products I received did change slightly after 1984 I started

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receiving a product called FVIII (Hoate) in 1985 and was given a blood product called FEIBA. The blood products I received may have changed due to Professor Bloom and his team being aware of my diagnosis.

5. Impact

1. Being diagnosed with HIV ruined my life. It made me feel worthless. I could never have steady employment due to how unwell I am and have been.
2. I will never forget a year after being diagnosed I was walking home from a night out in my home town; I had just bought curry and chips from my local takeaway. PC GRO-D who often patrolled the streets was walking towards me with his Sergeant, he said to me 'we do not want the likes of you walking around here, we know about you', he then pushed my curry sauce and chips into my face, this burned me quite badly. I then swung for him and I was arrested. I was about to be tried at Court before Dr Desani wrote a letter and the case was adjourned. I have not seen PC GRO-D since.
3. In 1989 I became addicted to Palfium, Diazepam and Tamazepam. I was on them for around two years. Palfium is a highly addictive drug; it is no longer prescribed in pure form. I would wake up everyday and reach for the tablets; I realized I had been doing this after about two years. I felt like I was constantly guessing about how long I had left to live.
4. It dawned on me immediately after my diagnosis that I could never have children. I had gone from a happy 20 year old man to a druggo. The lowest point for me was after two years of being prescribed and addicted to Palfium the GP told me I couldn't

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have anymore he had stopped it dead. I was so angry I went for him and ran, he then called the police.

5. After I ran away, I met up with some local drug users and we broke into the chemist. I was that desperate for Palfium and some sort of pain relief. I got caught breaking into the chemist and was arrested. Nobody understood that the Palfium made me feel nothing. That drug made me forget that I had been contaminated with the HIV virus and that I had a death sentence hanging over my head.
6. The Doctor at the police station that night told me I needed serious help. I was taken to the Heath to Dr Desani who said to me he knew that something had not been right with me. He told me that I might start going into withdrawals and gave me a dose of Palfium. I had been prescribed Palfium by both my GP and Haematology Consultant, I was taking three of these at one time when you were only meant to take one a day, the amount I had been taking would have killed the average person.
7. I was then admitted to Whitchurch Psychiatric Hospital where I was placed on Palfium for three to four days and then given Methadone. It was the worst feeling in the world I could not stop sweating, I had cramps, I felt like I was crawling the walls in that place, I just wanted to die.
8. I eventually went down to 5mg of Methadone. I liked the fact that in Whitchurch Hospital I did not feel judged, everyone was very kind to me.
9. I went home after 6-8 weeks in Whitchurch Hospital and felt as though I was going insane. The doctor had prescribed me a bottle of Methadone to take over the month, I downed the Methadone liquid in one go. I had never been a recreational drug user as a teenager but I started to smoke Heroin upon returning home as it was the only

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thing strong enough to numb how I felt. I could not thoughts going around my head telling me I was going to die all of the time.

10. A day I will never forget was when my mother found me on the floor blue in the face as I had tried to kill myself at the age of 22.

11. Mentally, I had lost it. All the adverts of the television about AIDS, people discussing the virus everywhere you go. The stigma in the late 1980s/ early 1990s was horrendous. I then tried to inject the Heroin; Dr Desani in a routine appointment noticed the needle marks on my arm and asked me about it, he then admitted me to Whitchurch Hospital for a second time.

12. The addiction specialist in Whitchurch Hospital called me a 'therapeutic addict' and I agreed with him. I never prior to my diagnosis of AIDS had the mind-set of a recreational drug user. I believe that if I had counselling this may have changed things slightly, but as I have previously said, I was not allowed to tell anybody what was happening to me.

13. In relation to the impact of Hepatitis C. I would say the Interferon treatment has changed me. I used to quite a placid relaxed person, but since going through the treatment I have no patience and I am uptight.

14. I feel as though before I met my wife I just wanted to get out of my own head and escape she changed my life. I feel as though I have put my mother through hell when I tried to kill myself. I have often found that the rougher and readier the person, the more accepting they are of me. I find that educated people are actually more judgemental and often look down on me.

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6. Treatment/Care Support

1. The tablets I was prescribed for my HIV have debilitated by joints. I am stiff and struggle to walk very far.
2. A treatment I had received for HIV called Indinvir caused me to have regular nightmares. I still get very tired a lot from the HIV drugs and I really struggle to wake up in the mornings, it takes a long time for me to come around.
3. Some of the tablets I have taken have made me violently sick. Strangely, I have developed OCD. I have had counselling for my OCD. I would wash the door handles in the house, shower three times a day. I would constantly wash my hands; I would even hide my toothbrush. I was so scared of passing the HIV on to someone.
4. Dr Desani at the Haemophilia Centre in the Heath was amazing, he took my bloods without any gloves on, and he made me feel human. If it was not for him I would not be alive today, he was best man at my wedding and my best friend.
5. Around ten years ago I had a horrible experience in Llandough hospital. The nurse completely barricaded my room with red tape, cordoned it off and put an out of order sign on the toilet by my room. She said to me 'this toilet is for you only'. The Haemophilia nurse who usually treats me came down and ripped down all of this. I then found out that the nurse who had done this was reprimanded. I was made to feel so inhuman.

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6. The main treatment I had for the Hepatitis C was Interferon and then Ribavirin. As I have said before the Interferon treatment was dreadful. People asked me if I had been in a car crash my physical appearance was terrible from the Interferon. I had to take sleeping tablets as a result of the treatment.

7. A fibre scan for cirrhosis in 2006 showed that I had a severely damaged liver, the doctor told me I needed to liver transplant. After another scan two years later and after being placed on the transplant waiting list I was given the all clear.

8. Initially I had problems getting treatment for Hepatitis C, this was due to where I live. I had to write a letter to the Head of Cardiff and Vale Trust telling them I was seeking treatment. Within a month they had was taken in and given the all clear.

9. I believe I have encountered a lack of professionalism. This is especially the case with Professor Bloom. The way he told me I had HIV was disgraceful and telling me I had to keep it a secret. He told me I had 'AIDS anti-bodies' instead of telling me the truth that I was carrying the virus.

10. I would have to attend the Heath Hospital to have any teeth taken out. I have always been very conscious of attending a local dentist as I would never want anyone discussing myself and forming a judgement on me. I still travel to the dentist in Cardiff for the same reason.

7. Financial Assistance

1. The financial effects of not being able to work have been terrible, I found myself in significant amounts of debt some years ago.

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2. It was through the Birchgrove group which was a group that included me and other Haemophiliacs in the 1980s that I found out about the Skipton fund. However, we had to sign a waiver; the waiver was some rubbish that we would not take the Government to Court. I have now found out that this waiver was illegal and has been ignored.
3. I received a one-off payment from the Skipton fund. It was around £15,000-£20,000.
4. Before the Skipton fund was the Macfarlane fund. This was for people who had HIV. I still receive monthly payments from this, but it does not amount to a lot.
5. The financial assistance I have received has been appalling; I have felt like a beggar many times on the phone to people who work for the funds. They make you feel like you are simple and worthless. The system in place was poor and still is poor.

8. Other Issues

1. All of my medical notes from my GP have been missing and this was even the case when I was part of an American Court Action years ago when they tried looking for my notes. The only GP notes I have are correspondence between the GP and the hospital that is it.
2. One of my letters from the addiction specialist told the Haematology Centre in the Heath that they had caused some of drug addictions due to the drugs they had prescribed me.

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3. I was involved in a U.S civil action against a pharmaceutical company some years ago, I can't recall the name of the pharmaceutical company off the top of my head. I received some compensation from this. However the compensation process for this did not make sense as if you lived in Wales you would get £15,000 compensation if you were infected, but if you were infected in Brazil you would only get £2,000; there was a lack of fairness in the way the compensation was handed out.

4. Overall, I feel as though my life has been completely from the moment I found out I was infected. I have not been able to have children with my wife who I would be lost without, I am unable to work and what is worse is that this information was held from me for many years.

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Statement of Truth

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

Signed,

GRO-B

Dated,

5/12/2018