

# ANONYMOUS

Witness Name: **GRO-B**  
Statement No: WITN2420001  
Exhibits: **WITN2420002**  
Dated: 16th January 2019

## INFECTED BLOOD INQUIRY

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

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

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

#### **1. Introduction**

1. My name is **GRO-B** My date of birth is **GRO-B** and my address is known to the Inquiry.

#### **2. How Affected**

1. My Husband has haemophilia A that is 0%. My Husband is a severe haemophiliac. My Husband also used to have an inhibitor. This means that when he would have a bleed the treatment used to treat the bleed would take longer to work as his body would try and fight the medication. As a result of his inhibitor, my Husband would spend more time in the hospital than the average haemophiliac.

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2. My Husband has always been given Factor VIII products since I've been with him. My Husband used to be treated with cryoprecipitate ('Cryo') before I met him. It would take hours for a bleed to stop due to his inhibitor and the bleeds were very painful.
3. As a child my Husband was constantly unwell, this impacted tremendously on his schooling and he had poor attendance at school. He couldn't do any of the activities the other kids were doing, he couldn't play any sports.
4. My Husband always received treatment at the [GRO-B] in [GRO-B] and before this he had treatment at [GRO-B]. He was the first patient on the [GRO-B] at the [GRO-B] that's where all the people with bleeding disorders went. I used to go down there an awful lot when we were younger, we would go a couple of times a week, I remember my husband being on crutches back then. I remember [GRO-B] he was fabulous, and he was our [GRO-B]. He was like a counsellor, and we had so much support from him. Most importantly, he was also our friend and we respected him dearly. My Husband wouldn't be here today if it wasn't for [GRO-B].
5. My Husband talks about [GRO-B] and the contaminated blood side-by-side. [GRO-B] gave out the orders, the nurses just listened and did whatever he told them to do. My Husband doesn't like him now, but back then he was known all around the world to be one of the [GRO-B].
6. My Husband wasn't given any information about the contaminated blood until 1987. [GRO-B] told my Husband in 1987 that he had contracted the AIDS virus at the [GRO-B]. I think my Husband was on the ward when [GRO-B] told him he had contracted HIV. At the time, [GRO-B] told my Husband not to tell his mother. I don't think [GRO-B] told him anything about how to manage the infection or what it meant to have HIV. [GRO-B] was the only person who provided support; he was brilliant.

7. I recall [GRO-B] that sat me down and explained the risk of contracting HIV and that you can catch it through sex. [GRO-B] said as long as we were careful and used protection then we would be alright.
8. My Husband contracted HIV in 1987 but they knew he had it in 1984, this can be shown in the Haemophilia Database records we obtained. I refer to Exhibit WITN2420002.
9. My Husband should've been told that he had HIV as soon as they knew at the hospital, his parents should've been told by [GRO-B] My Husband has been done a disservice; he lived a life of feeling like everyday was his last. We can never just relax, we would start to settle down and then something like the Inquiry comes up and unsettles everything all over again.
10. My Husband's Hep C has cleared now. He didn't know that he had Hep C until the 1990s. I think my Husband had Hepatitis C ('Hep C') in the 1980s but there wasn't a test for it during that period. It was during the 1990s that many haemophiliacs discovered that they had contracted Hep C through contaminated blood.

### **3. Other infections**

1. They ran tests on my Husband for CJD, he has been exposed to this but there are currently no tests for this. The Interferon treatment that is given to Hep C sufferers made him really ill. My Husband lost his hair after the Interferon treatment; he became irritable and developed OCD.
2. We haven't had sex for a number of years. After the Interferon treatment he became frightened of giving me HIV or passing it onto the kids, he would bath 2-3 times a day and he would hide things in the house, for example he would hide his toothbrush as he wouldn't want anyone to accidentally use it. When he was younger he would use the same cup. The whole diagnosis had terrible mental effects on him, he became quite paranoid.



3. My Husband would wash the toilet after him. He still has OCD now but it's not as bad as before. My Husband's skin gets irritated and goes blotchy at times. However, I'm not sure if that's from the haemophilia or HIV medication.

#### 4. Consent

1. I believe that my Husband was tested without his knowledge as not one medical professional said to him please can we take your blood as we suspect you may have HIV. They kept it from him for 3 years altogether. I think its murder, the fact he had friends dying in the bed next to him was just dreadful. The worst was when two of my Husband's best friends who were also infected with contaminated blood passed away, they were all extremely close.
2. My Husband didn't have a normal teenage life. He had a **GRO-B** just before **GRO-B** contracted HIV. That was terrible as he had to tell her that he was HIV positive. Their relationship eventually broke down as my Husband went off the rails as a result of his diagnosis.
3. He lost his young years. My Husband would still socialise and drink a lot when he found out but he just wanted to die. He was tested without his consent as he didn't give any permission to be tested for AIDS.
4. I think that my Husband was treated for the purposes of research as he was being tested for things he never thought he would have to worry about contracting!

#### 5. Impact

1. The impact of my Husband finding out he had HIV was terrible; he went off the rails and started using drugs. They told him he had 18 months to live when he was diagnosed. My Husband was prescribed vallium and benzodiazepine after finding out the news. They let him have what drugs he wanted as they thought he only had 18 months to live. One day, my Husband went to the GP and they decided to cut his supply of palphium, he was so

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desperate for this medication that he went on a rampage at the GP surgery. He was then banned from the GP surgery. When his prescribed supplies of drugs were stopped he would then get drugs anywhere he could. His addiction became so bad that he had to have addiction treatment at

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2. My Husband was upset when he found out he had Hep C, his Hep C diagnosis definitely made his OCD worse. The Interferon treatment for Hep C made him extremely unwell ill as I have stated above.
3. I would say that the HIV diagnosis has had more of an impact on his mental health than his physical health. Although, he's had to have new hips and a new knee. When he went for a new knee he went to GRO-B I remember that time very well, the nurse came in gowned up, wore a safety mask and barricaded the toilet. The hospital apologised immediately. We said they needed to be less ignorant.
4. My Husband was prescribed tablets for his HIV- he used to have to take a very large amount everyday; the amount of tablets he takes has now decreased.
5. My Husband had problems trying to get Hep C treatment; he wasn't able to get it as he was out of the catchment area. This was soon resolved when my Husband spoke to someone at the local hospital trust who were more than happy to have him on their books.
6. In recent years he's had counselling, prior to this he had counselling through the GRO-B He was one of the first members of the GRO-B GRO-B GRO-B would get sponsorships for going away for a weekend to socialise and meet other people who were in a similar situation to them. The members of GRO-B wanted to know all about the treatments, they wanted progression and answers. They would have people giving money into the pot so every Christmas they could have a night out.

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7. My Husband is still taking fiseptone- this is a methadone in a tablet form. He's not an addict anymore. His doctor described the drug as therapeutic pain control. I would class my husband as a therapeutic addict.
8. My Husband has a handful of friends that are really good friends. Years ago, my Husband would have to have half a bottle of vodka before he went out. Just before I met him he took drugs and I think he was living in a caravan. He contracted hypothermia in August 1993 when he had taken drugs and fallen asleep. I then met him in January 1994. He would be a **GRO-B** **GRO-B** and I would call him **GRO-B** as that was always what he ordered. There were a group of people my husband bothered with, that would **GRO-B** to drink and socialise.
9. There is **GRO-B** between myself and my Husband. The way we were brought together was strange. I was so down after my children's father cheated. My Husband had all his problems and I had my problems it was like God pushed us together, we are inseparable. **GRO-B** always said I saved him because I knew him as the drinker not the addict. I just couldn't stop loving him.
10. We weren't together long and he moved in with me. My Husband told me that he had HIV. My **GRO-B** didn't know anything for around a year or so that he had HIV. My nerves were wrecked, I couldn't show him how bad I was feeling for him and I couldn't show the children how bad I was feeling for him at the time. My **GRO-B: D** said **D** wanted to speak to me one night and asked if he had HIV **GRO-B** who worked **GRO-B** My Husband's condition was obviously being discussed in the local community as **GRO-B** The kids seemed alright at the time but when I look back I think that it must've been hard for them to take that news. They broke their heart so many times over him being ill.
11. I have been on anti-depressants for over 20 years. I try not to show my husband a lot of my anxiety, stress and nerves. I can't stand crowds, I used to go out and enjoy myself. We don't go to the pub and drink. Me and my



Husband had a GRO-B but don't anymore. We always go on holidays just the two of us. We usually go on a cruise, we socialise on a cruise with people we don't know. I have a best friend but my time is mainly focussed on my Husband.

12. I have gone down the doctors and said I feel as though I am going to crack mentally. My own family don't know what's really wrong with my Husband. My neighbours don't know, however I think a lot of people know more than they let on.

13. I had to give up work. I was a GRO-B but didn't feel like I could do that, everything was too much as all I thought about my Husband. He stopped drinking in GRO-B and he hasn't drunk any alcohol for the GRO-B Even on holidays he doesn't have a drink.

14. We have had loads of counselling over the years through GRO-B even now we are offered it. If I went to a counsellor I would be reliving it again and again, I don't want to keep reliving it.

## 6. Treatment/Care Support

1. The tablets my Husband was prescribed for his HIV have debilitated his joints. He is very stiff and struggles to walk very far. A treatment he has received for HIV called Indinvir caused him to have regular nightmares. He still gets very tired from the HIV drugs and struggles to wake up in the mornings, it takes a long time for him to come around, I would say it takes him longer than your average person.

2. GRO-B at the Haemophilia Centre GRO-B was amazing with my Husband he would take his bloods without any gloves on. If it was not for him my Husband would not be alive today.

3. My Husband had a fibre scan for cirrhosis in 2006 which showed that he had a severely damaged liver; the doctor told him that not all was lost and that he could always go on the liver transplant list. After another scan two years later

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and after being placed on the transplant waiting list he was given the all clear. My Husband no longer has Hep C.

### 7. Financial Assistance

1. Only recently have we received more money. For years we didn't receive a lot of money. Only the past few years have we had anything substantial. The financial effects of not being able to work have been terrible for my Husband. Until recently we have struggled financially.
2. I am aware that my husband found out about certain financial assistance through the GRO-B I know that it was in the mid 1990s that he found out about the Macfarlane Trust, however this was before me and my Husband met.
3. My Husband told me that he had to sign a waiver; the waiver was some nonsense that he would not take the Government to Court.
4. My Husband received a one-off payment which we couldn't recall until recently from the Skipton Fund. It was around £15,000-£20,000. However, my Husband hasn't received a second payment from the Skipton Fund. My Husband still receives monthly payments from the Macfarlane Trust, but that does not amount to a lot. The Macfarlane Trust is now known as WIBBS in Wales.
5. The financial assistance he has received has been appalling; I have felt like a beggar many times on the phone to people who work for the trusts/funds. They make you feel like you are simple and worthless. The system in place was poor and is still poor.

### 8. Other Issues

1. I want to find out why this was done, why they didn't tell them they had HIV in the beginning why people around my husband were dying of AIDS. We were



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close to 10-12 people and they're all now dead apart from two. There are handful that are still alive.

2. I just can't think of him dying, it's constantly on my mind, people will never understand the worry. I'm alright when he's alright. He's a pretty strong man. I've got to be strong for him.

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## Statement of Truth

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

Signed..

GRO-B

Dated

16-1-2019