

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3014001

Exhibits:

Dated: 7 May 2019.

## 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  
GRO-B  
GRO-B  
GRO-B
2. I make this statement as the GRO-B who was born on the GRO-B  
GRO-B and died at the age of GRO-B after being infected with HIV,  
Hepatitis B and C as a result of receiving from contaminated blood products.
3. This witness statement has been prepared without the benefit of access  
to my GRO-B full medical records.
4. My GRO-B has provided a Witness Statement to the Inquiry GRO-B

### Section 2. How infected

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5. My **GRO-B** had Haemophilia type A, classed as severe. **GRO-B** was diagnosed with haemophilia at birth when **GRO-B** was **GRO-B**. The operation almost killed **GRO-B** and **GRO-B** was cared for by **GRO-B** mother for a considerable amount of time. I remember **GRO-B** told me that when **GRO-B** was about 4 years old **GRO-B** spent about 6 months in hospital.
6. Initially my **GRO-B** was under the care of Professor Arthur Bloom at the University Hospital of Wales Cardiff (UHW) then Dr Peter Collins and Dr Dasani. (Haemophilia and HIV) and Dr Friedman for **GRO-B** Hepatitis C.
7. In the early 1950s, my **GRO-B** was treated with Packed Red Cells (PRBC's) and pig's plasma. In the 1960s/early 1970s **GRO-B** was treated with Cryoprecipitate, from the late 1970s/early 1980s **GRO-B** was treated with Factor VIII concentrate products such as FEIBA (Baxter) at UHW.
8. I remember that we had a touring caravan as children and we would often take trips all around the UK and **GRO-B** would often be treated in different hospitals. On one of these trips to Norwich in around the 1990s, my **GRO-B** had a particularly bad bleed and **GRO-B** was treated at a hospital in Norwich. I do not remember which hospital though.
9. I understand that treating my **GRO-B** was complicated due to the severity of **GRO-B** haemophilia and **GRO-B** inhibitors which meant doctors also had to treat **GRO-B** with Factor IX. **GRO-B** was a particularly rare case in this sense.
10. As far as I am aware my **GRO-B** tested positive for HIV and Hepatitis Non A/Non B (now referred to as Hepatitis C) in 1984.
11. I am unaware of what information or advice (if any) was given to my **GRO-B** beforehand about the risk of being exposed to infection from blood products.
12. I am also unaware of how my **GRO-B** found out **GRO-B** was HIV and Hepatitis C positive as I was very young at the time and I was not told about **GRO-B** infections.

until I was 26 years of age in GRO-C 2006, only a few years before GRO-B died. I did not really talk with my GRO-B from 2007 to 2009 as a result of GRO-B telling me about the HIV immediately after the birth of my first child. My GRO-B at the time took the news very badly as GRO-B had always been concerned that GRO-B was infected with HIV.

13. When I reconciled my relationship with my GRO-B GRO-B explained that the doctors in the haemophilia centre could not understand why GRO-B or my GRO-B had not shared this information with us. I believe it was down to the stigma associated with AIDS in the 1980s lingering on. My GRO-B were both GRO-B and they feared the repercussions of the diagnosis on them GRO-B and on us as a family socially. We grew up in the GRO-C Wales GRO-C where such matters were not openly discussed as they maybe in urban and metropolitan areas. Vandals painted some anti-AIDS slogans on our garage once which had a very negative impact on both of my parents.

14. I remember my GRO-B having Interferon treatment for GRO-B Hepatitis C but I am unable to recall the names of any other medication GRO-B received.

15. I believe that my GRO-B were given advice on minimising the risk of GRO-B passing on HIV to others or so they told me after 2006. I believe that my GRO-B was tested for the various infections as well.

16. As a child, I remember having blood taken from me in the UHW by Dr Dasani. I was told it was for Dr Dasani's research into how Haemophilia is passed on GRO-B. I now believe that this was a lie and that I was tested for HIV/Hepatitis. My GRO-B had no recollection of the event. I remember it clearly as the blood was taken by cutting my index finger it was not drawn out of my veins. My GRO-B was also tested.

17. My GRO-B was not told a great deal of information about the risks. I do not know if it was adequate or not adequate.

### Section 3. Other Infections

18. Once my **GRO-B** died, the medical professionals needed to test **GRO-B** for vCJD. **GRO-B** brain needed to be sent off to Edinburgh University hospital to be dissected. **GRO-B** did not have the infection in the end. I believe that **GRO-B** would have been told **GRO-B** was at risk. I do not remember **GRO-B** talking about vCJD.

#### **Section 4. Consent**

19. I believe my **GRO-B** was tested without his knowledge or consent as **GRO-B** did not know **GRO-B** was being tested for HIV and Hepatitis C.
20. As **GRO-B** was tested without **GRO-B** consent or his knowledge, I assume that **GRO-B** may have been tested and or treated for research purposes. If **GRO-B** was tested for research purposes, the data from those tests was unknown to my **GRO-B**.

#### **Section 5. Impact of the Infection**

21. My **GRO-B** experienced extreme depression and mood swings although I cannot say for certain if these were as a direct result of **GRO-B** HIV or Hepatitis C. **GRO-B** had always managed **GRO-B** haemophilia when working but it was the Hepatitis C and HIV **GRO-B** could not manage as a **GRO-B** and **GRO-B** had to retire early due to ill health.
22. **GRO-B** would occasionally have long bouts of flu symptoms and **GRO-B** complained of headaches. My **GRO-B** argued a lot when I was a child. This could have been down to **GRO-B** depression and short temperedness because **GRO-B** would often lash out irrationally. I did not realise that my family circumstances were different until I went to other people's houses.
23. Christmases would be ruined because of arguments. I remember that one Christmas, my **GRO-B** had been in hospital for a **GRO-B** replacement which the doctors completed incorrectly because they moved **GRO-B** into a very awkward position and some of the equipment had failed. This caused another



bleed and [GRO-B] almost died from loss of blood which resulted in a lot of arguments and again Christmas was ruined.

24. I remember that the medical professionals were going to try a new treatment on my [GRO-B] from Sweden whilst undertaking a [GRO-B] replacement. The equipment supplying the treatment that was meant to stop my [GRO-B] bleeding during the operation failed.

25. It was explained at the inquest into [GRO-B] death that [GRO-B] died as a direct result of the Hepatitis C.

26. I believe that my [GRO-B] was treated with Beta-Interferon for the Hepatitis C. The side effects of this were horrendous. I recall that there was some form of scandal surrounding Interferon and its side effects. My [GRO-B] was also receiving anti-viral drugs to manage [GRO-B] HIV. [GRO-B] viral load was low for many years. [GRO-B] was on numerous anti-depressants and saw a psychiatrist at UHW regularly.

27. My [GRO-B] received a variety of treatments for [GRO-B] haemophilia over the years. As a child I recall [GRO-B] taking lots of tablets and at times injecting [GRO-B] (for the Hepatitis C I think); this was on top of the treatments [GRO-B] took for bleeds. This was undoubtedly a burden on [GRO-B]

28. We did not, travel abroad as a family until 1994 as my [GRO-B] feared the complications of taking [GRO-B] medication into another country. [GRO-B] often had bowel problems with cold and flu symptoms in the late 1990s. This happened a lot as time went on.

29. My [GRO-B] never went to a GP or dentist and [GRO-B] was always at the hospital as [GRO-B] was such a severe Haemophiliac.

30. I believe that my [GRO-B] infections were a contributing factor in the breakdown of my [GRO-B] marriage. I lived in a home where my [GRO-B] argued regularly. My [GRO-B] told me towards the end of [GRO-B] life that initially [GRO-B]

did not face up to [GRO-B] infection. At the time my [GRO-B] wanted to talk about [GRO-B] infections and how they would deal with it, when my [GRO-B] did come to terms with [GRO-B] infections, my [GRO-B] no longer wished to talk about it.

31. As previously stated, my [GRO-B] told me of [GRO-B] HIV following the birth of my daughter. This led to animosity between [GRO-B] me and my [GRO-B]. I believe that my [GRO-B] infections contributed towards the breakdown of my first marriage as well as [GRO-B] own. In the 1980s and 1990s the shame of HIV caused my parents to keep the truth from my [GRO-B] and me. It was a burden for my [GRO-B] to live with such a lie. [GRO-B] wishes to keep [GRO-B] infection a secret from friends and family meant that in turn my [GRO-B] and I had to continue this out of respect to [GRO-B]. We still do. For example I have never disclosed to any midwife who has asked that there is a history of HIV or Hepatitis in the family.

32. Being lied to as a child has impacted greatly on me as an adult. As previously stated it led to the breakdown of my marriage as my [GRO-B] could not come to terms with the diagnosis and the fact that we had been lied to. She did not want my [GRO-B] to have contact with [GRO-B]. Inevitably this was psychologically traumatic for me and my [GRO-B]. When I began a relationship with my current [GRO-B], I told her of my [GRO-B] infections almost immediately as I thought it would be an issue for [GRO-B] too. Looking back it was absurd to tell her such personal information right at the very outset of our relationship.

33. My [GRO-B] and my [GRO-B] informed us of [GRO-B] HIV shortly afterwards. My [GRO-B] struggled with this. My [GRO-B] [GRO-B]. When [GRO-B] was 5 months old, my marriage broke down and I left the family home as a result of the weakened relationship caused by my [GRO-B] HIV and other issues. In [GRO-B]. By the time [GRO-B] was 9 months old his [GRO-B] died.

34. Luckily, down to my current [GRO-B] my [GRO-B] did get to know [GRO-B] albeit for a very short period of time. [GRO-B] died when they were all very young.

They have grown up without a [GRO-B] as a direct result of [GRO-B] infections.

35. As previously stated my [GRO-B] retired early and as a result [GRO-B] income was severely reduced along with [GRO-B] pension. [GRO-B] missed about 20 years of contributions. My [GRO-B] worked as a [GRO-B] but it was a big struggle. At the time I was growing up [GRO-B] did not tell me how tight things were but looking back I now realise that we struggled financially.

36. Professionally, I believe learning of [GRO-B] infection of HIV aged 26 led me to struggle at work. I was a [GRO-B] of [GRO-B] I relinquished this role aged 29. It was not until this last year I became the [GRO-B]. This has impacted on my finances greatly. Following [GRO-B] death, I took time off work due to anxiety and was subsequently sent for counselling by the [GRO-B].

37. As a child we lived relatively frugally as a result of my [GRO-B] not working. Yes [GRO-B] had pay-outs and looking back I remember there being more money around on these occasions but I was brought up without the latest trainers (not even branded trainers for that matter) and other amenities that I would have appreciated. When he had a pay-out I recall we had a new caravan for family holidays and a new second hand car. My [GRO-B] also bought me a [GRO-B] with this money which I took with me to study at university. Pay-outs such as this were not a regular stream of income for my parents.

38. When my parents split up my [GRO-B] had to borrow £30,000 from [GRO-B] in order to purchase a flat. This money had to be paid back to [GRO-B] upon [GRO-B] death. My [GRO-B] discovered that my [GRO-B] was going to leave the marital home when an estate agent phoned their house to discuss my [GRO-B] purchase of a flat. Until that point he had not discussed leaving [GRO-B] with [GRO-B]. This was how [GRO-B] behaved and it was irrational. My [GRO-B] has also had trouble in obtaining car, travel and life insurance.



**Section 6. Treatment/care/support**

39. I was never given any support or bereavement counselling from the hospital, only from my [GRO-B]. As a father I have had no support in how to explain to my [GRO-B] what happened to their [GRO-B]. My [GRO-B] had social workers which my [GRO-B] and I always hated being interviewed by; they were always awkward moments as we did not understand why our [GRO-B] had a social worker. [GRO-B] also had a psychiatrist.

**Section 7. Financial Assistance**

40. [GRO-B] had an extension built (to accommodate [GRO-B] when [GRO-B] could not climb the stairs) and new windows fitted. They received some money for the extension. Following having new windows fitted they were told by the Haemophilia Society that they could have claimed for them but were not able to make retrospective claims. This highlighted, yet again, a complete lack of support.

41. My sister and I received £3,000 from the Macfarlane Trust to bury my [GRO-B]. [GRO-B] probably received the £20,000 Stage 1 payment from the Skipton Fund whilst [GRO-B] was alive.

42. After inquest my [GRO-B] and I received the £50,000 Stage 2 from the Skipton Fund. It was my [GRO-B] that came across the Skipton Fund online. We had to contact the UHW ourselves. When we did, [GRO-B] consultant said "we've been waiting for you to get in touch, we couldn't contact you ourselves to let you know about the money available".

43. It is an outrage to think that we would not have received a penny if we had not researched and asked. This is disgusting. I had to sign a waiver to say I would not ask for anymore money.

**Section 8. Other Issues**



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44. This whole scandal has been a complete cover up from start to finish. I have carried out a lot of my own research and it just seems that everything has been covered up because the country did not have enough money to produce our own blood products. People were not told of the risks and subsequently, people were infected. I want the Inquiry to get to the bottom of this scandal and find out who was responsible and the people responsible to be held to account.

45. The Coroner stressed about the Hepatitis C when giving his verdict so I think he was hinting at this scandal. My [GRO-B] then went online and did [GRO-B] own research.

46. It was so obvious that there was a risk this blood was going to be infected and it should have been blatantly obvious to the Government/NHS. I cannot believe that they were daft enough to keep buying this contaminated blood.

### Anonymity

47. I wish to remain anonymous. I understand that this statement will be published and disclosed as a part of the Inquiry.

48. I am prepared to give oral evidence if it would be helpful.

### **Statement of Truth**

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

Signed .....

GRO-B

Dated

15/5/19