

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
2. I make this statement as the **GRO-B** **GRO-B: S** **GRO-B** who was infected with HIV and Hepatitis C(HCV) as a result of receiving contaminated blood products
3. This witness statement has been prepared without the benefit of access to my **GRO-B** medical records.
4. My **GRO-B** have also provided witness statements.

Section 2. How Affected

5. My **GRO-B** has provided a statement with the details relating to the treatment my **GRO-B** received however I will summarise the important facts within my statement.

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6. My [GRO-B] was diagnosed in 1982 with Haemophilia A classed as severe with a clotting factor of 0.6% and Haemophilia B with a deficiency of 38.1% at about 18 months old. [GRO-B] had shut [GRO-B] finger in a door and it would not stop bleeding. [GRO-B] was then treated with Cryoprecipitate to counter his low level of Factor VIII and deficiency of Factor IX (FIX). My [GRO-B] was advised not to have any more children. The Doctor was adamant that [GRO-B] was a carrier of the gene that caused haemophilia.
7. Until 1995, my [GRO-B] was treated at [GRO-B] under the care of Dr Harry Baumer and Dr [GRO-B]. [GRO-B] had also been seen by Dr [GRO-B] and Dr [GRO-B].
8. In 1995, we had moved house, to be nearer to [GRO-B] Hospital. [GRO-B] as my wife and I were told that [S] would receive a much better service at [GRO-B] than that at [GRO-B]. At [GRO-B] came under the care of Dr [GRO-B], Dr [GRO-B], Dr [GRO-B] and Clinical Nurse Specialist [GRO-B].
9. From the time [GRO-B] was diagnosed with haemophilia, [GRO-B] was given Factor VIII concentrates and other blood products, as and when [GRO-B] needed them. Between 1982 and 1985, we believe the doctors administered non-heat treated blood products.
10. In 1985 as we were aware of the risks of AIDS, we requested [S] be tested for HIV. The result was negative. In 1988 when [S] was 7 years old, my [GRO-B] and I requested as a precaution [GRO-B] be tested for HIV again. The result was positive it was heart-breaking. After the initial HIV test in 1985, my [GRO-B] received heat treated Factor VIII as this was considered safer.
11. My [GRO-B] and I were given minimal advice of the risks of infection associated with receiving blood products when we were at [GRO-B]. Doctor Baumer was particularly unhelpful, his advice about HIV was very brief and blunt and contained little or no information about the risk of infection to others. I believe that Dr Baumer did not even know himself how [S] could have contracted HIV. It felt as if the doctors at [GRO-B] were shocked at my [GRO-B] diagnosis.
12. Most of the information we obtained about HIV was from our own research or the media. I do not believe that the information provided by Dr Baumer was adequate. My [GRO-B] [S] and I all found that the staff at [GRO-B] were much more helpful and humane in terms of how

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they treated us. Dr [GRO-B] was particularly good. I found that we were treated more like human beings and less like guinea pigs.

13. Before my [GRO-B] could start treatment for his HIV, we had to wait for [GRO-B] viral levels to go up. In November 1993, [GRO-B] started taking Zidvudine (AZT). In or about 1996, and until 1998 [GRO-B] was treated with Didanosine and Stavudine. From 1999 [GRO-B] was treated with Lamivudine, Zidovudine and Nevirapene and my [GRO-B] statement sets out the full details of the side effects of these treatments. What I will say is that the side effects of these treatments were horrendous.

14. In 1986, 1987 and 1988, my [GRO-B] was tested for Hepatitis B. [GRO-B] had been vaccinated against Hepatitis B and the all these tests returned negative.

15. We have seen from the medical records we have been able to obtain that, [S], was tested for HCV in 1997. This test was carried out without the consent or knowledge of my [GRO-B] or I. It is evident that although the medical staff at [GRO-B] were aware of my [GRO-B] HCV infection, we were not informed at the time [GRO-B] tested positive.

16. In 2001, [S] developed testicular cancer. It was at this point that [S], myself and my [GRO-B] were all made aware of [S] HCV infection for the first time. We were told that due to my [GRO-B] infection, he would need a certain type of treatment.

Section 3. Other Infections

17. I am aware that [GRO-B] received a letter in 2004 from the NHS stating that [GRO-B] was at risk of vCJD.

Section 4. Consent.

18. Neither my [GRO-B] or I gave consent to the HCV tests that were carried out on [S]. We were not even aware of the tests that were being carried out on [GRO-B]. We had consented to [S] being tested for HIV as we requested those tests.

Section 5. Impact

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19. When my [GRO-B] and I were informed about [S] being infected with HIV, Dr Baumer advised us not to mention it to [S] straight away. On the one hand, this could have been a positive thing because if we were to tell [GRO-B] about [GRO-B] infection at that age [GRO-B] probably would not have understood. There was a massive stigma attached to HIV because of the media attention the infection was being given.
20. On the other hand, I also believe that the doctors were only looking out for themselves. They were more concerned with their reputation than the care of my [GRO-B]. As parents, our main concern was to ensure the safety of [GRO-B]. At the time [GRO-B] was a minor and [GRO-B] was probably not capable of understanding the full ramifications of what being infected with HCV and HIV meant.
21. [S] would just lie on the sofa every day when [GRO-B] was undergoing treatment for [GRO-B] HIV. [GRO-B] daily routine would consist of [GRO-B] waking up in the morning, lying on the sofa because of the sheer lack of energy, and then going back to bed again when it was time for bed. This meant that [S] would often miss a lot of time at school. [GRO-B] physically could not do anything. It was so hard to witness. A young [GRO-B] of [GRO-B] age should be able to play sports and live an active lifestyle.
22. In 1988 when we were told about [S] HIV infection, we as parents did not truly understand the full ramifications of the infection. The doctors should have provided us with a lot more information.
23. [S] condition was so bad at one point; we thought [GRO-B] might pass away. It was so hard for my [GRO-B] and I. We could not bear to witness it [GRO-B] mental state would steadily decline to zero [GRO-B] was not up for going anywhere or doing anything.
24. My [GRO-B] has provided details of some of the physical and mental impact associated with [S] infection and treatment. I particularly remember that the side effects from the medication used to treat [S] HIV infection, were particularly awful. My [GRO-B] immune system was pretty much non-existent. [GRO-B] had thrush in [GRO-B] throat and digestive system. We had to regularly call Clinical Nurse Specialist [GRO-B] in the middle of the night so he could advise us how to ease [S] pain.

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25. This infection led to **S** developing anorexia as **GRO-B** would be unable to eat and then digest food. I cannot put into words how difficult this was to witness. The only positive was that **S** would never really get a common cold.
26. The AZT was particularly bad for **S** **GRO-B** developed haemorrhoids which were extremely painful and led to a massive decrease in **GRO-B** mental health. **S** suffered with an immense amount of depression. The physical effect that impacted my **GRO-B** the most was the fatigue. **GRO-B** could not do anything.
27. My **GRO-B** and I were always concerned about the stigma associated with HIV. Most intelligent and informed people would realise that **S** would have been infected with these viruses through no fault of **GRO-B** own. But in reality, the majority of people would say that **S** led a horrendous lifestyle or that **GRO-B** was **GRO-B**. No one should be subjected to that kind of treatment; especially when it is not their fault. This had a profound impact on all three of our social lives as we could not leave the house. We also felt that we should keep this a secret and not tell anyone.
28. In the small **GRO-B** where we lived, we hardly told anyone about **S** infection because of the horrific stigma attached. We told a very small amount of people, because news would travel fast where we lived and because of a few uneducated people, the wrong impression would be given about **S**.
29. We have not been able to go on a proper holiday because of the costs of travel insurance and life insurance. A holiday would have just been too expensive for the family.
30. **S** would also have to wait a long time for **GRO-B** haemophilia treatment. This was most likely because of **GRO-B** HIV status. The staff at Plymouth hospital were horrendous. We were not treated like humans, we were told to sit there and be quiet. When we tried to access dental treatment for **S** the four doctors were dressed up like spacemen. All the equipment was covered in plastic wrap. **S** was very frightened and **GRO-B** got the impression that **GRO-B** would infect the whole hospital.
31. The haematologist in Plymouth was of no help at all. They barely gave us any information or help, without referring us to a specialist or anything.

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32. Following this, the financial impact on our family was immense. We would have to travel twenty five miles once a fortnight at least, to the hospital. This would sometimes be two or three times a week.

33. The impact of the infections on **S** education was broad. **GRO-B** missed a lot of schooling from the late 80's through to the 90's. The majority of the absences would be because **GRO-B** was too unwell as a result of the HIV infection. **GRO-B** did not even finish **GRO-B** education and my **GRO-B** and I would get visits from Education officers as they thought **GRO-B** was bunking off school. Even then, we had to keep **S** HIV status a secret because of the stigma attached to HIV.

Section 6. Treatment/Care/Support

34. We were not offered any kind of psychological support or counselling. We were offered no support from **GRO-B** at the time of the HIV diagnosis. We were offered a few types of alternative treatments at the **GRO-B** Hospital such as reflexology and massage therapy.

35. We had difficulty accessing the relevant treatments that **S** needed. He was offered Interferon treatment for HCV, around 2002. **S** had researched the medication at length and which course might be best for **GRO-B**. **GRO-B** felt that given **GRO-B** liver was not too badly affected by the HCV infection at the time, **GRO-B** would wait until newer drugs became available. **GRO-B** had to fight to receive the drug Harvoni in 2016. It was a lengthy process liaising with the hepatitis nurse. **GRO-B** would often be waiting months for a response. **GRO-B** was eventually referred to see a professor at Plymouth, Derriford Hospital who agreed that **S** was a good candidate for the drug, given **GRO-B** healthy lifestyle, the fact **GRO-B** didn't drink or smoke and would most likely adhere to the course of medication. It took several months before funding at **GRO-B** became available and the drug was prescribed.

Section 7. Financial Assistance

36. My **GRO-B** statement addresses this issue at length. But what I would like to say is that when we went through the HIV litigation with **GRO-B**, we had to sign a waiver of our rights in order to receive a sum of £23,000.

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37. The financial support was no where near enough to help us with our needs. We struggled for so long.

Section 8. Other Issues

38. It has been a constant struggle for [S], my [GRO-B] and I. The support we got from some of the medical professionals at [GRO-B] was nowhere near enough and the way we were treated as a family was an absolute disgrace.

39. This could have been so easily avoided if the people who were caring for [S] had done their job properly.

Anonymity, disclosure and redaction

40. I would like to remain anonymous. I understand that this statement will be disclosed and published as a part of the Inquiry. I do not want to give oral evidence.

Statement of Truth

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

Signed..... [GRO-B]

Dated..... 8/6/19