

ANONYMOUS

Witness Name: Mr.

GRO-B

Statement No: WITN1272001

Exhibits: 0

Dated: May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

GRO-B

GRO-B

, will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B
GRO-B and live at GRO-B
GRO-B with my GRO-B I am now retired.
2. I was infected with Hepatitis C as a result of being given contaminated blood products.
3. This statement has been prepared without the benefit of access to my medical records as I sent them off when applying for financial assistance and the documents were not returned to me.

Section 2. How Infected

4. I suffer from Haemophilia A classed as severe. I was diagnosed with Haemophilia at GRO-B when I was about 2 years old. I was tested due to several of my family members being Haemophiliacs.
5. My parents moved to GRO-B shortly after I was diagnosed with Haemophilia and I became a patient at GRO-B
GRO-B
6. My earliest memories of treatment were after suffering from epistaxis. I required a blood transfusion and would be taken in a wheelchair to a treatment room at GRO-B
GRO-B I would then receive fresh blood donated by my father. I remember at one point when I was receiving treatment I had cuts on both my elbows and ankles when the

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medical professionals were attempting to find a vein.

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7. Like most haemophiliacs I had very caring and protective parents and because of this my joints stayed fairly healthy until I was around GRO-B
8. I would have micro bleeds that would act with the bigger bleeds into my joints. These bleeds were treated with cold compress and immobilisation. After the bleed would settle down I required sessions of prolonged physiotherapy. With every bleed that occurred the damage to each of my joints was increased. As a result of this I had to wear a leg braces just to have mobility.
9. In GRO-B I had a really bad bleed into my left hip resulting in me having to stay in GRO-B for three months on traction to straighten my leg. I then required further.
10. During this period I needed a tooth extracted. The dental work took place at the GRO-B at GRO-B. In order to prevent bleeding I was given an experimental Factor VIII concentrate from pig and ox blood which was administered intravenously. It was a powder mixed with water that was developed Dr Gibbs and Macfarlane, two of the most energetic pioneers in haemophilia treatment. The treatment worked and I didn't suffer any bleeds from the tooth extraction.
11. My life continued in the same fashion after this. A cycle of bleeds and recovery periods.
12. Once I outgrew the beds as GRO-B I was transferred to GRO-B where my first treatment for a bleed was Fresh Frozen Plasma (FFP). This treatment was brutal. My body would shake terribly and I wouldn't be able to talk, my body couldn't function. Frozen plasma from a bottle would be pumped into me after the start of a bleed.
13. I initially received fresh blood that my father had donated. Back then nobody was aware of factor VIII. After this I started to receive Fresh Frozen Plasma (FFP) and then Cryoprecipitate. I was the first patient at GRO-B GRO-B to receive home treatment. It was a godsend as it allowed me to treat myself from home. I first began receiving Factor VIII in the early GRO-Bs I believe it was GRO-B I had quite a few consultants but I believe my consultant at the time was GRO-B.

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14. I was not warned beforehand there was any risk of possible infection through these blood products.

15. Since about GRO-B I have self administered, Amour was one of the products that I received but I have used many different brands of Factor VIII. The treatment was very effective, I used it on demand and the reality is it changed my life GRO-B

GRO-B which would never have been possible before Factor VIII. I only ever came across one person who questioned if the blood was safe and they commented that 'it looked like it had bits in it'. But regardless we believed there was no alternative. I went from using it when I had a bleed, to using it every couple of days as a preventative measure.

16. I would regularly collect blood for myself and GRO-B from GRO-B We both suffered from Haemophilia so I would collect around 24 bottles at a time for each of us. Although we both received the same batch number many times, GRO-B was infected with HIV. I luckily have shown no trace of HIV. GRO-B passed away as a result of to his HIV infection in GRO-B

17. In or about the early GRO-B I was tested for Hepatitis A and B. Apparently I am immune to type A and I have been immunised against type B. But I was diagnosed with Hepatitis Non A/Non-B. I was not given adequate or any information and I never received an explanation what it meant. I was not given any advice regarding the risks of others being infected as a result of my infection with Non-A/Non B Hepatitis

18. I found out that I have Hepatitis C at a routine visit to my GP in or about GRO-B during the check up the GP was looking through my medical notes and told me that I had Hepatitis C as a passing comment. I was shocked as I had never been told this before. This shows the lack of information I was ever provided as it is only now I have I learnt that the Non- A/Non-B hepatitis I was diagnosed with earlier, is now commonly referred to as Hepatitis C. Again I did not receive any information at this point to help me deal with, or understand, the infection.

19. I believe I should have been given detailed information when I was first diagnosed with Hepatitis C. I had to find out most of the information about the risk of infecting others and how to deal with the virus on my own.

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Section 3. Other Infections

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20. In or about [GRO-B] I was told by [GRO-B] that I was at possible risk of vCJD. To be honest it just seemed like another thing I had to deal with. I feel I have lived a longer life than was expected, after all the illnesses so I did not let this get to me. I was told some years ago that the chances of dying from Hepatitis C were almost nil but I now realise further complications like cancer and cirrhosis are a possibility.

Section 4. Consent

21. I believe I have been tested or treated without my knowledge or consent and without adequate or full information, as I did not know I was being testing for HIV or Hepatitis infections.

22. I believe they may have taken my blood for research but I do not know.

Section 5. Impact

23. When I was first told of my infection [GRO-B] was becoming ill because of his HIV infection so I wasn't really thinking of my own well being at the time as he was dying in agony. Even though I shared many of the same batches of blood with [GRO-B] I didn't spend too much time worrying about my own well-being, I had to get on with things.

24. I remember when I would visit [GRO-B] the medical professionals would all be masked and gloved up. He was treated in a side ward and treated like a leper. Nobody would really go near him and on occasion they would even leave his food tray outside of his room. I remember being warned that it was a risk to be in the room with him when I would visit. This did not affect the way I treated [GRO-B] but it hurt me to see others treat him like this. He had been ostracised at work prior to this. We received his diagnoses far after he was infected with contaminated blood. I was with him until he slipped into a coma and subsequently passed away.

25. There was a lot of bad publicity and stigma attached to HIV at the time and this contributed to the break down of my first marriage. When [GRO-B] passed away it was like a brick wall came down, my wife was fearful that I had HIV because I was infected with Hepatitis C and [GRO-B] had died of it. I had to leave my children and marital home because of this. When some colleagues found out I had Haemophilia I

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suffered homophobic comments as people associated it with the HIV virus.

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26. I don't believe that I've had any negative physical effects due to my infection. My consultant tells me that I should have treatment that could possibly clear the Hepatitis C infection. However it is impossible to arrange a meeting with the consultant I am told to see. I am meant to have a meeting with a specialist on hepatitis in the area. I am worried that the treatment is potentially worse than the cure. My motto is; if it isn't broke, don't fix it. Dr GRO-B agreed with me that I do not need the treatment. This issue is still ongoing and my Haemophilia consultant is very keen for me to start the treatment. I have reached out to Dr GRO-B to find out what the latest position is but have not been able to get hold of him.

27. I haven't faced too many complications or difficulties in accessing treatments. I was advised to undergo a fibro scan but they are only available at hospitals I have not previously attended and that are not always accessible. At one time they wanted to do a biopsy on my liver but I was not prepared to allow them to do this.

28. I've had no treatment for Hepatitis C. I don't know too much about the treatments that are available but there's nothing I believe I should have been given that I have not received.

29. I have always been open with people about my infection, I let people know for their own well-being. I have never received much in the way of bad treatment from people as a result of this. However, I do remember in the GRO-Bs some work colleagues would only talk to me with their hands covering their mouths.

30. People didn't really know about HIV or what it was at the time. The only stories you would see or hear were in regards to people like Freddie Mercury. Therefore the biggest issue I usually faced was that people would associate Haemophilia with HIV. There was also the social stigma, a connection with homosexuality and HIV.

31. Luckily I did not have to take much time off work. Whenever I did it was usually as a result of my Haemophilia Therefore there were not too many financial effects as a result of my infection.

32. I did not talk to my family much about the infection. I told my mother and father that I was fine and not to worry. I have GRO-B

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[redacted] GRO-B [redacted] but
have not been infected. My [redacted] GRO-B
[redacted] GRO-B

33. I rely entirely on my [redacted] GRO-B [redacted]. If
anything were to happen to her I would be completely lost.
My mobility depends on [redacted] GRO-B [redacted] I can't stand for
more than a few minutes so carrying anything is out of the
question. If anything happened to [redacted] GRO-B [redacted] I would finish up in
care. That is not going to happen. [redacted] GRO-B
[redacted] GRO-B
[redacted] GRO-B

Section 6. Treatment/Care/Support

34. I have not faced difficulty receiving treatment care or
support since being infected with the Hepatitis C. [redacted] GRO-B
[redacted] GRO-B [redacted] I
didn't face any difficulty when receiving these treatments. I
do remember one of the surgeons [redacted] GRO-B
[redacted] GRO-B wore a full gown and face mask. I am
not sure if this was out of the ordinary.

35. I was never offered counselling or any psychological
support. I remember there were posters on the walls of my
GP about counselling. I do not believe I would have
accepted the offer even if I had been made.

Section 7. Financial Assistance

36. I received a lump sum of £20,000 from the Skipton Fund
(now EIBSS) for Hepatitis C.

37. I was in contact with the Haemophilia Society and they
made me aware of the Skipton Fund. Dr Mark Winter was
the director at the time and I believe he told me to contact
them in the hope of receiving some funds.

38. At the moment I receive two separate payments through
EIBBS of £362 and £333 per month

39. I didn't face any real obstacles or difficulty in obtaining the
financial help. I found filling out the forms pretty straight-
forward. There was also no difficulty in finding a doctor to
sign it off.

40. I do not believe the financial assistance I received to be
adequate. The original payments were too small and I know
a lot of people depend on them. Now that I have retired I am

[redacted] GRO-B

also dependent on these payments. I don't believe I should have to fill out a form every year to continue to receive the payments. I think it would be better if I only had to notify them if my circumstances change.

41. The government have been fine spending billions on expenditures for Brexit and HS2 but show no regard or priority to helping those whose lives were permanently affected under their regime.

Section 8. Other Issues/Conclusion

42. I think the amount of people that have died before this inquiry began is criminal really. I heard on the news that David Owen has managed to take a step back from it all and said he was pushing for things to happen in the past. I remember we had a plant in the UK that was ready to produce Factor VIII and he was the one who opposed it and decided to buy it from America rather than be safe.
43. I have a feeling that the majority of Haemophiliacs think there is not much benefit finding out why this happened, we all know why it happened. I think people should be able to live a better quality of life before they die as result of their infections. We shouldn't be in a position where we have to beg for dribs and drabs.
44. I believe the whole process of applying for financial assistance every year is wrong. It means we have to be left on tenterhooks wondering if we will be allowed to get the money next year. People now have extra costs in life and this should be taken into consideration for those affected, I think its time people got more help.
45. I believe those responsible for this ordeal are going to try and take a step back to absolve themselves from blame. It has already taken almost 40 years to get this far and we must ensure that those responsible do not escape.
46. I think the most likely outcome of the Public Enquiry will be 'mistakes were made, we must learn so it doesn't happen again etc. etc.' somebody will become the scapegoat and everybody in government will carry on as usual, until the next disaster. All they want to do is mitigate their responsibility.
47. After [GRO-B] for nearly [GRO-B] you learn to be a bit cynical, especially about politicians.

Anonymity, disclosure and redaction

GRO-B

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48. I do wish to apply for anonymity and I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed. GRO-B

Dated. 12/6/19