

Witness Name: GRO-B

Statement No: WITN1553001

Exhibits: 0

Dated: December 2018

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 I was born on GRO-B and I live at GRO-B
GRO-B Birmingham GRO-B with my partner, GRO-B We have been
together about 23 years.
2. I have two children by my ex wife; a son GRO-B who is now 35 and a daughter,
GRO-B who sadly passed away in 1990 at the GRO-B GRO-B had
GRO-B which was diagnosed when she was just GRO-B old.
3. I contracted Hepatitis C as a result of treatment with contaminated blood
products.
4. This witness statement has been prepared without the benefit of access to my
full medical records. If and in so far as I have been provided with limited
records the relevant entries are set out in the medical chronology at the end of
this statement.

Section 2. How infected

5. I have moderate Haemophilia B (also known as Christmas disease) which means I have a Factor IX deficiency. I was diagnosed when I was about 5 or 6 years old because I had my adenoids and tonsils out. Although I don't remember much about that time my mother tells me that it was touch and go with the operation because there was so much bleeding.
6. My haemophilia has always been treated at the Queen Elizabeth Hospital in Birmingham (QEH). I was infected with Hepatitis C from blood products given to me at the QEH.
7. I cannot recall all the occasions that I had bleeds and was treated at the QEH but the following incidents stick out in my memory:
 - a. When I was about 9 or 10 I was admitted to the QEH with stomach pains. They discovered that I had appendicitis and my appendix was removed. I cannot recall what treatment I was given but I must have had some blood products administered prior to the operation.
 - b. When I was about 12 or 13 I was diagnosed with a duodenal ulcer after I lost a lot of blood going to the toilet and was vomiting. I was admitted to the QEH for about two weeks and given clotting factor and blood transfusions.
 - c. When I was 14 or 15 I had a very big bleed in my hip joint. Again I was in hospital for a couple of weeks. On this occasion I believe I received Factor IX concentrate.
 - d. When I was 22 I had several teeth removed. I was given Factor IX prior to the extraction and ever since that time I have always been given factor before teeth extractions.

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I am sure that there were other hospital visits in the 1970s and 1980s when I was treated with Factor IX but I cannot recall the dates or reasons for treatment due to the passage of time.

8. I have never been given any information about when I was infected with Hepatitis C. I assume that I was infected at some time in the 1970s or 1980s when I was treated with Factor IX concentrate.
9. I am unable to recall exactly when I was told about my diagnosis due to the passage of time but I believe it was in the very late 1980s/early 1990s. Nothing sunk in at the time. I was either ignorant or just didn't understand what I was told. I had no idea of the damage Hepatitis C could cause and I don't believe it was explained to me. I am certain that no one told me I could die from the virus.
10. The information given to me was minimal. I suspect this was because the doctors didn't know much about it themselves at that stage. I was told by my doctor that the virus could be passed on through sexual intercourse but I was also told that there had been no actual reported cases of this which gave me some comfort.
11. I was always responsible and honest with my sexual partners.
12. It wasn't until some time later that my haemophilia doctor, Dr Wilde, told me it would be best for me to see the doctors in the liver clinic to see what stage my Hepatitis C was at. Again, I was not made aware of how dangerous my situation was and because I didn't know much about the virus I didn't realise how worried I should be.

Section 3. Other Infections

13. I was advised that I was at risk of vCJD and that I could have a test for this but I refused.

Section 4. Consent

14. I believe I have given full consent to any testing and research.

15. Whilst I cannot recall being asked to consent to testing for Hepatitis C I am sure that if I had been asked I would have consented without realising the implications of the same.

Section 5. Impact of the Infection

16. I remember attending the first few appointments at the liver clinic and then being told that the doctors wanted to do a liver biopsy on me to check the condition of my liver.

17. I always believed that you shouldn't interfere with things internally in your body unless it was absolutely necessary because of what happened to my daughter. She was doing really well after going through radiotherapy and then, when she was GRO-B She GRO-B with her mum. A week later she complained of headaches so we took her to hospital. A scan was carried out which showed a tumour growing in her face. This led to chemotherapy and more radiotherapy and alas the cancer had spread so far that the only option left to us was for us to take her home. She died GRO-B months later. This experience left me with the strong view that you should only have medical intervention if absolutely necessary. I was not told the biopsy was crucial so I refused it.

18. A little while later I was told that the doctors could check the state of my liver with a FibroScan. I agreed to have the scan done.

19. The more liver appointments I had, the more apparent it became to me that my Hepatitis C infection was serious. I had regular blood tests and then one day, in or about 2012, my doctor told me that I needed to try and start treatment otherwise I would only have about 10 years left to live. That was when the full magnitude of my condition hit me.

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20. I agreed to try treatment with Interferon and Ribavirin. I was advised that it was quite invasive and had a number of nasty side effects. I wasn't bothered by any of that having been told that without treatment I would only live for another 10 years.
21. I started the treatment within weeks of it first being mentioned to me. After 3 or 4 weeks they tested my viral load and I was told that my levels were not reducing so there was no point in continuing the treatment because they were certain it would not work.
22. Sometime later the clinic team contacted me to say that there was a new drug available to treat Hepatitis C called Sofosbuvir and that in initial tests the success rate was promising. I was one of the few started on this new drug therapy and within weeks my viral load levels dropped. I was then put on a 6 month course of the new treatment.
23. After 6 months my tests showed no level of the virus present in my blood. Since then I have had 6 monthly FibroScans and blood tests to monitor my condition. To date I have been told that everything looks good and there is no sign of the virus returning.
24. The side effects of the most recent treatment were not too bad. I found I got out of breath easily, had some difficult chest pains and felt fatigued but that was it. I did have to take some time off work but I was able to tell my employer the reason and they were very supportive.
25. I still feel very fatigued at times and my limbs ache. I have had bouts of depression over the years and of course my liver is now scarred forever. The stories I have read about what other people have gone through are horrendous and, at this moment in time, I am grateful to still be alive.
26. Throughout most of my life I have only confided in those closest to me about my infection. Mainly I spoke to my ex wife, partners and of course my current partner who has been a great support. I kept it from other people because I wasn't sure how they would react. I am aware of the stigma associated with Hepatitis C but have never experienced it because I never really told anyone

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about my infection. I have always tried to keep my life as normal as possible and now that I have cleared the virus I have been more open about my infection.

27. My partner has always worried about me because of my haemophilia and Hepatitis C. She has had to deal with my mood swings, lethargy and of course the realisation that there was still something wrong with me.

Section 6. Treatment/care/support

28. I have not faced any difficulty obtaining treatment.

29. I do not recall being offered any counselling.

Section 7. Financial Assistance

30. I have received the Stage 1 and Stage 2 payments from the Skipton Fund.

31. I was made aware of the Fund by my liver doctor. My initial application for the Stage 2 payment was refused but was subsequently granted after the liver FibroScan.

32. I have not made any other requests for financial assistance.

33. Although I am grateful for the financial support I have received I find it difficult to reconcile the fact that the government allowed the biggest treatment disaster in the history of the NHS and has then failed to properly compensate those affected. I just want to be sure that my family are looked after in the future and proper compensation would achieve this.

Section 8. Other Issues

34. At that time my first round of treatment was stopped in I accepted the decision and looked to enjoy the time I had left. My view was 'it is what it is'; I knew I

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couldn't change it so I decided to just get on with my life. However, I believe that there are people responsible for this scandal and that the truth needs to come out.

Anonymity, disclosure and redaction

35. I confirm that I wish to apply for anonymity so that any names are removed for the purposes of disclosure. I understand this statement will be published and disclosed as part of the Inquiry.

36. I do not wish to be called to give oral evidence at the Inquiry.

Statement of Truth

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

Signed.....

Dated

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Signe

GRO-B

Dated 19th DECEMBER 2018