Witness Name: GRO-B

WITN: 1320001

Exhibits: 0

Dated: January 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. My date of birth is GRO-B 1972. I am married and live with my wife at GRO-B County Durham, GRO-B GRO-B. I have GRO-B children all of whom live with us.

2. I was infected with Hepatitis C as a result of being treated with Factor IX blood products. At no time has the hospital informed me of when I was infected and when the infections were cleared.

3. This witness statement has been prepared with the benefit of only some of my medical records. The hospital in Newcastle Upon Tyne has sent to me the recent records only and other hospitals I believe are also concealing from me important entries.

Section 2. How infected

Family history

4. Haemophilia runs in the family on my mother's side GRO-B GRO-B and some of my cousins and nephews also have the condition.

5. I was 6 months old when doctors diagnosed me with severe Haemophilia B. I am the youngest of 5 children and I am the only one of my siblings to have the condition. My Haemophilia was initially treated at Birmingham Children's hospital. I do not have any other bleeding disorders

6. I attended the following hospitals:

   (a) Birmingham's Children's Hospital – Haemophilia Unit (1972 – 1991)
   (b) Birmingham - Queen Elizabeth Hospital (1991-1993)
   (c) Leeds - St. James's University Hospital (1993-1995)
   (d) Birmingham - Queen Elizabeth Hospital (1995-2001)
   (e) Newcastle Upon Tyne – Royal Victoria Infirmary (1998- 2001)
   (f) Birmingham – Queen Elizabeth Hospital (2001- 2005)
   (g) Newcastle Upon Tyne – Royal Victoria Infirmary (2005 – date)

7. At Birmingham's Children Hospital, I was seen by Dr Frank Hill until I was about 19 years old. As a young boy, I remember reading information leaflets about Haemophilia whilst waiting to see consultants. From reading these leaflets I found out that I was treated with BPL products. I have also been treated with Alpha-9, Mono-9 and Benefix. I have no other bleeding disorders.

8. At Queen Elizabeth Hospital, Birmingham, I was seen by Dr Jonathan Wilde. That is when it used to be my local hospital but when I began voluntary work in Leeds, and later went to university in Sunderland, I began to attend other hospitals as and when the need arose.

9. My interest in my own condition was such that I went on to read Physiology and I am now a senior lecturer in this field at GRO-B

When I found out I had Hepatitis C

10. In 1996, just before my 24th birthday, I saw Dr. Jonathan Wilde, a consultant haematologist at Queen Elizabeth Hospital, Birmingham. At this routine appointment, he was looking at my medical notes and said "*...Do you realise you have Hepatitis C..?*" He went to say, *"...You have had it for at least 15 years and you could have had a liver failure at any time"*. It follows from this that I must have been infected with hepatitis C when I was being treated at the Children's Hospital. To this day, I have never received any explanation from any hospital as to what actually happened. If it was not for this consultant, I would never have known about the infection.

11. I have tried to obtain all my earlier medical records but to no avail. I have only been sent records from 1998. It has never been explained why important medical records are missing.

12. When the consultant told me I was shocked and very angry because all these years had passed and no one had warned me that my liver functions could have failed and that I could have potentially put other lives at risk. He went on to give me three options. Firstly, I could do nothing; secondly, I could request to be treated with a drug called Interferon; and thirdly, I could have a PCR (Polymerase Chain Reaction) analysis and a liver biopsy. The last option seemed the most appropriate because, at the time, he said he did not know whether I still had Hepatitis C.

13. The consultant left it to me to decide which option I wanted to take. He did say that the Interferon drug was known to have severe side effects and that the liver biopsy could rupture my liver. I did not see the purpose of taking interferon drugs because I did not know whether or not I was still infected. For this reason

I requested to undergo a liver biopsy and I received an appointment for the operation within a few weeks.

14. Until my meeting with Dr Wilde, the doctors had never advised me of the dangers of hepatitis C and the risk of it being passed onto others. They should have told me when they first became aware I was infected.

15. The doctors never told me whether I was ever tested for HIV. In the 1980s, HIV was receiving considerable media attention because high profile celebrities were dying of AIDS after contracting HIV. It was generally accepted that Haemophiliacs could be infected with HIV but doctors at this time never informed me or gave me any advice about the risks. The seriousness of this oversight should not be ignored.

16. The liver biopsy was carried out under a local anaesthetic and the procedure involved two needles being inserted in my rib cage. I had to remain in the same position for 8 hours during and after the doctors had carried out the operation. The results revealed that my liver was in good working order. The doctors did not find any detectable Hepatitis C RNA (ribonucleic acid) in my blood but they did find antibodies to Hepatitis C. They informed me that this meant the virus was cleared naturally and this was a huge relief for me.

What caused the hepatitis C infection

17. The consultant informed me that Factor IX was likely to have caused the infection. He ruled out contracting the infection through a physical relationship when I told him that, as a practicing Mormon, I did not believe in physical relationships before marriage.

18. I was courting at the time and the consultant requested that my girlfriend attend hospital to undergo tests to see if she was infected by me. When she found out that I was infected, she ended the relationship. I subsequently made a rule that future partners were made aware I was infected at one stage but was now cleared of it. In that way, future partners could decide whether or not they wanted to continue seeing me.

19. The hospitals should have told me about the infection much sooner. I believe all of them must have known about it and should have advised me fully about the risk to my own health and the risk that I was to other people. I could and should have been given the option of having a liver biopsy much sooner than I did.

Section 3. Other Infections

20. As far as I am aware I have also contracted Hepatitis B from Factor IX blood products, but I am not aware that I have contracted any other infections from the Factor IX blood products used to treat me.

21. In about 2000, the haemophilia centre at the Royal Victoria Infirmary in Newcastle Upon Tyne sent to me a letter stating there was a possibility that some of the Factor IX batches that I was treated with could have been contaminated by variant CJD. This is all that I am able to recall about this. This letter is not in the medical notes. This further supports my argument that I was infected by contaminated blood.

Section 4. Consent

22. The doctors at Birmingham Children Hospital never told my parents about the risks of Factor IX products, in particular when such products were safe to use. My parents merely followed the advice given to them. They were not told that they could cause an infection and if they were made aware, they would not have allowed the hospital to use those products.

23. When I was an adult, doctors at the children's hospital or St. James's Hospital should have told me of the risks involved with the treatment. If they had told me of the risks, I would not have consented to the treatment.

24. I do not know whether the doctors treated or tested my infection before I was first informed of the infection in 1996. The doctors have provided me with very little information about how to manage it.

Section 5. Impact

Effect at school

25. At a young age, I was regularly bullied and did not want to go to school or associate with people. Other children were aware I had Haemophilia and they felt I could pass on HIV to them. I felt segregated from others in my class. When I was about 10 years old, I attempted suicide because I did not see any point of living. I knew that other haemophiliacs had caught infections and were dying and I could die too. I did not want to see people around me and I just wanted to be left alone.

26. When I was 18, I was aware haemophiliacs were being infected by clotting agents, in particular Factor VIII and IX that were causing the illnesses through injections. My best friend caught HIV and subsequently died from AIDS after being treated with Factor VIII and I started to refuse treatment. I was in considerable pain and I tried to take my own life. This was a particularly difficult period for me as I felt depressed and thought the Factor IX was going to kill me too.

Higher education

27. My education was affected. I did not do well in my GCSEs or A Levels, and in 1996 I returned to college to re-sit my A-Levels. As an undergraduate student in GRO-B I was told batches of my Factor IX may have been contaminated with variant CJD. This was during my final year and had a big impact on me mentally.

Effect at Work

28. I started work as a volunteer and then, in and about 1995, I found a temporary job in an accountancy firm. I started my own business for a short while before deciding to go to college and university. I knew that I had to educate myself because I felt unable do any physical jobs.

29. I still have suicidal thoughts. In total, I have considered suicide 8 or 9 times, the last time being only 3 or 4 years ago. I have had CBT counselling and have been taking anti-depressant tablets. Although I have been cleared, I still think about what could have happened and what could still happen in the future. This is what causes the stress and leads to my severe depression which I was diagnosed with about 8 years ago.

30. The hospital used to provide funding for some psychological support. This funding has elapsed and I now have SSRI (selective serotonin re-uptake inhibitors) medication. I have not been back on any other courses since. I have now become obese as a result of my depression.

Relationships

31. In 1996 I was told that I had Hepatitis C for *"..at least 15 years.."* This placed a strain on my ability to form normal relationships at a time when I was looking for potential partners with whom I could marry and have a family. My girlfriend at the time left me when she found out I was infected and could pass on the infection. Afterwards, I decided to let all future partners know from the beginning of my medical condition. For this reason, I experienced difficulties forming and maintaining relationships.

Treatment

32. I have experienced difficulty getting treatment. My GP does not want me to receive diclofenac due to possible side-effects. Also community dentists refuse to see me in case they cause me to bleed or contract an infection from me.

Stigma

33. At school I was bullied. My peers often told me I had "the gay disease". They thought that if I had haemophilia I must also be infected with HIV and have AIDS. If my parents had been told and if my school was aware of my having Hepatitis the school could have given me some support through a very difficult period in my life.

Section 6. Treatment/Care/Support

34. No counselling or psychological support was offered to me as a consequence of being infected. I have only received counselling due to my severe depression, which was not linked with being infected at the time.

Section 7. Financial Assistance

35. I was told that I was not entitled to the Skipton fund or funding from the MacFarlane trust as I had naturally cleared the infection. Although I had to go through the physical and mental trauma of having to deal and live with the infection, none of it was taken into consideration.

36. I found out about the Skipton fund through the TV news. I received the forms, but they stated that if you had been infected but naturally cleared the infection without any treatment, you were not eligible to apply and I just threw the papers away. I have not received any funding.

Section 8. Other Issues

37. In and about 1998, I contacted solicitors to represent me in a class action against the NHS. This is what prompted me to obtain my medical records. For the purpose of pursuing my claim, it was confirmed that I had been treated with IX products and I underwent an examination at Queen Elizabeth Hospital in Birmingham.

38. My solicitors categorised my claim as "Hepatitis C but cleared naturally". Because, I did not require treatment, my solicitors were unable to proceed with the claim.

Anonymity, disclosure and redaction

39. I would like to apply for anonymity and I understand this statement will be published and disclosed as part of the Inquiry.

40. I wish to be called to give oral evidence.

Statement of Truth

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

Signe GRO-B ....

GRO-B

Dated 31 January 2019