

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2761001

Exhibits: 0

Dated: 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 I live at GRO-B
GRO-B My date of birth is GRO-B I live in a flat share
with a friend. I have been working as a GRO-B

2. **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

3. I was diagnosed with severe Haemophilia A at birth. I received blood products twice weekly until the doctors changed my treatment to non-blood products.

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4. I had two particularly bad joints; my right ankle and my left elbow. As a result, any injury could be extremely painful due to extreme swelling and pressure on my muscles.
5. My parents were told that it would be dangerous for me to be involved in contact sports and that I had to be particularly careful managing my day to day activities. I do not believe any other information was provided.
6. Growing up, I lived with my mother, father and older brother. My brother was also diagnosed with haemophilia A.
7. My parents therefore were already aware of the blood products when I was born and administered home treatment which was the usual practice for us both as children.
8. At the time, there were only blood products available and no chemical or biological alternative like there is today.
9. In or around 1989, when I was aged 7, I was diagnosed with Hepatitis C. I attended the Haemophilia Centre with my parents and my brother and I specifically remember my consultant, Dr Goldman, asking my parents: *"What would you say if we told you that both of your sons have been infected with the Hepatitis C virus?"*
10. I never really discussed this incident with my parents. At the time, all I knew was that it was something negative.
11. I believe I received human Factor VIII concentrate protein blood products. To the best of my recollection, there were various pharmaceutical companies who offered the blood products and so I do not know which specific batch infected me.
12. I believe I was infected at the Royal Free Hospital at the Katherine Dormandy Haemophilia and Thrombosis Centre. I still continue to attend this centre for treatment.

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13. I am not aware of any incident prior to my diagnosis which could have resulted in my infection. It was only later that I discovered blood products from American prisons had found their way into blood products in the UK.
14. My mother was a GRO-B which meant she probably had a better understanding of blood-borne diseases than the average person. However as Hepatitis C was so new, even the medical profession did not really understand the long or short term consequences of the virus apart from the fact that it severely affected the liver.
15. I was always aware that I had to look after my liver. As a child, I was too young to include alcohol as part of my lifestyle. However as I grew up, I was aware that alcohol had the potential to damage my liver. Nevertheless, I do not know how much of this information was provided to my parents at the time.
16. I attended regular check-ups at the Haemophilia Centre but which only related to my haemophilia. There was no treatment or support for Hepatitis and I did not attend a Hepatitis clinic until I was 19 years old and under the care of Professor Geoffrey Dusheiko.
17. Professor Dusheiko advised that I should undergo the Interferon and Ribavirin treatment to which I agreed. Upon the failure of this course (on two occasions,) I was referred for the combination treatment of Ledipasvir and Sofosbuvir which has appeared to clear my infection.

Section 3. Other Infections.

18. I was later diagnosed with Crohn's Disease and I questioned whether this was linked to Hepatitis C, but the medical practitioners assured me that there is no proven link.
19. To the best of my knowledge, I have not been exposed to any other infections.

Section 4. Consent.

20. I believe that I was treated and tested with my parents' knowledge and consent.

21. I am unaware of if I was ever used for research purposes as I was so young at the time.

Section 5. Impact

22. The mental effects of my diagnosis have been difficult to deal with. I was approximately 7 years old when I found out about my infection and at the time was only made aware I couldn't consume alcohol.

23. It was a blood-borne disease and I believe the general consensus was that it could be sexually transmitted. It was difficult to get intimate with someone later on in life because I could not process the fact that I had to discuss my infection with somebody. It held me back from initiating relationships and the thought still affects me to the present day, because I've always felt there was something different about me.

24. When I was aged 12, I began to play on the slot machines frequently and from the age of 17, I began to smoke marijuana quite regularly which continued into my late twenties. This was my way of escaping and a way of not having to process the fact that I was living with the Hepatitis C virus.

25. I believe my addictive traits stemmed from the pressure of living with a terrifying infection in silence, which resulted in the loneliness I felt growing up and my looking for an outlet to cope. The effects were so great that my addictions developed and consequently I am now a recovering cocaine and gambling addict.

26. Throughout my late teens and twenties, Hepatitis C was something that I did not feel comfortable talking about. I kept it a secret and none of my friends

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ever found out. I thought it was embarrassing and I felt ashamed. From my perspective, it held me back from doing things that I might have done and the social experiences I should have had as a young man growing up.

27. In 2001, as per the advice from Professor Dusheiko, I undertook a course of Interferon and Ribavirin treatment. The course was intended to last approximately 6 to 12 months. The potent cocktail of drugs which I ingested was horrendous, as I suffered with numerous side effects such as nausea, headaches, etc. I was unable to complete the entire treatment as a result. It was physically taxing.

28. It also took its toll on my mental health as I was trying to hide everything from my flatmates at university. I had to keep the injections in the fridge so I told them that it was my Haemophilia treatment instead, but I was always worried.

29. At or around the age of 21 in 2003, I repeated this treatment a second time but which was also unsuccessful. Although this time I completed the course of treatment and my viral load went down to 0, but I relapsed. At the time when the medical team told me that it was unsuccessful, they advised that it would be best to wait to see what other treatments would be available in the near future.

30. In approximately 2016, a new treatment came onto the market. I believe there was a real push in the Haemophilia Centre to encourage Hepatitis C patients to undergo the treatment. I was contacted and agreed to a 12 week course consisting of a combination of Ledipasvir and Sofosbuvir. I recall the treatment consisted of both injections and tablets but again, it was another horrible course. I suffered from insomnia and I was exhausted the entire time. It was difficult for me to focus at work for extended periods of time.

31. Despite the effects, the Ledipasvir and Sofosbuvir treatment cleared my Hepatitis C. I recall my viral count was monitored throughout the duration of the treatment. Approximately 6 months after the treatment, it was confirmed I was clear of Hepatitis C. It was a real relief to me as the infection had been psychologically damaging to me.

32. Once the treatment came to an end, there was no recovery period.
33. I was aware of the fact that if I needed to undergo dental surgery I would have to attend the hospital instead. This was not communicated to me but I knew that because I had a blood-borne disease I would have to go to hospital so that the medical staff could take precautions.
34. I believe my mother blamed herself for the fact that both my brother and I were haemophiliacs, as it is the female gene which carries the condition. The psychological effect of us then having been infected with Hepatitis C really took its toll on her.
35. My brother also had addictive tendencies and suffered a lot more physically as a result of his infection.
36. At home, we did not discuss our infections very much. We knew we had it and that we had to live with it somehow.
37. I feel my infection has had a huge impact on my education as I was unable to complete my course at GRO-B
GRO-B I had to resit my first year, and then went on to complete the second year but I failed by third year as I was managing treatment at the same time.
38. I became a GRO-B at that time which felt like a great path for me to take as I knew I could make money quickly, but in hindsight I know that it was a way of feeding my addiction and a way of escaping from knowing that I was infected with Hepatitis C. I continued with this profession for a decade before I realised my addiction had spiralled out of control.
39. I continue to have intimacy issues even now. It is difficult to assume that there is a direct link between my issues and the diagnosis, however much of my life has been impacted in some way with the knowledge that I have Hepatitis C.

Section 6. Treatment/Care/Support

40. I did not face any obstacles in receiving treatment.

41. I was offered psychological support through the Haemophilia Centre but I refused. I believe this was a way of internalising all I was going through, but additionally I did not want to open up to anybody about my addictions and tried to remain emotionally quite closed off.

42. As part of my 12-step-recovery programme for my cocaine addiction, I told my sponsor about what I had been through. I am currently 2 and half years into recovery which I am very pleased with.

Section 7. Financial Assistance

43. In or around 2001, I received a Stage One payment of £25,000.00 from The Skipton Fund. I found out about the fund through the Haemophilia Centre.

44. The application process was fairly simple as I was already registered with The Skipton Fund and I was already on their database.

45. Approximately 2 to 3 years ago, the Government began to distribute quarterly payments and I now receive payment of £4,500.00 per year (increased to ~£18k per year as of 1st April 2019). This includes a £500.00 winter fuel payment from the NHS Business Authority Services.

Section 8. Other Issues

46. Compensation payments are currently nowhere near what they should be, compared to the pain and anguish which the infected community has had to endure.

47. I would like to know whether there was any prior knowledge of the products that were being used and whether there was a cover up in relation to what

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was known at the time. Could the infections have been avoided? Could the contaminated blood products and blood have been taken off the shelf?

48. From my understanding, a lot of paperwork has disappeared which raises much suspicion. I do not feel strongly about criminal prosecution, however this may change depending on what evidence is presented in relation to what was known at the time and what might have been done deliberately.

Anonymity, disclosure and redaction

49. I would be happy to provide oral evidence to the Inquiry.

50. I would like to apply to retain my anonymity.

Statement of Truth

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

Signed.....

GRO-B

GRO-B

Dated.....

12th August 2019