

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2789001

Exhibits: WITN2789002-005

Dated: August 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** of **GRO-B**
My date of birth is **GRO-B**. I am married and with three children, one is in University and two are working and living at home. I work full-time in the **GRO-B**.
2. I was infected with the Hepatitis C virus (Hep C) as a result of receiving contaminated blood products.
3. 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

4. When I was young my brother had a fall in a playground at school and suffered from severe bleeding. Subsequently he was diagnosed with mild haemophilia at **GRO-B** **GRO-B**. As a result, the doctors assumed

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that I was also a haemophiliac and subsequently diagnosed me with mild haemophilia.

5. It appears that my blood count was 56 and was categorised 'borderline mild Haemophilia'. The doctors told me that if I was to have a surgery I would require clotting factor.
6. I initially received Cryoprecipitate for tooth extractions when I was aged 6 or 7.
7. My treating doctors over time were [GRO-B] [GRO-B], Dr Christine Lee, Dr Dusheiko, Dr Samuel Machin and Dr Chris Hatton.
8. In a letter dated [GRO-B] from [GRO-B] to [GRO-B] it states that I received Factor VIII concentrate (FVIII) in [GRO-B] prior to an operation for a dental cyst and also received FVIII in [GRO-B] for a [GRO-B]. A copy of the above letter is exhibited at 'WITN2789002'.
9. Dr Christine Lee states in her letter dated [GRO-B] to Professor Geoff Dusheiko that 'in [GRO-B] he had large pool unsterilised clotting factor concentrate to cover a dental extraction because he was allergic to cryoprecipitate. A copy of the above letter is exhibited at 'WITN2789003'.
10. I never had any real problems with bleeding so it has never really affected me and as a result I should never have been exposed to FVIII in the first place.
11. I was not provided with any information or advice in relation to risks of infection following FVIII treatment.
12. As stated above, as a result of being treated with FVIII I was infected with Hep C.
13. The Hep C infection was dormant for many years. I got married when I was 32 years old and I started feeling fatigued when we had children. I thought it was a result of the stress of having children and lack of sleep. This lasted for approximately 2 to 3 years. At the age of [GRO-B] I underwent a series of investigations with the doctors in the form of blood tests. I suspected that I had anaemia as I was constantly tired and required more sleep than normal.

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Finally, in approximately GRO-B, I saw my GP who tested me for Hep C, which tested positive. A copy of the blood test result is exhibited at **'WITN2789004'**

14. After my GP did the blood test he went away on holiday for approximately a month. I recall driving on a motorway when a junior doctor telephoned me and told me that I tested positive for Hep C. I was in shock when he told me the news.
15. After I was told that I tested positive, a friend told me to see a haematologist at St Peter's Hospital, Surrey. I arranged an appointment for two weeks later and when I attended the appointment the doctor at the hospital told me that I had 30% chance of dying. This caused me a lot of stress as my wife was pregnant with our third child.
16. I was not given any information on how to manage or understand what the infection entailed. I was just told it was a virus which attacked the liver. I researched it on the internet which resulted in me having a greater understanding of what Hep C was.
17. The way in which the information was communicated to me was unacceptable. I believe I should have been told straight away and I should have had a comprehensive appointment to follow-up and an explanation should have been given about the type of infection I had and what treatment was available.
18. I decided to take matters into my own hands following the lack of information I had been provided with by the GP and the hospital. I found out there was a Haemophilia Centre at the Royal Free Hospital, London (RFH) and it was under Dr Lee. I made an appointment to see her and as I was supposedly a haemophiliac at the time they took me under their wing. The time gap between the junior doctor telling me that I had been infected with Hep C and my appointment with Dr Lee was approximately 8 weeks during which my pregnant wife and I thought I was dying.
19. During my first meeting with Dr Lee, I arrived very distressed with my pregnant wife. As stated above at paragraph 8, Dr Lee states that it was likely

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that I was infected in 1982. In a another letter to Dr R Furness from Dr Lee, dated GRO-B, Dr Lee states that in the year I that I receive FVIII (1982) there was an alternative treatment available such as DDAVP and vasopressin that I could have been treated with. This was quite distressing to read as being infected with Hep C could have been avoided. I exhibit a copy of the above at 'WITN2789005'.

20. I believe I was told about transmitting the infection by Dr Lee.

Section 3. Other Infections.

21. I do not believe that I have been infected with any other infections as a result of FVIII.

Section 4. Consent.

22. When I attended the GP because I was feeling unwell, I was told that I would be tested for Hep C. I do not know if I have been tested for Hep C prior to this.

23. I do not believe that I was treated without my knowledge.

24. I do not believe that I was treated or tested without my consent. There was no reason for me to have blood tests except when I underwent a series of blood tests to diagnose why I was lethargic.

25. The RFH was good at providing me with adequate information in relation to the Hep C.

26. I do not think I was treated or tested for the purposes of research.

Section 5. Impact

27. The impact of finding out that I had been infected with Hep C was very devastating. The impact on my mental wellbeing was significant as I suffered from depression. I was prescribed anti-depressants for a period of time as I was very anxious at the time.

28. Physically, I suffered from tiredness and fatigue. I was unable to spend quality time with my family. An example of this was when I was on holiday I had to sleep for longer periods and I was too tired to do 'fun dad activities'.
29. My career was put on a standstill. I was coming up to GRO-B years old and I had been with a company for GRO-B years. The next step to progress my career would have been for me to apply for a directorial role for another company. Unfortunately for me, when I started to fill in the job applications it would always asked about the Hep C status. This was because I would be working in the GRO-B and some of the companies' protocol set procedure was to conduct a health check especially as HIV was prominent at that time. Even if I wanted to set up my own business I was unable to as my health was too poor. It had a huge impact on my career and I am still with the same company GRO-B years later. It passed me by and I did not progress which also had a financial impact on my life. I could have been earning a significantly higher income had I never been infected with Hep C.
30. In the early GRO-B I underwent a 6-month combination treatment of Interferon and Ribavirin at the RFH, which I completed. In the final month of the treatment the doctors started to see results and it was confirmed that I cleared the Hep C. Whilst I was on the treatment I had regular monthly check-ups and every month it was a disappointment finding out that I was still Hep C positive. I felt lousy and I felt even more anxious when I had not cleared it by the fifth month of the treatment. When I eventually cleared it I thought it was the end of the Hep C infection, however, I continue to suffer from physical effects, such as tiredness and fatigued from post-treatment to the present day.
31. I had no difficulties in obtaining treatment once I became aware that it was available to me. The doctors told me that this was the best available treatment at that time.

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32. As a result of the treatment I suffered from weight loss, anaemia, depression and memory loss. I believe that I continue to suffer from memory loss and brain fog.
33. Since the Hep C diagnosis I have developed **GRO-B** which affect my vision. There are some suggestions that the **GRO-B** are as a result of the Interferon treatment but there is no published study. **GRO-B**
GRO-B I know I have to address this medical complication but I have buried my head in the sand for the last 5 years. I struggle to face it because I will have to undergo another surgery which will prevent me from being able to drive which means that I will have to retire as I will be unable to continue working.
34. As a result of the **GRO-B** on my optic nerve I constantly have to move my head to a certain angle to be able to see. This resulted in developing arthritis in my neck. I underwent electric shocks and injections in an attempt to kill the nerve, but I continue to suffer from pain in my neck.
35. I also suffer with **GRO-B** which was diagnosed by Dr Lee. I have spells of dizziness as a result. When the Hep C treatment concluded I continued to suffer from brain fog and lack of concentration.
36. During the treatment I continued to work. I went to Geneva on a business trip and it was awful. I went into meetings feeling horrible and I used to put up a front of feeling fine. I kept my infection and treatment a secret in my professional life.
37. I told my immediate family and a couple of close friends about my infected status.
38. The infection and treatment had an enormous impact on my family, private and social life. My wife was pregnant at the time of my diagnosis. I feared that my wife could have been infected. She refused to be tested for a long time due to the anxiety and stress surrounding it. My eldest son who was teething used to chew my toothbrush to relieve the pain. I feared that my toothbrush may have had a spot of blood on it and that the infection could have been

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transmitted to him. For the first 5 years of my daughter's life I was poorly. I was unable to take any of my children out and I was unable to be a dad.

39. The diagnosis put a lot of pressure and stress between me and my wife. We were both incredibly worried and uncertain about our future. My parents were also very anxious for me.

40. I became more cautious around my family and friends when I found out about the infection.

41. I also became anxious about whether I may have exposed my previous sexual partners to the infection. It still plays on my mind.

Section 6. Treatment/Care/Support

42. Prior to my care at the RFH it was like the blind leading the blind. I went to see my GP who referred me to a haematologist at St Peter's Hospital and I found that they were not helpful. After I found out about the Haemophilia Centre at the RFH I moved on and left the rest behind. I am pleased with the care and support I received from Dr Lee.

43. I was not offered any counselling after I was diagnosed. I think if support was offered to me it would have helped. I had a lot of anxiety and I was unaware about what was going to happen. I needed some psychological support.

Section 7. Financial Assistance

44. In or about 2002, I registered with the Skipton Fund and I received the Stage 1 payment in the sum of £20,000.

45. From 2017, the EIBSS wrote to me and I started to receive per month from them. The amount has recently been increased to £1,500 per month. I also receive a annual winter fuel payment in the sum of £500.

46. The process of applying for financial assistance was straightforward. I received a letter with forms and filled them out. There were no obstacles as such. I also received letters to see if I needed any other financial help but the

46 The process of applying for financial assistance was straightforward. I received a letter with forms and filled them out. There were no obstacles as such. I also received letters to see if I needed any other financial help but the criteria did not apply to me so I did not apply further. I do not recall any preconditions being made on the applications.

47 My observation on the financial assistance is that I found it a bit confusing.

Section B. Other Issues

48 Before my diagnosis, we increased our mortgage and I had to take out life insurance in order to cover it. When I found out that I had been infected with Hep C, I was obliged to inform the insurer about it. I had to be tested for Hep C and HIV. I did get the life insurance but it was at an inflated rate so I had to pay a high premium due to no fault of my own.

Anonymity, disclosure and redaction

49 I would like to apply to retain my anonymity.

50 I do not mind giving oral evidence to the Inquiry.

Statement of Truth

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

Signed.

GRO-B

Dated

29/7/19