

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3023001

Exhibits: 0

Dated: 29th 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 and I live at GRO-B
GRO-B I was born on GRO-B 1974. I am married, and have
been for 13 years. I have GRO-B daughters GRO-B and am a contractor working in
IT within GRO-B
2. I am aware that my mother, GRO-B is also providing a
statement to the Inquiry.
3. This witness statement has been prepared without the benefit of access to my
full medical records.

Section 2. How infected

ANONYMOUS

4. In December 1992, when I was 18 years old, I was diagnosed with Leukaemia and I was given regular blood transfusions for about the next 7 or 8 months.
5. My treatment was initially at Luton and Dunstable Hospital (L&D) under the care of Dr D S Thompson, and then I was then transferred to University College Hospital (UCH) in London under the care of Dr A H Goldstone.
6. When I was initially admitted to L&D in December 1992, my records show that at the request of Dr Thompson I received a transfusion of 5 units of platelets and 2 units of blood.
7. Following my transfer to UCH I received several regimes of chemotherapy treatment and between December 1992 and May 1993 my records show that I received 14 units of blood and 15 units of platelets.
8. In April 1993 tests showed I was in complete remission from Leukaemia.
9. In May 1993 I was readmitted to UCH for the final regime of my treatment where I received a bone marrow transplant. During this time my records show I received 40 units of platelets and 4 units of blood.
10. In October 1993 I returned to L&D as an outpatient. Initially I attended each month for check ups to monitor my blood counts. After that I had check ups on an annual basis.
11. In early part of 2003, when I was 29 years old, I received a letter from L&D requesting me to make an appointment to see Dr GRO-D as something had been spotted in my blood test results. The letter also stated that I had missed several appointments but this was untrue.

ANONYMOUS

12. I attended the appointment where it is recorded in my records that I "was unfortunately unclear as to the reason for [my] attendance and when [Dr **GRO-D**] explained it was because my liver function tests were abnormal and that [I] had been found to be Hepatitis C (HCV) positive in September 2000, [I] appeared rather shocked".
13. I was indeed shocked and very angry. I questioned how this could be when blood is screened for HCV and I had been attending the regular check ups. I could not believe that I had HCV. The infection was not explained to me and the doctor's view was 'aren't you aware of this already'. He did not say when the hospital knew about the infection. He did not give me any information about it and there was no advice given regarding the risk of infection to others.
14. My records show that on 13 May 1993 my blood was tested and found to be HCV antibody negative. Further that the testing continued until around 19 March 1999 when a routine blood test showed raised liver enzyme, which indicated something was wrong. Also Dr Thompson, the Haematologist at L&D noticed my iron level was raised in my blood; however, he did not ask me back to inform me. My blood was again tested for HCV in or around 15 September 2000 when it was found to be HCV positive. But I was not told until the appointment referred to above, i.e. three years later in 2003.
15. It did not make sense that I was the only person after the 1991 screening started who became infected with HCV.
16. The constant thought that I have not been able to expel is that I could not be the only one to have contracted HCV from that particular batch of blood I was treated with and there must be many others in my position that were not picked up and have unfortunately not been told until severe liver damage has occurred. There must be other people in my position and I believe that the word has to be spread

to make sure that other people have not been infected as I have been beyond the 1991 screening window.

Section 3. Other Infections

17. I am not aware that I have any other infections.

Section 4. Consent

18. I do believe that I was tested for HCV without my knowledge. The hospital knew I had been infected with HCV and I was not told till several years later; they withheld information from me.

19. The tests were therefore undertaken without my consent and without me being given adequate information.

Section 5. Impact of the Infection

20. I was 29 years old when I was told I had HCV. I was working full time and I had only been at the company I was working for for five months. The owners were very controlling and I was unfairly dismissed after I told them I had contracted HCV, that I would soon be starting treatment and I might need time off. This really affected me mentally.

21. There was a lot of paranoia attached to HCV at the time, I became quite introverted. I was not taking anti-depressants but I was in a deep place and I probably would have benefited from them.

22. When I was told I had HCV, I felt physically fine and I had no symptoms. However, during the consultation with Dr GRO-D referred to above, he made it clear that I had signs of moderate liver damage and my liver function tests were

abnormal. He said that they showed early cirrhosis of my liver. Further he said that while I did not have symptoms I needed a liver biopsy. It was a very brief meeting, just to book me in for the liver biopsy really. All Dr [GRO-D] did was refer me to Dr Dusheiko, a Consultant Haematologist at the Royal Free Hospital (RFH). I had a liver biopsy very quickly after the referral as well as more blood tests and an ultrasound scan on my liver.

23. I was then seen by Dr Jacobs at RFH on 16 October 2003 who said that I was well with no sign of chronic liver disease. However, my liver showed moderate steatosis making me a candidate for anti viral treatment of Pegylated Interferon and Ribavirin. I was told I had the HCV genotype (3A) and the treatment period would be for 6 months not the longer 12 months. I was told of the potential side effects and what to expect so I do believe that I was given the full picture of what was going to happen prior to commencing. I started the treatment soon after.

24. During the appointments at the RFH, HCV was explained more, along with the risks of infecting others and other implications of the infection.

25. Around April 2004 I was transferred to the Institute of Hepatology at UCH (attached to the Middlesex Hospital) under Dr N Naoumov. I was reassured by Dr Naoumov that this regime of treatment could be quite effective against the chronic HCV (genotype 3A) that I was infected with.

26. The six month Interferon and Ribavirin treatment began on 2 August 2004 and was gruelling, really rough. I had to take daily tablets and I learnt to inject myself every month. As a result of the medication I lost my appetite, lost weight and had a period of fluctuating Thyroid function. After 4 months of treatment I became too ill and I was having severe palpitations. I therefore stopped the treatment on 30 December 2004 after four and half months.

ANONYMOUS

27. I went back to have blood tests to check my HCV status and about two weeks before I got married in around GRO-B 2005 I was told that the treatment had been successful and that I had cleared the infection. It was a huge relief.
28. Around the time of the BBC Panorama documentary (circa 2016-17) I requested my full medical records from L&D and it is clear there was a delay in the hospital finding out that I had HCV and then telling me. I do not know why this was but speculate that it was to try to allow the expiry of the limitation period to bring a claim to expire.
29. I was very paranoid starting the treatment. It was very strange to inject myself and it affected my wife and put a significant strain on our relationship. I was down on myself and I was not working so it was tough for us. My wife also reduced her full time working hours as a secondary school teacher to become part time so as to support me. So financially it was hard as well. By that stage we had brought a house and had a mortgage to pay, she had to support us financially but we managed to get by.
30. When I was told of the infection I was worried if I had infected my wife. We have been together since 1997 and we moved in together in 2001. My wife was not advised to be tested for HCV, but fortunately she was HCV negative when later tested in preparation for IVF treatment.
31. We both wanted to have children but my ability to have children naturally was severely reduced due to my cancer treatment so we therefore had to pursue the route of using IVF.
32. From early appointments it was made clear that the ability to receive IVF treatment would be restricted in terms of where we could receive it due to me being previously HCV positive, the only two clinics available for where GRO-B GRO-B and the Chelsea and Westminster Hospital. We eventually received a

successful referral to the Chelsea and Westminster Hospital and went for two of the three cycles of NHS funded IVF there. We were successful on our second IVF attempt GRO-B

33. If the IVF treatment had not worked we were considering that we might have to go abroad to access treatment.
34. The effect of my infection on my mother and father was huge as well. They saw me go through life threatening cancer and then have to battle with another life threatening illness; it must have been so hard for them. It was the same for my wife I did not know if she would decide to leave me, it really affected us all a lot.
35. As there was significant stigma attached to HCV at the time. I told my close group of friends and family about my infection but that was all. I played a lot of golf but I could not drink so socially I withdrew and distanced myself from these circles. I do not think my friends fully understood HCV and grasped what I had to go through.
36. The small IT company I was working for when I was told of my diagnosis in April 2003 was very strange and controlling. It was definitely the wrong company to be working for at the wrong time and as I stated above I was dismissed when I told them of the infection and that I needed time off for treatment.
37. I finished my treatment in December 2004 and in February 2005 I was well enough to start working full time again. However, the fear factor and paranoia was still present in that I was worried I would struggle to get another job, I thought I was unemployable, I had been out of full time work for around 14 months or more. I did not know what to say to explain why I had been out of work for so long during my interview.

38. I have not been able to get full life insurance; the premiums are too high and most providers will not provide cover (due to my medical past). But I have now received life cover through a US based provider though it is not full cover, but at least it is something.

39. My children do not know about my infection; to date they only know I have had to overcome Leukaemia.

Section 6. Treatment/care/support

40. The only obstacle I faced in obtaining treatment was when we were trying to obtain the IVF treatment.

41. I have never been offered any counselling and I feel this would have been helpful for me.

Section 7. Financial Assistance

42. I have not received any financial assistance from the Skipton Fund. My particular situation meant I was not eligible to apply as I do not meet the criteria as I was infected after 1991. I heard about the Fund from the Panorama programme two years ago. It also referred to the Infected Blood Inquiry alternatively I heard about the Fund on Twitter.

43. I have also been in contact with the England Infected Blood Support Scheme (EIBSS) but have again been refused financial assistance.

44. In around 2004 or 2005, with the help of my mother, I sought legal advice from a firm of solicitors in GRO-B with the view to bringing a claim of clinical negligence against L&D and the National Blood Authority, but it was not easy to pursue and I had to drop the claim due to the cost and the time involved.

45. In a letter dated 8 July 2005 from the legal advisor GRO-D representing the National Blood Authority it stated *"We understand from our client (National Blood Authority) that the transfusion history indicates a significant donor exposure. Unfortunately our client is **unable** to investigate all of these donations and such an investigation is, in any event, likely to produce a definite conclusion"*. My emphasis.

46. It is my view that there is a typographical error in the last sentence: the word *"likely"* should read *"unlikely"* as the letter goes on to state the following strong wording, *"We would like to explain why such an investigation would be **futile**....."*. My emphasis.

47. I also vividly remember being in a meeting with the solicitor when he stated the *"National Blood Authority are literally untouchable"*, which in essence is captured in the wording in the previous paragraph in the letter from their legal adviser..

Section 8. Other Issues

48. I would like to know if there is anyone else in my situation and was infected so late; post 1991/1992 screening.

49. Also, I want to know what happened and how it happened to me. Was it really just a freak accident and the blood donor just slipped through the net?

50. From the witness statements given thus far it is clear that this is now the case (referring to one of the statements given in the first week of the Inquiry) and as per this witness the Government **MUST** now look at the likelihood of people being given infected blood post 1991/2 screening.

Anonymity, disclosure and redaction

51. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

52. I do wish to be called to give oral evidence.

Statement of Truth

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

Signed...

GRO-B

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GRO-B

Dated: 29th May 2019