

Witness Name: GRO-B

Statement No: WITN2926001

Exhibits: WITN2926002- WITN2926003

Dated: February 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 or GRO-B
Bedfordshire, GRO-B . My date of birth is GRO-B 1945. I am married
and have been for 48 years, I have two sons, GRO-B: S and GRO-B and five
grandchildren.
2. I provide this statement in response to a request under Rule 9 of the Inquiry
Rules 2006.
3. I am preparing this statement without the benefit of access to my son's
medical records.

Section 2. How Affected

4. My son S, who was born on GRO-B 1974, was infected
with Hepatitis C by a blood transfusion during treatment for his Leukaemia.
When S was 18 years old and in his first year of A levels he began to
suffer from headaches and fatigue, so I rang the GP who came round to the

house and immediately arranged for [S] to go to Luton and Dunstable Hospital (LDH) that evening. He was diagnosed with Acute Lymphoblastic Leukaemia (ALL) on 8 December 1992, as his red blood count was only 4 when it should have been 12. He was then rushed to the University College Hospital (UCH), London and kept there in isolation for 9 months.

5. During his Leukaemia treatment, he was given chemotherapy and regular blood transfusions though a hickline. He was also sent to Middlesex Hospital for complete body radiation and out of all the young boys he was the only one that lived.
6. After [S] went into remission for Leukaemia in or around 1993 he went back to college. Every 6 months he went to hospital for blood sample testing to see if he was free of Leukaemia. Around this time on 13 May 1993 his blood was tested and found to be Hepatitis C antibody negative.
7. This testing went on and on, until one day, around 19 March 1999, routine blood test showed raised liver enzyme, which indicated something was wrong. Dr Thomson, the Haematologist at LDH noticed his iron level was up in his blood; however, he did not call [S] back to tell him.
8. [S]'s blood was tested for Hepatitis C again in or around 15 September 2000 when it was found to be Hepatitis C positive. However, it was not until around April 2003 that [S] was called to see [GRO-D] Consultant Physician. Both myself and [S]'s girlfriend also attended this appointment on 14 April 2003 with [S]. When we were told that [S] had Hepatitis C we were all very shocked as the three of us had no idea as we weren't told why we had the appointment. We were speechless; it was the most awful thing.
9. [GRO-D] made it clear to us that [S] had moderate liver damage and his liver function tests were abnormal. He said that [S] showed early cirrhosis of the liver. [GRO-D] did not say when they knew about his infection. He did not explain what Hepatitis C was and he did not give us any

information about it. There was no advice on risk of infection of others either and his girlfriend could have been infected.

10. During this meeting [GRO-D] said that while [S] did not have symptoms he needed a liver biopsy. It was a very brief meeting, just to book him in for the liver biopsy really. All [GRO-D] did was refer him to Dr Dusheiko, Consultant Haematologist at the Royal Free Hospital (RFH) and [S] had liver biopsy very quickly after his referral. We did not get any results but were just told to see Dr Dusheiko.
11. [S] was then seen by Dr Jacobs at RFH on 16 Oct 2003 who said that he was well with no sign of chronic liver disease. However, his liver showed moderate steatosis making him a candidate for anti viral treatment of Pegylated Interferon and Ribavirin. It was explained that he could have the treatment at the RFH or back at the Middlesex Hospital, which is attached to the UCH and he started treatment soon after. During appointments at the RFH Hepatitis C was explained more, along with the risks of infecting others and implications of disease.
12. Around April 2004 his case was transferred to the Institute of Hepatology UCH under Dr N Naoumov. We were reassured by Dr Naoumov that the treatment would be quite effective as he had chronic hepatitis C (genotype 3A).
13. The Interferon and Ribavirin treatment began on 2 August 2004 and was gruelling [S] had to inject himself every month and lost his appetite. The plan was to treat him with Pegylated Interferon and Ribavirin for a period of 6 months, but I think come Christmas 2004 he was so poorly that they took him off it early. I think he went back to have blood tests to check his Hepatitis C status and about 2 weeks before he got married in around August 2005 they told him that the treatment had worked. I attach a letter from Dr Naoumov dated 23 May 2005 summarising his treatment at Exhibit WITN2926002.

14. We tried to pursue a negligence claim against LDH. However, [S] could not even get legal aid for the solicitor. There was no help whatsoever so we had to drop the claim after I had spent about £1,500 in solicitor fees.

Section 3. Other Infections

15. I am not aware that [S] has contracted any other infections.

Section 4. Consent

16. I do not think that [S] was treated or tested without his consent.

17. I believe that he was told about the risks of the Leukaemia, but never anything to do with contaminated blood or Hepatitis C.

Section 5. Impact of the Infection

18. After [S] was told that he had contracted Hepatitis C around April 2003 he did not want to speak to anyone about it as he did not want people to know that he had it. His confidence and self esteem fell and he was unhappy. It was only when the recent Panorama programme came out in or around May 2017 that he spoke about it but otherwise has always been closed and quiet about it. I believe that the Panorama programme was good for him, as he realised that he was not alone.

19. The Interferon and Ribavirin treatment made him very angry and very bad tempered. He flew off the handle and was very hard to control. We got him a Jack Russell puppy, which was a rescue dog, to try to take his mind off things and I feel that the dog helped to keep him calm. He was affected mentally, shocked and it even affected his heart. He had a negative reaction as he felt so unclean and it was worse than the Leukaemia treatment. I remember at one point, a male nurse called me to ask if [S] wanted antidepressants. He had a horrendous reaction to the treatment. The treatment changed his personality and he had low self esteem up until a year ago.

20. Also his immune system very low after the Hepatitis C treatment. He developed a cyst on his spine through stress. He went to UCH and was told the removal operation was very dangerous.

21. [S] was working at the time in IT for a company called Genesis and so he told his bosses that he had to have treatment for his Hepatitis C, but as a result he was fired. He had no money coming in and a mortgage to pay. He did not even qualify for legal aid and this was no fair. [S] eventually got back in to work in or about 2005.

22. A couple of years ago, Nadine Dorris, our local MP, wrote to Health Secretary on our behalf and as a result in around 2016 we had an appointment with the Head of the Blood Transfusion Service in Hendon. She told us that we had to bring a case within 10 years of what happened, but we could not as LDH waited until after that before telling us. As [S]'s infection was outside the 10 years to bring a claim, we couldn't do anything. I remember that she also said that only one person had ever won compensation for something like this.

23. I do not believe that Hepatitis C affected any dental treatment [S] required.

24. When [S] had been diagnosed with Leukaemia I almost passed out when I heard, and had to have anti depressants at aged 48. Again, when I found out that [S] had Hepatitis C it had a huge impact on me. I felt dreadful, went downhill and again I went on anti depressants. It was a dreadful shock especially after he beat Leukaemia, and it affected me badly.

25. I told family and friends about the Hepatitis C. I did not suffer any stigma. I do not know about [S] and if he told his friends as he always kept everything to himself and went inwards. Just last year he has accepted it more and said there are people a lot worse off than him.

26. His diagnosis also affected his girlfriend and now wife [GRO-B] a lot. She was shocked and used to say that she could not handle the treatment and she was

almost was going to leave him. Up till last year [GRO-B] and [S] went to marriage counselling and it affected them a lot.

Section 6. Treatment/care/support

27. After they were married, [S] and [GRO-B] decided that they wanted kids and tried to go for IVF [GRO-B] but no one would help them due to his history with Hepatitis C. [GRO-B] had to go to the LDH first to be tested for Hepatitis C. They eventually got a referral to the Chelsea and Westminster Hospital who specialised in sperm washing and [GRO-B] went for two cycles of NHS funded IVF there. They were successful on their second IVF attempt and their twin girls were born about 10 years ago.

28. There has been no counselling or support for me or [S]. We have never been offered anything.

Section 7. Financial Assistance

29. [S] has not received a payment from the Skipton Fund as they told him that he was out of the timescale as he could only have been infected in 1992 or 1993. They kept telling us you had to have had it before September 1991 so we got nothing, although we tried many times. I attach copies of two letters from the Department of Health dated 2 April 2015 and 14 August 2015 at Exhibit WITN2926003.

30. We have also approached the England Infected Blood Support Scheme (EIBSS) but have again been refused.

Section 8. Other Issues

31. I feel lucky that I still have [S] but I feel dreadful as I believe that it could have been prevented. I asked why the batch of blood was not tested for Hepatitis C at the time. I believe that this was a dreadful blunder.

Anonymity

32. I wish to remain anonymous.

33. I do want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed...

GRO-B

Dated... 27th February 2019