

ANONYMOUS

Witness Name GRO-B

Statement No.: WITN2187001

Exhibits: none

Dated: 22th March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, GRO-B, will say as follows:

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1947. My address is known to the inquiry. I intend to speak about my son GRO-B: S and his contraction of hepatitis C. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our family.

Section 2. How Affected

2. I have four children, three boys and one girl. [S] is my youngest child. All my children are from my late wife [GRO-B]. We are a very close family. Despite [S] now living in London, we see each other regularly and speak on the phone frequently.

3. My son [S] was born on [GRO-B] 1986 at [GRO-B] [GRO-B]. In October 1986, when he was about [GRO-B] months old, he became very unsettled and was constantly crying. He was taken to [GRO-B] where he was seen by a [GRO-B] Mr [GRO-B]. He diagnosed [S] with osteomyelitis, which is a disease in the hipbone, and he was given antibiotics. He was referred to Raigmore hospital, Inverness. [S] was kept in Raigmore hospital for eight days. My wife was breastfeeding [S] at the time and therefore she stayed in the hospital with him. I remember my wife was very distressed at this time because the medical staff were constantly taking [S] away from her for blood tests. It was during this period that it was discovered that [S] had haemophilia. I cannot remember who the consultant was that gave this diagnosis.

4. [S] was diagnosed with severe haemophilia with less than 1% Factor VIII clotting agent in his blood. He was referred to [GRO-B] hospital in Glasgow.

5. Whenever [S] had a bleed or fall, he went to [GRO-B] Hospital, Glasgow and received Factor VIII blood products. He was under the care of Dr [GRO-B] and Dr [GRO-B].

6. Throughout [S]'s childhood, he was self-medicated at home with Factor VIII blood products. If he received a serious injury or bleed, he would be taken to [GRO-B] Hospital, Glasgow for Factor VIII blood products to be administered.

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7. My wife and I did not receive any information or advice about the risks of [S] being exposed to infection. I can remember Dr [GRO-B] saying that there was no risk of infection as the Factor VIII blood products had been heat treated.
8. [S] was infected with hepatitis C.
9. My wife took [S] to [GRO-B] hospital every three months for routine check-ups. At one of these check-ups when [S] was about 10 years of age, I remember my wife told me that Dr [GRO-B] had informed her that [S] had contracted hepatitis C. She told me that Dr [GRO-B] had said he had got it by being given infected blood products.
10. There was no information given to [GRO-B] about hepatitis C. [GRO-B] and I did not know what hepatitis C was. [GRO-B] and I had to find out ourselves what it was and what it meant for [S].
11. I believe that my wife and I should have been informed at the earliest opportunity that [S] had contracted hepatitis C and the implications of it.
12. My wife and I found out more about hepatitis C from other haemophiliacs who had been infected through the haemophilia society. We were informed that [S] was the youngest child in Scotland to have been infected with hepatitis C. When we were told this, at no time were we told the implications for [S]'s health. It was bad enough dealing with [S]'s haemophilia on a daily basis but to then discover through no fault of his own he had hepatitis C was very stressful.
13. When [GRO-B] was informed that [S] had hepatitis C, she was never told that hepatitis C could be passed on to others. I am certain of this

as we had three other children and she would have made every possible precaution.

Section 3. Other Infections

14. [S] did not receive any other infection or infections other than hepatitis C, as a result of being given infected blood products.

Section 4. Consent

15. I do believe that [S] was tested without his knowledge or consent. Every time [S] attended [GRO-B] Hospital, he had his bloods taken. [GRO-B] and I just thought it was routine. We did not ask what they were taking his blood for, you trust the medical staff to know what they are doing. I remember when [S] was about 10 years old, Dr [GRO-B] told [GRO-B] and I that [S]'s blood had been tested for Non-A and Non-B, she did not say hepatitis. We just assumed it was something to do with his haemophilia.

Section 5. Impact

16. No, [S] was just 10 years old when we were told he had hepatitis C. He did not have any mental or physical effects of being infected. We concentrated on living with his haemophilia on a daily basis. [S] was wrapped in cotton wool really to avoid him injuring himself.
17. [S] did not get any further complications or conditions resulting from the infection. [S] is still only 33 years of age so who knows, there may be future medical complications or conditions for him in the future.
18. [S] moved to London not long after his mother died in 2007/2008. As far as I am aware, he still has hepatitis C although he may have been offered further treatment. From the age of 17 years, [S]

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attended the haemophilia clinic at the Royal Infirmary, Glasgow every six months. He also had regular liver function tests and I do remember he had been told that his liver functions had stabilised even though he still had hepatitis C. This was not long before he moved to London. I do believe he has regular check-ups at a hospital in London.

19. When [S] was 10 or 11 years of age, he was offered treatment to try and destroy the hepatitis C. He was still in primary school at the time. This treatment was called interferon and he had to be injected with it three times a week. I remember we would collect him from the local primary school at lunchtime and bring him home. The district nurse would come to the house and inject him with the interferon.
20. [GRO-B] and I did not face any difficulties or obstacles in getting the treatment for [S]. The treatment was offered.
21. We were told at the time that interferon was the only treatment available for hepatitis C.
22. [S] had two lots of treatments of interferon lasting six months. It was a very stressful time for [GRO-B] and I. [S] hated getting the injections, it was a big long needle and [S] found it very painful. [S] dreaded the days when he knew he was to be injected. He got very down on these days. Physically, [S] did become quite fatigued. He complained of feeling nauseous throughout the treatment. This affected his appetite and he did lose weight.
23. [S] was a fit and healthy boy and teenager, apart from his haemophilia. His infected status did not impact upon any medical care as he did not need any. His infected status did not impact on his dental care. If [S] needed any dental treatment, we would always take him to the specialist dentist at the haemophilia Department at [GRO-B] hospital.

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24. As [S] was only 10 years old when we discovered he had hepatitis C, clearly he did not understand the implications of the infection. [S] and his girlfriend have recently bought a house together in London. When the mortgage company were told of [S]'s infected status, they refused him life insurance. This has had massive implications for him as he has recently had a young son. His name could not go on the mortgage so the house is solely in his girlfriend's name. I know he worries about his family's financial security should hepatitis C shorten his life.
25. Living with [S]'s haemophilia was very stressful. Neither [GRO-B] nor I knew what haemophilia was. We live [GRO-B] and there were only three other families affected by haemophilia on [GRO-B]. Discovering that [S] through no fault of his own, had been infected with hepatitis C from receiving infected blood products was devastating. I genuinely believe that this devastating news caused my wife such trauma that it triggered her cancer that ultimately took her life. [S] and [GRO-B] had a very special bond and I know she constantly worried about him.
26. We got to know there was a stigma attached to hepatitis C as it is associated with homosexuality and drug misuse. This clearly did not affect us as [S] did not come under these categories. He had been given infected blood as a baby and his infected status was discovered when he was 10 years old. We did however keep [S]'s infected status a private family concern. We did not tell anyone that he had hepatitis C as he was growing up.
27. There was no educational or work related effects to [S] from having hepatitis C that I am aware of. He did have to take a lot of time off school due to his haemophilia. At 17 years of age when he went to college in Glasgow, he did try various part-time work to see him

through his studies. He was not able to keep his part-time jobs due to his bleeds and constant time off work that was needed.

Section 6. Treatment/Care/Support

28. [S] was not offered any counselling or psychological support, my wife and I were never offered any counselling or psychological support to deal with [S]'s infected status.

Section 7. Financial Assistance

29. [S] was about 18 years of age and living as a student in Glasgow when he received financial assistance.
30. I know he received a lump sum from the Skipton fund. I do not know how much he received. I am not aware of any further financial assistance that [S] has received.
31. I do not know how [S] found out he was eligible for financial assistance. I can only assume it was from the Haemophilia Department at the Royal Infirmary at Glasgow.
32. I have no knowledge of the process [S] went through to receive his lump sum. I do not know if there were any preconditions imposed on the making of an application for financial assistance.
33. As stated earlier, I do not know how much financial assistance [S] received. I remember he told me he had bought a [GRO-B] with the money he received. I remember this clearly because I was concerned that he had wasted this money. I thought he should have saved it or invested for his future. In hindsight, his purchase was probably a good investment. [S] is now a [GRO-B] in London and travels all over the world [GRO-B].

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34. My only observations on the financial assistance that was available is that it does not cover [S]'s financial future security. He has been unable to get life insurance for his family in the event of a premature death due to his hepatitis C. He therefore could not get a mortgage.

Section 8. Other Issues

35. I do not wish to remain anonymous in this inquiry. I did give evidence in the Penrose Inquiry. I found this to be very stressful, it felt like a court case. The people infected and affected did not seem to be listened to.
36. I remember attending a meeting through the Haemophilia Society to discuss haemophiliacs contracting hepatitis C and HIV through receiving contaminated blood products. I remember Susan Deakin was at the meeting. She was the Minister for Health at the time. I remember she was asked why people had still been given Factor VIII blood products and blood transfusions when they knew the blood was contaminated. No answers were ever given to this question.

Statement of Truth

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

Signed

GRO-B

Dated

22-3-19