

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN3161001

Exhibits: None

Dated: October 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows: -

Section 1: Introduction

1. My name is GRO-B. My date of birth is GRO-B 1980 and my address is GRO-B. I am employed as a GRO-B and I am married, with GRO-B children.
2. I am making this statement to talk about my infection with Hepatitis C through being treated with contaminated blood.

Section 2: How Infected

3. I was diagnosed with severe haemophilia type A between the age of three and four months old. My father tells me that I had a limp leg, and that large bruises began to appear after minor knocks and bumps. People would look at my mother suspiciously when we were out of the house, because the bruises looked quite bad.

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4. One day I was taken to the hospital for tests because I was having difficulty breathing. I underwent various tests at GRO-B Hospital and tested positive for haemophilia. The reason for the breathing difficulty had been because I had a bleed in the tongue.
5. There was no history of haemophilia in my family as far as my father and I are aware. I was treated with the Factor VIII concentrate from the start in response to bleeds. I now take it prophylactically but when I was younger it was a responsive treatment plan that was undertaken in hospital, not at home.
6. I am told that six nurses would have to hold me down to administer the Factor VIII treatment to me. I expect it is very difficult to try and inject a wriggling child with anything. My father tells me that they were given no warning of risks or any information about the many varied types of Factor VIII concentrate that have been administered to me.
7. I am told I was about five years old when my treatment was moved from GRO-B Hospital.
8. I was moved onto a home treatment regime at around the age of six or seven years old. Treatment was administered by my mother until I was about eight or nine years old, at which point I began to inject myself.
9. The treatment regime was fine; it was a part of my life. I knew no different as a child. The home treatment regime made dealing with haemophilia much more convenient and gave me a sense of personal responsibility because I had to inject myself when I could feel a bleed coming on, or if I had hurt myself.
10. I had a false diagnosis of HIV when I was eight years old. The medical profession learnt that Factor VIII was tainted with HIV and a number of children had tested as HIV positive. They learnt that heat-treating the product killed the virus. As such, we had high confidence in the heat-treated product and this

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assuaged any fear of contamination. From there on, it was the NHS treatment plan to test me every six months for HIV.

11. When I was diagnosed with HIV, I was told by my parents that at the time, it was considered a death sentence. It was a diagnosis surrounded by fear and terror. My parents spoke to a consultant and they were surprised because heat-treated Factor VIII was now the norm, meaning I should not have contracted the infection. As such, the tests were repeated. It took three weeks for the retest results to come back. I have a lot of respect for the NHS, and I do not think there was any ill-intent, but making my parents wait three weeks for those test results must have been torture. My father refers to it as one of the worst periods of his life. We have always believed that the NHS are insensitive in the way that they provide feedback of results in cases like this.
12. The retest recognised a negative result, and so I was tested again six months later. This confirmed a negative result for HIV.
13. When I was around ten years old, I began prophylactic treatment for my haemophilia. There was a big change in my life when this happened. I was encouraged to adopt this treatment approach by the doctors at GRO-B GRO-C who described the many benefits that prophylactic treatment would have. It was the obvious next step in my treatment as it would prevent bleeds and by doing so, save joint damage. I was encouraged through their logic and no-one advised me or my family about any negatives of being treated this way.
14. My treatment for haemophilia moved back to GRO-B in 1992. I was diagnosed with Hepatitis C, when I was aged 15 years old, at around the same time as a number of other haemophiliacs I knew. I remember little else about this. I think there was a lack of understanding of what the long-term prognosis for this infection was. Incrementally, the NHS became more knowledgeable about this infection and so did we.

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15. I knew that there was a risk of transmission of Hepatitis C. I think my mother got it from me at one point, through a prick from an injection needle of mine, but had no treatment of this. In terms of sexual transmission of the infection, I was not sexually active at the age of [GRO-B] years old so it was not a significant conversation.
16. My concerns about the Hepatitis C infection changed between the ages of [GRO-B] [GRO-B] This is probably because I was becoming sexually active and began to feel that no-one would choose to be with someone that had Hepatitis C. I used to think that I would never get married or have children. I felt dirty, a victim of social stigma, and I felt embarrassed. This is a lot to deal with mentally. Haemophilia, by comparison, was a lot easier to deal with.
17. My mother died when I was aged 19 years old, after a short battle with pancreatic cancer. It was no surprise that this did not help my overall mental health.
18. During University I was treated by [GRO-B] and before University my main hospital was [GRO-B]. I recall that one of the doctors that I was in constant dialogue with there, repeatedly mentioned the risk of liver cirrhosis. This was always the warning behind the Hepatitis C infection, however it was only ever part of the loose and broad discussion about the infection. I was never really given a lot of detail about the risks and potential progression of the infection.

Treatment for Hepatitis C

19. I had heard about treatment options in recent years and the chances of successfully clearing the virus began looking a lot higher. In particular, my doctor spoke to me about treatment that had an 85% chance of success. At the time I was at my lowest ebb and desperate to have a family, and so I would have tried anything. I had previously spoken with doctors about treatment but it had less chance of success and I was not as desperate.

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20. The treatment that I was told of was Interferon. It was described as a mild form of chemotherapy with a cytotoxic drug. I was warned that the symptoms could be severe and could include hair loss and other terrible things, but the probability of these was low.
21. I knew that the first month of treatment with Interferon would be rough. I was told that I would need to "check out" of my life for a month. I knew I would have to lead a very healthy lifestyle. I was warned that I should not drink during the treatment period, and that this might have an impact on my social life however this was not a significant deterrent to me.
22. I had two liver biopsies. One of these was when I was 15 years old just after I had been diagnosed with Hepatitis C. The second was later on, when I was 23 years old. Both of these came back with positive results, showing little deterioration in my liver health. They did not feel significant, rather, they were routine procedures. Personally, I was reassured by the results of both.
23. I was told that I was a fit and healthy young person and so the treatment should work very well for me. I would not say I was pushed into taking this treatment, the decision was left to me, however it was positioned as a very positive option. My treatment began with "selected Interferon". I recall that not everyone had the opportunity to take this treatment, but it had been presented to me. There may have been other options but I felt like I was fortunate to get this one. That is certainly how it was presented to me by doctors.
24. I started the treatment when I was around 24 years old and living in GRO-B. I decided to move back to live with my father and step-mother. I had been warned the treatment would be a rough ride, and felt that I would fare better at home. Moving home was strange and must have looked like an odd decision because I had not told anyone about the treatment that I was going to have. This still felt like the right thing to do though.

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25. The first month of treatment was actually better than I had expected it would be. I did expect flu-like symptoms and did suffer these, however it was not so bad. This got progressively worse. I started to become very anxious. I do not know what depression is but I think that during that year I was very close to suffering it. I had isolated myself from any social structures outside of my immediate family and my interactions were pretty much limited to my father and step-mother. I felt, at the time, I had lost all of my friends. I thought I had lost my support structure and did not feel I could tell anyone about what I was going through. I was living in an isolated bubble.
26. My friends would try to see me and call me but I would always find excuses not to see or speak to them. This is not something I had ever done before and it made me very uncomfortable.
27. I took a month off work. I had been working in GRO-B at the time and after coming home for the treatment for a year, I then went back to GRO-B had told my boss that I was having this treatment and I think I told him it was related to the haemophilia. He was supportive of me having the time off.
28. After the initial month of treatment, I went back to GRO-B for about three months to work. I was not drinking and going out and I was very bored. I suddenly became quite ill, suffering extreme vomiting for about a week. I went back to the UK and felt like I had recovered so then returned to GRO-B after a few days. The same thing happened again but it got worse.
29. I recall going back to my hotel room one night, calling an ambulance and then passing out. I was diagnosed with a burst appendix. I do not know if this was because of the Interferon treatment. I lost a couple of stone in weight and had to undergo a lot of tests before they diagnosed the burst appendix. I recall that they initially thought it was related to my haemophilia. I spent three weeks in a GRO-B hospital and was flown back home.

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30. My only thought at the time, despite the symptoms, was wondering whether my Hepatitis C treatment would still work. I was worried that I had done something to hamper my chances. I recovered back at the family home and finished the remaining 6 months of Interferon treatment while off work. So I took the majority of the year off work. I then had a three month wait for test results and sadly they showed that I had Hepatitis C. The treatment hadn't worked.
31. My worst anxieties and fears were amplified after these tests. I felt that all of my friends around me were building relationships and their careers whilst I was ill and at home with my father. I was distraught, I felt battered and my future felt unsure. One year of compromise in my life, and focusing on the hepatitis and treatment increased the significance of Hepatitis even more more for me. I was in a really bad way.
32. I carried on working after the treatment finished. My employer was very supportive, but I took to work slowly. There was a loss of momentum in my career but the company were good to me.
33. When the treatment failed I had two options. The first was to repeat it, or alternatively, I could carry on as I was and wait for better options. The monitoring of my blood test results and liver function tests continued. My father and I discussed repeating the Interferon treatment but I did not think I could deal with it again.
34. A few years later, I met and married my now wife. I have spoken in more detail about the impact of my infection on our relationship below. I had a routine Hepatitis C test just before going away on our honeymoon. The doctor told me that even though it was "very strange", he could see no trace of Hepatitis C in my blood. I just thought it was another misdiagnosis. A re-test took place and the results came back either just before or just after my honeymoon (my wife and I think differently!) were confirmed. The Hepatitis C had been cleared. I could not understand it. I was elated and very confused, and I wasn't sure if

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the infection was dormant and coming back. The timing however was unbelievable. That was the end of the infection and I have been clear of Hepatitis C ever since.

35. I did ask if it was a deferred response to the treatment, but I was told this was unlikely, because Interferon kills the virus and the virus had been alive in my body and picked up in later tests. I've chosen to believe it as a miracle.
36. Before the virus cleared, my wife and I did talk about having children. We knew that there would be problems however we both wanted children and so we were okay with it being problematic. We carried on as we had planned and my health is now good. My children do not have the infection and there are no known ongoing effects from my treatment.
37. I do not know what Hepatitis C symptoms I had. It was too long ago for me to remember. My mother used to say she could tell that I was extremely fatigued and always tired, but there is nothing that I can pinpoint.
38. I have a lot of blood tests because of my haemophilia treatment and so some form of monitoring does continue. I trust the doctors and do not think about the recurrence of the infection or return of it. My six monthly reviews continue.

Section 3: Other Infections

39. When I was aged around 19 years old I received a letter about the potential risk of vCJD. The scare stories in the press were all going on whilst I was at University as well. I recall having a conversation with doctors at Bedfordshire Hospital, and I was asked if I wanted to know if my batch could have been contaminated. I recall thinking that if it was bad news was there anything I could do about it? Was there any value in having such knowledge? The answer was no, so I asked them not to send the letter and that I did not want to know. The vCJD was insignificant to me at the time and it did not weigh on me.

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However, it did impact on me in the sense that it was something else that I could not talk to anyone about.

40. I have not had any other infections besides Hepatitis C as a result of being treated with contaminated blood.

Section 4: Consent

41. Each time I was tested my parents knew the reason for this. The test was a response to knowing that the blood was tainted however, I did not know what was going on.
42. I do not think I was ever tested or treated without my consent. As I have said, we trust doctors in our family, and so would not have questioned what they were doing.

Section 5: Impact

43. My reaction to the diagnosis of Hepatitis C was that it was just another thing. I chose not to dwell on it too much and I wonder now if that was perhaps the ignorance of my youth. I cannot say it impacted significantly on me at that time.
44. This is also how I dealt with my haemophilia. I did not want to spend my life thinking about it and only considered it to the extent where it may impact on any healthcare decisions. I knew very little about both Hepatitis C and haemophilia, and so whilst the diagnosis unsettled me, I did not take on the magnitude of it at the time. The ambiguity around the infection and lack of information meant that I did not pin any emotions to it. This was the same when I had the vCJD scare in university, which I discuss later below.
45. To know what impact Hepatitis C has had on my life is sometimes difficult. The impact has been more than I would have thought it would have been but it is difficult to quantify.

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46. In my professional life, following my return to work (after ~ 1 year off) after the failed Interferon treatment, I was quite demotivated. I love my job and my work and I am very happy now, but I lost a lot of steam from the age of 23 to 26 years old because of the Interferon treatment. The hardest thing was to get back up to speed post-treatment and I do not think I ever got all of my momentum back.

Stigma

47. In terms of stigma from friends, I do recall that my [GRO-B] said something like *"you are a danger to us because of your blood so you should wear gloves all the time"*. I understood what [GRO-B] meant and so I was fine with it. It came from a lack of understanding from the people around me.
48. The stigma and embarrassment around having a Hepatitis C infection, and the impact that this might have on a family life really bothered me. This was all I had ever wanted.
49. A long-term relationship I had been in in the [GRO-B] ended as a result of me telling my then partner about my Hepatitis C infection. We had been together for about 18 months. I was [GRO-B] years old and had latched on to what the doctors told me about the infection being transmitted by blood alone, probably because this is what I wanted to hear. I had conversations about the Hepatitis C with my girlfriend at the time [GRO-B]
[GRO-B]
[GRO-B].
50. I did not tell any of my friends and people did not know about what Hepatitis C was so it did not come up in conversation. Haemophilia was a tangible thing. I had symptoms and took injections to manage it so people knew about it. Conversely, only select people knew about the Hepatitis C, probably because we did not know a lot ourselves. My parents shared it with our close family and their best friends and families knew. We did not face any stigma from them.

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51. After reaching the age of 23 years old and having broken up with my girlfriend as a result of disclosing my Hepatitis C infection, this triggered a lot of thoughts and issues that I had been worrying about for years. By comparison, haemophilia is about "the now", impacting me day to day. It was a way of life that I knew how to deal with. Hepatitis C on the other hand was about "the future". There was a lack of knowledge around the infection and that unknown element was very worrying.
52. I spent a lot of my life between the ages of 15 and 23 years old feeling trapped in the knowledge that there was something very significant about me that I was not allowed to discuss with anyone.
53. It was soon after this that I went to GRO-B with friends and met a local girl from GRO-B. In perhaps the second conversation we had, she told me GRO-B. GRO-B I felt a massive relief and blurted out that I had Hepatitis C, almost as if I was saying that we both had issues we had to think about. To say it out loud was great. It was like it was a trade of information that was real. The relationship was never going to last but it was wonderful to have that freedom, an opportunity to make a declaration. It did me a power of good even when the relationship broke up about four months later.
54. I met my now wife when I was 27 years old. She used to volunteer at a GRO-B children's charity. I met her through a school friend and told her about my infection quite early on. I was too emotional to be able to stand withholding it, and this outweighed the fear of facing more stigma because of the infection.
55. I said to my now wife that I needed her to know about the Hepatitis C. She said that she would reflect on it and come back to me. I had only known her two or three weeks at the time. She said she had thought about it and then said we should carry on and see how it goes. I remember her saying that she chooses

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a person not their circumstances. She was not afraid of HIV, and Hepatitis C was considered far more manageable than that.

56. I do recall having a horrific argument with [GRO-B] in the first month of knowing her. [GRO-B] challenged me about Hepatitis C and was understandably terrified for [GRO-B]. [GRO-B] was angry and aggressive and did not want this infection in [GRO-B]. I told [GRO-B] that I had been open and that it was [GRO-B] decision. This went on for at least a couple of months. [GRO-B] [GRO-B] conclusion was that "*it is what it is*". There was no apology or retraction of the things [GRO-B] had said and it was just left as if it was [GRO-B] [GRO-B] decision to deal with something like this. The relationship continued well and we eventually got engaged. We married when I was 30 years old.

Impact on my relationships

57. As I have said above, I was diagnosed with Hepatitis C at the age of 15 years old and I did not really discuss sexual transmission of the infection with the doctors at the time. As I got older, my conversations with medical professionals changed. The advice became to avoid disclosing this infection to potential partners. This was the hardest thing to deal with from my perspective.
58. I really struggled at University. I had become sexually active and I was very cautious, but I was always in a dilemma about when it was the right time to tell a partner that I had Hepatitis C. I remember wrestling with this for a long time. I wanted to be open and honest but I did not want to talk about the infection either. I explained this to one of the doctors at the hospital who was involved in my treatment. His advice was that the infection was not sexually transmitted, rather it was transmitted by blood and so I could confidently hide this infection from any sexual partner. This was a massive relief, but it still felt like it was unspecific and inconsistent advice with what I was hearing around me.
59. As I have described above, I faced stigma in different forms in a number of relationships in my life, but eventually, I was lucky that this did not stop me from marrying my wife.

60. I feel incredibly blessed that the infection has gone, I have an amazing family, and a great life. I feel obligated to help others in a dark period because I had needed such help from my teenage years upwards and did not recognise it.
61. As I have said above, my mother died of pancreatic cancer about three years after I was diagnosed with Hepatitis C. We have always assumed that this was not related to the infection she caught from me, which cleared quickly. It still bothers me that I did not have my mother with me to chat it through with however my father did the best he could.

Section 6: Treatment/Care/Support

62. In terms of general medical and dental treatment, Hepatitis C was a complicating factor, but so was haemophilia, because of the significant amount of blood involved. I do not remember being refused treatment at any point.
63. I do not believe I was offered any psychological support at any point either before or after my diagnosis with the infection, or before or after the treatment for it. I am not someone to have asked for it in truth.
64. I struggled to have an open dialogue about the mental effects of the infection and the treatment with my father. I cannot say with certainty that I would have accepted counselling had I been offered it although, in hindsight, it probably would have helped.

Section 7: Financial Assistance

65. I was given a one-off ex-gratia payment from the Skipton Fund in the amount of £20,000 when I was 23 years old. I found out that I was eligible for the Skipton Fund from a doctor I think. I applied for it and do not remember the application process being complicated. I was living in GRO-B at the time

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and it would have been GRO-B that gave me the information. I was treated by them from the age of 22 onwards.

66. I subsequently applied for and received EIBSS payments. The monthly EIBSS payments have been extended recently. All I can remember is that I was sent a letter saying that I was eligible for these payments because of a payment that had been made to me by the Skipton Fund. I have not received any other financial payments in relation to my infection.
67. I recall that I had to sign something to obtain the Skipton Fund payment. I did not really understand it properly at the time but recall it being about avoiding the implication of guilt. I did not think much of it at the time.

Section 8: Other Information

68. I feel like this Inquiry is more for others in terms of emotional closure. Many people want closure and some want to blame or for someone to be held accountable for what they have suffered. I had never felt that I needed this either in the past or now. I think mistakes were certainly made and there were serious consequences for many, including me. This is not to say that I think nothing should be done by this Inquiry in response to everything they hear. It may well be that accountability and apologies are needed, and compensation should be given, however the need to "square things" is for others, not for me.

Statement of Truth

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

Signed:

GRO-B

Dated:

23/1/21