

ANONYMOUS

Witness Name GRO-B

Statement No: WITN1556001

Exhibits: 0

Dated: 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 I was born on GRO-B and I live at GRO-B
2. I am going through a divorce. I am currently working.
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. I was diagnosed with mild Haemophilia A very early in my life. My brothers were Haemophiliacs and so the doctors kept an eye on me when I born.
5. I believe I started receiving Factor VIII (FVIII) concentrates in the early 1980s/mid 1980s. I only required FVIII as and when I required it. However, every time I would attend the hospital for a minor injury I was always given

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FVIII even though I did not require it. The doctors would tell me that because I travelled to the hospital they would give me FVIII just in case.

6. I have always been treated at GRO-B I do not recall the treating doctors' names.
7. I believe I was infected in the early 1980s. I believe that GRO-B was the batch numbers and dates of when I may have been infected.
8. My parents were in charge of my medical care and I know they were never told beforehand about the risk of being exposed to infection from FVIII concentrates. My parents were always told that FVIII was safe and heat treated and this was always reiterated to us. My brother was infected with Hepatitis C (Hep C) and HIV and even then my mother was reassured that the FVIII that I was receiving was safe.
9. As a result of being treated with FVIII concentrates, I was infected with Hep C.
10. I used to have annual reviews and blood tests in relation to my haemophilia. In or about GRO-B when I was GRO-B old, my parents received a letter from the hospital stating that I had potentially been exposed to Hep C and we were required to attend the hospital. I believe this was picked up during one of the annual reviews. When an appointment was booked, I initially thought I was going to be given information about it at the hospital or I was going to be tested for it. However, when I attended the hospital I was just told that I had Hep C.
11. When I was attending the hospital for regular check-ups I was told at one appointment that I had spontaneously cleared the Hep C. However, I have also been told that with the current testing methods the infection is below the level of detectability and they can't guarantee that it won't come back.
12. I cannot remember what information was given to me when I was told I had Hep C, but I believe it was played down and I was not told everything.

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13. I was not given adequate information to help me understand and manage the infection and neither were my parents.
14. I believe that information should have been provided to me earlier when the doctors found out that I had contracted Hep C.
15. The way the hospital communicated the infection to us was terrible. We were already living with the fact that my brother had HIV and to then receive a letter stating that I had been in contact with Hep C was awful.
16. I do not know whether we were given any information about the risks of others being infected as a result of the Hep C.

### **Section 3. Other Infections**

17. I do not know whether I was infected with anything else. However, in or about the late GRO-B shortly after receiving the letter about the Hep C, we received another letter stating that there was a possibility that I was exposed to vCJD. I did not have any follow-up appointments after that.

### **Section 4. Consent**

18. I believe I was treated and tested without my knowledge, consent and without being given adequate or full information.
19. I believe I was tested for the purposes of research. When I look back at some of the conversations now, I believe 100% that the doctors were taking blood tests annually to check if I was infected rather than monitoring my haemophilia. I believe the doctors knew that there was a high risk in the blood imported from America which I believe was the reason they were doing annual reviews. The fact that the hospital placed so much importance and pressure for the patients with haemophilia to come for the blood tests now adds up.

**Section 5. Impact of the Infection**

20. I suffered mentally as a result of the Hep C. I suffered with symptoms related to depression which has affected my day-to-day living. I always worry about a possible relapse of Hep C as my brother suffered and died as a result of it. This has also had an impact on my mental health.
21. My symptoms of fatigue and mental health problems are attributable to the Hep C. My brother had Hep C and HIV and then to be told I had Hep C too was a huge bombshell. I could not even quantify what had happened to my brother as it was. I was given antidepressants to cope with what happened as I was depressed following what happened to him as well as my diagnosis. The effects of depression have continued ever since. I often feel very low, unmotivated, discontent and thoroughly disillusioned. I regularly struggle with day-to-day life. I often lay awake at night thinking about the destruction that has ripped through my family and how helpless I was as the events unfolded. When things get too much for me to cope with, I drive out into a country lane, park up and cry because of what happened to me. I am not in a position to share these feelings with my ex-partner and definitely do not want my children seeing me in this state. I have and still feel that I am walking around with a disease that continues to affect me, albeit not physically at the moment, but a living mental hell of painful memories and constant anxiety that my future with my family is uncertain.
22. I have struggled to explain how the infection has affected me mentally. The effects are not something that fit into a specific category; the effects of having been in contact with Hep C have caused me emotional stress that is not easily explained. I have felt embarrassed, dirty, disgusting and mentally unstable at times unable to connect emotionally or even maintain a normal social life, the pain I have felt and continue to experience has left me an emotional wreck inside that I cannot properly describe it. I honestly don't know if anything could ease this constant suffering. There is not a day that goes by that I can escape the devastation that Hep C has and continues to have on my life. No amount



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of words can describe how Hep C has affected me. I have often felt like giving up altogether.

23. I also suffered physical effects as a result of the Hep C. I remember being very tired and lacking energy. I lost my hair at GRO-B but I do not know whether this was as a result of the Hep C. The whites of my eyes had gone yellow and I had slight jaundice.

24. I did not receive treatment for the Hep C as the doctors told me that I spontaneously cleared it. I am still being tested regularly for it.

25. The Hep C has had a massive impact on my private, family and social life. My brother being diagnosed with HIV initially and subsequently both my brother and I being diagnosed with Hep C was devastating for the whole family. I was married at the age of GRO-B and I believe that my marriage subsequently failed when I had to disclose that I had Hep C. At that time, in or about GRO-B my children were quite young and my wife left me and the children. My wife passed away in GRO-B following an epileptic fit and possible heart attack.

26. Approximately GRO-B years ago, when I was in my second relationship, my then wife became pregnant. I told her about the Hep C, which she took very badly. My ex-wife still blames me for not disclosing the Hep C to her earlier and she is very protective of the children as a result. She insisted that I did not undertake basic daily activities such as changing the nappies. She does not allow me to place plasters on their knees if they have a fall and suffer a graze. She used to look for cuts on my hands when I return from work.

27. At school, I felt stigmatised and I was told not to speak about the infection or the haemophilia or disclose it to anyone. However, my school was informed of my brother's diagnosis and subsequently there were lots of rumours that spread at school about me. 'AIDS' at that time was a known consequence of HIV and also it was portrayed as a 'Gay Disease'. Somehow the school found out that I was infected. I always lived under the constant stigma and shame of having Hep C as well as my brother having Hep C and HIV. When we went on

school trips, everyone was made aware of my infection which had a huge psychological effect on me.

28. I believe the social stigma that I continue to endure has been a direct result of the leaflets being distributed to homes throughout the UK, and the 1980s television AIDS campaigns. Warnings were broadcast showing gravestones falling with 'AIDS' written on them. This caused widespread panic and social unacceptance of Hep C. This left people like my brother and I carrying this infection feeling alienated and isolated.

29. I lost a lot of time at school due to both the haemophilia and the Hep C. At GRO-B following diagnosis, I left school and therefore did not get any exams. Had I not been infected, I would have carried on with school and pushed through my exams.

30. As a result of the infection, I also suffered work-related effects. I was always tired and as a result I lost my job.

31. I have always wanted to be in the police force but I would have had to disclose that I had Hep C, which put me off from applying. Had it not been for the infection, I believe that I would have been in a completely different situation now.

32. As previously mentioned, there was a traumatic impact on both my ex-wives'. They wanted answers that I couldn't give. I had to explain that I spontaneously cleared the Hep C but that the doctors said it's below detectability levels and unable to guarantee it wouldn't come back.

#### **Section 6. Treatment/care/support**

33. I was not offered any counselling or psychological support as a result of what happened. The initial advice they gave my mother about my brother was not to tell anyone. We tried to keep the infections a secret within the family.

**Section 7. Financial Assistance**

34. The Skipton Fund set up a new payment scheme which I applied for. My application was rejected. They stated that there was no evidence in relation to my Hep C even though the doctors confirmed that the infection did have a substantial and long term adverse affect on me. I then went to a psychiatrist who wrote a report which supported that the infection did have an adverse effect on me.
35. I applied for the Special Category Mechanism (SCM) payments on 1 March 2018 and my application was refused.
36. On the 13 March 2018 I contacted the EIBSS to find out why my application was refused and they said that the evidence that I provided indicated that the mental health issues that I suffered may have been caused by another life event.
37. On 27 April 2018, I asked the GRO-B for a supporting letter to appeal against the EIBSS' decision. GRO-B wrote me a letter in support for my application for reconsideration of the original application.
38. On 4 May 2018, I wrote to the EIBSS appealing. I was still turned down regardless of the psychiatric report I got supporting that the Hep C did have an effect on me.
39. I only receive £4,000 a year and I was informed that the payment was for being infected but that I do not qualify for the long term effects payments.
40. I received a Stage 1 payment in the sum of £20,000 from the Skipton Fund which qualified me to apply for the £4,000 annual payment.
41. I also received financial assistance with double glazing as I was raising my children on my own. I do not remember when this was but I believe it was a few years ago.

Anonymity, disclosure and redaction

42. I wish to remain anonymous.

43. I do not wish to give oral evidence at the inquiry.

**Statement of Truth**

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

Signed

GRO-B

Dated 13-05-2019