

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
GRO-B
GRO-B I am retired.

2. I was infected with Hepatitis C having received contaminated blood products.
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. In 1952, I was seen to at the GRO-B after I fell and split my lip. As the bleeding appeared to be continuous, tests were undertaken and I was diagnosed with severe haemophilia A.
5. My uncle suffered from haemophilia so my diagnosis came as no surprise to my family.
6. There was no on-the-go treatment at the time, so the main advice was to rest. The first treatment made available was fresh frozen plasma before I was later introduced to cryoprecipitate.
7. At the age of 14, my care was transferred to the GRO-B where I was under the care of consultant GRO-B. When I moved to Penicuik, I was treated at the GRO-B.

ANONYMOUS

8. I was first given Factor VIII concentrate in 1977 but was given no advice or information about the product. Initially I was made to go to the hospital for treatment, before I asked if I could self-administer treatment at home. I would continue to attend regular clinic appointments when required.
9. In June 1993, I received a letter requiring me to attend the liver clinic at the hospital. I had assumed the session would have just been for a routine check-up. When I arrived at the GRO-B that I had been infected with Hepatitis C.
10. They didn't tell me much about the infection or how it was going to affect me. When I asked what the outcome would be, they said they would first have to assess the scarring on my liver. They kept telling me not to worry, as it was not as bad as it sounded. I believed what they were telling me because up until then, I had always trusted doctors.
11. They told me I would need to go for an endoscopy, a liver biopsy and further tests the following week. I felt the consultation was very matter of fact and almost heartless. It only lasted a total of 15 minutes.
12. I was absolutely stunned when they told me. When I went to leave the room, I tripped over a chair because I was so shocked. It then became clear to me that many haemophiliacs had been called in and it was almost like I was one person on a long conveyor belt of patients called in to be given the news.
13. No advice was ever given to me regarding the potential routes of transmission. I remember being asked if I drank at the time. When I told them I probably drank about three pints over the week they said that should be fine and didn't advise me to drink any less.
14. When I went for tests and my biopsy the following week, I was told that I had been infected through contaminated blood products but I was not told which batch or when I was infected. I do not understand why it took so long to inform me of my diagnosis.
15. A medical report from 1996 confirms I was infected due to my treatment as a haemophiliac, as per exhibit (WITN1841002).

Section 3. Other Infection

16. I do not believe I contracted any other infection apart from Hepatitis C as a result of receiving contaminated blood products.
17. I was tested for HIV around 1992 but fortunately I was negative. This was extremely worrying at the time. I remember being asked if I wanted to be tested, to which I said of course I did. I had to wait 4-5 weeks for my HIV results which was an extremely nervous period of time for me.
18. I received a letter in the early 2000s telling me that it was unlikely but I may have been exposed to vCJD.

ANONYMOUS

Section 4. Consent

19. I had no idea that I had been tested for Hepatitis C until they told me about my diagnosis.
20. The Haemophilia Unit would always be taking blood from me but I had no idea they were testing me for such viruses.

Section 5. Impact

21. I had been feeling generally unwell for quite a while prior to my diagnosis. I felt like I had a permanent cold and always had flu-like symptoms. I visited my doctor who told me my immune system must be low and eventually put me on iron tablets as they thought I may just be anaemic. I was also told to eat healthily, but when nothing worked I just started to put up with it.
22. Around six months after my diagnosis in June 1993, I was put on the Interferon treatment plan in an attempt to clear the virus. Injecting the treatment into my stomach was painful and whilst on the treatment I suffered from horrendous side effects. These included night sweats and fevers, weight loss, hair loss, concentration issues and extreme fatigue.
23. I was not told anything about the treatment and I was told nothing about potential side effects, other than the fact that I might suffer from slight rigors. They didn't even tell me the drugs were actually used to treat blood cancer.
24. The initial plan was to keep me on the treatment for 12 months, but a few months into the treatment the doctors said it wasn't working as effectively. I then began a combination course of Interferon and Ribavirin. This 12 month treatment was like going through chemotherapy; I could sleep for 48 hours at a time and I would simply lose days.
25. My treatment was initially delayed as they were worried about the costs and were waiting to see if anyone needed the treatment more urgently than I did. I found it farcical that they needed to apply for permission for me to be given the drug to cure the virus that they infected me with in the first place.
26. When I was on the combination treatment I was told that the virus had cleared. However, I was not told that the virus had not and could not be cured. I was under the impression that the virus was gone and would never return. It wasn't until I went back to speak to my consultant in 2003, when he clarified this crucial difference.
27. They would only take my blood at 6 monthly check-ups but I was quite annoyed that it was done so intermittently because I felt like it should be more regular.
28. At this time I was working for a haulage company as a transport manager, which I had started around 1986. One night I was working whilst undergoing treatment. I completed a long drive and when I returned home, I couldn't even remember the journey. It was at this point I knew I had to stop working for my safety and the safety of others.

ANONYMOUS

29. Living with haemophilia can be hard. You have bad times and you have good times. Growing up my parents instilled a good working spirit in me. They always encouraged me to live a normal, active life and not to feel sorry for myself.
30. However when the news broke about my Hepatitis C my whole personality changed. I was angry with everyone and everything. I can admit now that I turned into a nightmare to live with. Looking back I believe I was suffering from bad depression.
31. I got married in [GRO-B] and my wife stuck with me throughout the problems with my haemophilia. However, we separated about a year and a half after my diagnosis of Hepatitis C. When I told my wife about my infection she really struggled to cope and when I started my treatment with Interferon I became quite erratic and would fly off the handle at her. It really took its toll on our marriage.
32. When my wife left she took our daughters with her. Fortunately I still have a relationship with my eldest daughter [GRO-B] but I haven't seen my youngest daughter [GRO-B] since we split up. My wife said she would tell my daughters about my infection, but she never did.
33. I didn't tell anyone about my illness as I had seen what had happened with the stigma around HIV. However, my wife told a few of her friends about my illness, and as such some of my friends also found out. I had friends refuse to shake my hand when they found out about my infection and I lost contact with them. Before this I had a good group of friends and was very sociable, but after people found out if I ever called up anyone to go for a drink, they would always be busy.
34. I remember on one occasion when I was at the [GRO-B] one of the doctors was going through my ALT results and he said 'I assume you are a heavy drinker'. I said 'no, that will be the Hepatitis C.' He was very confused by this and he obviously didn't really know much about the virus which wasn't at all reassuring.
35. When I left school I worked for a shipping company. I worked there for about 10 years until I was made redundant. I then went into insurance sales which I hated, and then I worked for a newspaper chain where I was an area manager. I always wanted to be a police officer but I couldn't with my haemophilia.
36. It wasn't until I started trying to find employment again that my Hepatitis C became an issue. I would have to declare it on employment forms and I wouldn't even get called in for interviews. They wouldn't explicitly say it was because of my infection but I know it was harming my opportunities.
37. When I was struggling at work I would just have to tell people that I was suffering from a viral infection. I was called for meetings with HR and told that I couldn't continue missing so much work due to my health.
38. I couldn't get life insurance and as a result it was difficult to obtain a mortgage. When I was finally able to get a mortgage in around 2000 it was an absolute nightmare with lots of pre-conditions attached to.

ANONYMOUS

39. I suffered from really bad depression so the doctor prescribed Prozac which just used to knock me out.
40. I had one sister at the Haemophilia unit advise me that I should tell people that I suffer from cancer because that is essentially what Hepatitis C was. She said Hepatitis C causes cancer, primarily in the liver but could cause it anywhere in the body. A lot of the nurses were disgusted with the way we were being treated and some were really upset.
41. Last year I was feeling really unwell and I was passing blood, which made me really worried that the Hepatitis C was coming back. When I went for blood tests the doctor told me that he was worried I had bowel cancer. Fortunately, it materialised that I didn't have bowel cancer but past experiences caused me to go through 6 months of sheer panic.
42. I don't mind telling people that I have haemophilia but I still don't tell them that I have been infected with Hepatitis C.
43. Financially, I went from being on really good money pre-diagnosis to having to claim benefits. I had to stop work when I was undergoing my second course of treatment as the side effects were so bad I just couldn't concentrate. I spent about 7 years out of work after this.
44. I suffered from the stigma of not working and having to claim benefits, on top of the stigma of being infected with Hepatitis C. I used to feel that people were looking at me because of my virus even when people didn't know about it.
45. I was always very weary about initiating relationships because I was worried about how I would come across to people after my divorce. I met my girlfriend on a photography Facebook page and we met for coffee a few times; it was very daunting when I decided to tell her but she understood which was a huge relief. My current girlfriend knows all about my history and everything going on with the Inquiry. She has been my backbone and encouraged me to get involved in the Inquiry.
46. Although my ex-wife never told my daughter, GRO-B is a very astute woman and she knew there was something wrong with me without me ever having to tell her.
47. I am permanently worried about the virus coming back. I could be sneezing with hay-fever and in the back of my mind I worry that it is the virus returning.

Section 6. Treatment/Care/Support

48. I remember someone telling me at the hospital that there was a psychiatrist available if I wanted to speak to someone. I initially thought it would be a bad idea but after some time I decided to give it a go. I saw the counsellor a couple of times but we just didn't get on. He made some callous comments about how I must have felt like I was 'moving out the way of the HIV bus but getting hit by the Hepatitis C train', so I stopped seeing him after this comment. He referred me to a local counsellor but I couldn't go there because I didn't want my community to find out.

ANONYMOUS

49. I don't understand the delays in starting my treatment. I was only able to start once they had obtained their 'permission', but many people have died unnecessarily as they have struggled to access treatment.
50. There have been surgeons who weren't willing to operate on someone with haemophilia, let alone someone with haemophilia and Hepatitis C. Dentists wouldn't go near me as a result of my virus. When I went to the dentist at the [GRO-B] after I explained that I had Hepatitis C but had cleared the virus, they left the room and came back dressed in space suits. It made me feel absolutely terrible. They walked through the waiting room dressed like this so when I left the room everyone was looking at me, wondering what was wrong with me. I couldn't go back there afterwards. I neglected going to the dentist after this unless my teeth were in real pain.
51. In the early 2000's at the [GRO-B] in Edinburgh, a nurse came in with her trolley and was giving out food and drinks. She came towards me but then went away, and came back with a mask and gloves on. I explained that Hepatitis C was not contagious through touch, but she said she didn't care because she had a young family and wasn't prepared to take risks.

Section 7. Financial Assistance

52. I was told by [GRO-B] that payment was being made by the Skipton Fund to those who had contracted the infection. I was told there were two payments; the first of which in the sum of £20,000 (Stage One) for those who had contracted the virus and a second in the value of £25,000 (Stage Two) for those who had suffered liver damage as a result. [GRO-B] confirmed that due to the severity of my condition, I would receive both payments. He proceeded to fill the medical sections on the form on my behalf.
53. In 2004, I received the Stage One payment from the Skipton Fund. I was told by [GRO-B] that I would be eligible for the second payment, but my application was denied. [GRO-B] explained to me that my liver could regenerate despite its scarring so didn't think I warranted the second payment. He said I could reapply, which I did, but I was denied again because [GRO-B] hadn't even submitted his report, which I found extremely annoying. He eventually said because my ALT levels were increasing, he didn't think I warranted the second payment as per the letter exhibited (WITN1841003.)
54. A few years ago, I received a letter from the Skipton Fund telling me they were planning on giving me a top-up payment of £30,000 to bring me level with other people in my position.
55. I was sent a questionnaire by the EIBSS at the start of the year. When I sent the questionnaire back they told me they would be giving me £500 per month due to the effect it has had on my mental health.

Section 8. Other Issues

56. As the years went on, I started to feel like there was a cover-up going on. I put a lot of trust in the haemophilia unit and I never really questioned them as they were the doctors I had always looked up to.

ANONYMOUS

57. I have many issues I would like for the Inquiry to address.

58. Firstly I would like to know when it was first discovered that the blood products were contaminated. Where these products came from and who knew about it? I want to know who gave the instructions to keep all knowledge quiet and to destroy all the medical records. I want to know who decided on the level of payments and why they thought these would be sufficient.

59. In many other countries, people have been prosecuted and those infected have been properly financially supported; why hasn't that happened here?

60. I should have been given the option to decide whether I wanted to receive the treatment or not, with knowledge of all of the risks involved. I could have decided to refuse the treatment or ask to be treated with something else if I was given the full information. I truly believe it is was completely unacceptable that my decision was taken away from me and made by someone else.

Anonymity, disclosure and redaction

61. I would like to apply to retain my anonymity.

62. I would be happy to give oral evidence provided I could remain anonymous.

Statement of Truth

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

Signed

GRO-B

Dated

6/6/19