

ANONYMOUS

Witness Name: GRO-B ANON

Statement No.: WITN5407001

Exhibits: WITN5407002 - 004

Dated: 05 August 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

ANONYMOUS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 21 July 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is name is GRO-B My date of birth is GRO-B 1947 and my address is GRO-B GRO-B
2. I retired aged 69, in 2015, having worked as a quantity surveyor for the majority of my working life. The last four years were part time. I live alone, I have never married and have no children.
3. I intend to speak about my infection with Hepatitis C (HCV) as a result of receiving infected factor VIII blood products. In particular, the nature of my illness, how the illness affected me and the impact it had upon me.
4. My younger brother GRO-B: B has provided a witness statement to the Inquiry GRO-B

Section 2. How Infected

5. I was tested for haemophilia in 1964, when I was 17 years old around the time when I left secondary school. My youngest brother B had been diagnosed with mild haemophilia A after an operation, so I was tested. I was also diagnosed with mild haemophilia A. My eldest brother GRO-B who was in the RAF must have also been tested and found to have a milder form of haemophilia. My other brother, GRO-B who was in the army was found not to be a haemophiliac.
6. Prior to my diagnosis I remember that I used to bruise very easily. I had some teeth extracted during my primary school years and I remember bleeding badly. My mother had to call the dentist out at night to try and stem the bleeding. In retrospect I attribute this to my mild haemophilia but nothing was suspected at the time. No further tests were done that would have established my haemophilia at an earlier point.
7. After my diagnosis, I learned that my mother's side of the family had some history of haemophilia. I know no further details
8. After being diagnosed with haemophilia, the medical professionals seemed to forget about me. Nothing was ever explained to me about haemophilia. Between 1964 and 1978 nothing happened that necessitated any form of care at hospital, nor did I receive cryoprecipitate or factor products during this period.
9. In 1978 I was suffering with stomach pains. I was assessed at my local hospital in GRO-B and they believed that I had appendicitis. I was referred to the Sheffield Royal Infirmary.
10. Before the operation I was put on a ward. At the time, I believe that the amount of factor VIII product required to be administered to haemophiliac patients, was calculated using the patient's weight. I remember receiving factor VIII as a prophylaxis prior to the operation, and again after the operation.

11. At the time I was heavily overweight at over 22 stone. The haemophilia team brought up a set of potato scales from the kitchen to weigh me. This was hugely embarrassing to me.
12. My weight meant that I received a lot of factor VIII prior to the operation to ensure adequate clotting.
13. When I was opened up for what was intended to be an appendectomy, the surgeon found that a diverticular abscess was the cause of my pain and discomfort. This was removed, along with my appendix while they were 'there'.
14. An hour after the operation I received further injections of factor VIII, which was repeated every 2 hours for a limited period, though I can't remember for how long. No record seemed to be taken of the levels of factor VIII I received as I don't think they knew enough about it back then. It seemed as if they were just guessing.
15. I ultimately stayed in the Sheffield Royal Infirmary from 05 December 1978, through Christmas and into the New Year, January 1979.
16. In early 1979 I attended the Sheffield Royal Infirmary for another operation connected to the 'appendix' operation. I had an abscess drained but this continued to leak so I was finally fitted with colostomy bag to collect the leaking fluid.
17. In June 1979 I started to develop black blobs of blood surrounding the scar where my appendix and abscess had been removed. This required another operation which took place at the newly-opened Royal Hallamshire Hospital. I was again administered factor VIII, though on this occasion it did not seem to be calculated on my weight. Perhaps the use of Factor VIII was evolving. I remember receiving less factor VIII product than in 1978.
18. In the early to mid 1980s I attended the Sheffield Haemophilia Centre at Royal Hallamshire Hospital for a check-up and blood tests every 3 to 6

months. At one of these appointments, I was told by the haemophilia sister Joy Farnsworth, that I had non-A non-B hepatitis.

19. Joy told me me face-to-face that my liver function tests indicated that I had non-A non-B hepatitis. She did not mention any treatment available to me, I was not given a prognosis neither was I given any advice about infection control. I don't think I asked these questions and in hindsight I was not particularly worried about the diagnosis. I simply thought that the doctors knew what they were doing and I had faith in them.
20. I continued to attend the Sheffield Haemophilia Centre for check-ups and monitoring every 3 to 6 months when, in the late 1980s, I was offered the chance to be part of an interferon trial treatment. To assess whether I was suitable for this I attended the Royal Hallamshire Hospital for a liver biopsy. I was also given lessons about self-injecting the medication using an orange as an aid.
21. The results of my liver biopsy, which was performed by Mr (now Professor) Trigger, showed that I had a fatty liver. Consequently, I was not deemed suitable to take part in the interferon trial. I recall being administered cryoprecipitate both before and after the liver biopsy. I was told that the cryoprecipitate would 'release any factor that was attached to my veins'. After this episode, I was not offered any further treatment.
22. Sometime in the mid 1990s, I attended Sheffield Haemophilia Centre at the Hallamshire hospital for a regular check-up when I was told that I had self-cleared the HCV infection. The nurses did a confirmatory blood test and again this proved to be clear of HCV.
23. Around this time a new GP started at my practice. My new GP wanted to take lots of blood tests, one of which showed small traces of HCV. He sent me to the hepatitis unit at Grimsby Hospital (now called the Princess Diana hospital). At Grimsby Hospital the specialist nurse refused to listen to me and insisted that she took blood tests to check for HCV. I asked her to ring Sheffield Haemophilia Centre but she again refused. Having

been determined to take these blood tests, the results showed that I remained clear of HCV.

24. To the best of my knowledge my liver is unharmed and the HCV has not returned since I self-cleared the infection.

Section 3. Other Infections

25. On 20 September 2004 I received a letter from the Sheffield Haemophilia Centre enclosing a letter from the Health Protection Agency and the Department of Health (enclosed as exhibit **WITN5407002**). This letter affirmed that haemophiliacs who received factor VIII between 1980 and 2001 were to be considered 'at-risk of vCJD for public health purposes'. Also attached to this letter was what looked like a print out of NHS Scotland internet pages on vCJD (I enclose the front page as exhibit **WITN5407003**).

26. I received a further letter on 01 November 2004 from Dr Hampton of the Sheffield Haemophilia Centre (enclosed as exhibit **WITN5407004**). This letter confirmed that I received 'UK NHS clotting factor concentrate at the Royal Hallamshire Hospital' and 'In view of this you are therefore "at-risk" for Public Health purposes' under the definition provided in the letter of 20 September 2004. The lines of highlighter pen were by me.

27. Also, within this letter was confirmation that I did not receive 'any of the implicated batches of clotting factor that have been prepared from plasma donors who subsequently developed variant CJD'.

Section 4. Consent

28. I believe that I consented to all testing for my HCV infection. I was not warned of any risk(s) with regard to factor VIII blood products. I was not told that I was specifically being tested for non-A non-B hepatitis, though I did consent to having my bloods tested and if I was explicitly asked for consent to be tested for hepatitis, I would have given it.

Section 5. Impact

29. On balance, I believe that factor VIII did more good for me than bad.

Without having received factor products I would be dead. My HCV infection has not had a great impact on me because I self-cleared it fairly early on it before it began to affect me or damage my liver. I have more pressing health concerns that makes it difficult to say precisely what was attributable to my infection with HCV and what was a result of something else.

30. I was overweight for a number of years before I abruptly and inexplicably lost 6 to 7 stone in a short period of time. I suffer with angina, I have fluid in my chest that causes me respiratory problems, I have glaucoma in both my eyes and I have a damaged retina in my right eye, consequently I have no peripheral vision in that eye. I also have two knees that need replacing but I am unable to go under general anaesthetic unless in an absolute emergency.

31. I used to react to cryoprecipitate injections with my face flaring up and appearing very red and flushed. I also had headaches and became sweaty. After the consultant saw this they immediately stopped administering me with cryoprecipitate. I have also suffered health problems in relation to extreme bleeds. One example was around 1990, after an operation, which I can recall as the ambulance drivers were on strike. After I returned home from the operation I had a massive haemorrhage from my anus. I had to drive myself to hospital to receive factor VIII.

32. I have encountered some stigma associated with my infection with HCV. Upon receiving my diagnosis, I decided that it was my responsibility to inform my employers and my colleagues. I started to notice 1 or 2 colleagues behaving strangely around me. In some ways this was a good thing as I was taken off the tea making rota!

33. One person in particular took an immediate dislike to my HCV infection and I remember an associate from a firm of architects making a comment about me. I later learnt that he received a stern dressing down from one of his senior partners and he was made to apologise to me. I cannot remember exactly what he said but it was disparaging. This was an isolated incident and, on the whole, not many people judged me, as far as I could tell.
34. Working in the building industry, I had to attend building sites and I would have to inform the site first aider of my status, in case something happened while I was there. This caused me no problems.
35. I was open and honest about my infection with my friends and family. I wasn't ashamed of it and thought if they were my true friends then they deserved to know. I warned them not to touch my blood without wearing gloves, for example, and I did not experience any adverse comments or reaction.
36. I continue to suffer with fatigue, and I have done for as long as I can remember. On reflection, I believe that my fatigue worsened dramatically after the two operations in 1978 and 1979. I do not recall being especially lethargic prior to these two operations. I therefore attribute this to my HCV infection, and this persists to this day.
37. Having witnessed what my younger brother **B** went through with all his HCV treatments, I count myself fortunate to have avoided this. He suffered enormously and I am amazed that he was able to continue working throughout, especially in the industry that he worked in. I remember Professor Preston using my brother as an example of how mild haemophiliacs could continue to live an active lifestyle in spite of their condition. **B** played rugby, as did I when I was much younger.
38. The greatest impact of this whole saga has been the problems that I have experienced with regard to my suspected 'infection' with vCJD. Having been told that I was 'at-risk' for public health purposes in 2004 I

noticed a significant change in how I was treated by the medical profession.

39. After receiving the letter dated 20 September 2004 (**WITN5407002**) I went to hospital to have my second cataract operation in October 2004. The anaesthetist arrived with a cap, a mask, a visor, double gown and double gloved. At my first cataract appointment, prior to the vCJD letter, the anaesthetist had only worn basic hospital scrubs.
40. Whenever I was at hospital as an outpatient I would be kept isolated in a separate waiting area and not with other patients as I had done before.
41. Due to my ill health I was an inpatient during my cataract operations. On the occasion of my second operation, I was put in a private room in complete isolation, whereas at my first operation I was in a ward full of other people. I remember overhearing the anaesthetist talking to a doctor walking through and making a comment about vCJD.
42. This whole event made me feel dirty, singled out and isolated. I was very annoyed by the anaesthetist's behaviour and attitude towards me. I noticed that the eye surgeon wasn't wearing the same level of protective equipment as the anaesthetist.
43. After the operation whilst on the ward I told the haemophilia nurse who was administering me with factor VIII, what had happened. After hearing this she was so annoyed that she decided to report this to the head of the centre. I understand that later that day they called an urgent meeting to establish why this had been allowed to happen.
44. I have been refused medical treatment and operations on numerous occasions since being labelled 'at-risk' by the letter of 20 September 2004. In 2005, I went to the Northern General Hospital in Sheffield for a colonoscopy. When I arrived, the surgeon didn't want to perform the operation as he didn't want to put his equipment into quarantine.
45. On another occasion I had to have a virtual colonoscopy in which they blew a balloon with carbon dioxide inside my anus. I was forced to have

a different, and more uncomfortable, procedure because of the perceived vCJD which I 'may' have but, in all probability, do not.

46. In 2011 I went to the Northern General Hospital to have fluid removed from my right lung. I was all ready for the operation but I began to get suspicious when I hadn't received any factor VIII. The registrar then came in and said there was a problem and that the consultant was trying to resolve it. The consultant then came in and explained that he was unable to perform the operation today because infection control wouldn't allow him to.

47. I had booked time off from work to attend this operation but I was back at work the following day. The consultant did not give in and he wrote a paper to infection control and my haemophilia centre. Six weeks afterwards he performed the operation.

48. Again, in 2016, a urologist at Scunthorpe Hospital wanted me to have a cystography. I said that I was at risk of vCJD on the phone prior to the appointment but this did not appear to be an issue. Then, when I arrived for the appointment, one of the nurses told me that they couldn't do it because of the risk of vCJD. They told me that they would contact GRO-B Hospital, which is part of the same North Lincolnshire NHS Trust, to see if they would do the procedure.

49. GRO-B Hospital sent me an appointment to attend that hospital. They then phoned me and said they couldn't do it but Scunthorpe Hospital said they now could. Whilst on the bus to the appointment that day I received a call on my mobile phone and was told that the hospital couldn't do it because of infection control again. I felt like I should be wearing a plaque with the word 'unclean' on. I never had that procedure and ended up having a CT scan at Scunthorpe.

50. I have had a lot of difficulties with regard to my treatment as a result of being deemed 'at-risk' of vCJD. It happens so often and it drives me mad, especially because of the number of appointments I have to attend. I have been made to feel dirty and these last minute changes of plan are

incredibly frustrating, not to mention the problems of actually physically getting myself to these places because of my other health issues.

51. I have checked with the haemophilia centre to confirm whether I was still deemed 'at-risk' for public health purposes and they said I was. I am not concerned about having vCJD, I am more concerned with how I am treated and perceived. It really upsets me.

52. How many more people have been inconvenienced and made to feel dirty because of this grossly unfair 'catch all' vCJD letter?

Section 6. Treatment/Care/Support

53. I have only ever faced difficulties in accessing treatment after being labelled 'at-risk' of vCJD 'for public health purposes'. As discussed in section 5, this has had a detrimental effect on my ability to access treatment and has angered me enormously.

54. The Sheffield Haemophilia Centre at Royal Hallamshire Hospital are truly good people and have been very helpful to me and my brother. I have known one of the nurses there for over 30 years, which is in stark contrast to my other medics who change regularly. We have also seen doctors rise through the ranks over a long period of time. It makes a big difference seeing a regular doctor or nurse with whom you have developed a rapport. This continuity with the haemophilia nurses and doctors has been beneficial to us both.

55. I was offered counselling by Royal Hallamshire Hospital but I declined. I did not feel that I needed it and I still don't.

Section 7. Financial Assistance

56. I was made aware of the Skipton Fund by one of the nurses at Sheffield Haemophilia Centre. I went to clinic one day and the nurses and consultants asked me if I had applied, to which I replied no because I

had self-cleared the HCV. They advised me to apply and said that people who had not had it as bad as me had applied.

57. I applied to the Skipton Fund around 2004 and I received a first stage payment of £20,000 around a month afterwards. The Skipton Fund raised queries with the haemophilia centre to confirm my infection before sending the money, but this wasn't an issue.

58. On 27 July 2021 I was awarded a 'levelling up' payment of £30,000. This payment, from EIBSS, was explained as being a payment to meet the same total received by those affected by infected blood products in Scotland, who received a first stage payment of £50,000.

59. I also receive monthly payments of around £1500 a month and I receive a winter heating allowance of about £500.

Section 8. Other Issues

60. I hope the Inquiry achieves justice for the people worse off than I am.

Statement of Truth

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

Signed

GRO-B

Dated

5/8/2021