ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN3543001
Exhibits: WITN3543002 – WITN3543010
Dated 21 October 2019

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 GRO-B 1949 and my address is known to the Inquiry.

Section 2: How Affected

2. I am a carrier of haemophilia A and contracted Hepatitis C through contaminated blood products provided by the NHS. I am providing this statement to the Inquiry to explain the impact that this has had on me.

3. I was expecting to go on to study at university at the time when, in around 1967, I required what should have been a relatively routine tooth extraction. I went to the dentist as normal and had the tooth extracted, but complications followed as the bleeding would not stop. I was told by the dentist to attend the local hospital in Manchester, which at the time was Ancoats. When I attended the hospital the

wound was sewn up with disposable stiches. I was distressed by these event and I did not do as well as was expected in my A-levels.

4. In 1976, I attended a dentist based in Manchester city centre who had a good reputation. I told him about what had happened in 1967 and, before treating me, he referred me to the Manchester Royal Infirmary (the "MRI") and a series of tests were conducted. I then received a letter informing me that I was a carrier. I do not recall being given any information other than being told I was a carrier. I was not directed to The Haemophilia Society or anywhere else for further information or support. I came across The Haemophilia Society myself and joined as a member.

5. Following this diagnosis, it was determined that I would need to attend the dental department of the MRI for future dental treatment, which I required in June 1977. During this dental treatment, I believe I was given Cryoprecipitate in order to stop the bleeding, but I did not question the treatment I was receiving. I also required stitches and I recall being treated in hospital for around a week. I do not recall being advised of any risks or warnings about the treatment I was given.

6. I went on to study business studies at college and had various jobs before finding employment GRO-B in Manchester in 1979 until I left in 2000.

7. I got married in 1980 and did not really think about having children. However, I do recall, in around 1984, a geneticist at St Mary's hospital in Manchester advising me that, if I was planning for a family and had a son, there was a fifty percent chance of him inheriting haemophilia.

8. In July 1984 I had a GRO-B procedure at Tameside Hospital ("Tameside"). I informed the doctor that I was a carrier of haemophilia and he said something along the lines of, "*we do not need to bother about that*." Following the procedure I went home and experienced some PV bleeding. My husband took me to Accident and Emergency

at the MRI and a haematologist came to see me. The haematologist was annoyed that Tameside had not contacted the MRI for advice before carrying out this procedure on me. I was treated with Cryoprecipitate, I have note indicating that I was given 2640 units, which seems like a large number of units, and kept in overnight. Again, I do not recall being advised of any risks or warnings about the treatment with which I was provided.

On 27 December 1984 I received a letter from the Haemophilia Centre at the MRI about Hepatitis (WITN3543002). In summary, this letter notified me of a risk to haemophiliacs of getting Hepatitis, which was described as the technical name for jaundice. It said that Hepatitis B and non-A and non-B Hepatitis were the main types of Hepatitis in haemophiliacs. It mentioned the risk of symptoms such as severe liver disease, but said that it was very seldom fatal. The letter also mentioned that the symptoms usually pass off completely in a few weeks or months and normal health is regained. The letter asked that I book an appointment to receive immunisation for Hepatitis B, but did not mention anything further about non-A and non-B Hepatitis.

9. I later received a letter from the MRI dated 22 May 1985 informing me that testing for HIV was now available and being offered to those who had been treated with blood products since 1980. It recommended that I should make an appointment to be tested (WITN3543003). I made an appointment and was tested for HIV. Thankfully, following this appointment, I received a letter from the MRI which simply said *"you will be pleased hear that it is negative"* (WITN3543004).

10. I got pregnant in 1990 and was referred to hospital again. My GP said I should attend St Mary's Hospital ("St Mary's") which is the woman's hospital attached to the MRI. The doctors advised me to have amniocentesis to determine whether I was expecting a boy or a girl so I could know of the risks of my child inheriting haemophilia and also to check the baby for down syndrome as I was 41 years old at the time. This was carried out and it was determined I was carrying a son. I was

then advised to undergo testing of the umbilical cord to determine whether the baby would be born with haemophilia, I believe they could also detect the severity of the condition with this test. This was only available at King's Hospital in London at that time. I decided not to have this test as I was already so far along into the pregnancy and the results of the test would not change anything. St Mary's did not put any pressure on me to have this test. When I said I was not going ahead with it, the haemophilia coordinator, Mrs Reading, gave me a hug. My son, GRO-B, was born on GRO-B 1991. He was diagnosed with mild haemophilia A at birth.

11. Having reviewed my medical records, I can see that on 8 June 1994 Dr Bolton wrote to my GP, GRO-B about my test results for Hepatitis (WITN3543005). This letter said I was immunised for Hepatitis B but suggested that I be tested again every five years. Dr Bolton also mentioned that a second generation test found that I was Hepatitis C positive and "*probably a chronic carrier of Hepatitis C*". He went on to state that there was a "*slight risk of transmitting the infection through blood*" and that "*Hepatitis C carrier state confers an increased risk of long term liver disease*". However, Dr Bolton stated that tests had shown there was no viral DNA of Hepatitis C circulating in my blood stream which reduced these risks.

12. I attended annual review appointments at the Haemophilia Centre at the MRI. I believe that my diagnosis of Hepatitis C was discussed at one of these appointments but I do not recall the details of this. I remember being very concerned about finding out that I was Hepatitis C positive, but I was busy working and was looking after a young child so just had to carry on.

13. From my medical records I can see that on 27 December 2000 in a letter to my GP (WITN3543006) Dr Grainger, a specialist registrar at the MRI, mentioned that my Hepatitis C antibody status showed that I had prior Hepatitis C exposure, probably from blood products. It also mentioned that my test for Hepatitis C became positive 12 months prior to the letter. However, repeat testing had indicated that this was a

false positive. I recall speak with Dr Grainger around this time who informed me that my body had cleared the virus.

14. In 2009, I received a letter from the Central Manchester University Hospitals dated 19 February 2009 (WITN3543007) notifying all of their patients about the risk of developing variant Creutzfeldt-Jakob disease ("vCJD"). The letter mentioned that there was an incident with one haemophiliac having developed vCJD and advised me to follow public health advice. My son, who was under the care of Pendlebury Children's Hospital at the time, was also advised to be tested for vCJD because their records showed that he might have been exposed to it. It was eventually discovered that the hospital's records were incorrect because GRO-B was on holiday on the date that they thought he had been given Factor VIII.

Section 3: Other Infections

15. I am not aware of any other infections I contracted as a result of contaminated blood products. However, as mentioned above, I received a letter on 19 February 2009 from the Central Manchester University Hospitals notifying me about a haemophiliac infected with vCJD and providing advice on how to reduce the risk of spreading vCJD to other people.

Section 4: Consent

16. As mentioned above, I was aware that I was tested for HIV in 1985.

17. In relation to being tested for Hepatitis, as set out above, I received a letter dated 27 December 1984 to notify me of the risk to haemophiliacs of getting Hepatitis B and non-A and non-B Hepatitis (which I now understand is the former name of Hepatitis C). This letter only asked me to book an appointment to be immunised for Hepatitis B and did not mention any testing for non-A and non-B Hepatitis.

18. I am not sure when I was first tested for Hepatitis C or whether I consented to this. All I am aware of is that I had regular tests (e.g. liver function tests and blood clotting level tests) at the Haemophilia Centre.

19. Whilst I knew I was having tests conducted at various points at the Haemophilia Centre, I did not always know what these tests were for. Whilst it is common today for people to discuss with their doctors and consultants what they are being tested for and treated with, it was not the case in the 1980s and 1990s. Nobody questioned doctors and consultants as they were like gods and you just let them get on with their job. On reflection I feel like I should have asked what the testing was for and why my blood was being taken.

Section 5: Impact

Psychological impact

20. I was generally busy getting on with life but, after I was told I was Hepatitis C positive, it was always at the back of my mind. I am still anxious today, with my son working abroad; I do not want him being treated abroad in case anything happens as a result of poor treatment/contaminated products in that country.

21. My husband was also impacted. I remember him getting really upset on one occasion after having read about the effects of vCJD and thinking the worst after seeing me struggling to get out of bed. Thankfully my husband was just worrying over nothing.

22. It is difficult to describe but it is something that just hangs over you, like the Sword of Damocles. I suffered from mental distress more than anything; always thinking of things like how will my family cope if I am gone.

23. Doctors are always warning of risks with something or other these days so you just do not know what is lurking around the corner. I still worry about what will be the next thing that comes to light in the future.

Stigma

24. On one occasion my sister-in-law told her children not to play with the same toys as GRO-B in case "*they caught anything*". This was because GRO-B had haemophilia. As a result of this incident, I only ever told my husband and did not tell any of my family about my Hepatitis C diagnosis.

Writing to my local MP

25. In around 1985 , after being told I had not contracted HIV, I started writing letters to my local MP as was being encouraged by The Haemophilia Society. I recall that The Society would send their members template letters which could be adapted and sent out by its members.

26. On 22 March 1995 I wrote to my MP, Mr Hendry MP, about having contracted Hepatitis C through contaminated blood products (WITN3543008). In that letter I asked for the government to provide financial assistance to those infected with Hepatitis C, similar to the financial assistance that had already been established for those infected with HIV. Whilst I sent this particular letter to Mr Hendry MP based on The Haemophilia Society's template, looking back at it now, I do not agree with the penultimate paragraph in which I say I am not seeking to put any blame on the NHS and/or individual doctors. Whilst I do not think individual doctors are necessarily to blame, I certainly believe somebody is to blame and should be held accountable for the contaminated blood scandal.

27. I continued writing to my local MP at various points in time in order to campaign for the haemophilia community, but also in relation to matters personal to me. For

example, on 13 November 1997 (WITN3543009) I wrote to Mr Levitt MP, after my son was refused recombinant Factor VIII by the West Pennine Health Authority on financial grounds. A Panorama documentary had recently aired regarding CJD and its potential transmission through blood. I therefore wrote to my local MP to help push for my son to get the safest treatment available.

Section 6: Treatment/Care/Support

28. I was not offered any support at the time I was told that I had contracted Hepatitis C. It is not like today where it is more common to be offered psychological support. I feel that it would have been beneficial to have been given psychological support given the emotional impact that it has had on me as described above.

29. I remember around the 1990s when the dentist within the Haemophilia Centre retired I was advised to register at a local dentist. I therefore tried to sign up with the same dentist my husband was registered with, but was turned down. All the dental practice said was that it was standard procedure, by which I assumed that it was something to do with me being a carrier of Hepatitis C.

30. I do not remember being refused any other treatment as a result of being Hepatitis C positive.

Section 7: Financial Assistance

31. I was aware of financial support, such as the Macfarlane Trust, but never applied for any financial assistance. For me, there was no financial impact as a result of the of being infected with Hepatitis C through blood products and, as mentioned above, it was more the emotional impact that affected me.

32. Despite not applying for financial assistance myself, I encouraged other members within the local haemophilia community, namely parents of my son's friends within the community, to apply for financial assistance.

Section 8: Additional Information

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Medical records

37. I requested my medical records in the 1990s but encountered some difficulties in obtaining the same. I managed to get some records in connection to a potential class action law suit being brought in the United States of America. The Haemophilia Society gave its members instructions on how to apply for their medical records, which involved getting someone to witness my signature and physically attending the hospital to get the records. I recall there being a bit of an atmosphere when I went to collect my medical records from the hospital as it was if they were reluctant to provide them and were saying *"these are our records"*.

Other issues

38. My son has been taken off the list at the Haemophilia Centre at the MRI because he has not been able to attend some appointments due to working abroad. I believe that he should be kept on the list because haemophilia is a lifelong condition and he will need regular treatment whenever he is in the country.

39. As a result, it is now more difficult for my son to get an appointment or go for a routine check-up at the local Haemophilia Centre. He is now required to be referred by his GP on each occasion which seems cumbersome. I believe it is somewhat hypocritical to tell haemophiliacs to go and live their lives on the one hand and then

do things such as removing them from the patients' list as a sort of punishment for living their lives.

40. I would also just add that I am not entirely happy with the care my son receives at the Haemophilia Centre at the MRI. I recall one occasion when he was given the wrong Factor VIII. This was almost immediately rectified when the nurse realised and called us back as we were walking down the ward to leave, but I just could not believe they could get it wrong in the first place.

Statement of Truth

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

Signed ..**GRO-B**...........

Dated........21 October 2019........