Witness Name: GRO-B
Statement No: WITN2055001
Exhibits: [WITN2055002
WITN2055004]
Dated: 16 November 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B. My address is known to the inquiry.

Section 2. How Infected

2. I do not know for sure how or exactly when I was infected with hepatitis C however I strongly believe that I contracted this infection through contaminated blood at an NHS hospital. I have applied for my medical records but have not been able to obtain records relating to every admission and procedure.

3. In 1976, when I was 17, I had a motorcycle accident and was taken to hospital in GRO-B I believe the hospital has now closed down. I had a big cut on my hip, it was so deep that it was nearly at the bone. They told me that I

could have been crippled for life. I lost quite a bit of blood. I still have a scar on my hip, it is about 4 inches long. I am not sure whether I was given blood during this operation or not. I applied for my records from West Suffolk Hospital NHS Foundation Trust which I believe is now responsible for the old GRO-B GRO-B They said that there is no record of me attending there for any clinical treatment.

4. I believe that the most likely route of infection was when I received blood products at Whitechapel Hospital in 1989. At that time I was visiting my friend GRO-B in London. I had terrible tooth ache which kept getting worse and worse. In the end I had to go and see the emergency dentist at Whitechapel Hospital. They told me that I had to have one of my wisdom teeth removed as well as two others next to it. GRO-B waited outside. During the procedure the scalpel broke in my mouth and part of it was lodged in my gum. The dentist called for help and eventually there were about six dentists standing round me trying to get this piece of metal out of my mouth.

5. There was blood everywhere, it really was bad, the dentists were very concerned, they did not know what to do. They kept saying that they could not stop the bleeding. They tried stitching but they couldn't because the bleeding would not stop. They were telling me that they were trying different products to stop the bleed. They tried a few different things which did not work and then I was asked to wait. They eventually came back with something that did work and the bleeding stopped for long enough for them to give me stitches. I do not know what products were used but I know that I had several injections.

6. My friend GRO-B came in the room while I was having the procedure, she recalls me saying that the dentists could not stop the bleeding and that they were trying different clotting material to stop the bleed. I remember it being very dramatic.

7. More recently I have been told on several occasions that my platelet levels are dangerously low. I have had to have several blood and platelet transfusions over the last few years. This may be an explanation for why I was bleeding so much that day.

8. I have not been able to obtain my records from Whitechapel Hospital. When I applied for these notes I received a letter stating that the hospital "*do not hold patient case notes post 1948 and other patient records from recent decades are very sporadic*" [**WITN2055002**]. My current dentist does not hold any records relating to the procedure in 1989 [**WITN2055003**].

9. In 1993 I had an accident at work, I tripped and put my back out. Over the next few years I had lots of problems with my back, I was in so much pain. In 1998 I had a major operation on my back at Ipswich hospital, I think they removed some bone. I believe that I was given a blood transfusion after this operation.

10. In October 2013 I was sitting at home one day and I suddenly felt dizzy and just did not feel right. I started to feel a pain in my chest. I phoned an ambulance and was taken to Ipswich Hospital. When I got to hospital I started throwing up blood. There was blood everywhere, it went all on the walls and all over the floor. It was horrific. I threw up so much blood and I heard the nurses say "we are losing him". I was admitted and was given four units of blood.

11. Overnight I was given more blood and in the morning I was sent for an endoscopy. I was told that the reason that I had been so sick was because I had varices and ulcers growing on the inside of stomach. These burst and that is why I was sick.

12. The next day a consultant came round and said "you have hep C, did you know?" I did not even know what Hep C was. He then started asking me whether I had engaged in wild sex or had orgies. He said that with 6 other consultants around, they all had Dictaphones. It was so humiliating. He asked

me how I thought I had caught it. I thought that was a bit much, he shouldn't have asked me at the time. I thought hang on he has just told me that I've got hepatitis now he wants me to answer all these questions, I did not know how I had got it, I did not even know what it was. I did not like what he said to me and how he said it. He should have taken me to a cubicle rather than tell me in front of everyone else and questioned me when I was so ill.

13. I asked the consultant whether I could have caught the hep C from the blood transfusion that I was given in 1998. He said that there was no way that I could have got it then, that all the blood was clear of hep C by then.

14. The doctor told me that I had probably had hep C for a long time and that I had just not known about it. He said that hep C leads to liver cirrhosis. I had an ultrasound scan on 21 October 2013, this showed that the hep C had already done some damage, my liver was badly scarred and I had cirrhosis. Before I was discharged they gave me a leaflet about hep C. I was not given any information about the risk of passing the infection to others.

15. After being discharged I was referred to a liver specialist, Dr Williams, who I saw a few weeks later. I got quite a bit more information from Dr Williams and the specialist nurses. I was told that I had hepatitis C genotype 3A.

16. I can't understand why they did not find the Hep C before, why didn't they test for it in 1998 when I had the back operation? I had to give lots of blood samples before that operation, why didn't they find it then? I feel quite strongly about this, I should have been screened before I had the operation. I probably had hep C at that time and I could have passed it to someone else.

Section 3. Other Infections

17. I do not believe that I have received any infection other than hepatitis C as a result of being given infected blood or blood products.

Section 4. Consent

18. I do not believe that I have been treated or tested without my knowledge, or without my consent, or without being given adequate or full information, or for the purposes of research.

Section 5. Impact

19. When I look back to before I was diagnosed I had a few aches and pains but I thought this was linked to my back injury. For a couple of years before I was diagnosed I had severe leg cramps and leg pain, I don't know whether this was because of the hep C or not. From about 2011 onwards I did have dizzy spells and vertigo but I did not make much of it at that time. In 2011 my GP did some blood tests, I think this was for monitoring my diabetes. My GP told me that my liver function tests showed abnormal results and suggested that I have a liver scan. I had the scan in August 2011 and was told that there was nothing to worry about.

20. However I am now concerned about this scan. I have seen my GP records which state that the liver appeared "normal", this was only two years before the scan in October 2013 which showed that my liver had a "nodular appearance consistent with cirrhosis". The 2011 scan also showed that my spleen was enlarged. The scan report states "***borderline***". I believe that more should have been done after the 2011 liver scan to follow up the abnormal results. They could have tested me for hep C then, if they had diagnosed me in 2011 I might have been able to have treatment to prevent further damage to my liver.

21. Having hep C just drains you. It has been a nightmare, it shuts down your body and the way you think. I have started to become very negative when I think about my life and what might happen to me. I have tried to get help and support online, but everything I read is scary.

22. When I was diagnosed they told me that there was not any treatment available for me because my liver was so badly damaged. I continued to go to see my liver specialist regularly and they said that they would keep me informed of any new treatments.

23. In 2015 I was told that there was a new treatment available. My liver specialists discussed the treatment with me to see if I was suitable patient and they put me forward for it as soon as they could. It was a very expensive treatment, not everybody could have it. I was lucky like that I suppose. I think they chose me because I had not drunk alcohol since I was 30 years old. Once I was on the treatment I was backwards and forwards to see the consultant and the nurses.

24. The hospital staff did take care of me and they did help me. I have no problem with the treatment that I received from the point of being diagnosed.

25. I started on treatment in November 2015. I had Sovaldi, Ribavirin and Daclatsvir for 12 weeks, I managed to get through the whole course. At lot of people give up on it but I didn't, I stuck to it. It was horrible. I could not eat properly, I was sick, sweating, having panic attacks, I was going up the wall. It sent me yellow.

26. I could not work, I couldn't really go out. When I did go out people were looking at me. It breaks you down, it is soul destroying. I did not know of any other treatments available at the time, I think that was the most advanced treatment they could give me. The medication they did give me worked and I cleared the virus.

27. The Hep C has gone, I'm thankful for that, but I am still living with the after effects. I still have liver cirrhosis. I have to take mediation every day that I will be on for the rest of my life. I feel sick a lot of the time. I have to have regular endoscopies to check for varices and have six monthly scans to check my liver.

28. I still feel tired and light headed, my memory is going a bit, I do forget things and get confused. I often feel very low. I do go into some dark places sometimes and feel totally depressed. I have read that having Hep C takes 10 years off your life. I am 60 now and so I am worried about what that means for me.

29. My social life ended when I was diagnosed, I stopped wanting to go out and often want to be on my own. I used to love playing the guitar but now I have terrible joint pain which means that I cannot play anymore. Having Hep C has turned my life upside down.

30. I did not tell anyone that I had hep C. I still can't talk about it, I find it embarrassing. If you tell one person, they are going to tell the next person and the next person and before you know it the whole town will know, that's how it works isn't it? Having hep C made me feel dirty and disgusting. I am lucky that I have not got it now, some people are not so fortunate. I still can't tell people that I did have it because I worry that they will presume that I have still got it. There is definitely a stigma attached to having hepatitis, even now. No one knows, not even my family. I told my sister that I have liver cirrhosis but she does not know that I had hep C.

31. When I was diagnosed it was very frustrating. I wanted to tell my family but I couldn't. When I was having treatment I did have support, I just told people that I had liver problems. I tell them a little bit but I won't tell them that I have Hep C, I just think that if you tell someone you have got something like Hep C they

will keep away from you. It changes your life. People say cheer up, but I have got other things on my mind that they don't know about.

32. I can't deal with my family sometimes. I get paranoid about what they think. I feel like they are looking at me and that they know more than I realise. I am worried that they might work it out if they read about liver cirrhosis and then find out what can cause it, but they have never mentioned Hep C to me. Last Christmas my niece's husband said that I looked thin in the face; he said the same thing the year before. They know that there is something wrong. I should imagine they are worried about me. I have a good family and they are supportive but I do not feel that I can discuss the Hep C with them.

33. I am self-employed and work as a teleport operator. A teleport is a big machine on construction sites. When I was first diagnosed I forgot about work and everything else and just went into another world. After a few months I did the odd bit of work, but I could not think straight, my mind was very clouded.

34. After clearing the hep C I started to work part time again but I started to get a lot of cramps and muscle spasms, my fingers started to lock and then spasm when I did too much work. In the last few months this joint pain has got much worse and I have hardly been able to work at all. Six weeks ago I was just about able to work for 2 days but have not worked since then. I have a frozen shoulder and can't move my right arm, and I have aches and pains all over. There is work around but I am just too ill to go in.

35. The financial effects have been terrible. My savings are dwindling because I can't work and so I have to use what I put aside over the years to pay my rent and bills.

Section 6. Treatment/Care/Support

36. I have not been offered any counselling since being diagnosed with hepatitis C. I have had counselling in the past in relation to a different issue. I found it very useful. I think I would find it helpful to have counselling to talk about my Hep C because I still feel sort of mushed up about it.

Section 7. Financial Assistance

37. I did not find out about any of the financial schemes until I was told by my solicitors that are representing me for the Infected Blood Inquiry.

38. Once I found out about EIBSS I phoned them and requested an application form. I asked my liver specialist nurse to help me with the application. She looked through all of my notes from Ipswich Hospital and said that she could not find any evidence of a blood transfusion. My solicitors applied to West Sussex Hospital NHS Foundation Trust and to Whitechapel Hospital but were not able to obtain any records for my treatment at those hospitals. My GP records do not mention me having a blood transfusion.

39. I applied to EIBSS in May 2019 with the form completed by my consultant Dr Williams. Dr Williams ticked a box on the form confirming that in his view it is probable that my infection was acquired in consequence of NHS treatment received before September 1991.

40. In response I received a letter requesting copies of my records or letters confirming that no records were available. I sent all the evidence I had back to EIBSS along with a statement from my friend GRO-B stating that she had been with me at Whitechapel hospital in 1989.

41. I received a letter on 21 August 2019 to state that my application had been rejected. I exhibit all of my correspondence with EIBSS to this statement

[WITN2055004]. I intend to appeal the EIBSS decision and will forward any additional correspondence to the Inquiry to be included in my evidence.

42. I have taken every reasonable step to obtain my records to confirm the treatment that I have received. Unfortunately I have not been able to obtain copies of these records. Therefore the only evidence that I am able to send to EIBSS is my account of what happened. I have not received an explanation from EBSS as to why my evidence about the medical treatment that I received has been ignored.

43. The letter from EIBSS rejecting my application states that "on the balance of probabilities in 1989 your dentist most likely used clotting material in your mouth". I do not know how they can come to this conclusion, I was the one that was in the room when the dentists were working on me. I heard them tell me that they were using blood products.

Section 8. Other Issues

44. I want the Inquiry to find out the truth and never to let this happen again to anyone else. I want them to carry on doing what they are doing now. At least they have set up something and they are doing something.

45. Since being diagnosed with hep C I have had no support from the government or the NHS other than the treatment that I have received. I am grateful for the treatment however I think there should be ongoing support for everyone that was infected through contaminated blood. There should be support to help you get your life back together after having treatment, both financial support and support to go and talk to someone. That would help. It would also have been helpful to have support to find out what can be done for ongoing symptoms and treatment. If you have the cirrhosis then it can lead to an early death. There is a lot of information online but it is not always nice to read it. I try to stay away from it because I start to get ideas in my head.

Statement of Truth

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

Signed .. GRO-B

Dated ....16/11/2019....