Witness Name: GRO-B
Statement No.: WITN1943001
Exhibits: 0
Dated: 21 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry.

Section 2. How Infected

2. I have Thalassemia. It's a genetic disorder where my body does not produce Haemoglobin (red blood cells). It is treated by having blood transfusions to keep the haemoglobin levels topped up. Unfortunately, apart from the risk of diseases from blood, with every blood transfusion your body is loaded with iron and iron deposits, which takes its toll on your vital organs. This can lead to organ failure and death. To overcome that you need to take iron chelation therapy to remove iron from your body. This used to be by way of painful injections, but now there are tablets. Every four weeks I need a blood transfusion. When I was younger I did not require blood transfusions so often; It might have been six weeks. However, for the past 20 years it has been every 4 weeks.

3. On Sunday I will have my next blood transfusion. I go in and on that day I will book the next one, which will be four weeks from Sunday. The week before I need to have a cross matched. I receive three units of blood about every 4 weeks. I now receive treatment at the Whittington Hospital. When I was a child I received treatment at the Royal London Hospital. I must have transferred to the Whittington Hospital for treatment when I was about 13 or 14 years old, which would have been around 1980/1981.

4. I do not know when I received contaminated blood. I do not know if the contaminated blood was given to me in a transfusion at the Royal London or the Whittington. The Whittington was so far ahead in terms of treatment for Thalassemia; the Royal London was the dark.

5. We have a specialist Thalassemia nurse; she was present when we were told about me receiving contaminated blood; being infected with HCV. It was either 1988 or 1989. I remember it because my mum and dad were there; they came to the meeting with me. My consultant at the time said there was something she had to tell me and that my mum and dad need to be there. At this time I was in my early 20s.

6. Regarding information, from what I recall I was not given much information. I had a lifelong relationship with my consultant so she didn't sugar coat anything. She said you have contracted Hepatitis C from a blood transfusion. She explained I would need to do a whole bunch of tests to check my liver to see we were going to see what we can do in terms of treatment.

7. To be honest, at that stage I was a bit oblivious to what was going on; I found out more by the actions of others. At first I wasn't too worried. My mum and dad were in pieces but there were no leaflets, no handouts; there really was no available information. My consultant, who was kind of a mother figure to us all, was adamant that they were going to take care of us.

8. I think I was given adequate treatment. It was the late 1980s; it was the best they could do. I think staff were candid and open. Given how many blood transfusions I had it is hard to know when I was given Contaminated Blood. I guess it is very hard to answer that now because of sheer quantity of blood transfusions I had undergone. I know that all of the Thalassemia's patients were told at that time – something must have happened and they told all of the patients at the time.

9. Now every year staff complete Hepatitis C and a HIV tests; they ask for your permission.

10. Every three to four weeks people in the hospital were talking about contaminated blood. I do not know how soon after the subject came up. We talked about what do, what you need to do if you bleed – what about sexually transmitting it. The answer I got was the risk is very low but that never sat comfortably with me and I readdressed that question many times after. There is a Thalassemia community. You would see the same people. It's like a little club, a little community. Going in for blood used to be a bit of a social event. People would bring chocolates; back in those days was an overnight stay.

11. Not many people talk about Hepatitis C. Lots of people even to this day will not say they were infected because of the stigma attached to being infected. All I knew about it back then was AIDS, but then as time progressed and there were a few clinics where we found out they would treat Hepatitis C. You started to see a few people that were attending those clinics with you – it was a nod. Many choose to be very secretive about it because of the stigma associated with being infected.

12. In all my life the risk of contracting infections through contaminated blood was never mentioned, but I do accept that with my condition I did need the blood so maybe I didn't have as much choice as other people.

Section 3. Other Infections

13. As far as I am aware I do not have any other infections. I know of the risk of vCJD because of the awareness of vCJD. Some of the bags of blood have a warning on it and that scares me.

Section 4. Consent

14. I do not believe that I have been tested without my consent.

Section 5. Impact

15. Initially when I got the diagnosis I was not sure about things. However as time passed I understood the implications of it; it is something that affected the liver and destroyed the liver. For me I had been dealing with Thalassemia which was not easy back then and then I had this on my plate. It led me to become depressed about it all. I do not remember a great deal but my partner said that I told her that I couldn't carry on taking my iron chelation therapy for the Thalassemia because what is the point; even if I am treating the Thalassemia, the Hepatitis C is going to kill me. My whole outlook on life changed and I thought *what is the point?*

16. When I started Interferon treatment I would inject myself into my stomach. After a few weeks things just got really bad and I felt even more depressed. I was having really bad thoughts - I was talking things through with my girlfriend but all I could think was that it would kill me. I could not cope so I stopped working. At the time I was in electronics. I had studied electronics. I was fitting security systems into houses and got another job in computers repairs and I was really happy. However, I had to quit work

17. The treatment the first time round was really harsh on me – I remember always being tired, always had pains, depression lethargic. I just couldn't be bothered –

I used to sit at home playing computer games. I did not want to eat. I think I was about 23. I remember even when therapy stopped the feeling sick and the aches and pains might have gone away, but my head was not good. The reason they stopped the therapy after 6 months is because I had not responded. At the time that was the only treatment available. If it did not work that was it.

18. I don't know whether I had any symptoms pre- treatment – it is hard because of the Thalassemia. I did notice times in my life prior to diagnosis and post – I could be talking having a laugh and a joke, but then I would have a mini breakdown 15 mins later. I would be overcome with feelings of worthlessness. Growing up as a teenager I never had that feeling of going from happiness to complete despair.

19. It was several years afterwards that I had my next treatment. I had peg interferon and Ribavirin. I had the same mental symptoms and I remember having extreme weakness. I always felt like I had a fever – one minute boiling, next minute freezing that is when I started to have anxiety which is one of biggest problems to today. I started worrying about things that I would never worry about before. While I was on the treatment I had no positive thinking. I just keep thinking this is not going to work, why are you going through all this suffering for no reason.

20. When you are on the medication you just crash right down. There is weight loss, loss of appetite and the pain from the injection sites. The Hepatitis C was the biggest problem for me; I would think I am going to beat Thalassemia but I am going to die of liver failure – it was horrible.

21. I had the third treatment around 2002. Again Ribavirin and interferon. Then there was the bright side. After I had treatment for about 18 months I cleared – this was in November or December 2004. While I was on the treatment, I was working, but then I started the treatment and the side effects started again. It started with the loss of appetite, the fever and then the emotional side. I became

even more emotional than when I was on any other treatment. I remember times when I would start driving somewhere and for no reason I would start crying. I felt completely sad and empty inside – the anxiety – I started worrying about how I would get there, what would happened if I crashed the car – illogical thoughts, paranoia. I was worried about going on train and the train crashing, what if got robbed or mugged? My head was full of irrational thoughts all day and night.

22. For me what hit me the hardest was not being able to sleep, the insomnia – I could not sleep. I would take my jabs in the evening, go to bed and then I would start worrying and suffering from anxiety. Eventually I would have a few hours' sleep and then I would go to work – I really struggled at work. I was working in a shop selling mobile phones, which I had done previously and could do quite easily, but I really struggled to make it through the working day. I can't put it into words how difficult it was to do a simple job and to go there and not let anyone know what I was going through.

23. I still have anxiety, insomnia, depression, mood swings and an over whelming sadness comes over me. I also have brain fog; before I became infected with hepatitis C I was always very sharp –super quick.

24. During the treatment the glands under my arm pits swelled up and it was horrible. I developed a lump on my face during the treatment and it left a mark on my face. The lymph glands swelling were due to the Interferon/Ribavirin.

25. In the last 10 years I have had lots of problems with my heart. I thought it was Thalassemia related and it might be, but hearing from others who have Hepatitis C I think it is the Hepatitis C. Also my stomach has never been the same. I had to stop eating certain foods. I have been diagnosed with pancreatic enzyme deficiency – before I eat I have to take a tablet to put those enzymes into my stomach so when I eat the food can be broken down.

26. I was going through treatment at the same time as one of my friends. I cleared and he did not. We used to laugh about it we had code words for – we would refer to the medication as the plague but we also referred to Hepatitis C as the plague.

27. I was made redundant last March and I decided I would take a break for a bit. I had got to a place where I had done well for myself; I was a project manager/business analyst. However, over the last 5 years I started to notice I was forgetting things. I would know what I want to say but when I go to say it, it has gone. Sometimes I lose words - I might be talking and I lose word. This is really concerning as I feel it will hinder me from getting a job at the same level.

28. I developed cirrhosis of the liver. I had to undergo several liver biopsies, I am no wimp when it comes to pain from procedures, but–the impact of the pain of the liver biopsies was terrible. I had a total of three biopsies. I was told I have cirrhosis of the liver and I think that is why with Skipton I was a stage 2 immediately. I have regular liver scans. With Thalassemia's we have to have MRIs of heart and liver every 18 months.

29. I had no difficulties accessing treatment for the Hepatitis C – our consultant at the time demanded it for me and got what she needed from the NHS.

30. I will avoid the dentist at all costs – dentists not a good experience anyway but with the whole Hepatitis C stuff in the background it's a truly horrible, embarrassing experience – I feel a real stigma.

31. In 2011 I was in a position where I was going to have my sperm frozen. In order to do that I had to have surgery to extract the sperm. I was due to go into hospital and there had been arrangements made with the cryogenics. Once the sperm are successfully extracted they would be stored there. However, staff contacted me and they would are not going store my sperm because I have

Hepatitis C. I was told they could not risk cross contamination. It was a hideous experience, but they had to concede if the end.

32. I think the stigma of society in general had a profound impact on me – talking about Hepatitis C was something that was never done; even with friends that I grew up with, we never spoke about it. My parents knew; I always used to tell them that it was ok and not to worry – it became a dirty secret.

33. I do feel that I was starting to cope with Thalassemia in my early 20s but this Hepatitis C was the sucker punch, the one you didn't see coming. I think without that I would have coped better and I honestly feel just in terms of my life I know I would have ended up with my girlfriend of that time. When I was diagnosed – we split up because in my head I thought I can't commit, because I didn't know if I will be around to look after you or any family. I was battling the demons. I also know from a career aspect I would have done much better for myself. I haven't done too badly but I could have been so much more.

34. Every new relationship you start, you have to disclose it at the right time. It is incredibly hard to tell someone. Then questions start *can I catch it.* I know at least two partners went away and googled it. It is good now that I am clear and I don't really have to talk about it anymore.

35. After I left college I had a job selling computer games – a big thing at that time. Then I moved on from that when I did the security systems and then I was doing the whole computer engineer. I specialised in fixing Olivetti (PC) computers at the time and Commodore computers but then it all went pear shaped because of the Hepatitis c and the treatment. After the treatment, I managed to motivate myself to get a job, but I started at the very bottom again. I dropped from a mid-level position to a bottom level position earning not a lot of money but I had to build myself back up again.

36. I think my career path would have been very different and I would have carved myself out quite a career. I had great potential; I was very ambitious.

Section 6. Treatment/Care/Support

37. I have been treated badly by the dentist. After I was diagnosed I remember having severe tooth ache. I went to the dentist and he gave me a form to fill in; on that was a question for HIV and Hep C; I ticked Hep C. The dentist then informed me that they are unable to treat me at that surgery because of the Hepatitis C. In the end I had to go to dental hospital at Kings Cross for them to extract the tooth. I suffered so much pain. From the time I first walked into the dentist to getting to Kings Cross hospital it was about 6 months or more. I went for treatment and they said to me you have to wait until you are the last patient. I questioned that and they said after we see you we have to decontaminate you – that was not great. In the end I could not be treated there because I did not have HIV.

38. The next problem with my tooth was after some years. I went to another dentist, filled in the form and again I was rejected. One of the dentists told me of a surgery who would look after me and I was accepted there, but still after all of these years and even though I am cleared I still get asked so many questions and made to feel "bad". I think that deep down it is the stigma of the Hepatitis C – they do not want to treat me but they have to treat me.

39. I was never offered any counselling or psychological support.

Section 7. Financial Assistance

40. I received stage 1 and 2 straight away. I did not even know about the Caxton Foundation until recently. I found out on Facebook. I get a monthly payment from EIBSS – I needed it to pay the mortgage. I recently received some top up

fund. I get about £1500. Now my earnings are currently zero so they give me about £475.

41. When I look at my peer group and they are on £100,000+ jobs. Before I was given HCV we were on the same level.

42. They also pay us £500 for winter fuel.

Section 8 – other information

43. I want to know – after watching that thing on BBC – there was talk about a letter warning the NHS. I want answers to the questions below.

44. If it was known and it was held back that needs to come out. If that is the case people need to be held accountable.

45. There needs to be a decent apology – I know many of the people that were around at that time many are no longer around. Every victim regardless of category should not need to worry about their future be that financial, medical anything else. There must be no discrimination based on route of infection.

46. Did they know, could it have been prevented? Was there a cover up, were notes destroyed on purpose? .

47. Conduct – we have to have the mechanics in place so that at the end of the Inquiry the community have to think that it was a good inquiry. I just want it to be fair and one that pleases us and we do not want to hear afterwards about a whitewash and a shambles. There will not be any future inquiries; we all need to get this one right.

Statement of Truth

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

Signed GRO-B

Dated ………21 February 2019………