ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN5758001
Dated: 5/5/22
5/5/22

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 03 February 2022.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B, my date of birth and address is known to the Inquiry. I run my own beauty salon in GRO-B

2. I intend to speak about my infection with hepatitis C ("HCV") that I contracted as a result of receiving a blood transfusion as part of my cancer treatment as a child. I will speak about the nature of my illness, how the illness affected me, the treatment I received and the impact it's had on my life. In particular, I will speak about the severe mental impact this has had on me and how it has not been properly understood or taken seriously.

3. I am happy to give my statement to the Inquiry, and I wish to be anonymous.

4. The Inquiry Investigator has explained the Inquiry's statement of approach and 'Right to Reply' procedure. I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

5. I wish to acknowledge that naturally as time passes, memories can fade and especially since I was a child when I was infected with hepatitis and I have suffered trauma as a result. I have therefore been able to provide my statement to the best of my memory.

Section 2. How Infected

6. At the age of 6, I was diagnosed with non-Hodgkin's lymphoma. I was really poorly as it had already spread and I was at Stage 3. It was thought that I wouldn't make it. I even caught septicaemia twice. I was in and out of Whipps Cross Hospital and Great Ormond Street Hospital ("GOSH"). That took up a few years of my life – and I missed years of primary school as a result. At one point, I caught a rare virus from a hoofed animal and they stopped my chemotherapy because of that. Normally, it would have gone on for longer.

7. As part of my cancer treatment, I had a blood transfusion. That happened sometime between 1989 and 1992. If I didn't have that blood transfusion, I wouldn't have been here - it saved my life.

8. When I was between 12 and 14 years old, I started to get bruises on the back of my legs without any apparent reason. I was sent to GOSH to undertake blood testing to ascertain whether I had haemophilia, which was what they initially suspected it could be. The testing concluded I did not have haemophilia.

9. However, I can remember being pulled into a small room at GOSH and being diagnosed with Hepatitis C. Although GOSH saved my life (for which I am extremely grateful), the way I was diagnosed with Hepatitis C

added to the trauma. I was spoken to like an adult and given information that was very difficult to process. I was told I wouldn't have a natural birth, that I wouldn't be able to breast feed and that I would have to be careful with having unprotected sex. I was just a child. I was also told I could infect other people if I wasn't careful. They also told me there was no cure.

Section 3. Other Infections

10. I do not believe I was infected with any other infections other than Hepatitis C as a result of my treatment with blood and blood products. I was tested for HIV and I was negative.

Section 4. Consent

11. I cannot comment on whether I have been tested for anything against my will or without my consent for the purposes of research. This is because much of my treatment occurred when I was a child so only my mother would have knowledge of this.

Section 5. Impact

12. I have always thought of myself as a survivor. I don't really have bad memories of the cancer. When people have cancer in their life, that is usually their trauma. But for me, as I contracted Hepatitis C, that is my main trauma in life. Although I went into remission with my cancer when I was 9 or 10 years old, I was immediately forced to face another battle straight after with Hepatitis C.

13. There is no part of my life that has not been touched by Hepatitis C. I have been robbed of so many things in life. For example, I will never have a child. I decided early on that I would never have kids because I would not want to risk passing on Hepatitis C to them.

14. I suffer from PTSD and have nightmares about being diagnosed with Hepatitis C when I was a child. At the time of diagnosis, I already felt so out of place in secondary school as I had missed so many years of primary school for cancer treatment. I was already out of my depth. My social skills were not as refined as other children because of the significant periods of schooling I had missed.

15. There is still so much shame associated with Hepatitis C. I have only recently started telling people that I had Hepatitis C, now that I am cured of it. When I had it, I didn't talk to anyone about it. Previously, I felt there was no distinction between how people perceived HIV and Hepatitis C. Now, fortunately, there is more understanding about it.

16. I've wasted so many years of my life because I felt so dirty and rotten from Hepatitis C. I was obsessed with being perfect on the outside because I felt imperfect inside. I needed to be whatever perfection was on the outside. That is how my eating disorders started. It began to happen when I was around 14 years old which was soon after my Hepatitis C diagnosis. My eating seemed to be the only way to control what was happening to me. I was out of control in so many ways, that this was one thing I could control. I was exercising constantly and vomiting lots. I would eat one meal a day and then throw that up. I had bulimia and anorexia. Nobody really understood what was happening to me – I was praised for my body. In reality, I needed attention for what was happening to me mentally. However, I didn't get that.

17. It all spiralled out of control. I started self-harming when I was around 15 or 16 years old. The harm I was causing to myself increased as the years progressed.

18. I was put into a day-centre eating disorder unit. That's when I first had contact with a psychiatrist. I was treated by Dr GRO-B They tried to treat the eating disorder in isolation, instead of treating the core problem. I cannot get my head around that. I should have been put into talking

therapy. Whatever they did to treat the disorder was never going to work because it only addressed the symptoms of my trauma, rather than the core problem. They put me on sleeping pills and anti-psychotic drugs. I did not have psychosis. My view is that it was cheaper to treat me with drugs rather than providing me with a therapist.

19. Mental health services have been terrible. I begged for mental health help – but all they did was pump me with drugs, instead of treating the root cause of my problems: being diagnosed with Hepatitis C. I was misdiagnosed with borderline personality disorder. That was later shown to be wrong. I was given a load of therapy to treat something that didn't exist. Properly funded and resourced mental health services are the preserve of the rich.

20. Many years later, a drug that I was given – Seroxat - was linked to suicide attempts. That tablet may have been a contributing factor to my first overdose. I've had five overdose attempts with one of them being a serious suicide attempt. With the suicide attempt, I needed to have my stomach pumped. I was then sectioned after telling a medical professional that I was going to commit suicide. I was sectioned to a place called GRO-B After a suicide attempt (of self-harming), I remember nurses would treat me in hazmat suits. They would enter my room in protective uniform which looked like a space suit, they were dressed as if they were going to Mars. It was really frightening, and not once did I see a psychiatrist or therapist in that place. I found that experience very intimidating, especially given the vulnerable state I was in.

21. My friends would come to visit me and were just so confused as to why I was self-harming. I couldn't tell them the reason why I was acting like this. I felt like I was living a double life and the people closest to me couldn't be told. It was traumatising for them too. As they had no idea what was going on, they made assumptions about why I acted the way I did. Even today, I still have to explain to new clients at my beauty salon why I have self-harm scars which can be seen on my arms, and that is

difficult.

22. When I was at college in 2017, I can remember a student telling our teacher that she had Hepatitis C, and she was told she wasn't allowed to undertake beauty treatments (which was in fact not true). I can recall sitting there hearing this being said but I didn't say anything to support the girl because I didn't want anyone to know about my condition. I felt really guilty that I didn't stick up for her. As I hadn't cured my Hepatitis C by that point, I felt uncomfortable saying anything. So even though we talk about stigma from decades ago, it still exists now.

23. When I was a child, I remember Hepatitis C coming up on an EastEnders storyline and so more people became aware of it. A teacher at school stood up one day and told everyone in class that I was infected with Hepatitis C. Luckily, no one noticed what she said or registered what was said. It was that day that I realised I did not want anyone to know. My school did not know how to deal with me or understand what I had been through. I then realised I had to internalise my problems. I made my mum promise not to tell anyone except some of her close friends, and it has been that way until 2019. So, I have lived this way – hiding what happened to me - for the majority of my life. That in itself has inflicted huge trauma on me. The biggest impact is how lonely I have felt and how much of a burden I felt. I found it really hard to explain to people what had happened to me when, visibly, I looked completely healthy and fine. I don't understand why I wasn't put in touch with others who were facing similar problems.

24. Having Hepatitis C has also massively affected my romantic life. I could never be with the love of my life because I didn't let myself get close to him due to my Hepatitis C. Now, he has children with someone else. I was a lesbian for many years because I thought that would reduce the risk of transmission. A nurse once told me that there was less chance of transmitting Hepatitis C to a woman. As a result, I identified as a lesbian. Hepatitis C robbed me of my sexual identity – it was dictated to me. Even

during relationships, I would never let them last significant periods because I did not want to open up. My relationships have been dysfunctional. After I cleared Hepatitis C, I immediately realised that I was not a lesbian and my life had been a lie. I don't know how to interact with men as a result. Most people learn this stuff when they are a child in their teenage years. I'm still learning to navigate normal, functional relationships. Hepatitis C had put all these blocks in place.

25. I was also date raped. That was connected to Hepatitis C because I would not have put myself in dangerous situations if it wasn't for the mental health effects. I was going out more than I otherwise would have in order to self-medicate. Sometimes, I would close my eyes and drive down country roads hoping that I would die. I purposefully put myself in dangerous situations as a consequence of my mental state.

26. Hepatitis C affected my relationships with family and friends. A year or two after being diagnosed with Hepatitis C, my mum was called in for a routine blood test. It showed that she had contracted Hepatitis C from me. My mum suffered a needle stick injury at one point whilst she was assisting with administering my medication as a child. They recognised that as the source of infection. I then had to deal with the fact that I had infected my mum. My mum was treated with Interferon which had terrible side-effects on her. It made her aggressive, abusive and she started self-harming. She wasn't herself. I would come in from school and see my mum on the floor screaming. It got to the point where I didn't even know if my mum would get out of bed that day to have a shower. I would have been only about 14 years old. My mum took all these medications given to her because she wanted to prove she could get rid of it. Then my mum tried to kill herself and so I had to live with my nan. Me and mum do not have a relationship anymore. My mum's mental health broke down as a result of everything that has happened as a result of Hepatitis C. She wasn't getting any help. Our relationship became so toxic when we were both battling mental health difficulties. She now has cirrhosis and her liver is damaged beyond repair.

27. My education was destroyed because of Hepatitis C. I didn't finish my GCSEs because I was sectioned. I will never know my full academic potential. Those chances were stripped away from me. That, in turn, has impacted me financially as I cannot access certain jobs. I have even been at the point of having to decide between gas and electric, and resorted to using food banks. I had no qualifications because I missed so much of my schooling. In primary school, it was my cancer treatment. In secondary school, my mental health disrupted my studies (i.e being sectioned during my GCSEs). When I should have been going to college, I was battling to keep myself alive.

28. I was self-harming. On top of that, I had no self-confidence or worth. People would assume that I was lazy and I couldn't explain to them what was going on. When you look at me, I look like a well-able person. Just because I look healthy, people don't take my mental health seriously. People who have destroyed their livers are getting better treatment than those who have struggled mentally because of Hepatitis C. At one point when I was suffering badly from mental health, I had to beg to be given back benefits that were taken off me. Then later they made my benefits conditional on taking medication for my mental health, and that I didn't want to take. I did not want them because they did not treat the root cause of my problems. I had to prove that I wasn't fit for work. The questions they asked me were always related to my physical disabilities. I didn't want to take the medication, but I had to in order to access my benefits.

29. That's how I ended up going to beauty school as other opportunities were very limited for me. Luckily, I excelled in it. I now run and own a beauty salon in GRO-B.

30. In my mid-20s, I used to be called to have a blood test to prove that I was 'fit to drive'. When I spoke to a doctor about it, they told me that they needed to check my alcohol and drug levels. In the end, I had to fight with the DVLA to not take these tests. I'm unsure why I was ever required to take this test.

31. Sometime later, there was a point when I was drinking and taking drugs in order to cope with my diagnosis.

32. I've been through so much trauma that it's hard to remember everything. Even though I've cleared the virus, I will have to live with the effects of Hepatitis C for the rest of my life. It affected me having my own family, it caused the breakdown of my relationship with my mum and it created a fear of forming close relationships with others.

Section 6. Treatment/Care/Support

33. I was never considered for Interferon treatment because of my mental health. The one thing that could possibly help me wasn't available to me because of mental health problems that I had as a result of Hepatitis C. I find that very ironic.

34. I should have been offered treatment for the psychological effects of having Hepatitis C. Not once did someone tell me or it was recognised that I was going through this because of Hepatitis C. They treated my mental health problems in isolation. When I was younger, I was put in touch with a child psychologist that I would meet once a week, and I don't remember it being particularly helpful. As I got older, that was removed as I was no longer connected to GOSH. That felt like a rug being pulled from underneath me. The difference in support that I received as a child to a young adult was stark.

35. I was constantly mis-diagnosed with things like borderline personality disorder. I feel as if they should have viewed my behaviours in the context of what I had been through with being infected with Hepatitis C through infected blood. My behaviours were a coping mechanism for all the things that happened. As a child, I used to self-harm and I have been sectioned. I now have a private therapist who tells me that my behaviours could have been treated better if it was viewed in context of the trauma that I suffered. They should have been dealing with the root cause. Instead of being met

with empathy, I was shouldered with so much responsibility about not infecting others. I think that was too much for a young child to deal with. I was just a child, and I was warned about child-birth and sharing razors. It was too much to deal with and it was billed as a prison sentence.

36. At this point, I had given up on getting any help from my doctors. I had given up on the mental health system. I had given up on Hepatitis C treatment, other than Interferon. One day out of the blue in 2019, I was at work and received a phone call. Someone said they were contacting me from the Royal Free Hospital to inform me that there was a cure for Hepatitis C. It was a very blasé conversation. They told me to come down for an assessment to make sure I fit the treatment's criteria. My mind was completely blown. From feeling like you would never be cured and being told that you were a risk to others all the time, to then being told that it could be cured with a simple pill. I went down to Whipps Cross Hospital to see the doctor and a specialist nurse. They told me that this treatment has been available since 2015. There is a complete failure in the system. I am really shocked and angry that it took them until 2019 to tell me that treatment was available to me. If I was someone who wasn't cautious about Hepatitis C, I could have been infecting other people during that period. That is four years of my life that was taken from me that could have been easily saved.

37. My viral load of Hepatitis C cleared after just the first two weeks of my treatment. However, I carried on the treatment for the full three months in order to finish it completely. As part of the follow-up process, I went for a check-up at six months and one year later. The treatment itself was a really easy process. Professor Dusheiko was very sweet to me.

38. Although, it is hard to measure the side-effects of that drug. I was going through so much. I had not even told my partner at the time about what I was going through. I had to hide my treatment even to the point of making up a story about why I was taking medication regularly. It was a tough period because I had to face Hepatitis C head-on again and was going to

the hospital for my treatment alone. I was also appalled that the GRO-B GRO-B did not tell me about the work of the Infected Blood Inquiry. Either she was covering something up and didn't want me to know about it or didn't even know that the Inquiry existed. Both reasons are not acceptable. Doctors and nurses should be letting infected people know about the Inquiry. Even during my treatment, I wasn't offered any psychological support. I was so vulnerable at this time. There should have been something set in place for people going through a traumatic process and being treated for an infection they've had for so long, let alone being infected through no fault of their own.

39. I once had a lipoma that was infected, and so I had to go to Whipps Cross Hospital to get it lanced. The first question the doctor asked me was whether I had Hepatitis C. I didn't want to disclose it at this point because my friend was with me at the appointment and she didn't know about it. I was put in a real difficult situation at that moment, however he had my hospital notes and so he should have been aware of my diagnosis. As he cut my lipoma out, some of my blood splashed into his eye and he ran off. I do not understand why he was not wearing adequate protective equipment like goggles. I could not believe what happened. It was a very traumatic experience for me to go through. It could have been avoided if he had taken the expected precautionary steps, spoken to me privately or read my notes.

40. When I was teenager, I was even told by my dentist to not kiss anyone because I might give Hepatitis C to someone. This is a traumatic thing to be told and I couldn't even go and share those things with my friends because no one knew.

Section 7. Financial Assistance

41. I found out about the Skipton Fund when I was around 18 or 19 years old. I'm not sure how I found out about it but I just assumed that it was some sort of charity, not connected to the government, to help people. I also

find that the constant name changing of the financial assistance funds to be very disruptive and strange. It means that people are less likely to understand what is going on. A constant name that allows it to be easily identified would mean that more people would be able to access funds. The next thing we knew the Skipton Fund was shut down. It appears to be that they have done the minimum possible to protect themselves from accusations of not doing anything but not actually resolving the situation for us. No one pro-actively contacted us to let us know that this support was available to us. I am very surprised that accessing support requires the individual to seek it out. If that person is in a bad place (as a result of Hepatitis C), then they won't have the energy or the fight in them to get the support they need. There should be a better functioning system to ensure support is accessible. I don't understand why I wasn't given annual updates about what was going on.

42. I am in receipt of stage one EIBSS payments.

43. I have also received a discretionary payment of £900 for a year of counselling support. As mentioned before, I have had difficulty in obtaining counselling support through the NHS. Although I had been in receipt of the EIBBS financial support, I had not been told that there was a discretionary payment for counselling support. It was only when I spoke to the Infected Blood Inquiry Investigator that she told me about this discretionary payment. I am currently receiving counselling support but EIBSS have told me that they will require me to prove that I need more sessions when this year of support ends. I believe it should be an automatic rollover to the following year and I should not need to prove that I still require the counselling support. Further to this, I even had to pay my doctor for the relevant forms to submit the application.

44. To access funds from EIBSS, my mum was required to prove that she caught Hepatitis C through a needle stick injury when she was treating me. Luckily, we could prove it because there was evidence archived by

the Skipton Fund that I'd had a blood transfusion and a record of her administering my medication.

45. Further to this, as far as I know, when I was around 9 years old, and my mum was acting on my behalf, there was a class action that she was a part of, whereby I was awarded £60,000. My mum was coerced into signing a legal document declaring that we would not bring further legal action if we signed and accepted the payment. My mum was told that if we didn't sign the full and final settlement by the solicitor, that I may end up with nothing. I am fuming about this and this legal document has caused me lots of stress and worry. Although I do not have a copy of it, I assume that it is kept somewhere in existence and it is restricting me. It is really unfair that this document was signed on my behalf when I was a child and it is therefore restricting me today if I wish to bring action for what happened. What I was given was a really small amount of money in comparison to what happened to me and it is unfair that it now restricts me. In recent times, I have contacted law firms to represent me and I have been told they cannot represent me as I have signed a full and final settlement. I think these law firms could have dealt with this issue more delicately with me. They all profess to be compassionate and kind, but as soon as I reach out, they say they can't help me. Also, the £60,000 was gone within a year. I spent it on cosmetic treatments and designer products. I should never have been given that money at such a young age – I wasn't mentally stable to have it.

Section 8. Other Issues

46. I want to be compensated. The £60,000 I was awarded is nothing for what happened to me. I feel like I have been silenced. Although no amount of money will give me back all the years that I have lost and all the trauma I have suffered, compensation will give me peace and justice – and it would be an acknowledgement that I was wronged. I need Sir Brian to ensure that those who signed a full and final settlement form many years ago are taken as seriously as those who didn't. My claim should be

measured just the same as those who didn't sign that form. Having this reassurance from Sir Brian that those involved with a previous class action are protected is key.

47. I want to know why the blood wasn't tested adequately for infectious diseases. As much as they're putting emphasis on why they needed to get blood from elsewhere, they also need to ask why that blood wasn't sufficiently screened. It seems pretty straightforward to me. The issue is not where the blood came from, but about why it wasn't screened properly. We should have also been warned about the risks of treatment – I don't know why I've lost so many years of my life. I want to know who is responsible for what happened.

48. I want mental health to be taken as seriously as physical illness. I find it frustrating that my mental health wasn't treated as part of my Hepatitis C infection. There was no real acknowledgement that my mental health was impacted by Hepatitis C. I am so fed up with getting people to understand this. I have to constantly fight to prove the impact of this condition. Those with cirrhosis don't have to do that. Physically, my body is like a powerhouse – it has dealt with so much. That is why it's so important for people to understand the mental effects of what's happened to me. The mental health system needs to be overhauled with immediate effect and there should be recognition of mental health issues that have arisen as a result of people receiving contaminated blood.

49. I find it disgusting that there are those out there that still don't know about the Inquiry but are living with the effects of Hepatitis C. I found out by luck through my relative. No information has been given to us by my hospital or doctor's surgery – we had to look for everything. As I said earlier, doing that is very difficult when you are battling with the mental and physical effects of Hepatitis C. Information needs to be more accessible. You feel so alone – there should be something in place to support us. For example, it would be nice to talk to someone else who was also infected and has been through a similar experience to me. I also believe the

Inquiry should be in the media much more than it has been to ensure more light is shone on the topic and to increase its awareness.

Statement of Truth

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

Signed GRO-B

Dated 5/5/22