

# ANONYMOUS

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Witness Name: GRO-B

Statement No.: WITN0358001

Exhibits: WITN0358002

Dated: 13/06/2019

## 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 12 February 2019.

I, GRO-B will say as follows: -

### Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1965 and my address is known to the Inquiry. I intend to speak about how I was infected with Hepatitis C through blood transfusions I received in 1991.
2. I am a single mother of two daughters aged 22 and 24, and a grandmother to my eldest daughter's two year old. I live in Manchester and currently work in a children's nursery.
3. I was only 24 years old when I was infected and, in many ways, it has drastically changed the course of my life. The infection and side effects of my treatment have impacted not only my health, but also my self-confidence, family life and finances.

**Section 2. How Infected**

4. Around April 1991, I took ill while I was working at a nursing home in Manchester. I went to the doctor with a headache and chest pains before going home to rest. The following morning, the headache was still there and I just didn't feel myself. My twin sister told me to lie down; however, I only got halfway up the stairs before I collapsed. My sister phoned an ambulance but I can't remember anything after this.
5. By the time the ambulance arrived, I had come to but my words were so twisted that the paramedics thought I was speaking another language. I was taken to coronary care at Manchester Royal Infirmary where I ended up in a coma for a month. The doctors said I'd had a mini stroke and I was diagnosed with Thrombotic Thrombocytopenic Purpura ("TTP"). I received multiple blood transfusions and plasma, both while I was in a coma and after I had woken up. I cannot remember the exact dates in 1991 that I was given these; however, my GP has told me that my medical records show it was around 10 April 1991. I also cannot recall whether I received any blood products, such as Factor VIII.
6. Once I had come out of the coma, I was just told that I was being given blood transfusions to help me get better. I was not given any information about the risks involved. My mum was with me at the hospital as well but I am not sure what information she was given as she has since passed away. However, at no point between the blood transfusions in 1991 and my eventual Hepatitis C diagnosis in 1996 was I ever told that I might be at risk of carrying any infection.
7. I faced a long road to recovery over the next year. I had lost my voice. My memory had been affected and I was unable to recall the names of people that I knew well. I also had a limp so had to receive physiotherapy for my leg and was given weekly exercises to complete.

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8. In 1993, once my health had improved, I returned to work at the nursing home. Every month I would visit the haematology clinic for various tests and checks and I would repeatedly be told that everything was fine. This remained the case until 1996, when I received a telephone call informing me that, while doing more tests on my blood, something had come up and the hospital needed to see me.
9. I had an appointment with a haematologist at Manchester Royal Infirmary. I can't remember his name. He told me that I had been infected with Hepatitis C through the blood transfusions I had received. I had no idea what Hepatitis C was and asked for more information but the doctor was very vague. He said that I had to return another time in order to discuss it fully.
10. The way that my Hepatitis C diagnosis was communicated to me was entirely not good enough. No one seemed willing to address how serious this was for me or accept any responsibility for it.
11. From then on, the doctors had to monitor me regularly. I kept being referred on to different people for tests and checks. Over time, my haematologist gave me more information but it was not until around 1999 that I finally started to understand what Hepatitis C was and how much it would impact my life. Even after this, I found that there was no ongoing support and I was not given enough advice about how to manage my health going forward.
12. At first, I was not given any information about the risk of passing the infection to others. I was told at some point not to share toothbrushes and to be careful with blood and sexual intercourse. However, I do not feel I was given enough advice about the risk of transmission.
13. My first daughter was born in 1994 and my second daughter was born in 1996, the same year as my Hepatitis C diagnosis. However, both of them were not tested for Hepatitis C until 19 March 2001. I know the exact date

because I checked this recently with my GP. Fortunately, they were both negative. However, it concerns me that it took so long for them to be tested. If they had been infected, they would have been suffering for that entire time and I would have been none the wiser.

### **Section 3. Other Infections**

14. As far as I am aware, I have not contracted any infections other than Hepatitis C. I do not recall ever being tested for HIV.

### **Section 4. Consent**

15. As far as I am aware, I was never tested or treated without my knowledge or consent. However, at the time I received the blood transfusions, I was not given any information about the risks involved. I was also not told that I was going to be tested for Hepatitis. I had regular blood tests due to my TTP but I did not realise that they were testing for Hepatitis C until I was diagnosed with it.

16. I have never been involved in any research but I do feel like a guinea pig at times. My doctors have recommended a number of different Hepatitis C treatments and give assurances that these are likely to clear the virus. However, every treatment I have tried so far has not been successful.

### **Section 5. Impact**

17. Years of being infected with Hepatitis C have had a significant negative impact on my health. For many years, I was told I had Hepatitis C genotype 2; however, I have recently been told that the specialists got this wrong and I actually suffer from genotype 3. I also suffer from fibrosis of the liver.



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18. I am constantly tired due to my infection. I also have arthritis, which I feel could be related to the Hepatitis C. My hand is always swollen and I have to use a walking stick to go up stairs.
19. I have also struggled with depression for a number of years and I believe my infection has played a big role in this. I feel as though I am in a bad mood all the time. I was first prescribed with antidepressants several years ago and, although I still have some now, I try not to rely on them.
20. For many years, my condition was only monitored and I was not offered any treatment. I was referred to a hepatologist at some stage but I can't remember when. I would see my hepatologist one month and my haematologist the other month. For a long time, it felt as though I was just constantly going to Manchester Royal Infirmary for endless tests and monitoring.
21. Then, in 2005, I was offered a treatment called Interferon. I took this for six months in combination with another drug called Ribavirin. The Interferon was an injection I had to give myself once a week and the Ribavirin were tablets I had to take everyday.
22. The side effects of this treatment made me feel horrible. I couldn't really eat anything so I lost a lot of weight. My sleeping patterns were entirely disrupted. I also suffered from severe headaches, mood swings, hot flushes, flu like symptoms and fatigue. I was basically a zombie for the entire course of treatment. I would get up, have a bath and then have to sleep through the afternoon. I wasn't well enough to go to work and had to take nine months off. Although I was given a leaflet explaining some of the possible side effects, I had no idea that they would be quite as horrific as they were.
23. Throughout the six months of treatment, I kept telling the doctors that I felt as though it wasn't working, but they insisted that there was a good chance that it would clear the virus. Despite this, when they tested my

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blood after six months, the treatment had not worked. I went through six months of hell at the advice of medical professionals, all for nothing.

24. I feel like the doctors were not honest with me about the real chance of success of the treatment. If they had told me the truth, this would have allowed me to make an informed decision as to whether the horrendous side effects were worth the risk.

25. After I finished the treatment, I told the doctors that I didn't want to put myself through the same thing again. I didn't want to have to go through another disappointment. However, in 2017, the doctors offered me a new treatment called Sofosbuvir and they again said there was a good chance it would clear the virus. I therefore started the treatment, again in combination with Ribavirin.

26. This time, the side effects weren't as bad; however, I still suffered from nausea, headaches and hot and cold flushes. I was on this treatment for three months and, although the doctors had said it was one of the better treatments, it still didn't clear the virus.

27. In January 2019, I started a new treatment called Vosevi. It is a 12-week course and I have just finished it recently. It gave me constant bad headaches and I had to stop taking my arthritis medication as it can interfere with the treatment. Because of this, I was in pain constantly.

28. The doctors told me that there was a 99% chance this treatment would clear the virus. However, I was worried that I would be the 1%. I feel that if something has been dormant in my system for this long, I am never going to be able to get rid of it. Everyone is different and so, just because it has worked for others, it doesn't mean it will work for me.

29. I finished the treatment in April 2019 and my hepatologist told me that, although my viral load had reduced, it still hadn't cleared the virus. Then, at my most recent appointment with my hepatologist on 2 May 2019, I was

told that my viral load had suddenly increased again, but they do not know why. It doesn't seem to make any sense given it had significantly reduced when I finished the treatment around one month earlier. I produce the letter to my GP regarding this appointment and dated 2 May 2019 as **Exhibit WITN0358002**.

30. I am going back to see my hepatologist in six months time. However, at this stage, I do not want to try any further treatments. I do not want to be their guinea pig. What is the point in me taking all these drugs if they're ultimately not going to help me? It is very difficult to remain hopeful after continually being told by doctors 'this one will work', only to be disappointed each time. I feel like I am going around in the same circle every time I start a new treatment and the disappointment only makes me feel more depressed. I am also concerned that these treatments may have caused or worsened some of my ongoing health issues, such as my arthritis and fibromyalgia.
31. The NHS is responsible for giving me contaminated blood and I therefore feel that they should have accepted responsibility for finding an effective cure sooner. I don't want to be waiting another ten years.
32. I cannot remember the names of the specialists I have seen, as I don't tend to see the same person each time. Throughout my monitoring and treatment, I have often felt like the consultants have no time for me. I am often unable to understand the medical terms they use and I have never really had a chance to properly discuss my condition and how I am managing my health.
33. My private, family and social life have been significantly impacted by my infection. I feel like being infected at such a young age changed who I was and how I felt about myself. Growing up, I was very sporty and I loved running and cycling. I enjoyed going out with friends and family. However, after I was diagnosed, this all changed. It was as though my life wasn't my own anymore; something else had taken over it. It is difficult to know just

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how different my life would have been had I not been infected because having Hepatitis C from such a young age has shaped so many of the important decisions in my life. It has stopped me from doing so many things. It's not fair when this isn't my own doing; when it's not my fault in the slightest.

34. When I was younger, my infection meant that I couldn't even face going out to places by myself. I often didn't feel able to leave the house and my sister would have to take me everywhere. I lost my independence, my confidence and my ability to lead a normal life.
35. Even now, I prefer to be on my own. I isolate myself rather than going out and being with friends because of the impact the infection has had on my life. I am constantly tired and so, while I do still try to get out and about, even going to the pictures will wipe me out for the whole of the next day. I therefore often just come home from work and sleep.
36. Events that involve alcohol can also be a challenge. I don't smoke or drink. At the moment, my liver function is stable and I am managing my health so the last thing I want to do is make things worse by drinking.
37. It has also been difficult having to cope with my infection while also managing family commitments. Before my mum died of cancer in late 1997, I helped to take care of her even though I wasn't well myself. My first liver biopsy was on GRO-B the day after her funeral.
38. I am a single mum and so it was especially hard dealing with my infection and the side effects of treatment while also raising two young girls. Fortunately, my twin sister lives nearby and all my siblings have helped me a lot over the years. However, it made me angry and annoyed when I wasn't able to care for my children on my own; it should be up to me as a mother to look after my children and provide for my family. I shouldn't be a burden on my siblings.



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39. My daughters are strong girls and they understood from an early age that I couldn't look after them as often as I'd wanted to. Fortunately, because they were told about my infection when they were very young, they accepted that there were certain things that I simply couldn't do.
40. Even now, it is hard for my daughters and those close to me to see me unwell. It has been especially hard for my sister to watch me go through this because we are twins and we are so close. Even spending time looking after my granddaughter can be difficult as I am always so tired.
41. Due to the stigma associated with Hepatitis C, I often felt as though I couldn't talk to anyone about what I had been through. Only a small circle of family and close friends in my life know about my condition and the circumstances of my infection. I didn't know how people would react and so I felt unable to tell friends and people at work. I worry that people will judge me and assume I am a drug user, even though my infection occurred through no fault of my own. I therefore just keep my mouth shut and carry on everyday as much as I can.
42. When I was younger, I found it particularly difficult entering into new relationships. I felt like I could not tell my partners that I had Hepatitis C, as I felt sure they would leave me straight away. It meant my partners would become suspicious when I always had to insist on using protection. I feel as though my infection has made it difficult for me to form full, trusting relationships because I am often scared to tell the person I am with that I have Hepatitis C.
43. I feel that, unlike AIDS, Hepatitis C has been brushed under the carpet. It's treated as though it's a disgrace, which isn't right. It shouldn't be hidden. They have World AIDS Day, but what about awareness for Hepatitis C? I wish the Government had done more through campaigns or leaflets to inform the public. At least then others would be aware of the fact that some people have contracted Hepatitis C through blood transfusions and not just drug use.

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44. I feel like even some medical professionals aren't well informed. At one point in the late 1990s or early 2000s, a haematologist asked me where I had caught Hepatitis C. She told me that I must have caught it from somewhere, as though it was my fault. I couldn't believe it. She hadn't even bothered to read my notes.
45. I also told my dentist about my infection and, soon after this, he told me that he no longer had time to see me as a patient and recommended that I start seeing another dentist within the same practice. It made me feel uncomfortable. I was worried that he was just trying to get rid of me because he was scared of contracting Hepatitis C. Fortunately, I have had no issues with my new dentist.
46. Being infected with Hepatitis C has had various negative effects on my work and financial life. I completed a childcare course before I was infected. Then, in 1994, I started working as a clerical officer for GRO-B I worked in this role for 17 years and I had to take nine months off while I was taking Interferon.
47. I currently work five days a week at a children's nursery. Although I have not told previous employers about my infection, the nursery is aware. They are supportive; however, I don't get paid for sick leave and so I often force myself to go into work even when I am feeling not well enough. I would like to give up this role because working with small children is so draining for me, but I cannot do so for financial reasons.
48. Financially, the most significant impact on me is that I have had to take a lot of time off work due to fatigue. On top of this, for about 25 years I have had to pay for my own transport to frequent hospital visits and doctor's appointments. I also often had to take unpaid leave from work in order to attend these appointments. Although I have just enough to pay my bills from my wages and the financial assistance I receive, there is nothing left after this. I am still struggling.

**Section 6. Treatment/Care/Support**

49. I was never offered counselling or psychological support as a consequence of being infected by the NHS. The doctors were always worried about my liver and my physical health, but no one seemed to care about my mental health. I did see a counsellor around 1994 but only after I had asked for this myself.
50. More recently, in around 2016, I asked my GP to refer me to a psychologist. In the end, I only did four or five sessions. I'd hoped I would be able to go into deeper discussion about my Hepatitis C and what I had been through. However, when I finished the sessions, the psychologist told me my mental state was fine and I would need a further referral from my GP if I wanted to continue seeing him. He gave me the impression that there was nothing more he could do for me, so I didn't bother asking for a further referral.
51. I feel there has been a complete lack of support for people in my situation. I have often felt as though I don't have anyone to talk to who understands what I am going through. The sense of stigma and my personal feelings of being isolated were and continue to be worsened by the fact that there has never been a local dedicated support group set up by the NHS for people in my situation. I feel I would really benefit from being able to speak to others who can appreciate what I have been through. I know there are groups in London, but I have never lived there so they are of no use to me. I can't help but feel like nobody cares.
52. Ideally, I would like to give up work and set up a support group to help others in my situation so that no one else has to suffer in silence. Even having someone who understands that I can speak to and message when I'm going through a difficult time would make such a difference.

**Section 7. Financial Assistance**

53. I had a biopsy around 2006 and, while I was in hospital, another patient told me about the Skipton Fund. If it had not been for this chance encounter, I don't know how much longer it would have been before someone told me about it. No doctors had ever mentioned it to me.
54. I contacted the Skipton Fund and was sent an application form to complete. When I asked my consultant to help me complete this, I was told that they are not there to fill in forms. I was quite shocked at this response and it made the process of applying more stressful and intimidating due to some of the complicated medical questions being asked.
55. Other than this, it was quite straightforward applying for the £20,000 lump sum. I received the payment soon after I applied; I can't remember the exact date but believe it would have been around 2006. I did ask about the stage two payment but was told that I wouldn't qualify. I find it frustrating that I have needed years of monitoring and treatment because my doctors are so concerned about my liver, yet I still don't qualify for the further payment.
56. Years later, I started receiving a monthly payment of £250 from the Skipton Fund. When the Caxton Foundation was introduced, I had to complete another form to apply for this further support. Then the England Infected Blood Support Scheme ("EIBSS") took over and, again, I had to complete a new form and provide the same evidence. When EIBSS took over, the payments increased to around £18,000 a year and, on top of this, I receive an income top up of £245 per month.
57. On 3 May 2019, I was sent a letter by EIBSS saying that my payments have increased to £28,000 per year. This will be backdated to 1 April 2019 and I will no longer have to apply for the income top up payments.



58. Money cannot get me my health back. However, I still think it is important that the Government and the NHS acknowledge what we have been through by giving us fair compensation. I think the amount of financial support I have been provided is an insult really. How can they say this is how much an individual is worth when they haven't been through it themselves?

59. I also feel that everyone who has been infected should get exactly the same amount of money. The contaminated blood wasn't given out in categories, so we shouldn't be put in categories.

### **Section 8. Other Issues**

60. I have never been involved in any previous inquiries or campaigns. However, I did attend the GRO-B meeting for this Inquiry in GRO-B 2019. I found the meeting helpful, but it was very apparent that my sister and I were the only black people there. I know that dedicated support groups exist for black AIDS survivors, so it is frustrating that similar options do not exist for Hepatitis C sufferers.

61. I strongly feel that it should never have taken this long for the Government to do a full Inquiry. We all need our health to get somewhere in life. This has stopped so many of us from living our lives and we still do not know all the reasons behind this. We are offering up our stories and experiences now in the hope that it will bring us more support, but there are no guarantees and we are still waiting for answers. We have already been waiting long enough.

62. There have been too many promises but not enough action. We are now so many years down the track and it's the same story. If the Government were to offer us more financial support in the interim, I feel this would do a lot towards building trust. The first thing the Government should be doing is giving people what they deserve.

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63. I also think that there needs to be some attempt to raise awareness for Hepatitis C and to create solidarity between those who were infected. What happened shouldn't be a thing that is hidden under the carpet; it needs to be understood so that it never happens again. I don't want anyone else to have to go through what I have been through.

64. Once the Inquiry has finished, we will all return to our lives. We are all still going to be suffering once this is all over. There must be some way to continue the conversations we've been having so that we can carry on supporting each other. I don't want us to be forgotten.

### Statement of Truth

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

Signed

GRO-B

Dated

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