2/6/2019

ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN0018001
Exhibits: N/A
Dated:

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 1 March 2019.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1956 and my address is known to the Inquiry. I intend to speak about my infection with Hepatitis C Virus ("HCV") through a contaminated blood transfusion.

2. I am a retired nurse and I currently live with my husband, GRO-B GRO-B We married in 1985 and we have two grown-up children and two teenagers.

3. I received numerous blood transfusions between 1986 and 1994 due to complications during childbirth and miscarriages. I would have been infected with HCV through one of these transfusions. However, I did not start developing symptoms until 1991 and I was not diagnosed with HCV until 2016.

4. Following treatment in 2018, I was able to clear the virus. However, the diagnosis was and is still difficult for my family and I to bear. It has affected us financially, psychologically, physically, socially and mentally.

5. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

6. On GRO-B 1986, I delivered my first daughter at Newham General Hospital, now Newham University Hospital. As I was going back to the ward, I started to haemorrhage, so was then taken back to theatre for evacuation of suspected blood residue in my womb. Thereafter, I was returned to the ward and received a transfusion of two units of blood. I was discharged home after seven days.

7. Around two weeks later, while I was at home, I started to bleed uncontrollably. I went to the bathroom and called out for my husband. When he came in, my clothes were covered in blood. There was blood everywhere. It was terrifying for both of us.

8. My husband called the London Ambulance Service who took me back to Newham General Hospital. On arrival, I was examined and was taken to theatre for evacuation of blood clots and placenta residue, which had decayed in my womb. The doctor, whose name I do not recall, explained to us that mistakes were made during the delivery of the child, which led to reoccurring bleeding. I was diagnosed with anaemia because of the continued bleeding and needed a blood transfusion.

9. On the whole, I was given four units of blood and spent seven days in hospital. The whole experience was terrifying. My husband and I felt that the consultant was bullish and uncommunicative. We tried to ask

questions about what had happened but he wouldn't respond to us. We also tried to get some answers from the GP but he wasn't able to give us much information considering he wasn't there for any of what had happened.

10. We were young and fairly new to the country at this time, as well as first time parents to a newborn baby. The whole process was therefore very overwhelming for us and we found it difficult not being given proper information about what had gone wrong. In the end, we had to just swallow it and move on.

11. On GRO-B 1988, I gave birth to my second daughter at Newham General Hospital. I again lost a lot of blood due to unexplained complications. As a result, I became anaemic and was given three units of blood. I cannot recall the exact date of the transfusion; I know it was not on the same day that my daughter was born but was possibly a couple of days later. I had the same consultant as the last time and, again, he didn't explain what had gone wrong or provide any answers to our questions. I was discharged from hospital after seven days.

12. In 1990, I fell pregnant again. One day when I was at work, I fainted and started bleeding. I was rushed to University College Hospital in London but was later discharged. I still didn't feel right a couple of days later and I went to my GP who called an ambulance for me. I was taken to Newham General Hospital where I was examined by the medical team. We were informed that I had miscarried and I was taken to theatre for removal of blood residue. Thereafter, I received a transfusion of four units of blood and spent seven days in hospital before being discharged. I can't recall the exact date I received the transfusion.

13. I had a further miscarriage in 1992 and another in 1994. Again, I lost an excessive amount of blood and was taken to theatre for blood

transfusions and evacuation of blood clots. I cannot recall the exact dates of these blood transfusions, but I remember being kept in hospital for four weeks in 1992 and seven days in 1994.

14. I was never told that there was a risk of being infected with anything when I was given the blood transfusions. It was just a case of being told the nurse was coming to give me blood and that was it. There was no explanation. Back then, we were naïve and the consultants acted like gods in that they were arrogant when interacting with patients. We felt that we couldn't ask questions and when we did try to get more information about my treatment, our questions went unanswered.

15. I received blood transfusions on six different occasions in total. Throughout this period, I was unaware that I had been infected with HCV and had been living a normal life working and bringing up my children. Because I had so many blood transfusions between 1986 and 1994, it is hard to pinpoint exactly when I was infected.

16. Around 1999, my health started to deteriorate. I felt like something wasn't right and I went to a series of hospitals to try and find out what was wrong with me. However, I was not able to get any meaningful answers.

17. In around 2000, I had a scan and was told I had pigments on my liver, but the doctors couldn't explain why. I had also started to experience jaundice, rashes, and skin irritation. The doctors were aware that I had received blood transfusions. However, even with this knowledge and the symptoms I was presenting with, they did not test me for HCV. On reflection, I don't feel that the medical professionals were trying very hard to find answers at this time.

18. My health continued to steadily decline and by 2004, it was clear something was definitely wrong. By this point, I was regularly having

nosebleeds, hyperventilating on exertion, fainting, suffering from itchy skin and was unable to do anything meaningful. I lost a lot of my confidence and started to become very depressed. It was very worrying for my family and I, as we had no idea what was happening.

19. I saw my GP regularly about my growing health concerns but they were not very forthcoming with any referrals. I was experiencing so many symptoms; however, the medical professionals seemed to just address each symptom individually while the underlying damage continued. I was on so much medication to suppress my symptoms; the amount of tablets I was on every day was like a chemist. My GP prescribed an antihistamine called Piriton and Oilatum skin emollient cream, which I was told to use before bathing to try to alleviate the issues I was having with my skin. Yet, nobody was looking for the core issue. This pattern continued until 2016. By then, I was very, very ill.

20. In October 2016, I was sent for blood tests by my GP. When the results came back that same month, someone from the surgery called me and asked me to come in. My GP informed us about the results, which showed that I had HCV. She said it had been in my system for quite a while and that my liver had already been badly affected. The news was catastrophic and deeply heartbreaking for me and for my entire family.

21. I didn't really know what HCV was at that time. The GP did say that HCV was serious but didn't explain anything more about it. No advice was given in respect of alcohol or how to manage the infection. Furthermore, at this stage it was not mentioned that the HCV could have come from the blood transfusions I had been given in the past. I was simply told that I would be referred to a hepatologist for consultation and treatment, and I was sent away to wait to hear from the hospital.

22. I strongly believe that there should have been early intervention from the GP and medical professionals. Frankly, I was left in the dark, on my own with a debilitating illness. Had information on the virus been provided to me earlier, it would have at least helped to prepare the minds of myself and my family in relation to what HCV is, the potential treatments and my prognosis.

23. I was also not given any information about preventative measures I should take in respect of transmission to others. For example, I was never told to take any precautions in respect of sexual intercourse or cuts. When I had my first appointment with the hepatologist, I asked if I could still have sex and he answered, 'yes, you can have your normal life.' It was never mentioned that we should use condoms.

24. Around two years ago, the hepatologist suggested that my husband and children should get tested. However when my husband went to the GP to request this, the GP said there was no point because if he were infected, he would have known by now. Therefore my husband and children have still not been tested.

25. The vast majority of information we have received about HCV was as a result of our own research using the Internet. We are fortunate in that we have the skills to be able to carry out research ourselves. I felt we had to do this in order to understand the infection and its consequences, and then to plan for the future. However it was scary seeing things such as mortality rates and having to deal with and understand this on our own. This added to the trauma of the diagnosis itself. It would have made a big difference if we could have had more information from the medical professionals themselves.

Section 3. Other Infections

26. As far as I am aware, I was not infected with any other viruses.

Section 4. Consent

27. As far as I am aware, I was never treated without my knowledge or consent. I gave my consent to be tested for HCV and for all of the treatment I received following this.

28. I feel, however, that I was often not given adequate information by the doctors. For instance, I was not given any information regarding the risks associated with blood transfusions and, following my diagnosis with Hepatitis C, I was given very little information about the infection. It was only during my first appointment with the hepatologist, in June 2017, that I was finally given information about treatment, side effects, prognosis, and possible complications.

29. Shortly after my diagnosis and while I was waiting for treatment, I was told that, because of the state of my liver, my file would be useful for research that was being carried out at the Royal London Hospital. It wasn't explained what the research was. I hoped it would help my progress and be of benefit to other people, so I agreed.

30. I did not hear back about my treatment or the research project for several months. The Royal London Hospital's research team were inaccessible, despite every effort to locate the people responsible for the study, including phone calls and a visit to the unit. It proved abortive and was unprofessional on their part.

31. In 2017, my husband and I went to Queen's Hospital and I asked them to withdraw me from the Royal London Hospital research project, as I did not feel this was helping me at all. It was just causing me more stress.

32. I believe I was withdrawn from the research as soon as I told Queen's Hospital that I no longer wanted to be part of it. However, it was not

right that I was given so little information about what this research was for and was unable to contact those responsible for the study.

Section 5. Impact

33. My family and I experienced and are still experiencing terrible mental and physical effects of me being diagnosed with HCV. For a long time, my family and I were unaware of the infection, its consequences, my prognosis and the reason why my health was declining. Not knowing about the diagnosis made it harder to cope and plan for the future.

34. My physical and mental health gradually grew worse and worse. By 2016, I had developed skin pigmentations, which made me continually itchy all over my body. I went yellow for a period from jaundice. I also lost weight and suffered from a loss of appetite, shortness of breath and chronic fatigue.

35. My mental health was also impacted. I became very fearful of the unknown and was frequently tearful. I suffered from depression, forgetfulness, paranoia and anxiety and even felt suicidal at times. I was always angry. Any little thing would spark me off and I would snap and shout. I had a complete change of personality; it turned me into a monster.

36. All of this had an extreme effect on my entire family's psychological and emotional wellbeing. Not knowing the reason for these symptoms was incredibly difficult, and we felt utterly hopeless for a very long time.

37. After my diagnosis in 2016, I still felt very alone and in the dark. My status as being someone with HCV was heartbreaking. It was psychologically demoralising.

38. Because the doctors did not give us much information at first, we started to do our own research. After doing this, we realised the HCV must have come from the transfusions, as we knew our social and sexual habits and there was no other explanation for how I could have come to contract it. For example, we had never used drugs, we are not promiscuous, and have never been involved in any risky behaviour. Once we learned more about HCV, the treatments and prognosis, we were heartbroken that I had contracted this.

39. My GP referred me to a hepatologist in October 2016, but I did not hear anything for several months. It was not until June 2017 that I first saw the hepatologist at Queen's Hospital. He asked me about my history and confirmed what we had thought, that I would have been infected through one of the blood transfusions.

40. The hepatologist advised that there was a waiting list for treatment. I was not given any timeframe but was just told to go away and wait. While I was waiting for treatment, my health deteriorated drastically. I became depressed and severely anxious.

41. I didn't hear anything from any of the medical professionals for months. During this time, I had no medical or psychological support whatsoever. While we were waiting to hear back, my family and I regularly tried to make contact with the hospital, both on the telephone and, on one occasion, by turning up in person. However, I couldn't find anyone to speak to who was able to help. It was very stressful.

42. I finally started treatment in March 2018, 18 months after my diagnosis. The treatment was in the form of tablets and consisted of Dasabuvir, Ombitasvir, and Ribavirin all together in one. It was a 12-week course. The side effects were awful, so much that my husband had to stop work to help look after me. I lost all interest in daily activities and relied on my family to meet my needs. It was difficult to

cope with the treatment as I became suicidal, extremely emotional, depressed, paranoid, angry and completely lost sexual libido. I also lost my appetite and was very weak and chronically tired. It was a very scary and challenging time for us all.

43. I had been warned about the likely side effects by the consultant before commencing treatment. This consultant had been very informative. I was told that 50% of people give up after six weeks because it is such a difficult treatment. I was able to prepare myself for this and I knew I would have to persevere. I wanted to be cured so I did persevere, but it was very difficult. I found it hard to walk because my legs were so weak and I experienced dizziness and giddy eyes. I spent a lot of time in bed as I was unable to get up.

44. The treatment period was a particularly challenging time for my husband as well. He resigned from his job and did not work from October 2017 to December 2018 in order to look after me, despite his own poor health issues. He said that he simply couldn't leave his wife alone when she had expressed a wish to die. He couldn't take the chance. He became my main carer without help from any agency, and this contributed to his failing health. Because he had to resign, it affected his career progression as well as having a huge impact on our finances.

45. When I last went for a blood test, I was told that the treatment had worked and the HCV had cleared. However, I do still have to go back every 12 months for repeat blood tests to monitor the virus and ensure there is no reincubation.

46. Before treatment, I had been told that I had a viral load of 1.6 million. I found this very scary at the time. I am, of course, very pleased this has now cleared. However, the impact of the infection, including my fading health and wellbeing, is still weighty. I am worried about having to go back to the hospital every year and the prospect of the virus

coming back. I am still fearful of the unknown, such as premature death, prolonged sickness, physical and mental disabilities, isolation from others and financial implications for my entire family.

47. Also, although I have now been cleared of the virus, my liver was severely challenged by the HCV and I have been told I have cirrhosis. I don't want this to become worse and don't know what impact it will have on my future.

48. Before my treatment, I did experience some further medical complications as a result of my infection. For instance, in 2017 I was diagnosed with gallstones and needed surgery to remove the stones. However, two hospitals, Queen's Hospital and a Bupa Private Hospital, refused to perform the surgery because of my infection. They were concerned I would contaminate the instruments, causing a risk of infection to others. This rejection increased my anxiety and depression. I started thinking why me? Why am I being discriminated against because of an infection that I knew nothing about and was given to me by the NHS in the first place? Fortunately my GP was able to prescribe tablets as an alternative to the surgery, and these have helped me to clear the gallstones.

49. My career as a nurse was also significantly impacted by my infection. From 1999 to 2004, my sickness record at work became very bad, as I was unable to physically and mentally cope with the work. I was tired all the time and frequently hyperventilating. I had to take more and more time off. I had also fallen ill on the ward on a number of occasions.

50. In 2004, I decided enough was enough; I had to give up work. I was sad to leave my career as a nurse as it was something I had previously loved. My decision was made all the more difficult by the fact that I did not know at the time that it was HCV making it hard for me to cope with the demands of my work.

51. Even though I have now had treatment, I am still not in a position to work because of the lasting effects of the HCV. I still find relatively simple tasks, like cooking and washing up, very difficult as I become breathless. I therefore have to rest in between tasks, which means I take a long time to get things done. Though I have had some relief following the treatment, I do still suffer with a number of symptoms.

52. My status also affected my sexual relationship with my husband and socialisation with others in the community. Before my illness, I went out a lot to meet with friends and family. I was very sociable. However, once I started to become ill, I spent more and more time at home. I became reclusive to the point that I hardly ever socialised with people in my community. I was very isolated.

53. Even now, although I go to church, I tend to come straight back home afterwards. I no longer spend lots of time outside of my home.

54. My diagnosis is still hard for me and my family to bear. I was very fortunate in that my husband and children were in it together with me. My family was there for me and supported me through thick and thin. We are a very close family. The impact of the illness would have been even more devastating without their support.

55. It has been very difficult for my husband and children to see me go through this awful experience and it has had a huge and catastrophic affect on the whole family. For my husband, it was incomprehensible seeing his wife not doing the things she used to do or being the person she used to be. He felt as though he was watching his wife dying in front of his eyes without knowing why.

56. Managing the demands of the household during this time was also very difficult for my husband, especially as he has had his own health issues. He would come back from work and would have to do the

chores in the house because I couldn't. He worked hard to make sure the children were happy, whilst holding down his job and being the sole earner. He told me that he had to try to be a man and put on a brave face for me and the children. He didn't want to express his worries as he felt that this would have made life even more difficult.

57. In terms of stigma, we have tried to keep the information within the immediate family as we feel it is very shameful. We know the reaction of our community regarding such illnesses, so we don't want people to know.

58. The HCV has taken a huge toll on our family's finances. Given I was forced to give up work in 2004, I have had years of lost earnings. My husband also had to take a long time out of work to look after me while I was receiving treatment. We had to remortgage our house, as well as rely on our overdraft, credit cards and a personal loan, in order to survive that period. I remain financially dependent on my husband and family whereas, before the infection, I had my own career as a nurse.

59. I am a lot better after the treatment and I am pleased that I am now well enough for my husband to be back at work. I am also now able to have proper conversations again. Before my treatment I was very confused and often talking in tangents. I was often unable to concentrate on anything. My husband has told me that at least he can see me smile now. There was no smile on my face for a very long time.

60. Despite these improvements, I am still not how I was before the HCV. Even now, I often feel tired and find daily tasks challenging. I still feel I suffer from depression, and I remain on medication for a number of conditions that I believe were caused, or at the very least worsened, by the HCV. My confidence is still low because of what I have been through and, unfortunately, the stigma still carries. I still do not go out

on my own; I only ever go out when I have family with me. It is impossible for me to be the happy and outgoing woman I used to be.

61. Even after the successful treatment, I still feel that I do not really know what the future holds, and I find that very difficult. I pray I don't develop HCV again. I don't want to die.

Section 8. Treatment/Care/Support

62. Waiting for treatment for 18 months was too long and during that period, my health worsened beyond comprehension. The frustration and embarrassment endured chasing the doctors for treatment was indescribable to say the least. My family and I were left unsupported and had no idea who to approach for support and advice.

63. Times have changed now in that knowledge has broadened so much, and patients are in a much better position to challenge medical advice and treatments. However, back in the 1980s and early 1990s, we couldn't look things up on Internet. We just had to just trust the doctors.

64. I have never been offered any counselling or psychological support. I know there is some support out there but have not been offered therapy or referred to any support groups. I feel that we should have at least been referred for counselling or to a charity that helps infected blood victims, as I feel that one's mindset is very important in this type of situation. Counselling or psychotherapy would have been very helpful for me and my family to help us to come to terms with everything.

Section 9. Financial Assistance

65. During my first appointment with the hepatologist in June 2017, the hepatologist advised us that financial support is available for victims

of infected blood and provided us with the contact details for the Skipton Fund. We then had to complete a form, which we had to get the hepatologist to sign. This took at least four to five weeks, and my husband and I had to chase the hospital to get it done.

66. When the form was finally returned to us, we sent it back to Skipton. However, Skipton said they needed more information from the hospital. We then contacted Newham General Hospital and paid £20 for my medical notes to be copied and sent to us, in order to support my claim. This took a further two weeks. I got the necessary information from my notes and photocopied and sent them to Skipton. After this, Skipton were finally able to process my application. I found the process very bureaucratic. It was complicated and daunting.

67. I received a one off payment of £20,000 from the Skipton Fund in November 2017, quite soon after I had submitted my application. I then started receiving monthly payments of £310. I was told the payments could not be backdated.

68. In July 2018, the financial assistance started being administered by the England Infected Blood Support Scheme. The monthly payments increased to £1,500 per month.

69. I don't think these payments are enough to compensate what happened to me. Considering the many years of lost earnings and the devastating effects on my health, the money is not enough. I have never claimed anything else from the Government as we don't believe in doing so; however, I feel I should have at least been properly compensated for the years of lost earnings.

70. I had been much better off financially before my illness. I had always worked and had never been on benefits. Furthermore, my husband had to take a year off work to look after me, so this interfered with our family income as well as his progression at work.

Section 10. Other Issues

71. I have never been involved in campaigning or litigation. In regards to this Inquiry, I would like to make sure that this type of scandal never happens again. It has destroyed so many families. For me, it has destroyed my career and future prospects, and it has had a devastating impact on my whole family.

72. Although we are disappointed in the overall care and treatment I received from the doctors, I have chosen not to criticise any individual clinicians in my statement. Any criticisms that I have made are intended to be of a general nature, rather than being directed at particular hospitals or individuals. We appreciate that, to some extent, the doctors were limited by what they knew at the time. However, we feel there is a lot to be learnt from what has happened.

73. I think stringent checks and mechanisms should be in place to make sure this doesn't happen again. So many people have lost their lives because of this blunder. When you go to hospital, you think you are going for treatment and help, not to get something that will kill you. I think it's reasonable to expect the NHS to be robust in managing blood products but, in this case, it wasn't. We are victims of this inefficiency and, though we don't want to point fingers at any individuals, we feel let down by the system as a whole.

Statement of Truth

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

Signed GRO-B

Dated 2|6|2019