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Witness Name: Mr GRO-B

Statement No.: WITN1967001

Exhibits: 0

Dated: 30 April 2019

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF MR GRO-B

Section 1: Introduction

1. My name is GRO-B My date of birth is GRO-B 1943. My address details are known to the Inquiry.
2. I live at home with my wife and am a pensioner. I have five children; the eldest is 51 this year and the youngest is 32. I have been married twice, for the second time in 2000.

Section 2: How Infected

3. I had a serious operation known as a highly selective vagotomy, in the early 1970s to treat a perforated duodenal ulcer. The operation took place in June 1974 at the North Middlesex Hospital; formerly known as The Prince of Wales Hospital, there is a record that I have managed to find which refers to the fact that this is the case. The surgery was performed by a Ms. K. M. Shetty who worked under the supervision of a Mr. O'Malley. I think that both surgeons worked in the gastroenterology department. My stomach was opened from my rib cage to my navel and part of my stomach was removed. I have a visible

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keloid scar to this which is approximately 12 inches long vertically which runs from the centre of my chest to my navel. I do not know why my stomach was removed. I was kept in hospital and in intensive care for some time; I was unable to eat or drink properly and had to be fed by the medical team. Following intensive care treatment I was sent to a rehabilitation facility through the hospital and stayed there for over a week. I was released to go home by a home care officer. The surgery did not go well; I went into cardiac arrest during it, lost a vast amount of blood and received multiple blood transfusions as a result. When I came around from the operation, I saw that I had blood bags attached to my arm and that blood was being transfused directly to me. I recall that after the operation a medic came to see me and explained that I had suffered a cardiac arrest during the surgery and had experienced a lot of blood loss and as a result I was transfused blood. I have not yet been able to find a record that confirms this. There are two pages of records missing from the records I have been able to find; they are pages 20 and 21 of a set that I have received and I believe these two records would have told the full story.

4. I was not infected as a result of a relationship with another person who was given infected blood. The hospital infected me through blood transfusions I received.
5. I recall that I had to go to the hospital in an emergency as I had started to bleed internally. When I arrived, I was kept in and was given an injection to help. It was frantic. The hospital staff took me to theatre. I cannot remember being consented for the surgery; but in any event, I believe no advice or information was given to me in advance of the surgery about the possible need for a blood transfusion or about the risk of being exposed to infection as a result.
6. I was infected with hepatitis C, (genotype 1B), as a result of receiving contaminated blood transfusions from the North Middlesex Hospital, formerly known as the Prince of Wales Hospital.

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7. I found out from my GP that I had contracted the hepatitis C virus.
8. As I have stated above, I underwent the vagotomy surgery in June 1974. Looking back on this now, I feel as though I never felt well after it. I fully recovered from the operation but I have been unwell ever since. I regularly attended my GP Surgery at [GRO-B] Medical Centre, [GRO-B] in [GRO-B], where I saw various doctors. The two main doctors were doctors [GRO-B] [GRO-B]. I was attending so often because I was feeling nauseous, experiencing a severe lack of strength, shortness of breath, pains in my back and my stomach, and dizziness. The main symptom was the lack of strength and shortness of breath. I noticed that if I was working I would become very tired and very sick, very quickly and that I would sweat a lot. I would need to sit down to recover to be able to carry on. After decades of going back and forth to the GP to try to understand why I was feeling so sick Dr. [GRO-B] finally decided to do some tests. I recall that he had become very irritated with me because I was going in to see him so often; during one visit he told me that he only had a certain amount of money per patient available to him and that the NHS was very short of money. He was effectively telling me that I was going to see him too often. In the end, he referred me to the hospital for blood tests. I think that this did not happen until 2013 as my records indicate that in December 2013, my GP requested liver and abdomen ultrasound and hepatitis B and C blood investigations. I recall that around one month later, my doctor called me one Friday evening when I was away with my wife. He asked me to come in to see him as soon as possible at the GP surgery because he had some results to inform me of; he told me it was important. This frightened me at the time. I managed to get to the surgery the following Monday, when he told me in person, that I had contracted hepatitis C. I asked him if it was serious, or if it was cancerous. He said that he did not know but that I should go to the hospital to have some tests taken. He told me that he could not do anything further for me and that I would now be under the care of the hospital. My GP told me nothing else. My memory is not so great these days but I can tell from the medical information that my GP requested liver and abdomen ultrasound and hepatitis C and B investigations. The date of my diagnosis with

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hepatitis C seems to have been 10 December 2013.

9. I eventually found myself at the Homerton Hospital and under the care of a quite a few liver doctors. I was told that the hepatitis C was serious. Eventually a biopsy of my liver was taken to investigate the extent of the problem. It was explained to me then that my liver was scarred and that I had cirrhosis and I would need treatment before it deteriorated further. I was told that I would need to be seen every six months to make sure that the cirrhosis did not turn to cancer. I remember being told by a doctor that I was very fortunate that I had not contracted HIV.
10. Yes I do consider that information should have been provided to me earlier. I had been suffering for many years and going back and forth to the GP before I was eventually sent for tests and diagnosed. My medical team; who I trusted with my life, failed me. If I had been tested sooner, I would have known what was going on, my condition would not have deteriorated to cirrhosis; something could have been sooner to stop this. My condition has been deteriorating very rapidly over the last few months and I have only just found out that I now have cancer of the liver.
11. My views about how the results of the tests were given to me, was very frightening and alarming. I did not know what was happening and the hepatitis C was not explained to me. I had been left for years without being tested despite having many symptoms, then, when the doctor finally decided he had enough of me annoying him with my visits it was found out that I had contracted the hepatitis C virus. I was told nothing and was just passed onto the hospital who also did not explain to me properly what was going on. I believe that as this was in 2013, my GP should have known more about the infection and should have told me more about it. I was frightened; I was also just recovering from intense radiotherapy treatment that I had to have for five months, for my prostate cancer. I was scared I was going to have a heart attack.

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12. Homerton Hospital gave me information about the risks of others becoming infected; I do not recall exactly when this was. I do know that my wife had to have tests at her GP. Thankfully they found out that she was ok. I know now not to allow others to use my toothbrush and things like this.

Section 3: Other infections

13. I believe I have been infected with hepatitis C only.

Section 4: Consent

14. I believe that I have been treated without my knowledge and consent and I believe I have been treated without adequate or full information. I say this because I did not know and was never made aware of the fact that a blood transfusion might have been needed during the vagotomy operation. I do not believe that I was tested or treated for the purposes of research.

Section 5: Impact

15. I have suffered greatly as a result of this infection.
16. The mental effects are that I have been completely devastated by this; I have a physical non-existence and very bad feelings about it. I feel (and everyone surrounding me, feels) completely let down by the system; particularly by the government. I feel great sadness, I feel that my children and my wife have greatly suffered and this has caused me great anxiety. I believe that the physical side effects that I suffer stem from the hepatitis C infection and include: fatigue; insomnia because of pain; shortness of breath; immobility (I cannot walk without the help of walking sticks and even with a stick, I can only walk 40 yards); I fall over regularly as the lower parts of my legs, my feet and my toes are numb. I have bad circulation as a result which can cause other serious problems. I have a growth on the chest due to my liver not breaking

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medication in my body properly. I also have a loss of appetite; a loss of energy; a feeling of being cold all of the time; terrible joint pains; a locking in my hands and hips; high blood pressure; diabetes; pains in my teeth and dental problems requiring numerous fillings in my teeth; headaches; involuntary shaking; urinary incontinence; loss of sexual appetite; pain in my groin and in my back; pains in my side; pain everywhere. I have to use two hands to feed myself. I also have constipation, painful defecation, bloating, repeated urinary tract infections, cataracts and glaucoma. I was also given iron pills to cover up the problems with my liver.

17. The hepatitis C has resulted in cirrhosis of the liver and both kidneys have cysts. I was diagnosed with leukaemia but received treatment and managed to gain remission. I have also been diagnosed with Type II Diabetes. I have been extremely unwell lately and have lost a significant amount of weight in a very short period of time (seven kilos in one month). The hospital has just confirmed that I have liver cancer. I believe that the hepatitis C has contributed to my prostate cancer, the cirrhosis and now the liver cancer. I believe that all of these medical conditions have come about following the hepatitis C.
18. Following the outcome of the liver biopsy I was given Sofosbuvir, Ledipasvir (as Harvoni) and Ribavirin beginning on 11 November 2015 and for 12 weeks. I was told by the consultant that the treatment was working and final outcome was that the hepatitis C was no longer in the blood but that my liver remained scarred. The liver specialists are still monitoring me. The treatment made me very sick and I was unable to move through tiredness; I had a complete lack of energy.
19. I think that treatment should have been given to me much sooner than it was. By the time I found out that I was hepatitis C positive, I had been carrying the virus for almost 40 years. The tests in 2013 discovered that my condition had deteriorated to cirrhosis. I was told that I would be fast tracked for treatment because of the seriousness of my condition but in the end I actually only

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received it in 2015; another wait for me. The provision of the treatment was delayed on numerous occasions until my gastroenterology consultant recommended it and even then, it was delayed. I was told by my consultant that the treatment was on trial and very expensive and he had to go to the Board of Doctors at the hospital to apply for the treatment for me. The treatment started much too late and meant that my condition was allowed to deteriorate even further. I am a very sick man as a result and have just been informed that I now have liver cancer.

20. I think that the Harvoni treatment should have been made available to me earlier. I was very sick and should have been given it sooner. Two years in someone's life can make a lot of difference.
21. I was sicker during the treatment. I was more fatigued and nauseous and became doubly incontinent. I was aware that I was sweating more too. I could not sleep in my own bed as I had to sleep in towels to absorb the sweat. The hepatitis C and the treatments for it have prevented me from fulfilling my role as a father, a husband and a grandfather.
22. I do not believe that my infected status has impacted upon my treatment, medical and/or dental care for any other conditions.
23. My private, family and social life have been very badly impacted by the hepatitis C infection. Hepatitis C turned the relationship that I had with my wife, into one of carer and patient such that I no longer have a private life with my wife. The infection has diminished my whole being and demeanor and has changed every relationship I had. I have been unable to be a proper father, husband and friend. The impact of this on my loved ones has been excruciating for me to watch. They have had to see me in pain, and they cannot help. They feel totally powerless. I have no desire to be social and I feel totally devastated and let down because I feel like I have lost part of my family and my life. Remember that for years I did not know what was going on yet I was suffering

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the symptoms. I always have to plan my day in advance to cope with my social life, which is non-existent. The real impact on my family and me is that I cannot interact with my children and my wife as I want to, this makes me feel terrible and very angry.

24. My family has never been negative towards me. I have been treated the same by all of them. I have not experienced any stigma associated with my diagnosis because outside of my family, no one is aware that I carry the virus.
25. The educational, financial and work-related effects have been numerous.
26. Educationally, I cannot think cohesively and do not remember things very well. I was studying to be a Minister of the Gospel back in the 1990s. I had to give this up because of my sickness; I could not cope with the study because of my illness.
27. I had been working at British Telecommunications as a Technician for around ten or 12 years when I had to retire as I was so unwell. I had been unable to work and was off sick often. I retired in around 1983 because of my general malaise; at the time my doctor wrote that it was because of my back and stomach problems. I did not know that the hepatitis was the cause of my sickness at the time, but looking back now I think that it was.
28. I had to retire because of ill health. As a result, my salary reduced to less than half of what it had been. I had been the main source of income into the family home. This had a devastating effect on my family and me. I could not even pay my rent. I was unable to support and provide for my family. My first wife and I separated because of this; there was no money coming in to maintain the house. I find it very difficult to talk about this because the ways in which this affected me and my family were numerous. To summarise this, I have suffered major loss of income, loss of savings, loss of homes, and loss of cars. I have been unable to work to send my children to have a proper education. I feel like I

and we, have completely lost everything.

29. The impact on my family has been huge. From around 2000, my wife has had to care for me constantly, 24 hours of the day, every day. My wife has had to work to support us and take care of me despite the fact that she has had to have surgery for hip and frozen shoulder problems herself. My children have lost out on the care and attention that they deserve; physically and emotionally, I could not be the father to them that I always wanted to be. Other family members have had to step in to help where my wife has been unable to. My family has been devastated by my sickness.

Section 6: Treatment/Care/Support

30. To begin with I have had to endure the consequences of being given the completely inadequate care from my GP. Then, when I was finally diagnosed, I had to wait again for treatment even though I was diagnosed with cirrhosis. The provision of the treatment to me was delayed often. At the time, I did not know hepatitis C was that serious. I now know that if I had been treated much sooner, I would not have become so sick and have felt so debilitated throughout my life. Perhaps my cirrhosis would not have turned into the liver cancer that I now have. I believe that treatment at the right time could have saved my liver and kidneys from further deterioration. At one point when I went back to my GP for help he told me he could not deal with me anymore and that I should direct all my enquiries to the hospital.
31. Counselling and psychological support has never been made available to me in consequence of being infected. I think that I could have benefitted from this. I feel like I was left to deteriorate.

Section 7: Financial Assistance

32. I have received nothing from the Trusts and Funds that were set up to distribute

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payments, this is because there are two missing pages in my notes (pages 20 and 21) that I believe can prove that I received blood transfusions when I had my vagotomy surgery. These pages have mysteriously disappeared.

33. I found out about the availability of the financial assistance by my solicitors Leigh Day in 2018 and so I applied.
34. I have received nothing.
35. With my daughter's help I have been trying to apply to the Skipton Fund and England Infected Blood Support Scheme (EIBSS). I have sent numerous documents including doctor/hospital reports to Nicholas Fish at the Skipton Fund and to EIBSS. Initially Skipton responded positively to my application and said that I would receive some financial assistance. Soon after they contacted me to say that they had made a mistake and that I should not have received the document I received. My first application was unsuccessful; the scheme stated that the supporting medical information submitted in my application did not prove that I had been chronically infected with hepatitis C through treatment with NHS blood or blood products in England prior to September 1991. I appealed their decision. Initially, I was asked to provide some further information to enable the panel to reach a decision on the appeal. I did this and the appeal was unsuccessful. Again they said there was insufficient evidence to prove that I had become infected through blood or blood products prior to 1991.
36. I have encountered nothing but difficulties in trying to obtain financial assistance and in trying to obtain a full copy of my medical records to help me. I have had no help.
37. The preconditions to the application were that I needed my medical records to prove I had a blood transfusion in 1974. I gave Skipton and EIBSS the information I had but it was not enough. As I have not received any financial

assistance, no preconditions were imposed.

38. They decided to help me initially and gave me the forms telling me that I would receive help and when I applied they withdrew. This is what I get from the NHS, nothing!

Section 8: Other Issues

39. There are no other issues in relation to which I consider that I have evidence which will be relevant to the Inquiry's investigation of the matters set out in its Terms of Reference.
40. There are no other documents that I have which I wish to bring to the Inquiry's attention which might be relevant to the Inquiry's Terms of Reference.
41. I have grave concerns about the accuracy and completeness of my medical records. There is a note in my records which states that potentially I could have become infected by my mother and that my sister carries in the infection which is not correct. I think that this happened at Homerton Hospital when I asked how I could have become infected with hepatitis C. I think that this person misheard my response to her question about whether any sibling had become infected. I have also uncovered that the two key pages of records which could potentially prove I had the stomach operation and that I received a blood transfusion are no longer in my records. I cannot understand this.
42. I would like to ask the Inquiry to investigate the NHS's involvement in the tampering of people's medical records including mine. I would like the Inquiry to investigate this problem thoroughly, including investigating those doctors who did not treat their patients humanely. No matter who you are, you should be treated equally. That is what the NHS is supposed to do.
43. I would like the Inquiry to get to the truth of this problem, to remain independent

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in their approach and to deliver the truth to those people who have been infected. I do not believe that justice can be achieved, too much time has been wasted; too many lives have been destroyed. This time cannot be brought back. I would like this Inquiry to make sure that something like this never, ever happens again.

Statement of Truth

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

Signed: GRO-B

Full Name: Mr GRO-B

Date: 25/03/2019