

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0888

Dated: 27.9.2019

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 21 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 1961. I reside in Lincolnshire, England, my full address is known to the Inquiry.
- 2 I am unemployed and live on the same property as my youngest son. I have three children who are alive; two sons born in 1978 and 1997, and a daughter born in 1980. Two of my children have died. One was a twin to my daughter who died aged five months, and one who was born in 1979 and died aged 35 years.
- 3 I intend to speak about my experience being infected with the Hepatitis C Virus ("HCV") following a blood transfusion while in the hospital giving birth to my twin daughters. In particular, the nature of how I found out about the infection in 2018, my illness, how the illness has affected me, the treatment I have received, and the impact it has had on my life and the lives of my family.

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- 4 I confirm that I have chosen not to be legally represented in regards to providing evidence to the Inquiry.
- 5 The Inquiry investigator has explained the anonymity process to me. I have elected to have my name and personal information redacted due to the possible stigma that myself or my family may face if it is widely known I was infected with HCV.
- 6 I wish to acknowledge that I did not make notes and have not been able to obtain historic medical records. Naturally as time passes, memories can fade. Despite this, I have been able to give approximate time frames for matters. These timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Infected

Blood Transfusion

- 7 In 1979 I became pregnant with twin girls. I was already a healthy mother to two young babies and I continued to be healthy for the first eight months of my pregnancy with the twins. I recall that at eight months pregnant I played a game of cricket with my family, I felt well and energetic.
- 8 On GRO-B 1980 the twins were born four weeks premature at the GRO-B GRO-B Hospital in GRO-B
- 9 The birth of the twins was a difficult one. I naturally gave birth to one but another was breached. The doctors recommended an epidural and advised that it is best for the birth of twins. I had the epidural and it did not work. It was agonising. The doctor proceeded to cut me, shove his hand inside me and pull the youngest twin out. I felt everything and it was intensely painful.

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- 10 The epidural caused me to feel unwell and dizzy. I asked the medical staff to take the needle out of my back because it was causing me a great deal of pain. The medical staff responded, 'in a minute'. When the epidural was finally removed from my back I became very cold and started shaking. I was freezing.
- 11 It was at this point that the doctors made the decision to give me a blood transfusion. I'm not exactly sure why they made this decision but I assume it is because I lost a lot of blood after the doctor cut me.
- 12 I recall that the medical staff alleviated my feet above my head and gave me a hot water bottle. They placed the tubes that were connected to the blood bag into a tub of warm water. The nurse told me the warm water would warm the blood before it entered my veins. I think I had about two bags of blood although it is possible I may have had three bags.
- 13 I believe it was during these transfusions that I was infected with HCV. This is the only occasion I have been given blood products.
- 14 After giving birth, my babies were placed in a separate unit to me. I was not allowed to hold them. After I received the blood transfusion, I was placed in my own room for a few days. I changed to another ward for one week where I could breastfeed my twins.
- 15 While I was in the hospital my husband was at home caring for our two other children. After ten days in hospital I was released. Five weeks later, the twins were released from the hospital. During those five weeks I went to the hospital everyday to breastfeed and care for the twins. In that period I bled a lot and was admitted to hospital. I don't recall having more blood bags during my second admission to the hospital but I believe they removed some afterbirth that had been left inside me.

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- 16 Apart from being slow to put weight on, the twins were fine. After the birth of the twins, I put my oldest into a nursery which had a scare of whooping cough. I was advised by medical professionals to give my twins an injection for whooping cough. My twins were given the whooping cough injection at the baby clinic. The next day the youngest twin was dead and the other was so unwell she had to be admitted to hospital.
- 17 After the blood transfusion my physical health was good but my mental health was not the same. I had poor memory, particularly my short term memory, and I didn't feel mentally well. In those days no one, including the doctors, seemed bothered about my mental health symptoms. I assumed my poor memory was brought on from the stress of having four children, one passing away and one becoming very unwell.
- 18 Very rarely went to the doctors. Whenever I became unwell I simply pushed through because I had little ones relying on me.
- 19 In 1998, a year after my youngest son was born, I started having frequent headaches. The headaches lasted for four days at a time and I would have approximately four headaches each month. They were so painful that I consulted my doctor who took some blood from me and sent it to the GRO-B Hospital, GRO-B for testing. Coincidentally, the person that tested my blood was my brother in law.
- 20 Out of curiosity, my brother in law conducted a range of blood tests on my blood samples that the doctor had not requested. He did not record the results of these additional tests but when he saw me, he made a passing comment that my blood results were high. He thought my blood levels would be more like the blood tests of his alcoholic wife. I did not fully understand what he meant by this comment but it was one that I did not forget.

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21 The only other time that my blood was tested was when I was pregnant with my youngest son and that was the standard blood test.

Hepatitis C

22 On 28 November 2015 I was at home with my daughter and my grandson. Three men invaded our home and assaulted me with a hammer. My blood was splattered across the living room, over the walls, in the fireplace and throughout all the downstairs rooms.

23 As a result of this incident, Police were called to our home. When the Police arrived at our house they observed that I had cannabis plants. Consequently I was charged and convicted for this drug-related matter and from January to November 2018 I served 11 months' in prison.

24 I was sent to [GRO-B] prison [GRO-B] where I was well cared for and I made the most of the opportunities offered at the prison. I completed a number of educational programmes [GRO-B] for a job and participated in the 'wellness programme' for prisoners over the age of 40 years old.

25 As part of the wellness programme I was tested for a range of medical issues. They took my blood at least 3-4 times. After my results returned, the doctor told me that I possibly had cancer of the liver. I was devastated when I was told I had cancer of the liver. I didn't want to die. The doctor felt my stomach and made the comment that my liver was enlarged. I was sent to [GRO-B] hospital for further testing.

26 At [GRO-B] Hospital I completed further blood tests and the conclusion of those tests was that I did not have cancer of the liver and my liver was not enlarged. I also had an ultrasound which showed that I had a lot of scarring on my liver.

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27 I returned to GRO-B prison and in July 2018 I was diagnosed with HCV. Naturally this was distressing news and it was frightening to receive this information in a prison without any family support.

28 In August 2018 I moved to GRO-B and I enjoyed my time there. I was given a lot of responsibility, including painting and setting up a room for the prisoners. The doctor at GRO-B prison conducted new scans and tests and asked me questions about my health. All my medical notes from GRO-B prison were transferred to GRO-B prison and I was seen at GRO-B Hospital. I understand that had I been in GRO-B prison for a longer period of time I would have begun treatment there.

29 On GRO-B 2018 I was released from prison and all my medical notes were sent to GRO-B Hospital in GRO-B. Prior to my release, GRO-B Hospital and the Prison arranged for me to have an appointment at GRO-B Hospital, GRO-B on 6 December 2018.

30 On 6 December 2018 I attended my appointment at GRO-B Hospital with GRO-B the nurse that looks after the people with HCV.

31 On 7 January 2019 GRO-B the Nurse gave me some tablets called 'Epclusa tablets' to begin HCV treatment. She told me to take the tablets once a day at the same time everyday for three months.

32 Over the next 8 months I continued having regular blood tests and appointments with the Nurse. In August 2019 she told me that the results from my blood tests confirm that I am in the clear and I no longer have HCV. However, I have an appointment for an endoscopy to assess the damage that HCV caused to my liver. The Nurse described the damage as like having varicose veins on my throat. I was informed that the varicose veins are caused by the liver scarring and that doctors will put a camera down my throat and into my stomach to make sure

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the veins are not present. In three months time I also have an appointment for an ultrasound and more blood samples.

Information

33 Prior to the blood transfusion on **GRO-B** 1980, I do not believe there was any discussion about the risks of having a blood transfusion.

34 I have been unsuccessful in my attempts to obtain my medical records from the **GRO-B** Hospital where I received a blood transfusion. I was advised by someone at the hospital that my records could not be found and a possible reason for this is that my records were destroyed.

35 On occasions that doctors took my blood they did not tell me exactly what they were taking the blood tests for.

36 After I was diagnosed with HCV, the medical staff at the hospital gave me the phone to speak to a lady who was able to provide me information about HCV. The lady on the phone told me about the available treatments for HCV. She answered all my questions and explained that the common treatment for HCV was a tablet that I take daily for 6-12 weeks.

37 The medical staff at **GRO-B** Hospital were good to me and helpfully answered my questions about HCV. It was explained to me that HCV can be contracted by blood if I have a cut and someone else has a cut. I was given information about how to reduce the risk of infection to others.

38 The Nurse at **GRO-B** Hospital was extremely helpful and informative about HCV and chronic cirrhosis, treatment and how to avoid transmission.

39 It was the Nurse who gave me two phone numbers to call if I needed more support and information about HCV. The first number I phoned was answered by

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a person who was abrupt and rude. I felt like they had fobbed me off and I remember writing a note 'not helpful' next to that phone number. The second number I called was answered by a helpful person called Sue. I think she may have been part of the Hepatitis C Trust. Sue told me to get in touch with the infected blood inquiry.

Section 3. Other Infections

40 I have been diagnosed with chronic cirrhosis of the liver. Hearing that I have this condition was frightening. I was tested for this while I was in prison but the results only became available after I had been released from prison.

41 The Nurse explained that chronic cirrhosis involves scarring of the liver that has a grading of 11 or higher. The scarring on my liver was graded more than 14. She explained that the scarring on my liver can cause cancer and potentially something else which I cannot recall the name of.

42 Doctors have not told me much about chronic cirrhosis but I have been doing my own learning, research and reading about this condition.

43 I do not believe that I have received any other infections other than HCV as a result of being given a blood transfusion in GRO-B 1980.

44 I assume that I would have been tested for HIV as part of the wellness programme in prison and when I had other blood taken, but I do not know this for sure.

Section 4. Consent

45 I do not believe that I was treated or tested without my knowledge or consent.

46 I do not believe I have been treated or tested for the purpose of research.

47 I believe I have had adequate information prior to treatment.

Section 5. Impact

Physical and Mental health of HCV

48 I do not view the HCV and chronic cirrhosis as illnesses that belong to me. I refer to these illnesses as 'the' HCV and 'the' chronic cirrhosis because I don't want anything to do with them.

49 Prior to having the blood transfusion on GRO-B 1980, I was a healthy person. When the doctor told me that I may have liver cancer I was in shock. I have always looked after my health, exercised regularly and I only eat vegetarian food.

50 The Nurse at GRO-B Hospital told me that the amount of scarring on my liver indicates that I have had it for a long time and it is likely that the scarring started when I got that blood transfusion. Since my diagnosis I have become fanatical about liver care.

51 The nurse at GRO-B Hospital told me that my healthy lifestyle assists with the treatment of chronic cirrhosis. I am not overweight, I eat vegetarian and I do lots of walking. I think that if I had not led a healthy lifestyle, it is possible that HCV may have caused more damage to my body and the chronic cirrhosis would be more severe.

52 Whilst I did not show any obvious signs of having HCV, since finding out that I have had this infection, it now offers a possible explanation for my severe headaches and short term memory loss which started after the blood transfusion.

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My Life

53 I make a point of not openly telling people about the HCV and chronic cirrhosis. I do not want people to broadcast my personal business. People are unaware and ignorant to the facts of HCV and I do not want my story to be picked apart.

54 One of the biggest impacts is other people's anxieties and ignorance in respect of HCV. The medical staff at GRO-B hospital emphasised that I was not to tell anyone in the prison that I had HCV. They said that there was a stigma attached to HCV and other women in the prison might treat me differently if they knew I was infected. I understood the importance of keeping my infection a secret and I did not discuss it with anyone in prison.

55 I have told three people about the HCV diagnosis; my youngest son, his father and my brother. I talked to my son and his father about my diagnosis because they were at risk of HCV and needed to do their own blood tests. Their blood test results confirmed that they do not have HCV.

56 Although you cannot call my situation positive, it is not as sad and disastrous as others. I consider myself fortunate that I have found out that I have HCV, and ultimately, if I had not been in prison, I would still not know that I was infected.

57 I believe I should have been tested for HCV at an earlier stage in my life. I may not have had this amount of scarring on my liver if the infection had been detected years ago.

58 My youngest son has suffered a lot. He had five family members die in one year and when I was in prison he had to care for the animals on his own. When I returned home from prison, he had to hear that I had HCV and that he was also at risk of being infected. Fortunately it has been confirmed that he does not have HCV.

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59 I do not believe my family has suffered from the stigma related to HCV, I have however, elected to remain anonymous to protect them. I worry that if my name is known to the public I am opening myself and loved ones up to the stigma from misinformed members of the public.

Treatment

60 Since being diagnosed, the treatment I have received has been very good. I have not faced difficulties or obstacles in accessing treatment. I believe I was able to make an informed decision about what treatment to undergo.

61 Initially I was very reluctant to undertake treatment for HCV. I have always been firmly against the consumption of unnatural products, including medication. The Nurse acknowledged that I did not like taking medication but she explained that taking the tablets will help me get rid of the virus and then I can let my body heal itself naturally.

62 I sailed through the HCV treatment. I was very good at taking my tablets. Every evening at 7:00pm I watched Emmerdale and that is when I took my daily tablet for the treatment of HCV.

63 The Nurse explained that I may get side effects including headaches from the tablets. I did get occasional headaches but they were not severe. I felt tired in that first month but I pushed through any feelings of exhaustion because I had so much to do at home and caring for my animals is my priority. There may have been other side effects but I cannot recall them.

Section 6. Treatment/Care/Support

64 I do not believe I have faced obstacles obtaining treatment once diagnosed.

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65 I was not offered any counselling or psychological support at the time of receiving the blood transfusion, nor at the time of being diagnosed with HCV and/or throughout the treatment of the virus.

66 I have discussed with the Inquiry Investigative Lawyer the existence of the counselling and psychological support service the British Red Cross is running in collaboration with the Inquiry. I have been provided their contact information and will consider using it.

67 Overall I have found the Hepatitis C Trust a useful supportive source of information and support to navigate this experience.

Section 7. Financial Assistance

68 The Nurse at GRO-B Hospital informed me about the existence of the England Infected Blood Support Scheme ("EIBSS"). The Nurse has commenced my application for financial assistance by completing and sending forms to EIBSS on my behalf.

69 To date, I have not received any funding or financial support.

70 My view is that the people who are responsible for providing financial assistance should make the process more straightforward and uncomplicated.

Section 8. Other Issues

71 I have lost confidence in the health system. I now have a damaged liver that stems from a blood transfusion. This should never have happened. I now have to be careful and aware of everything that I put in my body. I am fortunate that my condition is not worse and I believe that is largely due to my healthy lifestyle and good life choices that I have maintained over the years.

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72 My experience has led me to lose faith and confidence in the professionals and experts in the medical field. When I told my doctor that I wanted to be healthy and toxin free by avoiding all food with "E numbers", he laughed in response. I don't believe the doctor did enough when I complained about my headaches. I think that the tests and scans that were offered to me in prison should have been offered to me within the community and at an earlier stage.

73 My experience of being diagnosed with HCV in prison was a frightening one. No family or friends came to visit me in prison and I felt uncomfortable sharing the news over the phone in prison. Medical staff impressed on me that I had to keep my infection a secret. There may have been other female prisoners going through the same experience as me. I think that better education about HCV should be made available in the prisons which may help reduce the stigma associated with the infection.

Statement of Truth

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

Signed

GRO-B

Dated

27, 9, 2019