

ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN0251001

Exhibits: WITNO251002

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 16th January 2019.

I,

GRO-B

 will say as follows: -

Section 1. Introduction

1. My name is

GRO-B

 My date of birth is

GRO-B

 1946. I reside in

GRO-B

 West Yorkshire and my full address is known to the Inquiry. I was widowed in October 2007. I am retired, having worked in a variety of part time roles. The most recent being a special needs transport assistant.
2. I intend to speak about my HCV infection that I received through blood transfusions in 1982 and 1983 while in

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3. In particular, I intend to speak about the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and I.
4. I can confirm I do not have legal representation.
5. I have been advised by the Inquiry about the ability to have anonymity. I have elected to have my name and personal details redacted. I do so because I have not shared this with anyone other than my immediate family. I do not wish to be judged or stigmatised by others.

Section 2. How Infected

Blood Transfusion

6. In the summer of 1982 I went into GRO-B for a planned laparoscopy to remove a cyst on my ovary. My surgeon had explained that the procedure would require me to be in the hospital for three days.
7. After surgery, and by the time I was back on the ward, I was not feeling well. I remember getting a visitor in the night and saying to them "my head is spinning". I put this down to the anaesthetic.
8. The next thing I remember was waking up with nurses pushing tubes down my nose. They explained, because I had eaten a few hours earlier I needed to vomit so they could operate. My surgeon explained that it was necessary to return to surgery to investigate what was wrong.
9. I was rushed into theatre for an emergency operation. After the operation I was told they had to 'open me up' to stop the

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haemorrhaging and remove a portion of the ovary that had been damaged during the laparoscopy. It was in this operation that I was given my first blood transfusion. I cannot recall how much blood I received. I remember afterwards a nursing officer telling me, "we nearly got the co-op out to you." I spent six weeks recovering in hospital after that.

10. This was a very stressful time for my family. My son aged four, had just been diagnosed with type one diabetes. For the six weeks I was recovering in hospital my daughter needed to stay with a relative, I felt bad about that. A short time after my recovery, my husband started to become unwell. My husband collapsed once at work and since then his health did not improve. He needed to take time off due to stress.

11. In 1983, 12 months after my initial surgery, I was back in GRO-B GRO-B requiring a further operation. I had been getting pain in my stomach. I needed a hysterectomy to correct the complications from my previous procedure.

12. Again, I suffered haemorrhaging and required a post – operative blood transfusion. I required two pints of blood. I was recovering in hospital for three weeks. I remember my surgeon saying to me, "it's your body, you bleed too easily." I remember thinking I did not believe her and it was an odd comment but I did not question authority.

13. I believe it was on one of these two occasions that I received infected blood. Throughout the 1990s my health was not quite right and I did require further surgery, but this did not require a blood transfusion. I have had no other blood transfusion, or exposure to opportunities to get HCV.

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14. While my health never properly came right, or back to the level it was prior to the operations. I did however get on with life. It is just what I had to do. I had two children, one with a chronic health issue and a husband to look after.

Hepatitis C Virus

15. In 2007, I was unwell with an enlarged goitre. I went to my General Practitioner ("GP") who referred me for tests. I was meant to have my thyroid tested but the person testing the bloods made a mistake. My liver function ("LFT") was tested instead of my thyroid. The next morning my GP contacted me and asked me to come in. He asked me about my alcohol intake. I was confused, but told him about the small amount of alcohol I drank. He said, 'no that's not right, the results that are showing in your blood are far too high for that answer.' He referred me to GRO-B for more tests.

16. At GRO-B I saw two Consultants, one for my goitre and one for my liver. I underwent a number of tests including a bone marrow extraction while they tried to figure out what was wrong.

17. I remember meeting with one of the Consultants. There was a nurse and two other people in the room, but I don't know who they were. They did not introduce themselves. I remember the Consultant asked me if I had any blood transfusions, to which I explained I had two transfusions in the 1980's. He then said "I have bad news for you, you have Hepatitis C".

18. He informed me I was HCV Genome Type 1 Positive. He also said I had cirrhosis of the liver and an enlarged spleen. He said they were likely to have been caused by the blood transfusions.

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19. I was shocked. I have a memory of a long time ago, seeing a programme on TV about Haemophiliacs who had been infected with HCV and HIV from blood. I remember turning to my husband and saying, "I've had blood transfusions!" but I assumed I was okay. I thought maybe the Haemophiliacs were treated differently. I never thought more of it until I was diagnosed.

20. When the Consultant told me, my face burnt up with adrenaline. I thought I was going to explode. I remember getting up and walking out without saying a word. My husband and I walked out of the hospital and got into the car. No one spoke. News like that was hard for me to handle.

Information

21. When I was informed I do not recall being given much information. I think I was given a leaflet. No medical professional has helped me or warned me of the risk of passing HCV onto others.

22. A registrar once told me, in passing to support my liver "stay off the Paracetamol, don't drink alcohol and take a good antioxidant."

23. From what I understand, the reason why my Hepatitis was so far advanced was because it had never been picked up by any previous tests.

24. On reflection, I am surprised that throughout the 1990s-2000s when I was having on-going medical matters, that I never had my liver function tested. I find it hard to believe that I never had the test. I wonder why it was missed for so long.

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Section 3. Other Infections

25. I do not believe I was infected with any other viruses other than HCV from the two blood transfusions I received in 1982 and 1983.

26. I believe the cirrhosis of the liver is the result of the HCV.

Section 4. Consent

27. To the best of my knowledge, I gave my consent to all blood tests.

28. I am not sure whether any tests for Hepatitis were done without my consent.

29. I consented to all treatments for HCV.

Section 5. Impact

Physical and Mental

30. Since 1982, after my first blood transfusion, there has always been something underlying with my health. It is difficult to describe because I have the mentality to 'get on with it' and to try not to burden others. I have spoken to my daughter who said she, "cannot look back and say you were completely fit and healthy."

31. Over the years I have thought about the surgeon's comment about it being my body and bloods fault. I have told family and a few close friends about the comment. I wish I had said something about it not being my bloods fault I needed a transfusion. That comment has stayed with me. While it never sat well with me, I didn't raised it at the

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time because I was too ill, my husband was too ill, my son was too ill and we had no one else to talk to.

32. When I was first diagnosed with HCV, I felt sorry for my children and my husband. There was a feeling of an uncertain future. I did not know if my treatment would work, and that made my family and I very anxious. As a mother I tried to protect my children, I did not want them having my worries and this is one of the reasons why I try to keep my anxieties to myself.

33. HCV is not like other illnesses, such as cancer, where people can talk openly about it. I believe my illness comes with stigma, people just associate it with drug use and there is a lack of understanding. This means I have not disclosed it to people other than my children and medical professionals.

34. I just carry on doing what I have to do, and that is me, that is my personality, but my life has been made much harder because of the HCV. Since my husband's death I have lived alone, and that has made dealing with my illness all the more difficult. I am very isolated, and a lack of understanding has meant I suffer in silence.

35. I would describe having HCV as like having a curse. I feel dead inside. It is always at the back of my mind, and all I have been doing is waiting. It is a ticking time bomb. Whilst I am now clear from HCV, I still have to live with the affects.

36. Only family know, and it has made it hard to form real friendships. I cannot be my genuine self. I do not have a social life. The side effects the treatment has left me with, kills my ability to participate. If I were to

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go out and socialise there is no pleasure for me, if I were invited for a meal I would not eat, I have no appetite.

37. The impact of living with HCV taints everything I do. I do not like new social situations. I worry about whom I might have to address my illness with.

38. The hardest part has been keeping it to myself. I know that we now live in a world where people share everything, but that is not me. I am a very reserved person who does not show many emotions. While I do not wish to share with others it has been draining having to keep the illness hidden.

Medical Complications

39. I do believe I suffer from the on-going impact of HCV. I believe I have had a weakened immune system. I have suffered from an enlarged goitre, enlarged spleen, numerous digestive problems, scarlet fever, severe pneumonia, restless legs, anxiety and a low mood. I pick up illnesses very easily. I believe, because of my damaged liver, my body has to work harder to fight infections.

40. I have to take prescribed medication for a back issue and I am concerned about the impact this has on my liver. If it had not been for my HCV I would not have to worry about medication damaging my liver further.

41. As a consequence of having a damaged liver I have to undergo continuous tests to monitor my cirrhosis.

Treatment of Hepatitis C Virus

42. Following the diagnosis I was transferred to a consultant at North Manchester Hospital for treatment of HCV. I was put on 12 months of Interferon and Ribavirin. I began this in late August 2007.
43. I was told the reason why I had 12 months of treatment was because HCV Type 1 is harder to treat.
44. Prior to the treatment my nurse spoke to me about all the side effects that came with the treatment, they were scary. I remember once I heard them all I stood up and wanted to leave, but then something inside me forced me to sit down again. I knew I needed the treatment.
45. The treatment consisted of an injection once a week and daily tablets. I administered my own injections. It was not long before the side – effects started to show. I lost my appetite, I felt sick, my skin was terrible and my fingers were all cracked. I was constantly fatigued, and developed a “foggy brain”. I lost two stone in weight. During a check up the doctors said if I lost anymore they would have to take me off the treatment.
46. Approximately seven weeks into my treatment, I went to my GP feeling very unwell due to the effects of the treatment. They called for an ambulance to admit me to the hospital where I was kept in overnight. My husband had been admitted to the same hospital, following a heart attack a few days earlier. He was in the bed next to me. He died shortly after on GRO-B 2007. It was a tough time for the whole family, emotionally and physically.

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47.Despite the ongoing side effects I continued with my treatment for the full 12 months. I was having regular testing. My children used to take time off work to take me to the hospital.

48.Following the completion of the treatment I was clear of HCV. I still have cirrhosis of the liver.

Stigma

49.What was shocking for me was waiting at North Manchester Hospital for my treatment and being sat next to prisoners and drug users. I looked around the room and thought, ' do people think I am drug user?' I felt completely out of place. One time, when I went for a scan there was a doctor who made me feel uncomfortable because of his manner. He read my notes, did not introduce himself, made no conversation and only issued instructions to turn left and right. The atmosphere was uncomfortable. I often wonder what he was thinking, was he judging me.

50.Every time I go for testing I feel like I have to explain myself to the medical staff. I tell the nurses, " I got this from contaminated blood you know, I had a transfusion in the 1980's".They are always completely baffled. I am shocked that nurses are not informed about the different ways HCV has been passed on. If I do not explain myself, what assumptions are people making of me. These experiences are why I do not feel I can disclose to more people.

Employment

51.I used to be a special education transport assistant. It got to a stage where the illness was really telling on me. Some of the mothers at the school noticed my significant weight loss, and would ask questions or

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make comments. I did not know how to respond. I left that job which I loved because it was becoming harder to keep it a secret. I remember being exhausted but unable to tell anybody why that was.

Section 6. Treatment/Care/Support

52. I do not believe I have had any difficulties in accessing treatment for my HCV. It would have been better if I were diagnosed earlier and prevented cirrhosis of the liver.

53. There has never been any psychological support, or counselling made available during, or after, my treatment. It would have been beneficial if at the time there were people available at the hospital who were able to provide some psychological support or counselling. It would also have been beneficial if there had been a support group, where I could speak with people who had been through what I had been through. However, it's too late for me now. The time has passed.

54. The Inquiry Investigator has advised me that the British Red Cross is offering confidential counselling and psychological support line in conjunction with the Inquiry. I have been provided with their contact information.

Section 7. Financial Assistance

55. I have received financial assistance from the Skipton Fund. It was the nurse, not the doctor who informed me while receiving treatment.

56. At first I found it difficult to gather all the information they needed. I went to my GP, to ask for my medical records. He handed me a little piece of paper, which I exhibit as **WITN251002**, it was a record from 1983 and proof of my second transfusion. He said if I wanted my earlier

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records, I would have to hire a lawyer. I thought that was a strange comment. Looking back I am not sure if that meant they were destroyed, but I am annoyed I never queried his remark.

57. The Skipton Fund was satisfied with the record of my second transfusion. Once received, the financial assistance came through quickly.

58. It was an ex-gratia payment of £20,000. I receive regular payments every month. I have also received a lump sum of £25,000 due to the cirrhosis of the liver.

Section 8. Other Issues

59. I am aware that other people have also contracted HIV and Hepatitis B from transfusions, and blood products, and I am concerned the stigma remains.

60. I believe there needs to be training given to all medical professionals so they are aware there are people out there who have contracted these viruses, not just from drug use or sexual behaviour, but from contaminated blood given by the NHS. There needs to be a health campaign so the public at large are educated, through education the stigma could be dismantled.

61. I have been left with very little faith in experts. The contamination of blood transfusions, and blood products, is a major thing and should never have been allowed to happen. The Health Secretary at the time should be named and shamed. He should acknowledge what occurred under his authority. I just want there to be recognition.

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62. I would like to know the connection between the health issues I have suffered and HCV. I wonder if others have similar health issues too.

Statement of Truth

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

Signed _____

GRO-B

Dated _____

7 . 5 . 2019