

# ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0300001

Exhibits: **WITN0300**

Dated: 16 January 2018

## INFECTED BLOOD INQUIRY

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WRITTEN STATEMENT OF GRO-B

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, GRO-B will say as follows: -

### Section 1. Introduction

1. My name is name is GRO-B My date of birth is GRO-B GRO-B 1944 and address is known to the Inquiry. I am a retired home carer. I am married and reside in Wales with my husband. We have been married for 51 years. Together, we have three children aged 50, 49 and 47 as well as 12 grandchildren and five great grandchildren. In this statement, I intend to speak about my Hepatitis C (HCV) infection, which I contracted from a blood transfusion. In particular, I intend to talk about the nature of my illness, how the illness has affected me, the treatment received and the impact it has had on me, my family and our lives together.

### Section 2. How Infected

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2. When I was 11 years old I developed rheumatic fever and I was confined to bed for 18 weeks. At the time, I was told I would never be able to have children as rheumatic fever weakens the heart. At the time, I was not allowed to go to the local grammar school because the bus ride would put too much stress on my body and heart. I was later told when I was 66 years old that I was born with a hole in the heart.
3. Despite what the doctors told me when I was 11 years old, I had three children within four years. I fell pregnant for a fourth time in 1973 and I was told by my doctor that if I had more children it would be a choice between my life and the babies because of the stress on my heart.
4. In early 1973 I underwent a termination and sterilisation at the GRO-B Hospital in Wales. During the surgery, something must have gone wrong. I still don't know exactly what went wrong as I was not told at any stage but as a result I was in hospital for 10 days. I know it was very serious, as the hospital called my mother and asked her to come to the hospital to be with me.
5. When I woke up from surgery I was wired to two IV bags and I had two nurses taking care of me all night. I remember I was wearing a purple nightie and I was sweating so much that the dye from the nightie was all over the bed sheets. The nurses told me that I had received a blood transfusion but I was not told how much blood I received. I don't remember what colour liquid was in the IV bags I was connected to.
6. I know now from a letter sent to my GP that whilst in hospital I was under the care of Mr J C Du Heaume. I don't remember being informed or providing consent for the blood transfusion but I presume that was because the decision had been made while I in surgery under anaesthetic. I wasn't given full or adequate information after I woke up but at the time I put my faith in the medical professionals.

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7. After ten days in hospital, I was sent home under the care of my GP. I don't remember being offered any counselling or other support. I had three young children so I just got on with life.
8. Between 1973 and 1980 I didn't have any illnesses or symptoms to suggest I had HCV. I did have fibroids and heavy periods, and I was always very tired but I put that down to having three young children as well as working.
9. In May 1980 I had a hysterectomy at GRO-B Hospital, GRO-B Wales where I was under the care of Dr Jackson. When the hysterectomy wound was sewn up, the hospital did not use conventional stitches but instead used a new type of nylon stitch that was being trialled at the time. The nylon stitch was made out of a nylon cord with a bead at either end.
10. After seven days, the hospital took the stitches out. Shortly after lunch, I was in the next ward talking to a lady when I felt something pop in my stomach as my hysterectomy wound burst open. The stitches had been taken out too early and should have been left in longer. I was rushed back to hospital but could not have surgery straight away as I had recently had lunch.
11. While at the hospital, I was given a blood transfusion. I can't say a lot about it. I don't know how much blood I was given, as I was not told. I also don't know if I was just given blood or also given plasma. I can't remember what colour the liquid in the IV bags was.
12. After I was released from hospital, I was unwell for a long time and struggled to get over the procedure. I was always very tired. My doctor thought I was anaemic so I had regular iron tests.
13. From 1985 to 1987, I was regularly ill. I regularly attended the GP who said I had gall bladder problems but that nothing could be done as the gall bladder was inflamed. The GP would always ask me if I had been drinking too much alcohol or been smoking. I don't drink alcohol or smoke. The GP would do liver tests and the results would come back as abnormal, which

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the GP would attribute to the gall bladder problem. The GP never said my tiredness could be anything else. I always felt that the GP did not know what was wrong or what to look for. In May 1987 I had my gall bladder removed at the **GRO-B** Hospital.

14. After the gall bladder was removed, I stayed in hospital for ten days under the care of the surgeon, Mr Isaacs. As far as I can remember, I did not have a blood transfusion during this time.

15. After the gall bladder surgery, I was very sick for a long time. I was so weak that I could not lift a kettle and I did not go back to work for six months. After I recovered from the surgery, I had a relatively good health for a number of years.

16. In the late 1990s, I again suffered from extreme tiredness. I was so tired that it was a job to get out of bed in the morning. I went back to the GP who ordered some blood and liver function tests. The results of both were abnormal.

17. In 2001, my GP, **GRO-B** sent me to see Dr Boyd, a liver specialist at **GRO-B** Hospital. Dr Boyd sent me to see a radiographer at **GRO-B** for a liver biopsy test. After the radiographer stuck a long needle in my liver he said to me "I think you have Hepatitis C, I am almost sure". I remember sitting on the hospital bed not knowing what HCV was, as I had never heard of it. None of the doctors had previously told me about HCV or that I could have it. I was shocked.

18. The liver biopsy results confirmed I had HCV. The doctor didn't elaborate on the risks of HCV or provide me with detailed advice. I was not told about the infectivity of my blood or told about precautionary measures. Instead, the Hospital provided me with a HCV Patient Information booklet.

19. After reading the booklet, I realised how serious HCV was. The booklet outlined the risks of HCV and the precautions to take. My GP wasn't able to

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give me any information and asked to see the booklet as she said she knew nothing about hepatitis. I think the doctors and hospital could have given me more information about HCV at the time.

20. After the HCV diagnosis, I was sent to see Professor David Mutimer, Consultant Hepatologist, at the Queen Elizabeth Hospital in Birmingham. Dr Mutimer told me that I would have got HCV after being given infected blood during one of my blood transfusions. Dr Mutimer told me HCV could lead to liver damage or cancer if not treated. This was the first time I had heard this information and I was shocked.

21. Looking back, I don't feel my doctors, other than Dr Mutimer, gave me adequate or full information about HCV.

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

22. I don't believe I have received any infections other than HCV as a result of having been given infected blood although I sometimes wonder if my gall bladder problems are related to the HCV.

### **Section 4. Consent**

23. I have always been treated with my knowledge and consent. I don't remember the details of all the conversations I had with my doctors or surgeons but at the time I put faith in their judgement and treatment plans. If they said something was best for me, I would follow their advice.

24. As I was under general anaesthetic at the time, I did not know about the blood transfusion during my termination until after the fact. I think it was a case of the doctors doing what they needed to do to keep me alive.

### **Section 5. Impact**

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25. The HCV diagnosis made me feel depressed and low. When I was diagnosed, I thought why me? Why have I had a blood transfusion and this is the result? I wondered what I had done to deserve HCV. Who had given it to me? I had always taken care of my children, my husband and myself. I wondered what more did I have to do.
26. I don't talk about my HCV often. I have told my husband, children and siblings but I would not tell anyone outside my close family. It is not something to brag about. People would think, where has she been. People assume people with HCV have been where they shouldn't have been.
27. Luckily, I have family who pulled me out my depression or my low feelings. I wasn't treated for it and I was never offered any psychological help or counselling although I read somewhere that I could have accessed it.
28. After I saw Dr Mutimer I began treatment for HCV. Treatment involved a weekly Interferon injection and five Ribavirin tablets per day. At first, I had to travel to Birmingham each week to receive the interferon injections although after a few weeks I received these at my local GP surgery. I still had to travel to Birmingham once a month to see Dr Mutimer.
29. The HCV treatment was awful. I was told interferon is like chemotherapy. On Mondays, I would have the interferon injection and for the next three days I would have flu like symptoms and be too tired to move from bed or the settee. I was too sick and too tired to work. I remember my son would come around to the house and say, "you're always asleep". From Thursday to Sunday, I would start to feel better again and then on Monday I would have the interferon injection and the cycle would start again.
30. When I started the HCV treatment my grandson was four years old and attending a school a few minutes' walk from my house. Some days, I would pick him up from school. Even though the school was only a few minutes away, I would need to stop three or four times for a rest on the way to get him as I was so tired.

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31. The HCV treatment was supposed to last for 26 weeks, however after 19 weeks of treatment, my body rejected the medication. I was having a shower one day and I felt my stomach 'burst' at the scars from my previous operations. The doctors stopped treatment straight away.
32. Thankfully my liver responded well to the 19 weeks of treatment and my liver test results came back favourably. These tests were initially once a month, then every three months. Now, I have a liver test once a year. My doctor tells me my liver is "A1" and my liver function tests are normal.
33. I'm not sure if my HCV infection has impacted on my medical treatments. Now when I see doctors or dentists, I have to inform them I have HCV.
34. After I started HCV treatment, I had to give up work, as I was too tired to work. I found this very hard. I had worked since I was 15 years old. If I have not been diagnosed with HCV, I would have continued working until I was 65 years old and I would have a good pension. I have lost fourteen years of pension subscriptions.
35. As a consequence of me not working, my family had less disposable income. We have had to scrimp and save, we've had it hard. My daughter was married in Antigua in 1996 and we had to take out a loan to attend. We used to go on a holiday every year and we had to stop that. But we made do and I came to accept my diagnosis as part of my life.

### Section 6. Treatment/Care/Support

36. As explained above, I received treatment through the Queen Elizabeth Hospital in Wales. The course was very expensive, costing around £350 per week for the injections and tablets. When I first saw Dr Mutimer, he did not know whether NHS funding was in place for the treatment. He had to apply to the Health Authority for funding. Fortunately funding was made available

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for the treatment and I don't remember there being any restrictions or conditions attached to the treatment.

37. I have never received or been offered any psychological support or counselling although I now know this was available to me.

38. I have not been involved in any support groups. I didn't know they existed.

### **Section 7. Financial Assistance**

39. A few years after my diagnosis, I found out about financial assistance available to me and applied to the Skipton fund. The application process was straightforward. After I applied, I was told that I would receive a payment because I was infected with HCV through the NHS. The paperwork said if I contracted cirrhosis or cancer there would be additional payments available. In 2004 I received £20,000 from the Skipton fund. It was described as an initial payment.

40. I have also received payments from the Caxton fund. About two years ago, I received a payment of £1,250 from the Caxton fund. I have received the same amount every three months since. The Velindre NHS Trust in Cardiff is now responsible for the quarterly payments.

41. I think of the payments as compensation for my HCV infection.

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

42. I have been asked if I am legally represented in this matter and I confirm that I am not.

43. Having now spoken to 'The Inquiry', I am now going to make efforts to recover all of my medical notes which may help me understand my story more comprehensively.



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**Statement of Truth**

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

Signed GRO-B \_\_\_\_\_

Dated 12/2/19