

ANONYMOUS

Witness Name GRO-B

Statement No.: WITN6485001

Dated: *x 21. 10. 21. x*

GRO-B

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 22 July 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1949 and I reside in GRO-B Wales.
2. I intend to speak about my infection with hepatitis C ("HCV") that I received as a result of a blood transfusion when I suffered a haemorrhage during childbirth at GRO-B Hospital (which no longer exists). In particular, I will speak about the nature of my illness, how the illness affected me (including its many complications), the treatment I received and the significant impact it has had on my life and my family.

3. I lost my husband five months ago. We had three children together. By profession, I was a school science teacher until I was forced into early retirement due to my health conditions. My husband was an accountant and a Financial Director.

Section 2. How Infected

4. During the birth of my daughter, [GRO-B] in 1976, I had a post-partum haemorrhage. As a result, I was transfused with 7 pints of blood. To understand what fully happened, I must explain the context of what had happened at my previous childbirth and the warnings I gave the clinical team looking after me before [GRO-B]'s birth.
5. I lost my first baby. With my son (who was born before [GRO-B] I also had a haemorrhage – but they put a drip into my arms which was sufficient. I hadn't had a transfusion by this point. I came to [GRO-B] in 1975 after giving birth to my son. I warned them before [GRO-B]'s birth that I had these haemorrhages during childbirth previously and therefore, that I was prone to it. When I had [GRO-B] I had a massive haemorrhage. They called for an anaesthetist. But it was rush hour on Friday morning. All I remember was telling them that I had warned them and losing lots of blood. I had a 7-pint blood transfusion. A sister on the ward and my family doctor told me not to have any more children. But I fell pregnant for my son in 1978. My G.P. suggested I should have an abortion as a precaution. I had a private appointment with Mr Blair (a consultant at Morriston Hospital). I told him how frightened I was. Mr Blair reassured me that the necessary precautions would be taken and the baby would be induced. What he said was going to happen, happened. The birth – in [GRO-B] 1978 – was perfect. I didn't need a transfusion. But, for [GRO-B]'s birth, in light of the fact that they didn't heed my prior warnings, I needed 7 pints transfused.
6. The fact the blood was infected was unknown at the point of use. It took 44 years before I found out that I had been infected with HCV. I

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feel strongly that I have been let down by the medical profession on several fronts. There were many occasions over the years where better practice could have revealed my infection earlier. I have had a number of health issues related to this which I will describe in chronological order later in this statement.

Section 3. Other Infections

7. I do not believe I was infected with any other infections other than HCV as a result of my treatment with blood and blood products.

Section 4. Consent

8. I do not believe I have been tested for anything against my will or without my consent for the purposes of research.

Section 5. Impact

9. Looking back, my family were always worried about me. It was a constant game of going back to the doctor and trying to find out what was going on. It was like hitting a brick wall. We tried to make progress but it was to no avail. My daughter would join me on visits to the GP.
10. I hid it quite well, but my family were all aware that something was wrong. There would be periods where I'd be a bit better, but then periods when I was really unwell. My daughter recalls that when we went for a walk down to the beach, I was so ill that I collapsed on the floor. This is despite me being very healthy and fit otherwise. This became the new normal: I am a very resilient person by nature but it was quite obvious I was not well at all.
11. I had to retire very early at age 48. I was previously a Science teacher responsible for teenagers in a school laboratory but I struggled with it due to my ill-health. I had frequent bouts of diarrhoea which meant that

I had to ask a colleague to watch my class while I went to the toilet. This became unsustainable. I was rapidly losing weight and the GP treated me for irritable bowel syndrome. This was a misdiagnosis. Before this, I was a competent teacher who enjoyed her job; my classes were well controlled and I didn't have any problems. However, after spending 17 years in the same school, I gave in my notice and stopped work as a result of being continuously unwell.

12. In recent years, it was terrible finding out that I had HCV and going through all the treatment at the same time as my husband's last year alive. A liver scan revealed that my liver was damaged but had not quite reached the irreversible stage. My husband had amyloidosis (which is a rare, serious heart condition caused by a build-up of protein that mutates and attacks the heart) and he was treated at the Royal Free Hospital. I hated that he had to get tested for HCV when he himself was so poorly. I was also worried that the HCV could have

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but it was a stressful experience.

13. I haven't told people about my HCV infection unless they are very close to me. There is still a social stigma associated with hepatitis C and people don't understand it fully. I even found it hard to tell my dentist.

14. As I will describe in the next section, we used to attribute all of the symptoms of my ill-health to my thyroid issues. I used to be totally exhausted and have a significantly elevated resting heart rate. Sometimes, I would pass out and I even had difficulty swallowing and gulping. My physical appearance was also affected: for example, I had very dark circles around my eyes. I just couldn't understand why I wasn't getting better. First, they sorted out my thyroid issue. Then, they sorted out my atrial fibrillation. The inordinate delay in diagnosing the HCV has caused me a lot of difficulties. I feel very frustrated that previous doctors had ignored my abnormal liver enzyme readings over many years. Instead, it sometimes felt like they thought I wasn't telling

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the truth regarding my alcohol consumption. I could have been diagnosed with HCV a lot sooner and been treated for it.

15. I live a very healthy lifestyle: my alcohol consumption is low, I have never smoked, I do regular cardiovascular exercise and I eat a healthy diet. Despite all of this, I have had enormous struggles with my health that I believe to have stemmed from my HCV infection. My daughter feels that it was implied that my physical ill-health was a mental health issue: that my stress led to irritable bowel syndrome.

Section 6. Treatment/Care/Support

16. The biggest failure in my treatment and care is that my HCV infection was not detected earlier than it was despite there being good evidence to have conducted the necessary investigations for it. My old medical practice was [GRO-B] and I was treated by Dr [GRO-B]. I had been with that practice since I was in my teens. My new medical practice, that I recently joined because I was unhappy with the quality of service at my previous general practice, is [GRO-B] Medical Practice. In the 1990s, I was unwell in that I persistently had abnormal liver readings. In that context, I was questioned about my alcohol consumption although it was always at moderate levels. By this point, the relationship between blood transfusions and infected blood had been discovered. Despite this, and the fact that I was at the same medical practice (giving me a continuity of treatment and observation), I was not referred to a liver specialist for further investigations.
17. Eventually, after a number of years when I was around 40 years old, I was diagnosed with an overactive thyroid. My resting pulse rate was over 160 beats per minute. I have since read that this is a known effect of prolonged HCV infection and there is no family history of hyperthyroidism. As I described earlier, I also had terrible diarrhoea. I was very poorly and I had no idea what was wrong with me. The GP

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wrongly thought my symptoms were caused by irritable bowel syndrome.

18. I was given a drug, carbimazole, to control my overactive thyroid but it did not work. As a result, I had to have radioactive iodine treatment to destroy the cells in the thyroid gland. My thyroid then became underactive and I now have to take a daily dose of thyroxin for the rest of my life.

19. In the early 2000s, I was still unwell. Again, I was continually given blood tests, my liver readings were abnormal and I was questioned as to whether I was consuming excessive amounts of alcohol. I told them I was feeling faint during exercise and they gave me a heart monitor which revealed that I had atrial fibrillation. I was given bisoprolol and aspirin. In 2016, the hospital contacted me to change from aspirin to warfarin. I refused and asked for a private consultation. This consultation revealed that I no longer had atrial fibrillation but instead, had long pauses in my pulse. In response to this, I was taken off the beta blockers (which I had used for about 15 years).

20. Around two years ago, I was having increasingly frequent dizzy spells. That was put down to a combination of my heart condition and my husband's poor health which was, understandably, a stressful time. My pulse rate was also continuing to fall – I have read that some heart problems can be caused as a long-term effect of HCV. The doctor put me on a 24 hour heart monitor which showed that my pulse rate had dropped to 26 beats per minute. I had to have a pacemaker inserted urgently on 22 June 2021. I am now recovering from that operation. Their explanation of why this happened to me is that it was in the normal course of 'wear and tear'. My suspicion is that these health problems were caused by the stress my body must have endured fighting the 8 million hepatitis C viruses that had been recorded in my

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body, especially in the context of the known links between HCV and heart complications.

21. In December 2019, when I was 70 years old, a new doctor called Dr **GRO-B** at **GRO-B** sent me for blood tests after my resting pulse rate was dropping below 40 beats per minute. Once again, I had abnormal liver readings. Dr **GRO-B** was a dedicated young doctor who asked pertinent questions relating to my medical history. As a result of those questions, she found out that I had a blood transfusion in 1976 and had me tested for HCV. This test came back positive and I was so shocked.

22. I was given hepatitis C drug treatment and my first round of treatment worked: the viral count came down to zero. I was treated at Singleton Hospital and Dr Chung was the Consultant. We saw an excellent Specialist Nurse, Helen Thompson Jones. The course of treatment made me feel exhausted and I used to feel sick a lot. I would be better if I took the medication last thing at night.

23. I have never been offered counselling or psychological support as a result of my infection with hepatitis C.

Section 7. Financial Assistance

24. As a medical record of the blood transfusion doesn't exist, I can't access financial support payments. The Wales Infected Blood Support Scheme (WIBSS) told me it was unlikely that I could get financial assistance without supporting medical records of the transfusion.

25. I have tried to retrieve my medical notes. Unfortunately, I couldn't get any records about my daughter's birth. I also checked my children's medical records from the time of their birth. I wrote to Swansea Bay University Health Board about this and they wrote back saying that, after extensive searches, they couldn't find it.

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26. What seems strange to us is that all of the medical records on both of my son's births exist (from 1975 and 1978) but nothing for my daughter's birth in 1976. I find that very strange, distressing and difficult to understand.

Section 8. Other Issues

27. I want to feel my voice is heard and what happened to me doesn't happen again in the future. That is my biggest priority. I also feel like I'm in a vacuum here: I don't know what happened to others and how common my experience was. I wonder if others suffered the same difficulties as me.

28. My youngest son has been incredibly worried and angry about what happened. My children's biggest anger is that my abnormal liver readings were ignored for so many years. I feel I've been let down badly by the medical profession. I want to know why I wasn't helped sooner. It just seems it was left down to chance whether my HCV would be discovered. I remember hearing about HCV in the 1990s and the connection with the infected blood. I thought I was okay because I had continually received blood tests. I also feel terrible that I donated blood and may have passed it on to others. I think there should have been a much better, coordinated attempt to test for infection, all those who had been given a blood transfusion in the 1970s and 1980s.

Statement of Truth

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

Signed _____

GRO-B

Dated _____

21 . 10 . 21 .