Witness Name: GRO-B
Statement No.:WITN0600001
Exhibits: **WITN0600002**
Dated: November 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 3 September 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B 1966. My address is known to the Inquiry. I have two children. My daughter GRO-B is 23 years old and my son GRO-B is 24.

2. I was infected with Hepatitis C through the administration of a contaminated blood transfusion. In my statement I intend to speak about how I was infected, the nature of my illness and in particular how this disease and its treatment have affected my life and that of my family.

Section 2. How Infected

3. As a 12 year old boy, I fell off scaffolding whilst playing and injured my spine. On the 5th November 1983 I underwent an operation at The Heath University Hospital, Cardiff (the University Hospital) to correct a twist that had developed in my spine as a result of the earlier trauma. It was during this operation to correct the scoliosis that I received 8 or 9 pints of blood via transfusion and was consequently infected with the Hepatitis C virus. I was 17 years old at that time.

4. Prior to my operation, my mother had consented to me receiving a blood transfusion if necessary. She has told me that she was never informed by the doctors, nurses or any hospital staff of any potential risk of exposure to contaminated blood at the time.

5. In April 1997 I received a letter from the Infectious Diseases Department of the University Hospital requesting that I attend an appointment in a few weeks' time. An appointment date and time was set out in the letter. This letter came as a complete surprise as I had experienced no symptoms or ill health in the fourteen years since my back operation.

6. I met with Dr GRO-D who explained that I may have contracted Hepatitis C from contaminated blood used during my back operation in 1983. A nurse took blood from me to be sent off for testing and told me to return in one week for the results. A week later I went back and received the test results confirming my diagnosis of HCV. I feel that Dr GRO-D downplayed the seriousness of my infection. He gave me the impression that it was something I could live with and that it was nothing to worry about. He told me that there was no need for me to start any treatment then as the HCV was stable. It seemed to me that he did not know the long-term consequences of such a diagnosis himself.

Section 3. Other Infections

7. To the best of my knowledge, I have not contracted any other infections as a result of receiving a contaminated blood transfusion.

Section 4. Consent

8. I consented to being tested for Hepatitis C after being called into the University Hospital and told that I had possibly been exposed to the hepatitis C virus. I was not told how the hospital came to suspect that my blood transfusion fourteen years earlier had been contaminated.

9. I am not aware of any tests having taken place without my knowledge.

Section 5. Impact

10. Initially, my condition was very stable and I did not experience any symptoms of HCV. I had my blood tested every year, but despite being encouraged by my doctors to start the treatment to eradicate the HCV, my view was that its low success rate did not justify the gruesome process of injecting myself twice a day and suffering the potentially serious side effects.

Pernicious Anaemia

11. This decline persisted until in January 2000 when I was so ill that I had to be taken to hospital. I coincidentally had a routine appointment booked that day to check on my Hep C infection. To this day, I feel that if I had not had that appointment with the Infectious Diseases Department, I would have died. I was admitted immediately, placed on a drip and within 4 hours had been diagnosed with Pernicious Anaemia, a vitamin B12 deficiency which was a direct result of being infected with the Hep C virus and the cirrhosis of the liver. I was very thin and my skin was yellow. I looked like someone who was about to die. I was told by my doctor that

with my haemoglobin count so low, he was astounded that I was still alive. I spent 3 days in hospital receiving vitamin B12 injections. I continued to receive vitamin B12 shots every 3 months from that time until my last treatment for HCV in 2014.

12. The lack of vitamin B12 inhibits muscle lubrication, leaving me with joint pain and aches to this day. I attended a pain management course, which consisted of a single appointment, to help manage my joint pain and am now able to do so quite well. I had to research the course myself and feel that once again I was let down by the NHS through what I believe to be a very poor standard of care.

Deteriorating health

13. My health collapsed once again in 2005. My energy was totally depleted. Apart from my hospitalisation five years earlier, I had lived an active life, maintaining multiple motor businesses and often working seven days a week. I love cars, and considered my businesses as a passion, not simply a job. But as the exhaustion increased, I had to reduce my working days to just two days a week. I tried to keep the businesses going but I no longer had the energy or passion to continue with them. I closed down and sold all of my businesses over the course of a few weeks.

14. The HCV continued to really dig in, I could tell I was deteriorating. Doctors urged me to start the treatment but I was frightened that in my current state I would not survive it. I was also unwilling to subject myself to painful side effects when the success rate for clearing the infection was only around 60%.

Throat Procedure

15. In 2010, after coughing continuously for a few months, I underwent an investigative procedure to look for polyps in my throat which I was told is

a possible side effect of Hepatitis C. I would not wish it on anyone, an awful gasping feeling as though you are about to choke. No polyps were found but I live in fear of having to endure the procedure again, so much so that I have avoided having a persistent dry cough looked at by a doctor.

First round of treatment

16. I began my first round of HCV treatment, a 12-week course of Interferon, in 2011. It was unsuccessful. I was taking handfuls of pills daily as well as subjecting my then wife, who was not a trained nurse, to injecting me in my stomach. I was extremely tired during the entire stint. I split my time between the bed and the sofa.

17. In the tenth week I experienced side effects so debilitating that I had to stop the treatment altogether. I felt a constant burning sensation and cramped, hard muscles in my calf. It felt as though someone was passing a lighter flame over my skin. My legs went completely stiff and I walked into the hospital as if walking on stilts. I was kept in the specialist burns unit for three days.

18. Being so close to successfully eradicating the Hep C virus only to suffer in the final weeks left me frustrated and drained. I was so disappointed that after years of hesitating, the treatment had not worked.

19. I believe this contributed to the breakdown of my marriage in 2013. I was extremely moody and in constant pain. I also lived with the knowledge that my pain was someone else's fault. Instead of helping me, the treatment harmed both my health and my close relationships.

20. From Day One of being told that I had this virus, the psychological burden has grown heavily. The breakdown of my relationship with my mother has been enormous and traumatic. We were constantly arguing and finally the relationship totally broke down and I have had no contact

with her for about 8 years now. As far as I'm concerned, I have no mother.

Second round of treatment

21. My second round of treatment in 2014 was more successful. Under the care of Dr Brendan Healy, I was given a twelve-week course of Interferon. I was sent three batches of pills every 28 days. This made the administration of the medication more manageable. Although I experienced some side effects, such as tiredness and nausea, it was nothing compared to the hell I endured during the first attempt. The infection was cleared and I was told I was free of Hepatitis C.

Overall impact on physical health

22. Despite having my Hepatitis C successfully treated in 2014, I have chronic stage 2 liver disease. Recently there has been some improvement in the condition of my liver, but I remain unsure as to how much damage has been done. I am reminded of this by a stabbing, stitch-like, pain in my side. That said, for someone with chronic liver disease, my liver functions at around 97 to 98% capacity, something I attribute to my abstinence from drinking and eating healthily.

23. I still need to have my blood taken at GRO-B to test my liver function. Its deterioration is a constant worry. My capacity for any kind of physical activity is limited as I become easily exhausted. Some days I can barely muster the energy to get out of bed. I certainly no longer play sports or do any kind of the rigorous exercise that I once enjoyed. I'm further impeded by a constant ache in my neck and shoulders, a hangover from the pernicious anaemia. Still, I try to stay healthy through walking, managing my diet closely and not drinking alcohol.

24. Perhaps most frustratingly, the Hepatitis C has impeded my memory and recall. The prospect of completing a task such as this statement has at times, felt overwhelming to me. Not only is my memory of past events fuzzy, my daily recall can be poor, leaving my children with the burden of keeping house and remembering appointments. I have to be reminded of my scheduled liver function assessments. I am so tired of hospitals, doctors and tests that the physical exertion involved in getting to the appointments almost doesn't feel worth the effort.

Overall impact on mental health

25. Although I try to stay positive, I cannot avoid thinking that my life would have been dramatically different had I not been given contaminated blood. Only finding out about my HCV infection 14 years after the blood transfusion has made me regret drinking alcohol whilst a student at University. I constantly think about the damage I was unknowingly doing to my liver. I wish I had been told earlier.

26. Getting out of bed in the mornings is always the hardest. The physical pain I endure is at its worst then which puts negative thoughts in the forefront of my mind. I constantly ask myself why *I* was infected. This question plagues me. I try to avoid it, but on my bad days I see an angry vision of myself on the operating table, and the doctor authorising the transfusion of the infected blood into my body. My mind often returns to the unavoidable fact that someone has made a mistake and, as a result, I have been given infected blood and my life and that of my family has been changed forever.

27. I have spoken to a professional about the dark thoughts that stem from the anger that I feel, but they are too painful to discuss here. All I will say is that if it were not for my children, GRO-B and GRO-B, I may have allowed those thoughts consume me completely, it is them who keeps me going.

28. My relationship with my children is the most important thing in my life. We are all very close and support each other. Since my divorce, my daughter especially has taken on an active role in my care, accompanying me to most of my medical appointments even whilst she was busy with secondary school and university.

29. Despite being a tight knit family, I do sometimes feel as though I am a burden on my kids, both in that they have had to take on more adult responsibilities around the home, as well as endure my anger and irritation. This weight is made heavier as my relationships with other family members have deteriorated. As stated above, my marriage ended in 2013, and although I am happier now, my anger, tiredness and despondency definitely contributed to the breakdown of the marriage. I have no relationship with my mother, who I believe cannot get over the guilt that she had consented to me being given a contaminated blood transfusion at the time of my back operation. She simply has not been able to get past it. This, coupled with the fact I have little energy to visit friends, leaves me fairly isolated.

30. Finally, I feel a looming fear that, despite enduring two rounds of treatment to rid myself of the HCV, it will return. When I feel a stabbing pain in my liver, for example, I am frightened it is the disease coming back. Doctors assurances do not help as I have little trust in them after all I have been through.

Section 6. Treatment/Care/Support

31. I've always felt disconnected from the treatment I was receiving. The specialists at University Hospital seemed to me to have a 'god complex'. My fear and suffering were diminished. In fact, when I asked Dr Brendan Healy about the life expectancy of someone with Hepatitis C he told me, "well, we all die don't we?". There was very little sympathy. If I ever wanted any useful information or support I would seek out the hospital's nursing staff.

32. I have never been offered any form of counselling or psychological support by the National Health Service (NHS) or any of my treating doctors. Any counselling I have received in the past, I have had to seek out myself.

Section 7. Financial Assistance

33. I applied to the Skipton Fund for financial support in 2012. I did not experience any particular difficulty with my application to the Fund and received my first monthly payment of £1,157 on 4 December 2012. I have received payments each month since then and now receive an amount of £1,438 per month from the Velindre NHS Trust, which I believe is the Welsh arm of what was the Skipton Fund. I also receive a job seekers allowance of £74 per week.

34. Prior to the monthly financial contribution I receive from the Fund, I did receive a £20 000 Stage 1 lump sum payment from the Fund in 2007. In November 2012, after having been diagnosed with Stage 2 cirrhosis of the liver, I received a further lump sum payment of £50,000 from the Fund.

35. I would like to note that I do not consider these payments, both the lump sum and monthly payment, to be anywhere near to adequate or satisfactory. I have had to raise and support two children for 14 years on this amount. My family's standard of living has dropped considerably as I am unable to work and am forced to live on a shoe string budget.

Section 8. Other Issues

36. I would also like it noted that all but my most recent medical records have been lost by the University Hospital. I had seen my records on previous occasions and know them to be thick binders. I am told that they are

nowhere to be found which I find highly improbable and suspicious that the hospital may have something to hide.

37. As a consequence of the HCV infection, my application for a life insurance policy was declined. My father lives in Spain and I have also been forced to take out extra, top up travel insurance when travelling to visit him or elsewhere.

38. In August 2017 I wrote to the Welsh Cabinet Secretary for Health, Vaughan Gethan, expressing my anger at being a victim of the failure of the NHS and how it has profoundly affected my life and that of my family. I was extremely angry at the time and although I am coping much better now than I was then, I still have days when I feel very bitter about it all. I don't believe that the compensation paid to victims is anywhere close to being adequate for the pain and suffering the failings of the NHS have caused to me, my family and so many others. (WITN060002)

Statement of Truth

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

Signed GRO-B

Dated 14/11/19