Witness Name: GRO-B
Statement No.: WITN0522001
Exhibits: **WITN0522002–005**
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 22 January 2019.

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 1965 and my address is known to the inquiry. I am a specialist nurse working in bowel cancer screening. I have been married twice and am currently separated.

2. I intend to speak about my infection with the Hepatitis C virus ("HCV"), which I contracted as a result of receiving several transfusions of contaminated blood during my chemotherapy treatment for Acute Myeloid Leukaemia ("AML") in 1987 and 1988.

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 life and the lives of those around me.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

5. In 1987, I was a 22 years old qualified nurse and I was doing voluntary work. I was a healthy, normal person and had never received blood transfusions or products.

6. In November of the same year I was diagnosed with AML at the University Hospital of Wales.

7. For a year, from November 1987 to November 1988 in order to treat the AML I underwent chemotherapy and I received multiple blood products at the University Hospital of Wales. I was given 7 courses of chemotherapy and received at least 24 units of blood over this time. During the course of my treatment I also received a bone marrow transplant.

8. I developed dilated cardiomyopathy secondary to the AML treatment and in 2008 when my ejection fraction went down to 15%, I was briefly hospitalised **(WITN0522002)**.

9. By late 1988 I had cleared the AML and moved on with my life as best I could.

10. In 2005 I had begun experiencing severe skin problems including flaking, bruising and cutting. I was initially referred to the Occupational Health who then referred me to a dermatologist at Milton Keynes Hospital. Here I was diagnosed with porphyria cutanea tarda.

11. I tested positive for HCV and the doctors surmised that I contracted this from the blood transfusions I received during my chemotherapy in 1987 and 1988 **(WITN0522003)**.

Section 3. Other Infections

12. To the best of my knowledge, I did not contract any other infection as a result of being given blood transfusions and blood products.

Section 4. Consent

13. To the best of my knowledge I believe that I have always been treated or tested with my knowledge and consent.

14. I do believe that I was not given adequate information or full information regarding HCV in 2005, both before and after I tested positive for HCV.

15. I was not treated or tested for the purposes of research. I was offered to take part in some studies, but due to time commitments and already the numerous trips I was already doing to Oxford for tests and treatments, I declined.

Section 5. Impact

16. In 2005, when I tested positive for HCV, I underwent a liver biopsy; it showed that considering my age my liver was reasonably healthy. The test revealed that there was some fibrosis and slightly raised liver test function but no cirrhosis.

17. Aside from the liver biopsy, I received no information or advice about the nature of HCV, its implications in relation to my health, how to live with it and how to avoid transmitting it.

18. There was no further follow up or discussion regarding treatment options for 3 years, until a colleague told me that I ought to get it treated. I find it shocking that this was never raised with me in 2005.

19. In 2008, my boss at the time, Dr R Madhotra, who was a consultant Gastroenterologist referred me to the Oxford University Hospital **(WITN0522003)** for another biopsy. The test showed no signs of chronic liver disease. We discussed treatment options, in particular Interferon, but we decided to wait for the new drugs that soon were going to come up on the market **(WITN052204)**.

20. I was concerned about Interferon; I was told that it would only have had a 50% chance of success and severe side effects, similar to those I had experienced during chemotherapy **(WITN052204)**. The doctors agreed that at this stage, given that the Hepatitis was still relatively mild it would be best to wait.

21. I found these discussions regarding treatments extremely upsetting. I had not realised the extent of the impact that such treatments would have on my life.

22. When the doctors told me that I would have to cut out all alcohol consumption, it shocked me. I do not drink a lot but every now and then I enjoy a social drink with friends on the weekend. While I was driving back home I realised the huge impact that such treatment would have on my personal life.

23. I remember that after this discussion while I was in the changing rooms getting ready for my shift, I just broke down and cried until all set in. This was extremely traumatic, but I have always tried to move on with my life and keep my head up.

24. In 2012 I underwent triple therapy to treat the Hepatitis; I took Ribavirin, Interferon and Talapravir. But then I became very breathless as a result of

becoming very anaemic relatively quickly, and the deterioration in my heart condition came to light shortly afterwards. I experienced heart palpitations, I needed another blood transfusion and I was so unwell that I had to be placed in a coronary care unit for a few days **(WITN052205)**.

25. I had to stop the triple therapy treatment due to health concerns for my heart. The doctors agreed that it would be best to wait for further drugs to be developed: they said that there were some new treatments coming up which would not carry the risk of making me anaemic. It was not worth risking any further deterioration in my cardiac function **(WITN052205)**.

26. Finally in September 2016 I underwent a 12 week course of Harvoni, which is a combination of Sofosbuvir and Ledispasvir. The treatment was successful and I was deemed to have cleared the Hepatitis virus in early 2018.

27. The impact that HCV has had on my health, my family life and mental wellbeing has been life-changing.

28. When I underwent the therapy involving Interferon I was forced to relive the pain and trauma of my AML treatment in the 80's. I experienced nausea, weakness and I became severely anaemic, at the point that the doctors had to put me in coronary care. I experienced rigors, despite no raised temperature and weakness and breathlessness due to anaemia. While I am lucky that my cardiac condition has since improved, my heart will never make a full recovery from the damage caused in undergoing this treatment.

29. My husband became frustrated and angry with all of the treatments I underwent and we eventually separated. He came to resent me for my constant sickness and the logistics of getting to and from Oxford for regular tests; treatment definitely wore us both down. One night he exploded and called me selfish and accused me of infecting him with HCV, he kept on saying "what if I have been infected?".

30. I have had to live with a disease that is like a ticking time bomb, living with the knowledge that at any time I could suffer with liver cirrhosis and possibly cancer. This has caused me a lot of anxiety, especially before undergoing a period of treatment, as I knew how awful I would feel and the risks it would pose to my long-term health.

31. I was never given adequate information as to how to manage my infection. I had to attend medical lectures at Oxford as well as rely on my personal knowledge as a nurse in order to learn about and live with Hepatitis.

32. HCV had a financial impact on my life; I had to apply to Skipton Fund to obtain some financial relief. The frequent trips to Oxford were a substantial expense, which I had to cover myself.

33. While testing, treatments and subsequent illness disrupted my work life; but I feel that my infection has not ultimately affected my career progression. I think that working in the medical profession safeguarded me from stigma that may have arisen in other workplaces.

34. I have never been shy about my diagnosis. I have told friends, family and colleagues and I am lucky that I did not have to face any stigma – only love and support.

<u>Section 6. Treatment/Care/Support</u>

35. I have not faced difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with HCV. I never had any difficulty with obtaining dental care either.

36. Counselling and psychological support were made available to me. I was told about some support groups for carriers of HCV, but I felt that these primarily catered to individuals who were drug addicts. The decision to not attend these groups, was not out of prejudice; I simply believed that it was better to carry on with my life and move on as best I could.

Section 7. Financial Assistance

37. I asked my GP to help me with my application to Skipton Fund. The process was relatively straightforward and my GP primarily took care of it.

38. I received a lump sum payment of £20,000 in 2005 and I have received payments of £1,555.50 per quarter, backdated to April 2016.

39. Some colleagues of mine, once I shared with them that I had contracted HCV, told me about Skipton Fund. None of the medical professional I was in the care of ever told me anything about it.

40. I remember that some of the patients that I was treating as a nurse told me that they had also been infected as a result of being given contaminated blood products. No one had told them before that there was financial relief potentially available. I raised this with one of my doctors and asked why they had not told the patient of the option to apply for relief from the Skipton Fund. I was appalled and exasperated when the doctor replied "that's not our job". It seems wrong to me that so little information or help is provided to people who have already suffered so much and often desperately need financial assistance.

41. I cannot understand why they have decided to pay £4000 a year in Wales, or why they have not backdated payments to when that person received their last contaminated blood or blood product. The funds and current options for financial relief seem inconsistent, vague and poorly publicised.

Section 8. Other Issues

42. The Right Honourable Lord Owen, as Minister of State for Health at the time, made a speech to the house of commons calling for the development of a self-sufficient UK blood supply. At that time, it was known that the blood being imported from the US was bought primarily from donors living a high-risk lifestyle.

43. I do not understand why they never kept the promises they made. If we had become self-sufficient we could have avoided such a major catastrophe. In any case it is shocking to me that the inquiry is only taking place now, after all these years.

44. I also cannot understand why the government has not had recipients of blood products tested for HIV and Hepatitis, before 1992. It seems ludicrous to me that it is still likely that many people who have been infected are still out there and they have not been tested yet. This poses a danger to themselves as well as to the wider public.

45. I definitely believe that somewhere in the Department of Health or at other governmental level there has been a cover up.

Statement of Truth

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

Signed GRO-B

Dated 5/3/19