

# ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN3964001

Exhibits: 0

Dated: December 2019

## INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

GRO-B

I, **GRO-B** will say as follows:-

### Section 1. Introduction

1. My name is **GRO-B** I was born on **GRO-B** and I live at **GRO-B** with my husband **GRO-B: H** We have one son who is 24 years old.
2. My husband **H** (born on **GRO-B**), is co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) from contaminated blood products.
3. This witness statement has been prepared without the benefit of access to **H**'s full medical records.

### Section 2. How Affected

4. **H** has severe Haemophilia A, diagnosed within 6 months of his birth. As a child **H** was treated at the Sheffield Children's Hospital (SCH). He was treated with cryoprecipitate before being moved on to Factor VIII (FVIII)

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products. [H] attended the Lord Mayor Treloar College (Treloar) as a border between the ages of about 11 and 16 years. Whilst at Treloar, [H] was given FVIII concentrate. He has exhibited to his own Statement an extract of various brands of FVIII he was treated with there.

5. When [H] left Treloar in 1978, he was referred to the Royal Hallamshire Hospital in Sheffield (RHH) where he continued to receive FVIII concentrate. It was around that time that [H] believes he was told that he had non-A, non-B Hepatitis (later known as HCV).
6. Professor Preston told [H] at RHH that he had HIV in 1983. [H] was told that he had become infected with HIV through contaminated blood products.
7. I do not believe that [H] and his parents were provided with information regarding the risk of infection from FVIII concentrates.

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

8. [H] received a letter informing him that he may have been exposed to a new variant of Creutzfeld Jacob Disease (vCJD). It was then confirmed that [H] had indeed received blood products from a donor with vCJD.

### **Section 4. Consent**

9. [H] was treated and tested without his knowledge and without appropriate consent as detailed in his Statement. [H] was also treated and tested for the purposes of research and has exhibited evidence to his Statement of at least one piece of research to which he was made part.

### **Section 5. Impact of the Infection**

10. [H] and I met at a nightclub whilst out with our respective friends in June 1993. We began seeing each other. I felt that something was wrong but I

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couldn't put my finger on what it was. [H] gradually started to tell me things about himself over the first six months of our relationship culminating in him telling me that he was infected with HIV and HCV.

11. [H]'s first marriage had broken down. The break up related to [H] having HIV. His then wife could not deal with it and they divorced in [GRO-B]. [H] did not know how long he had to live. He wasn't enjoying his job and gave it up in order to go travelling.

12. I was shocked by the HIV diagnosis. I had to think about whether to carry on and stay in the relationship. I decided that I would sooner have the few years [H] had left than not. I had recently lost my own parents and my best friend. We found each other at the right time in our lives. We went travelling and spent three months together in Canada, the USA and Mexico (and later spent some time in Italy and Portugal). We knew we wanted to stay together and we both wanted to become parents.

13. [H] and I approached the RHH and asked a lot of questions. We looked into sperm washing but that was not an option in our locality. We wanted specific advice in terms of the risks associated with me trying to conceive naturally. The RHH did not have the figures. They contacted a specific department based in Cardiff and we were ultimately told that of 17 women, pregnant with HIV partners, none had been infected. I had a good feeling that I would be OK (I felt my parents and best friend were watching over me) and I was OK.

14. The Hull Royal Infirmary in Beverley Road did an assessment of [H]'s sperm count (as they refused to do it at RHH because of [H]'s HIV status) and that was fine because it was closer to where we lived. It would not have been worth the risk of trying if there had been an issue. Fortunately I became pregnant almost straight away but had to wait for three months before I was tested for HIV (negative).

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15. [H] sold his house and he and I moved to [GRO-B] in the Spring/early Summer of 1995. Before then, [H] had spent most of his time at my home in [GRO-B]. Our new home was in fact a small holding and we had goats, pigs and chickens. Our son [GRO-B] was born in [GRO-B] 1995. We thought about trying for another child but decided it was not worth the risk as we were lucky already to have a lovely son and that son needed his mother. In any event, in order to have another child and have the sperm washing at that time, we would have had to go to Milan. This would have entailed time off work, more cost and more disruption to our lives.
16. I returned to work after a period of maternity leave. [H] became the house husband and ran the small holding. [H] was relatively fit and healthy with no complications. [H] had been through a dark time but we had a new beginning together. We had a new son and things were good. It was a nice time.
17. [H] had his first attempt at HCV clearing treatment in 2003. He was offered the treatment beforehand but deferred it for over a year after I succumbed to an aggressive form of breast cancer. We could not have both been seriously ill from the treatments at the same time. I had a mastectomy and needed chemotherapy and radiotherapy.
18. The side effects to [H]'s 48 week course of Ribavirin and Interferon treatment in 2003 were horrendous. He suffered with flu like symptoms to include severe aches and pains, fatigue and brain fog (whilst trying to take care of a child). He had terrible mood swings and was horrible to [GRO-B]. I had to write him a letter about his behaviour because you just couldn't reason with him to his face. Having just had breast cancer I had some insight to what he was going through. We decided to go on holiday to Disneyworld in America with my sister and her family that year to celebrate the finishing of my treatment. [H] fell out with my brother in law there. [H] was irritable and angry. He was foul. There were a lot of falling outs.
19. [H] was never told that mood swings and depression were side effects of the treatment. He was only warned about the physical symptoms and about



the brain fog. The treatment was unsuccessful and it completely changed him. He became so depressed. It was so unlike him to be so down. He had a conversation with a nurse at the Haemophilia Centre and she was shocked that he had not been warned about depression. He was referred to a psychiatrist and a psychologist and then started receiving treatment for depression.

20. We have always lived with the uncertainty of never knowing when the day or trigger for [H] becoming fatally ill would come. [H] has tried to live the best life he can (on top of the complication of having haemophilia) and [GRO-B] was always a priority to both of us. [H] found work during school term time to fit in around [GRO-B]'s care. School term time hours also helped [H] to recharge his batteries and attend various medical appointments during the school holidays. He worked as a youth worker before taking a job in a school as a learning support assistant. He then became an Education Welfare Officer. [H] enjoyed helping young people and was great at it. It was however a far cry financially from the well paid and promising career he had developed in logistics, shipping and transport before we met. I continued to work full time after [GRO-B] was born.

21. The side effects of the HCV treatment to include peripheral neuropathy have stayed with [H]. The brain fog and fatigue symptoms increased to the extent that [H] would sometimes nod off on his journey home (just half an hour) from work and it was a worry.

22. [H] has been fairly fortunate with his HIV. He takes his antiviral medication, his CD4 count is high and he has not succumbed to any opportune infections. Having HIV has had a profound psychological affect on [H] and he has lost four school friends from Treloars to AIDS related illnesses to include his best friend in 1994.

23. [H] has had to have regular liver biopsies to monitor the state of his liver over the years. They wanted [H] to return to the Interferon and Ribavirin treatment but he couldn't go through it again because of the severe side

effects. He had further (Harvoni) treatment for HCV in 2016 and the virus is now undetectable.

24. We wanted to keep GRO-B's childhood and life as normal as possible for him and we decided not to tell him about his father's infections unless H became seriously ill. It was the same when I had breast cancer. He carried on with his school, his after school clubs and other activities. We wanted to protect him. We only told GRO-B when he was 21 years old and something related to the contaminated blood scandal came on television and GRO-B commented on how awful it was. H has told him about his friends from Treloars passing away and, later, his best friend. We have tried to reassure GRO-B that H has had HIV for well over 30 years is not going anywhere imminently. GRO-B understands but won't talk about it further. We have not discussed H's diagnosis with many people at all because of the associated stigma. I have only told my own sister recently. My nieces do not know.

25. H struggles to talk about it all. Some times he withdraws and pushes it out of his head as much as possible. He suppresses his feelings but there is an underlying anger about what has happened to him. At one point he was told that he only had two years to live and you have to think about how that affects a person. Having been through breast cancer I can relate to some degree to how he feels. Recently (since the Inquiry) H has opened up more and has even got back in touch with some of his friends from Treloars.

26. We have been under a lot of personal and financial pressure over the years. As stated, H had a well paid job in logistics, shipping and transport before we met. There was a clear path of progression and his boss was due to retire. H was earmarked for his job. If things had been different for H he would have had a job in management and done very well financially to include the use of a company car and other valuable benefits. When H returned to the world of work it was on a part time basis in a much lesser paid job. There was a pressure on me because I had to be the main breadwinner working in a stressful job as a Senior Practitioner heading

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up teams of social workers in the field of adult care. I was never able to reduce my hours or take time off because we had no financial security.

### **Section 6. Treatment/care/support**

27. As stated at paragraph 19 above, [H] was never warned that depression was a side effect of his clearing treatment. [H] was later referred for professional help and placed on anti-depressants because of the severity of the depression he experienced.

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

28. I agree with the comments made by [H] in his Statement. The application forms for financial assistance are very intrusive and it is demeaning to have to jump through the hoops placed in front of you when applying for assistance.

29. My income was always taken into account which is wrong. We have been penalised as a household in circumstances where [H] has been infected through no fault of his own and could not assume the role as the breadwinner.

30. We are now both retired, [H] taking voluntary redundancy when he had his right leg amputated (he did not receive a lot) and I have an average pension and do not receive my state pension until I am 66 years old.

### **Anonymity**

31. I would like to remain anonymous and would like this Statement redacted. I understand that this Statement will be disclosed as part of the Inquiry.

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## Statement of Truth

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

Signed.. GRO-B .....

Dated..... 25 - 08 - 20 .....