

Witness Name: GRO-B

Statement No: WITN3026001

Exhibits: 0

Dated: May 2019

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF GRO-B

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I, GRO-B will say as follows:-

### Section 1. Introduction

1. My name is GRO-B. I was born on GRO-B 1969 and I live at GRO-B.
2. I have been married to my husband, GRO-B for GRO-B years. Together, we have 3 children, GRO-B born on GRO-B 1986, GRO-B born on GRO-B 1992 and GRO-B born on GRO-B 1997.
3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

### Section 2. How Infected

4. When I was pregnant with GRO-B at approximately 20 weeks, I started to lose blood. I therefore attended Margate Hospital (MH) in GRO-B Kent and because of my blood group, I was given Anti-d injection. This was the very first time that I received Anti-d injection.

5. I cannot remember if I received any more Anti-d injection prior to the birth of GRO-B but on the GRO-B 1986, when GRO-B was born, I was again given another Anti-d injection at the MH. Later, during my other pregnancies, I was given Anti-d injections.
6. I was not told beforehand about the risk of being exposed to infection from blood products.
7. In or about 2006/2007, I went to the doctors for what I thought was an unrelated appointment and after many trips backwards and forwards, I discovered to my horror that I had been infected with Hepatitis C (Hep C). I was then referred to Norfolk and Norwich Hospital (NNH) GRO-B GRO-B Up until that point, I was not given any information from my doctor about the infection. I had previously heard about Hep C but had always associated it as something dirty that drug users had. I have never taken drugs in my life.
8. I believe that it was during the birth of GRO-B that I was infected with Hep C by contaminated blood products.
9. I did not feel as though I was given enough information from my GP about Hep C so I researched it myself. I had my first hospital appointment with a liver specialist and told him what had happened to me and that I was given an Anti-d injection in 1986. He said he believes that was how I was infected with Hep C.
10. When I was told that I had Hep C from the GP, I was not given any information about it. I was only referred to my local hospital. I cannot remember how long it took before my first appointment and meeting with my liver specialist. Up until that point, I had researched Hep C on the internet. I was not provided adequate information to manage the infection at that point. In fact, my GP was pretty useless. I can however remember his words were that "the good news is you don't have Hep B but you do have Hep C". This was laughable really as you can be vaccinated against Hep B whereas Hep C you can't (but I did later discover that at some point I did have Hep B but it

cleared itself). I have now only in the last 18 months been vaccinated for Hep B.

11. It wasn't until I met the liver specialist that he provided me with further information about Hep C. I believe that the GP should have given me some information when I was told. The news was not communicated to me very well. I had no knowledge that I was even tested for Hep C until I was told.

12. I believe I was provided with some information of the risks of others being infected by the liver specialist. I raised some queries myself in relation to this.

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

13. I have not received any other infections other than Hep B (which cleared itself) and Hep C.

### **Section 4. Consent**

14. I believe that I was treated and tested without my knowledge. I did not give my consent at any point to be tested for any infection. As mentioned above, I did not even know I was being tested for Hep C until they told me I had it.

15. I do not know if I was treated and tested for the purposes of research. When I was first given the Anti-d injection in 1986, I was not told anything, only the reason why I needed it because of my blood group and that it could be harmful to my unborn child if he had a different blood group. I was not provided with adequate or full information about it.

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

16. I suffered mental effects as a result of the infection. I was so ashamed and so embarrassed that I had Hep C and did not think that people would want to touch me or kiss me. I felt dirty and disgusting. I was so ashamed of who I was which made me lose all confidence in myself and I lost my sense of self-worth. It was only a year later that I could come clean to everyone as only my husband knew about this horrid infection. I only told my family when I was

starting my first lot of treatment as I did not know what impact it would have on me and I felt they needed to know.

17. I also suffered from physical symptoms as a result of the Hep C. I had always felt so tired, had joint pains and always felt like I had a flu or cold. I also had very poor appetite, brain fog, felt sick, had muscle aches and sharp pains over my liver. I had started to lose so much weight which prompted me to go to the GP as my family were becoming quite worried about me. Since being cleared of the Hep C, I have now gained weight but still have aches, pains over my liver and also muscle and joint problems. I also now have thinning of the bones and I was diagnosed with cirrhosis which are both as a result of the Hep C.

18. I have had roughly 4-5 liver biopsies over the years which were extremely painful.

19. In or about 2007 I started treatment consisting of Viraseron Peg and Rebetol. These were given in the form of injections and oral medication. I was told that the course was for 48 weeks but after only completing half the course, I was told by the nurses that it was not working and I was taken off the treatment. It took a good few weeks for me to then start to feel like me again and the weight of that treatment to all be out of my system. At this point, I had to wait until a new treatment was available. Approximately 10 years later, I was treated with the latest treatment consisting of Ribavirin, Viekirax and Exviera. The course was for 24 weeks and to my surprise and joy, I cleared the infection. However, I have now been left with cirrhosis as a result of the infection.

20. The treatment was horrific. It made me feel very weak, tired and angry to the point I felt I did not know who I was anymore. It completely destroyed me. I also lost some hair during the first lot of treatment and even now after all these years, my hair is still thin which feeds my low self-esteem.

21. The impact of being infected with Hep C has had a massive impact on my private, family and social life. The stigma of it is one I dread to the point that it

took a year before I told everyone. Prior to that, only my husband knew. He was the first person to know, and then, I told my parents, brother, sister, children and 2 close friends. My extended family members don't know I had Hep C as I have asked the ones who do know, not to tell anyone as I'm ashamed and embarrassed of it. When I first discovered that I had Hep C, I felt that people wouldn't want to touch me, drink from my cups, be near me or even be in the same room as me. It impacted on my mental state so badly that I couldn't tell anyone. I know Hep C cannot be caught through the ways as described above but other people's perception and ignorance of it made me feel that way. I don't have a social life as I have rather low self-esteem. I stay at home most days or visit my mother. My confidence is low and my children are the social life at home.

22. I still feel this way about Hep C even though I no longer have the infection. I still do not want anyone to know that I lived with Hep C. My family have been supportive but I still don't talk about it to my children as I am too ashamed of it. I become very depressed about it and I have suffered mood swings which impacted on the family home. However, we managed to survive and push through as a family. Some days, I would just lie in bed and cry and not want to be around anyone. During some points of my life, I felt as if I was staring death in the face. I went to a very dark place, but thanks to the recent treatment that worked, I am no longer in that dark place. However, I do still get emotional about it.

23. I haven't worked for years as I was too tired and drained. I raised my family instead. Had I not been infected, I could have continued working and this has therefore been detrimental to my financial situation.

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

24. I was told I could join a Hep C support group, but I refused as I didn't want anyone knowing I had Hep C. I didn't want to walk into a support group and end up seeing someone I knew there who would then tell others that I had Hep C. I couldn't risk that. I feel like I suffered in silence.



25. The care I receive now from the nurses at NNH has always been second to none. They have been amazing. I receive after care treatment and I have a liver scan every 6 months. I also have bone density scans and Endoscopic exams to check for varices which will be an ongoing matter.

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

26. In 2007, I applied to the Skipton Fund but my application was refused even though the liver specialist stated on the form that he believes that the Anti-d injection was the reason that I contracted Hep C.

27. I have never received financial help from any Trusts or Funds.

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

28. I believe, without a shadow of doubt that I was infected with Hep C through the Anti-d injection.

29. Within the last few months, my husband [GRO-B] has now discovered that he has contracted Hep C through me. He does not want to be a part of the Inquiry but I wanted to make it known that even to this day, the infection still impacts me, my family and affects my life. My husband is now having treatment for the Hep C and as a result he suffers from mood swings, low days and angry days, most of the things which are the sole effect of the treatment. He did not want to have any treatment as he witnessed first hand what I went through and the effects it had on me. The infection and treatment nearly destroyed our marriage of [GRO-B] years. We have no intimacy of fear of re-infecting myself. The infection has destroyed both of our lives.

#### **Anonymity, disclosure and redaction**

30. I wish to remain anonymous.

31. I do not wish to provide oral evidence to the Inquiry.

**Statement of Truth**

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

Signed

**GRO-B**

Dated 22.5.19.