Witness Name: GRO-B
Statement No.: WITN2698001
Exhibits: 0
Dated: 11 September 2019

WRITTEN STATEMENT OF MRS GRO-B
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is GRO-B My address and date of birth details are known to the Inquiry.

2. I am married to GRO-B and we have two children together, we all live together at home. There is no other family around.

Section 2: How Affected

3. My daughter GRO-B: D is the youngest child in the family. D and I are very close, probably closer than a lot of parents are with their children. This is because she became very sick as a child and I spent a lot of time nursing her so that she became well. She has been sick ever since.

4. D depends on me through most of her day to day life. I am her carer, her confidante, her educator, her book keeper, her friend and foe. I do everything

for her. Our relationship is complex and I think that this is because she depends on me and her father so much for the things that she needs. I love her dearly, she is my youngest child.

5. [redacted] became infected as a result of receiving blood and blood products when she was treated for her leukaemia condition when she was a child. The treatment has had a profound impact on her life. When she had to have the treatment for her leukaemia we were told her learning capability might be affected as a result, but we did not ever consider that it might led to her becoming infected with hepatitis C.

6. In terms of what has happened to [redacted], I include information from a report that was written by a medical doctor in February 2002 following a home assessment of her. "[redacted] *has very limited academic skills. The test results suggest deterioration in cognitive skills since her last assessment and suggest that* [redacted] *is functioning below the level reported in 1993. She has had an unsuccessful school experience and is approaching school leaving age with little in the way of basic mathematical and language skills. She is unable to handle money or look after herself. I fully appreciate the concerns of* [redacted]*'s parents and we must recognise the limited opportunities that are open to* [redacted] *as she leaves school. I have no doubt that she is unlikely to enjoy the freedom and independence that would be expected for a child from her social and family background. This degree of impairment is not typical for most children successfully treated for A.L.L. In considering* [redacted]*'s situation, it is apparent that a number of factors have contributed to her difficulties. These include her treatment by CNS irradiation" and chemotherapy, the later occurrences of seizures, and considerable school absence over many years resulting from her inability to sleep and continued tiredness (…). Clearly the family have shouldered a huge emotional burden which was made worse by knowledge of hepatitis C risks. These factors have all contributed to her unhappy school experience and learning difficulties (…). The deterioration over time is also consistent with CNS irradiation damage".*

7. My daughter does not have a bleeding disorder.

8. There was no information provided prior to the treatment or the risk of infection. In fact up until today's date my family and I have always believed D received only blood transfusions and was infected by one of those; however, it seems that she may also have received various products and became infected as a result of that.

Section 3: Other infections

9. I believe my daughter has been infected with hepatitis C only

Section 4: Consent

10. D deals with this in her witness statement as she is giving the main statement as she was infected.

Section 5: Impact

11. D has always had issues, all throughout her childhood. She was considered to have the mental age of a seven to eight year old girl when she was 18. This improved over the years with some work. At the age of 18 she was also deemed to be a "*vulnerable adult*". D does not like this term.

12. It was only after D found out that she had been infected with hepatitis C in 1997 (when she was only 13 years old) that she really deteriorated emotionally, and psychologically. She became suicidal, she was sectioned for making a second and very serious attempt to take her life and she was placed on anti-depressants. These suicidal thoughts have continued and have been very, very difficult for us as a family to try to manage. She often runs away and when this happens the police search for her with helicopters. Her problems are so deep.

13. In summary my impression of her is that she is a very vulnerable young woman who desperately needs careful, professionally care on a consistent basis. I have noticed deterioration in her memory. I notice that she cannot remember having had a conversation with me. I notice that she becomes vacant or absent during a conversation or an activity. The main the physical symptoms that I see day to day are her tiredness; her pattern is poor but probably as a result of never quite settling into a normal pattern from when she left the hospital after her leukaemia treatment in 1987. At the moment she sleeps for around 18 hours per day, she tends to stay in her pyjamas all day every day.

14. She has pains from her indigestion and from an upset stomach. She has serious problems with her diet and I fear that if I was not there to give her the food, she would not eat. D is also always cold in herself. We have also been told that D will have to have all of her teeth removed because they are rotting.

15. D suffers from epilepsy but I believe that this was as a result of the leukaemia treatment but I do not know for sure. Throughout D's journey it seems that the medics want to attribute all of her physical and psychological side effects to this. I find this extremely upsetting as her hepatitis C condition is a massive part of what she is dealing with yet it seems no-one wants to recognise this at all.

16. D was diagnosed with hepatitis C in 1997. She was unsuccessfully treated in 1999 and successfully cleared the virus 2018. Mu understanding is that her liver condition is not that serious. My husband and I were told that she had slight scarring of the liver but we are not sure what this actually means. Despite her clearing the viral load she continues to experience the depression, chronic fatigue, dietary issues, and memory problems. Her actual physical condition has not changed at all.

17. D was treated unsuccessfully with ribiviran and interferon in 1999, but she was taken off the combination treatment as her body had stopped responding positively to the treatment. She waited 18 years before being given harvoni in 2017 which cleared the virus after only eight weeks of treatment.

18. As a family we closely monitored D s condition to decide when she should receive further treatment. Prior to 2017 when the harvoni was made available the only treatment that was offered was the interferon and ribivrian that she previously had and did not respond to. We were reluctant to go down this road again because of the side effects and the outcome. On balance we decided to wait as long as possible without compromising her physical condition so that D could undergo treatment that was less severe and more likely to yield a positive result. D was promised the treatment at one stage and after a period of managing her epilepsy medication to allow her to receive it, which was the planned approach by everyone, the treatment was withdrawn from her. I had to fight in order to ensure that the Trust did not renege on its agreement to D

19. I think that D should have received the harvoni as soon as it was available but I do not know exactly when this was.

20. The effects of the combination treatment were extensive. D went through real trauma in receiving the injections. On each occasion that she had an injection; three times per week over the course of eight months, she had to be coerced for the whole day to have the injection. She became extremely ill on this treatment. D was in bed nearly all day long, every single day. She lost a lot of weight, she did not eat. I had to give her infant's food like Farley's rusks as she would not eat. She lost her hair. She did not want to continue with the treatment and constantly said that she wanted to stop. The attempts of her life and the pseudo-epileptic seizures followed soon after this treatment, I think that it had a lot to do with it. The harvoni was much less severe on the system and D did not really experience side effects through this. Thankfully.

21. There has been no impact on her treatment, medical or dental care for other conditions.

22. D was infected with hepatitis C when she was only three years old. It is extremely difficult for us to try to imagine how she might have been without the infection. It is impossible to attempt to unpick which symptoms might be related to the leukaemia and to the hepatitis C. D s private life is very limited. She lives at home and has always done so. She depends on me and my husband for everything. She has had support workers who come to see her twice per week for four hours per time for around 10 years. She also has befriended adult family friends who she visits from time to time.

23. She likes to go out for a pot of tea. She has a compulsion for shopping. She is desperate to move out of home but I cannot see and nor can the support workers see how she could cope on her own. I would love to see her being able to do this. This sums up her private and social life. The impact on her family life is such that she relies on my husband and me for everything. We fear for D when we are no longer here. She has a fractious relationship with her sister. She is very aware of the time that we have had to spend on D s care and support. D and her sister did not speak for several months at one point.

24. Having to deal with D s sickness as a little girl when she was only three years old was devastating and I was so relieved when we were told that she had achieved remission. I was obviously fearful for her future because I knew when the treatment stopped that her immune system was weak. I worried all the time for her health and this never stopped. I feared that the cancer would return and how I might cope because I did not think that I would.

25. When we learned that D had been infected with hepatitis C, I was in shock and denial and completely devastated. I could not understand how she had received blood that was contaminated. At the time, I thought that it had been given to her accidentally and that actually this was the most unfortunately thing

in the world to have happened. I found it extremely difficult to put a brave face on things in front of my children particularly because I did not want D to know about the seriousness of her condition. I have had physical problems which may or may not be related to what I have had to deal with and have been given antidepressant medication. I know that I have suffered from serious stress as a result. My asthma gets worse as a restful of my stress. This problem has totally destroyed my private, family and social life.

26. My husband is amazing. Sometimes I don't go to bed until 2 or 3am as I need to talk with D is she is dealing with something terrible. I feel constantly split because my daughters don't get along so I have to split my time with D my other daughter and my husband. I worry about getting the split right. I try to adopt a very organised approach to my life because I think that if I am organised I will get through it. My biggest worry is about what will happen to D when my husband and I are no longer here.

27. D has forbidden me from talking about her hepatitis C infection with anyone. I have shared the information with a few very close friends. Thankfully I have not experienced any stigma associated with the diagnosis.

28. I think that I have addressed this above except for stating the impact on my husband. I see that GRO-B is available to D all of the time but D does not realise that this is the case and this frustrates him. This causes him anxiety and sadness and some depression. I think that he is very upset about his inability to fix things for her.

29. D has not really received an education and she has not been able to work or to receive an income. This was touched upon in the report that was produced by the medical professional that I quoted from above. It is difficult to say whether this is all related to the hepatitis C or whether it is related to the leukaemia treatment. Either way this is the situation we are living with.

30. I used to work at the school that D attended. I had to give this up in order to be able to support D through the combination treatment she received in 1999. I was only able to get another job a few years later which was part-time. The impact on me has been in relation to my work and finances. I have had to claim benefits over the years so that we can live and pay our mortgage. I would have gone back to work when the girls were 14 or 15 but was unable to do so because of D s need for round the clock care and support.

Section 8: Other Issues

31. I would like the Inquiry to find the people who decided to carry on using the tainted blood knowing that it was likely to infect those who received it and I want them to face justice and the full force of a prosecution. These people are responsible for ruining the lives of so many people. I want the Inquiry to put measures in place to ensure that something like this never happens again.

32. I want the Inquiry to make recommendations that will delivery financial security to my daughter for when my husband and I are no longer alive. D will need help all of her life.

33. Although D is Hepatitis C free now she still suffers dreadful repercussions of the virus and it's treatments. D has now had all of her teeth removed. Although D had to wait for more than two months to have her teeth removed in hospital, this would have been much longer if we had not made numerous phone calls to the hospital and doctor. During this time she had been in constant pain from her rotting teeth. She was taking strong painkillers more often than she should have to try and ease the pain.

34. Also during this time D was suffering from severe chest pains which resulted in more than one hospital visit, once by ambulance when D thought her body was shutting down and could not cope anymore. She was in terrible pain. She is at the moment having tests done to try and get to the bottom of her chest pains which she has had intermittently for many years, but

nowhere as severe as she is now currently experiencing. Over the years of chest pain she has been treated for indigestion. During the last six months she has only been able to eat liquidised food and has lost a lot of weight. This is due to teeth/no teeth and chest pain. She is struggling to wear dentures although she has bought two pairs and rarely wears them. She is desperately trying to save money for dental implants. I don't know how she has coped over the years. It has been one thing after another for her. The physical and mental pain never stops.

Statement of Truth

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

Signed: **GRO-B**

Full Name: **GRO-B**

Date: 11. 9. 19.