ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN0861001
Exhibits: **NIL**
Dated: 27 JUNE 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 25 March 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1968 and my address is known to the Inquiry. I worked as a team secretary for Royal Mail from 1990 until my retirement in 2001. I live with my husband and we do not have any children.

2. I intend to speak about my infection with Hepatitis C through blood transfusions. In particular, I intend to speak about the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my life.

Section 2. How Infected

3. Both of my parents are carriers of Thalassemia. In 1968, when I was 3 months old, I was diagnosed with Beta Thalassemia Major at Great Ormond Street Hospital. I was treated at Great Ormond Street Hospital until 1986, when I turned 18 years old.

4. Since my diagnosis I have been the recipient of regular blood transfusions to treat Thalassemia. As a child I received blood transfusions every 3 to 4 weeks. I was kept in the hospital overnight whenever I had a blood transfusion because doctors didn't know much about the illness back then. They wanted to keep an eye on me and make sure I was okay the next day.

5. Apart from the regular blood transfusions, I do not remember having any other treatment for Thalassemia. I took folic acid for a few years, but I cannot recall when. I stopped taking it because I did not need it anymore.

6. In 1972, when I was 4 years old, I had a splenectomy; a procedure in which my spleen was removed. This raised other issues with my immune system and meant that I was more prone to infections, so I had to take penicillin everyday for a number of years. However, when I was 18 years old, I decided to stop taking penicillin on a daily basis. I was concerned that I would build up a tolerance and that it wouldn't work when I actually needed it. Now I only take penicillin when I have a sore throat or if I have a cut or something. I try to take as little medication as possible.

7. From the age of 18 onwards, I received treatment for Thalassemia from North Middlesex University Hospital, under the care of Dr Yardumaian, a consultant haematologist. I continued to have regular blood

transfusions and I was still monitored overnight whenever I received a blood transfusion. My consultant ensured that my haemoglobin levels did not drop too low and that they were maintained at a level of around 12g/dL. Dr Yardumaian did tests to see the level of haemoglobin in my blood, how often I needed a blood transfusion, and how many units of blood I needed. There was a period when I was receiving as much as 3 units of blood every 3 to 4 weeks, however this was just too much and I felt really bloated all the time. For the last 20 years I have been receiving 2 units of blood every 4 weeks, and this amount seems to work well for me.

8. I still receive my treatment from the North Middlesex University Hospital, however Dr Yardumaian recently retired so I have a new consultant who I am yet to meet. There is a day unit at the hospital now, so I no longer need to stay overnight to be monitored when I receive a blood transfusion. It is much more comfortable now. There is a television to watch while I wait for the blood transfusion, or I can socialise with the other patients.

9. One of the associated risks of treating Thalassemia with blood transfusions is that numerous blood transfusions can lead to an iron overload, where there is an accumulation of iron in the body. This can cause issues with your liver and your heart. Early on, many patients suffering from Thalassemia died from an iron overload because people were not familiar with the condition or did not know how to effectively treat it. When I was diagnosed with Thalassemia, my parents started to talk to the parents of other Thalassemia patients who, like my parents, didn't really know much about the condition. This eventually led to GRO- GRO-B the Thalassemia Society. The society raised money for research, which eventually led to the development of Desferal, a drug that helps to rid the body of excess iron.

10. Initially Desferal was administered by injection, but it became apparent that not only were the injections too painful for patients, but the efficacy of the drug was also reduced when it was administered in this way. I never used the injections, but in 1978 a new method of administering Desferal through a subcutaneous injection was developed. It involved the drug being administered slowly through an infuser pump that was connected to a needle and injected into the tissue layer between the skin and muscle. I would use the Desferal pump for 10-12 hours overnight, 5 days a week. In around 2007 they released a tablet called Exjade (Deferasirox) to be taken once a day instead of the use of a Desferal pump. I started to use Exjade instead of the pump on a trial basis in around 2007, and I have been taking it ever since.

11. In the early 1990s I was referred to Professor Duscheiko at the University College Hospital (UCH) Hepatology Unit so that he could monitor my iron levels and ensure that an iron overload was not affecting my liver. I would go for a routine check up and blood tests every 6 months to monitor my liver health and ensure that everything was okay. It was around this time that Professor Duscheiko found out that I had very mild Hepatitis C. It was the early 1990s but I cannot recall the exact year in which I was told I had Hepatitis C. Professor Duscheiko suspected that I had contracted Hepatitis C through the blood transfusions that I had received some time in the 1980s. As I was having around 13 blood transfusions a year, they did not really know for sure and it is difficult to pinpoint exactly when and where I contracted the virus.

12. I had been tested for Hepatitis A and B in the past and I think that I also had the vaccines for them, so I had heard of Hepatitis before I was diagnosed. However, I didn't really know much about it or the different types. I was not given any information about how Hepatitis C could be passed on to others when I was diagnosed – it never came up.

13. I met my husband in 1995 and we got married in GRO-B Just before we got married, I asked my doctor how Hepatitis C could be passed on to others but I don't really remember him offering me any advice on how to protect my husband. After I spoke to the doctor I just remember thinking '*oh well it must be okay then*' because he never really suggested that I should take any precautions or advised that I needed to be particularly careful. My doctor never said anything about it being spread through blood-to-blood contact, or whether it could be passed on if I became pregnant. I think that they should have definitely told me more about how Hepatitis C could be passed on. Since interacting with the Inquiry, my husband has been tested for Hepatitis C. Thankfully his tests results were negative.

14. When I was told that I had Hepatitis C the doctors did not seem particularly worried because they said that the 'level' of Hepatitis C in my blood was very low. They were not concerned. I don't think that I was offered any treatment when I was first diagnosed, and for years they just monitored my liver and made sure that the level of Hepatitis C in my blood stayed low.

15. I do not really have anything else to say about the way in which I was told that I had Hepatitis C. To be honest, I didn't really want any more information or details about it, and sometimes I'm not sure that I really listen to what the doctors say anyway. I think this is just the way that I cope, because sometimes you can have too much information and a lot of the time the information doesn't mean anything to me; it's just numbers and words. I know my body and how I feel, so I know when there is something seriously wrong. I felt completely fine and didn't have any symptoms of Hepatitis C. If they had not told me that I had it, I would never have known. Maybe that is why I didn't ask too many questions about it.

Section 3. Other Infections

16. In my view, I have not been infected with any other infections as a result of the blood transfusions that I have received. I have regular blood tests so I think I would know if I had been infected with anything else.

Section 4. Consent

17. I do not remember being told about the risk of infection through blood transfusions when I was 18 years old, nor do I recall my parents consenting to or telling me about any of these risks when I received blood transfusions as a child. However, I needed the blood so it wouldn't have been a choice anyway. Even if my parents had been warned of the risk of infections, the doctors would have said '*this is what your child needs to survive*' and my parents would have allowed me to receive blood.

18. I do not think that I was ever used for the purposes of research or treated without my consent. When I took part in the Exjade trial, I provided consent.

19. I also consented to the Hepatitis C treatment that I received in 2006. I was made aware of what it involved and the side effects. I have detailed what the treatment involved and the impact that it had on me further below.

Section 5. Impact

20. When Professor Duscheiko at the UCH first told me that I had Hepatitis C, I was not too concerned about it because that is just how I am.

When they told me that I had likely contracted it through a blood transfusion, of course I felt that this was unacceptable and should never have happened. However it did happen so I thought *'what else can I do?'*. I have been through so many other things in my life, like having meningitis and septicaemia, so it was just another thing that I needed to deal with and that was that. I try not to worry or stress about things because stress will just make my health worse. I have been putting my trust in doctors for such a long time, so I trust that if something is seriously wrong then the doctors will let me know - the rest is just detail that I don't need to worry about.

21. When the doctor offered me treatment for Hepatitis C, it had been a little while since I was initially diagnosed but I cannot recall exactly when. The doctor explained the side effects of the treatment to me such as feeling rotten for a few days after the injections that were part of the treatment. He also mentioned depression specifically as a possible side-effect of the Hepatitis C treatment. I had heard from other people who had the treatment for Hepatitis C that the side effects were really severe and harsh, and that some people even died. I knew of one person who had to have the Hepatitis C treatment for around 10 years. Hearing this really put me off of accepting the treatment, particularly because my Hepatitis C was very mild and the doctors were not that worried about it. The Hepatitis C was not affecting my health and I try not to take too much medication unless I really need it. The fact that the doctors didn't seem to be concerned about the Hepatitis C, or think that I needed to have the treatment urgently, led to me putting off taking it.

22. In 2006 I eventually decided to receive treatment for Hepatitis C. I wanted to clear the virus before it did too much damage to my liver. Exjade had just been developed and I wanted to use it instead of the

Desferal pump on a trial basis. However, I decided to clear the Hepatitis C first before starting the Exjade trial.

23. The Hepatitis C treatment consisted of Interferon and Ribavirin. The Interferon was a self-administered injection that I took at home each week. I cannot remember whether I took Ribavirin as a tablet or if it was administered through an injection as well. The treatment lasted for 12 months, during which I had to go to the hospital more regularly. I usually went for hospital check ups every 6 months, however this increased to every few months while I was on the treatment so that they could monitor my health and I could receive supplies of the medication. As far as I am aware, there were no other treatments for Hepatitis C available at the time that could have been offered to me. I only needed a very small dose of Interferon and Ribavirin as my Hepatitis C viral load was very low.

24. The year that I received treatment for Hepatitis C was horrible and it was the first time that I noticed the Hepatitis C affecting my health. I would feel rotten and have flu-like symptoms for a few days after taking the injections, such as aches, pains, and a general feeling of malaise. The side effects were consistently bad throughout the course of the treatment and did not get progressively worse, however I did get increasingly fed up and frustrated over the course of the year. I felt really nauseous and lost my appetite. I knew people who had required a much higher dose to treat their Hepatitis C than I did and who consequentially had really severe side effects. I just kept reminding myself of how lucky I was to have it so mild and just tried to push through.

25. One effect of the Interferon and Ribavirin was that I had to have blood transfusions more regularly than usual because the Hepatitis C treatment was depleting my haemoglobin levels more quickly. Instead

of 2 units of blood every 4 weeks, I had 2 units of blood every 2 weeks. I had a total of 26 transfusions that year. Psychologically it was like *'crikey this is just too much.'* Having to go to the hospital so regularly was taking its toll because the time between transfusions would go so quickly and it felt like I was constantly in and out of the hospital.

26. A knock on effect of the Hepatitis C treatment and the increased number of blood transfusions I was receiving was that my iron levels went up. I had to use the Desferal pump more often to avoid an iron overload, and I went from using it for 10-12 hours for 5 nights a week to using it for 24 hour periods every other day to help clear the excess iron in my blood. I was sore from having to use the Desferal pump so regularly, and often had to re-site the needle to other areas of my body. Having so many injections from blood transfusions, the Interferon, and the Desferal pump meant that my veins were collapsing and I was constantly bruised.

27. I was always tired, but I couldn't sleep because of the discomfort. My veins were so 'kaput' that I had to have a port-a-cath put in my chest so that I could have the blood transfusions and administer the Desferal through there instead. The port-a-cath then resulted in me getting thrombosis.

28. At the end of 2007, once I had completed the 12-month treatment, my blood tests showed that I had cleared the Hepatitis C. I still have regular blood tests and they have come back clear ever since. The side effects subsided quite quickly after I completed the treatment, perhaps because I had only been on a small dose of the medication due to my Hepatitis C being so mild. The only long-term impact from the Hepatitis C treatment was that it exacerbated the problems with my veins.

29. During the treatment for Hepatitis C I did get depressed. I wouldn't say that the Hepatitis C directly caused the psychological problems, however it is really hard for me to separate the effects of Thalassemia from the effects of the Hepatitis C treatment. I think that the depression was a result of everything combined - the Hepatitis C treatment and having to go to the hospital so much for blood transfusions. The pain I was in from the injections and needles all added more unnecessary psychological strain. I started to take an anti-depressant called Citalopram during my treatment for Hepatitis C. I continued to take this right up until 2011 when my depression became more severe, at which point I started to take Fluoxetine instead. I still take the Fluoxetine now.

30. In 1995, I was in hospital with meningitis. After I was released, they found out that I also had pancreatitis. Around the same time I also had to have my gallbladder removed, so I ended up being in hospital for about 3 months. I also have osteoporosis, which is a complication associated with Thalassemia. My bones are put under additional strain due to having to work harder to generate red blood cells. 8 years ago I needed to have back surgery in relation to this. However, I do not believe that any of these medical issues were related to my infection with Hepatitis C.

31. During the year that I was taking Hepatitis C treatment I didn't really go anywhere, but I am lucky because not only do I have an amazing husband, but also my sister lives 5-10 minutes away and my parents are only about 7 minutes away. They really looked after and supported me and brought me soup when I felt unwell. Fortunately, although my sister is a carrier of Thalassemia, her children do not have it. Her daughters are 28 and 21. Her 21-year-old daughter has 2 boys who call my husband and I "grandma and grandpa", and I love it. My parents are in their 70s but they are still well and healthy. It is really nice that they

are just a 7-minute drive down the road from me and I can spend time with them regularly.

32. When I was younger, there were a lot of preconceptions about Thalassemia, so some parents would put their children into special schools and think that their children had no hope of leading normal lives. My parents were different. They treated me the same as everyone else. They sent me to a normal school and treated me in the same way that they treated my sister. I think that this is what made me who I am. As a child I always wanted to run and have fun racing other kids. The way my parents raised me meant that I never listened when they would say *'don't run too fast, you might fall'*; I just ran anyway. The way my parents were with me as a child has had such a huge influence on the way I live my life. I was 24 years old when I bought my first flat and I lived there up until 8 years ago. I was motivated and determined because of my parents. I sold the flat so that my husband and I could move to our current home.

33. When I was diagnosed with Hepatitis C I think that I mentioned it to my parents, however as it was not a massive deal in my head I may have played it down. I don't really tell my parents too much even though they are so supportive, because my mum feels guilty and is always apologising for giving me Thalassemia. I don't really discuss the details of my hospital appointments with my family, partly to protect them but also because I don't see the point of telling them all the little details. My parents knew that I went through treatment for Hepatitis C and that the Hepatitis C I had was mild, but beyond that I didn't think I needed to go into it with them with all of the details.

34. When I was younger and being treated at Great Ormond Street Hospital, I also went to their dental surgery. However, I now go to a private dentistry practice in North London, and have done so for so

long that I cant really remember going to a different one. I had to tell my dentist that I had Hepatitis C, but there were no issues with this. My dentist is also a cofounder of the Thalassemia Society, so he knows about this stuff. I remember that he once said to his assistant *'be careful, she has Hepatitis C'*, but he was wonderful and took any precautions he needed to. He was good because he knew my parents and there was a history there.

35. Whenever I had a tattoo or surgery I always told them about my Hepatitis C. People have not reacted badly when I have told them. I have heard about other people experiencing stigma, and I have heard things like *'oh you know Pamela Anderson has hepatitis C right...'* so I know that preconceptions and stigma do exist, but I don't think that stigma has ever affected me personally. Being a member of the Thalassemia Society means that I know other people who were also infected with Hepatitis C through blood transfusions, and I have a friend at the hospital whose husband still doesn't know that she has Hepatitis C. However I don't really pay these things much attention because I am used to people having pre-conceptions. As a child growing up with Thalassemia, I was used to hearing people say that we wouldn't live for very long or would never have children, so I learned long ago to ignore these types of things. I never really felt it necessary to hide the fact that I had Hepatitis C. If it came up in conversation I would be open about it with people.

36. I do not think that my infection with Hepatitis C impacted my marriage at all. My husband and I chose not to have children because you need to be well enough to carry a child, as well as to raise the child. With Thalassemia, there is a huge risk of complications. When the doctor told us about how risky it would be to get pregnant and all of the possible complications, my husband said *'if there is a risk to my wife, then lets not have children'*. As my mother-in-law would say, deciding

not to have a child is one problem, but having a child is a whole host of problems. I don't know how the Hepatitis C would have impacted on the pregnancy if we had decided to have children, because it never came up.

37. I was not working when I had the treatment for Hepatitis C because I had already retired back in 2001. I had worked for Royal Mail since 1990, and they were really amazing and understanding about the Thalassemia. My bosses and everyone were so brilliant with my hospital appointments and me being unwell so frequently. However, in the end I had to give up my job because I had a whole year off sick and lots of things were coming up. I just could not be relied on anymore. I was lucky because they were relocating from London to Chesterfield. My boss was really good and gave me medical retirement, which means that I still get a pension from them.

38. I still have regular checks on my liver, as there is always the possibility of developing cirrhosis in the future as a result of having Hepatitis C.

Section 6. Treatment/Care/Support

39. The Hepatitis C treatment was made readily available to me at the UCH in Hampstead. While it was obviously a little bit out of the way for me in terms of travel, the medication itself was relatively easy to get and UCH was where all of the experts were, so I didn't mind making the journey. The North Middlesex Hospital, the hospital I go to for appointments now, is only GRO-B.

40. While I was on the Hepatitis C treatment, the consultant recommended that I attend group-counselling sessions at GRO-B I think that they were recommended more generally for everything I was going through. I went a couple of times, but I stopped going because so many

of the people I met at these sessions were much worse off than me. I would just think *'its not so bad'* about my situation when I heard what other people were going through.

Section 7. Financial Assistance

41. I found out about the Skipton Fund through the Thalassemia Society, and received a letter from the Department of Health about the Skipton Fund dated 26 January 2004. At that point I had not started the Hepatitis C treatment, but I knew that I had Hepatitis C. I can't really remember applying for financial assistance but I think it was quite a straightforward process. I don't have a copy of the application form and I think that if I had completed the form myself I would have a copy of it. This makes me think that the Skipton Fund must have contacted the doctors or hospital to get the information they needed. There is nothing that sticks out in my mind as being particularly difficult about applying to the scheme.

42. I received one lump sum payment of £20,000 paid on 1 October 2004. As far as I can remember the Skipton Fund did not say that there were any conditions attached to the payment, nor do I remember the Skipton Fund explaining why I was receiving the money. I do recall the lump sum payment being referred to as an ex-gratia payment. I was not really sure what it meant at the time, but even knowing the meaning behind this now, I don't really have much to say about it. I think the fact that I only had very mild Hepatitis C but was still able to get the payment was really good. It was more than I was expecting to be honest.

43. On 24 July 2017, I received a letter about the introduction of new 'Stage 1' regular payments from the Skipton Fund, and I think that this is regarding the monthly payments I have been receiving from the

Skipton Fund. I get a payment every 4 weeks. Previously I received £333 every 4 weeks, and a winter fuel allowance of £500. I can't remember exactly when these payments started. However the payments were increased in April 2019 to £341.33 every 4 weeks, and a winter fuel allowance of £530.

Section 8. Other Issues

44. I just feel lucky that it is over and that I have stayed clear of Hepatitis C, because I can now move on.

Statement of Truth

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

Signed GRO-B

Dated 27 JUNE 2019.