Witness Name: Terry McMahon
Statement No.: WITN5414001
Exhibits: Nil
Dated: 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF TERRY MCMAHON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 March 2021.

I, Terry McMahon, will say as follows: -

Section 1. Introduction

1. My name is Terry McMahon. My date of birth is GRO-C 1955 and my address is known to the Inquiry. I have severe haemophilia A, which was diagnosed within a year of my birth. I have an older brother, but he does not have haemophilia.

2. I intend to speak about my infection with HIV and hepatitis C (HCV), transmitted via my haemophilia treatment. In particular, I will discuss how I came to be infected, the nature of my illness, the treatment I have subsequently received and the impact it has had on my life.

3. Many of the relevant events happened many years ago and I make this statement without the benefit of access to my medical records. I have done my best to remember details and timescales as accurately as possible.

Section 2. How Infected

4. In 1956, within a year of my birth, I was diagnosed with severe haemophilia, type A. I needed to attend hospital for treatment roughly once every two to three weeks. I was treated with fresh frozen plasma (FFP) for a long time, which was administered at the Manchester Royal Infirmary (MRI) or the Booth Hall Hospital, a local children's hospital which is now closed. I don't remember the names of any doctors at Booth Hall, but the registrar at MRI was called Dr Barrett and the consultant was Dr Israel.

5. In 1966, when I was almost 11 years old, I was in hospital for a short while with a lad from Preston and he told me about the Lord Mayor Treloars College in Alton. Our parents became friends and Trelor's must have been discussed. It was decided it would be a good idea for me to go to Treloars to finish secondary school and complete my O-Levels. So, between 1969 and 1971, I boarded at the boy's school at Treloars, Upper Froyle.

6. It was at Treloars that I first received cryoprecipitate treatment for my haemophilia. I was treated with Cryoprecipitate or Cryoprecipitate and Plasma whilst there. The treatment regime was vastly different to anything I had been on before – you would get both cryoprecipitate and FFP every day and, if the bleeding didn't improve, you'd get the same again until it got better. It wasn't given prophylactically, just whenever you needed it. I remember I recovered a lot quicker from bleeds at Treloars than I did whilst at MRI.

7. At Treloars, we were under the care of Dr Rainsford, who was employed by the school. He either treated you at the sick bay there in the school or you'd go to see him down at the actual hospital. He would prescribe the treatment and then it was administered at the school.

8. In the mid-late 1970s, some years after I left Treloars, I began home treatment. Before this I had only been on cryoprecipitate, but when home treatment started I moved on to factor product. I think that it was

all American if I remember correctly. My bleed rate at that point was every ten to fourteen days, but I was able to treat them myself at home.

9. In 1985, when I was about 30, I was called into the MRI for a HIV test. This would have been done by Dr Wensley, the Consultant who was generally focussed on the whole HIV situation. There were lots of other haemophiliacs there for the same test and we all knew each other. They ran the test twice for everyone – both of mine were positive. I have a vague memory of them asking us to return the factor treatment we had and replacing it with heat-treated products.

10. Then, a few years after that, I had a test for HCV as well. I think it was pretty much as soon as they had a reliable test for it and, again, all the haemophiliacs I knew had a test around the same time. I actually had hepatitis A and B when I was very young, before I was five years old. I don't remember anything about it, but I know that I had it. So, when I found out I was also positive for HCV, called NANB at the time, it didn't really phase me that much.

Section 3. Other Infections

11. In 1995 and 1996, I had the two knee replacement operations. Shortly after I was informed that a donor whose blood had been used in my treatment for the surgery had died from Variant Creutzfeldt–Jakob disease (vCJD). I also received a letter informing me that there was a risk I had been exposed to vCJD.

12. Other than HIV, HCV and the potential risks of vCJD, as far as I know, I have not been exposed to any other viruses as a result of my haemophilia treatment.

Section 4. Consent

13. The treatment I underwent for my haemophilia was never really presented to me as a choice, so I wouldn't really say that I consented to the particular product. I'd just be told, this one is easier, so we'll do

this instead. There was no option, no explanation of the pros or cons of each, it was just given to me by the doctors. Every time the treatment changed, it did become easier, particularly when I started home treatment. It really was true that it was easier, but the corresponding risks were never explained to me.

14. I actually learned about the particular risks from my haemophilia treatment from a World in Action programme. It talked about the risk from certain donors and how a lot of the blood products came from high risk people in America. But this was after many years of taking a variety of different treatments – I never really felt that I had the choice whether or not to consent.

Section 5. Treatment/Care/Support

15. I never received any treatment for HCV and, as far as I know, my liver has never been assessed for the damage caused by the virus. I was able to clear the HCV infection naturally and, to my knowledge, it has never returned.

16. My treatment for HIV began in the late 80s, around 1987. Due to my low platelet count I started on a treatment called Immunoglobulin, which I think was just to manage my condition. I was put onto AZT shortly after. I don't remember actually being told whether the AZT was effective or not. I'd go to MRI, have the AZT and some immunoglobulin, and then go home. I did this for several years, until they said that AZT probably wasn't making much difference any longer and so they stopped it.

17. I am now on three different antivirals. My HIV is under control – my viral load is undetectable and my CD4 counts are within the normal range. I can't recall having any problems accessing treatment at all.

18. There was a counsellor at the MRI and he would give us information on how to contain the risk of contamination and the precautions to take

etc. It was intended that he would be someone for us to talk to about our mental state, treatment and life in general I suppose. You'd just have a twenty-minute chat with him at the end of your treatment.

19. But, oddly, he always seemed to want to talk to us about religion. He would tell us to 'hedge our bets' if we told him we believed in God at all. I have no idea if he managed to successfully convert anyone. He didn't provide a particularly useful service, it wasn't that beneficial, but it wasn't bad either. You could say whatever you liked so it was a good opportunity to get stuff out, I guess. But it was quite odd how it always seemed to come back to religion.

20. On the whole, the doctors at MRI were very good, but it is hard not to wonder what they knew about the dangers of our treatment. I couldn't ever tell what they actually knew about the risks so it is difficult to say whether I think they were at all responsible. At some point they must have known that it was infected, but I can't say that they had any choice, I don't know. I do wonder what the rationale was in giving us the treatment – it seemed to me that some of them knew more than they were letting on.

21. One area of treatment that has caused me problems is dentistry – I've had an absolute nightmare with dental treatment, though this is more to do with my haemophilia than my infections. I need to have prophylactic antibiotics when I go to the dentist as on two separate occasions I got an infection from the dental treatment that spread to my knee and prompted my knee replacements to be redone. I used to go to the MRI for dental treatment and they obviously knew about my condition. But I now go to a local clinic and my viral load is so low that I am not required to inform them of my HIV.

22. I think I got adequate advice from the hospital after my diagnosis. As I will detail further below, in Section 6. I developed a bit of an obsession with the precautions necessary to avoid passing on my infection, to the point that I took them a bit too far in fact. In a way, I think that any more

advice from the hospital may have made this even worse, so it probably wouldn't have actually helped all that much.

Section 6. Impact

23. If I'm perfectly honest, neither HIV or HCV had a particularly big impact on my physical health. As I have said, I was able to clear the HCV without receiving any treatment at all and my HIV was manageable once I began treatment. I still have health problems arising from haemophilia, such as arthritis, but I no longer have bleeds thanks to regular prophylaxis.

24. A friend of mine from school died of liver disease caused by HCV, and another haemophiliac I knew had a liver transplant, but that was kind of the extent of the impact that HCV had on my life. It wasn't talked about a lot amongst the haemophiliacs I knew. The HCV didn't really register too much with me. Having had hepatitis A and B when I was younger, it was just like getting the full set.

25. In some senses, being diagnosed with HIV didn't have a massive impact on my daily life either. Not much changed if I'm honest. It was like we were told we had this big scary virus, but then nothing happened, nothing was different from before. We were seeing stuff in the papers about people dying of HIV so it was real and it was dangerous, but nothing actually changed for us. I remember sitting around discussing it with other haemophiliacs and we didn't really know what it meant for any of us. It felt like we were waiting. Some others had symptoms right away; it was a regular thing for others we knew to be admitted to a ward and we would go and see them. We were just sort of waiting for the symptoms to kick in.

26. HIV has had a big impact on my ability to develop relationships. When I was younger, I was obsessed with the idea of infecting others. I had to keep away from people; keep my distance and not use the same cutlery and so on. This obviously made sexual relationships difficult. It

even feels strange today when people touch me. I knew it didn't constitute a risk, but it was in my mind constantly. They gave us info on what to do to contain risk and I understood the logic but it made no difference – I still couldn't get it out of my head. It still just felt like I needed to keep away from people. I knew that I could catch things from them too so I thought it was best if I just kept away. That is very hard to grow out of.

27. Before my knee problems made it more difficult, I'd go out for a drink with a small group of friends every week or so, but that was usually the extent of my socialising. I have never told any of these friends about my infection. It just didn't seem to be worth the hassle. I knew it was a possibility that I would be ostracized if I opened up to people so I just didn't bother.

28. I think a few people in my life have worked it out themselves, but fortunately no one has ever asked me directly. A few have done so in a roundabout way, dropping hints at the possibility that I have HIV. I would always say that I hadn't got it though – I lied non-stop. It was a defence mechanism. It felt very necessary at the time, in the 80s, to do so. It was seen as this disgusting thing, to be feared and ridiculed at the same time. I was never going to admit to having it back then and the lie has just carried on from then, like a habit.

29. It was bad enough being a haemophiliac, it was bad enough being infected and it was bad enough having to lie about it all. But then, on top of all that, you couldn't discuss it with anyone. Only when I was down at the MRI could I really talk about it openly. I certainly couldn't do it with the people that lived near me. I have no idea what would have happened if I had let it slip, it could have been fine or it could have been awful. It wasn't worth finding out.

30. Only my family knew and, even then, there were members of the extended family that weren't told. There was no discernible change in my relative's attitude to me when they found out, but they knew all

about my health conditions so it was just another thing on the list I guess. Even though hardly anyone knew, you could still feel stigmatised; The adverts, the news stories, the constant jokes about Rock Hudson. It made me really anxious about anyone finding out.

31. I wasn't particularly ambitious as a youth; I just wanted a job that I could hold on to and that would let me get by. I worked as a civil servant for a short period, but they let me go after a year or so as I struggled to keep up with the work alongside my treatment. I was forcing myself to go in as I knew they were on the edge of letting me go, but this was just making things worse.

32. I struggled to get a job after this. I started a part-time degree course at Manchester Polytechnic, but couldn't see it through. For most of my life, since 1978, I have been on the dole and sickness allowance benefits.

33. I did manage to buy a house later in life. My mother put up half the money and I managed to get a mortgage for the other half. None of the building societies would go near me – not only did I have to disclose my illnesses, but I had no employment history to speak of whatsoever. So, I needed to get the help of an independent financial advisor, who helped me get a tailored arrangement for the mortgage.

34. I have got specialist insurance, which is more expensive but at least it's available I suppose. I have never bothered to attempt obtaining life insurance – it's just not worth even thinking about.

Section 7. Financial Assistance

35. I can't recall exactly how I found out about the schemes offering financial assistance to infected people. I might have been told about it at the hospital or I possibly heard about it from the Haemophilia Society. I didn't really think that I was entitled to anything, particularly for my HCV infection, seeing that I cleared it without treatment.

36. Initially, I discovered that I could apply to the MacFarlane Trust for grants for specific things, so I got a down payment for a car in the 1990s. I then got a lump sum of about £20,000. I also got a dietary allowance around this time, which supplemented my income. Later on, I received a payment from the Skipton Fund as well. I don't think I was asked how long I had actually had HCV. I received a further payment of £23,000 when John Major's government made a 'final payment' in the 1990's.I now get a monthly payment from Skipton.

37. All in all, I think I got about £43,000, some of which went to pay off the mortgage on my house. I didn't really have much difficulty applying; I just filled in the form, told them about my finances and they told me how much I was entitled to. I know there are other schemes that have more complicated applications processes, but I haven't applied for these ones.

Section 8. Other Issues

38. I constantly have to remind myself that I have a life outside of my infections – it sometimes feels like I am living just to maintain my ailments. Everything I have ever done has had my haemophilia and my various infections in the background. I think I've gotten so used to it now, it just all seems very normal for me. But when I think about it logically, it has had a huge impact on my life. So big that I find it hard to think what my life would be like without them.

Statement of Truth

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

Signed GRO-C

Dated 11th April 2021