Witness Name: Darren Antony Guest
Statement No.: WITN6328001
Exhibits: Nil
Dated: 24 December 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DARREN ANTONY GUEST

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 September 2021.

I, Darren Antony Guest, will say as follows: -

Section 1. Introduction

1. My name is Darren Antony Guest. My date of birth is GRO-C 1972, and I reside in Dorset.

2. I am divorced, and I have a seven-year-old son. I currently live at home with my mother in Dorchester. I have one older brother Alan, and a younger niece GRO-C

3. I intend to speak about my infection with Hepatitis C ("HCV"). In particular, the nature of my illness, how it has affected me, the treatment I have received, and its impact on my family and our lives together.

4. I was diagnosed with haemophilia as a child. Therefore, I have very little recollection of its impact on me for much of my childhood. I am

providing this statement with the support of my mother, who has more information about my younger years, especially in terms of dates and names.

Section 2. How Infected

5. I was diagnosed with severe haemophilia as a baby when I was only six weeks old. GRO-C
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7. As a baby, I was given cryoprecipitate whenever I had a bleed. My mum says I was quite a good baby, so I did not injure myself too often, and bleeds were a rare occurrence.

8. In 1984, my parents split up, and my mother and I moved to Kent. Her new husband ran a roofing business which required him to travel to various parts of the UK, and so we moved to GRO-C village just outside of Chatham in Kent. When my stepfather passed away, my mother moved back to Dorset.

9. According to my mum, I was around 11 or 12 years old when I started receiving Factor VIII treatment for bleeds. I cannot really recall, however I believe this was around when I started secondary school in Kent.

10. I was under the care of Dr Hayes at All Saints Hospital in Chatham. Dr Hayes also used to work in Dorchester, and he was the doctor who diagnosed GRO-C me with haemophilia.

11. Dr Hayes was very good at his job. He used to go out of his way to make sure I was doing fine. I remember on one occasion when I was in the hospital for a reason unrelated to my haemophilia, and Dr Hayes came in specifically to check up on me. After he retired, Dr Andrews took over as my doctor.

12. Dr Hayes put me on Factor VIII, but only, when necessary, for instance before I had to have dental treatment or an operation.

13. I did not usually enjoy having dental appointments. I used to see a dentist when I was about four or five years old, in Dorset, and I hated it. The dentist was a bit of a bully. I can still recall being held down for procedures and having to endure them with no medication to numb the area because of my haemophilia.

14. The doctor used to say, put your hand up if it is painful, and I would raise my hand, signalling that I needed to stop, but he would continue to press the drill back down. The process was unbelievably painful, but then he would hand me sweets, afterwards. I have hated going to the dentist since then. That dentist has probably passed away now.

15. In the mid-1980s, I had to have exploratory keyhole surgery on one of my knees. The specialist surgeon, Dr Bevis, in Gillingham, told my mum and I that I could sign the consent forms, even though I was not yet eighteen.

16. I also had to have Factor VIII on this occasion, however no one spoke to me or my mum about any risks associated with receiving Factor VIII.

17. After I was diagnosed with HCV, Dr Hayes informed my mum at one of my regular outpatient appointments that he knew the exact batch number of the contaminated Factor VIII I had been given. My mum

believes that this was at All Saints Hospital in Rochester. He said he had it all written down in his notes.

18. I have received blood products on many occasions, and I cannot remember ever reacting differently to any specific batch. Therefore, I am unsure of how Dr Hayes would know this information specifically.

19. I have never seen my medical records or tried to obtain a copy, but I will make efforts to obtain these in due course.

20. By the mid-1990s, I was in a relationship. I had gone to King's College Hospital, London, with the girl I was seeing for a regular appointment. My girlfriend did not come into the room with me to see the consultant. The consultant, I cannot remember who he was now, informed me there and then that I had contracted HCV.

21. After informing me of the diagnosis, he explained what it meant and provided advice regarding the risks of transmission, although the only thing I can recall clearly now is that he said there was only a small percentage chance of passing it on sexually. He also advised me about managing the risk when I sustained cuts etc. I was then given some pamphlets on HCV.

22. Looking back, I think the doctors should have informed me of my diagnosis if they had this information much earlier. If Dr Hayes had been aware of my diagnosis, I am sure he would have informed me of the treatment options, even if he could not offer them to me.

23. In November 2000, I recall I was experiencing a bad headache for three days. I could not eat or drink anything, but I was vomiting. My GP thought I had meningitis and referred me to Medway hospital immediately to have a brain scan. It turned out I had a blood clot and a spontaneous haemorrhage. Medway Hospital transferred me to King's

College Hospital in London. Dr Hayes came down to see me while I was at Medway Hospital.

24. At King's College, they informed me that they could not remove the blood clot and had to leave it for a while. They decided to treat it with steroids and Factor VIII. I had drips going into each arm. I was hallucinating seeing people trying to climb windows to get to me. No one informed me whether this was due to having HCV or haemophilia. I remained in the hospital for around six or eight weeks. It was a horrible time for me.

25. I was later informed that I had developed liver cirrhosis and had to have a liver transplant. After my liver transplant, I was offered treatment, which did not work in the first instance. I had to have a second course of treatment a year after that, which worked.

26. Since having my liver transplant, my haemophilia has been downgraded to mild. Although I still attend St Thomas' Hospital once a year to review that.

27. I have never received medical treatment abroad, and I do not have any tattoos. I have never used intravenous drugs or lived the kind of lifestyle that could have put me at risk of contracting HCV.

Section 3. Other Infections

28. I do not believe I have received any infection other than HCV due to being given infected blood products.

Section 4. Consent

29. I do not know if there were ever any issues around consent. It was necessary for my brother Alan and I to have Factor VIII, so my mum says she would have consented to us receiving blood products in any event.

30. Dr Bevis, my specialist surgeon in Gillingham, said that I could sign the consent forms for treatment with Factor VIII when I had to have exploratory knee surgery even though I was not yet eighteen.

Section 5. Impact

31. At the time of my diagnosis, no one explained that HCV could destroy my liver. I was not offered treatment immediately, and I believed that this was because there was no available treatment at the time. I was left to live with the condition while my liver continued to deteriorate. Several years later, I was informed that I had developed cirrhosis and would require a new liver.

32. In 2011, I was living in Kent, but I came down to Dorset to visit my dad. That night I went to bed, although I was feeling weird. The following morning, no one could wake me up. I am not sure of what exactly happened, but I was rushed to the hospital. I believe that they said my liver was not working properly and the toxins in there had travelled from my liver to my brain. I was unconscious in a coma and in the ICU for nearly a week.

33. The doctors explained that the best way forward would be to have a liver transplant as soon as possible, and I was placed on the emergency waiting list. I had been on the transplant list for about three and half years before that.

34. When I woke up from the coma, it was horrible. I was freezing, and there was only one sheet covering my body. I could not speak because

of the tube down my throat, and I thought I was dead. It was cold, and all I could see was this bright light. I was trying to speak, but nothing was coming out. It was very scary.

35. My mum told me that when my then wife Luciana called to inform her of my condition, she could not sleep that night. The next morning, she caught the first train down from Kent to Dorset.

36. I was discharged after two weeks at the hospital and informed that I should expect to be called in at any time. I was aware that I could have died because of the toxins my liver was producing. I had difficulty sleeping because I was anxious about getting a call from the hospital. There were two occasions when they alerted me to come in, but later cancelled and apologised because I was not a match due to different tissue types.

37. I had my liver transplant at King's College Hospital in September 2011. The transplant was considered successful, and I still have that liver to date. There have been minimal problems so far, although I have to take Advagraf, an anti-rejection medication for the rest of my life.

38. The doctors have advised that the medication is not good for the kidneys and there is a risk of kidney failure later in life. They said it is rare, but it can happen.

39. I had never been offered any HCV treatment prior to my liver transplant, but the doctors began to advise on treatment options to ensure that HCV could not infect the new liver.

40. In 2012, I was finally offered treatment at King's College Hospital. The treatment consisted of a combination of Interferon injections and Ribavirin tablets. Luciana was taught how to administer the injections

into my stomach. I was also monitored by the hospital and had to return every fortnight for appointments.

41. The side effects were severe. I had a high temperature and used to have shakes, which would get really bad at times, and my body began to ache about an hour after each injection. When I first started the treatment, I used to have to get the injection at the clinic. It took approximately an hour to get back home on the train. My wife and I would rush to catch the train as soon as I had received the injection so that we could get home before I started suffering. By the end, my wife and I turned running home to catch the train into a game in order to cope.

42. The effects were immediate and lasted for hours. I could not do anything except lie down and wait for it to pass. It made it impossible to work. It was an awful treatment.

43. After being on the treatment for several months, I was told that it had to be stopped. My platelet levels were becoming dangerously low, and my red and white blood cells were disappearing. The treatment also made me very ill. I was told that I would have to wait for my body to recover and in the meantime, there was no other treatment option available to me.

44. A year later, I was invited to participate in a trial of a tablet that had just been released. I cannot remember the name, but I know it was a single tablet, and I had to take it for a year. The treatment requirements were strict, and I could not eat a few hours before taking the tablet or several hours after taking it. If I missed my chance to eat before taking it, it would be a long time before I could eat again. There were occasions where I would be so knackered because I had not eaten for a whole day.

45. Since the transplant, I have had problems with incisional hernias, and I have had two operations to correct them so far. I have been informed that I will need another operation because it has developed again, which is a direct result of the transplant.

46. When we were growing up, Dr Hayes trained my mum to give GRO-C GRO-C me cryoprecipitate at home. However, sometimes, my mum's friend Jackie, who was a nurse, would come around and administer it. My mum is not a very private person, so people knew GRO-C I had haemophilia. GRO-C GRO-C

47. I believe that there was a massive stigma around not just HIV but also HCV at the time, so I did not tell people other than close family and friends.

48. Luciana, knew I had haemophilia but not HCV, and she only found out in 2011, when I got admitted to the hospital for the bleeding in my brain. We got married in 2012, and our son was born in 2014.

49. I did not inform many people when I found out I had liver cirrhosis. In those days, everyone assumed that it was because you were a drug addict. The one time I said I had cirrhosis among a group of people, I remember one person discussing whether I was an alcoholic or something along those lines.

50. Doctors and medical professionals were also not immune to treating you differently. On one occasion, not long after I was diagnosed, I had to go to the hospital for something unrelated I cannot remember why now, but I had to ask them to prepare a room for me. They took a long time to do so, and I was left wondering why until I saw the room. There was tape on the door, and they wore masks, like full PPE, similar to that worn now when treating people with Covid.

51. During my stay, the nurses would come in with my meal, wearing full PPE and I thought to myself, why is she dressing like that? It was like they were about to carry out an alien autopsy. I did not understand it at the time. I know it may not have been the nurse's fault, but I was treated like a laboratory experiment. It was like being in prison, but thankfully I was not in the hospital for long on that occasion.

52. I attended a mainstream school, and my mother had to declare to the school that I had haemophilia. It did not impact me much except for the fact that I was not allowed to play some sports. I played football and cricket although I had to use a tennis ball when I started playing cricket. I was not allowed to play rugby, though.

53. It has not impacted my job prospects because there is nothing, in particular, I have wanted to do work-wise. I have had plenty of odd jobs, from doing maintenance work to stock taking. I currently do not work, and I get PIP.

54. I have never tried to obtain a mortgage because I live with my mum. My ex-wife is from GRO-C and we have travelled there a couple of times and taken trips to Italy and Greece. We never purchased holiday insurance.

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57. I am currently on antidepressants, and I believe this is a result of everything that has happened to me, that is, being a haemophiliac, getting infected with HCV, and all of the other health problems that the HCV has caused.

58. At first, I was not bothered when I was diagnosed with HCV, but as I grew to understand its effects and saw what it was doing to my body, it started to affect me mentally. I have developed anxiety, and depression, and it has been quite horrible. Even preparing for this meeting today made me incredibly anxious but thankfully, talking about it has made me feel a bit better.

59. I have been on three different types of antidepressants and seen three different people, including a psychiatrist and a psychologist, but none of the courses of treatment have worked. I am currently on medication, and that's about it.

60. I believe that it may have contributed to the breakdown of my marriage. I know it started with my HCV diagnosis and having to keep everything to myself. I even developed coping mechanisms and methods to avoid discussing the subject with friends and family.

61. I have probably been unable to reach my full financial potential as a result. There were times I was unable to work for prolonged periods, whether due to requiring a transplant or other health-related issues.

62. The was an incident when I was working on a garage roof, and I do not know if I was daydreaming or just spaced out, but I ended up treading on the wrong thing and I fell through the roof. I broke my back, fractured my skull, ribs and collarbone.

63. I am too scared to drive because I tend to daydream. My mind wanders, and I get lightheaded. I have had friends who have been in

accidents, and I don't want to end up having a car accident. I am permanently light headed, and I believe this is as a result of HCV. I find it hard to concentrate, and my memory is useless. I used to suffer from leg cramps but not so much now. At one point, I had itchy skin all over my body and I believe this is also a symptom of HCV.

64. I left school at 16, which has probably prevented me from having friendships. I started staying in a lot more, and was not as outgoing as other teenagers around me were. I have had the same group of friends since my teenage years.

65. It has also probably prevented me from getting into relationships since at the back of my mind, I know I have HCV and would have to reveal that to a partner.

66. I believe that it affected the relationship between my wife and me, because of the impact on my mental health, and it would have been a lot for her to deal with. I know that my personality also changed after my liver transplant, and I became a lot more moody.

Section 6. Treatment/Care/Support

67. As mentioned above, I am currently on antidepressants. I have been offered counselling and psychological services on multiple occasions with regards to my depression and anxiety due to contracting HCV, but these have not worked.

68. Before I could be offered the HCV treatment tablet that eventually worked, the consultant at King's College Hospital said he would have to have a word with chief executives at a meeting to seek their permission to give this to me. I don't know if there were any financial issues involved with that. All I know is that I was able to have the tablet in the end.

Section 7. Financial Assistance

69. For as long as I can remember, I have been involved with the haemophilia society in some capacity. I believe that I found out about the Skipton Fund through one of the magazines.

70. The Haemophilia Society put me in contact with the Skipton Fund, and I received the £20,000 stage one payment. When I developed cirrhosis, I received another payment.

71. The English Infected Blood Support Scheme (EIBSS) took over from Skipton, and I currently receive £2,300 a month from EIBSS. They may have increased the payments recently, but I am not sure.

Section 8. Other Issues

72. I cannot believe that they knew that the blood was contaminated. If they knew, they should not have given it to us. If I knew something was bad and I continued to give it to someone, I would be in prison. It is the same principle in this case, if they knew.

73. What was wrong with continuing to treat haemophilia with cryoprecipitate? It worked fine when I was a child.

Statement of Truth

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

Signed GRO-C

Dated 24/12/21