Witness Name: Darren Eveling
Statement No.: WITN4585001
Exhibits: Nil
Dated: 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DARREN EVELING

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 October 2020.

I, Darren Eveling, will say as follows: -

Section 1. Introduction

1. My name is Darren Eveling and my date of birth is GRO-C 1977. My address is known to the Inquiry. I am a 'mild' haemophiliac (type A) and I intend to speak about my infection with hepatitis C (HCV), caused by my treatment with factor products. In particular, the nature of my illness, how the illness has affected me, the treatment I have received and the impact it has had on my life.

2. I am not legally represented and I am happy for the Inquiry team take my statement. I can confirm that the anonymity process has been explained to me and I do not wish to seek anonymity.

3. I make this statement without the benefit of my medical records. I have never applied for my medical records, but I would be able to obtain them.

Section 2. How Affected

4. Three or four weeks after I was born, I was diagnosed as being a haemophiliac, with 4.2% Factor VIII levels. My grandfather was a haemophiliac, GRO-C GRO-C GRO-C

5. Apparently, doctors told my parents shortly after my birth that they shouldn't get used to me as I would be dead before I was two years old. Over the course of my life, I have been told many times that I only had so many years left to live and every time I have proved them wrong.

6. I was quite accident prone as a kid. My mum tried to wrap me in cotton wool because of my haemophilia, but I just wouldn't let her. I was always active and this obviously meant that I would have regular bleeds and hospital admissions. I have had more stays in hospital that I've had hot dinners.

7. One of my earliest memories is being aged four or five and being on holiday at Butlins. I was running up a metal staircase and my shins were banging against every step. They were so swollen that doctors thought I had broken my shins, but it was just a bleed. I didn't let incidents like this faze me; I didn't want to be that kid sat in the classroom looking outside at the other kids having fun, it's just not me.

8. I was treated at Great Ormond Street Hospital (GOSH) until I was 13. The doctors there told me not to do sports, something that I thoroughly enjoyed and was really good at. I remember the nurses telling me to ignore them and saying that I had the healthiest muscles of any of the haemophiliacs they looked after. I would have done it either way, but I

knew that I was more resilient to the bleeds than others with the condition. Of course, I was a mild haemophiliac, but they were very cautious with me because I was right on the edge.

9. When I was about five years old I was on a family holiday in Norfolk. On a day out to the beach one day, my brother and I were playing in a small garden area near the beach. There was a gardener that was working on the area and we ended up helping him. My dad came over to check that the gardener was happy for us to help, which he was.

10. As my dad turned to walk back to the beach, my brother and I were pulling a big garden hose. My dad was about 15 feet away when I slipped on the wet mud and hit my head on a brick wall, leaving me with a huge cut on my head. By the time my dad reached me, you could not see my face as it was so covered in blood.

11. My dad picked me up and took me to a beach hut nearby. When we arrived there, his white shorts were red with my blood too. As far as I remember it, we went to some sort of local surgery that stopped the bleeding and then travelled back home for me to be fully treated at GOSH. I had butterfly stitches across the wound and was treated with factor products. Several weeks later I still had a huge lump on my head and it was one of the worst injuries I have sustained. If I banged my knee, I was mild enough to only get a bruise, not a full-on bleed.

12. Roughly a year later, when I was aged about six, we were on another holiday. I can't remember for certain, but I think it was to Bournemouth. The trip had been organised through the church that we went to and it was a sort of wives group made up from the families that went to the Sunday school there, as we did.

13. We were on a day trip to the beach and I was just sick as a dog. I had no energy, felt very nauseous and had no get up and go, which is very out of character for me. After a short period of time on the beach, I

went white as a sheet and couldn't even move. Everyone was trying to get me to play and have fun, but I was in bits.

14. My mum was so concerned that she got us a black cab and we went to a medical centre there in Bournemouth. I don't really remember much else after arriving at the centre. From subsequent conversations with my parents, I believe that it was at this time that I was diagnoses with HCV. Obviously, I was too young to understand any of it and I don't even think that the doctors understood what it meant either. I certainly wasn't told anything about a diagnosis at this point in time, which is understandable as I was only about six years old.

15. Then, when I was around 12 years old, I came home from school to find my mother sat at the kitchen table crying her eyes out. At this time, the AIDS crisis was still ongoing and she was holding a letter from the hospital. I asked her what the matter was, but she didn't answer. I saw that the letter was from the hospital and asked again what it was. 'I've got AIDS haven't I?' I asked her, but again she didn't answer. Still in tears, she ran out of the house and left me standing there alone.

16. I didn't know what to do. I tried calling my dad and everyone else I could, but no one was around. After being alone for about 45 minutes, thinking that I had been infected with AIDS, my mother returned. It turned out that the letter just noted that I was HCV positive and someone had needed to explain to her that this was not the same thing as HIV or AIDS. I have never trusted my mother since. That was the first I knew about my HCV diagnosis and I was also alone for so long after my mother ran from the house, terrified that I had AIDS.

17. My mother told me that I had been tested for NANB hepatitis following the accident in Bournemouth but it was only called HCV some time later. I can maybe see where she was coming from, keeping it from me like that; now that I have kids if my own, I appreciate how hard it would be to discuss things like this with your child. She is my mum and I'd lay

down my life for her, but I can't get my head around how she could run out of the house and leave me like that.

18. I have no memory of a doctor sitting me down and telling me what I had. The only reason I found out about my hepatitis infection when I did was because I found my mum reading that letter.

19. Being a haemophiliac, I have used blood products such as Factor VIII concentrate my entire life. However, I believe that it was the treatment at GOSH following the injury I sustained in Norfolk that infected me with the hepatitis C.

20. I have no other risk factors for hepatitis C infection: I have no tattoos; no history of intravenous drug use; no treatment abroad or in high risk areas. To my knowledge, I have never received a blood transfusion.

Section 3. Other Infections

21. As far as I am aware, I have not been infected with or exposed to any infection or virus other than hepatitis C.

Section 4. Consent

22. Being so young when I was treated, I would not have been asked to consent to the treatment. As the parents of a haemophiliac, my mum and dad would have been very used to me being treated with blood products, so I also doubt that they would have needed to expressly consent to the treatment. Though these concentrates have infected me with this virus, I appreciate the fact that they are life-saving treatments and without them I would probably not be alive today.

23. I have had my blood tested so many times over my life, I cannot remember what I was told each and every time. That said, I don't think that they tell me what they are they testing for. I am not asked to consent to specific tests, for example. I assume that they are taking my blood to test the levels of Factor VIII, but they usually take four different

samples so it must be for more tests than just my factor level. But they never tell me what it is.

Section 6. Treatment/Care/Support

24. As I have said, my parents were informed of my HCV diagnosis many years before I knew anything about it. Because of this, I have very little idea what information as provided to them at the time of my initial diagnosis. My impression is that they knew very little about the virus back then and so were not able to provide much in the way of advice. All my life, my parents were being told I only had so long to live. I guess they thought of it as just another thing that could have killed me.

25. There have been quite a few times that I have felt adequate information has not been given to me. For example, I don't ever remember being warned about the risk of sexual transmission of HCV. I guess they just expect you to know that sort of thing yourself.

26. When I was about 18 or 19, I started my first course of treatment. It lasted for a year and consisted of Interferon and Ribavirin. Just before this treatment started, I went on a lad's holiday but I just couldn't enjoy it. I didn't want to drink because of my upcoming treatment and I found it hard not to think about the side-effects that may come along with the drugs.

27. In the end, my concerns did come true. The combination therapy really kicked it out of me. They had warned me about possible side-effects and I got almost all of them – hair loss, yellow skin, fatigue, malaise. The worst one, however, was the mood swings. I will detail the impact of these effects in Section 6, Impact, below.

28. I believe that this treatment was actually part of a trial. I swear I remember the word 'guinea pig' being written on the first bottle of pills. Whether or not I dreamed this afterwards or confused it with the word 'trial subject', I don't know. If I remember correctly, the trial consisted of about 900 people, roughly half of which were cured of their infection.

29. I did the whole course of treatment and it appeared to have restored my liver completely. I finished around September and by the following January, the damage was back – the treatment was unsuccessful. My doctors assured me that another treatment would come along soon. Throughout my life, doctors had told me on several occasions that I had 14 years left to live. This always sticks in my head for some reason. On this occasion, when my treatment had failed, they told me that the clock had essentially reset because of the temporary improvement in my liver and so it was back to having another 14 years left.

30. It was around the time of my first treatment that I really started to understand my infection and the consequences of it. Prior to this, it was only ever really mentioned in passing and nothing was ever thoroughly explained to me.

31. A number of years later, when I was about 22 years old, I was put onto another round of treatment. This time, they said that one dose of treatment was equivalent to about 30 doses from the previous round. I would take the drugs on Friday and would then remain in bed until Monday morning. My mum would come up to my bedroom and help me go to the toilet occasionally, but that was it.

32. I'd spend the whole weekend in bed. The whole experience was truly horrific. If I took it too late, I wouldn't be able to sleep for the whole weekend and I'd just lie there in bed unable to move. I suffered all the same side-effects as before but much worse, as well as awful ulcers.

33. So, I would lay in bed feeling horrible all weekend. Then I'd feel nauseous and lethargic on Monday and Tuesday and would be getting back to my usual self by Wednesday. On Thursday, I'd be chipper. But by Friday, the thought of another dosage brought my right down and I had to start the whole thing over again.

34. After about six months, they stopped this treatment. It was working for the first few months, but then it went backwards again and they said they weren't going to keep me on it. I was actually happy when they told me I was coming off this one. Obviously, they were only taking me off the drugs because they weren't working, which wasn't good to hear. But it was just so intrusive and made me feel so disgusting that I was happy to stop it.

35. For many years I didn't go through any treatment. But a few years ago, I was offered a third attempt at treatment. I was being treated at the Royal Free Hospital in London and would go there to pick up the medication. The treatment was relatively new and consisted of a single tablet to be taken once a day for a month. I, however, did it for three months. Thankfully this time it did clear the infection.

36. The NHS contacted me to offer this treatment a short while before the Infected Blood Inquiry was announced and a small part of me suspects that they were trying to make us feel special before the Inquiry started. That's certainly what it felt like. They told me that I was being put to the front of the queue for this new treatment, as if we should be really grateful for it. I don't know if this is the case at all, but it was like they were trying to make us feel important.

37. In terms of dental treatment, I have always been treated at the same hospitals (GOSH and The Royal Free) that I went to for my haemophilia care, so they were probably always made aware of my HCV infection through my notes anyway. I have, therefore, never experienced any difficulties obtaining dental treatment.

38. In terms of haemophilia treatment, I started administering my own Factor 8 concentrate when I was about 17. I am now treated with DDAVP, a synthetic form of Factor VIII which can be effective in mild haemophiliacs. I have some of this at home to administer myself if necessary.

Section 6. Impact

39. My infection with HCV has had a considerable impact on my life – my physical and mental health, as well as my work and personal life, have all been hugely impacted by the infection and the subsequent treatment I have undergone.

40. Over the course of my life, I have had lots of issues with my ears, nose and throat and, looking back now, I think that any symptoms of my hepatitis infection that I experienced were probably attributed to these other difficulties. I have been on loads of different antibiotics for years and had so many other health conditions that it is hard to distinguish between the effects of each.

41. I generally have a high pain threshold as well and I can't think of any symptoms I had when I was young that I can now be certain were caused by my infection with HCV.

42. When I was younger, I was a pretty good footballer, despite my haemophilia, and I was given the opportunity to go to football trials in the US when I was 15. However, my parents didn't want me to go. They knew that could have been the source of my hepatitis infection and didn't want to risk me going there and being infected with something else if I needed treatment, like HIV. I gave up playing football after that. I know it was cutting off my nose to spite my face, but I just really resented the fact that I couldn't go and do that trial.

43. There was a number of things that I wanted to do with my life, but the haemophilia got in the way. I wanted to be a police officer and actually go to the point of going for a medical exam. By sheer chance, the doctor undertaking the exam was my own consultant and he just said 'why are we even going to start this, Darren?'. However, my infection with hepatitis, I believe, has not had a huge direct impact on my educational or professional attainment.

44. The most considerable impact on my life has actually arisen as a result of my treatment for HCV, rather than the infection itself. The physical effects were really awful. It completely drained me of my energy. I was just constantly tired and run down. It didn't matter how much sleep I got, I'd be utterly exhausted. I got terrible ulcers that covered my whole mouth – my tongue, my cheeks, all over. I was on antibiotics to treat the ulcers.

45. I love my food and another side-effect was the near complete loss of taste. Every single thing I ate had this disgusting metallic taste. Even three or four years after my treatment was concluded, I couldn't taste a thing. I also suffered from jaundiced skin over the course of the first two rounds of treatment.

46. Another impact of the treatment was the toll that it took on my mental state. I'm not really the sort of guy to get depressed, but I do have a bit of a temper sometimes and the treatment made this much worse. Usually I am able to manage it easily, but the effects of the treatment made me completely unable to keep it under control. I would have terrible mood swings and just explode at people for the tiniest thing. You could drop something on the floor next to me and if it made a sound that annoyed me I would bite your head off.

47. It didn't matter who it was; the CEO of my company, my manager, a client, a family member. It just made me so aggressive and short-tempered. I'd get so angry at having to do the treatment as well. If I got a blunt needle or it caused me some pain I would be so enraged. I was essentially making myself ill and it made me really angry that I had to do keep doing it over and over again.

48. I don't think that there was a huge impact on my work life, but it certainly affected my attitude in the office. I was working the whole time; I couldn't sit around doing nothing, I'm just not one of those people. I probably took a week or two off at the start of my treatment,

but I'm just the sort of person that would go into the office even if I was dying.

49. However, the problems with my anger did sometime lead to me losing my temper at work. I work as a stockbroker and so it is a high-pressure environment anyway, but it could really get to me when I was in the middle of treatment. One time, I was on the phone to a client and the CEO was bugging me, trying to get my attention. I just lost it – I told him to get out of my face and not be so rude. Luckily, my manager came over and he was aware of the treatment I was going through. I think he may have saved me from getting the sack that day.

50. I never really had much of an issue informing employers about my condition. However, no one trusts anyone else on the stock floor so I did sometimes worry that my colleagues were doubting me if I took time off or left the office to do my treatment. On occasion, I'd do my treatment at my desk, just to prove to everyone what I was doing.

51. The treatment absolutely destroyed my social life. It was so hard to hear my friends at work talk about what they were doing at the weekend or planning to go out for a drink after work. I'd sometimes be tempted into going out with them on a Friday night, but just one or two drinks would make the effects of the treatment so much worse, it just wasn't worth it. The smell of beer or the pub would make me feel so sick. Being in my early twenties and not being able to go to the pub with my friends was devastating.

52. I haven't told too many people about my infection. My partner knows and I told my best friend when I was on holiday with him. I just haven't really felt the need to and I've been able to keep myself going and stay positive.

53. I haven't experienced much stigma as a result of my infection, though there a few times at school that I felt a bit stigmatised by my haemophilia and the impact of the AIDS crisis. One time, a science

teacher was talking about haemophilia and he said "that all haemophiliacs had AIDS". I challenged him on this and told him that he was wrong. He said to me, "Do you want to teach the class if you know so much about it?". I told him I am a haemophiliac and we got into a bit of a shouting match. In the end, he got suspended for a short period because of his comment about haemophiliacs.

Section 7. Financial Assistance

54. I was involved in the initial claim from the Skipton Fund. I refused to sign the waiver though and for nearly a year they couldn't get me to sign it. I was looking into what other countries were doing and saw that people infected by blood products were getting way more money in other countries. I hated the fact that they were asking me to sign away my right to future claims. In the end, I signed the waiver just to get on the treatment trial that I was put on, but I was one of the last to do so. They said I couldn't have the treatment if I didn't sign.

55. Within a week, I had the £20,000. If I remember correctly, my family will get another £20,000 if I die from the infection, but that's it. I have not received anything since the initial payment and do not get any regular financial support either. I have never been told of the more recent scheme, the English Infected Blood Support Scheme, though the Inquiry has now provided with me with the details. Money really isn't an incentive for me, but it would have been good to at least been told about the new scheme and advised if I was eligible for it.

Section 8. Other Issues

56. I applied to give evidence to the Archer Inquiry, but I didn't end up giving a statement or anything else. I can't remember why exactly.

57. One of the biggest issues I have is with the amount of information provided and the way that they go about discussing my illness with me. I know not a lot was known about HCV at the time, but to this day I am still given the kindergarten version. Medical professionals treat me like

a child when it comes to my own health, like I can't understand it. I still don't really know the extent of my own condition NOT RELEVANT NOT RELEVANT

58. That said, my biggest qualm is with the politicians. The doctors and nurses were just doing their best to treat us, but it seems like the government and politicians are trying to put the blame on them. It's the MPs and the government that are responsible for this. They are the ones that didn't want to spend the money to make the products safe.

Statement of Truth

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

Signed GRO-C

Dated 01/12/2020