

Witness Name: Gavin Leonard Jones

Statement No: WITN7284001

Exhibits: WITN7284002-10

Dated: November 2022

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF GAVIN LEONARD JONES

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I, Gavin Leonard Jones, will say as follows: -

#### **Section 1. Introduction**

1. My name is Gavin Leonard Jones. I was born on GRO-C 1981, and I live at GRO-C
2. I was infected with hepatitis as a result of receiving contaminated blood when I was a baby.
3. This witness statement has been prepared with the benefit of access to some of my medical records.

## **Section 2. How infected**

4. I was infected with hepatitis as a baby, and I believe that the treatment I received for my infection has had a severe and negative effect on the quality of my life.
5. Helen Isler, Senior Pediatric Registrar at Whittington Hospital, noted that at the time of my birth I was suffering from Rhesus disease [WITN7284002]. Quite simply, this is a condition that caused the antibodies in my mother's blood to attack my own blood cells. GRO-C suffered from the same ailment, however fortunately they did not suffer from it as severely as I did.
6. Whilst the disease doesn't harm the mother at birth, it can cause, and in my case did cause, anemia. I suffered from a lack of oxygen, resulting in my becoming a 'blue baby'. I was also mildly jaundiced when I was discharged from Hospital on the 21 August 1981 [WITN7284002]. My medical records briefly list that my anemia was treated with phototherapy, and it was 'resolved' with three top-up transfusions during the first month after my birth. I believe these transfusions led to me contracting hepatitis.
7. Due to my persistent poor health, coupled with my complication at birth, I often received regular check-ups from my pediatric doctors. On one such occasion, at the beginning of February 1982, I was admitted into Whittington Hospital after a resurgence of jaundice. After my treatment at birth my

jaundice had faded, but it returned, with the tell-tale signs of pale stools and dark urine [WITN7284003]. A liver ultrasound concluded that I was suffering from "idiopathic neonatal hepatitis" [WITN7284003]- it also appears from my notes that I underwent a liver biopsy in February 1982, and I was reported as having severe hepatitis at this time [WITN7284005].

8. My hepatitis didn't last long, although its exact characteristics are hard to ascertain as I have only been able to access a limited number of medical records. In truth, from the records that I have been able to get my hands on, I suspect that the doctors treating me did not make full and complete notes. I do not know the type of hepatitis I had been infected with and I am unaware of anything else that I could have caught, although I know I did not contract HIV.
9. From my limited records, I can see that by 17/03/1983 my jaundice, and I assume my hepatitis, had cleared [WITN7284004].
10. I only found out about my hepatitis infection recently. Not too long ago my dad had seen on the television news a report about the Infected Blood Inquiry. He told me that it was something that had happened to me when I was a baby. This provided me with some clarity about something my mum said to me when I was younger, that I didn't have much time left to live, as that my liver had been damaged. I had no idea what she was on about at the time, but now I know she was referring to my infection. It also strikes me that this is probably the information that my mum was told by the doctors.

11. As my hepatitis infection has not since recurred in my body and I have been jaundice-free, my dad did not think it important to tell me about my infection until he saw the report on the news. I assume that, with my other health issues, what appeared a comparatively minor infection was overshadowed and, as a result, slipped his mind.

12. I assume that the doctors did not properly inform my parents of the characteristics of hepatitis, as my parents did not take any precautions when it came to dealing with me. They did not act as though I was infectious in my younger years at all.

### **Section 3. Other Infections**

13. I do not know if I caught any infections other than hepatitis. I do not know what variant of hepatitis I was infected with. I know I was not infected with HIV.

### **Section 4. Consent**

14. I cannot comment as to whether either of my parents consented to me receiving a blood transfusion. I do not know if they were aware of the risks of contracting an infection from a blood transfusion.

## **Section 5. Impact**

15. There were various repercussions from contracting hepatitis, some more serious than others. One minor effect was the gawks and stares I received in the street as a child. Whilst not ostensibly ostracised for my appearance, my sister remembers people on the street calling me a 'yellow baby' and I too remember my yellow pigmented skin. Whilst this eventually faded and people forgot about it over time, I imagine it was very awkward for my family back then.
16. However, the main impact that hepatitis has had on me was in regard to the treatment that I received for it as a child. I believe that my treatment was a major factor in my loss of hearing at a young age, which has since worsened.
17. A letter from 13/11/1981 from GRO-D the Senior House Officer at Whittington Hospital to Dr David Rubra, notes that as part of my treatment as a child, I was prescribed Penicillin and Gentamicin [WITN7284006]. This medication was unnecessary and, I believe, paints a picture of the blasé manner in which I was diagnosed and treated as a child. To put it briefly, they seemed to throw everything at the problem until something stuck.
18. One of the known side effects of Gentamicin is that it can cause serious and persistent deafness to those taking it. I have since had huge issues with my hearing. It was first noted upon on 21/11/1983 where it was observed that I had difficulty with my speech. This was simply the beginning. As I couldn't

hear what people were saying, I was struggling to speak to people myself [WITN7284007].

19. I visited the Hearing Clinic at Crouch End Health Centre in 1985, where my mother was described as not being "worried about his [my] hearing" [WITN7284008]. From this, I gather that either the side effects of my treatment for hepatitis were not known at the time or they were not communicated to my mother.

20. Even with my limited medical records, I can see that the doctors have pieced together that my ailment as a baby and my hearing loss were linked, as Mr. T. Joseph, Consultant ENT Surgeon at the North Middlesex Hospital NHS Trust notes that my hearing loss "occurred following a severe jaundice in the neonatal period" [WITN7284009]. This observation suggests to me that there is a link between those two events. My dad has also mentioned that it was probably "the medication that he [I] was on for hepatitis that probably caused the hearing problem". My dad has kindly written his experiences with my health in a short note exhibited to this statement [WITN7284010].

21. Although they tried various, and sometimes strange (I remember when they tried injecting and draining liquid from my ears) treatments to engage my hearing, it has been irreparable. By the age of 14 my hearing capabilities were as sharp as they would ever be, and they have deteriorated year after year since then.

22. Around the age of 5, I was moved to a hearing-impaired school. I suspect to this day that the quality of my teaching at this school was sub-par, which

has had a huge impact on my work-life. I feel, due to my sub-standard education, that I have underperformed which has limited my occupational opportunities. I ended up joining a building firm and even this has been a struggle for me, as I had difficulty in passing the builder's health and safety test, as I struggle to read and write. Also, as you can imagine, working on a building site can be challenging and frustrating as I struggle to hear what is being said to me.

23. Another thing that has frustrated me, as a result of my deafness, has been the mocking that I have received all of my life. When I was a child, I was bullied for my lack of hearing/speech, which really upset and irritated me as I was being picked on for something out of my control. It can even happen at work, where new workers can come in and try to take the mick out of me for my hearing/speech. It's simply something that I have had to learn to live with.

24. There is also an increased risk to my health from being deaf. I have already mentioned that working as a builder with poor hearing can be a challenge. It can also affect you on the day-to-day life when you can't hear things coming towards you. I remember when I was a child and, as a joke, a few kids threw a brick at the back of my head and yelled "look out" but I didn't hear them, and the brick hit me. Although that isn't an everyday occurrence and is more to do with kids being stupid at a young age, it is indicative of the sort of issues I've had to face. Cars, people, and street construction are all things I must be constantly vigilant of. It still irritates me because up to the

age of 14 my hearing wasn't clear, but it was better than it was now, and I have a greater feeling of what I've missed out on.

25. The lack of hearing has also had some negative social effects. I struggle to go out in the rain because liquid interferes and can damage my hearing aid. I have to wear particular hats on wet days and simply hope the moistness doesn't seep through. As my mother had told me that my liver had been damaged, I felt I couldn't get be as social when I became an adult as some of my friends who could get far more inebriated than I felt I could safely get. I feel like I missed out on major experiences with friends due to this.

26. When I was young my poor health really affected my family. I had other siblings who didn't receive the attention that they sought as I monopolised my parent's time with my poor health, which was unfair on them. Nowadays my lovely partner, Sarah, is vital to me. She assists me with my everyday living, and I don't know how I would cope if she wasn't around.

## **Section 6. Treatment/Care/Support**

27. I have not received any treatment for hepatitis since I was a baby.

28. No counselling or psychological support was ever made available to me or any members of my family.



## **Section 7. Financial Assistance**

29. I found out about the possibility of receiving financial assistance after my dad had told me about my hepatitis. After finding out, I tried to apply to EIBSS for financial assistance. I received forms that I needed to fill in, however, to do so I needed to obtain access to my medical records.

30. I requested my medical records and upon receipt of limited medical records, my (new) GP pointed out to me that the type of hepatitis was not specified within them. As such, I have been unable to successfully apply through EIBSS for financial support.

31. From the medical records that I have received, I have noticed that there is a gap in my medical notes between the time of my birth and November 1981. It doesn't seem incidental that mainly the medical records of this time-period have disappeared, especially so since I was very ill at the time and was quite heavily involved with doctors as a child, so I assume that there are an abundance of medical notes relating to my infection that are missing.

32. It seems ridiculous and unfair that the lack of detailed medical records should be a barrier to me applying for financial compensation. I cannot accept that the onus was on my family to ensure that the doctors wrote and maintained accurate medical records. The right to compensation should not be restricted to people due to the type of hepatitis, they have contracted, and only if they can prove it is HCV. Despite the fact that there is evidence of my reduced liver function, and that I had hepatitis it seems arbitrary that

my application was still refused. It is particularly frustrating, looking back, that the doctors were so laid back in diagnosing and treating me and recording it accurately.

### **Section 8. Other Issues**

33. The whole process of finding my medical evidence and linking it to my health conditions has been needlessly gruelling. I would like to know how this process is going to be improved, because it must improve. I would like to know why the doctors were so reckless in my treatment when I was an infant. Overall, I think the whole process should be easier, as everyone who's been infected and affected by contaminated blood and blood products have already suffered enough from the ineptitude of our doctors.

### **Anonymity, disclosure, and redaction**

34. I do not wish to apply for anonymity, and I understand that this statement will be published by the Inquiry.

**Statement of Truth**

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

GRO-C

Signed.....

10.11.22

Dated.....