

Witness Name: Simon Downs

Statement No: WITN0093001

Exhibits: 0

Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SIMON DOWNS

I, Simon Downs, will say as follows:-

Section 1. Introduction

1. My name is Simon Downs. I was born on GRO-C 1965. I currently live at GRO-C West Sussex, GRO-C I have been married for 25 years and have two children, aged 23 and 26. I have worked as a Service Advisor for a Peugeot dealership for the past 30 years.
2. I prepare this statement in relation to contracting Hepatitis C, having received contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

4. When I was two years old, I accidentally ran into a fireplace which knocked out two of my bottom teeth. Soon after I was taken to St Thomas' Hospital and

diagnosed with Haemophilia A. No further information was provided to my parents at the time.

5. Despite my diagnosis, up until the age of 16, I felt well. I had begun my dream job as an apprentice at a mechanic's garage and I appeared to be in good health. I used to play rugby, run cross country and went to the gym three times a week.
6. In or around 1981, I began to experience recurrent pain in my knees and went back and forth to St Thomas' Hospital. I was advised that I would have to wait until I turned 18 years old, when my bones had grown fully to perform corrective surgery.
7. Finally, in 1984, I was admitted into hospital for tibial tubercle advancement surgery, which was performed by surgeons, Dr Mike Smith and Dr Cramer. The senior haemophilia doctor whose care I was also under was Dr Savage. In 1984, I went into hospital a fit 19 year old and I left as an old man.
8. The procedure lasted seven hours and as it was such a major operation, I was told that I would be off work for a few months and would have to learn how to walk again. I stayed in hospital for a total of eight weeks to try and recover.
9. In the days leading up to and following the operation I was given Factor VIII concentrate once, sometimes twice a day. I knew what I was being given, but I did not know that it was contaminated, nor was I ever made aware of any risks of taking it. All I knew was that it was to help my blood clot.
10. I worked out that I was given around 69,000 units of Factor VIII concentrate, which would have been about 45 doses. Quite obviously that would mean there was a pretty good chance of being infected with Hepatitis C!
11. Prior to this surgery, I was given Factor VIII concentrate for spontaneous bleeds and was always given this at St Thomas' Hospital as we were not

allowed to have it at home in the early days. I believe I was treated in this way around four times a year.

12. Around four weeks after the operation on my knee, I started feeling very unwell. I was unable to eat and I kept on being sick. I was told that I only had a bug and needed to stay in hospital for another two weeks but would be allowed to go home for the weekend for a break. I went home on the Friday night and woke in the morning having turned bright yellow from head to toe.
13. My mother was a nurse, so she assumed it was jaundice and took me back to hospital straight away. I endured an entire day of horrible tests and eventually left in a room alone that was labelled 'biohazard'. Anyone who came to see me would be covered up in suits and gowns and would not tell me a single thing. They installed cameras everywhere and administered numerous injections and blood tests, before I was put into isolation. I spent a total of four days this way.
14. My mother came to the hospital and demanded to know what was wrong with me, to which she was told, they believed I had Non A Non B Hepatitis, but they weren't sure how it was contracted. They repeatedly asked if I had been on holiday to any foreign places. My mother was very annoyed that I had been put in isolation and not given any information for so long.
15. A Haemophilia nurse came to me and told me that she thought I had Hepatitis. I didn't know what it was but she explained that I might feel a little rough for a few weeks and so I should avoid fatty foods and alcohol. I was 19 years old and so, at the time, this wasn't good to hear.
16. For ten months I just felt like an old man; I was living with my parents and I couldn't even walk to the end of the road. I was sleeping for around 18 to 20 hours a day. I would wake up, maybe have some soup, then go back to sleep. I feel like I have spent my life asleep. I lost around 15kg in about three months just from not eating.

17. No treatment plans were ever discussed with me and no advice was given on how to manage my condition. I was given no information about the risks of transmission either.
18. I had previously agreed that, in May of 1986, I would undergo the operation to have surgery on my right leg, which remained outstanding.
19. Again, when I had the operation, I had no knowledge that the blood was infected and so I was given 56,000 units of Factor VIII concentrate in that surgery. On this occasion, I stayed in hospital for about 11 weeks.
20. Also this time, I was given dietary advice to follow. I was to have no food with fat on it, no red meat or bacon, only skinless grilled sausages or jacket potato and beans. Things like Christmas roast had too much fat. I stuck to this regime and did not have alcohol from the age of about 19 until the age of 28; I was terrified to.
21. In 1986, the Sister from the Haemophilia Centre came back to see me and said, 'oh dear it looks like we have given you Hepatitis again' and then laughed. My older brother was beyond furious and shouted at the Sister, asking "how can you laugh at him?" She laughed and said, 'well you know the routine.'
22. On Christmas Eve, in 1992, I went for a blood test as part of my six month check up when the doctor requested to speak with me. This doctor was called Dr. GRO-D and had been my haemophilia doctor for around a year. I was told my liver was in a horrible state and that there was a pretty good chance that I wouldn't make it to 50 years of age.
23. After being told this however, I was advised of a new experimental drug trial for which they needed one more participant. They already had three people and needed a fourth in order to start the trial. I was told I would be one of only four people in the entire country who would get to try it and would be on one trial for two years. They weren't able to tell me what it did because it was new but I was told that I would have to inject the treatment into my stomach three

times a week and that it would give me flu like symptoms everyday for 24 hours.

24. I felt that I had no other option as I was told it may extend my life. They gave me no other information and nothing to even read. I was just simply told to come back next week and I would be shown how to administer it.
25. After the two year period, they stopped the treatment without any warning and without saying a single thing to me. They told me that the trial was over but they couldn't say why it had stopped. I never found out the reason and all mention of this is missing from my notes. I was told that my liver had improved a little.
26. Following on from this, in or around 1994, I kept complaining about pain under the right hand side of my ribs and so I went to see the consultant, Dr Thomson, who I saw for about a year. He gave me various pills and again said that I should be having no fatty foods and not be drinking any alcohol. Again there was no advice regarding risks of transmission. They said there was nothing more they could do.
27. Every time I go to hospital now I complain about being wiped out and tired all the time. I am still suffering from this fatigue, even as recently as last month. I go to bed at about 8pm and on weekends I have a four hour nap in the daytime too.
28. They keep saying it is nothing to do with Hepatitis but that I have low iron levels. They do not know why my count is so low. I am sure it is to do with Hepatitis but the doctors adamantly deny this.
29. The doctors tell me I am free of the virus but that I do still technically have Hepatitis C, because the levels are so low. I cannot get a mortgage or insurance despite this. I was told that I had cleared the virus in 1995, following Interferon treatment.

Section 3. Other Infections

30. I was also infected with Hepatitis B, and exposed to variants of Hepatitis A, D, E and G.

31. I am still suffering with exhaustion.

Section 4. Consent

32. I do believe that I was tested and treated without consent.

33. Apart from Interferon, I was never told a thing about anything to do with blood products, Hepatitis or anything else related to the matter. No information was ever provided.

34. I do believe that I was used for research purposes, as I was given a trial drug for treatment; Interferon. I am sure that they tested everyone's blood before but I cannot prove it. All reference to the trial is missing from my notes.

Section 5. Impact of the Infection

35. I struggled mentally following my diagnosis. I became a recluse because I couldn't go out as I was always tired. You find your friends do not knock on your door so much when they know that you have Hepatitis C; they thought they would catch it from me.

36. I was in a relationship at the time, but as soon as she found out about my condition, she dropped me like a hot potato. My infection ruined it all.

37. I was in the third year of my apprenticeship and had passed my exams, when I had to drop out because I was just so exhausted all the time. It was always my dream to be an F1 or rally mechanic and it was all taken away from me. I gave it all up before my fourth year, which was the most important one.

38. Although my work place was great with it all, they said that it was too expensive to pay to put me through college, so I was dropped as a technician.
39. Physically, I lost a lot of weight due to the infection. It ruined my life. I went from being a fit 18 year old, to effectively an old man, in such a short space of time.
40. My personal life changed dramatically, because you do not go to the pub when you cannot have a drink. I really just shut myself away in effect. I told my close friends whom I trusted at the time about my infection but they didn't know much on the subject matter and just assumed it meant that I had AIDS.
41. My relationship with my wife was greatly affected because of my diagnosis. I met her about 30 years ago; prior to my Interferon treatment and I chose not to tell her about my infection until about a year after we began dating. GRO-C
GRO-C and although she was shocked to find out, she still stuck with me. My mother, being a nurse, also spoke to her and explained it all. We were still unsure about how or if the infection could be transmitted and nothing was ever said to her about any risks during her pregnancies. There was just no aftercare.
42. I believe I suffered from stigma due to this infection, as I would have to declare it on any job applications and they would then ask me if I took drugs and if whether I had HIV.
43. Whenever you go to see a doctor for the first time they instantly just assume you are a drug addict.
44. It is easier to talk about Hepatitis C now but it has taken about 30 years just to make it a little more comfortable.

Section 6. Treatment/care/support

45. I have been faced with many difficulties in obtaining treatment as a direct consequence of being infected with Hepatitis C; especially with dental work.

Surgeries would never call me back after I enrolled with them and would tell me it was due to a full list of NHS patients already registered with them. When I offered to pay they still refused.

46. In 1995, I fell over and broke a tooth. I went to Guy's Hospital and the dentist exclaimed that I had not had my teeth checked in ages; I believe it was around 15 years by that point. When he found out the reason he just said 'I am not having that'. He was very good and administered treatment.

47. I feel I have had to push very hard to get liver scans as the hospitals just won't do them. I try and get them to do the scans at least once a year, but even that is a struggle. I am convinced they are lying to me about why I am still tired constantly and my wife feels the same way. The response I get is 'oh we will see in a year'. When I told them I am going to the Inquiry, they suddenly said they will see me in an hour!

48. In April 2019, I was offered counseling. I was offered two sessions at St. Thomas' Hospital but I had to call them and explain that I work, so cannot adjust to their timings. I received the letter on a Friday, for two appointments on the following Monday and Wednesday. Their response was 'well the sessions are there if you want them.' I just said that it is about 30 years too late. I have never been offered anything else and feel like I have been left to deal with it on my own. I've just learnt to get on with life.

Section 7. Financial Assistance

49. In 2000 I was speaking to a friend and by chance I found out about the Skipton Fund. They asked when and how I got Hepatitis C so I explained to them that it was through Factor VIII concentrate. They told me to fill out some forms which were about 30 pages long but I did not hear back from them for a year.

50. When I finally received a response they told me that, because I work, I would be entitled to significantly less. They also asked if I had cirrhosis and when I

said no, they advised I could receive £20,000 as a Stage 1 lump sum payment, but they stressed that this was an ex-gratia payment.

51. After this, I heard nothing for 10 years before they sent more forms to fill in and said that it would give me an extra £100 a month.

52. Since then, the payments have changed and they now come from EIBSS and I received £1,000 a quarter, which went up to £1,500 a quarter since the Inquiry began. To me, it looks like they know they are in trouble.

Section 8. Other Issues

53. I would like the Inquiry to find out who originally organised and authorised purchase of contaminated blood from America, knowing that it was not heat treated. They knew in 1979 that the blood was dodgy but they kept giving it out to everyone anyway. I want to know why this was done and who signed off to buy it; it must have been someone really high up to organise this all.

54. My children are growing up and I have missed out on so much already. If I am asleep now, they know why I am tired, but in the 1990s they couldn't understand and just say 'oh Dad's asleep again'.

55. I really would like the opportunity to tell my story.

56. I spoke to Sir Brian when I was at the Inquiry and explained that I was upset I had not been able to give evidence just yet. I explained that all of this ruined my life and he said that I am not alone. He assured me that the process will be thorough and long, to which I responded; "I have waited 35 years so I can manage a few more."

Anonymity

57. I do not wish to apply for anonymity.

58. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

GRO-C

Signed.....

Dated.....

14/8/2007