

Witness Name: Sajid Ahmed
Statement No.: WITN3471001
Exhibits: WITN3471002-003
Dated: 2 August 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SAJID AHMED

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 July 2019.

I, Sajid Ahmed, will say as follows: -

Section 1. Introduction

1. My name is Sajid Ahmed. My date of birth is GRO-C1967 and my address is known to the Inquiry. I am married and have two children, one daughter and one son. I formerly worked as a taxi driver on and off for 20 years. I intend to speak about my infection with hepatitis C (HCV) through blood transfusions. In particular, the nature of my illness, how the illness affected me, the treatment I received, and the impact it has had on me and my family.
2. The ways in which this statement will be used by the Inquiry have been explained to me. It is important for me to get my story out there in full, and as a result I do not wish to be anonymous. The right of reply process has been explained to me; I understand that any individuals or institutions I criticise in this statement may be notified.

3. I have chosen not to be legally represented and I am happy for the Inquiry team to assist me in drafting this statement.
4. One of the effects of the hepatitis C and the treatments I have received is that I experience some memory fade. Because of this, and because of the normal passage of time, I cannot be completely sure of the accuracy of some of the dates and specific details that follow. They are correct to the best of my recollection.

Section 2. How Infected

5. While my mother was pregnant with me, she and some of my siblings moved from the UK to Pakistan to oversee the building of a house. Within 3-4 months of my birth, it became clear that I was a sickly child. I was always crying and being sick, my stomach was bloated, and I was always tired. My mum took me all over the country to try and find out what was wrong with me, visiting hospitals and faith healers, but nobody was able to establish what was going on.
6. When I was 18 months old we moved back to the UK, joining my dad and older brothers in Nottingham. Shortly after our arrival I was admitted to Nottingham Children's Hospital. I was diagnosed with Thalassaemia Major, a blood disorder which means my body cannot make its own red blood cells, resulting in severe anaemia.
7. To treat the Thalassaemia, I started having to go into hospital to receive blood transfusions every three to four weeks. To this day I have blood transfusions every three to four weeks and will for the rest of my life. It was in 1969, when I was between 18 months and 2 years old, that I received my first blood transfusion.
8. Exhibit **WITN3471002** is a letter dated 14 September 1993 which demonstrates my transfusion and treatment regime for the Thalassaemia.

9. The blood transfusions enabled me to have a normal childhood. I don't remember my early childhood, but I remember that from the age of 7 or 8 I would feel fit, healthy, and full of energy after having a transfusion. Then, towards the end of the month when I needed another transfusion, my energy levels would start to deplete and I would feel tired. Having a transfusion would reset the clock and I'd feel full of energy again.
10. I played a lot of football and was in the school gymnastics, rugby, and cross-country teams. I remember being part of a gymnastics display we put on for the Queen's jubilee. Even when I would get toward the end of the month and start feeling tired I was able to participate in these activities, although I wouldn't perform as well. For example, in cross country I would usually come second or third right after a blood transfusion, but perhaps ninth or tenth at the end of the three to four-week cycle.
11. In 1980, when I was 13 years old, we moved to Bedford for my dad's work. From ages 13 to 19, I was under the care of the paediatrician Dr Barnes at Bedford General Hospital. It was during this period that I noticed a change. I wasn't as fit as before. I felt tired all the time and didn't have as much energy, even after my transfusions. Other boys were growing physically bigger and stronger, but I wasn't. I was around four foot eleven – probably the smallest boy in my year.
12. I was also suffering from chest pains. On a few occasions I was admitted to hospital but we never got to the bottom of what was going on. I also started to get depressed. I didn't want to go to school or get out of bed, and I was always thinking about what was going on with my health. I missed a lot of days of school.
13. For my Thalassemia, I had to go in to the clinic to get cross-matched a week before each transfusion to make sure I was given the right blood. When I went in for my transfusions, I also had to take the drug Desferrioxamine in order to get rid of excess iron in my system from the blood transfusions. My ferratin/iron levels were sky high, and this was

stunting my growth, so it was a very important medication. At first, I was receiving this through muscular jabs, which were very painful. Then, at some point, I switched to a tekmar pump and cannular drip, which meant I could receive the drug while I was being transfused.

14. When I was about 16 years old, one of the locum doctors who was transfusing me told me that people with my condition should get the Desferrioxamine through subcutaneous injections under the skin in a 12-hour infuser, five days a week. I was only getting treatment once every three to four weeks when I had my transfusion, and when I was at home I was getting nothing. The locum Doctor said I should ask Dr Barnes for my treatment to be changed. I didn't understand this very well, so when I tried to talk to Dr Barnes about it, all he did was change the pump with which the drug was being given to me at my transfusions. I do not think Dr Barnes followed the basic treatment protocol for my condition.
15. Over this period, I am not sure how much I discussed my worsening symptoms with Dr Barnes, although I answered any questions he asked me. He wasn't asking that many though, it was just a routine – come in, get it done, and see you next time.
16. At age 19, I stopped seeing the paediatrician and was put under the care of Dr Howes, a consultant haematologist at Bedford General Hospital. He introduced me to the subcutaneous infuser the locum doctor had told me about years before, and sent me down to Northwick Park Hospital in Wembley in 1985 or 1986 for a week to learn how to use it. I am grateful he did this, although I was going through a rebellious phase and wasn't very interested in getting on with learning how to use it. It was very painful, and I had lots of problems with it.
17. During this period I was experiencing a lot of fatigue. I remember there was a time in 1985/1986 when I was going to the gym and managing to go for short runs. Then, in 1986/1987, it got so bad that I couldn't run at all or lift any weights. I still wasn't growing properly, probably because of my raised iron levels: I was around five foot two by the time I got to my

20s. I was becoming increasingly depressed about my health and wellbeing, overthinking things to the point that I couldn't get to sleep at night or get up in the mornings. I was working in a plastics factory at the time, but found it increasingly difficult to do my job. I decided to move into taxi work, so I better could manage my own hours.

18. I can't recall whether I discussed these symptoms with the doctors at the hospital. I never went to my GP because I was always in the hospital for my Thalassaemia care. I feel that I should have been tested to see what was wrong with me.
19. In early 1991, my sisters were reading a women's magazine and saw an article about the Thalassaemia Society. I went down to their offices in Muswell Hill in London. They recommended I see a doctor called Dr Wonke, who was a haematologist at the Whittington Hospital in London.
20. Dr Wonke was a complete breath of fresh air. When I went to see her for the first time she just looked at me and said "*You're still alive?*". She was completely surprised I was still living. I could see where she was coming from, but at the same time I was shocked, and this was probably the kick up the backside I needed.
21. She carried out every test under the sun on me. Within a year under her care I found out I had type one diabetes, severe myocardial iron loading, gonadal failure, osteoporosis, and genotype 1B hepatitis C. Exhibit **WITN3471003** is a letter dated 28 August 2003 which lists hepatitis C as one of my diagnosed illnesses.
22. By the time I was diagnosed with hepatitis C, I estimate I had had around 300 blood transfusions. Usually I had three units of blood, sometimes four, so in total probably around 1000 units of blood. It is my belief I was infected through my blood transfusions. I could have been given multiple infected transfusions, I just don't know. I think back to when my health started deteriorating in my early teenage years and wonder whether that

was when I was first infected. I am still in the dark as to how many years I have been living with hepatitis C.

23. My memory of being told I had been infected is quite fuzzy. To the best of my recollection, it was Dr Wonke who told me. She said that I had hepatitis C, which is an infection that can damage the liver. I think I was told about the risks of blood to blood contact with other people. I was told I could possibly pass it on through sexual activity, but when I told her I was getting married she said don't worry it will be OK. My wife has never been offered a hepatitis C test.
24. It is hard for me to say whether the information I was given was adequate. I was told face to face, and then I had to go away and deal with it myself from there. I don't remember being told anything about the symptoms of hepatitis C, or how to manage it, but I might have been.
25. I believe I should have been tested for hepatitis C long before I got to Dr Wonke. The problem with contaminated blood and transfusions was common knowledge in the medical world. I feel disappointed my previous doctors didn't bring the subject up before. They were dealing with someone who was having regular transfusions. As far as I am concerned the proper protocols were not followed.

Section 3. Other Infections

26. To my knowledge, I have not been infected with any other conditions through contaminated blood. However, there is so much going on with me medically, and I have never been told that my other conditions were not caused by contaminated blood or my hepatitis C. I have cardiovascular and gastronomical problems, as well as diabetes. I couldn't say what is to blame for these, although I have been told my diabetes might relate to an iron overload in my pancreas due to the Thalassemia.

Section 4. Consent

27. I do not believe I have been treated or tested without my knowledge or consent, but I can't be sure. At Whittington hospital they have always been up front with me and told me straight how things are, but I do not have the same confidence in the hospitals I was at before that. However, I don't think they were testing me without my consent: on the contrary, my concern is that I wasn't tested when I should have been.

Section 5. Impact

28. When I was younger and found out about the hepatitis C, I had to take a step back. I wasn't comfortable dating. AIDS was everywhere in those days, and it made me think that hepatitis was similar to that problem. Because of the stigma attached to hepatitis C, it is never something that I have been able to talk to people about. I know what people would say, what their reactions would be. People would assume I'm a drug addict or alcoholic, and might not want to mix with me and my family. As a result I don't really socialise at all, and haven't done for years. Outside of the house, I only do what I need to do, like taking my son to his football and cricket matches. I just spend time at home with my kids.
29. I try not to think about it as much as I can, and that is probably one reason I have forgotten so much about what happened. When the people from the Inquiry came to interview me for this statement, I was able to talk to them because they were a couple of strangers – it's much easier to talk to strangers about it than people you have to see every day.
30. I haven't even really discussed it with my family. They all know I've got hepatitis C, but that is all, we haven't gone any further. My wife is supportive, she is there for me whatever happens, but I don't even talk to her about it. If she does worry about the future, she doesn't speak to me about it. I do the worrying. I'm worried that I won't be able to see my

kids grow up, get married, and supporting themselves in jobs. I worry about their futures.

31. In terms of mental effects, the hepatitis has made me depressed at times. I have good periods, but there are more bad periods than good periods. You can forget for a few minutes, but it is always there at the back of your mind and it brings you down. My mood swings impact on those closest to me. I take my anger out on them, and if there are any issues they are the first ones in line for it. The older ones understand what I'm going through and probably take it into account. Nevertheless, I have fallen out with most of my extended family members, so I don't see them very much. My children go around to see them without me.
32. As mentioned above, I missed a lot of school because of my health problems, especially in my later school years. When I was at school, my concentration levels were not that great. I feel very disappointed that I missed out on going to university or doing any kind of further education. My tiredness and concentration levels stopped me doing these things.
33. I would have followed a different career path but for the hepatitis C. I wasn't thick – I used to read a lot – but I started to find it difficult to concentrate, and still do to this day. When I went into the workforce my attendance issues continued. I had to take a lot of sick days, and this is one of the main reasons I ended up in taxi work.
34. Until I started to receive funds from blood support schemes (see section 7), I always struggled financially. We always lived in council flats. When I did eventually manage to buy a property, it fell into negative equity because of the policies of the Thatcher government, so I had to let that property go. We lived in rented accommodation after that until I was able to buy my current property with funds from the blood support schemes. Without that, I would still be in rented accommodation and on the poverty line.

35. I have been on benefits for the last seven years, and haven't been able to go back to work. Even on the benefits, they keep changing, and it becomes a bit harder each time. I would love to go back to work and do something to get me out of this boredom, but I find it hard to go back to the jobs I used to do. When I was taxi driving, I was getting bullied, other drivers pinching my work and things like that. I tried to raise it with the Council, but they didn't do anything. The other drivers blamed me for the problems, and the Council listened to them more than me.
36. As discussed above, I am unsure how many of my health problems are connected with the blood transfusions and hepatitis C. In 1995 I became very ill and was admitted to hospital for three months. I had been on holiday in Pakistan, and started feeling ill in the final week. When I got on the plane to fly back home I started bloating, and the day after I landed I went to Whittington hospital. They thought I had heart failure or maybe liver failure. I was transferred to the Royal Free Hospital, which is a liver specialist hospital, and was seen by Professor Geoffrey Dusheiko. They did all sorts of tests, and didn't know what was going on with me. I wasn't told anything other than that I might need a liver transplant.
37. Over the three months in hospital I went down to six stone from around nine stone. My brother was in Pakistan at the time and they said I should call him over because they weren't sure that I would survive. I did survive, and I'm not sure they ever worked out what was wrong. Since then I have had ongoing liver care from the Royal Free Hospital as well as through Whittington.
38. I have had two biopsies that have shown I have cirrhosis of the liver as a result of the hepatitis C. The first was on 26 February 1992 at Whittington Hospital. The second was around 2007, also at Whittington. I do not remember the first. The second, I remember that the nurse gave me an injection to numb the area and then the needle just went bang, straight into the side of my body like I had been punched. A student doctor fainted when she saw that and I just felt like the wind had been taken out of me.

39. I suffered severe side effects to the first and second courses of treatment I received. These are discussed below in section 6.
40. I have not had any problems accessing dental care. My dentists have always treated me just like everyone else even though I have always declared my hepatitis C status.

Section 6. Treatment/Care/Support

41. I have been through three courses of treatment for hepatitis C. The first was a three-month course of Interferon in 1992. Someone from Dr Wonke's team told me about this new treatment, and that they would like me to go on it. They told me it would make me very tired, and explained the other side effects, although I can't remember exactly what they said. Because of the memory fade I can't really remember the treatment regime, although I think I was going into hospital every one or two weeks for blood tests.
42. The Interferon left me feeling completely whacked. I couldn't work. I couldn't get out of bed. I couldn't do anything. I was living in my own flat at the time by myself, but my mum had to come around and bring food because I couldn't really look after myself. I lost my appetite, and my hair thinned.
43. After I finished the three months of treatment someone from Dr Wonke's team informed me it had not cleared the hepatitis C.
44. My second course of treatment was of Pegylated Interferon and Ribavirin in 2003. I had a consultation with Dr Wonke and she said other people had tried this treatment and it had worked for them so I thought I had best give it a go. Again, it was a three-month course, but other than that I cannot remember the details.

45. I experienced very similar side effects to the first course: headaches, tiredness, depression. I felt like rubbish, wasn't able to work, and found it difficult to get out of bed or out of the flat. At this point I was married, and my wife told me to stop the medication because it was making me so unwell.
46. I completed the treatment, but again, Dr Wonke told me that although it had reduced the viral load, it hadn't cleared the virus.
47. I was offered further similar treatments in the following years but I declined them all. Enough was enough. I felt so demoralised after the treatment failed twice, especially because I knew I just couldn't do it again.
48. In early 2016, a Doctor at the Royal Free Hospital (I think it was Dr David Andrew Miller) spoke to me about a new treatment called Telaprevir AbbVie 3D. He said they had tested it on people and it was working, and that it might work on me too. It was just a tablet and I was told there wouldn't be many side effects. I agreed to take it and the Royal Free sent a letter to Bedford General Hospital asking for me to be put on their programme. Bedford General never wrote back, and so I ended up getting my medication and follow up appointments from the Royal Free in London.
49. I completed the course of treatment without suffering any side effects. When it finished, I went in for blood tests every two to three weeks to check whether it had worked. They tell me it's all clear, and it has been that way since after the first month of treatment. I still go in for regular checks to make sure the hepatitis C hasn't come back.
50. I have never been offered any psychological assistance to help me deal with the hepatitis C. I was offered to see a clinical psychologist when my father passed away in 1995, and I went for a while. I think some sort of psychological assistance around the hepatitis would have helped.

51. When interviewing me for this statement, the Inquiry Investigator referred me to the British Red Cross counselling service. I am still deciding whether to use this or not.

Section 7. Financial Assistance

52. I first applied to the Skipton Fund in 2004 after one of my Doctors told me about it. I was given a stage one payment of £20,000 on 2 November 2004 and later a stage two payment of £25,000. Since then I have received ongoing financial payments from the Skipton Fund, which then became the English Infected Blood Support Scheme in 2017. Until recently I was getting £1,800 a month, but now it has gone up. I worked it out that I now get about £27,000 annually, plus a winter fuel allowance.
53. I found the initial process of applying quite easy. Now I have to fill out a form every year for the top-up payments, which is also quite easy when I have all the necessary paperwork. I know there are other things I can apply for, like the cost of travel to and from the hospital and improvements to the house, but I don't really apply for these as I do not understand the process. I usually drive to my hospital appointments, which are about 56 miles each way. I used to claim these costs against my sickness benefit, but I found that when I did I really had to fight them for it so I don't claim it any more.
54. When I look at some of the letters from the Skipton fund I see the words '*ex gratia*'. I understand this to mean '*without responsibility or fault*'. I feel gutted about this. It's like they've done it to us once, and now they are doing it to us again. This time they are putting money in our pockets, trying to wriggle out of responsibility. It took them so long to start giving some sort of compensation, but now they don't want to take on any blame for what they have done. They are trying to avoid paying proper compensation for what they've done.

55. I don't spend a lot of money; we only go on holiday once every few years. I feel I can't spend a lot of money because there will be nothing left for my children's futures. I feel that the ability to earn a future for them has been taken away from me. The government should pay proper compensation, because they were the ones importing the blood from America. All they are doing is dragging it out so that most of the people infected will have passed away and they won't have to pay much out. Now that I am in my 50s, I feel like I don't have much time left. The amount they were giving at the beginning was just the bare minimum. Now they have topped it up, but it is still not on par with what most people earn.

Section 8. Other Issues

56. I feel disgusted that the government didn't tell people they had this illness when they knew they were bringing contaminated blood in. They kept quiet, and nobody found out until it was too late and the illness had already taken hold. They did not do the proper tests and try and treat the illness in the early stages. Then to give us shoddy ex gratia payments has added insult to injury. It is time that the government settled this once and for all before many more people lose their lives because of this illness. I feel the doctors have a part to play too, as they were well informed but they never treated people properly and with dignity.

Statement of Truth

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

Signed GRO-C

Dated 8th August 2019