Witness Name: Mark Shaw
Statement No.: WITN4999001
Exhibits; WITN4999002-6
Dated; 27/10/21

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARK SHAW

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 March 2021.

I, Mark Shaw, will say as follows: -

Section 1. Introduction

1. My name is Mark Shaw. My date of birth is GRO-C 1964 and my address is known to the Inquiry. I have recently moved back to Manchester with my partner of 17 years, Colette Poole.

2. I intend to speak about my infection with HCV, transmitted via a blood transfusion. In particular, how I came to be infected, the nature of my illness, the treatment I have subsequently received and the impact it has had on my life.

3. I am not legally represented and I am happy for my story to be in the public domain, having had the anonymity option explained to me. I would like to point out that I am making this statement without reference to my medical records and dates, names and timings should all be taken as approximates.

Section 2. How Infected

4. In the 1980s, my parents spent some time living in Greece and I also travelled there to work for a period in 1987-88. I ended up with tonsillitis whilst visiting my parents in Athens. My father suggested that I go to an American-run hospital in Athens, but my mother had experienced problems there during previous visits, so it was agreed that I would return to the UK and attend the Bolton Royal Infirmary (BRI).

5. I had my tonsils removed in an operation at BRI – the doctor said that my tonsils were rotting away and were almost falling off. I was sent home from the hospital after two or three days, but I felt that something wasn't quite right. Round about four days after the surgery, I was reading a newspaper and suffered a coughing fit and spat loads of blood out onto the pages. I was a bit shocked by this and immediately went back to BRI. It turned out that they had failed to completely sew up the site of the surgery.

6. I needed to undergo further corrective surgery and required a blood transfusion for this subsequent procedure. I exhibit here (**WITN4999002**) a letter, dated 29 November 1988, which notes that I received a transfusion and was then discharged a week later.

7. I do not recall actually consenting to the blood transfusion and I was certainly not given any information in relation to any potential risks such a procedure may hold.

8. However, there was still something not quite right. I just didn't feel the same and developed strange symptoms almost immediately after the surgery. My skin was a strange yellow colour for a long time. I would get tired very easily and struggled to focus on anything. I was working as a chef at the time but I wasn't able to hold down a job for a prolonged period of time – after two hours in the kitchen, I was shattered – no use in a busy physical environment.

9. I went to see a doctor and they just told me I was working too hard. I was young at the time, so I was partying and socialising a lot – the doctor basically said I was burning the candle at both ends. I got my hours at work reduced, but I still couldn't handle it. I joined an agency to get part time work instead. My last job was as a senior sous chef in 1996. When I left this role, I moved to London to seek work there.

10. I wasn't able to find work in London and ended up living on the streets for a period. This was a traumatic period of my life and I will limit my recollection of this period to the relevant events. After about six months of being homeless, I was assigned a Community Aid Worker, Emma Brown. Emma helped me sign up to a doctor's surgery, which was part of Gordon Hospital on Bloomsbury Street. Some nearby hostels required residents to have a full health check, including STD tests and so on, in order to be admitted. So, these tests were undertaken at Gordon Hospital.

11. A few weeks later, I was informed by them that I was infected with HCV. I had gone back by appointment. I remember the doctor, a young French woman specifying that I didn't have AIDS or anything else, just Hepatitis C! She didn't know a lot about the disease and neither did I but I was aware it was serious and you have to remember, this was all on the back of the AIDS epidemic and I was terrified. I thought it may be something fatal. There wasn't much information given to me at that point. I was pretty much left to it.

12. Two or three weeks later I was referred to Chelsea and Westminster Hospital, under the care of Dr Meg Matthews. She sat me down and gave me a lot more information on the infection and its impact – risks, dietary advice, precautions to take and so on.

Section 3. Other Infections

13. To my knowledge, I have only been exposed to HCV as a result of my treatment with a blood transfusion. I was tested for HIV and this was

negative. I have had no other major operations, have not been treated aboard and have no tattoos or piercings.

14. I have used intravenous drugs on only a single occasion but this was after my diagnosis with HCV, so it cannot have been the source of my infection. I will detail this experience below, at Section 6.

Section 4. Consent

15. Though I did not specifically know that I was being tested for HCV and could therefore not give specific consent for this particular test, I did consent to the whole range of tests being undertaken at the Gordon Hospital.

16. I have always consented to the limited treatment provided to me for my infection, which I will detail further in the following section.

Section 5. Treatment/Care/Support

17. I have only been offered a brief course of treatment around 1997 administered by Chelsea and Westminster Hospital shortly after my initial diagnosis. It was a course of Interferon treatment, by tablets if I recall, although I can't remember how long it was supposed to last. I know I was in the hospital for two weeks of tests and then I picked up the prescriptions at my GP for the next few weeks. During the tests in hospital I can remember one of the doctors telling me that HCV was so serious I would be lucky if I saw 50 years of age.

18. Approximately nine months after my diagnosis, Emma Brown helped me to find a flat in London. She managed to get me a place in Hackney, which meant that I could no longer be under the care of Chelsea and Westminster Hospital. Although I had started the trial by this time, Emma told me that I would no longer be able to access the funding necessary to pay for the treatment and so my participation in the trial ended.

19. When living in Hackney, I went to see a hepatologist in Homerton University Hospital, but I never heard back from them after the appointment. It does feel like treatment was denied to me when I lived in London – I always had to initiate it. It felt like they intentionally wanted to move me away from Chelsea and Westminster as I wasn't priority. I don't understand why the treatment I had started there could not continue just because I had moved boroughs – and through no fault of my own.

20. The most effective treatment I recall having was actually acupuncture. An Italian girl from Brixton would come and give it to us when I lived in Hackney and it did help with some of the symptoms.

21. In around 2002/3, I moved back to the Manchester area for a while and had a liver biopsy at Whitley Road Medical Centre in Collyhurst. Unfortunately, I cannot recall the outcome of the biopsy. Around this same time, I also attended Manchester General hospital and received treatment for ongoing psychological issues as well as being seen in relation to my infection. Unfortunately, I don't recall a great deal about the outcome of my HCV consultation during this period.

22. Before moving back to Manchester again very recently, I lived in Chatham, having moved there in September 2008. I was contacted by Maidstone Hospital in 2017 and they offered me another course of treatment. I think this was after I had visited my local dentist. My teeth were in a bad state of repair – actually rotting away due to my infection. He wanted me to go to the hospital for treatment and must have passed them my details. I went to see the haematologist a few times and the medication was organised. I was monitored every three to four weeks there. By 2018, I was ready to begin the treatment, but then my partner, Collette, had a major breakdown due to a heart condition and I decided not to go ahead with it – the potential side effects meant that I may not have been able to care for Collette.

23. I have never been offered any counselling or psychological support as a result of my infection. I do, however, believe that this may have been

offered had I gone through with the treatment at Maidstone Hospital. They were very understanding and I do think that they would have offered this kind of support.

24. I don't recall having any issues when accessing dental treatment as a result of my HCV. I had an operation on my finger back in 2009 and I remember being completely isolated from other patients. However, I vaguely remember there being concerns about MRSA at the time, so it could have been that albeit it was only myself that was isolated.

Section 6. Impact

25. The impact of my infection with hepatitis C has been severe and wide-ranging. In order to accurately cover the totality of the consequences that I have endured since becoming infected, I will use the following sub-headings in this section: *a) Physical health, b) Mental health, c) Work life and finances, d) Family, friends and relationships* and *e) Stigma*

a) Physical health

26. I was very healthy in the early years of my life. I have had problems with my eyesight since I was very young and broke my arm at 15, but was generally in very good physical health. But since my infection with HCV, I have suffered from a range of physical symptoms and my overall health has been hugely impacted.

27. I get rashes very easily and seem to have a broad sensitivity to many different things – bright light, certain foods, chemicals and so on. My skin bruises and cuts very easily. I have a persistent 'brain fog', that prevents me from concentrating on anything for an extended period of time. For years, I have suffered with these symptoms, as well as night-sweats and terrible headaches.

28. One of the most debilitating aspects of the HCV is the impact that it has on my mobility; I feel like I am constantly exhausted. I can't even go down to the corner shop without becoming completely wiped out. I can

sometimes stay in bed for days on end, too tired to even eat or drink. I also struggle with food in general, finding it very difficult to keep it down.

b) Mental health

29. The impact that my infection has had on my mental health has been monumental. I have essentially been on antidepressants ever since my diagnosis, about 25 years ago. In all that time, I have not been offered a review of this medication. I am also currently on anti-psychotic medication. I can sometimes be very short-tempered and quick to anger, but I am able to control it.

30. Shortly after I was diagnosed, I'd say about a week later, I had a bit of a breakdown. I didn't want live anymore. I went and bought GRO-C GRO-C in an attempt to end my life. GRO-C GRO-C. The attempt failed but I remained in a terrible state for some time. I was drinking two litres of vodka each day GRO-C GRO-C, I was never hospitalised and I was out of it for around 48 hours before coming to in my room. I realised what I had done and tried to pull myself together. I spent about two weeks under voluntary section at Gordon Hospital around this time too.

31. Since that time, my mental state has improved a lot, but I still have lots of problems with it. I can get quite paranoid at times – I'll convince myself that people are looking at me and I think that they know about my infection. I always avoid people. I know they don't know, but I can't get that thought out of my head. I have very little self-confidence anymore. I am on Sertraline, which can sometimes make me slur my words and I am very conscious of this – people think that I am drunk.

32. It is difficult to put the impact on my mental health into strong enough words. It has completely devastated my life. This element of my infection has been further exacerbated by the other consequences, particularly the impact it had on my family life, discussed below.

c) Work life and finances

33. Before I was infected with HCV, I was a sous chef working in a great restaurant. I was bloody good at my job too. I got head hunted whilst working as an agency chef, after having done Ascot week at the Royal Ascot race meeting. I wanted to open my own café or restaurant. I even had a plan, a place I wanted to do it and everything. I was a very good chef but all my plans were scuppered by my diagnosis. There's no way I could do it now.

34. I haven't held a job since before I moved to London in the 1990s. I must have sent out over a thousand CVs, but nobody wants me. I have decided to always tell potential employers about my infection and so I think my honesty has got in the way. I think I have a duty to tell people – it's just who I am and I don't want to deceive anyone. I have asked my brother Robbie – he's in construction - to employ me a few times, but on every occasion, he has either said the other lads wouldn't have it or it's an insurance thing.

35. I have had a nightmare with the benefits system – the DWP have been really horrible to me on many occasions that I won't go into now. I once saw a judge and doctor whilst having an appeal against a rejected benefits application. This was held in Ashford in Kent. They were clearly embarrassed that the Job Centre had judged me to have perfect vision and as fit to work. I was born with blindness in one eye and was suffering with HCV! They actually apologised to me when they found in my favour.

36. I have actually managed to get life insurance through Sunlife, which I was quite surprised at. I have never applied for a mortgage – all my plans for the future, which included at the time having my own place, all went out the window basically.

d) Family, friends and relationships

37. I told my parents about my infection many years after my diagnosis and I think it broke them a bit. I had never seen my father cry until then. They were very upset that I hadn't told them before but they didn't shun me at all. It really affected them, but they were so sensitive and caring. My siblings, unfortunately, were not as understanding.

38. My parents sadly died shortly after I told them about my infection and I was left with the stigma shown to me by the rest of my family. I basically haven't spoken to any of my relatives since 2016. I have three sisters and two brothers – I am the youngest. I never really got on well with my eldest brother; he is a military man, very regimental. I had positive relationships with all of my other siblings, but I was completely isolated when the fact of my infection became known.

39. I have several nieces and nephews that I used to love spending time with. The last time `I spoke to one of them was with my nephew, whilst I was travelling to my sister's funeral in 2016. GRO-D GRO-D To hear that from a member of your own family is crushing. Some of my family can be quite snobby and want nothing more to do with me. They are successful and look at me and see that materially, I have nothing and they blame me for that. I don't even know where some of my brothers and sisters live now. It breaks my heart when I think of what I have lost. I have no children myself so the children of my brothers and sisters were special to me.

40. My HCV infection has also had a big impact on my romantic relationships. I essentially didn't have sex from 1992 onwards, mainly because I knew there was something wrong with me. I just knew that something wasn't right after that operation. I was so afraid of infecting someone that I didn't have a relationship for over a decade.

41. I am now in a long-term relationship that began in 2004, but I have no sexual drive at all. This is a direct impact of the phycological effects of

HCV. GRO-C
GRO-C

42. Collette is very understanding and all of her family know about my infection. They don't shun me because of it, but I can tell that it affects them. Some of them don't want to shake my hand or be too close to me in a room, which, to be honest, doesn't actually bother me too much.

e) Stigma

43. I have felt stigmatised and isolated as a result of my infection on many occasions. The most upsetting is the stigma I have experienced from my own family. GRO-D
GRO-D

44. In 2008, a neighbour of mine was round at my house and saw a letter from the Skipton Fund pinned up on a corkboard. The next day my windows were smashed in – people thought I had AIDS! It was a pretty rough area, but I was still surprised that there was that level of ignorance, in fact hatred towards people with certain illnesses. As soon as people find out they don't want to know you.

45. My sense of obligation around telling people about my infection has probably led to me being stigmatised a lot more than if I kept it to myself. When I lived on the streets, for example, I was assaulted many times when people found out about my HCV – simply for being infected. No other reason. The infection always seemed to be associated with AIDS and the violence was a way of pushing you away.

Section 7. Financial Assistance

46. In around 2008, I was told about the Skipton Fund, by whom I don't recall and sent off an application. I had huge trouble trying to get hold of my medical records, but did eventually manage to get a letter than noted my transfusion back in the 1980s.

47. I heard nothing back from them and so I assumed that I had been rejected. I did not see any point in appealing as I thought I had done what I could. I do not recall very much about making further steps towards applying for the Skipton Fund in the 2016 period but this appears to be the case from the records and I do remember trying to get medical records at one stage. I have been made aware that this application was rejected on the 17 August 2016 on the basis that there was evidence that I was an IV drug user between 1992 and 1995 and this was the likely route of infection. That letter dated 07.07.16 apparently came from my doctor at Maidstone Hospital, Dr Kwok. **(See Exhibit WITN4999003).**

48. This is totally wrong and I am at a loss to understand why this is on my records. I used drugs intravenously only once and this was after my diagnosis. The only reason then for injecting was that I saw it as a way of ending my life at the time. It therefore is impossible that this is how I came to be infected with hepatitis C. I have discussed my use of other recreational drugs with my doctor – as I have mentioned, I am open and honest with others, particularly medical professionals, and this may have led to some confusion when the application was endorsed.

49. I used this method to try and end my life because it was the easiest way for me at the time. GRO-C

GRO-C

50. I am not proud of what I did but I was in a very dark place at the time. I had nothing and now I was infected with a potentially fatal virus with no known cure. Ending my life seemed to be the answer. No one knows about this episode of my life except Colette, the doctors involved and my brother. No one else. I never talk about it.

51. In support of my position I would like to point out that there is a letter from my time under Manchester General Hospital dated 15.02.07 where the doctor notes my infection with HCV, genotype 1a and discusses

treatment with interferon. There is no mention made here that I was ever GRO-C **(See Exhibit WITN4999004)**

52. Furthermore, I have been made aware that the Skipton Fund apparently endorsed my original application for payment on 25.02.08. **(See Exhibit WITN4999005).** Why did it not go through? I have also been made aware that on the same day they sent me a request for further banking information. However, I do not recall receiving any request for this. Surely someone would have tried to contact me it that is all it was? Additionally, following a letter to my doctor at the Whitley Road Medical Centre dated 29.01.08, they were provided with a letter confirming my transfusion, **(See Exhibit WITN4999002)** as well as further proof of my HCV diagnosis. **(See Exhibit WITN4999006).** Both of these are endorsed as received on the day my application was 'approved', the 25th February 2008.As stated, I did move to Chatham in September of that year but that left plenty of time to contact me although, unfortunately, I did not leave a forwarding address.

53. I can't understand what happened. The Skipton Fund seem to have approved my application, having all the relevant papers they required except my bank details and it was just left at that. Approved, but not paid, so to speak. And then when I got back in touch in 2016, the letter from Dr Kwok has provided a reason to deny the application. Maybe there was another reason why I wasn't paid and if so I would like an explanation after all these years.

Section 8. Other Issues

54. I hate the politics of it all – it's not nurse's or doctor's fault that I was infected, but it feels like they see that I'm on benefits and just think that I am a bum. I know they didn't do it on purpose.

55. I would like to mention that College Health, my doctor's surgery in Chatham was difficult to deal with. When I approached them for my medical records in 2016 I was charged £40 which I paid. Having heard

nothing back from them, I went to the surgery and was told in no uncertain terms to get out. I was upset by their behaviour and complained to the Ombudsman although I heard nothing more from them either. The surgery did close down and the local rumour was that it was being investigated for fraud in relation to the numbers of patients registered.

56. Why on earth was the government buying this dirty blood or not checking it properly? That's a reasonable question isn't it? I appreciate the opportunity to speak with representatives of the Inquiry and would like thank those working on this matter. It is important that people like me get answers.

Statement of Truth

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

Signed GRO-C

Dated 27th October 21