

Witness Name: Mr David Skeen

Statement No.: WITN1972001

Exhibits: 0

Dated: 19 February 2019

**WITNESS STATEMENT OF MR DAVID SKEEN
INFECTED BLOOD INQUIRY**

Section 1: Introduction

1. My name is David James Skeen. My date of birth and address are known to the Inquiry.
2. I am divorced. I live alone in Nottingham. I have been married and divorced three times. I have four children; two sons and a daughter from my first marriage, who all live in Nottingham and one son from my third marriage, who lives in Newcastle upon Tyne.

Section 2: How Infected

3. On 18 August 1979; the last night of a family holiday in Great Yarmouth, I was attacked by an Oil Rig worker and stabbed seven times. I was rushed to the local Great Yarmouth Hospital where I was given an operation called a thoracotomy and received a transfusion of four pints of blood.
4. I did not become infected as a result of a relationship with another person.

5. I do not remember being given information about the possible need for a blood transfusion or the risk of being exposed to infection prior to the operation. I believe that this was because I was in and out of consciousness at the time. There was no-one else at the hospital at the time either so I do not believe that anyone else could have been told or consented on my behalf. My parents arrived at the hospital later; they have never mentioned anything to me about receiving a blood transfusion or about being told that there was a risk of receiving blood. When I became conscious I had to beg for information about my injuries, my scars and my treatment. I recall that I was told that I needed and received a blood transfusion during the surgery.
6. I was infected with hepatitis C as a result of being given contaminated blood; this is the only way I could have been infected.
7. In around 2008, I became aware that I had started to feel very fatigued; I was sleeping between 18 to 20 hours a day. This carried on for a number of months until I finally relented and in around January 2009 I went to see my GP, Doctor Leader at the Benfield Medical Centre in Newcastle to discuss it. Doctor Leader did various tests and within about one week called me back in to see her. Her first question was whether I had received a blood transfusion or blood products in the past and I explained the incident that had happened in Great Yarmouth in 1979 and the fact that I had a transfusion then. She told me that she wanted to do follow up tests and would request my previous GP's notes; I had been registered with her since 2000 but her comment made me think that it was strange that she had not yet requested my records. She called me back to the surgery within approximately one week to explain her findings. She told me I had contracted hepatitis C and that I quite probably had cirrhosis of the liver. She explained that she was referring me to the liver specialists at the Freeman Hospital in Newcastle. She was very sympathetic towards me and dealt with me professionally. Following the appointment with her, I requested my notes from Great Yarmouth Hospital and on the notes it explained in detail that I had

received four pints of blood during the thoracotomy operation. I gave a copy of the record to Doctor Leader and to Professor Bassendine, the Consultant Hepatologist at the Freeman Hospital when I first went to see her. I no longer have a copy of this record. I am currently trying to trace my medical records and I believe that this record should still be in the batch. I will send it onto the Inquiry when it arrives should the Inquiry deem it helpful for me to do so.

8. Professor Bassendine provided me with information about the infection. It was some time in 2009 and not long after the appointment with my GP. She told me and my wife who was with me at the time, that my case was very serious and that I would have to have a liver biopsy. She gave me leaflets which contained information about hepatitis C, and the Skipton Fund. She also told me that I had to stop drinking, which was never an issue as I didn't drink that much anyway.
9. During this first meeting with Professor Bassendine she explained that I had contracted hepatitis C and that I had cirrhosis of the liver as a result. I think that I was given adequate information to help me understand and manage infection. Professor Bassendine also gave me leaflets, and my wife and I asked her lots of questions.
10. Most definitely, information should have been provided to me earlier. It was almost 30 years following the attack and operation that I discovered that I had been infected with hepatitis C and that the condition had progressed to cirrhosis. If there had been any risk to me of infection from the blood transfusion I should have been given information on what to look for and I should have been monitored by the National Health Service. Doing this would have prevented the deterioration in my condition and me developing cirrhosis. I think that I should have been told that I had a blood transfusion and the risk associated with that when I was discharged from the hospital.
11. I don't really have any views on how the information was given to me, except to

say that my doctors were caring in their approach and I feel that they did their job.

12. Professor Bassendine discussed with me the detail of the risk to others of becoming infected; including children that I may have. I had to get in touch with my ex-wives, all my four children and my current wife had to be tested.

Section 3: Other infections

13. I tested positive for hepatitis C only.

Section 4: Consent

14. In relation to treatment or testing :
15. This is a very difficult question to answer as I was slipping in and out of consciousness but I cannot remember ever being consented about a blood transfusion or the risk it might carry.
16. I am sure I never gave consent for the blood transfusion or the risk of it, and my parents never mentioned to me that they had been asked to give consent either.
17. At the time I do not remember ever receiving any information about the need for a transfusion as above.
18. I do not think that I was treated or tested for the purposes of research.

Section 5: Impact

19. The impact of this on my life has been huge.

20. The mental and physical effects of being infected with Hepatitis c:
21. Mental effects: When I was first diagnosed with hepatitis C and told that it had progressed to cirrhosis I was in complete shock; I could not believe it. I was totally overwhelmed. I did not really understand what it meant for me. I connected the hepatitis C to drug users and the cirrhosis to alcoholics and the HIV (which I had to be tested for too) to sexual promiscuity. As time went by, I became extremely angry and bitter. I started the treatment very soon after I was informed that I had contracted the hepatitis and that it had caused cirrhosis so I focussed on that, all of my energy went into it. It is hard for me to unpick the effects that are attributable to the infection and those that are attributable to the treatment. In preparation for the treatment, I was placed on anti-depressants. I came off them and was put back on them, but came off them finally on the second occasion because I could not stand how they made me feel like a zombie. I was already trying to deal with the drowsiness that came with the treatment, so I stopped taking the anti-depressants. I worried constantly, about the treatment, about infecting my children and my wife, about my financial commitments. The worry about my family in particular was monumental. I suffered panic attacks. The worry took over my life. I felt an enormous amount of guilt: GRO-C, GRO-C
GRO-C To me, this infection was not something that a respectable business man faced. I had built up a good reputation in the community and it worried me intensely that people might talk about me having hepatitis C and cirrhosis. I worried about the impact that would have on everything. I have had many and continue to have sleepless nights.
22. Physical effects: I have an enlarged spleen, severe fatigue, gall stones, and suffer from brain fog. I used to read a lot but now I find it too difficult; I often read a paragraph and have to re-read it numerous times because I forget instantly what I have just read. I cannot concentrate. I have developed a tightening of the tendon on the fourth finger of my left hand, and cannot

straighten it. It seems to have locked out. The GP has said that this is related to the hepatitis C. I suffer pains in my joints, knees, hips and shoulders. I was diagnosed with prolapsed discs around 15 years ago. The pain from this in itself is extremely hard to bear and although I used to be able to battle through the pain barrier with the help of strong medication, I am no longer able to. The exhaustion that the hepatitis C brings makes it extremely difficult, if not impossible, to fight through the pain barrier. I sometimes cannot even make it upstairs and have to confine myself to bed until I can cope. Pain and exhaustion are not a good combination. I find that they make me give up and this is not the person that I am.

23. I have developed cirrhosis of the liver and suffer from the conditions indicated above. I await receipt of my medical records and it may be that there are other conditions that I have not been told about. I would like the opportunity to submit a supplementary statement to the Inquiry if I find that there are other conditions or complications or other information that I feel it should know about.

24. I have been through two lots of interferon and ribavirin treatment. The first lot started in 2009 and the intention was that it would last for 24 weeks. I had to come off it at 12 or 13 weeks because my kidneys shut down. It transpired that the morphine I was taking alongside it for my back pain caused my kidney's to shut down. I lost a lot of weight during this time. I had the second lot of treatment around three months later, and for 48 weeks. I lasted on the treatment for the full term. I lost nearly 20 kilos and to this day I have never felt the same. My taste for food has disappeared and I have an abnormal diet as a result which has compounded matters because I am not getting the nutrition I need. I now have scans every six months because I am at a high risk of developing liver cancer. As the time draws nearer to my scan dates my stress levels increase. To think that one test could turn my life upside down is really frightening. I have spoken to two people who have had liver transplants; both of whom were in their early 40's when I spoke to them and what they told me really concerned me. They said that the two year duration following the

treatment was the hardest they had ever experienced in their lives. These men were both at least 20 years younger than me and I seriously worry about how I would cope with a liver transplant especially because I am 63 this [GRO-C]. I pray that I do not have to have one.

25. I was treated very soon after diagnosis. I don't believe I faced any difficulties or obstacles in accessing such treatments.
26. I believe that because it was known by the hospital that they had given me a transfusion back in 1979 I should have been monitored regularly and made aware of the symptoms that could have arisen. If I had been told sooner that I carried the infection then my condition would not have deteriorated to the point that it has. I now have cirrhosis and I feel very sad and angry about this because this could and should have been prevented. I was not diagnosed until 2009. Yes, I was treated soon after but I had been carrying the virus for 30 years which is too long for something so serious.
27. Over the last ten years my mental and physical state has changed; both as a result of the infection and the treatment.
28. I have terrible problems with my concentration. I used to be able to read a 300 page book; sometimes within a day, now, I never read because I am unable to concentrate for any length of time. I used to love all sports but particularly football, especially American Football. From time-to-time I might watch American college football; but, I lack interest in it now. I do not seem to have any real interest in anything remotely connected to sports anymore. I used to love music and had a large record collection, but, now I have lost all interest in the majority of it. I used to go fishing all the time, not anymore, I cannot cope with the fatigue that I feel as a result. I am usually overwhelmed by the exhaustion I experience after setting up the gear and the concentration levels required for it.

29. When I was on the interferon, I ached all of the time, I felt like I had flu constantly. I was also consumed by an itch under my skin and all over my body but especially on my stomach where the injection went. I was completely incapacitated by it. I was unable to work and unable to function in any way that was productive. The effects of the treatment have been lasting, particularly the fatigue. I am grateful that I am now hepatitis C free, although I am still very concerned about the cirrhosis. All in all, it has been a completely life-changing experience to what my everyday life used to be.
30. As understand it when you have infection like cirrhosis you are susceptible to getting further infections like oral infections and I have many of these over the last three years. I do not think that the infection has had an impact on treatments, medical or dental care for other conditions.
31. The impact of the infection on my private, family and social life has been immense.
32. Knowing that I am infected and experiencing the destruction and end of my last marriage because of it, has caused me to not want to form any kind of relationship with anyone. I have a friend who visits from America to see her parents in Nottingham. She visits with her husband and they always come to visit me when they are here. She cannot believe that I have no-one significant in my life. She does not know why but the truth is that it frightens me, just the thought of having a relationship. I cannot begin to imagine falling in love to then have something terrible happen. As much as it would hurt me the thought of hurting someone else that I love and care about, hurts me even more, so I would rather not put myself in that situation. My oldest son understands my feelings but the rest of my family really do not understand.
33. I moved back to Nottingham from Newcastle in May 2016 so that I could have the support of my family close by. I am much more dependent on them now than I ever used to be. My family visits me regularly; this includes my three

children, my sister, brother-in-law and nieces. I am no longer able to take my children away on the holidays that we used to, I no longer have the energy.

34. I have no social life at all, friends do visit me now and again but I never go out. I don't even do any physical shopping, only online, and get it delivered weekly.

35. I have described the shock I felt when I first found out that I had contracted hepatitis C. It took some time for my children and my wife to believe that they could have become infected. At first, no-one wanted to talk about it. I had to tell them that they had no choice but to sit down and listen to me. First I had to reassure them it was quite probable that they were all clear but because that was not certain they had to get tested. I also explained that many people contract hepatitis C and never know they have had it, that many clear the virus without being harmed by it. It was extremely difficult to tell my second wife who was an American and her family reacted furiously. I have always tried to stay close to her as I have always valued her friendship as well as the love I have felt for her. It took sometime but they did come to understand that it was not my fault. As for my third wife, I think that if the diagnosis had come at a different time in our relationship and had we not been through so much anxiety already, things may have been different. My youngest son was too young to understand the implications, but as he has grown older he has done his own research into this scandal and is always there for me. He comes and stays with me as often as he can. As I have mentioned previously, I have no social life at all, which is correct. I have been out three times since I moved back to Nottingham; all my family try to get me out but I really have no interest. Making arrangements to do something and then not feeling up to it when the day comes round is demoralising. So, I would rather not bother arranging anything as it is so frustrating. Also the fact that everything I do is exhausting and that I feel that I am not only letting myself down but also my family prevents me from making arrangements.

36. The work-related and financial effects have been huge.
37. Work-related effects: In 2007, the year before that I was going through the 18-20 hours of sleeping, I had started an estate agents and letting business. I had 81 properties on my books at the time and was doing extremely well. However, with the exhaustion, the sleeping and the depression I was unable to keep up with the work, it was just impossible. After I had my diagnosis all of the landlords were extremely sympathetic when I explained that I would not be able to carry on working for them. I made arrangements for another estate agent to take over the business. I had been hoping that after the treatment I would be able to go back to work. This of course has been impossible. Feeling exhausted is an everyday part of my life now and something that I have had to accept. I have been on diets to reduce my weight but even after losing nearly four stone the exhaustion is still there. As I stated previously since doing the interferon treatment I have never felt the same. All my life I have been employed and worked hard. I have opened restaurants that have won prestigious awards, one the "Best New Restaurant in America" in 1988. In these restaurants I have hosted American presidents and actors such as Clint Eastwood, Frank Sinatra and Sammy Davis. I was made an Honorary Texan by Governor Bill Clements for the charitable work that I did. I am a proud person by nature and do not like having to depend on others; especially not for money, but I have been reduced to exactly that because of this illness. I am no longer able to work and retired on medical grounds.
38. Financial effects: When I became very ill in around 2008 I had a little money put by but nowhere near enough funds to stop work because I had bought a number of my rental properties, but the only way I could keep up the repayments was to tenant them fully, and manage them myself. That way I could avoid paying agency fees. I could only sustain this for about 12 months, until I was diagnosed.
39. Obviously the family home where my youngest son lived was my priority above

all else. As time went by the rental properties were repossessed; all went into foreclosure. If I had the strength I would have gone into bankruptcy but with the effects of the hepatitis C I could not even do that. I had never owed anyone anything before in my life and being in debt was completely alien to me.

40. My wife was so worried that every time we spoke she was on the verge of tears. When the money from the Skipton Fund arrived it helped but I was used to earning that kind of money annually so it did not go far. I had to completely change the way we lived. I found that very difficult to deal with and thought that it was so unfair. I had worked so hard all my life and to be reduced to benefits and begging because of something that that I did not do has been very difficult.
41. My wife and children were plagued by bailiffs knocking at their door. It came to the point where my wife would not answer the door. I sent letters to everyone that I was in debt to, but that did no good at all. My wife went to Citizens Advice but they couldn't help her with the complexity of the case, contaminated blood was still virtually unheard of, and we found that no-one really cared.
42. Over the years I have had to sell many of my possessions including football memorabilia and art that I had collected. I had to sell my Banksy print to pay for my daughter's wedding. That broke my heart but obviously family comes first.
43. I am still paying council tax bills from the properties that I had owned. Even though the bills belonged to the tenants, the councils held me responsible as I owned the properties.
44. All the plans that I had for retirement evaporated and living from day-to-day is now a way of life. When I think back I think that although I have slipped into

depression twice my state of mind has held up quite well. Still today, I do get very down about things, as things could have been so very different.

45. I know my children were in shock by everything that happened and struggled to understand how it could have got to the stage it had without some kind of intervention by the authorities. They basically saw their father go from a fun loving, easy-going, never let anything bother him kind of man, to a recluse. My sister who was a nurse was totally set back by it all. She had no idea that this had gone on in the NHS that she worked for, for so many years. As she has seen the contaminated blood scandal unfold she has been filled with disgust at the whole thing.

Section 6: Treatment/Care/Support

46. When I lived in Newcastle the Freeman Hospital was exemplary in the provision of their care and support. Since moving to Nottingham in May 2016 I unfortunately feel that the City Hospital is not up to the standards of the Freeman. An example is that I am supposed to have scans every six months on my liver as I am high risk for cancer. When I was at the Freeman I would go to my hepatology appointment during which the hepatologist would organise for my ultrasound appointment to take place within the following six months. The letter confirming the appointment usually arrived within a week. At the City Hospital in Nottingham, there have been problems. The appointment is due in March yet I still have no date for the appointment. I have had to contact them as it is extremely important that I have the scans on my liver.
47. The letters that I have received from the England Infected Blood Support Scheme (EIBSS) indicate that it offers financial support for counselling on a discretionary basis up to a maximum of £900. I do believe that there was a provision made by the Skipton Fund for counselling too but am not 100 percent sure on that. I have never requested counselling as I am quite a private person but if I thought it would help I would not have a problem with it.

Personally I think it is going to take a lot more than £900 to enrol someone in a counselling course that is going to be effective for a problem as monumental as this.

Section 7: Financial Assistance

48. I have had financial assistance from the Skipton and Caxton Funds.
49. I was informed about the Skipton Fund in my initial meeting with Professor Bassendine at the Freeman Hospital in 2009.
50. I have received:
- £70,000 from the Skipton Fund in around 2010;
- Stage One monthly payments from Skipton Fund, I am uncertain when these payments began;
- Stage Two monthly payments from Skipton Fund, I am uncertain when these payments began;
- £18,000 Stage Two annual payment from EIBSS starting in around 2018;
- £362 discretionary monthly lump sum payment from EIBSS starting in around 2018;
- £3,999 pre-paid funeral allowance;
- £500 annual winter fuel allowance, I am uncertain when this payment began;
- £1,700 financial support for removal expenses when I moved from Newcastle to Nottingham.

51. I think that the process of applying for Skipton was fairly straight forward. Regarding EIBSS; normally the scheme requires that you send two quotes for whatever it is that you are applying for. The application process for the Pre-Paid Funeral Allowance turned out to be an extremely difficult and upsetting experience. In the first instance I sent in the brochures from two well-known funeral homes; one was Golden Charter and the other the Co-Op. EIBSS informed me that they needed written quotes from the funeral homes and so I had to call back both companies and explain in detail what was needed. I was told that the brochures were not enough because they needed written quotes which identified exactly what would be needed, in a list. I could not understand this because all of the information that I received in the list that I eventually sent was exactly what was in the brochure. I feel like I was placed into a horrible situation that was totally unnecessary and about something that was extremely difficult to deal with. I think this is a terrible way to treat someone.
52. I have not really had any difficulties or problems with my Skipton applications but I have found Caxton to be very different. In fact so much so that I have decided they are just not worth wasting my energy on. Although I did apply for a computer grant I was offered a really small allowance and being an Apple user it did not come close to the cost, not even 20 percent. I appreciate that they cannot give a Rolls Royce when a Vauxhall will do the same job but a computer is an everyday thing to use, and I think that there should be some flexibility. I recently put in an application for some financial support because I had to get some work done to my car. I applied for a £500 contribution as it says on their scheme notes "Car Repair - £500". When I applied, I attached the quote from the garage which stated "*Attend to MOT and repairs to supply and replace nearside and outside faulty suspension, top comms and Bucko (illegible). Part used: two suspension arms. Parts used: rear seat belt*". The reply I received said "*Thank you for your email requesting assistance towards car repairs, we do not accept emailed copies of the discretionary one off*

application form; however, in this case I have reviewed your form and would not ask you to send a hard copy due to MOT tests not being covered as part of the scheme. Please see the discretionary one off criteria document, which is on our website". The guidance says that MOTs are not included. This makes no sense to me.

53. I think I had to indicate that I had received the money when it first came through, other than that I cannot remember anything about there being a precondition attached to making the application or receiving the financial assistance. At the time, I never thought about not working so I did not really take much notice of what might have been a precondition. There are preconditions attaching to the EIBSS application process, one of which is that you have to submit two quotes.
54. I did not expect the onslaught that came with finding out that I had been infected with hepatitis C. It was completely overwhelming. When I am first diagnosed everything came at me from all angles: treatment; Skipton; family members that could have been infected. It is extremely difficult to deal with. What I think would be a good idea would be to have someone available from diagnosis to coach you through the process. It can get quite confusing at times although I have no worries about picking up the phone and calling and getting information that will help with whatever it is that I am doing.

Section 8: Other Issues

55. I want accountability for what has happened. I expect that whoever is looking at this to uncover the truth of what has happened. I want the Inquiry team to leave no stone unturned in the quest to find out the truth. I want full transparency and accountability, as far it goes. I do not think we will get it but this is what I want.

Statement of Truth

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

Signed:

GRO-C

Full Name:

DAVID JAMES SEBEN

Date:

19/02/19