

Witness Name: Mr Paul Ames
Statement No.: WITN1818001
Exhibits: WITN1818002
Dated: 18 March 2019

**INFECTED BLOOD INQUIRY
WITNESS STATEMENT OF MR PAUL AMES**

Section 1. Introduction

1. My name is Mr Paul Ames; my date of birth is GRO-C 1959. My address details are known to the Inquiry.

2. I live alone. My brother, my sister and my mother all live close by. I do not work; I receive Employment Support Allowance (ESA) and Disability Living Allowance (DLA). I have not been able to work mostly because of my depression; I believe that I have suffered from this as a result of my hepatitis C condition. It started approximately one year after I became infected.

Section 2. How Infected

3. I was born with bilateral Congenital Talipes Equinovarus (CTEV), a condition which is also known as club foot. By the age of four, I had undergone 12 operations at Great Ormond Street Children's Hospital (GOSCH). From the very limited notes I have managed to find, I have seen that someone; and I assume that person was from the GOSCH hospital providing the records, has written in handwriting on a record dated 8 September 1960 '*notes missing*'. I

am curious about this. I had my first operation at GOSCH in 1960; I understand I was admitted on 8 August 1960 and discharged eight days later. The records state 'T.E.V.' in handwriting, they do not tell me what happened during this time. I can also see from the records that I was re-admitted on 8 September 1960 with a T.E.V. leg abscess. I assume that this was as a result of me having had an operation while hospitalised on 8 August 1960. The records state I was re-admitted on 31 January 1961 and remained in hospital until 22 February 1961 and that I had a 'right E.T.A.' which I understand to be a right foot Achilles tendon operation. The notes also say posterior capsulotomy; tendon transfer, incision and drainage of a leg abscess. The records indicate that I had another operation. It appears as though I was admitted on 28 May 1963 and discharged on the 3 June 1963; this is when I had a half an inch cadaver bone graft. The procedure that I had was called a Talipes Equinovarus. The particular note records in handwriting the following information 'T.E.V : OS Calcis Osteotomy : Cadaveric Bone Graft re attachment tibiali".

4. I had a further operation in 1976 at Brook Hospital. Brook Hospital, Greenwich and Bexley Area Health Authority no longer exists; it has become the Lewisham and Greenwich NHS Trust, Queen Elizabeth Hospital (QEH), in Woolwich. I have been able to retrieve an operation note from my doctor's surgery which shows that I was admitted on 25 April 1976 for a triple arthrodesis of the left foot. The operation note states that a '*longitudinal oblique incision was made on the lateral side of the ankle. The peroneus longus muscle was divided. The surface of the calcano-cuboid, calno-talus and talo-navicular joints were cleaned and trimmed. The foot was corrected in varus position. The wound was closed in layers. Below the knee P.O.P. was applied and anti-biotics were given. Post-operative recovery was uneventful and he was discharged home on 3rd May to be seen in Out Patients for follow up.*' The medical note was dated 11 June 1976 and signed by A. Afifi, S.H.O. in Orthopaedics. P.O.P. stands for Plaster of Paris. Approximately three days later, I was readmitted because I was in extreme pain.

5. As a result of the congenital abnormality and attempted corrective surgeries I am now registered disabled.

6. I do not know exactly how I have become infected with hepatitis c. I have never taken drugs intravenously, I did not have a tattoo prior to diagnosis and I have not been sexually promiscuous and I have never used another person's toothbrush. My hepatitis C medical team support this. The majority of my records have disappeared so I have not been able to prove how I have become infected with medical evidence. The only possible way that I could have become infected is through the surgeries that I have had.

7. A few years ago, I found out from my nurse friend, a retired doctor (a friend of my nurse friend), and also from my qualified hepatitis C nurse (all of whom looked at my medical records from Great Ormond Street Hospital), that the hepatitis C virus can be transmitted through a cadavers bone graft. My medical records clearly state that cadaveric bone was used in my surgeries in the 1960s. Cadaveric bone is bone that is taken from a dead body. The retired doctor friend of my nurse friend advised me that there are two parts to the sterilisation processes for cadaveric bone grafts. Part I sterilisation takes place within 12 hours of death. Part II is required if surgery takes place after 12 hours of death. The bone has to be taken within 12 hours of death in order to avoid the need for further sterilisation or risk of cross infection. The retired doctor also advised me that at the time of my operations aseptic harvest of bone would not have been used, so therefore the tissue would not have been sterilised, making the risk of contracting hepatitis C (and other viruses) very high. The retired doctor has also told me that there are many recorded cases of hepatitis C transmission via cadaveric bone grafts in the 1960s as bone harvesting would not have been conducted with the stringent infection controls that are in place today; that bone grafts can carry viruses from blood borne products and these are facts that are very relevant to my case. I have found a report on the 'PubMed' online medical source entitled '*Transmission of the hepatitis-c virus by tissue transplantation*' which is authored by Conrad EU,

Gretch DR, Obermeyer KR, Mooqk MS, Sayers M, Wilson JJ, Strong DM. Reference: J Bone Joint Surg Am. 1995 Feb; 77(2):214-24 and available here: <https://www.ncbi.nlm.nih.gov/pubmed/7844127> This report supports the fact that I could have become infected through the receipt of a cadaveric bone graft. The report states that '*The results of the present report demonstrates that the hepatitis-c virus can be transmitted by bone, ligament and tendon allografts. They also support the need for testing of all tissue donors for antibodies to the hepatitis-c virus before the tissue is released for transplantation.*' I have enclosed a copy of the report for your review [WIT1818002].

8. I would like the Inquiry to consider also that the operating instruments used would not have been what they are today. In the 1960s the instruments that were used were used again and again. Today they are disposable. This too increases the chance of infection.
9. The retired doctor that I referred to above has told me that the infected blood crisis was most prevalent in the 1970s and 1980s and this timeline coincides with the final procedure that I had on my feet in 1976. This retired doctor has stated that she is 100 percent positive that I would have needed a blood transfusion during this procedure and so it is possible that I contracted hepatitis C via this route. She wrote the following note to me '*Achilles Tenotomy and that type of orthopaedic operation always results in perioperative blood loss therefore a blood transfusion would almost certainly have been necessary.*' She has also indicated to me that she is surprised to find that although I had tendon replacements, the anaesthesia records that I have been able to find do not record loss or replacement of fluids, as they would today.
10. I also had all four of my wisdom teeth taken out at Greenwich District Hospital in the 1980s. I cannot remember exactly when it was and I have not been able

to find my medical records to help me but I recall that I was admitted and discharged on the same day and that I received a general anaesthetic.

11. I was not infected as a result of having a relationship with another person.
12. I was a baby at the time of my operations in the 1960s and 17 years of age at the time of my operation in 1976, I was not and nor were my parents provided with any information beforehand about the risk of being exposed to infection. I recall signing a document for my surgery in 1976. I was visited by a man in a white coat so I presumed he was a trainee doctor. He told me to sign the document, he told me it was for my consent to do the operation. He waited with me until I did so. I asked him if I could read it, and talk to my dad about it. He asked me to just sign it and I recall feeling very much under pressure to do so. The document was not explained to me, I did not have time to read it. I remember feeling angry about it afterwards.
13. I believe I was infected with hepatitis C as a result of receiving a blood transfusion in 1976 this is because of the timing of the operation and the fact that the retired doctor friend of my nurse friend has said that blood transfusions are always required for the Achilles Tenotomy orthopaedic operation that I had, she told me that they always result in perioperative blood loss.
14. I found out that I had been infected with hepatitis C in 1992; this was when I was 33 years of age, approximately one week after I had given blood for the first time. Soon after donating the blood, I received a letter from the blood people informing me that they did not want my blood any more because they had screened my donated blood and discovered that I had hepatitis C. The letter informed me that I should make an appointment to see my GP as soon as possible. I was completely and utterly shocked by this. I went to my GP straight away, at the most within one week of the letter arriving, my GP referred me to Greenwich District Hospital for follow up. I visited Greenwich District Hospital only once.

15. I remember seeing a doctor at Greenwich District Hospital, but I cannot remember his specialism. He told me that it was not good news that I had contracted the hepatitis C virus but that England was the leading country in the world in finding a cure. I told the doctor I was not gay, that I never injected drugs and I asked him if I was going to die. I had heard that hepatitis C was like HIV in that it was contracted in the same way.
16. At this time, I was not given adequate information to help me understand what the infection was nor how to manage it. I remember being told that the hospital had been treating a 12 year old girl who had contracted hepatitis C virus and that there was no evidence of sexual activity or drug abuse with her. The hospital staff was completely baffled as to how she had contracted it. I remember being told that the authorities were even considering whether it could be passed on through the water system and that the virus was so new to science that they were working hard to find a cure;
17. I cannot see how they could have given me more information about the infection when they did not know what they were dealing with themselves. When I asked questions about it I was repeatedly told '*we don't know*';
18. I think that informing me about the infection through a letter in the post was wrong and that it could have and should have been done in a much more sensitive way;
19. In terms of me managing the infection, I was told to wear a condom when I had sex and not to share another person's toothbrush, but that was it.

Section 3. Other Infections

20. As far as I am aware, I have been infected with the hepatitis C (HCV) virus only.

Section 4. Consent

21. I was not advised about the risk of infection at any point in time.
22. I do believe that I was treated with a blood transfusion without my knowledge and I believe that I was tested for the virus by the Blood Transfusion Service without my knowledge;
23. I was prevented from reading the consent form that I had tried and wanted to read. I was put under pressure to sign it there and then. I believe therefore that I was treated without my full consent;
24. I believe that I was treated and tested without being given adequate or full information about my treatment;
25. I do not believe that I was tested or treated for the purposes of research but I cannot say for sure.

Section 5. Impact

26. The impact of the hepatitis C virus on my life has been huge.
27. Having the virus has ruined my life mentally. Even my GP has said this to me. I always felt that I was different; I have been depressed since the age of 18. I lost girlfriends because of it and believe it is the reason I have not had a family. Depression shattered my confidence and if I think about it too long I get angry about it. When I was 18, I was admitted to a mental hospital for six months worth of treatment; I made attempts to take my life. I was on and off medication for depression for years. Physically I have felt tired and run down for the most part of my life, I haven't felt right ever since I was 18. The mental torture has been the worst thing for me. All I know is when I found out that

- hepatitis C causes depression, everything fell into place for me, everything made sense and it actually helped in a way. I have now cleared the virus, I did so in 2016 following Harvoni treatment and since then I have never felt so well mentally;
28. Other than depression, I suffer from psoriasis and asthma. I do not believe that I have suffered any further medical complications or conditions that have resulted from the infection;
29. In August 2007 I was given Peg-Interferon to treat the hepatitis C. I could not bear it; it made my depression much worse. I had to come off the medication within one week. I have discussed this further below;
30. I did not take any further treatment until a year after I met my hepatitis C nurse in around 2013. Initially I was offered the Interferon treatment again and I reluctantly agreed. The thought of taking the treatment scared me so much that in the end I told my nurse that I could not go through it again. My nurse was surprised because it had not been recorded in the records how severe my reaction was, so she did not know and would not have recommended me for it had she known. I think that there was a delay of approximately one year until I finally managed to get some new treatment called Harvoni; it was called off twice and I was told that the delay was because of budget controls. When I finally received it I took one tablet once per day for approximately one month. I had no significant side effects;
31. All I know is that I was waiting for the drug companies to develop the drugs. I am not aware of any other drugs that could have been made available to me;
32. I had a severe reaction to the Peg-Interferon which I explain below, and this scared me. The medical team tried to prescribe it again, at a lower dose but I would not accept it, I could not bear it. I had no side effects with the Harvoni tablets;

33. My infected status has impacted upon my dental treatment. I was treated by a leper at one surgery and so I stopped going. At the next surgery I did not say that I had contracted the infection.
34. Being infected with hepatitis C has ruined my private, family and social life. That is why I am on my own now. I have not been able to have meaningful relationships with women because of my depression and I believe the depression to have come from the infection.
35. I did not let anyone know that I was infected with hepatitis C as I was ashamed of it. I only told my mother and my brother. I did not tell my sister or anyone else. I have told organisations like Skipton and Eltham Labour Party since in order to find out if I can get help but no-one else knows. There is a stigma attached even with depression and I noticed that with hepatitis, as soon you mention it people immediately think of HIV and decide that you are gay. So I have decided to not mention to anyone else.
36. There have been educational; work-related and financial effects.
37. I have found it very hard to concentrate. I have brain fog. This has made it very difficult for me to follow a course of study;
38. The depression has made employment impossible.
39. I explain below that I have received no financial support from the various schemes that have been set up; this is because my hospital records have been destroyed and Skipton was unwilling to accept assertions made by my medical team that there was no other way that I could have become infected. Not being able to work and not receiving financial support has had a devastating impact on my life financially. I am not able to go on holiday, all I have known is benefits and I have not wanted that for myself. I was forced into it.

40. My mother has always blamed herself. She was told that her womb was too small to give birth to me and that this caused my club feet. This has turned out to be false information. My mum took advice to put me through the operations that I had and she feels very guilty about it because this is where I contracted the hepatitis C from. My brother never talks about; he never brings it up. He remembers how I was when I was really very depressed.

Section 6. Treatment/Care/Support

41. I was referred for treatment to Queen Elizabeth Hospital in Woolwich when I was diagnosed with hepatitis C. I think that this was because at the time, Greenwich District Hospital was closing down. At first my appointments took place every six months. I had at least three liver biopsies which confirmed that I had contracted the hepatitis C virus. After that I think that my appointments went to annual appointments. Every time I attended for the appointments I was told the same thing, nothing more other than to come back the following year for a check up. There was no offer of treatment initially; I just had blood tests to keep an eye on the progression of the virus/ infection. Eventually, in around August 2007, I was offered self-injection treatment consisting of Peg-Interferon and Ribavirin. When the treatment was first prescribed in around August 2007 the staff at the hospital was aware that I suffered from depression. As I have said, I understand that this is a side effect of carrying the hepatitis C virus. I was told that the treatment could make my depression worse. I decided to try it out. I injected myself only once and it drove me mad. I did not have a bath or wash for a week and I was getting more and more aggressive. I could feel it building up inside of me. I remember getting really aggressive at what I was watching on the television one day and snarling at it. I rang my hepatitis C nurse who told me to stop taking the drug immediately. It took one week for the side effects to wear away. The nurse reviewed me and discussed my case with the consultant and discharged me from the clinic. At the time my ALT level was 57; my levels had been between 50 and 75 in the previous year. The nurse explained in a letter that I should be referred back to

the clinic if my levels increased above 120 but that I should arrange to make annual appointments. After a couple of years of the annual appointments, I stopped going to the hospital. As I had been discharged and there was no treatment available to me I thought it was pointless going. I got really fed up with the blood tests and no offer of other treatment. I was told I could live a normal life anyway and that I had more chance of dying from a heart attack than from the hepatitis C virus, so I thought I was fine. It was not until about 2010 when I heard that someone had died as a result of contracting the hepatitis C virus that I requested my GP to refer me back to the hepatitis clinic at the Queen Elizabeth Hospital. Since then I have been put under the care of a hepatitis C nurse and doctor.

42. Counselling and psychological support has never been offered or made available to me in consequence of being infected. I did discuss my depression and suicide attempts with the consultant at the Queen Elizabeth Hospital, he never offered any support of this kind. I was given a leaflet once by my GP as she noticed that I was self harming. Apart from that I have not had any support of this kind.

Section 7. Financial Assistance

43. I have had no financial assistance from any Trusts or Funds that have been set up to distribute payments and I think that this has been grossly unfair towards me.
44. I found out about the financial assistance that might be available to me through my hepatitis C nurse and this was until around 2013 or 2014. She advised me to contact the Skipton Fund;
45. I have received nothing in the way of financial assistance from any Trust or Fund;

46. On the advice of my hepatitis C nurse, and my hepatitis C doctor who both said that without a shadow of a doubt I contracted the virus from the surgeries I had, I requested the forms from the Skipton Fund. I gave them to my hepatitis C nurse to help me to fill them in as I am not good at filling out forms. My nurse spoke to my hepatitis C doctor and they both filled out the forms for me. They both concentrated on the operations that I had in the 1960s and in 1976 and on bone grafts as opposed to blood transfusions. I made my application to the Skipton Fund in October 2015; my doctor had signed the Skipton forms supporting my claim. He stated that he had known me for 10 years. Within two weeks of my application to the Skipton Fund, around the 30 October 2015 my forms were returned and my application was refused. The letter I received stated that my application had been declined due to the lack of supporting documentation confirming that I received treatment with NHS blood or blood products prior to September 1991. They said that they were only able to conclude from the information they had seen that a blood transfusion was possible rather than probable. The letter said that if I managed to get further information in respect of my claim from the hospital or GP surgery then I should return the form back along with copies of the supporting documentation. The letter stated that I could apply to the Independent Appeals Panel (IAP). Approximately one year later I made an appeal to the IAP. Again, my appeal was rejected. The letter I received stated that there was insufficient evidence to show that I received a blood transfusion. The panel reviewing my application noted my surgeries in 1961 and 1965 and the fact that these were for bone grafts which did not appear to include blood or blood product transfusions and so these appeared to them to be outside of the scope of the Skipton Fund. The letter also stated that even if the Fund included tissue grafts, the recent risk of becoming infected with hepatitis C was below 1 in 1 million and the risk of infection in the 1960s was much lower than in recent times. Again they decided that it was not probable that I became infected through these surgeries. Their response to the Appeal seemed to conflict with what they said in their response to the original application because in that they said that the eligible exposure extended to tissue or tissue products. My

hepatitis C nurse and I are in the process of looking at whether I can make a fresh application on the basis of me having had blood transfusions; particularly during the 1976 Achilles Tendon operation

47. The difficulties that I have faced are indicated above and have resulted in an unsuccessful application.
48. I am not aware of any preconditions imposed on the making of an application for, or grant of, financial assistance;
49. I knew nothing about the Skipton or any other funds until my hepatitis C nurse told me about them. This should not be the case; I should have been given information much sooner. The system knew my address; this is how they contacted me to tell me I had contracted the virus, so I have often wondered why I was not contacted and advised that there may be schemes available to help me. I am suspicious about the fact that more was not known about the funds and the strict way in which Skipton approached my application, despite my medical team supporting the fact that I could not have become infected in any other way, other than through the operations I had. As I have mentioned I have received nothing by way of financial assistance.

Section 8. Other Issues

50. I feel that I have been ill-advised and kept in the dark over the years. When I eventually met with my hepatitis C nurse in 2013 or 2014, things really changed for me, for the better. I am extremely grateful to her for giving me the advice and support that she has given to me over the years. She has helped to settle my mind from worry.
51. I have included a report about hepatitis C infection via bone grafts for the Inquiry to consider.

52. I want the inquiry to find out who is responsible and whether there has been a deliberate cover up. I want the Inquiry to do its best so that something like this never happens again.
53. I cannot get hold of the important information in my medical records; the information that will explain everything and help me to get help. I have tried many times but have been told that they have been destroyed. The Queen Elizabeth has told me the records I requested in 1976 and 1980 have been destroyed. They advised me in writing that if there is an eight year gap between attendances that records are destroyed in accordance with Department of Health guidelines. GOSH sent me 60 pages of records which they have said comprises all the records they have.
54. I sought help from my local MP; Clive Efford, on 3 February 2017. I turned up to one of his surgeries as I had not received a reply from him when I contacted his office approximately one year before. I went to him for advice and support about putting in a claim. He said he had worked with the haemophiliacs and they had been treated really badly. He implied that I had not been treated badly so I responded by saying, so have I. I showed him my wrists so he could see that I had slashed them, to indicate how badly affected I have been by all of this. I told him that I had been backed up by my medics; that both my hepatitis C nurse and doctor had said it had come from my operations and supported my claim. I showed him the evidence I had about the bone grafts and the operations. He did not look at them. I asked him how he thought I got my hepatitis C and he said it was *'probably the way I lived.'* He asked how old I was when I found out I had hepatitis C, I told him I was 33 but I asked him what that had to do with anything and he just shrugged his shoulders at me. He turned around and said to me, *'no matter how many letters I write for you they will make no difference you will be better off going to a Union and using their legal advice.'* This is what I did. I have contacted Mr Efford's office on at least three occasions since asking for an apology but I have heard nothing.

Statement of Truth

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

Signed: GRO-C _____

Full Name: Paul David Ames

Date: 19TH March 2019