

Witness Name: Raymond John Phillips

Statement No.: WITN7309001

Exhibits:

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF RAYMOND JOHN PHILLIPS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 October 2022.

I, Raymond John Phillips, will say as follows: -

Section 1. Introduction

1. My name is Raymond John Phillips. My date of birth is GRO-C 2022 and my address is known to the Inquiry. I am married to my wife, Barbara, and we have two sons.
2. I intend to speak about my infection with Viral Hepatitis. In particular, the nature of my illness, how it has affected me, the treatment I have received and its impact on my family and our lives together.
3. I confirm that I am not currently legally represented and that I am happy for the Inquiry Team to assist with my statement. I do not wish to be anonymous.

4. The Inquiry Investigator has also explained the Inquiry's statement of approach and 'Right to Reply' procedure. I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

Section 2. How Infected

5. When I was a baby, about 18 months old, I was routinely infected with mercury poisoning. This was due to the teething powder used to rub the side of my gums when I was teething.
6. In those days, it was pretty common because the tin on the teething powder was made of mercury and the flaking off infected the user. Back then, it was known as pink's disease. It affected bones, muscles and the nervous system, and most babies died from it. For me, it caused me to develop muscle weakness.
7. By the age of 16, I had left school and began working as a gardener for the council. One day I was pushing a wheelbarrow, and when I went on my knees, I could not get back up, and I suffered from a prolapsed disc. This was the beginning of all of my problems.
8. In 1974, I was admitted to Basildon Hospital and received an epidural in my spine. When I came to, I could not move. I was in excessive pain, so the doctors put me out for about four days. Afterwards, it was decided that I would need to have a laminectomy to remove the disc at the bottom of my spine. At the time, this was considered a pioneering operation. Indeed, following the laminectomy operation, the doctor informed me that I had just had a million dollar operation.
9. The operation was not a success, but I was able to go back to work for about nine months afterwards. One day at work, I was walking across a mini golf course, and because it was in the evening, I did not see that

there was a hole dug out on the golf course. I fell, and I could not move. Again I was taken to Basildon Hospital after my fall.

10. The doctors suggested I try various forms of therapy, and I had to have pool therapy for about six months. This involved about five men on either side playing volleyball in a pool. One day during the games, as a man was reaching for the ball, he pushed me over the step-up trestles, and I suffered another fall. After this, the doctors confirmed that therapy would not work for me. I also tried regular physiotherapy and heat treatment. These went on for a few years until 1980 when the doctors decided I would have to have another operation.
11. This time, I had a knot rod fusion operation where they inserted a rod in my spine. My consultant at the time was Dr Gardener at Basildon Hospital. Following the operation, as I was coming to, I saw a tube coming out of a bag of blood inserted into my arm. I asked the nurse what it was, and she said, "You've lost so much blood. It was a big operation, so we've had to give you a blood transfusion". She did not mention how many units of blood I had received. I remained in the hospital for about a week after this surgery.
12. No one ever informed me that I might require a blood transfusion. I was not asked to give consent beforehand. I was 33 years old at the time.
13. When I woke up from the knot rod fusion operation, I noticed that I did not have any feeling in my left leg, which indicated partial paralysis. The feeling returned, but it began to appear and disappear frequently. Before the operation, I had suffered from some pain in my left leg, but now the pain was severe.
14. By the time I was discharged to go home, I could only walk with the aid of elbow crutches, and it felt like I was dragging my left leg because of the partial paralysis. The doctors reassured me that I would be able to walk unaided in due course.

15. The pain got worse, and one night about a week after I had been discharged, I was violently sick. I felt dreadful, and I was vomiting faeces. It was unbelievable. The sickness persisted for about two hours. I have since learned that this can be a reaction to receiving hepatitis and is linked to liver damage. The incident occurred about two weeks after I received the blood transfusion.
16. I reported this sickness episode to my GP, Dr Norwell, and indicated that I was suffering pain in my right side, where the liver is located, as opposed to pain in my spine.
17. Dr Norwell prescribed me a few medications for the pain, but nothing worked. The only thing he could then prescribe was opium.
18. I know it was now around January 1981 because I remember it was around when John Lennon died. My skin and eyes turned a noticeable yellow. They did not know what it was, so I was placed in a barrier nursing room at Basildon Hospital. They asked me if I had been in touch with anyone from Africa. I said I had been in contact with visiting missionaries in the church who might have visited Africa, but it was not likely that was the source of my illness.
19. Finally, in January 1981, the doctors carried out a test and confirmed a diagnosis of viral hepatitis.
20. The doctors did not ask me if I had any tattoos or received medical treatment abroad, but they asked if I drank a lot, and the answer was a firm no. I am not much of a drinker because I have always hated the taste of beer. I may have a glass of wine around Christmas, but that's it.
21. It is clear that the only way I could have contracted hepatitis is through the contaminated blood I received at Basildon Hospital in 1980.

Section 3. Other Infections

22. I do not believe I have received any infection other than HBV due to being given infected blood.

Section 4. Consent

23. I consented to take part in the research of a trial medication for my hepatitis. I believe it was a good trial, but they never confirmed if it was effective or improving my condition.

Section 5. Impact

24. Following my diagnosis, the doctors did not offer me appropriate treatment options. Instead, they gave me steroids and told me to return home and live a normal life.
25. The steroid was prednisolone which is known to have the common side effect of brittle bone disease if taken in high amounts. I developed osteoporosis as a result, and it caused further degeneration of my bones. I was also prescribed a variety of medications for back pain.
26. I spent the whole year of 1982 in bed because I was in so much pain from my liver condition and my back. I could not move, and my wife Barbara had to carry me around. She had requested a hoist from our local council, but they said they did not have the funding.
27. I believe the pressure of carrying me around led to Barbara suffering from a heart attack at 36 years old. After the attack, she was admitted into Basildon hospital, and the blood test result confirmed that it was a heart attack.
28. Barbara remained in the hospital for about three weeks, which was also a source of further stress. We had two young boys and she had been in

charge of looking after everyone and everything at home. During her first week at the hospital, she was frantic with worry because the hospital did not let her have a phone, so she could not find out how we were coping.

29. We had the support of our church which was very helpful to us. Our pastor visited Barbara at the hospital, and local church members took our son Mark in because he was only three years old. Our other son Chris had just started boarding school. He was around seven or eight years old at the time and was being sent to boarding school because of the disability support available for him there. He was very upset and did not want to go to school because he helped out around the house.
30. Barbara remained in Basildon Hospital for about three weeks so that they could monitor her condition to ensure there was no lasting damage. Barbara confirmed that she suffered from angina, so she could still feel the pain from the heart attack for about a year afterwards. Sometimes she would go to the GP to complain, but he would only refer her back to the hospital.
31. However, following this incident, the council agreed to fit a hoist in our house. The council also provided a set of carers to come in and help for about three or four months after Barbara came out from the hospital. We had six people a day to support me—two in the morning, afternoon and evening. When Barbara and I realised that she alone had been doing the work of six people this whole time, she said, "it's no wonder I had a heart attack".
32. Between 1982 and 1991, I continued to experience pain in my liver, and I was also losing weight and feeling generally unwell all over. Ultimately, I made an appointment to see a doctor at Basildon Hospital to complain. He referred me to Dr McIntyre, who later became a professor and a specialist at the Royal Free Hospital.

33. In 1991, there was an occasion when I was admitted to Basildon Hospital. I was visibly yellow, passing in and out of consciousness, and was hooked up to a morphine pump in my stomach. I overheard one of the junior doctors say to another doctor, "he'll never make it through the night, just turn the morphine pump up". They were outside my curtain by my bedside and did not realise that I was semi-conscious. I watched as the other doctor put a coin on the morphine pump, and proceeded to turn it up.
34. When the doctors left, I took the coin and used it to turn the morphine down. I don't know who the doctors were. However, it was in 1991, just before I was referred to the Royal Free Hospital.
35. Basildon Hospital was terrible at times. There was another incident where I had to have a liver biopsy done. The doctor had to insert a really long thick needle into my side. The doctor carrying out the procedure missed it five times, so he kept taking the needle out and inserting it again. It was extremely painful.
36. After the 5th attempt, I refused to allow him to insert it again. I had to say I'm holding my blood in as you're going to kill me. After this, he called a consultant to explain that I was bleeding and he had been unable to carry out the biopsy.
37. First, the consultant asked him to put gauze and a pad over it to stop the bleeding. Then he said the doctor should take me to the maternity ward and scan it with an ultrasound. The doctor was supposed to fire a special gun at the liver once he saw it. After firing the gun into the liver during the ultrasound, the doctor asked, "do we know how to get this out? They had to return to the consultant to find out how to remove the gun.
38. The results of the scans confirmed that my liver had shrunk because it was so diseased that by the time of the scan, it was not located where it was supposed to be.

39. Following my referral to the Royal Free, Professor McIntyre tried to find the source of my hepatitis infection. He asked if I had ever received a blood transfusion, and that was when I remembered that I had received one after the operation at Basildon Hospital in 1980.
40. I am curious to know if there is a record of that blood transfusion in my notes, and I plan to request my medical records from my GP, Basildon Hospital and the Royal Free Hospital to see if this was documented.
41. At first, Professor McIntyre prescribed me 40mg of prednisolone, a high dose, but I had to stop using it because I was suffering from significant side effects. I returned to the hospital and told him I had stopped taking the medication. He decided to admit me to the ward. Once on the ward, he inserted a cannula into my arm and began giving me a drug.
42. When my brother came by later to take my car home, Professor McIntyre informed him that I would not have survived through the night if I had not come to the hospital.
43. I remained at the Royal Free hospital for about a year after this. Professor McIntyre explained that there were additional problems with my liver. No one mentioned cirrhosis. Instead, it seemed like liver damage, the same as it had been at the time of the scans at Basildon Hospital in 1991.
44. While at the Royal Free Hospital, I was on morphine and another injection I cannot recall the name of. These were administered every four hours, and the second injection was to tide me over during the breakthrough pain period when I could not be on morphine.
45. In 1992, I had to have another operation, this time on my gallbladder. It was supposed to be a keyhole surgery, but the wound from that surgery is an extended vertical cut across my side, so it was more than a keyhole.

It was following this operation that I was informed that I had developed cirrhosis of the liver.

46. They explained that during the operation, they had realised that my liver was severely damaged, and they had to suture it. The operation lasted about six and a half hours, and afterwards, they said I was lucky to be alive. It was a complicated procedure, and they had to insert a stent in my back.
47. In 1995, I was put on a trial of an American drug. The trial lasted for about five years, during which I had to have an endoscopy every three months. I also went to the hospital several times for check-ups to confirm that the medication was working. I cannot recall the name of the drug, but I know it was a blue tablet for my liver.
48. Separately, I also started taking aloe vera tablets after carrying out online research, which said that they might be good for the liver.
49. In 1997, I was in the hospital a lot, and the doctors carried out several tests on my liver. They showed me the extent of the cirrhosis on the screens and explained that it had entered the arteries.
50. In 2001, I prayed a lot and believed that a miracle could occur. My wife and our whole church were also praying for me. On one occasion, I felt tremendous heat while praying and put my hand over my side. I do believe a miracle happened because I am still here.
51. Afterwards, I asked the doctors to carry out a liver biopsy to confirm the state of my liver. They said they could not do the biopsy the usual way, so they went in through the neck and the back of my heart. The results confirmed that I no longer had cirrhosis, but the scarring remained. The doctor said, "You still have chronic active hepatitis, and I still want you to continue coming to the hospital".

52. I have had a recent flare up of hepatitis over the last year and have suffered some side effects as a result. I was diagnosed with diabetes in March, but the medication prescribed, Metformin, to help with the diabetes caused the level of hepatitis enzymes in my liver to rise.
53. My current doctor, Dr Patch, prescribed a tablet for the hepatitis Captopurine, which has worked well over the years. Although I believe it is a good drug, recently, I have started suffering from some side effects, and I have informed my GP. Dr Rayner, one of the doctors at my GP surgery, put in an urgent message to Dr Patch to ask what she could do because she does not know as it is not her field of expertise. However, I have yet to hear back from Dr Patch.
54. A month ago, I tried to get some more, and they said I could not have it as they were waiting to hear back from Dr Patch. I have finally secured an appointment with Dr Patch, but in the meantime, another doctor at my GP Surgery decided that I should go back on it.
55. I was yellow and covered in a rash due to the hepatitis, but it gradually disappeared.
56. Physically the impact of hepatitis I suffer includes extreme liver pain, yellowing of the skin, and rash on my arms, face and body. The steroids I have taken to try and cure the hepatitis have given me osteoporosis, and I potentially have diabetes as a result, even though when I was first diagnosed, I did not realise they could be linked.
57. I have been unable to work. Before the blood transfusion, I was the head gardener on a golf course for the whole of the Basildon district, which was an excellent job. I was expecting to return to work, and the council said that they would hold my position for me, and perhaps I could retrain to another role, but after having that operation in 1980 and gradually getting worse, I could not go back to work.

58. I have been supported financially by help from people, especially at church, and social assistance.
59. Once my son said to me, "all my friends have a dad that plays football, but I have a dad that can't do anything". I am glad that I still have some control of my hands which means I can do some things, such as driving.
60. It has destroyed a lot of my hopes and dreams for my life. Before I could see myself being superintendent of the borough because I was his assistant, he was supposed to retire within six months, and I would have taken over. My family could have moved to a bigger house. Instead, we have had to make do and even changed properties to suit my health needs.
61. My brothers have travelled worldwide, but I could not travel out of this country. Even small family holidays were impossible because I could not be away from home for too long due to all the hospital appointments. It used to be an experience to get out of my room, and going to the hospital was the highlight of my day. I was going to hospitals all around London, and I even joked that I would bring a camera next time.
62. We cannot get on a plane or travel, which has been going on for years. Due to being in an electric wheelchair, there is no way I can walk. I have to be hoisted to get into the chair and then hoisted to get into bed. I spend most of my life in the chair now.
63. There were four years where I tried to drag my legs around and walk, however it became impossible since 1990. It is a nightmare trying to get any sleep. Sometimes I only get a couple of hours of sleep, so I spend all that time suffering. This has had a terrible effect on my wife.
64. It has taken 42 years out of my life. They give me drugs for my pain, but I cannot take too much because I am concerned about my liver condition, so I am suffering more because of my liver condition.

65. I am reluctant to take too much pain medication because it could adversely affect my liver, so I suffer greater pain.
66. Barbara has had to take responsibility for bringing up the boys, doing our banking and making sure we survived financially. Yet she could not work full time because she also had to look after me.
67. Barbara began working part-time when our son Chris was about two years old. She held various jobs, from working as a receptionist at two different doctor surgeries to being a teaching assistant, and one time she worked as a lollipop lady.
68. Before my health issues, Barbara had a promising career working at a secret department for GCHQ in London. We were able to buy our first bungalow because of her income from that job. After we got married, she gave up that job because we were going to live off my income, and Barbara would look after the kids. However, it was not long after this I fell ill, and Barbara had to pick up working part-time again so we could have some income coming to the family.
69. It was a lot of hard work, looking after the children and taking care of me, hence why she suffered a heart attack in 1982. It took Barbara a while to recover from the heart attack, but she kept working. She stopped being a lollipop lady because it was a little dangerous.
70. I have had some difficulties finding a dentist due to my diagnosis of hepatitis. When people hear you have hepatitis, they don't want to treat you. Because the dentist wouldn't treat me, all of my top teeth fell out, and I ended up in the hospital, having to have the roots taken out. I went down to five teeth. I am saving to get some dentures because I have to pay for them.
71. I wear hearing aids due to a gradual loss of hearing.

72. I currently wear a neck brace because, over the years, I have suffered from multiple degenerative fractures. I have a hairline crack in my neck and two broken discs that are at three and four, which are compacted, so there are no muscles there. Five and six are also out, and I have been informed that they may have to carry out a procedure to put gel in, which will form a paste, to push the discs back a little and hold it. The hope is that this will give me more support in my neck.
73. Presently, I need a walk-in shower so that I can roll my wheelchair in. I applied to the Basildon council for this, but they said we would have to pay for it. The money we have in our savings, £15,000, which we are saving to cover our funeral costs, is what the council says we would need to afford the walk-in shower. I have suffered from many falls in the past. However, because of the delicate condition of my neck, I cannot afford to have any further falls as my neck won't support me. So I no longer have showers, and now I wash down with a cloth.
74. Recently while at Basildon hospital, a nurse asked me to confirm whether I would still like to be resuscitated because I am 75 years old. She said, "you're in terrible pain and in a wheelchair. Why would you want this?". Then she said what if you get worse? My response was I didn't come here to get worse. I came here to get better. They said the decision would ultimately be out of my hands.
75. I am not content with the service from Basildon Hospital and the nurse's questions. She was not looking at me as a person. She was looking at a person in a wheelchair. The next day they sent someone to do a psychological assessment with 20 questions to confirm that I was mentally fit to make my own medical judgments.

Section 6. Treatment/Care/Support

76. The care I have received from Basildon Hospital has been terrible, but the royal Free has not been too bad. My current doctor at the Royal Free is very friendly, and I am on a first name basis with him unless there are colleagues of his around. I have known him since he was a junior doctor and now he is a professor.
77. No one has ever informed me or my wife of the availability of counselling or psychological support.

Section 7. Financial Assistance

78. No one ever informed me that financial support schemes were available for those who contracted hepatitis from contaminated blood.
79. I am currently in the process of obtaining my medical records in order to prepare an application for financial support to the English Infected Blood Support Scheme (EIBSS).

Section 8. Other Issues

80. What upsets me is that no one sought my consent or informed me of the possibility that I could require a blood transfusion before the surgery. I was totally unaware, and it upset me the next day when I realised I was receiving a blood transfusion because I would never have given my consent to that.
81. In those days, I was against having a blood transfusion, so I would never have had it. I always thought you should not have blood from another person. I was happy to give blood but didn't want to receive it from anyone else. I have the belief I was born with the blood in my body.

Statement of Truth

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

Signed

GRO-C

Dated

13th 12-2022