

Witness Name: Karen Phillips  
Statement No.: WITN3214001  
Exhibits: WITN3214002– WIT3214010  
Dated: 9 October 2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF KAREN PHILLIPS

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I, **Karen Phillips**, will say as follows:-

#### Section 1: Introduction

1. My name is Karen Phillips. My date of birth is **GRO-C** 1958 and my address is **GRO-C** Shropshire, **GRO-C** I am married to my husband Kevin and I have a son called Spencer. I retired from work around nine years ago for a variety of reasons, but mainly through ill health.

#### Section 2: How infected

2. I have mild haemophilia B and I am a carrier of haemophilia. I knew I was a carrier of haemophilia because it was in my family; **GRO-C** has haemophilia B. My son was diagnosed with severe haemophilia B around the time he was born in 1974. I was diagnosed with mild haemophilia B on 14 June 1982 after I suffered from prolonged bleeding (around 11 days) following a tooth extraction.
3. In 1981, I was sterilised. This was partly a personal decision of mine, but also partly down to Dr **GRO-D**, a Consultant at the Queen Elizabeth Hospital ("the QE"),

who was in charge of Spencer's treatment for haemophilia. I recall at the time that Spencer was really ill and Dr [GRO-D] asked whether I had ever considered sterilisation. He also asked me whether it would be fair to have another child given everything Spencer was going through. After thinking it through, I decided to go ahead with the procedure. Whilst I was not aware at the time of this operation, having reviewed my medical records [WITN3214002], I can see that I was given a blood transfusion during this operation.

4. I was treated with Factor IX for the first time following the bleed from the tooth extraction in 1982. I remember being injected with Factor IX and after two to three hours the bleeding stopped. I had a few other incidents between 1982 and 1994 such as an arm injury where I might have been given a few units of Factor IX by the QE, but I certainly did not have a lot of treatment.
5. It was not long after the sterilisation in 1981 that I started suffering from headaches and gastric pain. As a result, I went to my GP, but it was "brushed off" without properly being investigated. No tests were done and he suggested it could be expected because I had a busy life with work and looking after Spencer. The headaches and gastric pains continued until I suffered from a mental breakdown. My friend, Dolly, found me on the kitchen floor banging my head against the wall after I had dropped a bottle of milk.
6. Following this mental breakdown, my GP referred me to [GRO-D] a Community Psychiatric Nurse [WITN3214003]. This was useless; I was only given a relaxation tape to listen to, which did nothing to help at all.
7. I continued having regular appointments at the Haemophilia Centre at the QE under the care of Dr [GRO-D] and Dr Ian Franklin and I had blood tests every 12 months or so.
8. Kevin and I married in 1994, although we had been together for a long time already and originally met each other at school. A few months before we married, on 8 April 1994, I received a letter from Dr Wilde at the QE which I felt basically

said “*as you might already be aware, you are Hepatitis C positive*” [WITN3214004]. This was a surprise to me and I immediately booked an appointment to see Dr Wilde for an explanation. At the time I was really worried that Spencer might also have contracted Hepatitis C.

9. At the appointment, Dr Wilde said he thought that I already knew about it and did not give any explanation as to why I was not previously told that I had contracted Hepatitis C. I was not given any further explanation of how I contracted the virus. He went on to explain that I had a score of three out of thirteen. Whilst I did not know what this meant, I recall feeling like I had “dodged a bullet” because it seemed like a low score. I was also reassured by Dr Wilde saying that the virus will probably clear itself and did not require treatment [WITN3214005]. He said that it is not a severe case of Hepatitis C and my body will likely develop antibodies to clear the virus.
10. I was not given any information about transmitting the virus to others, like to my husband or my son. Kevin has never been tested for Hepatitis C; it has never been offered. Unfortunately, GRO-C also contracted Hepatitis C from contaminated blood products.
11. I had to have my own plastic cutlery and cups that could be thrown away, to avoid the risk of transmitting the virus. This was not something I was advised to do by any of the doctors I had seen, but a precaution I decided to take myself. I did not know how Hepatitis C could be transmitted but remember thinking it might be transmitted from one person to another, like HIV. The doctors did not really explain much, but there was a lot in the media about HIV and how it could be transmitted. I therefore took my own precautions.
12. At the time, I worked night shifts at a care home for the elderly and one of my colleagues commented that I looked like I was on “*death’s door*”. I felt that way too. I discuss the impact of Hepatitis C on me further below.

13. This colleague was the first person, other than Kevin, that I told about having Hepatitis C. I thought she was my friend and that I could trust her. Unfortunately, I was wrong and she told the manager at the care home that I had contracted Hepatitis C. Subsequently I was asked to leave my employment by the house manager. I believe I was asked to leave because of my diagnosis of Hepatitis C.
14. In 1997, I had a hospital appointment with Dr Wilde I mentioned to him how unwell I had been feeling and he told me he had some good news. Dr Wilde told me that I qualified for Hepatitis C treatment. This came as a complete shock to me because I was under the impression that I did not need treatment. Dr Wilde mentioned that treatment had been prioritised for patients more in need before this date but, as the treatment was now available to me, he suggested an appointment with Dr Ahmed in the Liver department at the QE.
15. I was given a treatment course consisting of Ribavirin and Interferon. GRO-C was already on the same treatment so I already knew about it. Before I could go on the treatment I had to have a liver biopsy, which was painful. The results showed that I had mild to chronic hepatitis and I was therefore eligible for treatment [WITN3214006].
16. I remember signing a consent form for the treatment and started the course straight away. I was told that it would be a 48-week treatment course (ending in September 1999) and that I would need three injections of Interferon a week and three tablets of Ribavirin daily.
17. GRO-C and I would still speak on occasion, but not as frequently as we used to, given that we were both on the same treatment at the same time and did not want to burden each other with our own problems. The last thing we wanted to do was to influence the other's treatment.
18. My mother was diagnosed with terminal lung cancer in 1998 and my father was looking after her. Therefore I decided not to tell them about contracting Hepatitis

C and the treatment course I was undergoing. My dad did not know about it for years after my mother's death, either.

19. I stopped having people around my house and lost lots of friends during the 48-week treatment course. This included some friends I had since school. I remember just feeling ashamed and I knew that people thought that one disease leads to another; that if I had Hepatitis C I might also have HIV. My HIV status has never been confirmed to me and I do not know whether I have been tested. Hepatitis C was a dirty word and it was a virus associated with drug addicts. People love to gossip and I did not want to give them something to gossip about, particularly in a small community such as the one we were living in.
20. I suffered in silence and after around three to four months, Dr Ahmed said he thought the treatment would be successful but recommended completing the full 48-week treatment course to be safe. I also saw Dr Sheilds during my treatment. After 48 weeks, in September 1999, the Hepatitis C virus was undetectable and my PCR tests were okay.

### **Section 3: Other Infections**

21. I recall one instance where Hepatitis B was discussed and I was told I had no immunity to it. However, I was never told that I had been infected with Hepatitis B and I subsequently had immunisation injections for it.
22. Upon receiving my medical records, I found out that I am at risk of contracting Variant Creutzfeldt-Jakob disease ("vCJD") [WITN3214007]. Whilst my doctors were aware of this, as the letter was sent from Dr Wilde at the QE to my GP, and the letter is dated 20 September 2004, nobody ever mentioned it to me at the time. The letter confirms *"I am writing to inform you that your patient Karen Phillips falls into the "at-risk" group of patients who are being asked to take special precautions to reduce any possible risk of further transmission of vCJD... Being identified as "at-risk" for public health purposes should not compromise the*

*clinical care your patient receives in any way. However, you may wish to consider your patients at risk status should they develop symptoms indicative of vCJD.”*

23. I have suffered from gastro problems as a result of Hepatitis C and/or the treatment for it. I always worry about it developing into something more serious like stomach cancer. I remember going to my GP about it, after I was struggling to eat one time and feeling like something was not right. I lost around two stone and was referred to a specialist coeliac doctor at hospital called Dr. [GRO-D]. In 2007, I asked for an endoscopy examination but it was refused and I was told I had to have a barium meal. It was only upon receipt of my medical records that I have known the likely reason for refusing an endoscopy is because of my potential exposure to vCJD and the risk of this to the £25,000 cost of the equipment to carry out the procedure [WITN3214008].

#### **Section 4: Consent**

24. As mentioned above, I was not aware that I had been tested for Hepatitis C until I received a letter from Dr Wilde in 1994. I therefore did not consent to being tested for the virus.

#### **Section 5: Impact**

##### *Physical Impact of Hepatitis C*

25. It was not long after being diagnosed with Hepatitis C that I was on holiday for a long weekend in Exmouth with my family. I started feeling unwell and could not shake it off. Kevin and I had made plans to go out that evening and I told him to go without me whilst I rested in the caravan. Kevin decided to stay with me because I was sweating so much and lost all sense of feeling down the left-side of my body. He had to call an ambulance and I was taken to Exeter Hospital.
26. I was in terrible pain and, after being discharged from Exeter Hospital, Kevin and I decided to cut short our holiday and go straight home.

27. After returning home from Exmouth I continued feeling pain and my speech became impaired. I booked an appointment with my local GP and I was referred to QE to have a brain scan, to check whether I had suffered a stroke. I was in constant pain throughout and lost a lot of time off work during this period.
28. It was determined that I had a urinary tract infection and I needed antibiotics to clear the infection [WITN3214009].

### *Psychological impact*

29. There has been a lasting impact on my memory and I suffer from brain fog. I recall on one occasion, I went out to get a chicken from the supermarket and got lost driving down the lane from my house to the main road. I must have been driving for about 40 to 50 minutes before I had to stop to let a tractor go past and I just thought to myself "*where am I?*". I started panicking and it was getting dark. I had no mobile phone signal so had to continue driving until I could telephone Kevin. Kevin did not know where I was so just told me to drive back the way I came. I calmed myself down, turned around and drove all the way back until I got to a familiar road and eventually saw Kevin driving towards me; he was coming to find me. It turned out that I had managed to drive all the way to Ludlow, which is nearly 20 miles away from home, without even realising.
30. I also suffer from bouts of memory loss every so often. Sometimes I will accuse Kevin of moving or taking things and will make a big deal out of something very small. For example, I blamed him for taking my kit-kat out of the fridge before finding it somewhere else the next day. It feels like I also cannot retain information which is really frustrating. Sometimes I see people I recognise but I cannot remember their name anymore.
31. I would say I am an over-thinker and sometimes become very down and concerned thinking the Hepatitis C is going to come back. My experience

definitely still has a psychological impact on me. I am generally a lot more anxious following my experience with Hepatitis C and the treatment I underwent.

32. I have never had a Fibroscan on my liver. I have Liver Function Tests (“LFTs”) at least once a year, but I think this should be every three to six months for people that have cleared the Hepatitis C virus. I just feel like I need to know for my own peace of mind. As such, I make a habit of requesting an LFT every time I go in for a regular appointment now.
33. I never used to be like this because I would just trust what my doctor told me. Now I make sure I am more outspoken with my doctors, especially if I feel like something is wrong. It gets me into trouble sometimes.

#### *Impact of the treatment for Hepatitis C*

34. During the first week of treatment I developed a few shivers and shakes. I had been advised that I might develop flu like symptoms [WITN3214005]. However, what I experienced was much worse than flu. It was like being hit by a train. By the Wednesday of the second week of the treatment I had significant headaches and suffered from diarrhoea and sickness. I had to keep myself in bed and Kevin had to take weeks off work to look after me.
35. One of the side-effects of the treatment is that it clouds your thought process and judgement, so I felt it was better to stay in bed to rest, rather than go to work. I remember thinking that I would not be able to carry on for the full 48 weeks given how bad I was feeling after the second week of treatment.
36. The side effects also included debilitating fatigue, joint and muscle pains, mouth ulcers, alopecia, chest infections, laryngitis, skin irritation, insomnia and anxiety. I was also bad tempered and very tearful.
37. My symptoms only got worse and my eyes starting bulging. I went to see Dr Ahmed and he said that if the side-effects got too bad, then I should go back to



see him again and he would take me off the treatment. I did not know what was worse, dying from Hepatitis C or doing the full 48 weeks on the treatment with all the side-effects.

38. However, I did not want to stop the treatment because I was not sure if I would develop liver cirrhosis and complete liver failure as a result of Hepatitis C. I decided to shut myself off from the world and did not tell anyone about the Hepatitis C or the treatment I was undertaking.
39. I lost around two stone and my hair fell out during the treatment. I also developed really bad mouth ulcers. It was horrible and I remember wanting to die, but then felt the need to carry on with the treatment for Spencer. I did not want him seeing me like that and basically had to stop being a mother to him during the treatment.
40. I was highly emotional and irritable and I felt like a psychopath, sometimes throwing cups and plates around the house. I feel terrible for saying it but a friend recently told me of the side-effects of her chemotherapy and I actually thought to myself that it did not compare to what I experienced with my treatment for Hepatitis C. It really was that bad.
41. I still experience some ongoing symptoms as a result of this treatment including asthma, arthritis, gastro problems including coeliac disease, inability to retain vitamin B12, acid reflux and anxiety.

#### *Impact on my family and financially*

42. My relationship with my family has changed drastically since I contracted Hepatitis C. Kevin and I have suffered intimately and I am surprised he is still with me. No other man would go twenty odd years with what Kevin has had to put up with.
43. There have also been instances where we have cancelled family holidays (even at the last minute) because I start feeling anxious. I remember one instance

where we had a holiday booked and I wrote to my GP to get a letter so that I could take needles abroad for my Hepatitis C treatment. However, in the end I decided to cancel the holiday because I was worried I might not be allowed into the country for being "diseased". I felt like I should not be part of society.

44. Whilst I went back to work after the treatment for Hepatitis C, Kevin and I struggled financially until we started receiving financial assistance. Bills started piling up after I stopped working during the treatment course and we accrued a lot of debts. I remember we changed our mortgage to an endowment policy in 1995 and told the insurers about my Hepatitis C. As a result, I was told that I could not be named on the endowment policy. Then in 2000 we had to sell the house as we could no longer afford it. With the money we received from the sale we bought a mobile home to live in because we knew that I was unlikely to get a mortgage.
45. Living in the mobile home was great, but again ground rent kept increasing until it became too much for us to afford. Unfortunately, Kevin also GRO-C  
GRO-C had to be off work for around ten months. We really struggled during this period and Kevin had to cash in his private pension early when he was 50 years old. There was a penalty for cashing in the pension early, but we needed the money to survive.
46. As mentioned above, I also had to stop being a mother to Spencer when I had Hepatitis C and during the treatment. My mother and father had to care for him, as I could not, and it really strained my relationship with my father in particular. I did not tell him about my battle with Hepatitis C until after my mother passed away because I did not want them to have any additional worries. However, at the time my father just thought that I was neglecting my son and he never forgave me, even after I told him the reason. I assume he felt like I took away the years he should have been enjoying with my mother but instead they were looking after Spencer.

47. I also feel like I missed out on a lot of Spencer's childhood; time that I will never get back.

### *Stigma*

48. Other than Kevin, [GRO-C] and the ex-colleague who I thought was a friend, I did not want to tell anyone else about having Hepatitis C or the treatment I had to go through. Kevin's family never actually knew about it until this Inquiry was established. I just felt like I did not want people pointing a finger at me. I lived in a little close with lots of "fishwife" types. I knew that once one person on the close knew, everybody would know and it would change my life. I did not want to subject my family to that, especially Spencer.

### *Impact on our social life*

49. Kevin and I basically cut ourselves off from everyone socially. We even walked away from friends we had since school, because of the stigma and not wanting to tell anyone about it. We had heard so many stories, particularly in relation to what those with HIV were facing, such as graffiti being sprayed on walls and children being bullied in schools. The last thing I wanted was for Spencer to be singled out by other children because I had Hepatitis C.

## **Section 6: Treatment/Care/Support**

50. Overall I would say that I have not lost confidence or trust in the care provided by the NHS. However, I did experience difficulties with Dr [GRO-D] who I had known for over twenty years. Dr [GRO-D] was treating my son at Birmingham Children's Hospital initially, and me, [GRO-C] at the QE. We trusted him and thought we knew him, but that trust has now been broken.

### *Psychological support*

51. As mentioned above, I was referred to a psychologist by my GP after suffering from a mental breakdown but it was useless. I also remember one doctor asking me if I was “making a fuss” for attention.
52. I therefore had a bad experience with psychological support, but I still would have accepted it if it was offered to me when I was told I had contracted Hepatitis C or during the treatment course. However, I was not offered any psychological support at these times.
53. I also think it would have helped to have been given more information about Hepatitis C and the implications of it. This would have helped to stop some of the irrational thoughts I experienced.

### **Section 7: Financial Assistance**

54. I received a £20,000 lump sum from the Skipton Fund. I found out about it during a hospital stay in around 2003 or 2004. I overheard two other patients talking about it. I did not ask them, but I remembered the name so I could look it up when I got home. I rang up the Skipton Fund and after giving my details, they said they had been trying to contact me at my old address. I confirmed my new address and information about the Skipton Fund and how to apply was posted to me.
55. In order to receive the financial assistance, I recall that I had to sign a waiver which said they would pay me £20,000 because I contracted Hepatitis C but if I developed anything else then I had to agree not to take any legal action. I also remember the waiver saying that everyone had to sign it or nobody would get anything. I discussed it with GRO-C and we both signed the waiver.
56. I also remember having to send medical evidence that I had been diagnosed with Hepatitis C which I thought was a bit strange; they must have known about it

since they had already attempted to contact me. However, I did not think much about it and sent off the evidence. The money was then received into my bank account, which was a god send. I would not say I had a negative experience with the Skipton Fund, other than it was a bit strange having to send off medical evidence.

57. In around 2017 **GRO-C** received information from The Haemophilia Society about the England Infected Blood Support Scheme ("EIBSS"). He is always looking into things more than me. **GRO-C** rang me and we both applied for financial assistance from EIBSS. I remember they sent out some forms and I had to make an appointment at the Haemophilia Centre to complete the medical section of the form. Dr Percy, my current haematologist, completed this section and I sent the forms to EIBSS with my medical and financial evidence. Some of the questions were a bit difficult and Helen at the Haemophilia Centre helped to complete the form.
58. About six months later I received a letter from EIBSS asking for more financial evidence because they thought I might be eligible for a top up payment. I completed this and started receiving the top up payments too.
59. I had no problems with EIBSS but the forms to complete were not self-explanatory. The money has made a difference to our life and it is easier now financially. We no longer own our own house or have a private pension, but we live in rented accommodation and manage financially without having to worry about the next bills.

### **Section 8: Other issues**

60. I have never been told which batch of treatment was the one that was likely contaminated and I have never known what genotype of Hepatitis C I had. This is something I would like to know, and is why I requested my medical records,

but I have never found out. There is a letter in my medical records from Dr Mutimer which says my genotype was not taken [WITN3214010].

*My son*

61. As mentioned above, Spencer has severe haemophilia B and was under the care of Dr [GRO-D] at the QE. When Spencer was six years old he had jaundice. I asked [GRO-D] in the children's ward what was happening to him. She brushed it off and said it will pass.
62. Spencer then developed what was then known as Non-A and Non-B Hepatitis when he was around eight years old. I actually did not know Non-A and Non-B Hepatitis was the previous name for Hepatitis C before the Inquiry.
63. Spencer's treatment was transferred from children's ward when he was 18 years old. He only started home treatment for his haemophilia at this point, when his care was transferred to the QE. I recall Dr [GRO-D] would not give Spencer prophylaxis home treatment. He also thought it would be in Spencer's best interests to be sent to Treloar School ("Treloars"), which was a boarding school. However, I disagreed and did not allow Spencer to be sent to Treloars. I found Dr [GRO-D] to be really obnoxious at times.
64. There was a really supportive community within the Haemophilia Centre at the Birmingham Children's Hospital. I remember we arranged a parents' meeting to discuss concerns affecting parents of children on the same ward as Spencer. Dr [GRO-D] attended this meeting, but did not say a word.
65. On one occasion Dr [GRO-D] withdrew Spencer's treatment following a significant bleed, which was showing no signs of stopping after 28 weeks. Dr [GRO-D] said the best treatment would be to amputate Spencer's leg. I could not believe it and would not accept Spencer's treatment being withdrawn and his leg being amputated without trying everything else first. We had to transfer Spencer's care

to Dr Charles Rizza and Professor Stuart at the Haemophilia Centre at Churchill Hospital in Oxford for treatment.

66. As part of the transfer of Spencer's care to Oxford, we needed to request his medical records from Birmingham. Dr [GRO-D] refused this request initially. However, we persisted with moving Spencer's treatment to the care of Dr Charlie, despite it being really difficult for us having to travel so far. Spencer stayed at the Churchill Hospital in Oxford for seven months. After seven months, Spencer was able to walk out of the hospital, despite not being able to walk for around seven years before this admission. This was despite Dr [GRO-D] saying the best thing he could do would be to amputate Spencer's leg.
67. One of the first things we did when we went back to Birmingham was to go straight to Dr [GRO-D]. We told him that we were back from Oxford and that Spencer was walking. He was so arrogant and brushed it off by saying "*clearly*". I said that we will never be coming back to his hospital again and Dr [GRO-D] simply responded by saying "*what kind of mother are you*".
68. Whilst I disliked Dr [GRO-D] a lot, on reflection, I did not want to jeopardise Spencer's treatment in any way, particularly in the event of an emergency when it was too far to travel to the Churchill Hospital. Therefore, we decided his care should remain at Birmingham Children's Hospital. His treatment whilst still under Dr [GRO-D] was never the same again. I just did not trust him.
69. I also remember asking Dr [GRO-D] if Spencer was exposed to any other virus, such as HIV or vCJD, and he did not tell me. He brushed me off by saying "*Spencer is an adult*".
70. I am aware that Spencer refused treatment for Non-A and Non-B Hepatitis because he could not afford to go through all the side-effects. He does not really talk about it now, but thankfully he was able to naturally clear the virus.

## Conclusion

71. I am hoping that the Inquiry will provide some form of closure and that someone will be held accountable. For a long time, those affected by contaminated blood products have been suffering both mentally and physically in silence and have almost become a forgotten community.
72. No amount of money will ever repay the debt for all the wrong done and all the lies told. I feel there should be compensation given to those affected by contaminated blood products, but I am more concerned about getting justice and someone being held accountable. We know there was a cover up and now we need the truth with some form of acknowledgement.
73. Hopefully the Inquiry will be able to provide answers as to why the contaminated blood scandal happened and why the UK was not sufficient in producing its own blood products. I just hope we are not left disappointed at the end of the day, like we were with the Archer Inquiry.

## Statement of Truth

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

Signed .. GRO-C: Karen Phillips .....

Dated..... 9/10/19 .....