Witness Name: Brenda Scott Stafford
Statement No.: WITN6959001
Exhibits: WITN6959002 - 4
Dated: 9|1|2022.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BRENDA SCOTT STAFFORD

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 November 2021.

I, Brenda Scott Stafford, will say as follows: -

Section 1. Introduction

1. My name is Brenda Scott Stafford. My date of birth and address are known to the Inquiry. I am the wife of Bill Stafford (W5274), who was infected with Cytomegalovirus (CMV) as a result of a blood transfusion, which has led to him becoming blind. We have been married for 56 years and have two daughters together, and one grandson. I was a community nurse for 31 years, working with the NHS.

2. I intend to speak about Bill's infection with CMV. In particular, the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him, myself and our family.

Section 2. How Infected

3. Bill had always been healthy, and had to go through regular medicals to get on the oil rigs where he worked offshore as an electrician.

4. In November 1998, Bill developed a pain in his leg and was medically evacuated from the oil rig when he could hardly walk. It was thought that he had developed a blood clot, however, once Bill had reached the hospital, he was diagnosed with an autoimmune disease called polyarteritis nodosa, a severe inflammatory artery disease.

5. The polyarteritis nodosa caused Bill to suffer from numb extremities, ulcers and the loss of the tip of his tongue, and the blood supply being cut off from his bowel, causing it to burst. Bill had to be transferred to GRO-D GRO-D and was placed under the care of Mr Trevor. Crofts. Once there, Bill underwent bowel surgery in November 1988, performed by Professor Steve Hayes, resulting in him having to have an ileostomy bag fitted. This bag remained for two to three years. It is presumed that Bill had multiple blood transfusions during this surgery.

6. Bill was treated with high doses of immunosuppressant drugs and steroids for the polyarteritis nodosa. His rheumatologist, Dr. Clifford Eastmond, told Bill that he would usually treat polyarteritis nodosa with high doses of Prednisolone (a steroid), but that he knew there was an experimental treatment taking place in England, using a Chemotherapy drug called cyclophosphamide as part of the treatment and that he wanted to try treating Bill this way.

7. Bill was started on this experimental treatment straight away, and once the Hickman line was put in, I used to inject Bill with all of his medication.

8. The treatment knocked Bill's immune system and caused him to become anaemic in June 1991. Bill subsequently received three units of blood to treat the anaemia and received a further three units of blood in October 1991.

9. Soon after the blood transfusion in June 1991, Bill's eyesight started going and floaters started to develop in his vision. Bill went to see an optician, and had an eye test done where he was told that something was wrong. Bill went to see a doctor and was diagnosed with CMV on 17 March 1992. Bill learned that the eye problems that he had been suffering were a result of CMV retinitis, a serious viral eye infection caused by having CMV. Because of how badly the CMV affected Bill, it was thought that he had AIDS, as CMV does the same thing to the eyes to HIV-infected patients. Bill was taken off the ward to do two HIV tests, and these both came back negative.

10. After diagnosis, Bill and I tried to find out how he had come to be infected with CMV. Bill's ophthalmologist, GRO-D was very dismissive of our concerns, saying that viruses were all around us and Bill could have

picked up CMV anywhere. We later found out that this was not true as CMV is a direct contact virus and it became clear that Bill had been infected with CMV through the blood transfusion he had been given.

11. Bill and I fought tooth and nail with the hospital to get to the bottom of the route of transmission, as well as multiple complaints as to the way that Bill was treated.

12. Whenever we went to the eye clinic, the hospital could never find Bill's notes, and they were always in the Chief Executive's Office. The CEO, and the hospital, were always looking into Bill's care, mainly with a view to covering up negligent care and there were other issues, where we presumed that they had been altered. At one point, the CEO said that they would get things cleared on Bill's record, and ordered a clinical review with doctors from other hospitals. Despite this, the review was basically a rubber-stamping exercise to say that everything was done properly and above board, and we were not happy with the resulting decision.

13. During one of the meetings with GRO-D and GRO-D GRO-D snapped at Bill, stating "for God's sake man, you've only lost your eyesight". I thought this was completely insensitive, and so I got up with Bill and we immediately left the meeting. We never received an apology for that. In fact, the hospital never apologised for any of Bill's treatment or care.

14. Fighting against the hospital was hard, especially as they had multiple solicitors to fight back with, whereas I just had a pen and paper. At that meeting, Bill and I realised that we needed to get our own solicitors involved. We then decided to go to Ross Harper solicitors, who helped us via pro bono work. We had also involved our MP and MSP, Malcolm Bruce and Brian Adam at this time to ask questions about people who had been blinded through infected blood, and if any recompense would be made for people who developed those conditions through infected blood.

15. We have had confirmation from Dr. Urbaniak, then the regional director of Aberdeen and North East Scotland Blood Transfusion Service, that the blood given to Bill in June 1991 tested positive for CMV antibodies via a letter dated 18 December 1995 which I identify as exhibit WITN6959002. However, we have received conflicting letters about this blood being CMV antibody positive since, and it has felt like those in charge are now changing their tune and doing everything in their power to avoid owning up to their wrongdoing.

16. In January 2003, Mr. John K Drury, a consultant surgeon, wrote an independent medical report in relation to how Bill became infected with CMV, where he concluded that on the balance of probabilities, the blood that Bill was infused with to treat his polyarteritis nodosa was the source of his CMV infection. I identify this report as exhibit WITN6959003.

17. Drury's report was the best thing that came out of our struggle to prove that Bill had been infected via contaminated blood. However, it was a case of persistence on our part and constantly writing letters, which Bill dictated. This was particularly hard as I am not a letter writer, but due to Bill's blindness and fatigue, he was not able to do it himself.

18. The uphill struggle with medical professionals and solicitors to prove that Bill's CMV infection was a result of the blood transfusions took over our lives. I am so incensed by the fact that the transfusion service is fighting tooth and nail and going back on their previous letters confirming that the blood was CMV positive. They have all the people and resources they can turn to, and all I have is a pen, paper, and Bill's memory, which is fading as the years go by. It has been a 'David and Goliath' fight and a battle that has not yet been won. The NHS and transfusion service have an army at their disposal, whereas we've got nothing really.

19. After Bill was diagnosed, we were told by a doctor that blood was only screened for CMV if you were a transplant patient or a newborn baby. Some years later, we had a chance encounter with a lady who worked at SNBTS, and she told Bill and I that SNBTS now routinely screen all blood for CMV. This clearly shows that SNBTS have realized their error in not previously screening all blood for CMV.

20. I am angry that the NHS gave Bill unscreened blood that was contaminated with CMV, especially since they had made him immunosuppressed at the time and knew he had a compromised immune system, the stage at which CMV has the worst impact.

Section 3. Other Infections

21. I do not believe that Bill was infected with anything other than CMV as a result of the blood transfusions he received.

22. Bill was tested twice for HIV and also requested to be tested for HCV, all of which were negative.

Section 4. Consent

23. Although Bill had to sign consent forms prior to having his operations, Bill was not asked to consent to the blood transfusions he was given.

24. Bill was never really asked for consent when receiving other treatments either; Bill was just told what the doctors were going to do. What Bill wanted as a patient did not really come into it.

25. Although Bill needed the blood for his treatment, at no point were the risks associated with receiving a blood transfusion explained to Bill. Nor was he given the option to consider the risks and make his own choice.

Section 5. Impact

26. The CMV that was transmitted to Bill in June 1991 has had a devastating effect on Bill, myself, and our lives together.

27. Bill was registered as legally blind in 1992, causing endless suffering and destroying our plans for the future.

28. Any time Bill went into hospital and was put on a normal ward to treat the polyarteritis nodosa, he would get a chest infection and become very ill due to being immunosuppressed from the medication he was on for the polyarteritis nodosa. I would tell the hospital staff that Bill should not be in hospital on a normal ward due to the infection risk, but nobody would listen to me, despite having 31 years of nursing experience myself.

29. Under the care of GRO-D, Bill started on Ganciclovir, a treatment for CMV. This was in March 1992. Bill was subsequently transferred to the GRO-D hospital isolation ward for barrier nursing with this treatment due to Bill being immunosuppressed. It was thought that a fortnight of the drug would be enough to flatten the CMV virus, however, this did not work, and Bill stayed on this treatment for over two years.

30. The treatment Bill was receiving at the GRO-D was awful. For example, Bill was supposed to be getting the Ganciclovir at certain times, however, there were many times that the nurses would come up at 4 am instead of 10 pm, waking Bill up to give him his medication, with the excuse that 'they were busy'. Both Bill,and I, resisted complaining about this as we did not want Bill being seen as an awkward patient as that would not do any good.

31. After the initial failure of the two-week treatment in the isolation ward, a system was set up for us to allow Bill to come home. It was called 'hospital in the home'. This involved a company in Glasgow delivering doses of the Ganciclovir daily, and myself injecting it into Bill via the Hickman line that had been fitted as Bill could not see to do this himself.

32. The administration of the Ganciclovir took around one and a half to two hours, and as I was still working, this could only happen once I had come home from work for the day. The process involved myself first cleaning all around the line, removing the cap, and flushing out the tube with heparin to prevent infections. I would then have to attach the Ganciclovir. This was provided in pressurized containers and i'd release it so that it would start to push itself out, down the Hickman line. The drug would take around an hour to administer itself and I had to fit it into a pouch that allowed Bill to move around whilst being hooked up. Once finished, I would have to take it off, wipe around the line, flush the tube out again with heparin, and put on a new bung. This went on for around two and a half years, between March 1992 and November 1994.

33. Due to Bill's blindness, he was unable to see to deal with his ileostomy bag effectively. As a result, I was having to deal with this alongside the injections of the Ganciclovir. The ileostomy bag was not ideal, and due to the exit point being where the band of Bill's trousers was, every time he sat down it would leak. I was responsible for changing the bags, maybe twice or three times a day, and if it burst, cleaning up and fitting a new one.

34. **GRO-C**

35. Every time Bill went into the hospital, I had to go into the hospital after work to give Bill his Ganciclovir drugs that were being delivered, and stored in a special fridge at home. The Ganciclovir had to be kept at a certain temperature, which meant I had to rush up to the hospital to inject it into Bill once I had taken it out of the fridge. The nurses at the hospital were not allowed to open Bill's Hickman line to inject him with his medication, which was for doctors only.

36. Due to Bill's veins collapsing, whenever Bill was in the hospital, the doctors decided that the Hickman line was a handy thing to get blood from. The doctors would take the bung off, instead of going through the rubber to get the blood, take the blood and then put the same bung back on that had often

been laid in Bill's bed. Additionally, the doctors never flushed the line out before or after taking blood, which resulted in the line getting infected.

37. For about a year, Bill was fine during the day, but then after flushing the line and giving Bill his Ganciclovir injections, Bill would feel a bit chilly, and would then start to shake uncontrollably, jumping about in bed. I called the GP out on multiple occasions, who would say that Bill had an infection and prescribed antibiotics and that was it. It later came to light that the Hickman line was infected and each time I was flushing and injecting Bill with a dose of Ganciclovir, the infection was going into his bloodstream making him feel worse. I recall one occasion, following a funeral for one of Bill's friends, Bill was called into the hospital due to blood poisoning. We had had a long day, and were frustrated, I called the hospital back to say that we have been telling them something was wrong for the past seven to eight months. I told them it could wait until the morning.

38. I had been doing everything correctly, and I was very particular about making sure Bill's Hickman line was kept clean, and so I know that this infection came from the doctors using the line incorrectly, not flushing it out, and replacing the dirty bungs back on the line once they had taken the blood.

39. The doctors decided that the Hickman line needed to be removed, and this was done under local anesthetic, so Bill was awake during the operation. When Bill was first taken to theatre for this operation, the doctors were suddenly notified that a serious road accident had occurred and that they needed to clear the theatre for those patients. Bill had to go back to the ward and return to the theatre later that day.

40. The Hickman line is attached with stitches under the skin, and these have to be cut in order to remove it. During this process, the surgeon operating on Bill accidentally cut the plastic tube of the line, and a piece of infected plastic around three inches long traveled to Bill's heart, lodging itself in the left ventricle.

41. As Bill was awake during this surgery, he could hear the surgeons say that they thought that the tube should have been longer. They subsequently got a new line out to measure it against the one they had removed from Bill and realised that part of it was missing. Bill was booked in for further emergency surgery to remove this piece of infected plastic.

42. We were told that there was only one doctor that could do the open heart surgery required, but that he was away. However, the next day we were told that he was back in the hospital and that he could do the required surgery.

This was done using a wire via a vein in Bill's groin, and he was kept awake during this surgery too. Bill said that his heart was fluttering all the time, and he could feel it when the surgeon was touching his heart, trying to locate the plastic. Once removed, the surgeon showed Bill what he had recovered, and Bill was put on a course of antibiotics. This was a particularly hard time for me, as I was trying to work through Bill's illnesses and all the avoidable incidents and issues that resulted from poor NHS care.

43. In November 1994, Bill was taken off the Ganciclovir treatment. After stopping the treatment, Bill was treated with a dose of steroids, however, no further treatment was given to treat the polyarteritis nodosa.

44. The impact of the Ganciclovir on Bill was terrible. Bill was exhausted most of the time, and had bad sweats and shaking at night. Although the administration of the Ganciclovir was time-consuming for me, I knew that if I did it, it would be done properly.

45. Long-term, Bill suffers from severe varicose ulcers, getting so bad that they would even expose his bone. There were incidences where Bill has been in hospital to treat these splits on his leg and the nurses have removed the dressings for a couple of hours until the doctor comes around, not only leaving Bill's open wounds exposed to infection, but his nerves exposed as well.

46. I have made complaints about the way that Bill has been treated in the hospital, telling the nursing staff that leaving the dressings off for so long is when infections get in, and when it is most painful for Bill. Furthermore, I have been in the hospital when nurses have been washing Bill's legs, leaving them lying in a pool of dirty water. I have been so incensed at the treatment provided to Bill, that I have put on a pair of gloves myself, held Bill's leg up out of the water, and told them how the washing needs to be done. I would also sit with Bill until the doctor came around so that I could remove the dressings myself just a few minutes before it was required.

47. There were also occasions when I would go into the hospital and Bill had not had some of his medication or legs dressed, and I would have to tell the nurses that it is supposed to be done every day, not as and when they think they want to, and that Bill was in pain.

48. After Bill started suffering from the polyarteritis nodosa, he was unable to work offshore, and his employer was kind enough to offer him an office job in recruitment so that they could give him a wage. Bill initially took the company up on this offer, but he was so unwell and exhausted, that after I picked him

up at the end of the day, he would open the front door, crawl up the stairs on all fours, and go straight to bed. It was too much for Bill and after a month or so, Bill had to give it up. As Bill worked for a contractor, he had no pension payout, and as he was not working, there was no money. This was a particularly hard period, and I became the main breadwinner, and we were forced to live off my wages from my part-time work as an auxiliary nurse and government benefits, including disability living allowance. Luckily, we were good savers and had already paid off our mortgage by this stage, otherwise, we could have lost our house.

49. Bill and I had plans that we would retire when Bill was 50 and went away to look at flats in Spain for a holiday home to spend part of our retirement in. When Bill was diagnosed with CMV and had to give up work, this plan was curtailed and we had to forget about our dream due to not having the money to do so. We have had to give up so much due to Bill's infection.

50. Although working alongside caring for Bill has been tough, you just have to get on with it. I have learned to manage, and my time at work is now 'my time', away from my caring responsibilities.

51. Bill's illness completely consumed my life and our life together. As Bill could not do anything for himself or on his own, I would do everything with Bill, and there were a lot of social events that I did not go to as it meant leaving Bill. For the first few years following diagnosis, I did not have a life and we could not go out as we had done before.

52. When Bill grew in confidence and knew the limitations of his eyesight, I started to go out more and leave him at home.

53. During Bill's treatment with Ganciclovir, I had to drive Bill to the hospital weekly. There were always episodes when Bill had to go into the hospital for his eyes, or CD4/CD8 steroid blood test checkups. Despite the journey only being about six to seven miles, I would have to go in with Bill and wait, even at the eye clinic. On average, we would be there for about four to five hours for each appointment, and this was considerably worse if Bill went in without me via patient transport. As such, it was easier for Bill to go in if I took him on my days off, despite this being more work for me.

54. I believe that Bill would not be here if it was not for me. If he had to go into hospital for any length of time it would have been horrendous, and Bill would not have lasted long in the hospital. I have seen Bill be in for two, three, or four weeks at a time, and he deteriorated noticeably during that period. The care that Bill received in the hospital was also quite terrible - he was in

different wards, seeing different people, who often did not understand his treatment plan and medications. For them, it was easier if Bill was at home, and I was happy enough to look after him as I knew he was being looked after properly.

55. Socially, we lost friendships as Bill was not well enough to socialize, and our relationship with family members became strained. If we went to visit relatives, we would not have been in five minutes and Bill's ileostomy bag would burst, and it put them off having us to stay all together. In the end, I went to visit my parents and Bill's mum myself, and Bill's brother and his father used to visit us at home instead of us going there. This was nice for Bill, as he had people in the house when I was out at work.

56. I would not say that we experienced any stigma from our friends due to Bill's illnesses, just that we realized who our 'fair weather' friends were. The number of years that Bill has been ill has resulted in us being unable to go to the pub as we used to on Friday and Saturday evenings. When we did start going out, I used to be the driver, but I continued with it just to have a little bit of contact, especially male contacts, for Bill. These friends have all subsequently had their own problems, and we are friends now and do things on the weekend together.

57. I haven't let Bill's infection and illnesses affect our family or outside life. What has to be done will be done at home. Jill, our daughter who lives in London, used to come up a lot and go and visit Bill in hospital - this was initially when Bill's bowel burst, and we thought it was the end.

58. The girls always used to turn to Bill for advice and help with simple things such as putting a shelf up. Bill cannot give them the help that he used to be able to, however, the girls know his limitations now.

59. Bill still thinks that everything should be done like we used to, however, we are older now and I am starting to get cataracts. Over the years, Bill has taught me how to do the electrical jobs that he used to do around the house. I feel like I am the apprentice!

Section 6. Treatment/Care/Support

60. Despite being nominated by the hospital to be in charge of all of Bill's medication and treatment plans, nobody ever asked if I was ok, I just had to order the drugs every fortnight and get all the things down to the chemist. I don't think the hospital acknowledged my professional skills in doing that, rather that I was the wife. Looking after Bill at home, however, was the only

way that Bill could be out of the hospital, and I viewed it as a far better alternative.

61. I do not think Bill experienced obstacles obtaining treatment. However, as the nurses were aware that I knew what was supposed to be going on, and would question everything or pull them up on things that were not being done correctly, Bill and I were certainly seen less favorably on the wards. Bill definitely got a bad name in hospital from us querying everything.

62. No psychological support was ever offered to me with regards to Bill's illnesses, and all the caring responsibilities that I had.

Section 7. Financial Assistance

63. I cannot remember exactly how Bill and I first learned about the Skipton Fund, but it may have been on the news, or I may have heard about it from my work as a nurse.

64. We were aware that the Skipton Fund was providing financial support to those infected with HCV due to infected blood. Bill was encouraged by his lawyers, GP and MSP to apply, in the event that they would expand their remit to support someone who had been infected with a different infection as a result of infected blood, with just as significant consequences as those that were infected with HCV and HIV.

65. Bill registered with the Skipton Fund in November 2004 and submitted an application for financial assistance in January 2005, attaching confirmation that the blood Bill had been given was positive for CMV antibodies. However, Bill's application was rejected on the basis that the Fund was limited to providing financial assistance only to those who had contracted HCV as a result of infected blood. Bill and I were not surprised by this rejection, but we were disappointed. Here was just another organisation rejecting Bill's request for support.

66. Bill and I decided to appeal the decision of the Skipton Fund, in order to demonstrate that in our quest for support we had followed every possible path available to Bill.

67. In October 2006 the Skipton Fund appeal panel denied Bill's appeal, stating that their remit did not allow them to provide support for those not suffering with HCV, and also that Bill had not demonstrated evidence that he had acquired CMV through a blood transfusion. Albeit, in their letter of 21July 2007 the Skipton fund accepted evidence of CMV blood contamination.

68. This really angered us as we had provided them with the evidence of the CMV being as a result of the blood transfusion Bill had been given. In a letter dated 21 July 2007, Nicholas Fish, from the Skipton Fund, apologised to Bill for this error on behalf of the Chair of the Appeals Committee and explained that the reason they could not support Bill financially and had to reject our appeal was only because Bill had CMV rather than HCV, and this was not within their remit. I identify this letter as exhibit WITN 6959004 They accepted that Bill had become infected with CMV as a result of a blood transfusion.

69. The Skipton Fund also advised Bill to seek a judicial review in relation to his case. However, they said they could not support us in funding this in any way as they are not a charity.

70. I feel that it is unreasonable that the Government and the NHS are being selective on what viruses they are going to take responsibility for in relation to infected blood, and offer financial support to only those who fit their narrow criteria. The impact CMV has had on Bill's life is as bad as it gets apart from death, and definitely has had as bad an impact on Bill as having HCV or HIV would have.

71. Bill is on benefits now and also receives industrial industry benefits for being exposed to asbestos at work. Due to being a contractor, Bill does not receive a work pension.

72. All our attempts to apply for funding via the Skipton Fund, and now the Scottish Infected Blood Support Scheme, have achieved nothing and have all been thrown back in our faces. Due to clause 9, only those who are infected with HIV or HCV are eligible, despite it being proven that Bill was infected with CMV from infected blood.

Section 8. Other Issues

73. There are other infections apart from HIV and HCV that have been given to individuals from infected blood.

74. We were made aware that blood was only screened if it was being given to a transplant patient or newborn baby and if it had been screened for Bill the CMV in the blood would have been picked up. You would have thought that if you were giving people blood, it would have been screened for everyone, especially for someone who was then, immunosuppressed.

75. We have not received money from anybody in relation to the infected blood that Bill was given, and the devastating effect it has had on our life. Without the state benefits that Bill claims, Bill would receive nothing.

76. Caring for, and helping Bill never goes away, and whether he likes it or not, I am always helping. I have to make sure I do not move anything that Bill puts down as he cannot find it again otherwise. Despite it being a challenge at times, we rub along together.

77. As Bill cannot do things on his own, it also doesn't take much for him to get annoyed with the things he cannot handle by himself. As I am the only other person here, I bear the brunt of it all. But then again, Bill is still here.

78. We have fought a lot, and Bill has had a hard struggle. The nights are particularly hard, as it is then when Bill starts to think about things, and all the thoughts about his treatment and infection go through his head.

79. After the Penrose Inquiry, I thought that the Infected Blood Scandal had died a death. Now that it has been brought up again, I dare to think that something would come of this Inquiry and that it will all be resolved.

Statement of Truth

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

Signed GRO-C

Dated 9\1\2022