Witness Name: Maggie Stack
Statement No.: WITN5575001
Exhibits: **WITN5575002-5**
Dated: 29|3|22

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MAGGIE STACK

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 February 2021.

I, Maggie Stack, will say as follows: -

Section 1. Introduction

1. My name is Maggie Stack. My date of birth is GRO-C 1947. I am 74. I live with my sister and my son in GRO-C, London. I am retired. Previously, I was self-employed. I intend to speak about my late husband, Colin Gleeson and his infection with Hepatitis C (HCV or Hep C) following an operation in 1976. In particular, I will discuss the nature of his illness, how the illness affected him, the treatments received and the impact this had on him and our lives together.

2. I can confirm that I am not legally represented and that the Inquiry Investigator has explained the anonymity process to me. I do not wish to remain anonymous.

3. The Inquiry Investigator has explained the 'Right to Reply' procedure, and 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

4. I believe that Colin was infected with Hepatitis C following a blood transfusion administered during a circumcision operation in 1976. He was born in GRO-C on GRO-C 1953. He died on 7 March 2019 from liver cancer and mouth cancer; both of which I believe were caused by his original infection with Hepatitis C. His death certificate is exhibited at **WITN5575002.**

5. I met Colin in the early seventies. He went on to become a lecturer in environmental engineering at Westminster University. When we met in the seventies, we were students and lived in the same area. We had a good social circle. I had known him for a couple of years and we then worked together very briefly. In 1977, we started a relationship which continued until his death. Although we were romantic partners throughout the years, I didn't intend to get married. We got married when he became ill and we knew there was no prospect of recovery; we thought it would be more convenient when I would come to sort things out after his death.

6. In 1976, the year before we began a relationship, Colin had a circumcision as he was having trouble in this area. He was told that he had bled more than usual in this operation and would need a transfusion. I am not aware of whether he was given whole blood or plasma. There was certainly no mention of possible consequences or risk of infection. If I recall correctly, the hospital was near Hyde Park. It no longer existed by the time he applied to Skipton as his records could not be located. I will go on to discuss this in more detail later in my statement. I was not with Colin at this time so I do not know the exact details however he was quite certain that he was given a blood

transfusion. He remembered it well and I clearly recall him recounting the fact on several occasions.

7. Over the years, Colin grew more convinced that there was something wrong with his health. He and I were persistently seeking to find out what was wrong with him. This meant many visits to his GP, to osteopaths and various other medical professionals, all with specialisms in different fields. Unbeknownst to him, he had Hepatitis C which went undetected for many years.

8. One day in 2004 or 2005, I can remember him walking in through the door crying. He was very, very upset. He said, 'I've got HCV'. He must have received the results from his GP. He hadn't been to hospital. He must have requested a blood test or a doctor had decided that he needed one. What upset him most of all was the fear that he had passed the virus to me. At that time, we were not aware of how the Hep C could be transmitted. The reason I remember it particularly well was because I recently found a record of a request I had made to my doctor in 2005 for a Hep C test. However, I was not tested in the end. I thought, I've either got it or I don't. I do remember being devastated for him and it was a very emotional – and worrying time for both of us.

9. Once it was confirmed, he then wondered how on earth he got it. We were happily married. Colin was never an IV drug user, nor did he have any tattoos or piercings. He was never medically treated abroad. We both travelled in the seventies. We weren't together at that point but he never mentioned any medical necessities during his travels.

10. The most obvious source of infection was the operation in the early seventies during which he was given a transfusion. He had undergone no other operations since. In fact, I don't think he even saw a doctor for years after that until he began to develop the health problems for which he sought an answer.

11. We educated ourselves quickly after that to find out how it was transmitted. Colin wasn't provided with any information by his doctor following his diagnosis. Nothing about precautions or what it meant for his or our future. He came out so totally upset and was worried for me. We had to find out all about the virus for ourselves.

Section 3. Other Infections

12. To my knowledge, Colin did not contract any infection other than Hepatitis C as a result of the contaminated blood that he was given.

Section 4. Consent

13. I have never been under the impression that Colin was tested or treated without his knowledge or consent.

14. I presume, but can't be sure that Colin was aware that he was tested for Hep C as he was on a quest to identify what was wrong with him.

15. I have no idea whether Colin was tested for HIV or other viruses. It is not something that he mentioned.

Section 5. Impact

16. As mentioned, over the years, Colin felt that there was something wrong with him. Every now and again, he would tell me that he had a strange feeling across his waist line and towards the top of his stomach; a kind of pain or tension. This was his primary complaint when it came to his health. He suffered from bad fatigue – much more than he should have for his age. Colin also thought because of pain that he had a back problem. Over the years, as stated, he continuously saw medical professionals from different fields in order to identify what was wrong. He was proactive in trying to recognise and solve his health problems. For instance, I recall he got a chiropractor for his

back. When there were no answers, he tried not to worry but I know he could not shake the feeling that there was something seriously wrong somewhere. I don't know why it took so long for them to realise that he had Hepatitis C.

17. Over the years he continued to complain about the fatigue but he always tried to make light of it saying it was caused by me keeping him up late! He had great determination in spite of his ongoing health issues. There was no stopping him. He really liked his job very much, that gave him great satisfaction.

18. He also had Lichen Sclerosus. However, I am aware that this condition predated his operation in 1976 and in fact necessitated the operation on his penis that led to him contracting Hepatitis C. He had one patch on his neck and on his back. He was always very thin but he had a good appetite. Otherwise, it is difficult for me to retrospectively ascertain what else was wrong with him as he wasn't one for complaining or moaning. He kept things to himself. He was also very studious when it came to his work as an academic and so he must have had some mental retention!

19. When Colin was diagnosed with Hepatitis C, it was a shocking development for both of us. It actually felt a bit like a bereavement. I felt helpless as if I had no power or control. It was like he had been handed a living death sentence. That's what it amounted to. This might not have been the case initially as we were not aware that treatments were not easily accessible. Colin did as much as he could. He continued working whilst sourcing alternative therapies to try and make himself better. He just wanted to take his mind off his illness. In spite of this, I am very much aware that he suffered with ongoing anxiety.

20. Shortly after his diagnosis, Colin began to research which treatments were available. He spoke to other patients with Hepatitis C and investigated which therapies they had used. In 2005 he began a trial

with Interferon at Whitechapel Hospital but became so sick that his participation had to be brought to an end before completion.

21. Either prior to the first or second trial, he was given a liver biopsy which was very painful. He described it as one of the worst medical experiences. The biopsy revealed cirrhosis. I do not know the level of scarring. However, the impression we got from the doctors at the time was that this procedure only gave a small picture of the state of his liver as oppose to its condition as a whole.

22. Following this, he was seen by Professor Graham Foster at the Hepatitis Department of Whitechapel Hospital. Professor Foster was in charge of a clinical trial for drugs aimed at clearing the virus. There were some problems in getting onto this trial as Colin was told that he couldn't be put onto trials consecutively. There may have also been an issue with the fact that he hadn't completed the first trial. Eventually, shortly before October 2007, he was allowed to participate in this second trial consisting of weekly injections of interferon, together with a daily oral dose of ribavirin. This trial was also unsuccessful. He was genotype 3 which didn't respond well to this treatment.

23. Colin was very sick during all the trials. He suffered from a combination of nausea, hair loss and insomnia. He would never get proper sleep; his sleep pattern was terrible. This problem predated his diagnosis but was exacerbated by treatment. He also had rashes. He was always finding creams to rub on his hands and feet to try and get some relief. It's amazing how much it all blurs into one over the years.

24. We were both distressed and disappointed when the treatments were unsuccessful. Colin was miserable and anxious for the future and this also affected me. I wanted so much to be able to help him and for the treatments to work. After his diagnosis, having spoken to the Hepatologist and other patients, we were told that if he didn't get a

cure, he would not last more than 12 years. It was like a death sentence from the very beginning.

25. After the second trial there were no more treatments available for HCV for the foreseeable future. We were all biding our time hoping that things would go well and that doctors would develop a cure for genotype 3. It was difficult for Colin to learn that other patients with whom he had become acquainted had managed to successfully treat the virus whilst he could not. We both knew somebody who drank a lot and developed hepatitis. They went on to get a cure straight away. The fact that they could get cured and he couldn't, was quite galling.

26. Colin didn't like to cause other people problems. He kept a lot of his emotions to himself. However, I did notice that he became far quieter and more withdrawn during his treatments. Nevertheless, he kept going. After his diagnosis, he took up Qigong, a form of Chinese martial art to improve one's health. He continued with this pretty much until the day he died. I did notice an improvement in his mood and demeanour when he was using the discipline. He always wanted to try to help himself. Towards the end, he was visiting private doctors at Harley Street and coming away with prescriptions for all sorts of drugs. He even planned to go away on a Buddhist retreat. From my point of view, I thought it was hopeless – I am sorry to say that I had almost given up, although I supported him in all his ventures. However, Colin never gave up on himself. He wanted to explore every avenue available to him to get better.

27. In early 2016, Colin embarked on a final clinical trial to treat his Hepatitis C; 'A Phase I, Randomised, Open-Label Clinical Trial to Study the Efficacy and Safety of the Combination Regiment of Elbasvir/Grazoprevir (EBR/GZR) and Sofosbuvir (SOF) with and without Ribavirin (RBV) in Cirrhotic Subjects with Chronic HCV GT3 Infection.' The study was sponsored by Merck Sharp and Dohnme Ltd (MSD) and overseen by Professor Foster. The patient information

sheet, dated 25 February 2016, detailing Colin's agreement to take part in the research is exhibited at **WITN5575003.**

28. Colin received the all clear for his Hepatitis C in December 2016. I can't recall exactly how long this trial lasted and the side effects were pretty much as before but there was that renewed hope. This was such a long time after his diagnosis. We were euphoric and incredibly relieved. It was cause for a celebration.

29. Our joy was very short lived. He was being scanned every 8 weeks as an ongoing part of the clinical trial. By March 2017, the results of the scans revealed a shadow on his liver. He was diagnosed with liver cancer. Within 3 months of being cured and thinking we could go on and enjoy the rest of our lives we were back to square one.

30. By this point, Colin's care was transferred from Whitechapel Hospital to the Royal Free under the care of Professor Tim Mayor. They initiated him on sorafenib. It has several trade names, including Nexavar. He started on the set dose but as his condition deteriorated, the dose was halved. I am not sure for how long he was on this treatment. It was like chemotherapy. He was extremely sick. He experienced complete hair loss and a loss of appetite. At that stage, he was so poorly that he would just sit in the armchair. He had no energy left. He still had some students that he would attend to occasionally. He tried to keep going. He was such a determined character. The Royal Free then informed us that his liver cancer was under control.

31. By 2018, he had developed a small spot in his mouth which transpired on examination to be mouth cancer. He was told that the mouth cancer was rapid and would develop quickly and therefore this should be attended to as a priority. His care was transferred from the liver cancer specialists to those who dealt with mouth cancer at UCL. When I was looking through his papers the other day, I read that the drugs he was

given to treat the liver cancer were likely to be the cause of the mouth cancer. He was operated on at UCL in July or August of 2018.

32. Shortly thereafter, he developed necrosis of the bone in his jaw. He was in such terrible pain all the time. Each time, we had to go to different A&Es. Doctors would look at him and whilst they knew that he had mouth cancer, he was only ever treated for his immediate symptoms. They did not have a holistic picture of his condition. Nobody identified that the problem was back in his liver. The specialists at the Royal Free were no longer in charge and at the time Colin was transferred over to UCL his liver condition was stable and the tumour not growing

33. In the months preceding his death, Colin and I went back to the Royal Free. They agreed to initiate him on another drug. When we returned just two weeks later for a progress report they said that the cancer had totally spread and the only option was to return home for palliative care. To say we were both shocked would be an understatement as two weeks earlier we had been given the impression that he would be starting another drug. It was a crushing blow to Colin. All I could do was try to comfort and support him. By this point, his mouth was in a terrible way. He developed a hole out through the side of his cheek and couldn't eat. Several times a day, I would look after his mouth and clean it out. We were concentrating on ensuring that he did not get an infection. At this point, we were not aware of the severity of the necrosis.

34. Having consulted various medical professionals, everybody told us that palliative care was the only option. We realised at that stage that nobody would be able to do anything. I still didn't realise that he was so close to death. Colin was very reluctant to go into palliative care and therefore a team from St Christopher's visited the house on a daily basis. One of the doctors told us there was no way back. Colin appreciated his candour as he was one of the few individuals who

provided us with unambiguous information. Some people may have found this approach harsh but Colin only ever wanted to know what was going on. He told it exactly as it was.

35. Colin died at home on 7 March 2019. We brought him down to the front room so he could be close to the family. I stayed with him. I don't think I had any sleep in the two or three weeks before he passed away. The causes of death were liver and mouth cancer.

36. He was at home when he died and was later taken to the undertakers from here. I don't think they were aware that he had had hepatitis. They just came and got him.

37. I can't really say whether his diagnosis impacted his career. It is impossible to speculate what energy level he would have had had he been in full health. He was pretty dogged about carrying on and doing one's best. He liked the teaching and he loved the research because he felt that he was doing something for the future. He was concerned with environmental issues and climate change and felt that he had a unique perspective in his field. He transitioned from a practical trades background to an intellectual research field. He felt that he could import a lot of his knowledge and experience from the work force into the academic world. He was studying housing in light of climate change.

38. Only towards the end of his life, did he suffer financially. Having spent 10 years teaching students face-to-face, as his health deteriorated, he felt that he no longer had the strength to continue teaching. He took sick leave but continued to conduct his research. When this period came to an end, he proposed to the university that he continue with his research but no longer teach. But he was being pressured to teach by them and thus felt that he had no choice but to retire. He didn't take this choice freely. He agonised over it for some time. There would undoubtedly have been a financial loss by early retirement.

39. I found it amusing when his union rep advised him against retirement because if he died in the service, he would receive so much money. But he decided to retire because he didn't want to keep fighting the university about whether or not he should continue teaching. The stress of the confrontation was affecting his mental well-being.

40. I was self-employed by that time. I had more power over when I could work. That was much better for me. I was no longer going into work and had more time and flexibility to be with him if necessary.

41. I am of the belief that one should go with what life dictates to you. It is difficult to identify with hindsight what things could have been like and what Colin's life span would have been had he not been infected with Hepatitis C.

42. I have been pretty badly affected by the course of Colin's illness leading to his death. I am more surprised in the sense that I have known relatives who have died. I have not ever felt anything like what I have in the last two years. I suppose I am still trying to live with it. I try to put my devastation to the back of my mind otherwise I wouldn't be able to go on. I used to be very optimistic and outgoing and I now feel much quieter, reserved and withdrawn.

43. I didn't look for any help. Both Colin and I had pretty similar upbringings. Our parents were pretty 'no nonsense'. We were brought up with the ethos to just get on with it and deal with it. I think we both inherited that can-do attitude.

44. As Colin's condition deteriorated, in the 8 to 9 months preceding his death, I provided 24-hour care. Only the hospice assisted. I helped to feed, clothe and bathe him. This caused a terrible dose of sciatica. Bending down and lifting played havoc with my back. I couldn't do anything apart from stand up. When I went to lie down all I could do was lie down on my face. I requested painkillers from my GP but they

refused. My practise is Stockwell Group Practise on Stockwell Road. I couldn't see the doctor I normally see. In the end I had to ask around from people I knew for really strong painkillers. The sciatica went on a long time until I saw an osteopath. I was in agony for much of that period.

45. The hospice advised me to apply for a carers allowance. I received one payment before he died. Then the DHSS asked for it back.

46. Nobody shunned Colin nor I following his diagnosis with Hep C. Luckily, we had pretty open friendships. People accepted that these things happen. However, in general society I found things different. Anybody who has got Hepatitis C is viewed as an alcoholic or drug addict.

47. Prior to his diagnosis, Colin and I enjoyed going to the pub for a drink. After his diagnosis, he did not drink a thing. He didn't want to damage his liver any more than it already was.

48. When he started teaching at Westminster University, I was curious as to whether he would disclose his infection and as far as I recall he did so, although I can't be sure of the extent. I was certainly concerned about the stigma. I do not know whether or not he was worried or whether he was subject to stigma from his colleagues. He never mentioned anybody in particular.

49. I don't know whether his dental treatments were affected by his Hep C status or whether they were aware of his infection.

50. Our son Toby was born in 1981. He was older when Colin was diagnosed. Nevertheless, he was upset when he discovered the truth. Colin and I tried not to lay it on him very much. It wasn't until very much later that he realised the extent of his father's condition. My son has never been tested. It was never suggested by medical professionals.

We didn't think of it. We didn't think I would have it so we both presumed that Toby would be ok.

Section 6. Treatment/Care/Support

51. Colin had difficulty accessing treatments for Hepatitis C. He was only ever treated with drug trials. Moreover, the limitations of the trials were such that once he had been initiated onto one, he might not be eligible for another. That was very stressful after the first trial didn't succeed. He wanted to have a chance to have anything that would help him yet obviously the system wasn't going to accept that. Whilst he embarked on various treatments eventually, none of them were without their stresses and delays. Having been diagnosed in 2004, it wasn't until 2016 that he cleared the virus. If he had received treatment and been cleared earlier, then the cancer might not have developed.

52. As mentioned, Colin was proactive about his care and he was aware of the state of his liver in 2006, following his first failed treatment, in that he had cirrhosis. He challenged his doctors and wanted answers. **See Exhibit WITN5575004 (Letter dated 6 March 2006).** Colin obtained a second course of treatment in 2007 which unfortunately was also unsuccessful. However, it was not for another nine years that he was offered anything else, that being the Merck trial. You can see on the consent form that this trial was for those with a cirrhotic liver.

53. Colin was never offered any counselling or psychological support following his diagnosis with Hepatitis C nor during the resultant treatments. He never went for or sought any help from anyone. He dealt with his own mental struggles. He was offered a brief chat with somebody at UCL after his operation for mouth cancer but that was it.

54. I have never been offered psychological support although Colin often attended appointments alone. He felt that I was wasting my time joining

him. We also weren't married during this time and perhaps he was viewed as a single person.

55. As for suffering from depression at any stage during his illness and subsequent treatments, I suspect that he may have done but Colin was not the type of person who would talk about it to anyone, even those closest to him. He would simply deal with it in his own way. He would not have taken any medication for such a problem as that was not in his character.

Section 7. Financial Assistance

56. I haven't a clue how Colin found out about Skipton. I know that it was available and that we discussed it. I don't remember much in the early days of his application.

57. He was a bit sceptical about the whole thing. He felt that having infected thousands of people, without an admission of responsibility, the government just wanted to take an easy route and give out money. He almost didn't go ahead with the application. However, friends persuaded him. They felt that at least it was something to compensate for his suffering.

58. Colin made his application in April 2009. This was endorsed by Dr Foster who was satisfied, in the absence of concrete evidence, that the virus came from a transfusion. In fact, he was so sure of success that he advised Colin to apply for the next stage payment. **See Exhibit WITN5575005.** However, Colin's application was refused in June that year. His appeal was also refused in March 2010, the reason being that there was no record of his blood transfusion. The panel also didn't believe that his operation would warrant a transfusion in any case. I recall the latter reason for his refusal in particular. How can they be so sure?

59. When Colin sought to enforce his appeal, my sister, Cathy Stack and another two friends; Pat Sampson and Tony Edwards wrote to Skipton to testify to the fact that Colin had mentioned the blood transfusion after his discharge from Hospital in 1976. Myself, Cathy and Pat shared a house with a few others during this time.

60. I remember the whole drama of the application process. I think he was shocked and upset when he discovered that there were no records of the transfusion. He trusted that the National Health Service would have these to hand. He applied to King's College Hospital in April 2009 and received a reply to the effect that his records had been destroyed. I was surprised that when a hospital closes down, this would be the protocol.

61. Colin was annoyed and upset when his application was refused. He thought it was unfair that the option of compensation was dangled in front of him only to be told that he was not worthy. He felt that they had made him out to be a liar. He was pretty disgusted with the whole thing. It all felt like a waste of time, to the extent that he regretted applying in the first place. I felt the same as him. I thought to myself, what kind of a compensation scheme is that for all the thousands of poor people who have been infected and since died? It just seems that it is all about saving as much money as possible and the least excuse will be used to turn you down.

Section 8. Other Issues

62. I think it was a complete scandal that the government continued to dish out contaminated blood even when they were aware that it was infected. At the point at which the government had the information that the blood was unsafe, they should have made people aware and the use of such supplies suspended and the batches destroyed. Is that not what normal thinking people would do?

63. The circumstances surrounding Colin's infection and untimely death have dented my faith in the government. Whoever was the health minister at the time knew what was going on yet continued to import blood from the US. They handed out a living death sentence to thousands of people. Until Colin received a positive outcome from treatment, he knew he had no chance of surviving. Living with that knowledge was very hard.

Statement of Truth

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

Signed GRO-C

Dated 29th March 2022