Witness Name: Graham Clarke
Statement No.: WITN1855001
Exhibits: WITN1855002-WITN1855018
Dated: 2 August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRAHAM CLARKE

Section 1. Introduction

1. My name is Graham Clarke and my date of birth is GRO-C 1956. My address is known to the inquiry.

2. I am retired and live in Glasgow with my wife. We have two adult children – a son aged 30 and a daughter aged 36.

Section 2. How Infected

3. In my youth I suffered from Crohn's Disease, which is a degenerative bowel disease that left me continuously in pain and discomfort and requiring many operations.

4. From 1981 to 1988, I had regular operations on my bowels, some of which required blood transfusions. I know from my medical records that I had at least one transfusion in 1981 **WITN1855002**, followed by 3 transfusions in 1986

WITN1855003, 5 transfusions in 1987 **WITN1855004**, and 3 transfusions in 1988 **WITN1855005**.

5. In 1988, my liver function test had abnormal results, and I was told that this was likely due to my Crohn's disease **WITN1855006.** No further tests were carried out to determine the cause of my abnormal liver function.

6. In January 1989 I was approved to have a permanent ileostomy. This surgery was intended to significantly improve my quality of life and give my body and bowel a rest. I had the operation at Gartnavel General Hospital in February 1989. **WITN1855007**. Shortly after the operation, I required a transfusion of 8 units of blood due to complications **WITN1855008.** Otherwise, the operation was a success and I had no further problems with my health for about 7 years.

7. Around 1996 I began to feel very tired. I was in my final year of a teacher training course, and I was so exhausted that I had to ask my university if I could extend my course. I went to see my GP but he told me that my tiredness was likely due to the stress of the course. However, I knew it was more than this.

8. In August 1997, my GP phoned me to say that he had received a letter from the blood transfusion service saying that I had received blood which is now known to be from an infected donor. A letter from the Hepatitis Clinic to my GP from 19 August 1997 states **WITN1855009**:

> *He received a unit of blood from a donor subsequently found to have hepatitis C infection. In fact he has received a number of units of blood since 1981 over which time he has received a lot of surgical treatment for Crohn's disease. For the past two years he has complained of tiredness, rashes affecting his face, scalp and chest, intermittent headaches and myalgia. He thinks that in 1987 he was jaundiced when he was treated in an Intensive Care Unit following a leaking*

anastomosis after small bowel resection, which was complicated by peritonitis and septicaemia.

I do not know which of the transfusions I received was infected or, therefore, how long I have been infected, as I received many transfusions between 1981 and 1989 and it is not clear which of these infected me. However, I do believe I may have been infected before 1988 due to my abnormal liver function test results from that year.

9. I was not informed of the risks of having a blood transfusion before any of my transfusions. I do not know if I was told before each transfusion that I would be having one, as I was not aware of the extent of how much blood I had received over the years until I saw my records.

10. When my GP told me he had received the above letter from the blood transfusion service, he did not tell me what the batch of blood was contaminated with or what I would be tested for, just that I needed to come into the surgery and have a blood test.

11. When I went to the GP surgery, I was taken to a room with no one in it, rather than waiting in the usual waiting room. The doctor and nurses seeing me were all suited up in protective clothing. I wanted to know what was going on – why I was being quarantined and what blood tests I would be getting done. However, when I asked these questions the staff were very reluctant to give me any information. I could tell I was not getting the full story.

12. After that initial round of blood tests, I was asked back to the GP surgery several times for more blood tests over the next year. I was never told what I was being tested for, and I still don't know. In November 1997, my GP confirmed to me that the tests revealed I had contracted Hepatitis C (HCV), that my liver function was abnormal and that this was due to the HCV **WITN1855010.**

13. My GP did not give me any information about my infection other than that I was HCV positive and would be referred to Gartnavel General Hospital for further investigations. He did not tell me about what my treatment options were, what my prognosis was give any advice on how to avoid infecting others. I surmised, however, from my experience being tested by people in protective suits, that the infection was contagious and serious precautions had to be taken to avoid spreading the infection.

14. About a month later I was able to see a consultant at Gartnavel General Hospital called Professor Miles. HOSP 1943. A liver biopsy was performed which confirmed I had chronic HCV but had not yet developed fibrosis. **WITN1855011.** Professor Miles confirmed my diagnosis and explained that I should not share toothbrushes with anyone and should wear a condom during sexual intercourse in order to avoid spreading the infection. He also provided information about the available treatment, which was a course of interferon and ribavirin.

15. I felt that the information provided to me by Professor Miles was adequate. However, I was shocked by the delay of at least 8 years in finding out that I was infected. In the years between 1989 (the latest possible date I could have been infected) and 1998 I had raised two small children, and feared I could have put them at risk of becoming infected. I don't know why it took so long for the blood transfusion service to tell my GP that I had been exposed to HCV, or why the hospital never informed me that I had had a blood transfusion during my surgery.

16. It is likely that if my GP had not received the letter from the blood transfusion service stating that I had been put at risk of infection, I would never have found out that I received a transfusion at all and could have gone much longer without being aware of my infection.

17. I even asked Professor Miles what he thought had prompted the blood transfusion service to get in contact with my GP at that stage, and he said he wasn't party to that information and I should ask my GP. My GP did not have any further information aside from the letter from the blood transfusion service.

18. I now know from my hospital records that in 1999, a letter was sent to my GP confirming that I had been added to the Hepatitis C Register. My GP then received follow up letters requesting an update on my condition for the purposes of the HCV Register, on 1 February 2001 **WITN1855012**, 27 January 2003 and 4 September 2005 **WITN1855013**. I did not know until viewing my medical records for the purposes of this Inquiry that there was a HCV Register or that my details were on it.

Section 3. Other Infections

19. I was infected with HCV only from my blood transfusions.

Section 4. Consent

20. I could not have consented to a blood transfusion at the time of my operations as I presume it was not known that I needed transfusions until I was on the operating table. However, due to the number of transfusions I required over the years, I would have expected to have had a conversation with my doctors at some stage about the recurring need for transfusions and the risks involved.

Section 5. Impact

21. As a result of my HCV I have developed kidney disease, which has now progressed to stage 5 kidney failure. At this stage my kidneys are unable to process and expel uric acid, so the acid builds up in my joints and causes severe joint pain. I have a permanent catheter to get rid of my excess urine and uric acid. My joints are so swollen that I can't put shoes on, and walking

any more than 10 yards is impossible. This year my movement became so restricted that I qualified for a motability scooter and motability vehicle, which I now use to get around. My kidney failure is too advanced to qualify for a kidney transplant as it would likely kill me. The only treatment available for me is to have regular dialysis, which I will need for the rest of my life.

22. I also suffer from extreme tiredness, and osteoporosis to the extent that even a sneeze can cause my bones to snap. I am not sure which of the conditions I suffer from are related directly to the HCV and which are a result of the kidney failure. However, I understand that the HCV is a causal factor for the kidney disease, and that late stage organ failure weakens your body, making you more susceptible to a range of conditions.

23. I do not currently have any problems with my liver. My liver function was found to be abnormal in 1988, which was not picked up as related to my HCV as I had not yet been diagnosed. My liver function was found to be normal in 2002 after clearing the virus, and remains normal. **WITN1855014**.

24. In February 2019, I had an incident where my heart stopped and I was unable to breathe. I was taken to hospital in an ambulance and put in the high dependency ward. I do not remember how long I was there for or what happened while I was there, but since I have recovered I have been having flashbacks and nightmares about being in hospital. Sometimes I get a jerky feeling, and it feels like my mind is trying to figure out what happened to me. I understand that my time in hospital was physically traumatic; for example, the doctors broke most of my ribs trying to get my heart beating again (as a result of my osteoporosis). I have since seen a counsellor who has told me that I appear to be suffering from post-traumatic stress syndrome as a result of this experience.

25. In the early stages just after my diagnosis, I worried greatly about the potential harm to my wife and kids. The last thing I wanted to do was harm them. I would have done myself in not to harm them. I had no problems about

committing suicide at that time and it did cross my mind, when I heard that I could possibly infect my family, as it would devastate me to find out that my kids or wife had got it from me. Around 1998, during my treatment, was the most difficult time for me.

26. I received interferon and ribavirin treatment for my HCV beginning in August 1998.

27. Before being given the treatment I was first given counselling to see if I was suitable to have the treatment. The specialist nurse told me that not everyone is suitable, but did not tell me what the criteria were. I asked why I had been assessed as suitable and was told that it's not for me to know.

28. The treatment was new at the time, and lasted 52 weeks. It involved self-injecting interferon into a fleshy part of my body and taking ribavirin tablets several times a week.

29. I do not feel I was adequately informed about the possible side effects of my treatment. There is a letter from my gastroenterologist to my GP informing him that I had started interferon treatment, which notes that "side effects were discussed at length and the patient is fully aware of the likelihood of flu-like symptoms with the first one or two injections and the appropriate use of Paracetamol tablets to control these." Regarding side effects, however, the letter states "Interferon is usually well tolerated. However, it is known that patients can experience lethargy, fatigue, hair loss, depression, dry mouth and bone marrow suppression. These effects are infrequent, dose related and entirely reversible on dose reduction or cessation of treatment." **WITN1855015**

30. In fact, the side effects of the treatment were terrible. I was in terrible joint pain, to the extent that I couldn't move. I had headaches, nausea, and diarrhoea. I felt extremely tired and wanted to sleep all the time. I couldn't think, and sometimes talked gibberish. It felt like the symptoms of the flu or a terrible hangover. These effects lasted all day and the next day after taking the

medication, and then shortly after they subsided it was time to take the medicine again. The medication also caused terrible mood swings which I found difficult to cope with. I also developed severe acne on my back after my dose of interferon was reduced.

31. The strangest thing about the treatment was that I had to inject myself repeatedly, knowing that it would help me eventually, but that first I would have to feel horrible for a couple of days, recover and then keep doing it over and over again knowing what was coming up. I hated doing it. As a result of this I became very depressed.

32. In the end I was not able to complete the course of treatment due to feeling severely depressed and suicidal. I stopped the treatment after 36 weeks, in April 1999 as a result of this.

33. I did not return to the clinic to until January 2002, when I was called to attend with other patients who had been treated at the same time as me, to be given our results. It was nerve-wracking to sit there while others came out distressed, having just found out that they didn't clear the virus, and anticipating what my results would be. at which point it was confirmed that I had successfully cleared the virus. **WITN1855014**

34. I now continue to be monitored by the hospital and have check-ups once a year to ensure the virus does not return. I'm also being monitored regularly by the Renal Unit for kidney disease. The frequency of the clinic visits depends on how well my kidneys are functioning. When things are going quite well, the appointments are every two months and then when the disease is a bit more active, they become a lot more frequent. Currently, I am returning to the clinic every month but earlier this year after the fraught incident in February, my appointments were every week.

Even though I have cleared the virus, I am still in acute kidney failure. Over the years, I did some research on the correlation between kidney problems and HCV. During my research I eventually found something called MPGN (membranoproliferative glomerulonephritis), which is a renal manifestation of chronic HCV infection. I asked my various renal consultants about this. However, they were reluctant to believe me that the two were linked.

35. In February 2012,my consultant wrote that "he may have a glomerulonephritis associated with his Hepatitis C, although I think this is unlikely as he doesn't have very much protein in his urine." **WITN1855016** In February 2013, this was still being investigated.

36. In August 2016, a new renal consultant stated that he thought it was "highly unlikely that he has a Hepatitis C associated MCGN given the recurrent negative HCV PCRs and what sounds successful therapy in the 1990s before his renal disease started to develop. I am not aware of any cases of Hepatitis C associated MCGN in the absence of a detectable viral load." **WITN1855017**

37. In 2017, I moved my treatment to the Queen Elizabeth Hospital in Glasgow. I asked my new renal consultant about the link between HCV and kidney disease and she looked up my history to see how long my kidneys had been affected.

38. She found that I had had a blood test done in 1994 that said my kidney function was normal, but that tests in 1998 right after the conclusion of my HCV treatment showed that my kidneys were badly damaged. She concluded, on that basis, that "this does suggest that his renal impairment coincided with his interferon-based anti-viral treatment which did successfully eradicate Hepatitis C". **WITN1855018**

39. I initially was not sure whether it was the HCV virus or the interferon treatment that caused my kidney disease. However, due to the blood results from 1998 showing the significant deterioration in my kidneys post treatment, and the confirmation from my renal consultant, I do believe that if I had not had the treatment my kidneys would be much better.

40. I am also concerned that I did not find out about the blood test done in 1998 until nearly twenty years afterward. If this was the first time my kidneys showed significant deterioration I would have expected to be told about these results. I believe that I was not told because the doctors did not want to own up to the fact that the interferon and ribavirin treatment they gave me caused damage to my kidneys.

41. I never faced any difficulty in getting treatment, just in getting the answers I sought about the origin of my infection and my prognosis. At the conclusion of my HCV treatment I was told that I had cleared the HCV virus but not told of the damage to my kidneys, despite blood tests results from the time confirming this. The biggest regret I have is that if I had known about my kidney damage earlier, in 1998, I could have had treatment for my kidneys earlier and avoided going into kidney failure. Instead, I lived with the damage for years and still do.

42. I was told by a renal consultant recently that there was effective treatment available in the late 1990s that I could have had back then, but which I would not be able to withstand now due to the extent of the damage. Now there is nothing that can help my kidneys. Last week I was told that I will not be getting a kidney transplant, so the only thing left to do is dialysis, which I will need for the rest of my life. This could have been prevented, and it angers me.

43. Having HCV has not hindered me in getting other medical treatment. In fact, it may have helped me get dental treatment. I sought out a dentist who is familiar with HCV and works mainly with people who have contracted it through drug use. I feel that some doctors and dentists like to do a good thing and help out disadvantaged groups, and that in my case this may have been an advantage to me in seeking dental care.

44. At the time of my diagnosis, the stigma around HCV in my community was very significant. We lived in a small community and I could feel people looking at me if I went out. Once I was diagnosed with HCV, a big yellow sticker was placed on my medical records stating my diagnosis. I was disgusted by this.

The sticker was visible to anyone at the hospital or GP surgery if my records were sitting on a table or passed between clinicians. As I lived in a small village I was concerned that other patients in the surgery could see the sticker and know I was infected.

45. In around 2000, one of the receptionists at my GP surgery was particularly upset that I was a patient there as she believed I would infect others. She decided to tell everybody in the village that I had AIDS and was contagious. As a result of this, many people in the community began to fear me. People would cross to the other side of the road if they saw me out. I was told I wasn't welcome at my children's nursery, and I received hateful letters in the post saying things like "get out, we don't want your kind here" and one threatening to burn my house down if I didn't move away. I was too distraught to go to the police as I would have to tell yet another person about my infection and explain everything again, so I got a new job elsewhere and moved away.

46. I found out from people in the community that it was the GP receptionist who had told them, and I told my GP about this. The GP confronted the receptionist about it and she admitted it, so she was dismissed from the practice. However, the damage had already been done. Unfortunately, the lady in question got another job in the only pharmacy in the village (because she was related to the owner of the chemist) so that made it really difficult for me to even get my usual medication from there. I had to get it from another chemist much further away and at great inconvenience to me and my wife. It just made an already fraught time even more difficult to cope with.

47. People started to treat me worse during my treatment, when I began to look more and more visibly ill, lost a huge amount of weight and looked like a bag of bones. People began to talk about us, and my son started getting bullied at school because his friends' parents said if he spent time at their house I would give them a disease.

48. My first wife, whom I had been married to for nearly 20 years and had two children with, struggled with the mood swings caused by the interferon/ribavirin treatment and this stigma. We ended up divorcing just after my treatment in 1998.

49. I remarried in 2000, but we split up in 2008. This marriage was fraught because my second wife already had children, and her children were not understanding of my infection. They called me a leper, which hurt me quite badly.

50. In 2016 I reconnected with my first wife and we ended up remarrying in 2018. The knowledge of HCV in the community is much better now, so people know I won't contaminate anyone and there is less of a stigma.

51. The stigma of my infection has continued to affect my children in their adult lives. My daughter's relationship broke down because her boyfriend found out I was infected. My son grew up earlier than he might have normally. He became a different kind of person; angry all the time and extremely protective of me.

52. As a result of my infection, I was no longer able to pursue a career as a teacher. I was in a teacher training course when I was diagnosed, which involved a placement in a school. I told my supervisors there that I had been diagnosed with HCV, and the matter was progressed to the educational council, who eventually they told me that I could no longer be a teacher due to the risk of infecting children. They told me that I was a liability, and that if I infected a child it would ruin their life. Someone saying something like that wouldn't bother me as much now, but back then it was very upsetting. The last thing I wanted to do was to hurt any other person. After that I resigned from my position and never went back to my course.

53. After leaving my teaching course, I didn't work again for about 2 years. I then started to work in banks from about 2000, and eventually for the HMRC.

54. In 2012 I retired from my position at the HMRC due to ill health as a result of my progressing kidney disease. If I had not been ill, I am sure I would still be working now. I have now missed out on a typical retirement, a pension and am unable to get any insurance as a result of my infection. For a while, before I started receiving financial assistance from the Skipton Fund, I was living hand to mouth.

Section 6. Treatment/Care/Support

55. I have not faced any obstacles or difficulties in obtaining treatment, only in finding out information about my infection, the link between the infection and the kidney disease, and my prognosis, as I mention above.

56. I had about 5 sessions of counselling in 1998-1999 on the NHS. The counselling was included with my HCV treatment. I would go in to the clinic in the morning and have counselling with a psychologist who was familiar with HCV in the afternoon. We discussed how I was coping with the treatment and life in general. The psychologist told me about the nature of HCV, its pitfalls, what it does, and how to live with it.

57. The counselling was a very rewarding way of getting my mind around the infection. I came away with the conclusion that there's no point crying over spilt milk, but what I can do is avoid giving it to anyone else. I was given practical tips on how to do this. I was also told how to conduct myself in terms of disclosing my infected status to people, and that I'm not required to tell everyone right away. Initially I had thought I would need to disclose this information to potential employers, for example, but I learned that it was my right not to.

Section 7. Financial Assistance

58. I found out about the Skipton Fund in about 2004 or 2005 from the media. I was never told about it by any medical professional. I made a Stage 1 application to the Skipton Fund at that time.

59. I didn't have any issues making the application, but it was initially delayed because my doctor had lost my medical records so there was no proof that I had HCV. I had to go back to Gartnavel General Hospital, where my diagnosis was confirmed, and ask them for my records. They did have some records on file, which I was able to submit to the Skipton Fund. My application was then accepted and I received a lump sum payment of £20,000.

60. I found out in December 2018 about the possibility of applying for a Stage 2 payment from the Skipton Fund. I made the application, but was rejected because kidney disease was not included in the criteria for the Stage 2 scheme. The conditions stated that you had to have liver disease.

61. I then sent the SIBSS a letter a copy of the letter from my doctor confirming the link between my interferon treatment and my kidney disease **WITN1855018.** SIBSS wrote back confirming that they acknowledged that the HCV was a causal factor in my kidney disease, but that they would still have to reject my application because kidney disease was not included in the conditions set out by the government.

62. I went to see several solicitors at this time to have consultations about bringing a claim against the NHS, but none of them would take on my case as they said it was time barred.

63. In February 2019, the Scottish Government changed the conditions for compensation to include kidney disease. My Stage 2 application was then accepted and my first payment made. My monthly payments are now £2,250.

64. I don't know why SIBSS is so strict about the conditions set out in their scheme, even as they acknowledge the link between kidney disease and HCV. They never entertained my explanations at all when I appealed their decision to reject my application, they just responded with a brief letter saying that I didn't meet the conditions. I felt they weren't willing to consider the practicalities of my situation and were just following the rules set out for them.

65. I currently receive PIP and ESA benefits as a result of my kidney disease. This, along with the SIBSS money, has allowed my wife to stop work and look after me. I am grateful for this and think the amount of compensation, once I was able to get it, has been reasonable. However, I have lost a lot over the years as well. No amount of money can compensate for what's happened. I would rather have had the proper treatment for my kidneys years ago than get money now.

Section 8. Other Issues

66. I am very angry at what's happened. I've lost a lot over the years. I've lost my health, earnings and future earnings, a considerable pension, my employability, my marriages broke down and my relationships with my children have been changed (and in turn, my grandchildren). Because I've been sick for a long time, I (couldn't and) can't provide the usual family services a healthy father would be able to for his wife and children. Both my children have witnessed traumatic things they'd rather not have over the years, as has my first (and present) wife. At the time of the treatment, our family life revolved around how well I was and a lot of the usual activities a family might have reasonably been expecting to do (such as a day in the park) were just not available to us because I was so ill. I've had to endure malicious gossip from ill-informed villagers, poison pen letters, been shunned and lost several jobs because of the contaminated blood and its treatment. I've been made to feel a leper by the uninformed and by supposed healthcare officials who judged me erroneously.

67. Because of the negligence involved in diagnosis of the blood tests (i.e. the blood tests in 1994 showing kidney impairment but only being advised of this recently) I'm also now experiencing ongoing problems with my health and these are simply going to worsen with only a limited remedy available when rather, if the results of the blood tests had been made known to me in 1994, I could have been given the then available treatment which would have helped a great deal and left me not so incapacitated. My mental health was also badly affected.

68. I can't get life assurance to provide for my family when the inevitable happens and, also, I'm restricted to what types of flights I can take. I can only go on short-haul flights which limits the choice of family holidays and, in any event, holiday insurance is extortionate and that's only when its seldom available. It's affected even mundane, routine things such as that.

69. It seems to me that although I was the one given the contaminated blood and was severely affected by it emotionally and physically, I wasn't the only one to suffer as my children and wife suffered (and still do) from the fall-out. I feel as though I've been poisoned by the NHS or whoever was responsible for it and it's time they faced up to their responsibility for it.

70. In terms of my expectations of the Inquiry, I would like the government to turn round and tell me what happened – how it happened, how they did it, and who did it. I want justice. I want someone to stand up and say yes, we did this and give an answer to why they did it. I would like a truthful answer to why I was contaminated.

71. Aside from the last two years at Queen Elizabeth Hospital, I have felt that the doctors treating me at every stage were reluctant to answer my questions or help me understand my infection or the complications it has caused. For example, I had consultants who told me that my HCV did not cause my kidney failure, without even doing any tests or investigations to find out if it did. They just said that in their opinion it wasn't the cause. I don't want an opinion, I want

clinical evidence. This is important to me because it's not just me they're messing about. There will be lots of other people with kidney problems who are not aware of the causal link between HCV and kidney disease, whom this evidence could help. That's why I'm doing this, because I want people to know that HCV affects more areas than just the liver.

72. When I applied for my records from my then GP, for the purpose of making my Skipton application, I was told they had been lost. I don't understand how they were lost or indeed if they still exist somewhere. I have since obtained some records from Queen Elizabeth Hospital but am not sure if I have seen the full file. I understand my solicitors are in the process of applying for them but would like clarity on what happened to the records I have not been able to access.

73. Since I moved my care to the Queen Elizabeth Hospital, I have been treated very well. I feel the doctors there want to clean up the system, and do their best to get things done for me. Their attitude has been wonderful. They are willing to take on what you tell them take steps to figure out what you need. The doctors also no longer place yellow stickers on my medical records to indicate my infection, and I am no longer quarantined from the other patients. This makes me feel better as I no longer feel isolated and stigmatised.

74. Before 2017, I was under the care of Monklands General Hospital for five years. I did not feel they were helpful and felt they were not interested in giving me answers.

75. I have found my GP to be generally helpful in getting me the referrals I needed, but not forthcoming with any information about my infection or diagnosis.

76. As I mention above, I was treated poorly by the school I was doing my teacher training placement with, who told me I would ruin children's lives by infecting them. Once I moved into banking, I went for an interview once with a bank and they said they wouldn't give me the job because I might infect someone.

77. Aside from these instances, I have found most professionals to be more respectful of me than general community members. Most of my problems have come from the ignorance of people in the community whom I knew socially.

Statement of Truth

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

GRO-C

Signed ....

Dated ....2 August 2019.....