Witness Name: Abby Mace
Statement No.: WITN5244001
Exhibit: WITN5244002
Dated: 31st August 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ABBY MACE

I, provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 2 July 2021.

I, Abby Mace, will say as follows: -

Section 1. Introduction

1. My name is Abby Mace. My date of birth is GRO-C 1991. I reside in Northamptonshire and full details of my address are known to the Inquiry.

2. I intend to speak about my uncle Stuart Fuller born on GRO-C 1969 and diagnosed with severe haemophilia at eight months old.

3. I intend to speak about Stuart's infection with HIV and Hepatitis C (HCV). In particular, the nature of his illness, how it affected him, the treatment received, and its impact on him and my family's lives together.

4. I make this statement with the assistance of my grandmother Violet Fuller, who is Stuart's mother and, my mother Sarah Burns, Stuart's sister.

5. I confirm that I am not legally represented, and I am happy for the Inquiry Team to assist with my statement. We have previously taken part in inquest proceedings relating to my uncle's death between 2012 and 2018.

6. Karen Ashton at Public Law Solicitors in Birmingham initially acted on our behalf during the early stages leading up to the inquest however, due to rising costs, we had to forego legal representation during the Inquest. The Department of Health had legal representation throughout the proceedings. The documents I refer to in this statement largely come from Stuart's medical records provided by the coroner in the latter stages of the inquest and

documents the family received during those proceedings.

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

Section 2. How Infected

8. Stuart was born in GRO-C in 1969, the second of three children, with an older brother John, and a younger sister Sarah. At the time, the family was living in GRO-C

9. When Stuart was about eight months old, he fell and hit his head suffering a bruise which was quite extensive. Alarmed at this, my grandparents rushed him to Queen Elizabeth Hospital on Commercial Road, where he was seen by many doctors who were unable to determine what was causing Stuart's head to swell and therefore, after eight hours, he was transferred to the Royal London Hospital.

10. I believe Professor Brian Colvin had just commenced working at the Royal London Hospital, and he recognised Stuart had haemophilia A. Dr Brian Colvin offered Freeze- dried cryoprecipitate, which was mixed with saline. The procedure to mix up the treatment took approximately 20 minutes, once ready, it had to be administered intravenously by drip which took approximately four hours.

11. My grandparents never recalled being asked if there was a history of haemophilia in the family, and there was not much known about haemophilia at the time. Historically on my grandmother's side, she had three brothers, two of whom were haemophiliacs, GRO-C GRO-C GRO-C GRO-C My grandmother confirms that they did not test her to see if she was a carrier of the gene when she was younger. My grandparents had little knowledge of Haemophilia however it is documented within Stuart's medical records that they asked if my grandfather could be a blood donor. At the time they had heard of "closed donor groups" so decided to raise it. This suggestion was dismissed without explanation and without ever being explored.

12. As a child, Stuart attended a state-run infant's school however, my grandmother would frequently receive telephone calls from concerned teachers at the school whenever Stuart bumped him. They would insist she collect him. Eventually the school's concerns about the consequences of Stuart's illness whilst he was in their care, was too great and my grandparents were offered a home tutor for one hour just once a week until Stuart was roughly 9 years old. It was then recommended by Stuart's school that he be enrolled at Suntrap School

for disabled children on Hayling Island as it could provide a protective environment. This was a residential school and despite my grandparents being told it was in Stuart's best interests, they were heartbroken when he finally started there as this meant he was away from home for weeks at a time.

13. My grandmother told me it was difficult balancing working two jobs, running a household, and caring for three small children, especially when one of them was so poorly at times. Constantly worrying that Stuart could injure himself just by playing with his siblings. My grandfather worked full time as an electrician at a Brewery and therefore my grandmother was the main caregiver to their children.

14. In 1971, my grandparents moved to GRO-C in Kent and despite the need for my grandfather to remain at his job in London, they believed moving to the coast would be beneficial to Stuart's health and wellbeing. Once there, they enjoyed walks down to the Bay each morning and my grandmother started to feel less strained.

15. Once my grandparent's moved to Kent, Stuart's care was taken over by Dr Skelmdale at Thanet Hospital in Margate however, Professor Brian Colvin remained his leading consultant from the time of his haemophilia diagnosis.

16. By the time Stuart was nine or ten years old, he could mix the cryoprecipitate at home. My mum Sarah remembers helping to mix Stuart's medicine for him, and my grandfather, made a machine that helped agitate the mixture inside the bottles by shaking and vibrating them.

19. If ever Stuart needed treatment whilst in the care of Suntrap School, he would be taken, along with a member of staff to St Mary's Hospital in Portsmouth, where he would be administered cryoprecipitate treatment if required.

20. In 1978 or 1979, the family moved to GRO-C in Essex, and once again started appointment directly with Professor Brian Colvin. He had remained to be Stuart's lead consultant throughout the time they had lived in Kent.

21. Then at age 11, on the recommendation of Professor Brian Colvin, Stuart was enrolled at Lord Mayor Treloar School in Alton, Hampshire. This had a regional haemophilia unit on-site, and a large number of the pupils were haemophiliacs. Professor Brian Colvin told my grandparent's that attending the school would be extremely beneficial to Stuart's condition and places there were highly sought-after. I believe the council paid for Stuart's school fees.

22. Whilst Stuart attended Lord Mayor Treloar, Professor Brian Colvin once again monitored

Stuart's medical status and would request information regarding Stuart from the Headmaster and the school's senior consultant haematologist Dr Aronstram. I know this because I have seen a letter to the headmaster of the school dated November 1979 Professor Brian Colvin, also requesting the consultant haematologist Dr Aronstram contact him directly about Stuart.

23. Some of the documents also show Professor Brian Colvin writing to the Barking education authority, and my family has found this difficult to read. When Dr Colvin speaks about Stuart and the other boys, he talks about them being difficult and challenging. He has formed an opinion on their personality rather than providing just a medical opinion.

24. Stuart was extremely intelligent and understood a lot about what it meant to live with haemophilia from a very early age. He knew what treatment worked for him and tried to express this as best he could to the medical professionals around him however, they did not listen most of the time preferring to label him difficult and challenging when in fact he just wanted his voice to be heard.

25. Given Stuart's intelligence and reasoning, my grandmother would often support Stuart's wishes when it came to treatment of his haemophilia. Doctor's caring for Stuart would often want him to have prophylaxis treatment all the time. Stuart felt that given the fact he had haemophilia A, meaning he has less than 1% Factor VIII deficiency, he was acutely aware the treatment the doctors were insisted he had, would not have improved his body's stores of Factor VIII. Despite these concerns, my grandparents felt there was a degree of pressure from Lord Mayor Treloar and Professor Brian Colvin to have the prophylaxis treatment.

26. It is my grandmother's belief that Stuart was transferred from freeze-dried cryoprecipitate to Factor VIII treatment sometime in 1981/82, which was soon after he was enrolled at Lord Mayor Treloar. My grandmother does not recall ever being consulted nor giving consent to a change in Stuart's treatment. My grandmother recalls being informed by Professor Brian Colvin during a quarterly review meeting she attended with Stuart. My grandmother assumes the changes to Stuart's treatment must have been made by Dr Aronstram in discussions with Professor Brian Colvin given that he was monitoring Stuart whilst at Lord Mayor Treloar. Professor Brian Colvin relayed to my grandmother that Dr Aronstram was very much in favour of progressive treatments and wanted his patients to receive the latest treatments. My grandmother recalls asking whether there were any disadvantages with Factor VIII and was told that the new product was "like gold dust" and assured here that there was nothing to worry about at all. My grandmother confirms that despite hearing Professor Brian Colvin medical opinion, she challenged him about the logical necessity of prophylaxis treatment, and they clashed because she believed that if Stuart's reasons for refusing treatment were logical, she would move heaven and earth to make sure his wishes were listened to. Stuart was

concerned that if he had prophylaxis treatment, he would build up inhibitors which would prevent the treatment from working when he suffered a bleed.

27. A year or two later, after this appointment, in approximately 1983, my grandmother saw an article in The Sun newspaper relating to three people who had died from AIDS, one of them was a hemophiliac who they said may have been infected as a result of the blood products they received for their haemophilia. My grandmother spoke with Professor Brian Colvin who once again assured her that there was nothing to worry about and even went as far as to say, the person must have had something else wrong with them. My grandmother had no reason to disbelieve what Professor Brian Colvin was telling her. After all, he had treated Stuart since he was eight months old.

28. It is also noted within the medical records that they documented that Stuart was allergic to cryoprecipitate. This information had never been relayed to my grandparents who were still using cryoprecipitate during home treatment and Stuart was not having any reactions to it.

29. Stuart had needed on one occasion to attend another hospital when he suffered a bleed, and whilst there he received cryoprecipitate and did not suffer from an allergic reaction to it.

30. My grandmother recalls having a continual supply of cryoprecipitate for when Stuart came home at weekends and school holidays, Stuart received cryoprecipitate as treatment for his bleeds, and she kept records of these by serial numbers which was then given to Stuart's residential nurse Caroline. Unfortunately, many of the records of these serial numbers are incomplete or missing from Stuart's medical records.

31. Understandably Stuart's family are confused by what is contained within Stuart's medical records as they seem to be conflicting and contradictory at times.

32. From around age 11, Stuart began struggling with bleeds into his knee. On one occasion, he suffered a haematoma to his right groin, and he spent weeks at the Royal London Hospital in traction to get his knee straight. He had a back slab which is like half a cast they use when you break your leg to prevent the knee from flexing. Stuart then returned home with a cast on which meant my grandparents, my mum and uncle, carrying him up and down four flights of stairs before using his wheelchair to get to the car. Stuart was in a lot of pain and this would often cause him distress.

33. Stuart wanted and often requested to have a procedure to his knee replaced but the doctors kept refusing without giving an actual reason as to why it was not possible. Stuart medical records confirm this to be the case and they show that just before his 12th birthday in 1983, Stuart being refused the procedure again, and the family did not understand why.

34. On reviewing Stuart's medical records, it is evident that the doctors knew by 1983 that Stuart had contracted HIV. The family believe that it was for this reason only that they continually refused to repair his knee.

35. Within Stuart's medical records there is a letter dated 28 June 1983, from Dr Wasif to Professor Brian Colvin which indicates they were carrying out AIDS-related investigations. It goes on to say that Stuart did not exhibit any stigmata of AIDS, such as palpable lymph nodes. They said results would be sent separately, but we have no record of this, and the test results were never sent to us. In a set of clinical notes from 14th December 1983, it is stated that Stuart had Lymphadenopathy greater than 2cm for at least 3 months.

36. In January 1984, the doctors carried out tests which confirmed that Stuart was HIV positive, and another test in March 1984 confirmed the same. However, the letter dated March 1984 states that January 1984 was the first time Stuart was tested for HIV. None of this information was communicated to the family at the time.

37. The family finds it inconsistent that the letter dated March 1984 states the first time Stuart was tested for HIV was January 1984, however other records show investigations were being carried out in 1983.

38. On 25 July 1985, at an appointment with Professor Brian Colvin, concerns about AIDS from contaminated blood products were raised. Professor Brian Colvin, tried to reassure my grandmother that the actual chances of being infected with AIDS from its use was 1:1000. At this appointment Professor Brian Colvin took a sample of Stuart's blood to be tested.

39. On 14 August 1985, my grandparents accompanied Stuart to an appointment with Professor Brian Colvin. It was at this meeting that Stuart was told he had contracted HIV due to the use of Factor VIII blood products. At that meeting, Professor Brian Colvin acted as if Stuart's diagnosis was news to him. However, since reviewing Stuart's medical records, we know this to have been disingenuous because they show Stuart had already been tested for HIV several times and positive results were documented as early back as January 1984. The most recent test before the appointment in July, being dated June 1985.The records confirm that Professor Brian Colvin had been looking out for the stigmata of AIDS in Stuart as early as April 1980.

40. Following Stuart's diagnosis, the doctors did not provide advice on managing the infection and the risk to other family members contracting it. The only advice that was given was purely in relation to present and future sexual partners, and Stuart agreed that he would inform any he intended to have a close relationship about his diagnosis.

41. Professor Brian Colvin did not explain how Stuart might have contracted the infection, and when my grandmother asked Professor Brian Colvin if it could be the Factor VIII. He responded that it was the best medicine Stuart could receive and mentioned that it cost £500 per bottle as if that somehow was relevant. No alternative treatments were offered.

42. My grandmother still feels an overwhelming sense of guilt as she had believed Professor Brian Colvin and continued to administer blood products via injections to Stuart at home. Not only did she unknowingly put herself at great risk administering the products, she also put her other children and any one visiting their home at risk of contracting HIV.

Section 3, Other Infections

43. From a dentist form which Stuart filled out in 2004, Stuart confirmed that he had contracted Hepatitis A, Hepatitis B {HBV), Hepatitis C (HCV), and Hepatitis G (HGV). To my and the family's knowledge, he had contracted HBV, HCV and HIV as a result of contaminated blood products.

44. Stuart also received a generic letter which stated that he may have been exposed to blood and could have been at risk of contracting vCJD.

Section 4. Consent

45. Information contained within Stuart's medical records and other documentation seen by me and my family during the Inquest, leads us to believe that Dr Wasif and Professor Brian Colvin had treated and tested Stuart without his parent's knowledge and/or consent for many years.

46. It is evident from these records and documents that from as early as 1983, the doctors were testing Stuart for HIV without his or his parent's knowledge or consent. Professor Brian Colvin and other medical professionals knew of Stuart's positive HIV status as early as January 1984 when it is documented, and they withheld this information from Stuart until August 1985.

47. Before Stuart's death, he was never made aware that he contracted HIV prior to being told in August 1985 or was being tested from as early as 1983.

48. The family have also seen documents which suggest that whilst Stuart was at Lord Mayor Treloar, there was in-depth scrutiny of three individuals, including Stuart, and two others (whose identity/ names we are aware of) for unknown purposes.

49. Stuart's treatment was also changed from cryoprecipitate to Factor VIII at Lord Mayor

Treloar, without my grandparents' knowledge or specific consent.

Section 5. Impact

50. Stuart recalled a time to me when Professor Brian Colvin tried to admit him to an adult bed in a hospital ward, he was only 13 years old at the time. He was so distressed as his parents were not around that he discharged himself and rang his mother to take him home despite having a bad bleed Stuart would not go back to the hospital until his mother took him home so he could calm down. When they returned to the hospital, at his mother's request, Professor Brian Colvin agreed for Stuart to be admitted onto a children's ward.

51. Following this incident, my grandparents took Stuart to a child psychologist who stated that Stuart was distrusting of adults. Children cannot always communicate what is going on because they may not have the words to express how they are feeling, but their behavior will demonstrate how they feel. These feelings Stuart had were never fully explored by the psychologist. This was the late 1970s/early 1980s and children's mental health was not viewed as an essential part of a child's overall wellbeing which hopefully it is today.

52. Stuart would regularly try to run away from Lord Mayor Treloar. During the holidays and at weekends after returning home, he would always refuse to go back saying to my grandparents that he did not like the prophylaxis treatment the school insisted he have.

53. At home, he did not talk about his time at Lord Mayor Treloar and even as he grew to be an adult, he refused to speak of his experiences unless it was to recall his memories of many failed escapes from there. Stuart made it quite clear he had no fond memories of the place.

54. Contained within Stuart's medical records are notes which show the opinions of the various doctors who were treating Stuart during the time he attended Lord May Treloar, namely Professor Brian Colvin, Dr Aronstrom and Dr Wasif. These notes label Stuart as having challenging behaviour. However, when he was at home, he was not challenging. When it came to his medical treatment, he often took over the task of injecting himself or at least trying to assist my grandmother in doing so. The family now wonder if these opinions tainted the medical care provided to Stuart.

55. Professor Brian Colvin was always dismissive towards my grandparents and especially my grandmother. She challenged him repeatedly when she began to see the news regarding HIV and the risk of contracting the infection through blood products, but Professor Brian Colvin dismissed her concerns. On several occasions, my grandfather offered to be part of a closed donation group to donate blood directly to Stuart, as this used to be the practice before Factor products and cryoprecipitate, but this was declined.

56. My grandparents were never warned about the risk of contracting an infection through blood products, and in fact, Stuart was moved over to Factor products without their knowledge.

57. As soon as Stuart was able to, he left Lord Mayor Treloar and moved into independent accommodation with one of his friends.

58. The stigma surrounding HIV had a massive impact on Stuart and the entire family's lives in general. People with HIV and HCV are treated like their lives are of lesser importance than other "normal" people.

59. The diagnosis changed Stuart, and he was very angry and scared after finding out he had contracted HIV. As far as Stuart was concerned the medication supposed to save his life had now taken his. Stuart lost the little trust he had in the medical professionals taking care of him. Some of his friends at Lord Mayor Treloar had started dying and this impacted Stuart, mentally, emotionally and physically. The thought of dying at such a young age was terrifying to Stuart.

60. After Stuart's diagnosis he was always in a hurry to live life, he felt he had very little time and given the prognosis at the time, he wasn't wrong in thinking so. He enjoyed driving and could not wait to pass his test and get his own car which he managed to do, passing his test first time at 17. Unfortunately, due to his diagnosis he was take risks say when out driving and, in the end, he had a serious car accident resulting in a broken his neck.

61. When Stuart was diagnosed with HIV, he was already in a serious relationship and as a result of the diagnoses, they decided to get married as soon as Stuart turned 18. Stuart told me he felt time was running out for them. Sadly, the marriage only last a few years because Stuart was adamant that he did not want children and despite being offered a type of "sperm washing" to try and ensure he could not pass on HIV, he felt the risk however small was too great. I later learned that Stuart had wanted children but was too afraid of the consequences.

62. Stuart secured a job working at an insurance company after leaving school, but he found

it difficult to maintain his position there because of his ill health and medical appointments. His employers frowned upon the amount of time he was taking off and eventually had to "let him go". Stuart felt that he could not tell them of his HIV status, due to the stigma attached.

63. Stuart told me that after leaving office work, he started repairing car's at one of his friend's garages. Stuart earned very little money from doing this but he loved working on cars and this provided him with the freedom to attend to his medical issues when they arose so he made it work.

64. Stuart had to give up working at the garage as the bleeds into his knee and had badly damaged it leaving him in extraordinary pain. When Stuart was approximately 31 years old, the Royal London Hospital agreed to replace his knee and he was able to get a part time job as a manager at a pub.

65. Stuart's career was impacted by his ill health, which had a knock-on effect on his income. When he secured a mortgage, he had to pay some upfront costs and could only afford it because it was a council property. He later sold that property, and the funds from that were what he used to secure a proper mortgage. By this time, he was in his mid-30s.

66. Within a couple of years of this operation, the replaced knee had become infected and started to eat away at his skin, creating a hole at the surface of his knee. The doctors at the Royal London Hospital refused to let him have knee replacement surgery because of his HIV status and told him he would not be getting another one.

67. At this time, my grandparents had moved to Northamptonshire and Stuart was living in Essex. I recall my grandmother telling me that after they had moved away, they had not heard from Stuart for a few days and this was unlike him as he had a very close relationship with them and his siblings. My grandfather drove back to Essex only to find Stuart extremely unwell in bed. My grandfather drove him back to stay with them. Stuart stayed with them for about a year. During this time, his weight dropped to under 5 stone and Stuart took the decision to be admitted to the Sussex Beacon in Brighton which is a wellness centre for people living with HIV and AIDS. Whilst there, Stuart was fed through a tube which went directly into his stomach. I recall visiting him with my mother and stepfather. We all came out feeling like Stuart was going to die.

68. Whilst Stuart was at the Beacon Centre, my great Uncle GRO-C GRO-C Stuart was so shocked. On his last visit to see GRO-C in hospital. He had been put on a noisy alcohol dependency ward along with alcoholics and drug addicts GRO-C

Sometimes the staff on these wards treat patients in a certain way i.e., they have brought their illness on themselves and assume they contracted HIV through illicit drug taking or risky sexual behaviour.

69. This is the stigma my uncle Stuart lived with throughout his life. My family have witnessed this to be the case on numerous occasions. The death of my great uncle intensified Stuart's belief that he did not have much longer to live and therefore decided he should sell flat and give up his life and independence in Essex to be closer to his parents.

70. It was devastating for Stuart to give up his independence. He did not want to die in the surroundings he had witnessed his uncle die in and wanted his family close by to take care of him when the time came. He stopped seeing his friends when he moved away from Essex in 2007 to live with my grandparents. This was after his visit at the Beacon Centre, when he had been particularly unwell and felt that it was best, he was remembered the way he was, outgoing, funny and most of all, that he looked so healthy and that's how he wanted them to remember him.

71. In 2008, Stuart took the decision to move his haemophilia care to Oxford hospital who eventually agreed in 2009, to take out his infected knee joint. After it was removed, they could not replace the knee straight away as the infection was too severe due to the lengthy time it had been left untreated. Stuart was sent home with an antiseptic block in his knee and had to be given antibiotics intravenously for 6 weeks to see if the infection could be cleared. During this time, Stuart was not allowed out of bed.

72. After his knee operation, Stuart's weight improved but his health was still deteriorating. it was getting harder and harder to fight off infections. Photos of Stuart at these times in his life are extremely hard to look at as you can see the infection taking hold of. Making him a gaunt and unwell shell of his former self. Stuart found times when he looked so thin and gaunt to be extremely difficult mentally and physically. Stuart was by no means a vain person he just did not want to be reminded every time he looked in the mirror that he was dying. He would often tell me he was going to get cheek implants, something he never got to do. My grandmother recalls attending an appointment with Stuart to see Professor Brian Colvin on an occasion when Stuart looked very gaunt. Professor Brian Colvin called Stuart a "dead man walking", my grandmother was too shocked and saddened to respond.

73. Despite Stuart's own deteriorating health, he worked tirelessly to try and obtain justice for other people like himself. He was on committees and trustees of various organisations including the Macfarlane Trust and was working towards securing financial support from various charities to assist people impacted by contaminated blood. He volunteered and was a part of many charitable endeavours.

74. In October 2010, he contributed to an article published in our local newspaper, but he hid his face and last name to protect us from the stigma.

75. Stuart was concerned about the stigma associated with HIV and took several measures to protect himself and his family. On Facebook, Stuart lied about living up north so people would not know where he was living and try to find him.

76. Stuart was very close to his family, we always loved hanging out and supporting each other. In the end, Stuart's circle of friends was his family.

77. Stuart and his sister Sarah were the best of friends growing up and into adulthood. They chose to spend a lot of time just hanging out, they went on holidays together with their partners and social events. He was extremely close to my stepfather. My mother says Stuart was always there for her like a safety blanket if life got too much. Stuart always managed to find the humour to fit any situation.

78. Most of my mother's school holidays were spent entertaining Stuart whilst he was in the hospital having traction or pushing him about in a wheelchair, none of which she minded as they'd always have fun together no matter where they were.

79. From as young as I could remember, I knew my uncle Stuart was ill. I could always tell when he was getting worse as he would go from looking healthy to looking gaunt. It was extremely hard to watch endure all the pain and suffering and not be able to do something about it. As a child, I did not understand what was going on, so it was traumatic for me having to care for a family member and knowing they might be gone at any time.

80. I was very close to my uncle, and our relationship was more like father- daughter than uncle and niece. I believe he was equally very attached to me because he did not have children of his own. I was ten when my father passed away, and Stuart was the one who told me that my father had died. After my father passed away, Stuart took on a more father figure role. As a teenager, he was always there. He would praise me and cheer me on. He was my biggest motivator and I worked hard to make him feel proud.

81. My grandfather felt extremely guilty about Stuart's HIV diagnosis, he felt he had failed to keep his son safe. My grandfather died feeling guilty in 2018, he never got over what had happened to Stuart and he will never get the chance to see justice for his son.

82. My grandmother dedicated her to life to caring for Stuart. Even in the early years she sacrificed her career to care for him and later on in life she remained his primary career. I can't imagine how hard it was for her to care for her son at times when his health was so

poor, never knowing if he would pull through. I know like my grandfather she has felt a great deal of guilt about Stuart's HIV diagnosis and finds recalling the past extremely distressing.

83. When I was 16 I moved in with my grandparents to be closer to Stuart. I used to assist my grandmother in getting Stuart up in the mornings. When I was 18 I made the decision to move in with him permanently, not only to ease the load on my grandmother but because I simply adored Stuart so much. We used to go out together and play poker at our local, pub until he became too sick to do things like that anymore. We would stay up late talking and go out for adventures, memories I will cherish forever.

84. Stuart was seeing a psychiatrist because of the toll living with HIV had taken on his mental health. Stuart was too skilled in hiding his feelings of worry and pain. Preferring to hide himself away when his illness got too much. He tried to stay positive and upbeat around us but in the quieter moments he would let us know some of his troubles. I know he was taking medication to try and help with his insomnia and Amitriptyline to manage pain, although they did not help him and he ended up taking a lot of painkillers just so he could take part in everyday life.

85. Stuart also tried taking various medications for HIV. I remember taking him his medicine along with an orange to help with the taste. However the side effects were so great, at times he had to take a break from it. It just made him violently sick and dizzy. Also the medication along with the HIV caused him to get mouth sores and this made eating uncomfortable. Stuart tried taking to the doctors about this but they would just tell him he needed to take it, if he wanted to live. Stuart did want to live but the medicine was making him ill to the point he could not function.

86. At the age of 20, I purchased my first house, just around the corner from Stuart. Stuart encouraged me to move out, I think this was because he was trying to protect me from his deteriorating health.

87. On Christmas Day 2011, just two months after I moved out, all of my family were coming over to celebrate my first Christmas in my new home. Everyone had arrived apart from my mother and Stuart. Eventually I drove over to my uncle's house to find him in bed vomiting a huge amount of blood into a washing up bowl which he would not let anyone empty. My mother was there waiting for the ambulance to arrive. The sight of seeing him being wheeled into an ambulance on Christmas day will haunt me forever.

88. Stuart was taken to hospital where they discover some veins in his throat had burst and

they performed an emergency procedure. Amazingly at approximately 9pm that evening Stuart was sitting up in his hospital bed trying to make us feel better about what had happened and that everything would be alright. He was later sent home.

89. On 14 January 2012 Stuart's varices burst again, and he was rushed to Northampton General Hospital where he was intubated and put into an induced coma whilst they decided the best course of action. After a couple of days Stuart, still in a coma was transferred to the Royal Free Hospital to undergo a TIPS procedure on his liver. Myself, grandparents, mother and stepfather went straight there and despite the shock and trauma of what was happening to Stuart, we were asked to read, and fully understand a permission form giving consent before the operation could take place. I still don't recall to this day what was signed.

90. Me and my mother attended the hospital everyday despite having full time jobs, we had to make the decision to lose our incomes so that we could be by Stuart's side whilst he was in a coma. Given our own experiences with some of the medical profession we felt anxious about leaving Stuart, we did not trust them to take care of him properly.

91. I took so much time off from work to be with my uncle, I lost my job. In December 2011 I had just qualified the second year of my accounts training. I was due to start my final year, which I had to delay.

92. We spent each day at Stuart's bedside whilst he was in hospital. It was an extremely distressing and anxious time, machines were keeping him alive, we never knew if he would wake up. We remained by his side, until he awoke from his coma several weeks later.

93. When Stuart woke up from his coma, he was transferred to the John Radcliffe hospital in Oxford. Again, given Stuart's failing liver, he was admitted onto a ward for liver patients. He felt unsafe due to the irrational behaviour of some of the patients. Stuart discharged himself despite still being attached to a cannula that was attached to his neck. Stuart had requested it be removed before he left but he was told it would need to be remove by a consultant and one was not available. Stuart decided to leave and seek the help of his GP the following day.

94. Following his discharge, Stuart was becoming increasingly disoriented and confused. We now realised this could have been a sign of pneumonia and although we recall being told this could be caused by being intubated, we were never told what symptoms to look out for. In fact, a week after Stuart died, a consultant's letter arrived confirming Stuart had a cough at an appointment he had had on the Friday prior to his death. We wonder why the consultant did not investigate this further during that appointment. This letter caused us much distress as once again we felt Stuart had been failed by the medical profession.

95. On the 21st May 2012 Stuart was rushed by ambulance to Northampton General Hospital, after my grandparent's found him in bed barely conscious. I went straight to the hospital to find he had been admitted into the high dependency ward. There were five staff members around his bed, made up of doctors and nurses, one of whom was saying firmly and loudly, "do you want to die?" to which Stuart replied "no", "If we have to intubate you, you are going to die".

96. They suspected Stuart had contracted pneumonia, and the staff were chastising him for not taking his HIV medication. I was so shocked, horrified and surprised that I did not say anything to them, not wanting to cause my Uncle any more stress that he was going through. When I think back to that time, I consider that behaviour from the medical profession could be considered abusive. I cannot think of any situation where someone is dying and you ask them if they want to die. My uncle was extremely ill at this point and finding it difficult to communicate.

97. My mother did not want to leave Stuart's side after witnessing what had happened and remained with him, only taking breaks whilst another family member was there. My mother recalls running out of Stuart's room around 3am the day before Stuart died, Stuart thought he was having a heart attack and as no one came when my mother pushed the alarm, she went out of the room to try and fetch someone, only to find the staff gathered around, on what appeared to be a break. They did not seem in a hurry to attend to Stuart.

98. We were with Stuart when he took his last breath on the afternoon of the 24 May 2012. The sight of Stuart dying will remain with us forever. There were so many questions we felt left unanswered. Why did none of the medical profession spot Stuart's pneumonia from the time he had his intubation tube removed and the time he was admitted to hospital especially given that we know my grandmother and Stuart attended a medical appointment on the Friday prior to Stuart's death. One of the many questions left unanswered and which has left our entire family trapped in a mind loop forever.

99. My stepfather was the one who went to identify Stuart's body three weeks after Stuart passed away. It shocks me to the core to know that when he saw Stuart that one last time, Stuart's intubation tube and other medical equipment had not be removed from his body. I'm unsure if this is general medical practice or whether it was because of his HIV status.

100. Due to delays from the hospital and the issuing of a temporary death certificate, we could not bury Stuart until 18 June 2012, nearly a month after he had passed. The funeral director informed us that when they collected Stuart's body, it was not in a good condition and had started to decompose. This meant Stuart could not be embalmed or dressed for his funeral. Sadly, we did not get the chance to take his fingerprints which we were going to have made into a keepsake necklace, something we could all wear and feel like we had a piece of Stuart with us forever. My family and I do not understand why Stuart's body had

decomposed and wondered if it had been stored appropriately. Even after Stuart had passed away his body was treated inappropriately.

101. The impact on our family did not stop even after Stuart died. An inquest was held, which lasted five years. Our letters to the coroner were ignored for the best part of 18 months. After all, we had not requested the inquest. We were still so very shocked from Stuart's death and now we were getting increasingly distressed by the coroner's lack of communication. We feel that we may have been treated this way because of the way Stuart had contracted his HIV, i.e., via contaminated blood that had been provided to him by the NHS during the treatment of his haemophilia and they did not know what to do.

102. While we were going through the inquest process, we could not grieve properly. We had to constantly read documents about Stuart's life, see solicitors, and continue advocating for justice.

103. I had purchased a home at the age of 20 and was working hard to create a great career for myself when suddenly I lost focus because of this. It felt like we could not move on while going through the inquest process. GRO-C GRO-C

104. The inquest process was additionally emotionally challenging and distressing because we were unearthing and bombarded with a lot of documents, records and information regarding Stuart's life and care. We were piecing together the truth of how long the doctors had been monitoring and making comments about Stuart.

105. My grandmother was hurt to realise how dismissive Professor Brian Colvin and the entire medical profession had been. They were dismissive towards her concerns back in the 1980s.

106. We self-funded the inquest process. My grandparents were retired, and we had to find the money for the solicitor's fees. It meant that we had to sell Stuart's car, which he had loved so much and worked on a lot while he was alive.

107. We were initially issued a death certificate; however, this was withdrawn while the inquest was pending. This meant a long delay in having a final death certificate which also affected aur ability to close Stuart's accounts and sell his property.

108. During the inquest process and the final inquest hearing we did not feel that the Department of Health and the coroner were very helpful, sometime even asking us to obtain and provide to them documents which were not in our remit and was for them to obtain. Stuart died in May, and by August, we had secured legal representation ahead of the inquest, but we did not have any substantial communication from the coroner's office until approximately

September 2013.

109. We later learned that the coroner assumed Stuart had received contaminated blood from a transfusion but after locating Stuart's medical notes, he could not see any blood transfusion documented. This was confusing because, clearly had received contaminated blood products due to his haemophilia, especially given the temporary death certificate stated the conditions he had died from and there had never been an issue regarding a blood transfusion.

110. In June 2013, we received a letter from the coroner informing us that she would no longer be conducting the inquest and it would be a senior coroner in Milton Keynes. There was no communication with us or our solicitors about the reason behind this.

111. There were many incidents like the above during the inquest process, which felt drawn out and caused further anguish for the entire family.

112. As late as 2017, during the inquest, Professor Brian Colvin claimed that he first knew about Stuart's diagnosis when Stuart was 16, which is contradictory to that shown in the records. So, we are unclear why he said what he did.

113. During the inquest, Professor Brian Colvin also berated my grandmother regarding her parenting from observations he claimed he had made over 25 years ago.

114. As a family, we did not feel the inquest was answering the questions as to how, when, who, where Stuart contracted contaminated blood during his treatment of haemophilia and eventually lead to his death but more to ensure it was just recorded as a terrible accident, one of those things that unfortunately just happen. This has left me and my family extremely sad, the medical professionals my grandparents put their trust in did more than just fail them.

115. It has been ten years since Stuart passed away. As a family it is difficult to put Stuart's death to rest. We still have so many questions that remain unanswered. We are grateful for this Inquiry however it was launched not too long after the end of the inquest process and was another reminder that Stuart should still be here with us, living his life and to not have answered to why he isn't is at times is too much to bear.

116. Dealing with Stuart's death and the following inquest which took close to 5 years to conclude has left it toll on our family. We have known about this inquest some years before we felt we had the emotional strength needed to put together this statement.

Section 6. Treatment/Care/Support

117. My grandmother, mother and I recall many occasions when visiting Stuart during his

various stays in hospital and nearly every time they were shocked apart some part of the treatment Stuart was receiving from the medical staff. My mother recalls trying to reason with Stuart after an incident in which he was being left to sit and wait for hours to be treated because none of the staff seem to want to treat him. Stuart said it was because of his HIV status and despite trying her best to reassure Stuart it was not the case, it was evidently clear they were avoiding treating him. They said he would have to be seen by a consultant despite not examining him. The consultant eventually arrived at midnight, some 6 hours after Stuart had arrived with an extremely painful shoulder. Stuart firmly believed this was because they had seen his HIV status on his medical record.

118. On another occasion, my family and I recall visiting Stuart after his first knee replacement operation at the Royal London Hospital. After he came out of surgery, they had not even cleaned his bed and he had dirty equipment around him. As soon as they were able, my grandparents took him home.

119. Stuart said it was a frequent occurrence that once they read the file, they would ask for a consultant who would then take forever to arrive. Even Professor Brian Colvin refused to give his approval for the first knee operation because of Stuart's HIV status.

120. Stuart had his first knee operation in 2002. However, it became infected and was causing problems for Stuart, yet the doctors left him with that knee for seven years. By the time the knee was removed, there was a hole in the metal in the knee and in his flesh. At one point, the doctors believed that they might have to amputate his leg.

121. After his second knee operation, he had to discharge himself from the Royal London Hospital. Stuart was ignored by the nursing staff, and they treated him like he was a drug addict. He was admitted onto a ward with other drug addicts due to his diagnosis of liver cirrhosis. He hated the ward because there were drug addicts using drugs in the bathrooms, he had to share with them. He requested to be moved several times and, after being ignored, moved to discharge himself.

122. After waking up from his coma in 2012, he was again admitted onto a ward for liver patients and had to discharge himself as he felt unsafe.

123. I believe that Stuart was able to access psychological support during a particularly challenging period with his mental health while he was waiting for his knee operation.

124. No one in our family has ever been offered psychological support.

Section 7, Financial Assistance

125. I believe Stuart may have received the stage one payment of £20,000 from the Skipton Fund and the stage two payment of £25,000.

126. I know that Stuart struggled financially throughout his life. It felt like a constant process of begging and having to prove that he had contracted HIV and required financial assistance.

127. When Stuart lived in GRO-C, he was investigated for fraud by the DSS. They explained that they had been monitoring him for a year to build a case against him because he was not working and receiving disability financial support. It was horrible for him because he was accused of making a false claim even though he could not work.

128. It is my belief that Stuart was part of a group HIV litigation in 1990 and in order to secure support from the outcome of the proceedings, he had to sign a waiver which stated that he could never make a future claim even if he found out that he had contracted other infections from contaminated blood. They also instructed him to destroy all of his documents and records. He received £6,000 from this litigation.

Section 8, Other Issues

139. Stuart died on the 24th May 2012, initially the Stuart's death certificate was signed however a clerk thought that as Stuart had not died of natural causes then his death should be reported to the coroner. An inquest was opened the very next day. However, despite our legal representative continually requesting a pre inquest review and reminding the coroner of his duty to conduct the inquest in a timely fashion, we did not get that review until March 2014, nearly 2 years after Stuart had passed away. During this period, we did not know what was happening and could not grieve as we were continually having to go back and forth with solicitors and not hearing from the coroner was becoming increasingly upsetting.

140. The whole inquest process took five years to complete. By the time the inquest took place in 2017, we could no longer afford legal representation. The Department of Health had a Barrister present the whole way through the proceedings and we therefore felt that the coroner did not get the benefit of hearing both sides properly.

141. As part of the inquest, we were asking for Stuart's death to be looked into under Article 2: Right to life under the Human Rights Act. We asked for a public inquiry to be opened. The request was denied by the coroner, as he said the issues had been covered in the Penrose report.

142. We did not feel the coroner was independent and impartial in his final analysis. During the inquest it was clear from conversations between the coroner and the Department of Health

that they had been having private communications, that we were not party to and have not since been shared with us.

143. Due to this, we feel that the coroner and Department of Health worked together to provide a narrative on Stuart's death certificate, that we still feel is not the truth.

144. As a family we do not have trust in the Department of Health and the NHS, we feel the system is fundamentally broken at its core. We feel that money and profits were put before human lives and still feel that is the case to date.

145. When the inquest into Stuart's death begun, justice for us looked like a public enquiry being held. Now that it is here, it's hard to put into word what justice looks like. We would like to see those involved held to account.

146. We have never understood why it has taken decades for a public enquiry to be held, or why our request was denied. We have always felt the contaminated blood scandal has been covered up. To date, not many people know about the infected blood scandal, yet everyone knows about the Hillsborough disaster, which killed 96 people, yet this scandal has affected the lives of thousands many more.

Statement of Truth

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

Signed GRO-C

Dated 31/08/2022

Table of Exhibits:

Date	Notes/ Description	Exhibit number
2017	Coroner's report following inquest	WITN5244002