Witness Name: Jane Elizabeth TWYMAN

Statement No. WITN7342001

WITN7342002

Dated: <u>17</u> / <u>04</u> / 2023

INFECTED BLOOD INQUIRY

Exhibit:

WRITTEN WITNESS STATEMENT

OF

JANE ELIZABETH TWYMAN

I provide this statement in response to a request under Rule 9 of The Inquiry Rules, 2006 dated 28th October, 2022.

I, Jane Elizabeth Twyman, will say as follows:-

Section One - Introduction

- My full name is Jane Elizabeth Twyman and I was born on GRO-C 1970 in GRO-C I currently live in the North West of England, at an address that is known to the Infected Blood Inquiry.
- I am a mother of two, the eldest being my son Corey Paul Victoria Twyman (born: GRO-C], 1990) and my daughter Martha Mary Binns (born: GRO-C], 1996). Both are providing the Infected Blood Inquiry with witness statements.

- 3. My children and I are intent on telling the Infected Blood Inquiry of their father, and my former partner, now sadly deceased, Andrew David Binns GRO-C, 1964 to 14th March, 2014), a person who having been born with an hereditary medical condition, was treated by the National Health Service, and who went on to become infected as a result of that treatment which included both the use of blood and organ transplantation.
- 4. Andrew contracted Hepatitis C (which I will also refer to as Hep' C, and / or HcV within this statement). I intend to speak of the nature of his underlying illness and how that impacted upon him and his family, including my children and I, how he was treated, his Hep' C infection and its treatment, and how that affected us all.
- 5. Although I was born in GRO-C, I actually grew up in GRO-C as a result of my family circumstances. I lost my mother to cancer when I was only four years old, and didn't live with my father until I was about seven, as other family members stepped in to help in the absence of my mother, but I never really settled.
- 6. My father looked after me, as best he could as a single parent, but he too died when I was just fourteen years old having had a heart attack. Apparently, he had a heart condition that had previously passed undiagnosed (Angina), and so I became a Ward of Court, staying in <u>GRO-C</u>, passing between various relatives and family friends of my father's, but never settled in anywhere for any appreciable period of time.
- 7. I mention this now, as there was no bereavement counselling over this period, certainly none that was either offered or made available to me as a four-year old or young teenager, and I encountered this situation again when we lost Andrew many years later. It is a serious shortcoming which I feel needs to be addressed.
- 8. The death of my father caused a lot of upheaval and I moved between five families in the space of five years but never truly settled anywhere, which I now believe as I probably couldn't adapt to family life without him.

- 9. Only a few months after his death, I was groomed by <u>GRO-C</u> into a sexual relationship that lasted several months. Over the following five years, four other older men<u>GRO-C</u> had sexual relationships with, or sexually assaulted me. At the time, I believed that I was in love, and in control, but looking back I can see how vulnerable I was, looking to replace the love of my father, and how wrong they were by using me for their sexual gratification only. I have no doubt that none of this would have happened if my father had remained alive. With hindsight, it is hard to say if counselling at the time would have left me less vulnerable, but it certainly couldn't have done any harm.
- 10. Whatever impact counselling may or may not have had, I found that elder men interested me and at the time I inadvertently welcomed their attention, but it wasn't right and should not have happened.
- 11. My childhood and formative teenage years were punctuated by upheavals of one form or another and although I was a good student whilst living with my father, expected to achieve good examination grades, with his passing and the resultant changes in my life, that expectation passed from 'A' grades to 'D's and 'C's.
- 12. All the same, I feel that in more general terms I was quite well balanced and seven years of living with my father had led to my gaining a lot of inner strength and resilience. I was only an infant when I lost my mother, and never really knew her. By contrast, my father and I enjoyed a close, loving relationship and he brought me up well. Not all men are bad, he was a selfless, tender and caring individual and I miss him to this day.
- 13. At eighteen years of age, I rented a place of my own. I met and entered into a short relationship with a man called Eddie. I had known Eddie and a friend of his called Andy since I was about seventeen, with them having been a few years older, in their twenties. My relationship with Eddie only lasted for a few months, and I then entered into a relationship with his friend Andy, this being Andrew David Binns.

- 14. At the time I was a college student, studying to boost my GCSE qualifications which had not been they had initially been anticipated to be, as I have stated. Andy and I were both into the same music scene, a cultural scene of the time, and had a lot in common – we fell in love and a very passionate relationship developed.
- 15. I had by then become rather intolerant when it came to relationships, but with Andy it was different, but our relationship was not to be without its difficulties. We had both been living in the GRO-C area, but after a trip we made to Paris, he told me that he was leaving to attend teacher training in Lincoln, and then I too was moving on, to study at a college in Manchester. All the same, we maintained our relationship, in spite of the distances involved with us writing to one another to maintain contact as best as we could.

Section Two - How Infected

- 16. Prior to our relationship developing, Andy had confided in me that he had been given a kidney transplant. I do not know why he chose to confide in me at that time, but it was clearly not information that he had shared openly, not even amongst friends, but then as a young man admitting to having a serious health issue was probably not a means of endearing yourself to others. It obviously meant something to him, to have told me, when he had told no one else.
- 17. This was a very long time ago, but as I recall we were sitting in a GRO-C café at the time, so I don't think that he went into too much detail of one of his kidneys having failed, but it was quite clear that he had gone through a lot but was then feeling well, having had a transplant. When he told me, he wasn't on dialysis, but had earlier received dialysis treatment over a couple of years.
- 18. Andy's family were originally from Yorkshire, but his father worked for a bank and as a result they had had to move around a fair bit, in GRO-C
 GRO-C and other places, but had been living in GRO-C (quite close to GRO-C) when we first met.

- 19. I subsequently learned, from Andy himself but also through his family, that he had been close to death when one of his kidneys first failed. At that time, which I believe to have been in 1980, he had been living and studying in London when he became unwell, but thought that it was no more than a severe bout of flu, but was found to have kidney disease.
- 20. He was treated, given dialysis and then underwent a kidney transplant operation in Hull. I don't know *why* his surgery was performed in Hull, but at the time his home address would have been in **GRO-C** fairly close by.
- 21. At some point in time which I do not know, but believe to have been in his teen's, Andy was diagnosed as having Alport Syndrome, an hereditary condition which usually comes to the fore in late childhood or as a young adult. It impacts upon your kidney function in particular, leading to chronic kidney disease and loss of function, but can also other organs. Kidneys aside, Andy also experienced audial issues as a child and had to start wearing a hearing aid as a young adult, and also wore spectacles.
- 22. Andy GRO-C, and as a consequence nothing was known of any familial history of any health issues, so when he was found to have kidney disease and in particular Alport Syndrome, it had come completely out of the blue.
- 23. My memories and knowledge are now rather sketchy for this period, as whilst away at college, I met someone else. So, feeling that if I fancied someone else, I couldn't be in love with Andy, I broke up with him. This was entirely my decision, and I was able to deal with that, emotionally, but Andy was left completely devastated.
- 24. Our situation was complicated because shortly after split-up, which was quite acrimonious, I was pregnant (with our son). GRO-C

GRO-C

- 25. I became a single mum, living in Manchester whilst Andy was going through teacher training in Lincoln. My fresh relationship never really got off the ground, so Andy and I maintained contact even when he found someone else himself, as he wanted to keep in touch especially regarding his son.
- 26. Soon after this, Andy's transplanted kidney began to fail and he eventually had to recommence dialysis treatment. He returned home to **GRO-C**, to receive his treatment in Hull;, and as a consequence had to leave his studies.
- 27. Andy and the lady he'd met whilst undertaking teacher training were engaged, but never married and the second instance of kidney failure, when it came, was a contributory factor to the breakdown of that relationship, at least that's what I believe to have happened.
- 28. In around 1992, as a single mother, I moved to Lancaster in order to study culture and communications at the Lancaster University. Andy was then living in <u>GRO-C</u>, with his parents. We exchanged letters and 'phone calls, and after a while agreed to meet in person again, in Manchester, so he could see his son.
- 29. Neither of us were aware that by then, Andy had contracted Hepatitis C he was having dialysis treatment in Hull, but in so far as we aware, his only issues were kidney related together with Alport Syndrome.
- 30. Our rapport slowly returned, and he'd come to visit our son and I at weekends, whilst having kidney dialysis three times each week in Hull General Hospital. As our relationship strengthened, Andy moved to <u>GRO-C</u> so we could all live together as a family, which we both wanted to happen, and as such his dialysis was transferred from hospital in Hull to Preston.
- 31. In spite of the thrice-weekly dialysis necessity, Andy sought to remain fit and healthy, and unlike other kidney patients he was being treated alongside, took regular exercise and cycled, even entering cycle races, there was no inkling that he had Hepatitis C.

- 32. Andy had always been very artistic, and his teacher training course had been undertaken with a view to him teaching art, and he was always drawing or painting. At this time of his life, only the dialysis requirements served to hold him back and meant that he was unable to secure employment, so he focussed on his art. I was still studying, so Andy became a house-father to our son.
- 33. Our local hospital in Lancaster was, at that time (which was around 1993 / 1994), unable to offer dialysis treatment to renal patients, and as a result when transferred from Hull, his care passed to the Royal Preston Hospital. Here, it was apparently hospital policy for new patients to be required to undergo blood tests. The tests included screening for Hepatitis C and other ailments, not only for the sake of the patient, but also for the safety of hospital staff dealing with patient's blood.
- 34. In what came as a complete shock to us all, the Hep' C screening revealed that Andy had contracted HcV. Despite continuing ill health and treatment, Andy had always been quite upbeat around his kidney issues and dialysis, but the news that he had Hepatitis C came as a devastating blow.
- 35. I cannot now recall how we were told of his infection, when, where or by whom, but think that we were not formally told, and at the time no one offered any explanation as to how he may have contracted the virus.
- 36. However, sometime later, Andy was told by the clinicians treating him at Preston, that the source of his infection had been traced back to a blood product he had received as a kidney patient of the Hull General Hospital at the same time as his first transplant operation, in 1980. I do not know if this was as part of that surgery, or if it happened before or after this surgery, but any of these options would have been possible.
- 37. The information he was given had not been speculation by the doctors, but fact, as at the time of him being told, they were able to confirm what he had been given, where and when, even down to them knowing the relevant batch number of the product used.

- 38. Having been told that he had Hepatitis C, and of its origin, I do not believe that he was provided with adequate information about the virus itself what it was and how it could impact upon him; nor was he given sufficient information as to steps he could take to minimise risk be that to himself or to others as he presented an infection risk.
- 39. This was a most confusing time for us both, neither of us really understanding what he had, how it would impact upon him (especially as regards Alport Syndrome), what he or we needed to do, or the risks Hep' C posed. AS an example, I didn't think it necessary to submit to a test myself at that point, and we didn't consider the need for our son to have a test, but we did discuss him contacting his former fiancée, which he did, giving her the option of having a test. She had a test but was fortunately found to be negative.
- 40. This proved to be a difficult conversation for Andy, not least because his former girlfriend then had another partner herself and had she tested positive, then he may have had to be tested as well.
- 41. Our position wasn't helped by the mixed message he had been given when diagnosed on the one hand he was told that Hepatitis C was a serious matter, but on the other that there was nothing to worry about. All the same, as a transplant patient, someone reliant upon dialysis and a man with Alport Syndrome, Hep' C had a massive impact upon his treatment, as post diagnosis he could no longer be treated by Preston and would have to go to Manchester.

Section Three - Other Infections

42. I have no reason to believe that Andy received any other infection, or was exposed to any other ailment(s), by virtue of the contaminated blood product he had been given. I say this as I believe the blood screening he underwent would have identified any other conditions, but I do not know what his blood may have been screened for, in particular HIV.

Section Four - Consent

43. Andy had always been a person who held a lot of faith in the various members of the medical profession, and in particular the NHS in which he pl aced a lot of trust, believing that they would always seek to do what was best for him and others they treated. I believe that he would have given his consent to any procedure a clinician may have suggested, and would have done so without question.

Section Five - Impact

- 44. From our home in Lancaster, treatment at the Manchester Royal Infirmary meant lengthy journeys and long days spent passing to and from hospital, either under his own steam or when using ambulance transport (a volunteer service). It was tiring, which in addition to dialysis he found debilitating.
- 45. It was just over 20 miles from home to Preston, whereas it was well over 50 to Manchester, so a hundred mile round trip, three days a week, every week. If there were traffic problems, which was often the case, the journey took even longer and Andy hated it. He had also become accustomed to the unit in Preston, so it was all new territory for him to learn again, new surroundings, new doctors and nurses.
- 46. On one occasion he returned home in tears, telling me that he'd been made to feel like a leper as he had Hepatitis C as since his HcV diagnosis, he had had to receive dialysis on his own, in isolation, and overseen by staff who came in and out of his room in full protective covering, fully gowned and masked.
- 47. He told me that his isolation and their conduct made him feel different from the other patients, told others that he was somehow contagious, and that people appeared fearful of him, which he found very upsetting.

- 48. Andy's cheery outlook, often in the face of considerable medical adversity, changed with the Hep' C diagnosis and the manner in which it impacted upon his treatment and what he saw as how people then looked at him. His parents had always adopted a positive attitude, and had encouraged Andy to do the same, which worked, until he learned that he had HcV and he changed he had always refused to consider any 'what-if' considerations, but began to worry.
- 49. He was concerned that the virus posed a considerable threat that he would go on to develop cancer, that it would aggravate his Alport Syndrome and / or adversely impact upon his one remaining kidney. He began to question, *"Why me?"* something he had never done before.
- 50. He became very unhappy at times, especially when he was having to get up early to go for dialysis and experiencing long days away from home. He told me that he felt that he had no friends, and no life beyond one of treatment and recovery from treatment interspersed with childcare. He felt that he was caught in a vicious cycle where every week was the same with little or no respite.
- 51. All the same, neither of us saw HcV as having been life threatening, although like other conditions it could 'flare up,' but we tried to accept that 'shit happens,' but there is no point in dwelling on it, you have to move on, but he became very grump whilst I found it increasingly more and more difficult to look at someone in so much distress.
- 52. Eventually, worried about Andy's ability to care for himself, his unhappiness, and generally his desire to simply carry on, I gave up my university course to care for Andy and our son, as we had lost the 'househusband' he had become. So his illness(es) had a major impact upon my life and its trajectory from that point onwards, in addition to all that had gone before.

- 53. Andy felt that his contribution to the family had been unduly or unfairly diminished, as having moved to Lancaster to be with us, he had become a house-husband, looking after our son whilst I went off to university to study. He had also sought to concentrate on his artworks, which he could do around general domestic and childcare requirements, and occasionally selling the odd piece or two, but all of this was lost as was his self-esteem, adding to his unhappiness and becoming ill-tempered.
- 54. When first diagnosed as having Hepatitis C, no suitable treatment plan was available to him, and he entered into a monitoring regime of blood screening and liver biopsies, but not immediately. At one point he *was* offered some form of Hep' C treatment, but declined to take it, which I think may have been as it was incompatible with the dialysis treatment he was having, and all that this entailed.
- 55. During this time, Andy believed that he was on the transplant list. However, he inadvertently discovered that he had actually been removed from the list as a result of his Hepatitis C status.
- 56. Apparently, this had been an error, an accident which should not have happened, and he was put back onto the list when hospital protocol was revised, but at the time his removal from the list came as another crushing blow to him as a transplant had been the one potentially positive thing he could look forward to, such as you can when facing a transplant, as it offered hope of making his life easier.
- 57. Having left university, Andy and I considered having another child together, although we had been told by the doctors treating him that the chances of my falling pregnant would be slim, so our hopes for another child faded as he underwent dialysis.

- 58. Late one night, in September 1995, we received a call from the Manchester Royal Infirmary from someone telling us that a donor kidney had become available. This was exciting news and we rushed to the hospital where even though he still had Hepatitis C, and had to undergo a number of tests first, he received a replacement kidney.
- 59. This was the first time when I ever felt afraid at what may happen, as he was not a well man and this was major surgery, so I worried, but fortunately the operation proved to be a complete success. It was whilst visiting Andy whilst he was a hospital inpatient, post-transplant, that I came over rather 'queasy,' and a pregnancy test revealed that I was going to have another baby. After so much bad news, the success of the operation and the fact that we were going to have another child, lifted both of our spirits.
- 60. The transplant proved to have been so successful that he was taken off of dialysis, so he no longer had to make the thrice-weekly round-trips to Manchester, and although there were restrictions placed upon his diet and fluid intake, he became a lot happier, returned to something of his former cheerful self, and then further good news came when using an inheritance we bought a house, and in GRO-C 1996, our daughter Martha was born.
- 61. Another positive in our lives was the fact that although he still had Hepatitis C, Andy had not yet presented with any symptoms of the virus. His mental health appeared to be improving with increasingly better health, and although he wasn't working, he was encouraged to do so but concentrated upon his art.
- 62. Life carried on, but he found it quite difficult to make any money from art, and wasn't working, so financially things were tight. It also became apparent that Andy was suffering some social anxiety and remained quite an unhappy person, his situation not helped by the fact that he was quite socially isolated and more often than not only had me as another adult to converse with. He had mood swings, and didn't appear to me to relish family life.

- 63. His approach to the children was also affected, as his attitude towards them differed from son to daughter he was quite strict with Corey, his father-son relationship wasn't healthy, and he considered me to be 'soft' with our son all of which led to tension within the family. He treated our two children quite differently at that time.
- 64. Our finances had never been good, I worked to support myself and our son, as well as my studies, but he was on income support. I stopped working when Martha was born, for about six months, but then went back to work as someone had to be bringing in a wage.
- 65. In or around 2000, the doctors who had been monitoring his Hepatitis C condition provided us with more detailed information about this virus, and as a result I decided that I should be tested. Fortunately, this proved to be negative, so I hadn't caught Hep' C from him, but all the same we started taking precautions, telling our children of the care they needed to take, avoiding sharing razors, toothbrushes and the like, just basic care to avoid any transmission of HcV amongst us.
- 66. As the virus hadn't been passed on to me, we felt it unlikely to have been passed on to our son or daughter, so we did not arrange for them to be tested.
- 67. In 2005, the donor organ he had received in September 2005 was found to be failing and he had to return to regular dialysis treatment, but fortunately, by then the provisions for renal care at Preston had been improved, so he was treated there rather than having to travel to and from Manchester for dialysis as he had before.
- 68. I have no reason to believe that his continuing Hepatitis C infection contributed to the failure of this kidney, as it could well have been wholly attributable to his body rejecting the transplant, as is common after a length of time, but then I equally have no reason to believe that it did not. I have never personally linked his kidney issues with Hep' C, and do not know whether they may be related, or not.

- 69. As an aside, I should mention at this point, that tests undertaken in later years revealed that Andy had passed Alport Syndrome on to our daughter, albeit that she is currently asymptomatic.
- 70. Andy received no Hep' C treatment until late 2006 or early 2007 when the HcV monitoring régime revealed that he needed treatment. I do not know what change in his medical situation had indicated this, but a bi-annual test had revealed the necessity.
- 71. The clinicians and our focus changed from monitoring, I think using blood tests and / or ultrasound scans, or both, which for us was by then commonplace, nothing unusual, to ensuring that he received HcV treatment at the earliest opportunity, despite his being on dialysis.
- 72. Looking back, as he was attending hospital so often, and being monitored I various ways for his kidney condition and Hepatitis C, it is hard for me to say when the need for treatment became apparent or upon what tests it was based, as he was always being tested, but I believe it had something to do with the condition of his liver, but he had not shown any outward symptoms at that stage (e.g. no jaundice was then apparent).
- 73. The HcV treatment necessity having been identified in Preston, Andy's Hep' C care was transferred to the Royal Lancaster Infirmary (RLI) which was far more convenient. Another positive was the fact that the consultant responsible for his care in Preston, whom he liked, trusted and appeared to get on well with, also worked at the RLI, so approaching his treatment, Andy was quite encouraged.
- 74. He was placed on a course using two medications, Interferon (which he had to self-administer, using injections into his belly), and Ribavirin (which was in tablet form which he took orally). He was advised that he could experience some adverse side effects whilst on this course, with nausea, fatigue, weight loss, depression and a general feeling of being unwell all having been suggested as likely problems that could arise.

- 75. Andy commenced the course, but from the outset struggled to cope with the side effects he experienced. I cannot now remember how long he was on the course, but we found that he had all of the side effects that had been expected, and very quickly became unwell once he had started, the weight loss becoming very apparent as time progressed as did bleeds which he was unable to staunch.
- 76. It transpired that the dosage of Ribavirin and Interferon had not been adjusted to suit a patient with kidney failure, a matter which I believe his consultant should have identified and addressed accordingly. As a result, the drug toxins that should have been gradually filtered out by a functioning kidney were allowed to build up in his body between his dialysis sessions. In short, the drugs Andy was taking to clear him of the Hep' C the virus were slowly killing him.
- 77. Matters came to a head when he attended dialysis where the clinicians administering it found themselves unable to stop him bleeding and he'd have to remain far longer in the hospital as they fought to control this. It was a situation which went on for months, and he was really unwell throughout.
- 78. One day, the medical staff in Preston were unable to stop him bleeding following dialysis, and he had additionally been bleeding from, his nose. I was called by the hospital to go in, as the clinicians, in trying to resolve the issue, had found both his platelet count and blood cell count to have been dangerously low.
- 79. I went to the hospital with our daughter, and found that the only way in which the doctors had been able to staunch the flow of blood from, his nose had been to cauterise blood vessels in his nostrils.

- 80. When we saw him, he was in bed, in a side room, alone, hooked up to several different machines and with something, some yellow coloured wads stuffed up his nose. He looked terrified. I had never seen him looking so poorly or so afraid as I did at that moment, and can only attribute that to his having been told how close he had apparently been to death, and the trauma of experiencing such an unstoppable blood loss.
- 81. Apparently, as we subsequently learned from one of his consultants, the treatment he had been taking for Hepatitis C, with the dosage not having been adjusted from a 'normal patient' to someone having dialysis, had very nearly killed him.
- 82. Having our daughter with me meant that I tried to keep a brave face on and tried not to cry, she was only about ten or eleven years old at the time, but it was very traumatic and I went to the lavatory where I broke down in tears. It must have been really frightening for our girl, as not only did she see her dad in such a terrible state, but to have also witnessed me breaking down as I did.
- 83. Andy was a resilient individual, a real tough-cookie so to speak, and someone who had always thought that whatever was thrown at him, he would deal with. Even when he became unwell, whilst on the treatment he was pragmatic and accepted the side effects as having been part-and-parcel of the treatment, something he had to endure in the short-term in order to get better, so he just tried to soldier-on until things came to a head as they did.
- 84. He'd always been this way when his kidney had first failed, leading to the initial transplant, he'd felt unwell but carried on until he'd actually collapsed in his flat, only to have been found by his landlord and his parents called. He'd thought it was mere flu, so he'd gone to a corner shop, bought some off the shelf medication and sought to deal with it himself, that's how he was. However, taking Interferon and Ribavirin had such an effect upon him that he told me how difficult he was finding it, something he would rarely, if ever, have done before.

- 85. To prevent any further harm, following the situation which arose when he went for dialysis, Andy was withdrawn from the Hepatitis C treatment course, but subsequent blood testing revealed that what he had taken had actually done its job – after many years, he was finally clear of Hep' C.
- 86. He had to return to hospital, for further tests to confirm this conclusion, but he was indeed clear of HcV. I can recall one of the doctors treating him joking that "... we nearly lost a damn good liver consultant there ..." as he apparently acknowledged that Andy's situation had been their fault entirely.
- 87. By the time this happened, Corey had already moved out of our family home. As he'd grown up, he suffered at the hands of his father as he increasingly stood up to his strict, unforgiving and intolerant nature towards him which I saw myself as being unfair.
- 88. The final straw came when an almighty row broke out over whether or not Corey wanted tea at home. Andy lost his rag and Corey stood up to him, particularly once Andy had shouted at me. They were in each others' faces, GRO-C and subsequently we had to go to A&E – it was horrible, and Corey never lived with his father again.
- 89. Some months prior to this, I had ended my relationship with Andy. At first, I had slept on a camp bed downstairs, and then in Martha's bedroom, but had then moved in to a room which a friend was letting. We still tried to function as a family, as much as we could, taking our meals together, and more often than not I would go to the house each morning to take Martha to school. However, as I had never seen Andy this angry and / or unreasonable before, I took Martha to live with me that night.

- 90. Andy had always treated our children differently, and appeared jealous of Corey whom he looked upon as having an easy life. He'd often berate him, picking him up on almost anything, almost always without reason, and he'd often refer to him as being lazy, which was far from the truth as he was a very hard working, diligent child.
- 91. It is hard to say how much of an impact Hepatitis C may have had upon Andy's mental health, and in particular his anger, frustration, depression and unhappiness which more often than not manifested itself in his approach to our son and I. He definitely felt that he had been dealt a poor hand in life, and was jealous of others, especially Corey who, as a young man, appeared to be enjoying the sort of life he felt that he had missed out upon. Our son, in his eyes had a very simple life compared to his.
- 92. His attitude to others, especially Corey, was unacceptable to me, which caused problems of its own, and we drifted apart albeit that once we separated, I remained at home for some time, as I couldn't just walk out Andy was ill, not evil, and I also had Martha to consider.
- 93. His mental health had deteriorated, and the often complicated health issues he faced had led to his becoming ever more frustrated, with me being the only adult he had available to vent his anger upon. We cooled emotionally towards one another, and when the end came, it was a very difficult and unhappy conclusion to our relationship.
- 94. As I now reflect upon what happened, Andy's intemperate flare-ups tended to coincide with health issues, and he had an awful lot going on in that regard and was not in a good place mentally. It meant that he never had the sort of relationship with his son that they would both have wished for had things been different, a matter of considerable sadness which, with Andy's passing, may never be resolved.

- 95. I was thirty-six when I left Andy, and we had known one another for almost twenty years, my late partner having been the one person I had known for longer than anyone else in my life. He had been very important to me, and we tried to remain friends, and had meals and Christmas celebrations together if for no other reason than I felt it necessary to function as a family, as best as we could, so we also involved Corey and Martha. Andy found this difficult, at first, and just wanted to get on with his life, but he was the children's father so we had to develop some form of working relationship together.
- 96. Around 2009, through routine dialysis related blood testing, the clinicians identified something amiss with Andy's lymph nodes and blood count, but didn't manage to get to the bottom of it.
- 97. The HcV treatment Andy had taken had also caused another medical problem. He was diagnosed as having Endocarditis, the result of an infection he had contracted from a needle used to address his bleeding issues. Apparently, whereas the clinicians were meant to swap the site being used to insert as needle, they had concerns as to their ability to find a new line, and used the same more than once, leading to an infection.
- 98. Endocarditis should have been a wholly avoidable condition, but the infection affected the blood vessels around his heart and it proved very hard to clear using antibiotics, as a result of which he had to have heart surgery.
- 99. Andy, encouraged to enter the workplace following the transplant in 2000, found a job in an outdoor clothing shop, but this was short lived and he returned to benefits but he never received any disability or ill-health based allowance. He was basically a stay-at-home parent, not through choice but by virtue of the health issues he faced. We received child benefit and I was paid a maintenance allowance – times were hard, but we managed.

- 100. In the summer of 2013, Andy's appetite had declined and he was complaining that he had a persistent backache. At this time, Martha and I visited Andy several times a week and ate tea together. I had bought Andy out of the family home, by remortgaging, so Martha and I could live back there, and Andy bought a shared ownership house in a village closeby. We had got into the habit of visiting him for tea. At first, I'd just thought that he was being a little stingy with his food, as he appeared to be eating less and less, but I later realised that his appetite had become very low.
- 101. Passing urine had always been an issue for Andy, due to his kidney issues, as generally he didn't do that, but there was an incidence of him passing urine which was unusual. It turned out that some fluid had built up in a pocket within his bladder, which he then had to have drained in hospital, so he was still experiencing the odd health issue over and above that which had become the norm.'
- 102. Sometime over the summer, Andy and Martha had had a massive row, and she no longer had contact with him. In the Autumn, I bumped into him one day in town and he told me that a lump had been found upon one of his ribs. Usually a positive person when it came to any new medical issue, on this occasion he told me that he *'had a bad feeling'* about it, which was again unusual.
- 103. This situation led to him having to go to the RLI for tests, and I went with him on a couple of occasions. I think that he had an inclination that it was to be his last Christmas, and he wanted to spend it on his own. The three of us, Corey, Martha and myself had a very strange Christmas without him. Then, in January 2014, further test results led to him being diagnosed as having liver cancer and he was told that his position was terminal. I had attended the hospital with him when he was told, and it was a terrible thing for us to hear after all that he had gone through.

- 104. I can remember that I thought it to have been a good thing at the time, that they had clearly waited until after Christmas to tell him what they had found, a compassionate act on the part of the clinicians involved, but it couldn't lessen the blow.
- 105. In so far as I am aware, no one treating Andy directly attributed his liver cancer with the fact that he had had Hepatitis C, a virus which attacks the liver, but this possibility should not be ruled out just because no one said that this was the cause, as it could well have been, I simply do not know.
- 106. Andy was given some Chemotherapy treatment, in an effort to delay the progression of the cancer, but it was too little too late, and in March 2014 he passed away with liver cancer having been cited as the cause of his death. I cannot now remember if his death certificate mentioned Hepatitis C, but if it did not then in my opinion it should have done, at least as a contributory factor.
- 107. In the lead up to his death, Andy became upset when he was called in for interview as regards his benefits, where his need to continue receiving income support was being questioned. He had to ask the benefits office to defer the interview, explaining that he was required to attend both dialysis and cancer related appointments and couldn't just drop everything to visit them at that crucial time in his life.
- 108. They rearranged his appointment, but it was particularly insensitive on their part as they knew full well that he was unfit to work, and it annoys me to this day how inflexible they were. At the time, he had but a couple of months left to live, so his health was actually worsening, not improving, and never would have been.
- 109. Andy had always been able to take what fate threw at him, but that was a step too far and upset him greatly. But he remained resilient, and on the day of his actual death, although he had pneumonia at the time, walked into hospital one last time, under his own steam.

110. As a family, Andy's health was something which my children and I didn't discuss much, as it had different impacts for each of us. Our daughter had only ever grown up with her father in varying degrees of ill health, and often hospitalised, which must have taken its toll upon her. Once our son moved out, Andy changed the focus of his frustration to our daughter, so she started to receive the sort of undue, unfair attention which had led to her brother leaving home.

111. I worry for the impact which visiting Andy in hospital may have had on our daughter's mental health, especially when she was so young and yet experienced such trauma as the occasion when he almost died, having been effectively poisoned by an overdose of HcV medication.

11:	2. Following her father's death, our GRO-C	
	GRO-C	
ľ	GRO-C Although they had fallen out, and she	
	had left home, they had always enjoyed a very close father-daughter	
	relationship, and his death came was a great blow to her. I know, from my own experience, how losing a father I your teens can impact not only upon your academic success but also your vulnerability in relationships as a direct result	

of loss.

113. Fortunately, Martha and Andy became reconciled before he passed away, but Corey never did, although they had begun to see one another again, prior to his death. I believe that his son wanted to ask him *why* he had always acted so poorly towards him, to try to secure some answers, but Andy would have skirted around the issue, it's what he did and Corey wouldn't have pushed too hard for any answers. However, I believe that had Andy still been alive today, they would have become reconciled, and Corey and Andy could have gone on to develop a close bond. 114.

GRO-C

GRO-C

- 115. They lost their father, I lost my longest friend and for many years a partner I loved very dearly. His death came as a devastating loss, even though we had separated, especially as he was still so young at the time, which was quite a sobering experience for me. I am saddened that my children, albeit at times estranged from him, no longer have their father around as they should still have, and in particular that Corey never found out that Andy had actually loved him, something which to our son, would have meant more than anything else.
- 116. I had a turbulent upbringing, as I have mentioned I my introduction, which perhaps allows me to understand a little more of the impact Andy's ill health and early death has had for me, and in particular for our children. Even where we may be considered by some to have been a dysfunctional family, losing Andy struck us all very hard and in many respects, it was as if the lynchpin of our family had been removed.
- 117. I have found it tough to adjust to life without Andy, to deal with the loss and with the changes it has brought about, including its impact upon my own mental health and emotions. I now have a most loving partner, and whereas he may be able to empathise with us, he is not the father of my children, and both they, and I, miss him.
- 118. Whilst Andy had been alive, and in the latter few years of his life, I had been working on the management team of a theatre, but following his death I sought a change in direction as I considered life to have been too short and management too stressful, so I took a minimum wage job, and one with less responsibility.

119. His death made me make bolder decisions as to what was or is important in my life, so in that way it has had a most positive impact. I am now in full time employment, managing my own gardening business – Andy loved gardening, and I like to think that I acquired most of my gardening skills from him.

Section Six - Treatment / Care / Support

- 120. I have previously mentioned most of what I know of Andy's treatment and care, and have touched upon support in terms of bereavement counselling when at the time of my having lost my parents. What I have not mentioned is the fact that at no time did anyone offer or refer Andy or I, or our children. To any form of psychological support.
- 121. Andy never had any support in this regard. He was never offered any psychological support or counselling whilst dealing with his kidney issues, dialysis, transplants or having to accept continuing care. He was not helped when diagnosed as having the life-limiting and lifelong condition of Alport Syndrome, and received no assistance when found to have Hepatitis C nor did he have any counselling or other assistance once being treated for Hep' C. He was allocated a MacMillan Nurse when he was diagnosed with cancer, and I know that he considered this to be of great support.
- 122. I believe that had counselling been available across these areas of his health, he may have been far better equipped to deal with the various setbacks he encountered and treatments he received. Suitable support may well have improved his overall mental health, and as such allowed him to conduct himself in a better manner and possibly prevented the deterioration of his relationships with his son, his daughter and myself.
- 123. I cannot now say whether or not Andy would have voluntarily accepted counselling, all I can say is that he never had the opportunity and as such we all suffered. Fortunately, of more recent times, Corey and I have been able to arrange suitable therapy sessions for us all, and these seem to be having a

positive impact – but it should not have been left to us to source this sort of assistance ourselves.

Section Seven - Financial Assistance

- 124. No one involved in Andy's treatment, including those involved in his Hepatitis C monitoring and then treatment, told him of the existence of The Skipton Fund – his father found out from a news item which should not have been the case, especially as the clinicians *knew* that he was Hep' C infected and importantly *knew* that the source had been an NHS blood product.
- 125. His father helped him complete the application form, but I do not know a great deal more of the process, as we had by then separated. All I can say is that his application was successful and he received a financial award.
- 126. Much of this I have learned in more recent conversations with his parents, who told me that he was awarded something in the region of £10,000but that they had needed to persuade him to accept it as he hadn't wanted to.
- 127. Apparently, once he had been diagnosed as having liver cancer, he could have applied again, something his parents and he were aware of, but he never did, as according to them he simply didn't then have the inclination or energy to do so.
- 128. Having already detailed our difficult financial position, s it was over many years, the reader will fully appreciate that had Andy been in receipt of any form of regular financial support, it would have been most useful and could have gone some way to easing his concerns that he was not contributing to the family and as such boosted his self-esteem. As such, it may have taken some of the pressure off of him and improved his mental health and as such our family dynamics.

Section Eight - Other

- 129. More information should be made available to people with life limiting conditions, and their immediate families. Suitable support needs to be made available for people with these conditions, and / or those undertaking treatments where adverse side effects are likely to occur. Bereavement counselling, especially for children and young persons, should be accessible to all and made available at the earliest opportunity.
- 130. In order to further assist the Infected Blood Inquiry with their understanding of the situation I have sought to detail, I would like to present the following document as an exhibit:-

WITN7342002

A two-page letter, dated 6th September, 2013, from Dr M. Brady, Consultant Physician and Nephrologist, in which Andy's health position at that point in time is summarised.

131. Andy would have hated to have been defined by his ailments. He was, and would have liked to have been remembered as, an accomplished artist, a painter in both oils and watercolours, and self-taught engraver in wood. Whilst living in <u>GRO-C</u>, he painted and sketched the docks, and upon moving to <u>GRO-C</u> produced many images of the surrounding countryside and local landmarks. His works were later exhibited in the Bellwood and Wright (Fine Art) Galleries, with one painting from the 1980's being listed by Art UK, a national online art collection. He loved music, cycling and having a good laugh.

Statement Of Truth

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

Signed:	GRO-C
Dated:	17 04 2023