Witness Name: Mark Bradley
Statement No. WITN5351001
Exhibits: **WITN5351002**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARK BRADLEY

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

I, Mark Bradley, will say as follows: -

Section 1. Introduction

1. My name is Mark Bradley. My date of birth is GRO-C 1963 and my address is known to the Inquiry. I am married to my wife Jackie and we live in Brighton. Jackie works full time as a self-employed nurse prescriber, but I no longer work due to my ill health. We have one daughter, Charlie, who is a year 3 student nurse.

2. I intend to speak about my infection with HIV and Hepatitis C (HCV). In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on myself and my family, and our lives together.

3. I can confirm that I am not legally represented and that the provisions in respect of anonymity have been explained to me and I am happy for my story to be known. I am also aware that if I am critical of any medical professional then they may have a right of reply.

Section 2. How Infected

4. I was born with Haemophilia A and was found to have less than 1% clotting factor, which meant my haemophilia was severe. My parents were actually told that I would die by the age of 14 years old because of the severity of my condition.

5. From a very young age, I was in hospital on a regular basis due to various bleeds. Until I was around 6 or 7 years old, I only received whole blood and I can recall having a needle in each ankle with a pint of blood going into both legs. Treatment times were very long and life was really horrific. I was treated at the Royal Alexandra Children's Hospital in Brighton as we lived in Peacehaven at this time.

6. When I was around 7 years old, treatment switched to the use of cryoprecipitate. This was stored frozen and it had to be defrosted and put into syringes before it could be injected, which meant any bleed was already quite bad by the time you had your treatment.

7. I would often suffer from late night bleeds and this would be quite complicated in terms of my treatment. My mum would have to call the Alexandra Hospital to tell them I had suffered a bleed. They would then call Sussex County Hospital where the cryoprecipitate was stored and their porter would have to drive over from his home in Worthing to unlock the freezer and get the cryoprecipitate out. This was then sent by taxi to the Alexandra Hospital where it would have to be defrosted.

8. When I would attend the Alexandra Hospital in order to get cryoprecipitate injections, I would have to undergo a full examination each time, even if I had told them where the bleed was. I would then be admitted to hospital, for example, for a week for something like an elbow bleed, which was frustrating at the time. It was very difficult to go through this over and over again.

9. Between 1976 and 1977, I started to have Factor VIII concentrate injections. I remember that I was excited about this change from cryoprecipitate to the Factor VIII injections, as the Factor VIII injections were small and only consisted of about 7ml, whereas with cryoprecipitate I would require four 50cc syringes to treat a bleed. My parents were never warned about any risks associated with Factor VIII treatment nor indeed any of the prior treatments I have received and it was considered a very positive development in haemophilia care at the time.

10. As the Factor VIII injections did not need to be kept in the deep freezer, we asked my doctor at the Alexandra Hospital, Dr GRO-D whether I could take some Factor VIII injections home so that I could treat myself without coming to the hospital. Sadly, this was refused which was annoying at the time as I had been injecting myself for years. I had been very scared of injections when I was younger, so a lovely doctor had taught me how to inject myself with the cryoprecipitate when I was just 10 years old. It did not make sense why I could not treat myself at home.

11. My mother went to see Professor Jones in London to ask him directly about whether I could switch to home treatment. I'm not sure what hospital she went to see him at, but I believe he was in charge of haemophilia care in the South East area. In around 1978, I was able to start on home treatment as Professor Jones overruled Dr GRO-D decision on this. Home treatment was life changing as my regular and sometimes lengthy hospital visits ceased.

12. From the time of starting home treatment, I would have Factor VIII injections about twice a week, eventually as a prophylaxis. I also switched my care from the Royal Alexandra Children's Hospital to the Royal Sussex County Hospital around this time, as I was no longer deemed a child by the age of14 years. I was given my Factor VIII concentrate from the Royal Sussex Hospital and continued with this until the 1980s.

13. In 1978, just before my 15th birthday, I had a major operation on my left elbow at St Thomas's Hospital in London. This was the first of many elbow operations and I have had about 20 in total over the years, a consequence of the number

of bleeds I have suffered. On this occasion, the operation was required as my elbow joint had been so badly damaged when I was a child meaning that it had stopped growing from when I was around 10 years old. I was given Factor VIII concentrate for the surgery and prophylaxis factor post-surgery. The centre director at St Thomas' Hospital was the late Professor Geoff Savage.

14. I was back in hospital for my 15th birthday as the doctors wanted to do some manipulations to my elbow under anaesthetic, but I remember screaming in pain when this was done. I was given factor VIII injections again prior to this.

15. In around April 1983, I noticed that after I injected myself with Factor VIII, little red dots would show up on my skin. Initially, Jackie who was a student nurse at the time thought it might be because my tourniquet was too tight. I spoke to my consultant at Sussex County Hospital, Dr Martin Fisher, about this but he wasn't sure what was causing it. Jackie did some research herself and believed I had thrombocytopenia, and later Martin Fisher confirmed that this was the correct diagnosis after ordering some blood tests for me.

16. After this diagnosis, I was placed on a course of steroids for a month which caused me to balloon in weight to over 15.5 stone. They were not working and I saw Professor Savage at St Thomas's Hospital in relation to this and for further tests. After the results of these tests came back, I was told that I needed to be admitted to hospital straight away. I told them I would come to the hospital on Monday, as I knew if I was admitted over the weekend nothing much would be done anyway.

17. The weekend before being admitted to hospital, I went down the pub with my mates and tried to be as normal as possible. I was only 19 years old and it was difficult to have to be in and out of hospitals all the time. After being admitted into hospital, I was told my tests were showing I had almost no platelets, and Professor Savage said that I would need to have my spleen taken out.

18. My platelets were so low that they could not even do the surgery straight away, so I was placed on a drip of sando-immunoglobulin to improve my platelet count

before they could remove my spleen. This medication had to be imported from Switzerland and I was on a slow drip of this medication for 3 to 4 hours a day.

19. Eventually, my platelet count improved enough so that I could have my spleen removal surgery. I had been told that I would have a small scar but I woke up after the surgery with a huge scar. I asked what had happened and was told that they had decided to take out my appendix too. I was stunned by this. Nothing had been previously discussed with me about such a procedure and despite repeated requests I was never given any explanation as to why exactly this was done.

20. I had been in hospital for a month before the surgery, but it took me another 3 months at home to recover from this, what was major surgery. It was a very difficult time as Jackie was training at Barts Hospital and was really struggling and unhappy there, and my dad had suffered his first heart attack the day after I left hospital. There were a lot of other things to worry about, not just my health.

21. I believe that at this point in time when I was in hospital, the hospital may have suspected that something was going on with my blood. 1983 was when HIV was first spoken about in the media but I'm not sure if they had developed a test for it yet or knew what to look for. There was no mention of any blood-borne infections and I continued to have regular check-ups and blood tests throughout the rest of 1983, and also in 1984. My care was moved from Sussex County Hospital in Brighton to St Thomas' Hospital after my operation and I received my Factor VIII from them. I am still a patient at St Thomas'.

22. In around October 1984, GRO-C GRO-C We had not been told anything about HIV by this point GRO-C GRO-C

23. In March 1985, I was told about my HIV status by GRO-D at St Thomas' Hospital. I had just been invited to come for a normal check-up and while I was there, he said that he wanted to have a chat with Jackie and I, as

he had something to tell us. We were taken to a tiny little room and there was no confidentiality at all, there was just a curtain drawn across and he stood in front of us.

24. I will never forget the way GRO-D told me about my HIV. The talk was; "basically, you have got something called HIV and this has been proven because you have antibodies in your system. I'm sorry about this, but it will affect you in some ways especially with regards to your sex life if you two have one. I'm afraid it means from now on no wet kissing, no oral sex, no vaginal sex and no anal sex. Okay, right then that's about it. Off you go and take care".

25. Both Jackie and I were left speechless and to a degree upset and confused. There was no explanation about how cross contamination worked or any potential treatment. There was a complete lack of advice or information. We were not told when they had found out about my HIV or begun testing me for it. I had had my last blood test at St Thomas' 3 months before this appointment, so they would have waited a long time to tell me after finding out if it had been diagnosed following that last blood test. In the meantime, GRO-C GRO-C and I was unknowingly putting her at risk. Jackie was not offered a test at this stage and was only offered one in the late 80s.

26. I found out by accident in 1995 that I had HCV. Dr Mark O'Docherty at St Thomas' recommended that I apply for the care component of disability living allowance under the special rules, as my CD4 count was below 200. I agreed and applied for this, as money was tight at the time. It was only when I looked at the form they had filled out on my behalf, I saw that it said I have HCV. Again, nothing had been mentioned about this during my visits to hospital. It was devastating to find out like this with everything else that was going on at the time.

27. At my next appointment at St Thomas' Hospital, I discussed this with the doctor who I think was Mark O'Docherty and asked why I had not been made aware of my HCV diagnosis. I was told that 10 years earlier I had asked not to be informed about anything new about my health, so they did not tell me about

this. I couldn't believe that they had kept it from me, doubly so when they then hit me with the next bombshell that in around 5 to 15 years my liver would fail and I would die. They seemed to imply that living 'til 2010 would be a best-case scenario for me.

28. Once more, I was not given any information about precautions I should take like drink less alcohol, and no liver biopsies or scans were suggested at the time, despite the jaw-dropping evaluation of my possible life span. There was no suggestion that Jackie should have an HCV test, although by then she had been having regular HIV tests. I was also not given any information about when or how I had been infected.

29. I was more than a little annoyed that they did not discuss this with me sooner, or at the very least ask me if I still did not want to be informed if anything else happened in relation to my health. 10 years before I had been sure I would die very soon, but I had survived a lot longer than I thought I would and my attitudes had changed. A review of my thought process in relation to this should have been done rather than deciding this was information they should keep from me.

Section 3. Other Infections

30. As I mentioned above, I was infected with HIV and HCV as a result of blood products I have received over the years. I think I did receive a letter in the post that mentioned I was at risk for vCJD as a result of the blood products I had received, but I would have thrown it in the bin and I have not thought any more about it.

31. I believe that the HCV may have been responsible for the liver problems I experienced around 1993 when my readings were all over the place. Additionally, during that year for a lengthy period I suffered bad gastric attacks, including stomach cramps and nausea which had a negative impact on both my working and home life.

32. Furthermore, to me the loss of my spleen combined with the HIV and HCV infections has left me with a greatly reduced immune system meaning that I have great difficult in fighting of colds and flu. It has also made me more susceptible to chest infections and I have suffered from many of these including pleurisy over the years

Section 4. Consent

33. Although my mum would have consented to the use of Factor VIII and earlier treatments on my behalf as a child, we were never made aware of any risks associated with their use. I don't think the doctors even knew about any potential risks at the time.

34. I was not asked to consent to an HIV test and only found out I had been tested for HIV when I was given my diagnosis. I'm not sure how long they had been testing me for.

35. I was not asked to consent to an HCV test and I have no idea when I actually tested positive for this, as I was not told about my diagnosis until I found out by chance in 1995. I'm not sure when they started testing me for HCV.

36. I also did not consent to the removal of my appendix, but the decision had been made while I was having the spleen removal operation to also take my appendix out. I'm not sure why this decision was made at the time, but I had been told I would have a small scar following the operation but I was left with a huge scar.

37. I have consented to the HIV medication I take to manage the infection.

Section 5. Impact

38. Following the talk where I was told I had HIV antibodies, Jackie and I did not really grasp the basic information that had been provided to us, and as a student nurse she had more medical knowledge than I did. I was just 20 years old at the time, and it went over my head. We thought that having antibodies to HIV

was a good thing because it meant my body was fighting the infection. Both Jackie and I told our parents about the HIV, but said having the antibodies was a positive thing, which we were obviously wrong about.

39. About 4 months later, I attended an appointment at St Thomas' and while I was off having an X-ray on my elbow, GRO-D told Jackie that I probably had 2 years left to live and to enjoy the time we had together. This was devastating for her and she has said that it felt like the end of her world. We had not been given any indication of this previously so it was a massive shock for her, and it must have been very difficult for her not to share this with me. She did her best to get as much information about HIV as possible through her work, as we were so uninformed.

40. GRO-D had said this to Jackie with very little emotion but I think he could not handle telling me that information directly which is why he told this to Jackie in passing. He had been a good pioneer for haemophiliacs and had wanted to improve treatment, but he could now see everything unravelling around him and I think he found it very hard.

41. I was officially told about my prognosis in around 1985 or 1986, when I asked what it was. I was told it is likely that I would get AIDS and die in the next few years. This was at the Haemophilia section at St Thomas' Hospital, but it was still not a proper haemophilia centre at this stage. There was still no proper information provided about living with HIV. I remember thinking that I just wanted to get on with what life I had left and it was at this point that I told my doctors that if there was anything else that was going to get me in the next few years not to tell me. My reason at the time was that I didn't feel I would be able to cope with anything else. I was expecting to die at any moment.

42. I decided to try and enjoy and live whatever time I had left. I started working for the Civil Service for the Department for Health and Social Security, now known as the Benefits Agency. They had been the ones responsible for importing the products that had caused my infection, which I thought was quite ironic. I was working in the area of income support in a public facing role, which was quite

stressful. I also had the additional stresses associated with the ongoing AIDS campaign at the time. Some people at work knew I was a haemophiliac but I tried to hide that as much as I could in case anyone saw the potential association.

43. One day, my boss GRO-D blurted out in front of our unit, "aren't you scared about HIV?" which was horrible as I didn't want people to make that link – I didn't know where to look. Living with HIV was like having a dirty little secret and trying to keep it hidden was very stressful and difficult. By about 1989 everyone was talking about the AIDS epidemic at work and I became quite depressed about the whole thing.

44. In May 1986 I caught chicken pox from my best friend and I didn't speak to him for a year as I was so unwell from it. He is still my best friend and we speak about this even now. Jackie had recently qualified as a nurse and noticed the spots on my wrist. Although my sister had chicken pox when we were children, my parents had tried to protect me from catching it as I was already so unwell with the haemophilia. However, it probably would have been better if I caught it at a young age as the impact of chickenpox tends to be worse the older you are.

45. I had been sick for a few days and was living on my own in my flat at the time. My GP at the time, Dr Gill told me that I was too unwell to stay at home and I was admitted to York isolation ward at Sussex County Hospital and placed in a side room at the end of a corridor. I was so unwell that I even saw the 'stairway to heaven'. I had a very high fever and I was covered in spots and extremely weak

46. I recall if any medical staff came in to see me, they would be in full PPE and it was barrier nursing. They would treat me as quickly as possible and then leg it out of the room. I began to realise this was probably because of HIV and not chickenpox, and I started to feel very sad about the stigma I was facing, not just then, but potentially later. At one point I had a bad nose bleed and I needed Factor VIII, but when I pressed the buzzer to call someone, no one came. I had

to walk through the hospital to the haematology department to get Factor VIII while bleeding and they didn't even recognise me there as I looked so unwell. I remember being wheeled back to the ward after getting the Factor VIII and being left on my own again.

47. Jackie recalls having to provide my personal care as when she came to visit me, I was lying in my own vomit, I was hallucinating and I had not been given any water. I was pretty out of it but the medical staff just ignored me. I ended up complaining to the hospital and it went right to the top but it was never resolved. We were invited to attend a board meeting but they would not accept that I had received poor care and said I had been looked after. We thought we may as well forget about the complaint after this, as it clearly wasn't going anywhere.

48. In 1987, Jackie and I sold the flats we owned and moved in together that November. I was surprised I was still alive, as I was not expecting to be. AZT treatment had become available and I discussed with Dr Mark O'Docherty whether I should start this. He told me it wasn't a great treatment, but it might help me a little bit. Generally, I was quite well at this time apart from bouts of gastroenteritis and extended periods of colds and flu due to my low immunity, but this was quite normal when working in an office environment. Because I was still well, it was decided that I would not start AZT at this point.

49. In November 1990 I had surgery on my ear drum, having burst both ear drums when flying to San Antonio in 1984, which caused me to partially lose my hearing for some time. I had kept putting the surgery off due to the time I had previously spent being hospitalized but decided to get it over and done with. I recall that the ward had the names of the patients outside it, and next to my name it said 'HIV' in red. I was not happy about this but I was told it could not be removed due to infection control. It was degrading. There was no confidentiality. I also had bad gastroenteritis in 1990 and a bad bout of flu, which meant we had to cancel Christmas. In the back of my mind, I was wondering whether this was the beginning of the end, but I kept fighting.

50. I continued to have to take Factor VIII regularly, about twice a week, for various bleeds. These bleeds could be triggered by the most insignificant things like picking a coffee cup up the wrong way. I could bleed anywhere in my body; often I would feel a weird pain somewhere and realise I was probably suffering from a bleed. This was really nothing new to me as I had lived with haemophilia all my life.

51. I had regular check-ups at St Thomas' every 3 months, and would always be counting down until the next appointment. It came to feel like I was living my life in 3-month intervals, waiting to find out if my health had deteriorated further. After another 3 months had passed, I was always surprised – and grateful, that I was still here.

52. I tried to continue to live a normal life and would enjoy going down to the pub with friends and having a few pints of Kronenbourg and a smoke. I didn't worry about the impact that would have on me, given everything else I was contending with and bearing in mind my prognosis, I was never expecting to live very long.

53. I was still working as a civil servant but my job was causing me a lot of stress. I couldn't tell them what was going on but I was under immense pressure from the constant threats and intimidation as well as the emotional drain that was often part and parcel of meeting claimants face to face. I remember someone saying to me, "you don't know what it's like to live with HIV", and I could not even respond as I had to hide what I was going through. It was horrible to be consistently shouted and screamed at and it was really affecting me.

54. Jackie and I joined a support group for other haemophiliacs living with HIV, so we had a place where we could openly discuss our experiences. It was sad because after a period of time someone would stop coming, and we would find out they had died. I had met one of the guys who came to the group when we were quite young, as our dad's had founded a haemophilia support group when we were children. He had told me that he didn't want to die of HIV and I told him to fight it. Sadly, he passed away and it was another friend missing from

the group. Yet one more instance that kept on making me think; when is it going to be my time to die?

55. Jackie and I decided to stop going to the support group in around 1991 and gave up our places for some others who could benefit from it. We just felt sad and didn't look forward to going to the group any longer. We also had 2 dogs at home that we didn't want to leave for too long, and it was a 2-hour drive there and back.

56. In around 1993, I decided to go part time at work due to the stress, so I had the Friday off. However, in the end all this meant was that any work that came in on a Friday had to be done by me on a Monday, which only added to the pressure. I knew that stress was bad when you were living with HIV and I was concerned about this. My doctor had given me a letter to give to my employer which asked them to reduce my stress at work, but nothing was ever done about this.

57. Around this time, I had gastroenteritis and suffered from an upset tummy for weeks and weeks which was very worrying, and my skin had a yellow hue to it. This was due to the HCV, which I didn't even know about yet. I would get very tired very easily. I felt like I was living on borrowed time and like every day I had was now a bonus, which just added to my nervous tension.

58. Recombinant Factor VIII became available as part of a 10-year trial, and I had to go up to the hospital in London regularly for this. I could not explain to my work why it was so important to change to this type of Factor VIII without explaining to them about my HIV being caused by the Factor VIII I had been having all these years. It was a very difficult time, living with this huge secret.

59. By early 1994, the stress was getting too much. My doctor at St Thomas' told me that I needed to relax and he signed me off work for some time. On the 24 September 1994 I finally told my boss that I had HIV and that I was leaving work, and that they would never see me again. I think this was a huge shock for them.

60. I was given medical retirement in July 1995. I remember they sent someone over to my house to discuss why I needed medical retirement, and when I told him I had HIV he physically shifted in his chair. He could not wait to get out of my house. I had worked at the civil service for 15 or 16 years and got my pension, but I had hated my time there. I would have liked to do a job that involved time spent outdoors but because of my haemophilia I never thought this was something I could do. Leaving the civil service was the best decision I ever made, even though if I had been well enough to stay, I would have been promoted up the chain.

61. After we learned about my HIV diagnosis, GRO-C GRO-C I had always said to myself that I didn't want children and that I hated children, but I think I made myself feel this way because I had thought I could never have children of my own. I always thought Jackie felt the same way, so when she told me that she wanted to have a child, I was shocked. This is something we had never discussed, GRO-C GRO-C

62. GRO-C

63. GRO-C GRO-C We were so lucky to have our daughter Charlie in GRO-C 1999. She GRO-C and her face is in a medical journal. We were offered various radio and media interviews to discuss this which we turned down. We probably would have had more children if not for my HIV and at times, this is a source of sadness but we feel very lucky to have Charlie. We did think of trying GRO-C but I had to consider that I was still to my mind seeing out a death sentence. Would it be

fair on Jackie to have another child when I might not be around to help care for her? We felt blessed to have Charlie and decided to use the time to concentrate on her.

64. After I left the civil service, I ended up working in car valeting for classical and sporting cars for about 6 years until 2001, and I trained to be a professional vehicle valet. I would do private work as well as working for a company. I really enjoyed this line of work but it was not a good job for a haemophiliac as it is quite physical work and resulted in a lot of bleeds. I had to have many surgeries on my elbows and I suffered arthritis in my ankle. I also started to feel very tired and even doing a bit of shopping exhausted me to the point where I would have to sleep for a few hours. I eventually told my GP that I could not work anymore and he said I had done well to work as long as I had.

65. By 2001, I was surprised that I was still alive as so many of my haemophiliac friends had died of HIV or HCV. Everyone had told me I was dying but I was generally okay health wise. I had been living my life looking forward to the next 3 months only and had no future vision at all. I just wanted to know why I was still alive and what my prognosis was, not just for me but for my wife and family.

66. I asked my doctor to retest me for HIV and HCV. My results came back confirming I was HIV positive, but my HCV PCR test was negative. I was told I had self-cleared the HCV, which only happens in about 5% of cases. I felt very relieved by this news but I remember GRO-D said that I shouldn't take much notice about clearing HCV as I probably have Hepatitis E, F and G because of "all the shit I had been given", before stomping off. This was not very nice to hear and dampened my mood somewhat.

67. By about 2004, my health had deteriorated a fair bit and, in my heart, I knew that I wasn't very well. I had been feeling hot and bothered for quite some time and in the previous year I had 3 attacks of bronchitis. I had a permanently upset stomach and felt like I was always coming down with the flu. I had also started to get eczema and my face was constantly red and itchy. I was constantly tired.

I had lost my dad in February of that year and the grief was a contributory factor but I was feeling pretty down in general.

68. I attended an appointment with Dr Mark Smith, my brilliant orthopaedic surgeon, and while I was there, one of the nurses commented that the doctors were upset that I kept refusing HIV treatment. I was so confused by this and asked what she was talking about, as I had never been offered any treatment for HIV apart from the AZT in 1986/7. Everyone seemed to assume that if you had been living with HIV for a long time you would either be on treatment or have refused it, but this was not the case for me. It transpired that because I had said – after being advised to some extent to do so, that I would wait for better treatment to become available rather than start on AZT, they thought I had refused all HIV treatment, which was just not the case!

69. The nurse mentioned a doctor that was highly regarded in relation to treating HIV patients and that there were various new treatments available. I explained that I had never met this doctor let alone turned down any treatment from him. However, this did prompt me to make an appointment with this doctor who I call Dr Babu, a top virologist in London. I still see Dr Babu regularly for monitoring.

70. At the initial appointment, I was given information about the various types of HIV medication available and was told to think about it and decide how I wanted to proceed. In the meantime, I was asked to start on a course of mild antibiotics every day but it turned out I was allergic to this drug. My face became red and swollen and it felt like I was on fire. It dawned on me that whenever I had taken this particular medication in the past the same thing had happened, but previously I had only taken this drug for short periods so the reaction was less obvious. I phoned the hospital and they told me to stop taking it. I believe this allergy is linked to having had my spleen removed.

71. I had been thinking about starting HIV treatment and what this would mean. I knew that the treatment would buy me time, but I didn't know how much and the impact it would have on me and those closest to me. I felt like I was starting to lose the battle I had been fighting for years and did not know what I should

do next. Jackie wanted me to start the treatment but said it was up to me to decide what I wanted to do.

72. By the time of the next appointment, I still wasn't sure what I was going to do in terms of the treatment, but on the way to the hospital I told Jackie I had decided to start the medication. At the appointment I was told what tablets I would be on and that I would have to take 3 tablets once a day and then another 2 tablets once a day, but they had to be exactly 12 hours apart. I suppose I thought that every time I took the tablets it would remind me that I had HIV, and didn't like the thought of this. I was told these tablets would eventually only need to be taken once a day.

73. I was sent home with 2 weeks-worth of tablets, as in the first few months I would need to go back for regular blood tests to make sure I was not having any negative reactions to them. We were due to go on holiday at Easter and decided it would be best to start the tablets after the holiday. We went away on a caravan holiday with another family, and I felt terrible. I wished I had brought the tablets with me to start taking them then and there.

74. After we came back, it was almost like D-day and I just wanted to start taking the tablets. My T cell count at its lowest was 90 and before I started the tablets it had been 140. 6 weeks after taking the tablets it had risen to 185. The doctor was very pleased when he saw me and explained that my body had been running a marathon without me realising it, and it was finally having a rest. Although I was feeling better and not as tired, I was still feeling a bit emotionally fragile. I wasn't necessarily scared of dying, but I worried about my daughter being left without a dad and I felt sorry for Jackie who had always been a tower of strength for me.

75. Not long after starting the treatment, my viral load became undetectable and has stayed that way. There were virtually no side effects to the medication. My CD4 count was lower than normal in April this year, but I had just had my second Covid jab so I have been told it is likely linked to that. My CD4 count is also lower because I have no spleen. As I've mentioned, I am annoyed that I

had my spleen out and I have tried to get additional compensation for this as in my opinion it has affected my health. However, none of my doctors will commit to the fact that I had to have my spleen out because of my HIV or HCV, even though this is the case - and a doctor has confirmed this to me in the past.

76. In 2017 or 2018 I had a fibro-scan of my liver. Dr Babu always laughs because it should show that I have a fatty liver but I don't. I know that I drink too much which could be affecting my liver, and Dr Babu has said certain liver test results might be raised because of my drinking, but I have never been told to stop drinking completely. I always laugh and joke with my doctors and nurses, and this is part of my coping mechanism. As I was never told about the HCV when they first found out about it, I was never given alcohol related advice.

77. Jackie hates that I drink and smoke too much, but this is my form of self-medication and I have been doing it since I found out about my HIV diagnosis. Everyday could be my last day and I always live without looking too far forward.

78. The last 2 years or so I have tried to think a bit further ahead, but previously I would always think if we booked a holiday too far in advance, I might not make it to that point. Usually around October, I start to think whether I will see another Christmas, as Christmas has always been a big thing for us. Now I can see things a bit differently but it is still difficult. It is Jacky who has always gone ahead and booked things like summer holidays, as she likes having things to look forward to. I thought if I caught Covid I would have no hope, but thankfully I have not caught it so far.

79. In 2007, I decided to do some training to become a counsellor, as I had benefited from some counselling and felt that I could help others, as I had always been a good listener. I felt like I had never been listened to as a child and was totally ignored, so I always made sure I brought up my daughter in a very different way, listening to everything she had to say.

80. Sadly, in around 2008, I was mugged and attacked while out with my friend Kevin. I became very ill and my hair fell out, but it did not grow back in full. I'm

not sure if this was because of the attack or due to an immune response. I thought I had PTSD as a result of this attack, and put my counselling training aside.

81. In 2012, I finally received some money from the Skipton Fund and decided to do a 3-year diploma in counselling. I had to stop seeing my regular counsellor, as I decided to train with her. I became an integrative counsellor so I would use different types of therapies and tailor it to the individual patient.

82. I offered to do voluntary counselling work at my local GPs, as they had very limited counselling resources and were forced to just prescribe medication to patients instead. By about 2016, I felt like I had done enough work to help people and wanted to be a bit more selfish with my time, and to do more things that I enjoyed so I stopped working. It was difficult, and at times draining but I am glad that I trained in this area as it gave me various skills.

83. We did not tell our daughter Charlie about my diagnosis until she was 16 years old. She knew about my haemophilia from a young age and took it in her stride, but we did not want her childhood to be impacted by my HIV and HCV diagnosis.

84. Charlie met her boyfriend when she was 15 years old, and he was always staying with us or she was staying with him. With the Inquiry taking off and it being widely spoken about, we decided it was the right time to share the news with Charlie and her boyfriend.

85. When telling Charlie about my diagnosis, Jackie and I were very apprehensive. I had been fearful about rejection by her as we had always had a great relationship, as I looked after her a great deal when she was growing up while Jackie worked full time. I loved being involved with her life and we were very close, sharing everything. The mums at her school didn't really involve me, but I didn't mind. I enjoyed being such a big part of her childhood and always wanted to make her feel listened to. We still speak about anything and everything.

86. When we told Charlie, she was brilliant about it and really was as good as gold. I really had nothing to worry about in terms of her rejecting me, but you always have these thoughts in the back of your mind when it comes to sharing news about your diagnosis.

87. Her boyfriend also took it well. We all had a big sob and she gave me a big hug. I think we told her at the right time, as we didn't want her to work it out on her own and ask us about it. Telling her when we did also meant that her childhood wasn't affected by worries about my health problems and she was able to do well. She is still with her boyfriend and they recently got engaged.

88. My HIV diagnosis did have an impact on my parents. Mum felt a bit guilty about it as if I didn't have haemophilia, I wouldn't have become infected with HIV. My dad and I never really got on when I was a teenager, but once I left home our relationship improved and we got on well. I remember moving out on 01 January 1986 and my dad couldn't wait for me to leave!

89. After my diagnosis in around 1985 or so, I recall my dad wiping down door handles with Dettol. My dad never did any of the household cleaning, and I believe this was linked to my HIV diagnosis, although my mum denied it. As time went on, things improved and I think he realised he had been over the top. He loved Charlie but sadly, he died in 2004 and never knew that I had treatment for HIV.

90. I never really spoke about my thoughts or feelings with my parents and I protected them from a lot of things that were going on in my life. My parents had a hard time bringing me up with my haemophilia and they were always in hospital with me, which did take a toll on them. I didn't want to burden them further with my fears and concerns about HIV or HCV.

91. My sister and I were close when we were younger, but she was quite unaware about the extent of my haemophilia related trips to hospital, as often they were in the middle of the night. She was quite sneaky and would often deflect things

onto me or put the blame on me for things at home. She would also sometimes cause me to suffer bleeds, so she could be on her own at home!

92. We don't see each other that often anymore and we never really discussed my HIV and HCV much, and I don't think she really understands it. I have never spoken about my diagnosis openly with her, although I am generally very open about it and willing to speak about it with others. However, recently I did speak about my HIV at a family event and she had to sit and listen to what I was saying, although she did not say much in response. I am close to my niece and nephew, but generally, I am closer to friends than my surviving family.

93. Jackie's parents were also impacted by my HIV diagnosis. She told them about the HIV antibodies I had as soon as we found out, and at the time we didn't realise this was a bad thing. I think both her parents worried about my health problems, including the haemophilia, and believed we may never be able to have children. Her mum did mention this to me, but her dad never said anything and kept everything in. She was their only child and she was her dad's worshipped daughter, so it was natural that they would worry. Jackie lost her dad when she was just 23 years old to a stroke. She believes this could have been stress related. His worries for her future and us as a couple.

94. Jackie always had a love-hate relationship with her mum and they fought a lot. As I trained as a counsellor, I used a lot of my skills to communicate with her and got her to see where I was coming from, and we had a good relationship. The HIV side of things had never really been an issue with her except when she was coming round from anaesthesia after an operation and she started shouting about me being HIV positive! She had a lot of gay friends and was compassionate about the issues they faced. She did various types of volunteering including giving people lifts to hospital. She had a kind heart, but she just clashed with Jackie.

95. We had been quite lucky when we told our friends about my diagnosis and we only lost a few as a result but then, were they really friends in the true sense of the word? We always prepared ourselves for negative reactions from people,

but thankfully this rarely happened. Our closest friends, including some friends I grew up with, knew about my HIV all the way through.

96. Some of the friends we lost were a girl I had used to work with and her partner, who we had been close with. We would go away on weekend trips together in the late 80s. One evening while we were at their flat, it felt like the right time to tell them about my HIV and we did. They did not say anything negative at the time, but they never made plans with us again.

97. In 1990, we received a financial assistance payment and I bought myself a speedboat. In 1992, we received the out-of-court settlement money and we swapped this for a bigger boat. I know some of our friends wondered where this money came from, even though they enjoyed spending time on our boat. One of our friend's husbands did financial enquiries for the police and I know he wanted to find out how I had come into so much money, so we decided to share the news. It was emotional for them and for us, as it was never easy to relive it all.

98. Financially, I used to joke about not going to bother having a pension plan as I would never live to be a pensioner. I made light of the situation and I think this made other people more comfortable, as I was open with what I was going through. Thankfully, I received a pension from my work at the civil service, as I was medically retired.

99. I was able to get an endowment mortgage independently to buy my own flat, but I did not tell them about my diagnosis and just blagged it really, which was easier to do in those days. When Jackie and I wanted to buy a property together, she got the mortgage in just her name. Jackie was later left her grandparents' house and we put some of the financial assistance I received into the house, but still things were very tough financially when I became too ill to work. We also had to pay huge amounts for holiday insurance when I went away, but I believe this was also linked to the haemophilia.

100. The psychological trauma of having HIV and HCV has been horrific and both of these were terminal diagnoses. Each day you are just waiting to die and you never feel like you have a long-term future. It is only through extensive counselling that I have been able to look further ahead than a few months.

101. GRO-C GRO-C She struggled during her nurse training at Barts as she was very unhappy there, and she had the additional worries about my health as I was in hospital at the time due to having my spleen removed.

102. There has been a lot of additional strain on Jackie over the years, due to the concerns about my health and worries about our future. GRO-C GRO-C GRO-C there was always the associated fear factor. It can't have been easy living with someone who could not really see a future and who would not plan ahead. Then, there was the constant tension and having to provide physical as well as emotional support during the various illnesses, hospital visits and periods off work. I am eternally grateful that she has always stood by me and Jackie and Charlie provide the spark that keeps me fighting for life.

103. Keeping the HIV a secret has been a huge strain on my mental well-being. It does feel like a dirty secret although I'm pleased to say it is now not as bad as it was in the 80's and 90's. It has had a colossal impact on my life and I feel lucky to be alive, as so many of my friends who had similar diagnoses are not here to tell their stories.

Section 6. Treatment/Care/Support

104. As I mentioned above, my doctor and I discussed whether I should start AZT treatment for my HIV in around 1986/1987. It was decided that I should wait for a better treatment to become available, as my health wasn't too bad at

the time and AZT had its share of issues and side effects. After that, I was not made aware of any HIV treatments, despite regular monitoring appointments.

105. It was only in 2004 when a nurse asked me why I was still refusing HIV treatment that I realised that new treatments were available. I have no idea why they assumed that because I did not have the AZT treatment so many years before, I would not be interested in new treatments. I should have been asked regularly whether I would like to try treatment but there was clearly a lapse in communication. Once I decided to start the new treatment, I have had no issues in accessing it and it has successfully managed my HIV.

106. As I was not officially told that I had tested positive for HCV, no treatments were ever discussed with me. I was not given any advice in relation to alcohol consumption or lifestyle changes that could be beneficial to me. When I found out by chance about my HCV status in 1995, I was still not offered any treatment or advice. I don't know why I was not retested regularly for HCV, but when I asked to be retested in 2001, I learned that I had cleared HCV naturally, although I'm not sure when I did. This meant that I did not require any HCV treatment.

107. I have a fibro-scan to monitor my liver every few years and I had an ultrasound in around 2017/2018. I'm not sure why I still have this monitoring given that I have cleared HCV. The receptionist at my local health centre still thinks I have HCV and I'm sure my doctors forget that I have actually cleared it. I think this is why I am still monitored like I have HCV.

108. One thing that I have noticed is that I have never been directed to resources like the Haemophilia Society, the Skipton Fund or Macfarlane Trust through the hospital. I have always been left to my own devices to find out about them, but I think I should have been directed to them by the doctors or nurses treating me. Surely this is something they as staff at the clinics are all made aware of?

109. More recently, I have found that no one will support an application to EIBSS that I am trying to make for additional financial assistance to show that I had to have my spleen removed due to HIV or HCV complications. All the doctors I have asked for an opinion have passed it onto the next person, saying it isn't their place to deal with it. Whos' responsibility is it to make that judgement call? I wish I could find out.

110. I haven't really had any problems with dental work, although I have a phobia of dentists. One dentist at the Martin King Oasis clinic would not take me on as a patient because of my haemophilia. However, I have been treated at a dental clinic in Morley Street in Brighton and I've never been treated badly and they have always been brilliant. I have normal appointments there and have not faced any prejudice.

111. I have faced some prejudice when receiving hospital treatment. As I described above, when I was in hospital for my eardrum surgery, my HIV status was listed next to my name outside the ward for everyone to see, which I was not happy about. Even after complaining about this, I was told it was necessary for this information to be visible.

112. When I was in hospital with chicken pox, I did not receive the care that I needed and my personal care needs were often ignored, which I believe was due to my HIV. Jackie had to look after me while I was in hospital. Although I did escalate my complaint in relation to this hospital stay, the hospital denied any wrongdoing and we felt like there wasn't much more we could do. I was often the first or last patient of the day when having a surgical procedure or test, but I understand that additional cleaning is required and I don't believe this is prejudicial.

113. As I mentioned above, Jackie and I attended a support group for those infected with HIV and their partners in around 1989/1990, but we left in 1991 as we were not enjoying attending it any longer. You had to face up to too much death and suffering when involved and it takes a toll. In around 1991, I had a

meltdown and really suffered with my mental health. I ended up being on antidepressants for a long time prescribed by my GP.

114. Jackie and I both saw a nurse GRO-D up at the HIV unit which was part of the sexual health clinic in St Thomas' for what was meant to be counselling and support. This was sometime after my diagnosis. It wasn't the best setting and there were lots of drug addicts in the waiting room. She was quite ferocious and not really a counsellor. We both felt uncomfortable seeing her and she also told us we shouldn't try for a baby, which we were not happy about. There was no offer of such counselling or of psychological support at the time my diagnosis with HIV was provided by the hospital. Regarding the HCV, again nothing was specifically offered at the time I became aware of being infected.

115. I received counselling in 1995 to 1998 through a referral from my GP. I have since been offered counselling support from St Thomas' Hospital but have not taken it on. The reason for this being I am a counsellor although I no longer practice, but I am still registered and insured. Until the pandemic arrived, I was seeing my own therapist regularly and did not feel the need for additional support.

Section 7. Financial Assistance

116. In February 1990, I received a £20,000 one off payment from the Macfarlane Trust, which had been assigned to us by Ken Clarke. I'm not sure exactly how we learned about the trust, but I think someone Jackie met at a women's support group told her about it. I recall phoning the Trust in January 1990 to find out when we would receive this payment, as we were having some financial problems at the time. Our mortgage rate had gone up to 13% which was very difficult to pay. I recall buying a speedboat later with this money. There was no waiver or conditions that I recall.

117. The second payment we received was in May 1991 as part of a group litigation settlement against the government we had been a part of. I can't

remember exactly how we got involved in this litigation but we have been passed on the details from the Haemophilia Society. We claimed legal aid and had lawyers representing us.

118. Around Christmas 1990, we had a meeting with the other people involved in the litigation and I recall there was a big room full of us as it was a big class action. They told us that the case had gone as far as it could and said that we should take a settlement offer, otherwise we would not be alive to see any further money. Although everyone knew it wasn't right, the advice was that we should accept it. The settlement would be £32,000 for a couple, £20,000 for single people and £50,000 if you have a child. As Jackie and I had been living together for over a year, we would qualify for the couple's payment.

119. They did a show of hands to see if people would agree to this settlement and then we had to sign a document to say that was the end of the matter and we could not make another claim in the future. I remember thinking that my life was just worth 32 grand.

120. Once I found out we were going to receive this payment, I ordered a new, better boat but unfortunately the money was delayed. I had to end up borrowing money to pay for the boat which caused additional stress.

121. I can't remember which year I started to receive monthly payments, but I think it was in the late 1990s. I believe it used to be £350 pcm. I think I heard about these monthly payments from other people in the same situation as me and I contacted the McFarlane Trust directly in relation to this. The amount of monthly money went up gradually over the years. I think during most of the 2000s it was about £480 pcm. We were given the option of a top up depending on our income and that came to roughly £780 pcm. It always puzzled me that we had to find these things for ourselves. Having been on record with McFarlane as having received the lump sum they must have been aware of us but made no effort to make contact – I suppose being Government backed it comes down to not paying any more than they have to.

122. We had to fill out forms each year detailing all our income so they could work out whether we could have a top up. I found this to be very frustrating as it was not easy to find and sort out all the information they required. They made it difficult but I was obviously grateful for any financial help given.

123. I think the money started to go up in around 2013 to about £1800 pcm and then recently after the Inquiry started it rose to £3500 pcm, which was life changing. I have also had grants paid to me over the years for courses I was doing, including the counselling training. These grants all came from the Macfarlane Trust. I also had a grant towards having a downstairs toilet installed because in 2004 I was having tummy problems and one day fell down the stairs and hurt myself badly when rushing to the loo. They were very kind and awarded us £4500 towards the cost. I have to say that I have always found the staff at the Macfarlane Trust to be very helpful, understanding and caring whenever I have had to deal with them.

124. In January 2004, I applied to the Skipton Fund. However, the doctor who looked at the form did not tick the necessary box on the application form as they said I was now PCR negative. The form said you needed to have persistently raised ALT/GGT for a certain period of time, but there was no way they could have known how long I had HCV for as they weren't testing me regularly. This really frustrated and upset me, but I just didn't have the fight in me to push this further. I had been told I had 5-15 years to live, I was feeling unwell and depressed and I had just lost my dad at the time.

125. In 2010, a lady we knew applied for the Skipton Fund payment on behalf of her late husband who died in 1995, who had HIV and HCV but actually died of an unrelated cause. She was remarried, but still got a payment from the fund. I was fuming as I couldn't believe they would make a payment to her but had rejected me. I was determined to pursue it after this.

126. I decided to reapply to the Skipton Fund in around July/August 2011 and I spoke to Dr Graham Thompson on the phone around Christmas 2011. I almost pleaded with him to tick the relevant box on the form and this time he actually

went through my medical notes properly and found something about my HCV diagnosis from 1993. He also found in my notes that it showed elevated liver readings during the period from 1989-91, indicating a chronic infection. (**See Exhibit WITN5351002**) He ticked the relevant box on the form and I was paid out from the Fund just after Christmas 2012.

127. Although I was glad to finally receive this payment, it made me angry that I had to wait so long to get it. In 2004 that money would have made a huge difference to us as we had work done on the house and had some major issues when our builders left half way through it. We had to re-mortgage the house to pay for everything. If the hospital had been cooperative and helpful it would have made the process easier, as the information about my HCV had always existed but they had not looked into it properly. I think receiving the payment also helped us avoid falling out with our friend, as seeing her new husband spend the Skipton Fund money did cause a strain in our relationship.

Section 8. Other Issues

128. I would like to thank the Inquiry Team for the opportunity of giving this written evidence. It has been a cathartic exercise going through all the details and I'm sorry that I do not have any actual documentation to add. I never thought I would need any and have never applied for my medical records.

129. When I am asked whether this experience has dented my faith in the NHS, I would say yes and no. I don't think the doctors who prescribed Factor VIII knew that it was infected with HIV and HCV, and I don't think they wanted to infect us, so I'm not going to blame them. I'm sure doctors like GRO-D felt great responsibility when he found out what had happened.

130. I believe the fault lies way up in the government and there were issues with self-sufficiency which really should have been addressed. I'm sure those at the top had an idea of the potential risk, if not immediately, at some stage when going public could have made a difference. We, the haemophiliac

NOT RELEVANT

Statement of Truth

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

Signed GRO-C

Dated 28.1.2022