Witness Name: Anthony Vincent Francis Caira
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ANTHONY VINCENT FRANCIS CAIRA

I, Anthony Vincent Francis Caira, will say as follows:-

Section 1. Introduction

1. My name is Anthony Vincent Francis Caira. I was born on GRO-C 1966 and I currently live at GRO-C Australia.

2. I am married to my wife, Desiree Caira. I am the stepfather to four adult children aged 30, 22, 18 and 16.

3. My parents reside in the UK. I have a half-brother. He is a UK resident and GRO-C

4. I have British and Australian dual citizenship.

5. I was educated at Sheffield-Hallam University, University of Newcastle-Upon-Tyne and Bristol University.

6. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Infected

7. I was diagnosed with severe Haemophilia A at birth. My clotting factor is less than 1%.

8. In or around the summer of 1982, I was put on a new home treatment product called Factor VIII concentrate (FVIII) to be given post-trauma and self-administered intravenously. I do not remember the name of the product I received prior to FVIII. I was wary of changing products because I had already heard through reports from the media of haemophiliacs being infected with Hepatitis B (Hep B) and Non A Non B Hepatitis (Hep C) through such products.

9. I was told by a doctor at the GRO-D that the risk of being infected was very low; around 1:32,000. I was only 16 years old at the time, not highly educated in statistics and that sounded like a fairly low risk to me. One of the products given to me was produced by Blood Products Laboratory, UK.

10. I was infected with Hep B and Hep C as a result of being given contaminated FVIII concentrate. I do not know which one. All concentrates had been supplied/administered to me via either the Sheffield Children's Hospital or the GRO-D

11. With the exception of the regular bleeding episodes, I was a healthy young man. In the gap between ending secondary school and starting at Ecclesfield School sixth form, for some six weeks or so, I started with involuntary and surprising vomiting attacks. This was particularly the case if my mother was cooking fried food. Simply the smell of a fried egg would make me rush to the toilet and vomit. We thought that this it could have been some kind of stomach bug from something that I may have eaten. When I started sixth form, I became more and more ill with the vomiting and I lost a lot of weight. My 26-inch trousers were falling down.

12. One evening, I was taken to the GRO-D, I believe by my stepfather, although it could have been by ambulance. As a severe

haemophiliac at that time, emergency hospital admissions were routine for me, monthly if not more, due to my bleeds. Some spontaneous. Some trauma related. On this occasion it was different. They took me away from the other patients in the emergency area and put me into a hospital bed in what I assumed was an isolation room with plastic sheeting hanging all around. I was scared. A tall, Indian-Asian doctor that I recognised as one of the regular haemophilia centre staff, came in and checked my stomach regarding pains. What really scared me about this occasion was that when I normally saw this doctor, he would be in smart attire. Relaxed, a calm and friendly reassuring doctor. However, on this occasion, he was wearing protective gloves, full face mask and looked like something from a science fiction movie. He looked extremely serious; the little I could see of his face beyond the face mask. I had blood tests and my stomach/abdomen examined. I believe that on that occasion I was sent home and told it was not a bleed and that maybe I had had a heavy meal.

13. Sometime in September of 1982 I was notified, I believe by letter, that I had contracted Hep B and that it had come from a certain batch of FVIII that I had used. I was also told that the batch had been recalled and the manufacturer was closing down the area in which it was made, for sterilisation. I was notified during the second week of a relationship with my first ever girlfriend. I had to notify her, then her family. By payphone. She too, was 16. Her family were extremely understanding. After tests, it was shown that she had caught it from me. We had not had sex of any kind, but we had kissed. She had a nervous habit of pushing one side of her cheek in with her finger and biting the inside of her mouth. It would sometimes make her mouth bleed. My front teeth nearly always bled, around the base. Near the gums. They still do. Worse now. This is how she caught it. I was scared that I may have, via the virus, killed my first girlfriend. At the time I was told that people can die quickly from Hepatitis B. I felt indescribably bad and worried for her. So ashamed. So dirty. So ashamed to see her parents. I spoke to her mother and father about it. They were so kind. Our relationship lasted for two years, two months, two weeks and two days. I did not have another relationship for approximately 18 months.

14. I cannot remember at which point in time the Hep C was identified, nor at which point in time a test came out for the Hep C. I do not feel that it was during my years working for the civil service in 1984-87. I feel it may have been sometime around 1987-88 when I started my degree at Sheffield-Hallam University. The reason I write this is because at that time I had part-time earnings from playing in a band, which I formed in late-1988. We frequented a venue called The Leadmill, a popular spot with musicians. I was, still am, a musician. I know that this was the time I was told I had Hep C or Non A Non B (NANB) it was on a day when I was to play Bass guitar in a band that night. I kept it to myself.

15. It was a great barrier to forming any relationships of any kind. I had already spent most of my life being treated like a leper, with haemophilia, now the television companies were spreading news of the Three H's to avoid: haemophiliacs, heroin addicts and homosexuals. I avoided my university medical examination, a practice I would continue for some years as I could have been banned from campus due to the virus. Returning to another night at The Leadmill, I bumped into another haemophiliac. I have known him since I was four years old. I quietly asked him if he had Hep C too, typically for him, he made a joke and said "yes I think they will be running out of letters soon". I did not ask him if he had HIV because I felt guilty about "just" having Hep C and not HIV. All I can remember is that this is the earliest I shared the information that I was positive for Hep C with anyone else.

16. I was advised at the GRO-D that I was most likely to have been infected by the blood administered by the haemophilia centre at the GRO-D with the Hepatitis B. I was treated at SCH as a child and then GRO-D when I was about 15 or 16. I could have been infected at either of those hospitals with the non-A non-B (now known as C). Some years later I also received a letter on yellow paper (a public health notice?) to inform me that I had been treated with a factor viii product that was from a batch from which a man had died of the so called 'Mad Cow Disease'. The letter stated that they did not know if he had

contracted this from the blood product or another source, but he had died. Therefore I was now on some kind of national public health register as having been infected with Hep B and Hep c and that this Bovine Spongiform Encephalopathy issue now was on this public health record.

17. I can recall having two appointments with a liver specialist, one in a traditional English surgery, maybe 1920s vernacular architecture, with a middle-aged Caucasian man. I remember him giving me tips on how not to spread the Hep B to others and I also remember him telling me there were some 240 strains of Hep B alone. He told me that there was another strain called Hep A and another they were simply calling NANB. I was told that I could recover in six weeks or so or that I could be dead within 8 weeks or less, or that I could go on to become a chronic sufferer of Hep B. The second appointment I can remember in relation to the Hepatitis was within a modernist block which I believe to be part of the GRO-D I remember asking again, a middle-aged Caucasian man, slightly younger than the first, how I could maintain a healthy liver and beat the virus. Many have queried me on this since but I remember him telling me to avoid fats and the distinct detail of telling me to spread butter on bread more thinly. I was told there was no cure.

Section 3. Other Infections

18. I do know if I was infected with anything else.

Section 4. Consent

19. I do not remember whether I was treated or tested without my knowledge or consent. It was too long ago.

20. I believe I was not given adequate or full information, certainly not in the early stages when I was 15 or 16. No one at that point ever told me that the Hep B and Hep C was incurable and that I could die from it. I did not want to ask too many questions as the response from the medical professionals at the time was that I was asking too many questions. I did not want to cause trouble. I received more information from the news than I did from the doctors and

medical staff. The media was directed towards HIV back then and there was not much about Hep B or Hep C at the time.

21. I do not know all of the times that I was treated and tested for the purposes of research. The hospitals I was treated in were research and teaching hospitals. As far as I know GRO-D did research and there were often medical students around whilst being treated.

Section 5. Impact

22. I have suffered mental effects as a result of being infected with Hep B and Hep C. These include PTSD, major depression, anxiety and hypertension. My health issues are vast and complex, resulting in daily flare ups of my Complex PTSD and major depression. I have been on medication for depression since 2003. The only thing keeping me going is the hope of some day soon, returning to pick up my career as a university lecturer and completing my PhD. Medical professionals and allied health workers seem quite incapable of managing my extraordinary range of serious health issues and I am desperate for a solution. I have been affected more mentally as I grew older than I did previously.

23. Due to the severe pressure upon my mother, the misplaced sense of rof personal responsibility, guilt, that she felt; from the age of 14-16 after school I would take responsibility for my GRO-C half-brother from birth until he attained the age of 2 on weekdays. His father was often away at night, working night shifts. I would change his nappy, sterilise his bottles, make up his bottles, wash his bedding and make up his cot. I was afraid to bathe him so I would sponge him down GRO-C GRO-C. When I found out I was infected I did not feel like I could go near my brother anymore which also depressed me. I had a leper complex. I knew there was no cure for Hep B. There is still no cure today. The message I have always been given is that I can infect someone and they could die. I had just changed schools, different town and with this extra dimension that you think you can kill someone just by talking to them, you do not feel like you can talk much. I had seen so many deaths already in

hospitals that I was quite aware at a very early age that I did not feel immortal. I was acutely aware as a haemophiliac not on prophylaxis that I could trip on a paving stone and die. However, something changed in me when they were saying the virus could mutate, it could break out, it could kill at any time I thought "is there any point in making any plans at all?". The goal posts are moved so dramatically that I thought is there any point in studying, conform to societal norms when I am clearly not normal anymore and everything is against me. It adds an extra layer of difficulty and everything becomes a fight. This was the beginning of my hypervigilance. Everything I do can have a tragic effect on others.

24. I also suffered physical effects as a result of the infections. I was vomiting, had diarrhoea, chronic fatigue, stomach pains and bloating. A liver specialist told me that fatigue and depression are common symptoms of both Hep B and Hep C. I also had liver scarring, liver cysts, arrhythmias and osteoarthritis in multiple joints. I do not care what people say, I have never felt the same. The same sense of clarity, ease of movement and wellbeing since contracting Hep B. I have had friends ask me why I sleep so much. When I was lecturing full time, up to 24 contact hours a week; I had to sleep whenever I had a chance. It was and is like tunnel vision. It was impossible to ever feel normal. I wish I could feel the way I did when I was 15. This is something I feel I am fighting all the time. Nobody wants to be around a miserable git so I would cut myself off and stay in my bedroom, go for a drive in the countryside and it meant I became often reclusive, often too outgoing.

25. After I did a master's degree in or about 1997, I was put on the Interferon treatment (15 million units per week). I would inject it into my stomach. It was meant to be a 6 month course but I was only on it for 3 months as the treatment made me very sick. I have been on anti-viral/chemotherapy since November 2018. It has never been made completely clear to me what this treatment is, but I am told that I must be on it for life and that a two day break without it could lead to a breakout of the the virus and possible death due to liver failure.

26. I faced difficulties in accessing treatment and the usual argument that was given to me was that I was not sick enough to receive treatment. Dr GRO-D was not keen on giving me treatment and I tried to explain to him in or around 1997 that I had just started a relationship and wanted to have children. However, Dr GRO-D pushed for me to start the treatment, which I did.

27. I believe that I should have been put on the Ribavirin and Interferon combination therapy as I believe it would have been more effective. I remember doing my own research. I went on a Usenet forum and commented on it to see if there was any treatment for me. Later, a senior haemophilia sister from the hospital called me in for a private conversation; she told me that I should not go on the forums and make such comments, that Dr GRO-D preferred that we did not do that.

28. I suffered mental and physical effects as a result of the treatment I received. I was in my first year of lecturing when I started the treatment. Prior to treatment, I was able to work for 16-24 hours during the week. However, during the treatment I was very exhausted, sweaty and tired. I still look like that now. My friends noticed that I had a very short temper. I alienated my friends apart from one. I felt like I was suffering from flu-like symptoms. My depression got worse. The ALT levels in my liver had increased and I suffered from hair loss and lots of fatigue and I became a very angry and irritable person. 3 months later, I was told that the Hep C had gone into remission but the Hep B persisted. There is no effective treatment for Hep B.

29. I received dental care at a dental hospital where I was usually treated by students. At this hospital things took a longer to organise and I would have preferred to attend a local dentist like everyone else.

30. The infections had an impact on my private, family and social life. At secondary school, I was known to be a happy person and a joker, probably too much. I was not a depressive type. I was positive and driven, especially in my final year and I participated in sport to the extent that I was awarded a certificate by the haemophilia society. If it is possible to be too sociable, I was too sociable, always cracking jokes and mucking about. I had seen a lot of

things in hospital wards that made me sad, some terrified me, but the overall effect was to make me determined to achieve as well as I could. I even tried to join the air force but I was refused twice. That is how determined I was. After I found out I had Hep B, I can see now that I definitely started to suffer from depression. I developed a touch taboo, I was scared of touching people, and I was scared of breathing, sneezing or coughing near people. In the first few weeks of 6th form, people would share an apple or a mars bar and I would refuse and they thought I was weird. I became an introverted person. In the first few months of finding out I was infected I cut myself off from everyone and stayed in my room. I had physical fights with my stepfather because he said I was not being part of the family but I thought I was a leper. Family members could not understand why I was suddenly so morose.

31. I found it hard to have relationships. I had to find someone who was okay with my haemophilia and also with me not kissing them. I infected a previous partner with Hep B as I kissed her with a bleeding tooth unknowingly. It was very difficult for me. When I first got into a relationship with my previous wife, I did not tell her about the infections for 6 weeks. When I did tell her, she went absolutely crazy. As a result, I felt like I could not nurture any friendships or personal relationships. It gave me a feeling of absolute impotence. My family were traditional and it seemed normal for me to get a job in the RAF or medical science, have a career and a family. If we take it that I wanted to follow the above path, then if I had sex with a partner to create a child, I would infect them and they would go on to die young because of me. I had come to terms that my daughters would be haemophilia carriers and I could infect a partner with hepatitis, which could kill them.

32. There was a stigma attached to hepatitis at the time. When we moved towns, I went to school and came home to a family that I felt I had let down, of course I was depressed. The TV stations were showing the advertisements about the three H's. People at school already knew I was a haemophiliac and the media just made things tougher. My social life completely shut down. I was not able to speak to anyone about what was going on in my life and at that point, it was not even made clear to me whether I had NANB or Hep B. Other people in 6th

form at the time were going through normal hormonal changes as a result of puberty, but for me it was more of a leper effect.

33. When I was possibly 16, people would keep making remarks about my short life expectancy. They would give me hints that I was costing the hospitals millions of pounds to keep me alive and that I should not be alive. I felt like a worthless asset. An ex-partner's father (I had been in a relationship with her for 6 months) banned me from seeing his daughter as soon as he found out I was infected and because of the stigma that was attached to it at the time.

34. I was brought up as a Roman Catholic and so I was not keen on lying or concealing information about my infections. At university, I was once sent home by a colleague who I confided in about my situation as I was falling asleep in the lecture that I was giving and was feeling diabolical due to the treatment. I was sent home, I wanted to be open with everybody but I could not because of the stigma.

35. I suffered work-related effects. I had been working in my father's shop on the weekends and he was worried about being infected by me from cups of tea and he was worried about me talking to customers. I worked for the civil service for 3 years and I found I could not save very much so I applied at an agency to find more work. I remember going into an agency, sitting down to fill out the application form and there were questions such as whether I was a haemophilic. I got up and walked out. Most job applications started to ask this question so all the doors felt like they were closing on me in relation to getting a job. People started to ask if 'Haemophilia' was similar to 'Paedophilia'. Between 1982 - 1984 I could not find any work at all. I avoided answering any questions in relation to haemophilia when I was making a job application. I did not want anyone connecting my Haemophilia to the infections. It was a constant war.

36. Currently, I am just voluntarily, occasionally helping out a friend from Oxford University to do proof reading. I am not getting paid for it. I work between midnight and 4 am, as I feel that this is the only time I can concentrate. I do it to keep my morale up and my brain active.

37. I also suffered educational effects as a result of the infections. For 4 years, I was applying to the Economic and Social Research Council (ESRC) to get a scholarship to do a PhD at Bristol University. I did not want to tell them that I had Haemophilia or any infections. Later, I found out that if I told them I had haemophilia, I would have been given an extra scholarship allowance as a disabled person. I was suffering depression at the time and the university subsequently withdrew my scholarship as a result. It must be said that I was also depressed at the time as my long term partner, my Common Law wife, GRO-C around three months into the period of depression that I was already experiencing. My Scholarship was cancelled; /I received the letter, exactly two days after GRO-C GRO-C I never revealed my infections to them as I was scared of the stigma that was attached to it. As a result, I was never able to finish that PhD.

38. I am not the kind of person to be out of employment and to claim benefits, and so I did not do it then. I feel a sense of shame, I cost too much already. Since I have not been able to work, I have suffered financial impacts.

39. My family members have suffered as a result of the infections. My stepfather worked nights doing long-distance lorry driving whilst my mother GRO-C GRO-C GRO-C GRO-C I felt like I was killing my mother.

40. The infections have also put such tremendous pressure on my current wife. The current health service in Australia has made things worse for me because I have a chronic condition. I came here to try to find work.

Section 6. Treatment/care/support

41. I have not received any useful or continuous, holistic counselling treatment, care or support as a consequence of what happened to me. Sometimes with the chronic fatigue, I find it hard to make and attend my medical

appointments. I have been scolded for this and I received sarcastic remarks from the medical staff even though it was not intention to miss appointments. That I was having days affected by fatigue, by the Hepatitis.

42. I was not offered any counselling or psychological support. During my teens, I would have liked someone to have offered me some counselling in relation to the stigma I was facing and how it would affect my relationships. The difficulty was that I was not even aware that any kind of support was available. When I told people I was depressed, they thought that there was no difference between depression and being a lunatic back then; depression had, still has, stigma attached to it. People are wary of people with any mental illness. It would have been nice if counselling or psychological support was offered to me.

Section 7. Financial Assistance

43. In 2003, I received a lump sum payment of £10,000. I am not sure which Trust or Fund I received it from. This money was useful as it covered some of the cost of my first common law wife's funeral. The precondition of the payment was that I had to have been be infected by blood products.

44. Last year, I received a lump sum of £7,000 in arrears. Again, I am not sure which Trust or Fund I received it from.

45. About a year ago, I started receiving £333 per month from the EIBSS. I believe this amount is means tested. I applied for this payment after my ex colleague, a retired lecturer from Sheffield, saw it on the BBC news and informed me about it. I believe this money is not sufficient. I currently live in Australia where this amount would only be enough to cover a 2 hour visit to the doctor. I have been desperately trying to save the funds to get back home for year. I have finally achieved it by 'family pooling' of and thus and amassing of 90,000 Virgin Velocity points.

46. I have heard that the government is willing to increase the amount to £18,000 a year which I believe would really help me if it is to happen. Since I originally wrote this, these payments have commenced.

47. There was other financial help available such as top-up payments but I believe that I missed out on them because there were so many forms to fill out and no help was provided in this regard. I was psychologically overwhelmed.

Section 8. Other Issues

48. All living haemophiliacs are still told by friends and family that they are attention seeking, milking the issue, that we were lucky to have survived into our teens. This attitude was amplified by the media in the 1980s while people, often still minors, were given insufficient information regarding the risks involved in relation to their future prospects of productive life. My C-PTSD is directly related to the nature of the deaths and pre-death suffering I witnessed, and the still omnipresent unknowing of when my possibly-benign cysts may begin to metastasize. The prejudice, ignorance, media frenzy, the almost bribe-like nature to remain silent by treatment centres has been cruel. My response to this cruelty as with many of my blood brothers and sisters is one of resilience. I will die fighting this or if fortunate, live to see justice for those who have died already.

49. In the two years before I left the UK to go to Australia (which was only originally intended as a short visit: illness marooned me here) my medical notes in the UK 'mysteriously' went missing. It has been suggested in the media, by other haemophiliacs, that someone wanted these to go missing. It was in their best interests for them to go missing. That my experience here is not unique.

50. I had requested the notes because there was yet another legal case in the USA, an action against a pharmaceutical company. I 'missed the boat' on that one as I could not locate my medical notes.

51. I tried to make an application to be part of the class action in the USA but was rejected as I made it too late because I was too ill from the infection, the fatigue to locate the missing medical notes. I did try as hard as I could. I was told that I would now have to get individual representation.

52. When I tried to get hold of my medical records for the class action, I was told that they had been transferred from Sheffield to GRO-D. When I called up the body in GRO-D, they also said they did not have them. I have never lived in GRO-D and they conveniently vanished. I have since been told, read, that I am not alone in having an experience like this. I have seen my medical records before, two were very big black files at least. Where are they now?

53. I am lucky to have managed to live this long. I am fortunate enough to be alive during clinical trials where haemophilia can be cured, where the body is reprogrammed to have a 20% clotting factor. However, I was recently told that I could not be put forward for the gene therapy, an 'almost' cure, as I ham Hep B PCI positive.

Anonymity, disclosure and redaction

54. I do not wish to remain anonymous.

55. I wish to provide oral evidence at the hearing.

Statement of Truth

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

Signed GRO-C

Dated 16/9/2019