Witness Name: GRO-B

Statement No: WITN3300001

Exhibit: N/A

Dated: May 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B

GRO-B will say as follows:

Section 1: Introduction

1. I am the daughter of the late GRO-B: F who tragically contracted Hepatitis C arising from the receipt of contaminated Factor concentrates. The circumstances surrounding my father's infection are somewhat unique in that he was not aware at the time of a procedure being undertaken at the Hastings Hospital in 1985 and then when transferred in critical condition to the Royal Hammersmith that he was a person who had a bleeding disorder.

2. At that point my father and our family were unaware that he was a haemophiliac and he had been fortunate in avoiding all issues relating to his status during his life up until that point. Accordingly, he received all types of blood products, suffered sepsis and was later informed that he had contracted Hepatitis. He also had been given blood contaminated with CJD.

3. On 7 May 2020, he was admitted into Conquest Hospital by ambulance after vomiting blood. He underwent an endoscopy to examine the cause and attempts were made to cease the bleeding from his oesophagus. He was diagnosed with cancer on the same day. He was transferred to palliative care

at a hospice on GRO-B and died two days later of sepsis and cancer. He did not have coronavirus.

Section 2: How Affected

4. My family and I were all tested early on and luckily the results were negative, especially as the situation that we were now presented with was one where my sister, mother and I would take on the role of my father's primary carers.

5. From a very young age, all I have ever known is having a very ill father. During my teenage years, his health seriously deteriorated.

6. In 1999, my father commenced two courses of Interferon, as the first did not work. This treatment started during my early teenage years and I recall that the after-effects of that treatment were harrowing. I remember that he was no longer active, instead often wheelchair bound or confined to bed. Understandably, it was a very stressful time for everyone.

7. He also lost multiple teeth due to acid erosion caused by the constant vomiting that his medications caused him. Any teeth he had remaining were small, broken stubs. In the mid-2010s he had all of his remaining teeth removed under anaesthesia. He was given dentures to wear but could not manage them due to the sores and bruising they caused in his mouth and also because they were heavy and his already limited energy could not afford to be sapped any further. After this he could only eat soft or liquid foods. Adaptations and experiments were undertaken to try to make his favourite food more accessible, but the loss of his teeth and the limitations it brought, further triggered his depression.

8. Another side-effect of the infection and treatment was that my father's brilliant mind started to waver. His memory worsened and he would have terrible mood swings. He was so worried about his memory fading that he went to the doctor to test for any dementia like illness and also in case the CJD that had contaminated the blood he had been given had now progressed to a non-dormant status. Thankfully these tests came back negative. His memory loss

and mental issues were purely side-effects of his infection and illness. He retained his brightest thoughts and his expert knowledge, but the edges of things, the day-to-day and recall aspect of memory became fuzzy. It was like a garden maze where the centre was pristine but the outskirts unruly.

9. In early 2018, my father's health became markedly worse. He developed a constant cough, dryness in his throat, started coughing up blood, and had flu-like symptoms that he believed to be interferon induced. He had heavy night sweats, and severe pain around his middle and back. He started to have a build-up of fluid in mouth, and an increase in formation of blood blisters. He was increasingly bloated and suffered prolonged bouts of constipation and diarrhoea. He attended his GP and was sent for standard blood tests. He was informed that these were likely side-effects of his treatment and the cough was nothing to worry about. He was told that it could also be due to his allergies and the pollen count.

10. In November 2018, after more months of continued coughing and weakness he reattended his GP and informed them of his worry that it could be cancer. I had read that Hepatitis C could sometimes lead to raised varices on the oesophagus and that these could cancerously mutate, and we had discussed this together. There was always, also, the existing fear that the cirrhosis of the liver caused by his infection could trigger liver cancer.

11. This time he was sent for a chest X-Ray in relation to coughing blood but it was decided that it was due to his medication and his haemophilia status.

12. In early 2019 he attended the GP surgery as an emergency having started coughing copious amounts of blood. The doctor attending to him was not his usual GP and put forward a request for an urgent referral to the cancer unit at Eastbourne District General Hospital. He was, however, never referred to the specialist cancer unit, instead somewhere the decision had been made by someone to instead refer him to the thoracic medicine department at GRO-B GRO-B. Other tests that had been scheduled to test his lung capacity were cancelled because of his non-stop coughing of blood and were not rescheduled.

13. The department of thoracic medicine conducted x-rays on his lungs and found that they were very scarred and that shadows were present on the x-ray. We were told that it was likely that my father had had TB as a child in Greece and the scarring and discoloration was likely due to this. It was recommended that he undertake a historical TB test and the consultant discharged him from her care. The tests, when carried out, returned negative: he had never had TB and the scarring was, therefore, not caused by it.

14. He had also previously been diagnosed as having gallstones, yet another side-effect of the many medications he was taking and had also attended several appointments in relation to this. There was a tentative plan, in conjunction with his haematologist, to attempt to remove the gallstones if they continued to cause him intolerable pain but that it would be done at a future date.

Section 3: Other Infections

N/A

Section 4: Consent

N/A

Section 5: Impact

15. My parents were both born in Greece, but my grandparents were born in four different countries. None of them spoke English as a first language. I did not speak English as a first language. This may seem like a superfluous detail, but that this statement is in being delivered in British English is itself a direct consequence of my father's infection and its subsequent stranding of our family in a country where there was no intention for us to remain and thus where we had no familial or generational safety net.

16. While my father was studying in London, my parents were also operating a small corner shop, above which we lived. It provided enough income that my parents could cover their studying costs and family expenses, but it was a means to an end.

17. My parents were actively planning to leave the UK just before my father's infection in 1985, and had both separately received offers of work, further study and sponsorship from France, Brazil, Australia, the USA and Sweden; my father was sought after as an innovator in AI and aeronautical engineering, and my mother for both her training as a specialist midwife and also her, at the time, more recent specialism and studies in economics. They had accepted invitations to visit and review the most interesting offers and were in the process of organising travel and accommodation when my father was infected by Hepatitis C.

18. My parents could no longer follow the natural progression of their interests and talents and had to retire their ambitions, ambitions which had been very much within their reach.

19. There were numerous attempts by social services to remove us from an "unsafe" and "unstable" home environment (my father's Hepatitis infection and treatment being the source of said unsafe/unstable categorisations) but my parents, in particular my mother as my father was often incapacitated, fought very hard to ensure that we would not be taken away. She was successful in this but it was an extra burden of stress for her that the local council and authorities kept trying to break up our family. My mother was sometimes very ill. She suffered a series of strokes due to stress and myself and my sister were looked after by visiting members of our extended family and family friends during those times.

20. As my career path and work was freelance and could easily adapt to flexible and remote working patterns, after my father's health took a drastic turn for the worse, I decided that it would be best if I made a base locally and attend to my father's care. We have always been very close as I am the most similar to him in looks, demeanour, character and personality. I, also, could not bear the

thought of our local authority taking on exclusive care of my father especially considering the terrible experience that we had had with social services throughout our time here.

21. My father was a big, strong, burly man in build, and very active. After he was infected, he became a small, frail, birdlike man who could not move freely unaided and was in constant pain. He developed a stoop from the internal scarring he had and lost several inches in height due to this and also the bone loss triggered as a side-effect of multiple medications he was on. This took a terrible toll on him mentally and affected all of us, also. He also became allergic to multiple things during the course of his treatment. He would constantly be covered in itchy, raised patches and rashes, and previously mild existing allergies such as shellfish became severe to the point where he would always require an EpiPen near him in case of emergency.

22. We all took on equal shares of the responsibility of being my father's carer. The stress of being carers meant that my sister and I had a difficult, atypical childhood. It was not care-free and I was often absent from school due to medical emergencies. Furthermore, I endured bullying at school due to my father's status, with peers deliberately isolating and "quarantining" me for fear they would get infected. Vicious and crude rumours were also circulated about where the infection and illness had come from.

23. There has never been a time in my childhood or adult life where I was not worried that my father would not be there in the morning when I woke up, fearing that he had succumbed to the ravages of his illness. There is also the overarching anxiety that comes with having a desperately, chronically sick parent.

24. As a result, from a very young age, I was acutely aware of mortality.

25. From the time of his infection onwards, my father was unable to go out to eat or socialise outside of the home. He could not, for example, go to a restaurant or to the cinema, or visit the house of a friend. He was too weak, too ill, and too susceptible to infection to have these options available to him. He would

also worry about the facilities available and also needed to be close to his medication in case he took a turn for the worse. Another concern he had was that his complex needs required specific accommodations that he did not think fair to impose on others hospitality.

26. Travel was also impossible. We are not a "holidaying" family by nature (we travel for work and study rather than for pleasure), but we do not have family in England. Prior to his infection my parents, and when we were infants, myself and my sister, would travel to see our family. After his infection, we were confined to a small radius of our house in England and my father was confined, effectively, within that house. My father could not even travel to his parents' side when they were ill nor to their funerals when they died. This greatly upset him. Our small branch of the family, cut off by distance and illness, became more isolated. Personally, I did not like to go abroad often, although sometimes my work required it, for fear that something would happen to my dad and he would not be there when I returned. I would have felt incredibly guilty and selfish had that been the case.

27. My father was a very successful person, he acquired many Engineering qualifications and achieved the position of Researcher in Artificial Intelligence. He was at the beginning of the AI revolution.

28. He was also an excellent driver and, due to his specialist interest in aeronautics, an excellent pilot also. The torture of being tethered to the same place was excruciatingly cruel for a man who adored long drives to relax, and the freedom and excitement of flying.

29. Unfortunately, the consequences of his status meant that he lost his career, my parents marriage broke down and he lost his independence including his ability to earn a livelihood and support our family.

Section 6: Treatment/Care/Support

N/A

Section 7: Financial Assistance

30. As far as I am aware, the sole entitlement that he received in relation to his Hepatitis C stage EIBSS programme was a monthly payment from 2016 onwards.

31. My father suffered significant financial losses and my mother had to sell her home and business at a loss in order to initially assist him financially in relation to his requirements. Up until the time of his death, he was absolutely dependent upon the UK Government.

Section 8: Other Issues

32. In order to avoid the consequence of his viral status situation, my sister and I had to change our surnames. As a consequence of his Hepatitis C status, my father lost his career and my mother had to sell her business at a significant loss to assist him with his treatment and requirements.

33. During 2019 and into 2020 my father, already very underweight, steadily lost weight. It became so pronounced that his bones start to cause sores and cuts through his skin.

34. In April 2020, my father attempted to arrange an appointment with his GP. He had very suddenly lost another 3kg and had been in persistent pain, a pain that felt more pronounced than the usual pain that he was used to. He was also feeling weaker than usual and had been unable to go to the toilet. His feet had also swelled and his skin was both paler and more yellow than it would normally appear. He told me he had never been in so much pain in his life.

35. He requested to see a doctor in person due to his deteriorating condition but was informed that he could not as the Surgery was enacting coronavirus restrictions.

36. At his wit's end, he called his haematologist who told him that although there were restrictions in place due to the coronavirus, the NHS was working as normal and that he should insist on a face-to-face appointment with his GP. He told my father that if needs be he could step in to ensure an appointment.

37. My father then managed to arrange a telephone appointment with his GP where he explained his symptoms. His GP said it was likely that these symptoms were because of his gallstones and that they should make a plan to deal with them to enact after the pandemic had subsided. She said she would prepare some laxatives to be collected the next day and that he should come in for an in-person appointment in two days' time to discuss his symptoms further.

38. At that in-person appointment his GP was particularly concerned with the area around his back and abdomen, but not in regards to his feet which were so swollen by this point that they were bruised and tearing. She rang Conquest Hospital and asked for advice and gave my father the direct number of the consultant in case he should need to call him if things got worse. This number, when we attempted to contact the consultant the next day, redirected to a switchboard at the hospital with no-reply. After his appointment my father was in excruciating pain as it had been a very "hands-on" examination.

39. On May 2nd 2020, at about 5pm he was rushed to hospital by ambulance after he suddenly started vomiting a huge amount of blood. As we were unable to go with him due to the pandemic, we sent his medication with him, including his Advate (Factor VIII). We had been told by the paramedic that because it was the weekend the hospital pharmacy would not be open and that it was unlikely that they would have that specific medicine in stock. We later found out that his medication was lost in transit.

40. We were informed on the 3rd of May that the problem did not appear to be his gallbladder. My mother and I were informed by telephone by Mr Sandison, a consultant surgeon at the Conquest Hospital Hastings, that my dad had multiple necrotising lesions on his liver. He also had oesophageal thickening, swelling and cuts to his oesophagus. We asked if it was cancer and the

consultant said it could be any number of possibilities. We were told that these would have to be investigated further with a biopsy and endoscopy. A biopsy was scheduled for the following Monday, May 11th.

41. On May 5th my father was discharged from hospital and brought home by a hospital volunteer. He looked very ill. He was yellow, had difficulty moving, was sweating profusely and had lost yet further weight in hospital. He couldn't eat and he was constantly nauseous. He had been given some painkillers but they were insufficiently strong. He was unable to take the medication from the hospital without choking.

42. The next day he deteriorated. He could neither eat nor sleep. He suffered frightening audio and visual hallucinations which caused him huge distress. He was still unable to go to the toilet and remained nauseous. He started to vomit with increasing regularity. We called his GP and she prescribed anti-emetic tablets that were dropped off outside our door, but he could not take them, again as he was choking. He had difficulty breathing due to pain across his abdomen and back, and his oxygen levels low.

43. On the 7th May 2020 he was taken to hospital at 5am by ambulance to Conquest Hospital Hastings after once again vomiting large blood clots and a large amount of blood. He was in intolerable pain and in great distress. Once again, we sent more Advate (Factor VIII) with him but this was also misplaced. He called me and my mother at 11am and told us: "I've got cancer and it's spread everywhere. I don't have long left." We were distraught.

44. Doctors at the hospital arranged for emergency endoscopy at noon, carried out by Dr Fong. We were told that he must have been swallowing large amounts of blood for some time because of the condition of his oesophagus. At 4.30pm we were told there was nothing they could do because it was too late. A decision was made for him to be placed into palliative care as he was now too ill for any further treatment or exploratory procedure. We arranged palliative care overnight ourselves as the palliative care team at the Conquest Hospital were unavailable due to a bank holiday.

45. On the GRO-B GRO-B we were allowed to visit him at Conquest Hospital, one at a time. He was in tremendous pain. He couldn't sit still due to discomfort and pain. He was very happy to see us but he was sweating, swollen, tired and weak.

46. The next day he was transferred to GRO-B at midday. We were allowed to visit from 4.30pm. As only one of us were allowed to stay with him due to the pandemic, it was decided that I should stay. He could not eat and had difficulty drinking, despite being thirsty and hungry. He was happy to be with us, but he was scared. Unfortunately, Conquest Hospital had not attached his drug port into his thigh correctly so no painkillers were administered until around 11pm when a hospice nurse checked the port due to his worsening pain and found the error.

47. His condition continued to deteriorate over the course of that night and the next day.

48. He could not keep eyes open and was excessively tired. He suffered hallucinations. I called a nurse because he was in unbearable pain. She came and called the on-call doctor who diagnosed sepsis. The doctor told me there was nothing he could do. He told my mother the same when she arrived at the hospice. We were broken by this information. We were told that we should take a decision to not resuscitate him should he go into cardiac arrest as he would be too weak to survive the trauma of resuscitation. I asked how long he had left and the doctor told me that he could die anytime between "2 hours to 2 days". I later found out that my mother was told differently, that he had a few days to a week left. We were unable to take him home to die. Later that night he started to spasm and convulse. At about 3am he took a turn for the worse and nurses were called to assist, but it was considered dangerous to move him from his bed. Instead, his bed was adjusted to be more secure and make him more comfortable, and his medicine was updated. He fell into unconsciousness halfway through the nurses attending to him.

49. He did not regain consciousness. He started to sweat profusely. His breathing became increasingly laboured. At around 10.30am he stopped spasming and lay peaceful. He died at 11.21am. I was beside him, holding his hand and talking to him. I was absolutely devastated. As my mother had been told, both by the doctor and by the nurse on duty that day, that my father was unlikely to die within the next few days she had gone home to prepare a number of things to bring for him and also to make sure our pet dogs were OK. I called her and told her what had happened. She was in the car on the way back to the hospice, about 5 minutes away. When she arrived, she was extremely distressed.

50. The cause of death on his certificate was given as biliary sepsis; cancer of unknown primary; haemophilia; and Hepatitis C.

51. Both myself and my mother are very upset that someone with his unique medical and health profile, caused by the infected blood he was given thirty-six years ago, was not being monitored more closely, especially with regards to cancer (liver cancer, non-Hodgkin lymphoma and certain throat and neck cancers are much more common in patients with Hepatitis C) and changes in bleeding. We are also particularly concerned that the thickening in his oesophagus was not detected, especially as oesophageal changes are another "down-the-line" change in patients with Hepatitis C and, as you can imagine, one that is grossly more complicated when the patient is a haemophiliac.

52. He was failed by the medical professionals that were supposed to be looking after him twice. Firstly, by being infected with Hepatitis C and secondly, despite his efforts in repeatedly informing his doctors of his symptoms, by his cancer being undiagnosed until four days before his death. There was an insistence that it was gallstones to be dealt with later, even when cancer was brought up by my dad with his doctors.

53. Before he was infected with Hepatitis C he was an active, strong man. He was a basketball player and a swimmer. After his infection and the litany of mistakes that happened afterwards, he became a different person on the outside, but

inside he remained the active, intellectually curious, highly intelligent and kind hearted man he was in his youth before his infection tore apart his physical self. He always told me he felt young because that's when, for him, time stopped. He had difficulty in reconciling the external him and the internal version.

54. My father's parents and grandparents all lived to be nonagenarians and centenarians. There is little doubt in my mind that had my father not been infected with Hepatitis c that he would also have lived into at least his nineties.

55. I am one of life's more melancholy people by nature. I have become even more melancholy since, and also angry. I am angry that none of the team of haematologists, GPs, consultants et al. that were entrusted to care for him seemed to realise what was happening.

56. In my opinion, my father's sepsis was caused by his cancer; his cancer was caused by his Hepatitis C; his Hepatitis C was caused by the infected blood he was given. He died in 2020 but it started thirty-six years ago.

Statement of Truth

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

Signed GRO-B

GRO-B

Dated ______________________