

ANONYMOUS

Witness Name:

GRO-B

Statement No.: WITN0988001

Dated: 19 October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

GRO-B

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 01 August 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1961 and my address is known to the Inquiry. I am an architect, and I live together with my wife in GRO-B London. I intend to speak about my late brother, GRO-B: B B In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.
2. I am providing this statement to the Inquiry with my best recollections and the help of my other brother, who through discussions has assisted me to recall certain events surrounding B's infection and subsequent illness.

Section 2. How Affected

3. I am the youngest of four siblings, three boys and a girl. I am going to talk about [B] my eldest brother. [B] was born on [GRO-B] 1953, in [GRO-B] hospital. My family originally come from [GRO-B] London, but chose to move down to Devon in the early 1950s, initially to [GRO-B] and then to [GRO-B] because of our father's work. In 1980, I returned to London to go to university. During [GRO-B] 1981, our father died from a rare form of cancer, attributed to asbestos exposure when a young man.

4. From the mid-1970s, [B] had a girlfriend, living together near [GRO-B] Devon. They subsequently married and their only child, a son - [GRO-B] was born in 1981. In the late 1970s/early 1980s, [B] wished to improve his work prospects and because he had always been interested in electronics and computers, he enrolled as a mature student at [GRO-B] [GRO-B] to gain a recognised qualification in electrical engineering. Sometime after [GRO-B]'s birth, [B] and his wife separated. Later, his ex-wife moved to live in Australia for some years, but has since returned to live in Devon.

5. At some point during the early to mid-1980s, [B] had more than one personal accident whilst living in Devon. I do not personally recall this because I was at university in London, but my other brother [GRO-B] (who was living in [GRO-B] at that time, having returned to the city following completion of his degree at university) has said that [B] was admitted to hospital after at least one of these incidents. Whilst still living with his wife, [B] had a domestic accident and suffered cuts to his hand and arm having put it through a pane of glass. This particular incident was treated by [B]'s then-mother-in-law, who was a GP doctor. However, [GRO-B] has said that [B] was admitted to A&E for treatment following an accident to his hand/arm, which I understand was after his separation from his wife. I am unaware whether this subsequent accident was related to the first accident with the pane of glass (due to restricted

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mobility and/or dexterity of his hand and arm), but I understand that it was not long after the first accident. I believe that [B] had a blood transfusion following the second accident which lead to his admission to hospital, which would have quite naturally been required for injuries of that severity and nature.

6. [B] was an avid guitarist, playing in bands during his youth, but the injuries affected his ability to play guitar. After the accidents, [B] didn't play for some period of time, but he did subsequently resume playing guitar (but not to the same high standards) and making music in his spare time.
7. Following his death, my brother and I have looked back at this incident and believe it to be the cause of his hepatitis C ('HCV') infection. Having learnt of the scandal surrounding infected blood and blood products, I believe this to be the only possible cause of his infection with Hepatitis C.
8. Life went on for [B] and by the mid 1990s he was living in London and working with Volkswagen as a delivery driver as part of the [GRO-B] [GRO-B] team. When Volkswagen were taken over by Porsche, [B] was promoted and transferred to Porsche with the same [GRO-B] role – but now delivering high value vehicles to prestigious customers. [B] had been a habitual smoker since his teenage years, and would occasionally have a drink with his friends. This changed when he began his position at Volkswagen and then subsequently at Porsche – Porsche do not permit smoking on premises or in cars, and have a zero-tolerance policy on drinking with random staff testing in place. This led [B] to considerably improve his personal health and lifestyle, as he substantially reduced the amount that he smoked.
9. Until the late 1980s, I lived in [GRO-B] whilst at university and started work in my first job. When I was a student for 6 years and then employed in my first job leading to qualification, I would see [B] every

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few months when he visited London and then around once every couple of months when he moved to live in GRO-B London.

10. I then moved to GRO-B London and would meet B around once every few months, often at our mother's house in Essex. Over the course of the 1990s and 2000s I began to notice that B was showing odd behaviours, in particular paranoia and anxiety. For example, he was convinced that climate change had been disproved by Russian scientists and argued that carbon dioxide concentrations were nothing to do with climate. He would always cover over the webcam on his computer and mobile phone. With hindsight, I believe these odd and unusual behaviours were likely a consequence of B's infection with HCV.
11. In GRO-B I got married. I recall that here, only because it was around this time that I noticed B did not look particularly healthy. He complained of aches and pains in his muscles and joints, and always seemed to catch a cold or the flu if it was going around.
12. In GRO-B B's son GRO-B, my nephew, was getting married in Manchester. When I saw B he again did not look well, and he complained of a sore back. Later that year, we were all supposed to meet as a family at our mother's house near GRO-B Essex. B phoned my mother and told her that he could not get out of bed because of severe pain in his back.
13. It was not until last months of 2012 that B was forced to take days off work as a result of his back. One day, he was told to take a battery out of a car from under the front seat. Despite this being a job for a mechanic, and suffering from a bad back at the time, he attempted to do so. This caused his back to seize, and he was subsequently off work for a period of time in late 2012. B was unable to sit down, only finding comfort when lying down in bed. Whilst I was abroad with my wife at the end of 2012, I was told that B had been unable to visit our mother or the rest of our family during that festive and New Year period.

14. [B] had been living on his own in a housing association flat in [GRO-B] since 2003/4. His flat was on the first floor, which required climbing a flight of stairs to get in and out. [B] told me that he asked his housing association in early 2013 if he could be re-housed, but they couldn't help him find a flat on the ground floor because his back problem was thought (at that time) to be temporary.
15. [B] returned to work in early 2013, where soon after, he again hurt his back. This seemed to happen again and again whenever he returned to work. I was phoning him regularly at this time to check on his wellbeing, and urged him to return to his GP. He finally saw his GP in February/March 2013, who suspected he had strained something in his back, or perhaps had a slipped disc. His GP advised him to undertake physiotherapy and gave [B] a referral for physiotherapy. However, [B]'s back would feel far worse after any physiotherapy sessions, so after only a few sessions [B] decided that he could not continue, because the physiotherapy appeared to be counterproductive. The painkillers he was prescribed did little to ease the pain, and he was only told not to exert himself. By this time, [B] was unable to drive and was using local buses (in great pain) to get to his GP and to travel to locations for X-Rays and scans.
16. By April 2013, [B]'s GP became increasingly concerned, because there appeared to be no obvious cause for the deterioration of his back condition. The GP sent him for an X-Ray, which failed to show up any issues. Finally [B] was sent for a scan in May 2013 – I don't know exactly what sort of scan, presumably a CT scan, in a location that [B] didn't mention. By this time [B] had severe mobility problems, finding it very difficult and painful to move at all.
17. As soon as [B] had the CT scan, the doctor phoned his GP right away. The doctor then said to [B] that they had arranged for an ambulance to take him straight to Charing Cross Hospital. The scan had shown that [B] had cancer of the spine. Because the ambulance took [B] directly to hospital for immediate admission, he never subsequently

returned home to his flat nor did he have any opportunity to put his affairs in order.

18. During that afternoon I had three missed calls from [B] in quick succession. When I rang him back a short while later, [B] said that he had just arrived at Charing Cross Hospital and was waiting to be taken to a ward. He then said to me that he had cancer in his spine. He told me to come over tomorrow, rather than right away, as he was unsure where he would be put within the hospital.

19. The next morning, I phoned [B] to find out which ward he was in, and he gave me a shopping list of items to collect for him. From then on, I went to visit [B] every day from mid-morning to evening until the day he died. I became the single point of contact for the family.

20. [B] did not have a prognosis at this stage. However, following initial tests soon after his admission to the oncology ward, [B] was told that the cancer of the spine was secondary cancer but they did not yet know the primary source of the cancer. Upon being told of this, [B] immediately thought that it was lung cancer as a result of smoking. After a few days, he told me he had been tested and that they had found no cancer in his throat or lungs. We were both astonished at this- we had both assumed this would be the primary source of the cancer. The mystery then started after this.

21. I felt that little effort was being made to keep [B] informed of the tests being undertaken and to develop a programme for investigation. [B] had been on morphine for his back pain from the very start of his admission to hospital, and I was concerned about his ability to follow medical information and the complex issues that clinicians explain. I was not informed of what the doctors were doing, as [GRO-B] was his next of kin, not myself.

22. One day, [B] was taken for an X-ray. The staff in the X-ray department were carrying him, and somehow managed to drop him from a height of

about one foot (30cm) onto the bed whilst transferring him to/from the X-ray machine. The ball joint to the head of one thigh bone, at [B]'s hip, had completely snapped off causing him extreme pain. The nursing staff refused to accept responsibility for this incident. [B] said that they didn't appear to know that he had cancer of the spine or that other bones could be affected. I believe that this event delayed the clinicians' investigations to determine the source of the primary cancer.

23. The clinical decision was made to give [B] a metal ball joint replacement in his hip. [B] was taken to St Mary's Hospital in Paddington for this operation at the end of June 2013. I do not believe the staff at St Mary's were told that he was a cancer patient as he was put in an orthopaedic ward. The nurses did not appear to know anything about his cancer, and when I informed them they seemed shocked.

24. The staff at St Mary's Hospital were very rude to both [B] and myself. I recall the two orthopaedic surgeons were particularly rude, once effectively telling me to go away when talking to [B] about his treatment. I believe that this was an inappropriate place for him to be treated, and the clinicians appeared to be completely ignorant of [B]'s cancer and obvious need for treatment.

25. I began to question why [B]'s hip would fracture so easily from a relatively minor fall. I was concerned as to why the clinicians failed to investigate the reason why his thigh bone fractured so easily. I also recall that the ward itself was very hot and noisy, which was undoubtedly worsened by the birth of a royal baby, Prince George, opposite [B]'s ward.

26. [B] returned to Charing Cross Hospital three weeks after his hip operation and he was put in a high dependency oncology ward in July 2013. They then finally started to question the primary source of [B]'s cancer and to set a definitive plan for investigation. We met the lead consultant for the liver cancer department, who was based at another hospital as part of the same trust. The consultant said to [B] that "we

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think you have liver cancer" and that this could be the primary source of the cancer.

27. It took the clinicians another week for blood tests to be done and then for [B] to be diagnosed with Hepatitis C. At this time, my knowledge of hepatitis was extremely limited; I had heard of it but knew nothing about it, how it is transmitted and the impact it has. I remember being frustrated that [B] had been in hospital since May and it took them until the end of July for them to do further blood tests and identify the primary source of [B]'s cancer.

28. On one occasion when visiting [B] during May, he had asked me to bring razor blades to allow him to shave his face. The next day he had shaved and had blood all over his face. He was bleeding profusely, and I now look back with worry that the staff had no idea he was HCV positive.

29. The clinical staff had implied that [B] drank heavily, which he never had, and could not have done regardless because of his work duties. We were not informed, to the best of my knowledge, of the link between HCV and liver cancer. They did not tell me of [B]'s cirrhosis of the liver, and we were not informed of the extent to which the HCV had impacted on his skeleton and bones in relation to his fractured hip joint.

30. Following his diagnosis, [B] had wanted to get out of hospital and get back to his flat. We advised against this due to the stairs at his flat and his general lack of mobility. The Macmillan nurse was of great help to [B] and myself, at all times giving us clear and useful advice.

31. Having been at the hospital all day until late afternoon on [GRO-B] 2013, the same Macmillan nurse phoned me in the early evening and informed me that it was not looking good for [B]. I called my nephew [GRO-] in Manchester to keep him up-to-date and to relay the Macmillan nurse's comments. The next day, at around 9am, the nurse phoned again and told me that they had transferred [B] to a separate, individual, room

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and to come to the hospital as quickly as I could. I immediately phoned [GRO-B] and left a message as he was in a work meeting. I arrived at the hospital around [GRO-B] on [GRO-B]. I now realise that this separate room is where they put patients immediately before they die.

32. [B] was on an automatic morphine drip and was clearly not all there. He knew that I was with him, and we were able to chat when I first arrived until the early afternoon. He ultimately faded away in front of me, and died [GRO-B]. [B]'s death certificate stated that his cause of death was metastatic hepatocellular carcinoma, as a result of hepatitis C infection.

33. At the time, [B] and I had no idea how he came to be infected with HCV. As far as I am aware, the hospital did not seek to link it to anything, and did not make any effort to ascertain if he had had a blood transfusion. They did ask if he had been a heavy drinker, but did not question if he was an intravenous drug user or a sex worker (of which he was neither). He was scared of needles and told me that he had never taken intravenous drugs. I also highly doubt if would ever have had sex with a prostitute.

34. [B] did tell me that he visited Casablanca, Morocco, in the early 1990s for a work contract. He was sent there to repair, improve and install a sound system in a tourist hotel nightclub, owing to his electronics qualification. He was there for around a week and a half to complete this job, and told me that there was no possible way that he could have become infected with HCV during this time.

35. Until [GRO-B] before his death on [GRO-B] 2013, [B] had no idea whatsoever that he had hepatitis C, that the HCV infection had severely affected his liver or that the primary source of his cancer was liver cancer.

36. My other brother and I are both certain that [B] was infected with HCV as a result of a blood transfusion. Although I am unable to say where

that took place, I believe this to be the only explanation as to how he came to be infected with HCV, and ultimately come to his untimely death.

Section 3. Other Infections

37. To the best of my knowledge, [B] did not have any infections other than HCV.

Section 4. Consent

38. I do not believe that [B] was fully-informed of the testing and treatment being performed on him at Charing Cross Hospital. He was administered high doses of morphine for more than two months, and as a result found it very difficult to take in such new and complex information.

39. I do believe that [B] consented to testing for the purposes of his diagnosis and treatment, despite not fully understanding what exactly he was being tested for.

Section 5. Impact

40. [B]'s infection, treatment and passing has had a devastating impact on myself and my family. I am saddened and frustrated by the way my brother suffered despite not knowing the primary cause of his illness. He was unaware that he was infected with HCV and had lived with HCV for such a long period, and this certainly had a detrimental impact on his quality of living.

41. I am particularly saddened by knowing that [B]'s grandchildren will never know their grandfather. This has also had an impact on my nephew, who is naturally saddened by this fact. [GRO-B] has been able to put his father's death to one side, focussing on his family life and bringing

up his two young children in Manchester. He does not feel as strongly about [B]'s treatment as I do.

42. My mother took [B]'s death badly. She is now frail and weak, and I believe that she would not have deteriorated as rapidly had [B] not died when and how he did. We as a family are unable to understand why this happened to [B]. We are helpless, saddened and frustrated at his passing.

Section 6. Treatment/Care/Support

43. My opinion of [B]'s treatment during the period May to [GRO-B] 2013 is that they could have done more in terms of knowing very early on that his cancer of the spine was secondary. Tests could have been done earlier and more efficiently to locate the source of the primary cancer. I would have liked a more realistic and honest prognosis for [B].

44. We were completely oblivious as to the true nature of his illness and the fact that he would never leave hospital before his death. He was not given the opportunity to get his affairs in order as a result. Charing Cross Hospital had a culture of not keeping the patient and his family informed, and they only told us what they wanted us to know. As I was not his next of kin, the clinicians often refused to keep me informed despite knowing that I visited my brother on a daily basis and that I was there because he wanted me to be. Surely, if nothing else and for practicality of the circumstances there was an implied consent.

45. In my view, the hospital operates in a way that is best for the hospital, which for 90% of the time is the best thing for the patient. Unfortunately, [B] fell into the 10% or so of those who did not get the best treatment for himself. I never made a complaint to Charing Cross Hospital in relation to [B]'s treatment. We agreed as a family that it is not right for us to make complaints about things that are more systematic; [B]'s case was unusual and we understand that. I think that there are lessons

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to be learnt from people who have been identified as having secondary cancer and then identifying the source of the primary cancer.

46. [B] myself and my family were not, and have not been, offered any form of counselling or psychological support as a result of [B]'s illness and passing.

Section 7. Financial Assistance

47. [B] only found out about his hepatitis just before he died and when he was heavily drugged. Therefore, the possibility of claiming financial support as a result of [B]'s infection with HCV was established far too late and tragically it soon became a moot point anyway; [B] had no dependants at the time and so there could be no beneficiary.

Section 8. Other Issues

48. I have given this statement because I believe that [B]'s story should be heard and told. It falls on me to provide this statement on behalf of the family as my nephew, [B]'s next of kin, feels unable to talk about this.

Statement of Truth

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

Signed [GRO-B] .

Dated 19 October 2019