

ANONYMOUS

Witness Name :

GRO-B

Statement No.

WITN3733001

Exhibits : WITN3733002 – WITN3733009

Dated :

17th / May / 2023

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

GRO-B

I provide this witness statement in response to a request under Rule 9 of the Inquiry rules 2006, dated 25th September, 2019

I, **GRO-B**, will say as follows:-

1. I am one of the seven children of **GRO-B** and **GRO-B** and was born on **GRO-B** **GRO-B** 1968 in **GRO-B**, England. I have four elder siblings and had two younger, one of whom is now deceased.
2. My family story is one of haemophilia and resultant infection through the use of contaminated blood products given to the haemophiliacs within my family. In this statement I intend to show how haemophilia impacted upon my family and I, how it has impacted upon our individual families (my son and daughter together with my nephews and nieces as well as my brothers and sisters), and in particular about my son, **GRO-B: S**, and my brothers **GRO-B: B1**, **GRO-B: B2** and **GRO-B: B3**.

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3. By way of an introduction, I will provide a brief history of our family to place each person I may mention in the context. My parents are both Jamaican. They were born there and met one another there, forming a relationship. In Jamaica they had three children together, my sisters **GRO-B** and **GRO-B** and then my brother **B1**.
4. In 1965, my father left Jamaica for the United Kingdom, seeking work. At the time many of his fellow Jamaicans were doing the same, and it was nothing unusual. About nine months later, my mother left Jamaica to join him, leaving **GRO-B**, **GRO-B** and **B1** behind, where they were cared for by their grandparents.
5. My parents settled in **GRO-B** where they married and established our family home. My father found work in manufacturing (working in a factory making oxygen tanks amongst other things), and my mother having started work in a lace factory, became a nurse at the local children's hospital.
6. They then had four more children, my sister **GRO-B**, then me, followed by my brothers, **B2** and **B3**, **B3** being the youngest. We were all born in **GRO-B** where we remained, attending school there and eventually setting up our own homes as we moved into adulthood.
7. The only exception to this was **B3** who for a short while attended a school out of our area, and who settled in the vicinity of that school for a short while thereafter – but he then returned to **GRO-B**.
8. In about 1974, **GRO-B** and **B1** came from Jamaica to join us, with **GRO-B** staying behind for a few years longer before she too came over from Jamaica. This united the children, but shortly before she arrived, in the early part of 1976, my parents **GRO-B** and **GRO-B** separated from one another.

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9. One of the reasons that **B1** came to the UK was that whilst living in Jamaica he was found to be unwell – he wasn't diagnosed as having anything in particular wrong with him, whilst he lived there, and in so far as I know wasn't treated there in any manner or form that would be of interest to the Infected Blood Inquiry, but he has made his own witness statement which may assist. All I know is that my mother had been told by his carers in Jamaica that he was 'a bleeder'.
10. He had been suffering from episodes which we would now readily identify as being classic 'haemophilia bleeds', but in Jamaica all that was known at that time was that he was 'a bleeder', and when suffering any form of bleed, it took a long time to stop the bleeding and for him to heal.
11. By the time he was brought over to the UK both of his younger brothers, **B2** and **B3**, had been diagnosed as having severe haemophilia, so my parents worked out what was wrong with him and caused him to join us where they believed he would receive better care – there was little to no care available for anyone with this condition in Jamaica at that time. **B2** had been diagnosed in infancy, **B3** from birth.
12. We then discovered that our whole family had been touched, in some manner or form by haemophilia, a genetic condition which my mother, an apparent carrier of this ailment had passed on. She had absolutely no knowledge of the fact that she was 'a carrier' whilst having her children, and only found out about it after we had all been born, by which time it was too late. However, I am not sure if this would have prevented her from having children as my father actually seemed keen on her having even more, or so I am told.
13. **GRO-B** was found to be a carrier of haemophilia – she has three children, one of whom (a boy by the name of **GRO-B**) is also a severe haemophiliac. **GRO-B** was not a carrier so it could not be passed on to her daughter. **B1** has eight children, four boys and four girls. **GRO-B** was not a carrier and as such, her two children do not have haemophilia.

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14. **B2** was born with severe haemophilia, he has no children. **B3** was also born with severe haemophilia. He had four children, all girls, all of whom are known to me to be haemophilia carrier's. One of his daughters is **GRO-B** who has also made a statement to the Infected Blood Inquiry. Her father, my youngest brother **B3**, passed away on **GRO-B** 2019.
15. I was born as a carrier of haemophilia. I have two children, a boy and a girl. My daughter **GRO-B** is also a carrier. My son **S** was born with severe haemophilia.
16. I was in my late teens when I fell pregnant with **S**. He is now 36 years of age and is an adult with learning difficulties. All three of my brothers, **B1**, **B2** and **B3** together with my son **S** have seen their lives impacted upon due to their use of contaminated blood products as a means of each being treated for haemophilia – my brothers all acquired viral infections, and were exposed to vCJD whilst I was told that **S** also had been exposed to vCJD.
17. I had been working as an accounts clerk for a cleaning company when I found out that I was pregnant with **S**, but having only been with the firm for a short period of time, and being only 18 years of age, I was immediately 'required to resign', and lost my job (I have held other jobs since then, and am currently employed as a professional singer).
18. Although I had been told that I might be a carrier of haemophilia, I almost did not believe it. As a young girl I was physically very fit and a fast sprinter (but **GRO-B** and **GRO-B** were faster than me). I remember **B2** always seemed to have a poorly elbow because he liked to sleep with his arm tucked under his body. He would wake up with a swollen elbow and he would be in so much pain he would have to have the day (or days) off school. School was not a happy place for me and I thought I'd try sleeping on my elbow so I could have the day off too. It didn't work, but I did seem to have almost as many nosebleeds as my brothers. That should have been a clue.

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19. [s] was born at the NOTTINGHAM CITY HOSPITAL in [GRO-B] 1986. I was young and naïve and did not want to think about my carrier status, but I asked for [s] blood to be tested soon after his birth. My beautiful little baby boy looked so perfect I had deluded myself into thinking that he would not be affected. His father and I were given the news when he was twelve days old - haemophilia had been passed on to [s] through me. This was such a reality check I could not stop crying. At a later date, [s] was also diagnosed with Sickle Cell trait, another genetic blood condition which he inherited from his father.
20. [s] was immediately referred to the QUEENS MEDICAL CENTRE (Nottingham) for haemophilia care and general health monitoring from that point onwards. Thereafter, all of his haemophilia care was conducted through 'Queens'.
21. Here he was initially placed under the care of a Dr Peter BARBOR, who confirmed the initial diagnosis (as Haemophilia A), but I wasn't immediately asked to register him on the National Haemophilia Database – something which didn't happen until I was approached to do so when he was around 11 years old. I don't know why there was a delay.
22. During the first sixteen months of his life, [s] was given blood clotting treatment with CRYOPRECIPITATE (or 'Cryo' as it is also referred to). Then in March 1988 he was given an alternative blood clotting treatment, FACTOR VIII for the first time.
23. The change in his treatment regime, from Cryo to Factor VIII came about as a direct result of his suffering a major crisis as an infant. My elder sister [GRO-B] who was and still is a nurse, had been looking after [s] for me whilst I was at work. [GRO-B] told me that all of a sudden [s] slumped over, went blue, had difficulty breathing, and she could see that his eyes were 'flicking' involuntarily to the left.

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24. She called for an ambulance and he was taken to the Queens Medical Centre (hereafter referred to as either 'Queens' or 'QMC'), where having been taken in through the Accident & Emergency Department, he was admitted into the intensive care unit.
25. I had been called and went straight to the hospital where doctors initially asked me what had happened and then asked me if he had been vaccinated recently. I told them that I had taken him for his scheduled measles jab, but I was told that he could not have it because it had been replaced with a new 'triple' jab which had measles in it. He had it nearly three weeks ago. They left and a paediatric Neurologist came to speak to [GRO-B] and me several hours later told us that they weren't sure whether [s] had suffered a bleed on his brain, or had contracted meningitis. Eventually I was told that [s] had suffered a small bleed into the right side of his brain, but that as a haemophiliac he was susceptible to such bleeds. I believed this at the time, but I have recently discovered that crucial information had not been disclosed to me regarding my son's condition at that time.
26. [s] had to remain as an inpatient for ten days following which his haemophilia treatment was altered from being given Cryo to address any episodes of bleeding, to Factor VIII being administered instead. There was a short period over which he had either one or the other, but with time he passed onto receiving only Factor VIII.
27. As a result of this seizure and bleed, a subsequent seizure and bleed the following month in April 1988, another seizure in July 1988, and a further seizure and bleed on the left side of his brain in September 1988 which resulted in a state of status epilepticus, [s] was then diagnosed as having epilepsy. Restrictions prevent me from saying what really happened to my son, but if it had not happened, my son would not have had any brain injury or been in hospital at all and I believe that his haemophilia treatment would not have changed from cryoprecipitate until much later in his life.

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28. I have recently had sight of his medical records, as held by the QMC, and found that whilst an inpatient following his March 1988 hospital admission, he had been tested for HIV. His nursing record had been noted, regarding this test, *'parents unaware of testing'*.
29. At no time had I been asked for consent for this test to be carried out, and with the benefit of hindsight now wonder why they believed that he may have had HIV – unless it was the result of his having been given something untoward as a result of their haemophilia treatment of him, either then or at some time beforehand. I can't help but wonder if they knew or suspected, that he had been given contaminated Cryo and / or Factor VIII, but whatever the case, they didn't tell me.
30. In April 1988, [redacted] again suffered a seizure and I took him to the QMC where I was told that the episode may have been a direct result of the earlier bleed. I have since learned that he had actually suffered further bleeding and brain swelling at the same site on this occasion, but wasn't told this at the time. I only found out from his notes when viewing them many years later. After the second bleed, he suffered a third in September 1988. Every time I had been required to complete forms on his behalf where I have to give details of his neurological disabilities, I only ever mentioned the March and September 1988 episodes because I had never been told about what happened to him in April 1988. This episode was played down to me as a seizure because he had a high temperature.

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31. Following these three incidents of bleeds into his brain, [s] started to behave differently from before, and began to display signs that he had developmental problems. I knew something was wrong so I mentioned it to the paediatricians whenever I took him for his regular outpatient appointments. I was repeatedly told that there was nothing to worry about and that I should stop looking for things that weren't there. He has continued to struggle from the time of these bleeds, and has learning difficulties to this day. He also has Autistic Spectrum Disorder (ASD) which had been noticed by the headmaster at his nursery school, but when I asked at the hospital I was told that it was "just another label, I wouldn't worry about it if I were you". During his entire childhood, [s] was never formally diagnosed with ASD by anyone at the hospital. However I did receive a document confirming this diagnosis in 2013, 25 years after I first brought it to their attention. By then he was 27 years old.

32. In February 1993, [s] suffered a bleed into his stomach. At first he vomited up a large volume of brown 'stuff' (I did not realise that this was actually old blood because of its colour). After an hour's sleep he woke up screaming, unable to walk straight and then he vomited up a large amount of fresh, red blood. I rushed him into the QMC where I was told that he had lost so much blood he required a blood transfusion – which he was given, with my knowledge and consent. Under the circumstances, I considered that it was essential, and again he had to be admitted.

33. An endoscopy was performed on him, again with my consent, to try to establish the root cause of the problem. This revealed mild antral gastritis, which, at the time, was described to me as "a bit of a stomach ulcer". Having inspected his medical record, I have seen that whilst he was anaesthetised during the endoscopy procedure, two biopsy samples were taken from the antrum of his stomach and were tested for *Helicobacter Pylori* (also known as *H.pylori*), which is a bacterial infection which I believe to be related in some way to Hepatitis B (which is also known as Hep' B or HbV).

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34. I can recall having signed a consent form regarding the anaesthetic and scope being used, but was given no information about this test and had not agreed to it. As with the HIV test which had also been performed without my knowledge or consent, I now question why they had to do this, and what did they then know which I was not being told as his mother?
35. [redacted] s progressed to home treatment using Factor VIII when he was five years old – until then he had been treated with either Cryo or Factor VIII at Queens as there was no other alternative form of treatments available. Cryo could then only be given in a hospital setting, and although home use of Factor VIII had been available for about ten years, I hadn't trained in its use.
36. A QMC haematology doctor, whom I believe to have been a Dr HARVEY, taught me how to treat [redacted] s at home using Factor VIII. Prior to this, I had been having to take him to Queens on average between 3 and 4 times per week for treatment. I found that it was all becoming too much for me and I found myself feeling quite dejected at our forever having to travel to and from the hospital at all hours of the day or night, and more often than not having to wait for several hours prior to our being seen and his problems addressed.
37. [redacted] s had experienced so many bleeds because of his haemophilia, but their number has in part been exacerbated by virtue of his learning difficulties and hyperactivity. He had absolutely no sense of danger or understanding of what he could or should do or more importantly, not do. I was told that if I were to treat him at home, then he wouldn't need to attend the hospital so often and accordingly neither would I – home treatment would help us both. I was trained in how to administer Factor VIII to [redacted] s by Dr Harvey, and started to treat him at home, making life a little easier for us.

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38. In order to secure a supply of Factor VIII, I had to complete a treatment card each and every time Factor VIII was administered – on it I had to record the Factor VIII bottle number, the date(s) of use, why it had been used (e.g. for a bleed into an ankle, elbow or knee) and the result of its use (e.g. had any swelling and / or pain been reduced?). A completed card was exchanged at Queens for another batch of Factor VIII.
39. I remember that the very first batch of Factor VIII [s] was given at home was called '8Y'. It came in a cardboard box with the bottles of the product stacked inside and which I kept in my refrigerator. From 1988 to mid 1995 a few different Factor VIII products were used on [s], both at home and in hospital, namely 8Y, Profilate, Oxford, and Behring. In September 1995 he was given REPLENATE, something which he used for about 3 years before moving on to KOGENATE in 1998, REFACTO from 1999 to 2000, then back to Kogenate from 2001 till 2011.
40. All of my brothers had been being treated with Factor VIII when I started giving it to [s]. I saw it as being really useful, as I could administer it at home, but didn't think anything was particularly 'special' about it, as all of my brothers were using it. I cannot recall there having been much, if any, information on or within any of the Factor VIII packaging, or on the bottles themselves, other than batch and bottle numbers which I remember being evident, as I had to record them.
41. I cannot at any time recall having been warned of any risks associated with the use of any Factor VIII which [s] was treated with, be that verbally or in writing, by any of the doctors or nurses at the QMC Haemophilia Centre, or when I had been collecting stock – nor do I recall any form of warning being printed on the packaging, bottles or on any leaflet / pamphlet which may have accompanied it until following our having discovered that my brothers [B1], [B2] and [B3] had all become infected. I then asked, as there was still nothing available with the product, only to be told at the hospital that there was little or no chance of [s] having been infected, as the products were then of high purity and had been heat-treated.

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42. With more recent supplies, a written (typed) set of instructions have been included with each batch, similar to the sort of thing which comes in every packet of over-the-counter medicines you purchase, but I didn't read any and don't know what information, including any warnings they may have contained – I had by then been treating **S** for so long, that I didn't need the instructions, and as with other medicines, if you have been taking them for any length of time you tend not to read the accompanying leaflet.
43. As a young man, my brother **B3** had been sent to a boarding school in Hampshire which catered for children facing a broad range of illnesses and / or disabilities, including haemophilia (the LORD MAYOR TRELOAR COLLEGE, which he simply called 'Treloars'). My mother had wanted to send both him and **B2** to the school, but their place had to be sponsored by our local social services and / or education service (Nottinghamshire County Council), and they had only been prepared to pay for one of them to go.
44. **B3** attended 'Treloars', as although both he and **B2** were severe haemophiliacs, **B3** condition was less well controlled than **B2** and as a consequence he had to take far more time off of school than **B2** did, so they sent him.
45. All of the boys (**B1**, **B2**, **B3** and **S**) were treated through the Haemophilia Centre at Queens, but attending Treloars meant that **B3** was additionally treated through a haemophilia centre they had on site at the school, which had been one of the reasons for his having been sent there. Although it was hard for my mother, having reunited her children in the UK to then send one of them away, she did it and would have done it for **B2** as well, as she felt that it offered a better environment for them given all the circumstances.

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46. [B3] [B2] and [B1] were all treated through the QMC Haemophilia centre and given the same material at what was basically the same time and from the same sources. Although all three became infected as a result of the products they were using having been contaminated, both [B1] and [B2] remain alive, whilst [B3] who had been additionally treated at Treloars, is dead as a result of the infections he was given.

47. There was never any question of [S] being sent away to any sort of 'special school' such as Treloars. The issue was never brought up, no one ever suggested it to me, either from education or social services, so it was going to have to be 'mainstream' schooling for him. I found it very difficult to secure a place for him, starting with nursery school as his medical needs were such that few places were available.

48. In addition to finding him a school place, [S] also suffered through racism (we are all from what would today be referred to as an ethnic minority), stigma and ignorance. Placing ethnicity and racism aside, we experienced other parents saying that they didn't want [S] as a fellow pupil of their children as *'they didn't want their children to catch AIDS from him'*.

49. [S] hadn't developed AIDS, nor had he been found to have contracted HIV, but fear and ignorance came together to unduly influence people and consequently cause problems for us. The stigma attached to these conditions, which ignorant people directly but incorrectly associated with haemophilia simply made matters worse.

50. We are fortunate that despite his having been given both Cryoprecipitate and Factor VIII over a protracted period, and his uncles having become infected during the course of their treatment with the same, [S] appears to have remained free of infection with hepatitis, HIV or anything else.

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51. Other than Factor VIII containing the hepatitis B virus which was given to him less than a week after his sixth birthday, he has not been exposed to any other viruses. Dr Blecher told me that it was necessary for them to give [s] this product because he had not produced a sufficient immune response to the course of hepatitis B vaccines he had been given from December 1988 to June 1989 – and they needed to use the virus to 'wake up' [s] immune system. He asked me if I would allow them to use this product on [s] and I immediately said "No". After he told me that the vaccine would not work on him unless they did this and assured me that [s] would be safe from infection, I reluctantly agreed to let them do it. Dr Dolan was present when this was being said, but he said very little.

52. Three months later, the events described in Paragraphs 32 to 34 of this statement happened. I was told that the blood in [s] stomach was due to a nosebleed. This did not make any sense to me because he had not had a nosebleed for a whole week. It is possible that the brown 'old blood' he initially vomited up on that occasion was from that previous nosebleed, but he hadn't had another one since.

53. So why did he start screaming in pain an hour later and where did the next stomach-full of fresh blood come from? How did he develop antral gastritis? Why was his neutrophil count so high when he had not actually been ill prior to this incident? Nobody could (or should I say, would) explain this to me.

54. I believe that this was actually the result of his hepatitis B vaccine being primed with the hepatitis B virus, also known as pathogenic priming, otherwise there would have been no need for them to take two biopsy samples from the sore antrum of his stomach, test for H.pylori (which incidentally was negative), start a second course of hepatitis B vaccines while he was still under general anaesthetic from the endoscopy, and prescribe Cimetidine. I am not a doctor, but even I know that a nosebleed could not cause this level of damage all by itself and this is not how to treat 'a nosebleed'.

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- 55.** I have heard oral evidence during this Inquiry saying that virally active Factor VIII products were not deliberately used on anyone under the age of six. It now makes some sense to me why my son was given an appointment with Dr Dolan and Dr Blecher less than a week after his sixth birthday.
- 56.** I had been left wondering what really happened to my son on this occasion. Also, why both **B3** and **S** suffer some kind of reaction and / or a drop in their haemoglobin and red blood cell count three months after a new treatment, infection, illness or vaccinations. This always happened within 2 to 3 months, but mostly at 3 months. I have asked, but nobody answers. This is why I research so much.
- 57.** In 2001 and 2005 I received two separate letters, originating from the QMC Haemophilia Centre, each related to vCJD. The letters told me that **S** had been exposed to vCJD as a batch of the Factor VIII he had been given had been found to contain material drawn from someone with this incurable illness.
- 58.** These were not repeat letters, each telling me the same thing and referring to the same batch numbers, but separate notices as he had been given Factor VIII from separate batches, each of which exposing him to vCJD. The letters did not express any cause for concern, but that was easier for the author to have said than for a parent with a poorly child to accept – I panicked and continue to worry about it to this day.
- 59.** Both of the letters were authored by Dr G Dolan and signed by him and the Haemophilia Nurse Specialist at the time, Anne Massingham. I was invited to contact the centre 'if I wanted to know more', but each letter also stated that there was no known cure for vCJD, that it could remain dormant for a protracted period, and that there was no known test available to identify those who may have it. As such, I didn't go in for any further information as I couldn't see that they'd be able to tell me anything.

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60. The letters initially asked me to fill in a form and return it if I wanted to know whether s had been given any of the implicated batches. I did this and then received confirmation of his exposure, not once but twice.
61. The letters arrived over a lengthy period, spread out and each bringing about its own stress. When a third letter arrived, I called the centre to ask why they continued to send these letters out to me. I was told that each time a batch of Factor was found to be implicated for vCJD, they wrote to those who may have received product from that batch to warn them of the risk of their having been exposed – even though they could do nothing about it. I asked if this meant that there were three implicated batches and I was told “Yes”. I was so upset I hung up the phone and tore the third letter to shreds.
62. I never told s of this, he has learning difficulties which means that to have done so would have been relatively pointless as the information would have gone 'straight over his head'. He is able to read, but often does not understand what he is reading and he can write his name and address, but doesn't always know when or why he may need to do so. As an example, he received correspondence from the Blood Transfusion Service to whom he had submitted a form (which he had apparently completed without my knowledge), asking him to be a donor.
63. I had to call them to tell them that he had applied without understanding what he was doing or its implications due to his learning difficulties, and that in any event he couldn't do it as he was a haemophiliac.
64. Initially I hadn't known a lot about haemophilia, it was something my brothers had, but they got on with it and seemed to cope. It never affected me, although I did know that I was a carrier. In later years, having learned as time progressed all about the condition, as it affected my son, I also started researching other allied illnesses and learned about them as well.

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65. In particular, I researched all that I could about vCJD. When I had first known of haemophilia, there had been no ease of access to the internet as there has in more recent years so I'd have had to go to a reference library and hoped that I'd be able to find something, so it didn't happen, but by the time I was contacted about vCJD, things had changed.
66. Until I had been told of [redacted] s exposure to vCJD, I hadn't thought that it was an issue for us. To me, it was just something you got from eating contaminated beef, and as we didn't eat a lot of meat, I hadn't been concerned about it. It never occurred to me that it could possibly have been in blood products such as those given to my [redacted] s. This all changed with the letters, and I set about learning all I could about vCJD and continue to research this and other blood / blood product borne ailments to this day.
67. I experienced many a sleepless night having found out that vCJD was a degenerative brain disease that could take over ten years to manifest itself, if not more. Rather than put my mind at rest that as the letters said, 'there was nothing to worry about', what I learned caused me even more concern. I have also discovered that contrary to what I had been told, there is a test for vCJD which can be applied, an issue which I will address to the end of this statement (using an exhibit).
68. In January 2005, [redacted] s suffered another significant health crisis and he appeared to be having another major neurological event very similar to the ones he had in 1988 (he also had another in 1994). I called for an ambulance. The paramedics were initially dismissive of me, saying that he was only having a seizure and that accordingly he didn't need to go to hospital; but he wasn't just 'having a fit'. After he had vomited and I tried to give him a glass of water he couldn't raise his arm to take the glass from me and he was struggling to form any words, just making strange noises. I began to worry that he was either having another bleed into his brain, having a stroke or that this was the onset of vCJD because it had been about ten years since he was given the implicated Factor VIII products. I am not sure what this was because nobody has ever explained it to me, but I could clearly see from his symptoms that this was definitely a neurological problem.

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- 69.** I explained to the paramedics his past neurological history, and in particular his having been exposed to vCJD and they were persuaded, but not until after some considerable time, to take him to the QMC. Once there, he actually appeared to have stopped breathing. He started to breathe again after some 'coaching' from me – it took what felt like an eternity before the medical staff were prepared to at least look at what was happening to him. I asked the staff to call the haematology doctor on call four times. Each time I was told that this would be done, but a good twelve hours later, there was no sign of any doctor.
- 70.** In a panic, I went home and collected some Factor VIII from our fridge while my (then) husband stayed with s. I then went to the Haematology Department and acquired some more. I then went back to the ward, mixed the Factor VIII and administered it myself.
- 71.** I gave him a 3000 iu dose of Factor VIII while he was still sleepy and incoherent. He slept for a few hours then woke up and was able to speak to me in a slightly dazed sort of way, but at least he was forming his words properly. He had no idea what had happened to him. I made a point of speaking to both the haemophilia and neurology departments, to make sure that it wasn't vCJD, seeking reassurances as I was worried sick, but was told that 'as he had recovered, it couldn't have been vCJD'. When he was brought to hospital in similar circumstances as a child, he was seen and treated immediately. At this point he was eighteen years old and having similar symptoms as he did before. This was his first time in adult A&E. I can not believe how none of the medical professionals could see any urgency in his situation. I am now terrified of him having to go into hospital as an inpatient again. This episode was the catalyst for my research.

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72. I now believe this neurological episode may have been the result of my son taking Vioxx (Rofecoxib) for two years. This drug was prescribed for him in out-patient clinic for his arthritic knee in 2002, but it was withdrawn worldwide in 2004 because it was discovered that the drug company who produced it, Merck, was aware that it caused heart attacks and strokes before they put it on the market. They settled out of court for \$4.8 billion to settle a huge class action lawsuit after killing thousands of people with this product. However, when I asked why we couldn't get it any more, I was told that the product had been found to be carcinogenic, but I should not worry because S is showing no sign that he has any kind of cancer.

73. On 7 March 2011, haematology doctor, Dr Charlotte GRIMLEY requested that I go and see her so that I could sign a document which would have allowed his Factor VIII treatment to be changed from KOGENATE to HELIXATE. I attended with S as requested by Dr Grimley.

74. I was told that there was nothing to worry about as both Kogenate and Helixate were identical products and did exactly the same job – it's just that Helixate was cheaper than Kogenate and accordingly better for the department to purchase. She had the document in her hand. All that was needed was my signature.

75. She showed me where she needed me to sign, then held the document in front of me, but she was holding it very carefully, making sure to only expose the signature strip on the last page while concealing the other pages. This caused me to feel very nervous, so I said "But I haven't read it". She calmly repeated what she had said previously then she put a pen in my hand and held the form in front of me again, in the same way, but I asked again if I could read it first.

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76. Dr Grimley clearly did not want me to read the document before I signed it, but eventually, she reluctantly held the document out to me. I tried to read it but I was now so nervous that I couldn't process any of the information and found myself reading the same line over and over again. I tried to calm myself and tried to process one word at a time. I took ages. I think I recall seeing something about testing and I asked what this was about. Dr Grimley told me that [redacted] **s** [redacted] would have his blood tested to make sure that the product was working as it should. I thought that this was strange – if the two products were identical in composition, they should work equally. Although I was struggling to control my anxiety at the time, I was also worrying about what might happen if I did not sign, I asked myself, “would they not treat my son if I did not do what they wanted?”

77. I really could not think clearly. The parts of the document that I did not understand, I circled and wrote 'I do not know what this means so I do not agree to it', and initialled each note I made. I then signed the form and handed it back to Dr Grimley. I felt under pressure to sign it and I still feel a little ill when I think about it because I actually don't know what I signed my own son up for as I had allowed my nerves to get the better of me.

78. A couple of months after [redacted] **B3** [redacted] funeral, haemophilia nurse, Linda Trower, phoned me and invited me to come in for an informal chat with her and Dr Grimley. She told me that they could look for the documents I had asked for so that I could prepare my statement for the Infected Blood Inquiry. I went to see them and I asked Dr Grimley if I could have a copy of the document to ascertain exactly what I did sign and to what purpose, but she told me that she had 'no idea' what I was talking about and accordingly had no such document.

ANONYMOUS

79. I managed most of [redacted] S health issues without any problems, but the one thing I could not manage was his volatile temper and immense strength when he becomes agitated. I have been physically attacked by him on several occasions, not that he knew or understood what he was doing, and sadly he had simply reached a stage where I could no longer adequately cope with this. As hard as I found this to do, I had to place him into full time care, with assistance from both the local authority and the NHS.

80. I have never received any financial assistance or compensation as a result of [redacted] S having been exposed to vCJD by using an NHS supplied blood product which had been contaminated. Nor have I ever applied for any such help, as I am unaware of any being available to me or to him.

81. I have never been offered or received any form of assistance by way of counselling for the concerns I have had, or the worry I experience when thinking of [redacted] S and his future, and in particular what the years to come may bring regarding vCJD, or whether or not any other infections from contaminated blood use will manifest themselves.

82. Regarding vCJD, I feel that there is more that I could have been told, and should have been told, but wasn't, having had to rely upon my own research to fill in gaps in my knowledge of this and a number of other conditions.

83. My daughter [redacted] GRO-B is also a haemophilia carrier. She has made a conscious decision not to have children and by doing so not to inflict this condition on any children she may have had. I would like to have become a grandmother at some stage in my life, but this condition and what she has seen her elder brother and I go through has taken that away, coupled to her knowledge of how it has impacted upon our broader family and in particular [redacted] B3 death.

ANONYMOUS

84. Haemophilia has caused many problems for our family, and as individuals or as part of a group we have faced a great deal of prejudice and stigma, especially as all of my brothers had HcV, and as with haemophilia, HcV was closely linked in public perception to HIV and accordingly to AIDS.
85. Each one of my brothers has had to learn to be economical with the truth or simply just lie in order to conceal the truth of their conditions as otherwise they would have had issues with their jobs, securing loans or insurance. There are a couple of letters in [redacted] s vast medical notes which referred to us as 'the well-known [redacted] GRO-B family' and have always wondered why we were considered in this way – it was a term we heard from time to time used by some of the doctors whilst they were speaking to us.
86. My mother told me of how she felt isolated, that we were isolated as a family and that she didn't know of any other families of our ethnicity facing the same issues, and she was a nurse working in a hospital so if there had been any locally, she may well have learned of them – she only knew of one other black man with haemophilia, but he had died. There was no one she could turn to.
87. My late brother, [redacted] B3, was born on [redacted] GRO-B 1972 and died on [redacted] GRO-B 2019, just eleven days before his 47th birthday. He left four daughters, the eldest of whom was just 25 when he passed away. He was a severe haemophiliac with sickle cell anaemia trait who had been treated from birth for haemophilia, firstly at the Nottingham Children's Hospital then when the QMC was built in 1978, all paediatric patients were moved there.
88. He had Cryo from soon after birth and moved on to Factor VIII in 1980. He was also treated whilst a pupil at Treloars, using CUTTER FVIII (Koate), BPL FVIII, TRAVENOL / HYLAND / HEMOFIL FVIII, and OXFORD FVIII products. Of all my brothers, I would say that [redacted] B3, the youngest was the most affected.

ANONYMOUS

89. From the age of 7 or 8 he needed to wear a leg calliper as a result of a knee joint problem, and he also had a curvature in his spine, a result of his having walked with a limp for so long. I distinctly remember seeing him having to throw one leg out to the side in order to be able to walk.
90. Often as youngsters, when one of my brothers had to go to hospital, I would accompany my mother or visit them, and can remember that when on Cryo, they could only be treated at the Children's Hospital and later Queens where it was administered. If they needed treatment they'd be taken into the outpatients department where they would usually be seen by either Dr FRENCH or Dr BLECHER who following a physical examination could establish whether or not they needed any blood product.
91. If they needed treatment, they used to be taken to PRINCESS MARY WARD (at the Children's Hospital) for their Cryo, which was given to them on the ward but by staff from the haematology department. I believe, from hearing it from my mum, that it was Dr Barbor who had first suggested that she consider sending him to Treloars.
92. He went there in 1986 and left in 1989. He loved it there. To B3 everyone was in the same boat, they were all facing some sort of illness or disability, and he could play and make friends in a way that he could never do at school in Nottingham. At first, he really did not want to go to Treloars and he had to be bribed to even consider it.
93. Both B3 and B2 were bullied at school in Nottingham – it was bad enough being racially abused, but B3 was also on the receiving end as he appeared physically disabled and as such was an easy target, and additionally became a further subject for abuse as he had haemophilia, which other pupils linked to HIV and AIDS.

ANONYMOUS

94. Every time he came home from Treloars he had something positive to say about the place, somewhere in which he felt included and safe. He learned very little in Nottingham, but at Treloars he learned to play the guitar, to drive, and had friends. One of his best friends was a boy, from Egypt I believe, but they never experienced the racism or bullying he had been subjected to elsewhere.
95. My mother visited him whilst he was a pupil there, where on one occasion she found him in traction in the haemophilia centre, being treated for a problem with his right leg. According to his records, B3 was in traction from 26th February to 16th March 1987. It appears that a Mr Richard Browne was involved in his care. Also regular updates on his joint progress were sent from M. WASSEF, (SCMO), and blood test results were being sent from a Dr A ARONSTAM to Dr French in Nottingham. I have never been asked, but do not know, if he was ever subjected to research work which may, or may not, have been undertaken using haemophiliac pupils of this school.
96. B3 enjoyed his time at Treloars so much that initially upon leaving, he stayed in the area of the school for some time and found a job working for GRO-B before subsequently returning to GRO-B with worsening health and as a result, declining employment prospects.
97. I know that B3 had been given contaminated blood products. Our whole family knows that he and our other brothers contracted HcV as a result of contaminated Factor VIII use, but what we did not know is that B3 had also contracted HbV, which I have seen in his medical records. It is shown on the test results sheets sent from Treloars. The test was conclusive four months after he arrived there. Like S, B3 had also been exposed to vCJD. His hospital records suggest that he developed chronic kidney disease as a result of his HcV status. He then went on to suffer from both thyroid and heart problems which I believe were directly associated with his infections and their treatments.

ANONYMOUS

98. According to [B3] hospital records, it was in December 1994 that all three of our brothers were in hospital at the same time for a 'surgical procedure', they were told. They assumed it was something to do with their joints. [B3] was taken to theatre first. When he was returned to the ward, he was clearly distressed and warned our brothers not to go. [B3] told our brothers that he had been given a liver biopsy without anaesthetic. When my sisters, [S] and I went to visit them, [B3] clearly appeared to have been traumatised by his ordeal and could not speak to anyone. He just lay there silently crying. Our brothers heeded his advice.

99. Dr S RYDER, Consultant Hepatologist at the QMC wrote to [B3] on 31st July 2001, about an Interferon and Ribavirin combined HcV treatment, inviting him to take it as there was a 35% - 40% chance of success in clearing patients of HcV. The letter mentions side effects of possible 'flu-like' illness which usually occurs in early treatment and apparently gets better as treatment progresses, then tiredness and depression which tend to get worse through the treatment. It also says *'there are a number of other medical side effects of treatment which will require close monitoring'*. It does not mention what these 'other more significant side effects' are (e.g. cardiac and thyroid issues). There was also no mention of the possibility that HbV could be reactivated if the treatment was successful, but to our knowledge, [B3] did not know that he had been infected with HbV. We know that he believed that he was immune to Hepatitis B because he had been vaccinated.

100. The test results from Treloars showed that [B3] had both positive core and surface antibodies for HbV, but negative HbV antigen. This proves that he had been previously infected with HbV but he was now immune and not infectious. Despite his immunity to Hepatitis B, which was confirmed in January 1987, [B3] was vaccinated against Hepatitis B with the rest of the family starting on 21st December 1988, but he already had core and surface antibodies so he didn't need it. It also appears that he may have been given Factor VIII which contained the Hepatitis B virus during the 1990s, like [S]

ANONYMOUS

101. Dr Dolan actually checked **B3** hep B immune status in June 2000 which confirmed his immunity, but he'd already done 3 previous tests with exactly the same result so one would be justified in asking why he would need to test my brother over and over again knowing that he would get the same result every time, then question his immunity. Core antibodies would not just disappear would they? Does natural immunity to hepatitis B wane over time? What was Dr Dolan looking for so often?
102. **B3** avoided the Interferon / Ribavirin combination treatment for four years, then in June 2005, he tried it. He suffered with generalised aches and pains, fatigue, insomnia, backache, abdominal pain, headaches, diarrhoea, excessively dry skin and reduced appetite. Also, after three months on this treatment his haemoglobin had dropped from 17 g/dl to 12.7 g/dl. The following month it had dropped further to 11.9 g/dl. The lower reference limit for haemoglobin is 13 g/dl, so it had dropped below this. His red blood cell count had also dropped to 3.91 which is below the lower reference limit of 4.2. This treatment had caused **B3** to become anaemic. After 6 months, the treatment showed no sign that it had worked so it was stopped. After treatment stopped, his blood steadily normalized over time.
103. His next HcV treatment which commenced at the beginning of August 2017, did clear his HcV. His haemoglobin and red blood cell count remained stable this time, but three months into this treatment he developed autoimmune thyrotoxicosis (Graves disease). **B1** was offered the interferon / Ribavirin treatment, but he never tried it as he considered the success rate odds as being too low. **B2** had tried it in 2003 but found that he couldn't cope with the side effects and had to stop the treatment after just four months.
104. My research has led me to believe that HcV can affect the kidneys as well as the liver, and I believe that it is this infection which caused **B3** to suffer kidney damage. I also found that Interferon treatment may exacerbate HcV symptoms and feel that in this case that is exactly what happened, not only was his HcV impacting upon his kidneys, but I believe that the treatment for it merely served to enhance that impact.

ANONYMOUS

105. [B3] was on holiday in Florida, USA when he died. My niece, [GRO-B] [GRO-B] was with him when it happened. He had apparently experienced ill health on his way to Gatwick immediately before he left, at the airport, on the plane, and then whilst in the USA, but hadn't sought any help for it. Eventually he collapsed, with my niece having to perform CPR on him in an effort to revive him. I believe he felt it was pointless seeking help because he had taken himself to A&E many times in the months leading up to his holiday, but he was discharged after tests. The last time he went was on 28th May 2019, about a month before he went on holiday. Again, he was discharged.

106. An ambulance crew attended to help him and [GRO-B] and he was taken to hospital and somewhere between [GRO-B] efforts, the ambulance crew intervening and the hospital staff taking action, he was resuscitated, then moved to another hospital and put onto a life support machine, gravely ill. His kidneys appeared to have stopped working and he had a few rounds of dialysis because of excess fluid build up. His stomach had stopped processing food and his lungs were filling with fluid. Eleven days later the doctors told us that there was nothing more they could do for him. As a family, we made the heartbreaking decision to switch off his life support. I held his hand while he passed away on [GRO-B] 2019.

107. [B3] body was repatriated to the UK and a death certificate issued following his return. This reads that he died of a heart attack, nothing more. I was not happy with this at all because I feel that this does not adequately reflect what actually killed my brother at 46 years of age and I asked the coroner (for the Nottingham area) to review this.

ANONYMOUS

108. It may well be that technically a heart attack was the actual final cause of death, but the certificate, in my view, should also include the contributory factors to that heart attack – he was a severe haemophiliac who had been given contaminated blood products which resulted in his having contracted HbV, HcV and being exposed to vCJD. He developed kidney and heart defects due to HcV which were enhanced by HcV treatment, the second treatment left him with autoimmune thyrotoxicosis which would have had an impact on his heart function. Then he was prescribed a heart failure drug which, I have read in a few articles published shortly after his death, does not work well for black patients, especially if they'd had prior arrhythmia, as B3 did. Exactly three months after starting this drug B3 collapsed. He never made it home to the UK alive.

109. I believe wholeheartedly that this awful chain of events would not have happened if B3 had not been infected after using contaminated blood products through no fault of his own. One thing just led to many others, which is why it has been impossible to separate his infections from his treatments, his drugs from his existing and acquired conditions. After he was infected, he did not have one of these things without at least one of the others, which had a devastating impact on our little brother. Now that he is gone, we worry constantly about our remaining brothers and my son. I also believe that most of the medical professionals who treated B3 genuinely did do their best to help him and for that we will be forever grateful, but there are others who made mistakes and did unethical things who are too afraid to admit their actions. We just wanted to know the truth so that we could come to terms with losing B3 and find some kind of closure. It now seems like we will never get that.

ANONYMOUS

110. I have mentioned the fact that I believe a test for vCJD is available, contrary to that which I had been told. Whilst conducting my own research, I have found a document from the HOUSE OF COMMONS, SCIENCE AND TECHNOLOGY COMMITTEE entitled 'After The Storm? UK Blood Safety And The Risk Of Variant Creutzfeldt-Jacob Disease'. It was published on 24th July 2014. A copy of this document I now produce to assist the Infected Blood Inquiry as my **Exhibit WITN3733002**. Points of interest are on pages 32-35 paragraphs 61-66 under the heading: 'The technology: the MRC Prion Unit blood test'.

111. The main point which I would like to highlight from this document is that by the date of it having been published, and accordingly at some time beforehand, a test for vCJD had been developed and H.M. Government appears to accept that its use would be advantageous, but they were reluctant to fund its development.

112. If the materials currently being used to treat haemophiliacs were tested, any batches containing vCJD could be removed from the supply chain as in the absence of a viable test being applied, I believe that vCJD could still be present within blood products today.

113. People could be carrying vCJD, but are unaware of it and there are then the people like S and my surviving brothers, B1 and B2, who have been told they have been exposed to it, but don't know if they have it or not. A screening process, using this test would help remove doubt for some of the 'exposed' people and a broader screening programme would help others.

114. In order to assist the Infected Blood Inquiry, I would like to provide copies of other documents I hold as regards B3 and S and their treatment, these being:-

115. Exhibit WITN3733003 - A letter from the QMC Haematology Department (Jasmina KHALDI, Virology Nurse Specialist) dated 1st August 2017 to B3 general practitioner in which his treatment with Zepatier and Ribavirin (to address his HcV status) is detailed.

ANONYMOUS

116. **Exhibit WITN3733004** - An extract from my son's medical record at Queens, dated 24th March 1988 in which (item 3, centre of page) it is noted "Still awaiting results of HIV testing, parents not aware of testing".
117. **Exhibit WITN3733005** - An extract from my son's medical record at Queens, dated 4th February 1993 in which (final entry of the page) it is noted amongst other observation / treatment that "*Hepatitis B vaccine sent up with* s *to be given in theatre subcutaneously*". I had not been told that they intended to vaccinate my son on this occasion.
118. **Exhibit WITN3733006** - A copy of a Histopathology Department form dated 4th August 1993, showing that tissue samples of the biopsy taken from the antrum of s stomach on 4th February 1993, were tested for H.pylori.
119. **Exhibit WITN3733007** - This exhibit consists of an extract from the medical record of s from the Queens Medical Centre, dated 17th December 1997 showing my having discussed the issue of contaminated blood products with Dr Kate FORMAN. She wrote about our discussion in the notes which shows that at this point in time, I was being offered a UK sourced product, which may or may not have been contaminated, or a product from the USA which may also have been contaminated.
120. I was told that I could either run the risk of exposing s to vCJD if I used the British product, or place him in jeopardy of infection with HcV or HIV if the American product was used – both were then known to pose a risk, at least by this doctor who accepted that Factor VIII came with these risks at that time, but didn't leave me with much of a choice as his mother trying to decide what was best for him. I didn't know it at the time, but by then s had already been exposed to vCJD two years earlier in 1995.

ANONYMOUS

121. Exhibit WITN3733008 - I have mentioned the fact that we received three letters from the QMC Haemophilia Unit (which was also known as a Comprehensive Care Unit), which mentioned s possible exposure to vCJD. I now produce one of those letters (dated 30th January 2001) which shows on the attached 'factsheet' what little was then known about variant Creutzfeldt-Jacob Disease.

122. As I had been invited to, within this letter, I responded to the above, and received a response which I now produce as **Exhibit WITN3733009**. This confirmed his exposure to vCJD from an implicated batch. This was the first of the communications we had with the Haemophilia Unit telling us of his exposure.

Statement Of Truth

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

GRO-B

Signed : _____

Dated : 17th May 2023