

# ANONYMOUS

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Witness Name: GRO-B

Statement No: WITN0662001

Exhibits: WITN0662002

Dated: 22 February 2019

## INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006, dated 17<sup>th</sup> December 2018.

I, GRO-B will say as follows: -

### Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B 1940, I make this statement with the help of my wife, GRO-B whose date of birth is GRO-B 1945, our address is known to the Inquiry.
2. For personal reasons both my wife and I want are identity to remain anonymous. We fully support the Inquiry and it's important that GRO-B: D's story is told and that she has a voice.
3. I am a retired Engineer. I intend to speak about the death of my daughter D who I suspect received contaminated blood and blood

products during her treatment for Acute Myloid Leukaemia ('AML'). D  
was aged 12 when she passed away.

4. In particular I will speak about the nature of her illness, how the illness affected us as a family, the treatment received and the impact it had on her and our lives as a family.
5. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

## **Section 2. How Affected**

6. As a young man I obtained a degree in engineering and went on to work for various engineering companies; I was promoted to managerial roles working for GRO-B later to become GRO-B When I moved to Kent I was promoted to position of GRO-B
7. It was whilst living in Kent that I met my wife GRO-B We married and went on to have a son GRO-B who was born GRO-B 1971. After the birth of our son we moved to GRO-B in Somerset. There, we had our second child D who was born on GRO-B 1976.
8. In 1983, aged 7, D became unwell. GRO-B recalls seeing her on stage at Brownies and thinking to herself that her child was fading away.
9. After having a series of colds my wife and I decided to take her to the doctors who initially dismissed her illness stating that she was just getting over a virus.
10. My wife knew that something was wrong with D and asked for a blood test. Our local GP performed the test and rang back quickly after obtaining the results suspecting that D had Leukaemia.

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11. [D] was taken to hospital in Yeovil and was quickly transferred to Bristol Children's Hospital at St Michaels Hill. It was there that doctors confirmed her diagnosis as Erythroleukaemia, a form of Acute Myloid Leukaemia. This diagnosis was made early February 1983.
12. My wife r and I remember details about [D] s treatment, which are described below. [D] received excellent care at the Bristol hospital; she was treated by Drs Tony Oakhill and Martin Mott.
13. These two doctors oversaw her care; they worked together as lead oncologists. [D] received an extremely severe course of treatment, which included chemotherapy and transfusions with whole blood, platelets and plasma (Fresh Frozen Plasma).
14. [D] received a series of cycles of this treatment. After each session of chemotherapy the levels of haemoglobin and platelets in her blood would reduce significantly. This resulted in her being extremely pale and bruised.
15. 10 days after the chemotherapy treatment she would usually be given a blood transfusion and or blood product in order to return these levels back to normal. At first she was treated by injections given through a cannula inserted into her wrists. Later she was given a Hickman line, which was inserted to make treatment administration easier.
16. After these first blood transfusions, [D] complained that her skin felt very itchy. To combat that she had to take Piriton.
17. [GRO-B] remembers that [D] also suffered with mouth sores, presumably from the chemotherapy. Her reactions to the blood transfusions varied but I do remember her suffering with the itchiness. This reaction only happened during her initial treatment.

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18. [D] was treated in both Yeovil and Bristol hospitals. However there was a lack of expertise in the Yeovil hospital, which resulted in a lower standard of treatment than previously experienced at Bristol. The staff at Yeovil did not have experience with using a Hickman line, as at the time, it was a fairly new practice.
19. Happily, in September 1983, we were told that [D] was in full remission. She was a success story for the hospital. The doctors involved in [D]'s treatment were thrilled with how she had recovered. She quickly began to look much better physically and her hair grew back.
20. All the way through her treatment she was incredibly brave and resilient; she was accepting of her situation.
21. In the summer of 1986 we returned to the hospital and saw Dr Oakhill, he was generally delighted, [D] had had nearly three years with no problems and as far as he was concerned [D] had passed the unofficial time benchmark and was completely clear. After this she had several check ups to make sure all was well.
22. However, in November 1987 [GRO-B] knew that [D] was not well, she suspected that the Leukaemia was back.
23. [GRO-B] first realised that [D] wasn't well when they were out in Marks and Spencer's together, [D] had to sit down whilst [GRO-B] was paying for their shopping. [D]'s skin was tinged with yellow and appeared waxen.
24. I called Bristol hospital who just thought [GRO-B] was being a 'fussy mother' They told me to take [D] to Yeovil Hospital in order to put our minds at rest. It was whilst at [GRO-B] Hospital that blood tests were



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taken which sadly confirmed within a few hours, that the Leukaemia had returned.

25. The doctors sent **D** off to produce a urine sample to ensure that she was out of the room when my wife and I were told. The ward sister said to us 'you are right it's back'.
26. We recall that the first time **D** was diagnosed, Doctors performed a bone marrow test. However, the second time it was just a blood test, **D** was 11 at this point. We were sent on to the Bristol Hospital the same day to see Tony Oakhill.
27. **GRO-B** noticed that **D** had a yellowish tinge to her skin. Tony Oakhill decided to give **D** a blood transfusion during which **GRO-B** remembers her turning progressively more yellow throughout the treatment. She remembers saying to the doctor that something wasn't right with **D**'s liver.
28. **GRO-B** is a nursing sister's daughter and she remembers having intuition and knowing that something wasn't right.
29. Later whilst at Bristol Hospital **D** was diagnosed with Hepatitis. I remember the doctors telling me it was Hepatitis. My wife recalls the doctors explaining to her that it was a very rare type of Hepatitis but couldn't remember what they had called it; she presumes that they must have been describing Hepatitis Non A Non B. I had a memory that they said it was Hepatitis C. After all this time I cannot be certain.
30. The doctors treating **D** were absolutely perplexed by the situation

GRO-D

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31.

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32.

After the diagnosis of Hepatitis the hospital did tests on D's liver, they said her liver was in failure and not functioning properly. This meant that she could not start the Leukaemia treatment until her liver function improved. This was a major setback.

33.

Doctors said the Hepatitis had caused D's liver to fail. They consulted with their colleagues and they suggested a holding treatment that could be used in the meantime.

34.

D was prescribed the holding drug Vincristine to take whilst the doctors waited for her liver to recover sufficiently. During this period D suffered with very high temperatures, this caused her to have fits known as Rigors.

35.

This holding drug is a relatively gentle cancer treatment, which is usually prescribed along side other cancer treatments. It is not used normally as a treatment on its own.

36.

Unexpectedly whilst taking this drug D went into remission for a second time. D's condition improved before Christmas 1987 and she had perked up enough to leave the hospital in a wheel chair for short outings such as Christmas shopping with me.

37.

D was a very keen horse rider; she loved her time in the GRO-B GRO-B On the odd occasion when she was allowed home from the hospital D wrote out a fitness program, which focused on how

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she would get fit so that she could continue with the hobby that she loved so much.

38. [D] recuperated at home in order to get her strength up so that she could have an Autologous Transplant. This is where Doctors collect stem cells from the spine; they then clean and grow these cells before injecting them back into the body.
39. Unfortunately, [D] could not be given a bone marrow transplant because a donor could not be located. Before the Autologous transplant took place they gave [D] a very strong dose of chemotherapy in order to kill any Leukaemia cells left in the body.
40. They then injected the processed stem cells in the hope that her body would accept them leading to recovery.
41. This procedure was given in the spring of 1988. Before proceeding, the doctors from Bristol discussed [D]'s situation with their colleagues all around the country. Her course of treatment was decided upon with the advice of these colleagues.
42. [GRO-B] remembers that during the time she was in hospital [D] suffered from terrible nose bleeds. Due to her condition Doctors operated on [D] to cure the nosebleeds in her cubicle on the ward. It was found to be a piece of plastic in [D]'s nose, which was causing the bleeds, presumably left there accidentally after a previous procedure.
43. Despite her illness [D] would light up every room she walked into. People were always drawn to her; she was a very bright girl. [D] made a huge impact on the Dr's and the hospital staff.
44. [D] lived a very full life. She used to love singing and was pitch perfect. People would say that with a bit of training [D] will go far

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with her talent. My wife remembers feeling the sadness comments like this would bring, knowing how ill our daughter was.

45. We spent as much time as possible with [D] in hospital. My wife vowed never to be miserable around [D] and never to leave her side; she used to sleep on the hospital floor. There were parents in the hospital 'mourning the living' and my wife and I vowed never to do that. [D] felt terrible guilt due to the fact that we were caring for her. We had letters from [D] saying thank you for helping her.
46. When [D] was in hospital [GRO-B] decorated her cubicle; we did the best we could to make it the happiest place on the ward for her.
47. She had terrible temperatures so had to constantly have all of the windows open and fans on around her bed. It was freezing.
48. My wife arranged for [GRO-B] a famous horse rider to visit [D] in hospital. He was completely overwhelmed with [D] and invited her to his stables once she was better. She made such an impact on everyone she met.
49. [GRO-B] an Olympic horse rider medallist also visited [D] in hospital inviting her to ride one of her Olympic horses when she was better. [D] managed to accept this invitation and had a wonderful time riding with [GRO-B]
50. When [D] was in hospital she often couldn't eat, she was skeletal and had yellow skin. [D] suffered greatly throughout her treatment complaining of stomach aches, nausea, and other side effects.
51. [GRO-B] helped [D] to visualise her situation, which helped her to keep fighting. When she regained some liver function I helped her to



visualise her liver as having tiny green shoots growing out of it symbolising it repairing itself.

52. Unfortunately in [D] 1988, [GRO-B] and I were told that our daughter wasn't going to make it and that she had around three days left to live. It was during this time that we found out she had been selected to compete in a [GRO-B] competition. She was absolutely adamant that she wanted to participate so we took her. We didn't tell her about the three-day diagnosis at that point.
53. A nurse from the hospital came along to the competition with us. [D] was on morphine at this time but amazingly she managed to compete in the competition. She competed in cross-country and show jumping as well as having to prepare her pony for the competition. In between events she would crash out on a table.
54. The girl that won went on to raise lots of money for Cancer and Leukaemia in Childhood {CLIC} in tribute to [D] The nurse was so impressed with [D] she had never seen anyone do something like that who was so so ill.
55. Soon after this competition [D] asked her mother if she was dying and [GRO-B] sadly told her that she was. [GRO-B] told [D] "that they couldn't get her marrow right and you know what that means?"
56. [D] said to her mother that she didn't want to live if she couldn't do the things she wanted to do with her life.
57. They gave [D] more blood after this point. [GRO-B] remembers [D] being so brave and saying 'if it had only been flu – didn't we have a good time!' describing the happy times she had experienced during her illness.

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58. My wife and I asked to bring **D** home for her final few days and the hospital agreed. She was given oxygen at home and **GRO-B** administered her morphine. She had breathing difficulties, which had been caused by the blood transfusions.
59. When she got home **GRO-B** recalled that **D** crawled up the stairs because I had had a bad back, an example of how selfless and determined our lovely daughter was.
60. Our son **GRO-B** was 18 at the time, and found the situation very difficult to deal with. I recall that on the day she died he went to college to enrol, he didn't come back until a lot later in the day. By the time he returned **D** had passed away. We feel that he couldn't deal with what was happening to his little sister.
61. **D** died at home on **GRO-B** 1988; a month after she had been given the three-day prognosis. In the time between the initial three-day prognosis and her death she had the best time taking trips to Cornwall and participating in the horse riding competition.
62. As sad as it was, we feel that we were in some ways fortunate that we were able to be with our daughter when she died, not all parents get that opportunity.
63. I couldn't help wondering if it was a wise decision for us to agree the Autologous transplant, as she seemed so much better up to that point.

64. 

<b>GRO-D</b>	<b>D</b>	<b>GRO-D</b>
<b>GRO-D</b>		

65. Doctors prescribed her Paracetamol but could not prescribe much because of the damage it could do to her liver. They also prescribed Intravenous antibiotics that caused her severe tummy pain.
66. The Doctors did not understand how she could be in pain so continued to contact their colleagues to see how they should proceed. The doctors said to GRO-B we give her this antibiotic treatment or she dies. They were treating the infections with these antibiotics, which caused the high temperatures.
67. Neither myself or my wife were ever given any warnings about the safety of the blood. When D received her second tranche of treatment I do recall overhearing a Doctor saying to a colleague, 'make sure you give her the right blood'. I didn't think anything of this at the time, I assumed he meant the right blood type, but now I think he could have been talking about giving D the safe blood. I don't know in what context this was said so cannot establish the full meaning.
68. I believe that there must be a great deal of cancer patients that suffered these same horrible consequences as we have done; I know that many were given blood and blood products as part of their treatment.

### **Section 3. Other Infections**

69. As far as we are aware D was only diagnosed with Hepatitis. We have no idea whether she was infected with anything else.

**Section 4. Consent**

70. As [D] was a child we had to agree [D]'s treatment. We had to put our trust in the hospitals expertise; she was fighting for her life. Had we know that there was a risk of her becoming infected with virus's through the blood we would have asked more informed questions.

**Section 5. Impact**

71. [GRO-B] and I have spent the years since [D]'s death wondering where the Hepatitis came from? An answer to this question would be helpful. I can only assume that [D] had a compromised immune system after the chemotherapy and as result, her Hepatitis infection progressed and allowed the Leukaemia to take over again.
72. As far as the hospital and we were concerned, [D] had made a full recovery from the Leukaemia. They couldn't understand why it had come back. On reflection my suspicion is that the Hepatitis was partly responsible, her immune system was seriously compromised by the Hepatitis infection.
73. We believe that the absolute worst thing a parent has to face is dealing with a dying child. Before [D] was ill [GRO-B] raised money for CLIC after hearing the story of a little boy who had died. She recalls how ironic it was that she was then helped by that very same charity when her own daughter was ill.



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74. [D]'s illness has had a huge impact on her brother [GRO-B]. He was 5 years older than [D] he was 13 when she was first diagnosed and 18 when she died.
75. I believe [GRO-B] has never fully come to terms with the loss of his younger sister. [GRO-B] and I always felt guilty for not being able to give [GRO-B] the attention he needed whilst we were supporting [D] through her illness.
76. Thankfully he achieved a degree and managed to obtain a good job as a Systems Analyst, but his life will always be impacted by the loss of his sister.
77. We suspect that he has a degree of 'survivor's guilt'. He has two children, a son, [GRO-B] aged 12 and a daughter, [GRO-B] aged 9. He worries when his children are taken ill with colds and flu.
78. Throughout [D]'s illness [GRO-B] and I felt powerless there was nothing we could do to help our daughter. We could only be there for her which we believe was the most powerful thing.
79. At this time there was no support for siblings to help deal with the situation. We believe that [D]'s illness and death has affected [GRO-B]'s life. No one ever asked about or offered to provide counselling services for him.
80. [GRO-B] says that there is a word to describe people whose spouses have died, Widow/Widower; a word for someone whose parents have died, orphan. However there is no word for parents that have lost a child because it is beyond words.
81. We had 12 wonderful years with [D] but the repercussions still go on. My wife and I find it very difficult thinking about all the things we

miss out on. It is also painful to talk to our friends about their seemingly perfect family lives with their healthy children.

**Section 6. Treatment/Care/Support**

82. [D] was not treated for her Hepatitis infection, as I have already mentioned, her Leukaemia had returned. The treatment she received related to that.

**Section 7. Financial Assistance**

83. My wife and I never received any financial assistance. I was lucky that my employer was very supportive of me throughout my daughter's illness. I continued to work throughout.

**Section 8. Other Issues**

84. I want to know if it was common knowledge amongst the medical profession and the political establishment that the use of blood around the time that [D] received her blood transfusions carried a serious risk of deadly viruses?
85. For my wife and I, this is not about compensation; this is about establishing the truth in order that all those individuals affected and infected can be provided with some answers. Additionally, to raise awareness so that such traumatic life changing episodes can be avoided in the future.

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86. On reflection we have a strong suspicion that it was the Hepatitis that caused [D] to relapse so dramatically. We had no idea she was infected and the virus was able to do its damage to her liver when her body had already been so seriously weakened by the intensive chemotherapy she had received. Sadly we will never know if that was the case.
87. To end, we have allowed the Inquiry to have a copy of a picture taken of [D] in the summer before she died. As you will see she looks so healthy and radiant. This is for the Inquiry only and I do not want her picture publicised. **Exhibit WITNO622002 refs.**

**Statement of Truth**

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

Signed

GRO-B

Dated 22nd Feb '19.