

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2764001

Exhibits: 0.

Dated: NOVEMBER 2019.

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

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

Section 1. Introduction

1. My name is **GRO-B** I have two daughters, both of whom are married and live in the UK. I also have a number of grandchildren with whom I speak with regularly. I moved to the USA and partake in voluntary work at senior food camps.
2. I make this statement in relation to my late daughter, **GRO-B: D**
GRO-B
having contracted Hepatitis C after receiving contaminated blood.
3. This witness statement has been prepared without the benefit of access to my late daughter's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

4. From birth, [D] seemed to be a normal baby. Her delivery was uneventful; she weighed 6 oz. and appeared to be happy and healthy. [D] health was good until she turned 3 years old. She then started to suffer from recurrent nose bleeds, bruise easily and have horrendous fevers. On one occasion I called an ambulance and she was taken to Birmingham Children's Hospital. After undergoing a number of tests, [D] was diagnosed with aplastic anaemia.
5. The medical team advised it was crucial that [D] had a bone marrow transplant as her own bone marrow was not producing enough platelets. I was told that, from this moment on, she would have to rely on blood transfusions for the rest of her life.
6. The consultant in charge of her care was Dr Derbyshire, whom I believe is retired now. Quite early on, [D] was exposed to a new treatment; Anti-lymphocyte globulin (ALG,) which was unsuccessful and so [D] continued to have regular blood transfusions. At first the transfusions were once every 2 months, but as the years went on they became much more frequent.
7. In 1990, when [D] was around 5 years old, she began to experience problems with her liver. I took her to the doctors because her eyes developed a yellow-ish tint, and we were referred straight to the hospital. I was told her liver had become significantly enlarged and that she had contracted Hepatitis C through a blood transfusion.
8. I did not know at the time that the NHS was buying cheap blood from the USA without it being screened first. Nor was I aware that no filtering process was in place for the blood that was being donated. I was only made aware that a number of haemophiliacs had also been infected with awful diseases because of this blood and that [D]'s lifespan would be drastically cut short as a result.

9. Alongside all of this, [D] was still in need of a bone marrow transplant. I joined the British Bone Marrow Appeal in order to try and find a suitable donor and had all family members tested too. No match was found until [D] was 6 years old and a compatible donor was found in the USA.
10. Dr Derbyshire advised [D] was still unable to have the transplant because of the presence of Hepatitis C in her body. The infection however had no treatment available at that point.
11. I was never made aware the NHS was buying blood from the USA without it being screened. If I were told this information at the time this entire scandal could have been so easily avoided. I would never have allowed my child to be given contaminated blood, but because I was not in the know about the products she received, her life was cut short.
12. I am unsure as to which blood transfusion specifically caused the infection but in any event I could not refuse my daughter from receiving the blood, because the doctors would just override my decision anyway.
13. I do not believe I was given adequate information to manage the infection. I did not know anything about Hepatitis C and did not know you could catch anything from the blood. All I knew was that [D] needed it as her own bone marrow was not producing enough.
14. The doctors never said that you could catch an infection from the blood they were giving [D]. The doctors were the Gods; I looked to them to save my child's life. Everything they did, I believed, was in the best interests of my child.

Section 3. Other Infections

15. I am not aware of any other infections [D] may have contracted as a result of receiving the contaminated blood.

Section 4. Consent

16. I was never given much in terms of information regarding the transfusions; only that they were a necessity for

17. I never provided consent for to be tested on.

18. She did have blood tests when she was in hospital but I thought they were just routine. The doctors always had the overall say as to how to proceed with her treatment anyway.

19. I am not aware if she was tested on as part of medical research; there was no way for me to know if this was ever the case.

Section 5. Impact

20. Whenever was admitted into hospital, it would be for about a week and each time I would stay with her. On some occasions she would have to stay much longer, but I couldn't bear to leave her on her own. During these stays she would have her blood transfusions, but the bruising would remain long after she was discharged.

21. Whenever I did have to leave in the hospital, I would have other family members visit and look after her. Looking back, this was a bit strange because she was already in hospital and had the best care imaginable, but I just couldn't let anything bad happen to her.

22. It was devastating that was not able to play with other children because of the amount of time she was spending in hospital. When she was young, friends would visit our home and have a great time playing in the Wendy-house we had in our garden. As her condition deteriorated, she would get out of breath quickly and when she finished playing, she would spend the rest of the day recovering in bed. In winter, she wouldn't be able to play outside at all.

23. The doctors said that over time the body gets used to the platelets received from the transfusions and so they no longer continue to have the same effect. Her hospital stays became lengthier because she was so prone to infection with the production of her white blood cells considerably reduced.
24. After [D] diagnosis of Hepatitis C, my whole world fell apart. From then on I would live by the hour. I wrapped her in cotton wool and focused the majority of my attention on her, which upset my other children. How could I explain the circumstances to my other children who constantly asked; "Where's Mummy" or "Why can't [D] come home?" They were only babies themselves.
25. I had to ask others to constantly look after them whilst I stayed in hospital with [D]. It must have been so traumatic for them at the time. My daughters later told me they thought I loved [D] more than them because she got all the attention.
26. Despite this, when they came to visit [D] in the hospital, they never wanted to leave her when it was time to go. When [D] was at home and if one of my other children had a cold, they made sure they did not go anywhere near [D] in case she got sick. The other children were very good about washing their hands and their toys after they were finished playing.
27. Having been infected with Hepatitis C meant [D] became quite bloated and incredibly fragile. After her diagnosis, you could physically feel how enlarged her liver was over her abdomen. I was told this was due to the iron count in her body being too high for her liver to process. She would suffer from terrible nose bleeds and have massive bruises; I soon came to recognise these signs as [D] needing yet another transfusion. My other family members picked up on her symptoms too. In particular they commented on her eyes being yellow, her being so bloated and being on steroids.

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28. My family and I are devout Christians, so we even tried taking her to church for healing. We attended a sermon conducted by the Billy Graham Evangelistic Association at the NEC in Birmingham and began to believe she had been healed. This was short-lived.
29. I am not too sure about how the treatment impacted D I know she was given ALG for her Hepatitis C but anything she had didn't help. Back then there was no cure it.
30. I always checked the blood D was being given to make sure it was the right blood type even before the Hepatitis C infection.
31. D health put a great strain on my marriage and ultimately was the reason for our separation. We were childhood sweethearts; I married at 17 years of age, whilst my husband was 19. I recall I still needed my father's permission to marry, but my husband was my best friend and we were supposed to last forever.
32. Towards the end I just couldn't cope and asked for him to stay with his mother instead. I blamed everything on my husband and because I spent all my time with D I was not there for him. I expected him to understand because he always used to be there for me. I always thought that D being ill would have brought us closer together, instead it drove us apart. I gave all of my time to D I had to.
33. The consultant noted I was coming on my own more and more frequently so I even asked him why our marriage had broken down. He suggested it may have been because D was my one and only focus, but it wasn't like that. In fact I know many parents who had been brought closer together since their own tragedies.
34. The doctor once spoke with me and said GRO-B "you really need to take a break." It was only then I decided to go on a shopping trip with some of the other mums to help take our minds off things.

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35. The "Make A Wish" charity also organised a family holiday for us to go to Disneyland for a week. It was probably when I saw [D] at her happiest. I still look at the pictures that bring back so many lovely memories. They're now invaluable to me.
36. On the day she passed, [D] was already in the hospital having a transfusion. She was lying in a cot bed and in an isolated ward so as to protect her from other infections. I was holding her hand when she said she had a pain. I took her out of the bed and held onto her in an attempt to comfort her. I rang the bell for the nurses and suggested we pray together to help her through the pain. Praying through the pain had become something we used to often do together. My little girl said no more and passed away whilst I was holding her in my arms.
37. The doctors were not there at the time. I asked them why she had that pain but they had no explanation for me. It was only until after the post-mortem that I discovered she had a brain haemorrhage. I believe this was the cause of the pain [D] spoke of in her final moments.
38. The doctors did nothing after that. I phoned my family to give them the news and [D] was moved to the mortuary where I was able to sit with her body until they arrived. I believe I was sedated soon after, however much of this time period has been blocked out in my mind. I would visit her everyday until the funeral was done.
39. All my daughters wanted to know was when their sister was coming home; it was heart-breaking. After [D] death, they would still go into her room looking for her or other times question why I wasn't at the hospital with her.
40. All anyone else ever wanted to know was why or how this could have happened. I questioned why God hadn't healed her and my brother who was a minister said that [D] was an angel that God had leant us and she had to go back to God now.

41. My daughter's loss really tested my faith in God. It was terrible. Now when I dream about her, [D] is always with animals. [D] always loved animals growing up and I remember we had to give away our pet dog because [D] needed to keep away from anything that would antagonise her illness. Sometimes it feels like it all happened just yesterday.

42. I moved from [GRO-B] because it was too traumatic for me to remain in [GRO-B]. My other daughters still live in [GRO-B] today and although I miss them terribly, I moved to the USA for my brother, because he now needs me more.

43. Only recently, my daughters apologised to me for being selfish at the time but they were only babies themselves, they could not have known any better. They genuinely believed [D] was still coming home.

44. My eldest, [GRO-B] is now grown up but still has counselling. I would not wish any of this on my worst enemy. It ripped my family and my heart apart. My daughter has taken her children to Disneyland and always talks about her sister to her children. My sister also sends me flowers for [D] birthday to celebrate and commemorate her life. My ex-husband will also visit [D] grave and send me photos when he takes flowers to lay down for her. Even my granddaughter calls to tell me they will be lighting a candle for Auntie [D] birthday. This year we all sent balloons up to [D] on her birthday. The impact on my family continues to be devastating.

45. Although we didn't experience much stigma as a result of [D] condition I remember one awful incident when [D] was about 4 years old waiting for her transfusion and the nurse assumed I had been abusing her. I brought her to the clinic to be weighed as per usual and as the nurse was getting her undressed, she noticed all of the bruising. She took [D] away into another room where I assume she asked [D] a series of questions. They should have known that it was her platelets, but because this information was not

effectively communicated, I had to explain myself. I would never beat my child.

46. The impact on education was immense. I informed her school about her diagnosis straightaway and they even started a fundraising campaign. They were excellent and really helped out with her bone marrow transplant. They insisted I did not let miss out and continue to bring her to play. However, could not engage in normal activities, i.e. running around and playing with the other children. schooling was heavily disrupted by the hospital stays and for her final two years she would either be home schooled or a tutor would come to the hospital to teach her. wanted to be a nurse because in the end they became her role models. She wanted to help people.

47. The impact on my working life was immense. I had enrolled onto a nursing programme and was a pupil nurse when was born. Upon diagnosis, I left the course to prioritise her needs, because I just wasn't able to devote any time. I made the decision to re-enrol a year after passing.

48. Money was not an issue as my husband had a good job. He managed the mortgage by paying a reduced rate and contributed significantly for us to manage how we did. In if your child passed away the council would give the family £2,000 - £3,000 to put towards the funeral.

Section 6. Treatment/Care/Support

49. Although I feel I was offered all the treatment I should have been at the time, I do not believe I was given all the information on the matter.

50. I was kept in the dark and under the impression that was getting the best treatment, because it did not matter what time of the night I phoned for an ambulance, they would be there and take her in straightaway.

51. I was offered counselling by my own GP which I didn't find so useful. I was however part of a parent group with others who were around in the ward, where I picked up tips on how to manage lifestyle whilst she was still alive.

Section 7. Financial Assistance

52. I received no financial assistance during lifetime.

53. In or around 2016, I heard from the Skipton Fund and having completed a number of forms, received the Stage 1 payment of £20,000. I was told I was entitled to another lump sum so I filled out more paperwork, only to be told that this time I had not met the criteria and would need to provide additional information. At this point it all became too painful to relive again.

Section 8. Other Issues

54. Nobody can ever prepare you for losing a child. Your whole world collapses. I felt as though I had lost everything. I can't help but wonder what life would have been like were alive today. Would she have been married? Would she have had children? Now when I see a child, all I think of is my 13 year old angel.

55. Why did the NHS let this happen? If this had happened to their relatives, what would they do differently and how would they react? Why were they buying blood from foreign countries, when we had a blood bank?

56. The Government could have campaigned for people to give blood. Many would have willingly given. I want to know about the knowledge the NHS had relating to the risk of infection from these blood products and if people like were just sources to conduct experiments on.

57. There should have been transparency and truthfulness. They should have told us at the time where the blood was coming from and that it was not heat

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treated. I do not believe it was down to money and now look what people are suffering through. Many have lost lives without fulfilling their time on earth. We trusted the Government and they let us down.

Anonymity, disclosure and redaction

58. I wish to remain anonymous. The media are too intrusive and horrible; they say horrible things about people even in tragedies.

59. I understand that this statement will be disclosed and published as part of the Inquiry.

60. I am prepared to give oral evidence.

Statement of Truth

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

Signed..

GRO-B

Dated.....

31/5/2019