

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN4142001

Exhibits: WITN4142002-3

Dated: January 2020

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** and I live at **GRO-B**
GRO-B I was born on **GRO-B** I am retired and I help look after my grandson **GRO-B** Prior to retirement I was a nurse whilst also being the sole carer for my son, **GRO-B: S** He has also provided a witness statement to the Inquiry under witness number **GRO-B**
2. I make this statement as an affected mother of my son who was infected with Hepatitis C as a result of receiving contaminated Factor VIII concentrates.
3. **This witness statement has been prepared without the benefit of access to my son's full medical records.**

Section 2. How infected

4. My son has severe Haemophilia A and received Factor VIII concentrates in Alder Hey Hospital, Liverpool, St. George's Hospital, London and St Thomas's London .

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5. My son received Factor VIII concentrates since the age of 10 months old which was when he was diagnosed with Haemophilia.
6. I believe that my son was infected with Hepatitis C at St. George's Hospital and his consultant at that time was Dr David Bevan.
7. I was given absolutely no advice or information in relation to the risk of infection from Factor VIII concentrates. Being a nurse I carried out my own research and as a result of what I discovered I was very concerned that there were significant risks attached to Factor VIII. I questioned the medical professionals about this but my questions fell upon deaf ears; I was told that Factor VIII was the only available treatment.
8. From around 1991/1992 and as a result of the medical staff at St George's being unable to control recurrent bleeds in [S] left ankle that I requested that his care was continued by Professor Geoffery Savidge at St. Thomas's Hospital. He immediately changed my son's treatment regime and got [S] bleeding episodes under control. Both myself and my son describe him as a "legend"....
9. In or around 1992 Dr [GRO-D] told me that my son, who was only aged [GRO-B] had been infected with Hepatitis C. This was a very matter of fact conversation in which I was given absolutely no information or advice to enable me to understand and manage my son's condition. I was also given no information regarding the risk of transmission.
10. I then received a letter dated 13th March 1992 from Dr Rowley, Senior Registrar in Haematology (Exhibited to my son's statement at **Exhibit [GRO-B]**) confirming that my son had Hepatitis C. This letter also confirmed that my son was HIV and Hepatitis B negative.
11. I remember giving [S] an injection of Factor VIII on 8th May 1991 before he went to school because he had injured his right forearm and was unable to flex the right wrist this type of injury always results in bleeding. Following the fusion he appeared to be collapsing he had dilated pupils and was

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complaining of dyspnoea and nausea which lasted for 2 minutes. I was really scared to see such a reaction in him particularly as I was on my own as a single parent and in those days we only had a telephone land line in the hallway of house and clearly I could not leave him alone. I was scared. He was also complaining of fuzziness in his frontal forehead for the duration of the day. **Exhibit WITN4142002** is an extract from [S] home treatment notes I made on 8th May 1991 which detail this incident. [S] Hepatitis C result was confirmed on 13th March 1992 as a result of blood having been taken in November 1991. I now believe that [S] may have contracted the Hepatitis C on 8th May 1991 as that was the only time he displayed such a reaction to an infusion of Factor VIII.

12. Being a nurse and [S] mother and given that I received absolutely no information, advice or support from the medical professionals, I took it upon myself to fully research Hepatitis C and I left no stone unturned. I embarked upon a crusade and life journey to ensure that [S] was given the best possible chance of beating the virus by concentrating on providing a healthy diet and lifestyle so he could lead as normal and enriched a life as possible.

Section 3. Other Infections

13. My son has been put at risk of vCJD. Dr Bevan wrote to him on 16th September 2004 confirming this fact and a copy of the letter is exhibited to my son's statement at **Exhibit WITN1194004**. At this time [S] was old enough to understand and we had a discussion regarding the offer of finding out if he had had an infected batch. We concluded that as there was no treatment available for vCJD we would not pursue the issue

Section 4. Consent

14. I note that my son's statement confirms that, as far as he was aware, he was not tested or treated without his knowledge. However, I don't remember being told that [S] was being tested for HIV and Hepatitis B and I refer to paragraph 10 above in this regard.

Section 5. Impact of the Infection

15. I was extremely touched by the way **S** described me in his statement. He referred to me as a **GRO-B** He also said **GRO-B**

GRO-B
GRO-B
GRO-B I would like to say that **S** is the most wonderful son that any mother could wish for.

16. **S** married his long term partner and the mother of his son in May 2019, thankfully as a boy born to a haemophiliac he cannot inherit the faulty gene. I am incredibly proud of him and it was a moment to savour.

17. In or around the Summer of 2019 **S** was called by DWP to be assessed for PIP. This assessment was to ascertain whether he should still be entitled to receive his Attendance and Mobility Awards which was an insult in itself.

This assessment was heavily stacked against **S** **GRO-B**

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accompanied **S** to this interview and was fully appraised of the assessment procedure as I had read all available literature from the DWP and the Haemophilia Society. I was completely flabbergasted by the way in the questions were structured which almost guaranteed failure on the part of the person being assessed. We challenged the assessor during our interview but never once would she enter into conversation or deviate from the script on her computer.

18. **S** duly failed the assessment because the assessor concluded that **S** could walk when they had asked him to walk. He had had a bleed prior to the assessment and should not have been walking at all but he made a concerted effort to both attend the assessment and to walk. I was so angry and upset at the way this assessment was conducted. I was fully appraised regarding how

the regulations should have been applied but the assessor appeared to have no knowledge regarding applying '*descriptors*'. Descriptors are there to drill down into the problem and not just look on the surface as she did when she could see [S] could walk from A to B albeit with difficulty. The assessment was a paper exercise to reach a predetermined decision to remove any financial benefits

19. Prior to the assessment [S] had been informed by letter that his must return his Motability car on a specified day. We used the car to get to the Assessment Centre. [S] was informed by letter that he had failed to get enough points and would therefore have his benefits withdrawn. We set about preparing our appeal.

20. The day came that [S] car had to be returned to the local Motability garage. I drove us in my car and we then travelled back to my house. Before we reached home [S] received another telephone call; this time to inform him that there had been a High Court decision that all Haemophiliacs were to be eligible for both elements of the Award so the whole assessment along with submitting an appeal had been a complete waste of time and had unnecessarily caused [S] psychological and physical stress. [S] made a telephone call to the garage where he had taken his car and asked if he could have it back. That request was declined however he was told he could apply for another Motability car. In the meantime he had no form of transport; you could not make it up.

21. Worryingly over the Christmas period of 2019, [S] had a second gastric bleed, the first and more serious was some years earlier. He initially went to Epsom General Hospital in Epsom, in hindsight he should have gone straight to St. Thomas' Hospital to where he was eventually transferred and following various tests he was diagnosed with four gastric ulcers and the helicobacter pylori infection.

22. Whilst [S] was in Epsom General Hospital one of the nurses was preparing a drip and letting the bubbles come up when she dropped the end of the drip

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on the floor and then just picked it up again. I looked at [S] and said "*I hope that is not for you*". When she came over with the drip and we realised it was for [S] we both looked at each other but neither of us said anything. I wanted to say something but felt a little awkward because he is [GRO-B] years old! The end of the giving set did in fact have a cap on it so I knew it would not endanger [S] however it was so disappointing to witness such shoddy standards of care.

23. Then in January 2020 he had a scan on his liver and we are awaiting the results of this. I am desperately hoping that the Hepatitis C has not damaged his liver.

24. [S] consultant is going to put him on Hemilibra (Emicizumab) which will encourage his body to produce Factor VIII. He was provided with an advice booklet about this and I attach a photograph of the front cover of the same as **Exhibit WITN4142003**.

25. When he was aged 5 months old and prior to his diagnosis he woke up a short time after going to sleep and then continued to scream and all night, he could not be pacified, I had no idea what the problem could be. The following morning he seemed more settled so I placed him in his baby bouncer which he loved. I then became aware that he did not put his left foot to the floor preferring to hold it up in the air. As soon as I could I took him to the Royal Surrey Hospital where he had an x-ray with the result that nothing was wrong. His ankle pain settled over the next few days.

26. One morning when [S] was about 9 months old I remember hearing him scream which made me rush to him in his cot. At this time [S] was just beginning to learn to walk with a push along trolley I lifted him from his cot to comfort him and then tried to see if he could stand. He seemed unable to hold onto the trolley with one of his hands although now I cannot remember which hand. I took [S] to [GRO-B] where they examined his now swollen hand. Yet again, the medical professionals could not find anything amiss. I told them that this was the second time, in a very short

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space of time, that there appeared to be a problem with his joints and I questioned whether it could be anything to do with Haemophilia, given that I was a carrier of the same. I was then referred to Alder Hey Hospital where S was examined by Dr John Martin who said *"I am sorry to tell you that you have been misinformed when you had your carrier status confirmed, I will test your son however from my examination my feelings are that your son does have Haemophilia and I suspect it is not a mild form as you have been told it would be. The condition does not follow true to a family it mutates as time goes on."* The diagnosis of severe Haemophilia was confirmed via a telephone call from Dr Martin shortly after this. S was aged only 10 months old. I was heartbroken.

27. I was extremely shocked when I received this diagnosis particularly the severity of it as I had sought clarification of my carrier status prior to becoming pregnant from Dr McVerry of the Royal Liverpool Hospital. I was informed that my blood tests showed that I was a carrier of Haemophilia, also that if I was to produce a son it was likely that he inherit Haemophilia from me. He also informed me that Haemophilia follows *"true to a family"* and that if my son was affected with Haemophilia his condition would be a mild form like my Grandfather. My daughters would be carriers of the condition.

28. I remember returning home from Alder Hey Hospital and looking at S playing in the hall and thinking *"I have just given you a death sentence"*. It was horrible, and I was overwhelmed with fear for my child. Then as time goes on as a mother you have to accept what has happened and accept the facts and learn to cope with what is ahead. My priority in life was always going to be this little boy of mine but now I had the extra responsibility of ensuring that he had all the opportunities to achieve in life and to ensure he was healthy. So you get over that and think it will be ok and then you worry about AIDS and you somehow manage to dodge that dreadful card. However, just around the corner we were saddled with Hepatitis C, which had patiently lain in wait for us.

29. During 1984-1985 I set upon a mission to learn all I could about Haemophilia.

I am a nurse and despite many years in my profession had never come across this condition in my professional capacity. I joined the Haemophilia Society and read everything I could to enhance my knowledge. I also made a plan that I would keep [S] condition to myself with the aim that others would treat him as a 'normal' child and in so doing he would be exposed the normal bumps and clashes with other children. It was when I felt I was beginning to make some headway in my mission that the AIDS virus became the subject matter of all of the media headlines. I was surrounded by this life threatening virus; it seemed that everywhere I turned; every radio station and television would have AIDS as their subject. The Haemophilia Society correspondence was an obituary of haemophiliacs that lost the battle following infusion of infected blood products. During all of this I was trying to care for my Haemophiliac toddler and had no choice but to treat his bleeding episodes with Factor VIII. I vividly remember the red writing on the bottom of the BPL vials which read "*Although this has been heat treated we cannot guarantee that it is HIV free*". I had to inject this into my son. I received no support whatsoever. I was isolated and left to deal with my fear. I wanted my little boy to have treatment but feared that his life was endangered as a consequence. To this day I do not know how I got through this. I was completely alone and believed I was injecting my son with a death sentence. It was a terribly horrid and frightening time for me.

30. There was a particular incident when [S] had a clash with another little boy which resulted in four of his front teeth being pushed into his gums. His mouth had swelled up and he was bleeding profusely. I said to the girlfriend I was with at the time "*Don't worry it looks worse than it is*" as I tried to downplay the incident. I rushed [S] to Alder Hey Hospital and we were on the children's ward which was sadly for children receiving chemotherapy. As normal we waited about an hour for a medical professional to see [S] It was also 'normal' for the nurses to take [S] from me and take him to a treatment room, I was never allowed to accompany him! I could hear him screaming so loudly down the corridor which was heart breaking for a mother.

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S was given his Factor VIII and we were discharged. The bleeding stopped quite quickly following this injection however almost 24 hours later, his mouth started to bleed again; the blood literally poured out of him. We returned to Alder Hey and they repeated the traumatic process of administering the intravenous Factor VIII.

31. This cycle continued for 5 consecutive days and on the 5th day I asked the medical professionals why the Factor VIII was failing to control the bleeding. The reply was *"Are you sure you are giving him the Tranexamic Acid?"*. I said something like *"I did not know anything about this"*. No one had mentioned or informed me of this treatment which I was about to discover was a vital. I had been witness to seeing my little boy bleed for nearly a week which was avoidable if the medical staff had paid attention to detail. I found it difficult to contain my anger and stood in the middle of the ward and demanded *"Whoever is in charge of my son's care, I want them here now"*. When someone appeared I said *"I want you to teach me how to look after my son and following that I will not be bringing him back here again"*. I therefore took over **S** care when he was aged around 3 years of age.

32. In terms of **S** education, from a very early age, I realised that if **S** body was going to let him down then he would need to use his brain. I therefore took on housekeeping jobs after work so I could pay for tutors so that he could attain the highest possible level of education. I also made sure that he lived life to the full and that he did something every day. He had an English and Mathematics Tutor, he went to **GRO-B** and he undertook both swimming and violin lessons. I was exhausted because after working a full day I would then clean people's houses in the evening. However, I knew that **S** was accessing the best possible education and extra curricular activities.

33. I did not disclose **S** Haemophilia status to anyone until he went to school and I downplayed it to the people I told. I remember telling the Headmaster but I don't think he really understood the implications. I said *"just bleep me if he injures himself or you notice he can't walk properly and I*

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will come". It was frightening leaving him at school and effectively letting go and this was before the Hepatitis C diagnosis came which was when **S** was aged **GRO-B**

34. Looking back I realise that I lived with a burden and a heavy heart every single day waiting for a telephone call from **S** school which would mean that I would have to immediately down tools as a District nurse where I was working and rush to be with **S**. This happened on numerous occasions and my colleagues with whom I worked in **GRO-B** were extremely supportive. When I had given **S** his injection I would head straight back to work. Writing this today makes me sound heartless that I would treat my little boy and then leave him and go back to work. In my head I tried to instill in **S** that for him it was a way of life and we had to get on with it. There were, however, many times when we just cuddled each other and sobbed. Nursing in those days meant pulling together and supporting each other and I worked with the most phenomenal team of ladies. I still meet up with them every 6 months which is lovely.

35. I was contracted to work 30 hours per week although I worked 40 hours because that is what you do when you are nursing. My take home pay was £800 and my rent was £600, I received Housing Benefit. I was left with about £65 per week for **S** and I to live on. I was totally stuck in the poverty trap. I refused to give up work and claim benefits because I did not want **S** growing up thinking that it was ok not to work. I wanted to instil a good work ethic in him. I am a strong independent woman and I wanted to support my son. I decided that going out to work doing nursing visits would help reduce my outgoings because by being home all day you put the heating on and boil the kettle for hot drinks etc. However, being a nurse and going out to visit people at their houses meant that I would be offered hot drinks and could enjoy the warmth of their houses and the heater of my car between visits. Making small savings like this made living on a budget tolerable.

36. I remember money being extremely tight and I learned how to cook and care for us on an impossibly small budget. I remember coming home from work

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one day and finding that someone had put £30 cash through our front door and there was note with it which said "*I know you are struggling, get you and S something to eat*". This was in or around 1992 and £30 was an awful lot of money in those days. It was amazing in fact; both the amount and the gesture. It was a struggle but we got through. It felt like S and I versus the whole world.

37. I remember that on one occasion S wanted to be Mighty Mouse so he climbed onto a roof and was planning to jump down! I said to him "*Do you think you can fly then? I have a feeling that you are going to hit the ground pretty hard and then need an injection (of Factor VIII)*". S himself then took the decision to climb down safely from the roof. I adopted this sort of strategy whenever he wanted to do something dangerous! When I think about it, I realise how accepting S was of his situation and he rarely, if ever, made a fuss.

38. When S was diagnosed with Hepatitis C in 1992 I spent a long time researching the type of diet that he should be following to give him the best possible chance of good health and a robust immune system. I took S to see Dr GRO-B and we discussed S diet and the importance of foods high in antioxidants. He prescribed high doses of arnica, vitamin C and Calcium, there was something else but my memory fails me. I made sure that S was fed lots of superfoods to include blueberries and broccoli and foods with Mediterranean colours such as apricots. I ensured that S was fed properly on a very tight budget. This meant that every meal, including his packed lunch for school, contained absolutely no chemicals and only pure goodness. I ate the same food as S when I could but often I went without and around this time I weighed about 6 and a half stone.

39. I recall attending a Harvest Festival with S following a request from GRO-B for a donation of groceries. I did not have enough food for us to eat let alone anything to donate. In the end I donated a tin of tomatoes. During the Harvest Festival Service, it was announced by the Priest that the donated food was going to be given to those people in the Parish who were poor and

needed help. [S] then spoke out quite loudly "*Does he mean us, Mum?*" It was embarrassing as everyone in the Church heard him.

40. I would have liked to have another child but I thought that bringing another child into the world knowing that he may have haemophilia was an unbearable thought. The alternative would be to ensure that the male child was free from Haemophilia. If that were to happen my thoughts were with [S] who maybe would feel envious having a brother who could engage in physical activities without consequence. I could not entertain that. If I had a girl then she would be a carrier which would create problems for her family in the future. [S] life was more important to me than having another child so it remained as just [S] and me.

Section 6. Treatment/care/support

41. [S] has had the majority of his dental care at St Georges' hospital. Generally dentists are not prepared or equipped to deal with any complications that may arise from dental procedures. [S] dental care is now undertaken by St Thomas's Hospital.

42. In or around 2010, [S] called me as he had fallen from his bike for no reason other than feeling a bit dizzy. I was on my way to work when I got the call and told him to administer his factor VIII. Professor Savidge drilled it into us that '*if there is a problem inject factor VIII and then think about what the problem is*' I instinctively knew I had to go to him turned around to head to his home. When he opened the front door for me I was astonished at how pale he looked, he was at the point of collapse, He was clearly bleeding and I needed to get him to hospital. I helped him into my car and took him to the local hospital which in hindsight turned out to be a bad idea. The Accident & Emergency Doctor at the time asked me if Factor VIII was in tablet form, thus illustrating his complete and shocking lack of knowledge in relation to blood products and the nature of [S] condition. [S] was then immediately placed into a quarantine room in A&E. The doctors did not tell us why he was being put into this room he was then admitted to a cubicle in a ward. During

the time he was in this ward he had an intravenous infusion through which medication was administered however the staff of duty where reluctant to administer his factor VIII so [S] with a drip in one had had to do it himself. An endoscopy to establish where he was bleeding was to be performed imminently but this didn't materialize and no explanation was given. We waited and waited, all the time [S] nil by mouth in a hospital gown with the fear of further bleeding. We were told that the Consultant would come and speak with us and we waited. I believe the Consultant to be Dr [GRO-D] Consultant Gastroenterologist, he informed us that they would not perform the endoscopy in Epsom Hospital and he was organising a transfer to St. Thomas's Hospital for the endoscopy to take place there.

43. Given that I was a nurse, I confidently asked why my son would need to be transferred to another hospital. The doctor responded "*St. Thomas's is a specialist unit*". I therefore persisted with "*You do endoscopies every day of the week at this hospital*". The doctor then replied with the most shocking answer which was "*St. Thomas's have a separate set of endoscopy equipment for patients that have been exposed to viruses*". This fact was horrifying in itself not to mention very distressing for me and my son to hear.
44. It was only due to my knowledge and bravery in standing up to and confronting the medical professionals that my son's endoscopy went ahead at that hospital on that day. Sadly, despite the fact that the endoscopy did go ahead, my son felt that he was being treated differently to a "*non-infected person*" during the procedure. The stigma is always there.
45. Over the years I have got used to standing up to medical professionals and particularly to consultants and doctors. When I was a Ward Sister on a surgical ward, Mr Walker, who was a Consultant and eccentric, would arrive at the hospital on horseback and then tether his horse outside the hospital. I remember one occasion he turned up with his entourage to see one of his patients who was 'lodging' on my ward. I took the team to the patient's bed, pulled the curtains around the bed and proceeded to update Mr Walker about his patient when suddenly everyone around the bed fell silent. I wondered

what on earth was wrong so I said to Mr Walker *"Is something wrong?"*. He replied *"Sister you are standing on the wrong side of the bed"*. In response I said *"Maybe it is an appropriate time to tell you that you are standing on my ward and I will stand on whatever side of the bed I choose"*. I think everyone thought that he was going to kill me! I survived and lived to laugh about it.

46. Neither my son nor I have ever been offered any counselling or psychological support.

Section 7. Financial Assistance

47. I found out about the Skipton Fund (SF) purely via my own research. No one told me about the possibility of financial assistance which could arise following infection with Hepatitis C.

48. I applied on behalf of my son but the application was rejected because my son had naturally cleared the virus without the use of Interferon treatment. The SF wrote to my son on 31st January 2005 confirming the same and a copy of the letter is attached to my sons' statement at **Exhibit WITN1194005**.

49. I feel that the SF was very unfair in refusing their financial help because my son had cleared the virus. My son still received contaminated Factor VIII concentrates which infected him with Hepatitis C.

Section 8. Other Issues

50. I was told by various doctors treating my son that the blood donor mechanism in the UK was under-funded and therefore they could not continue to provide blood products utilising British blood. That was why the NHS had to source blood from the USA. The NHS should have screened the blood and in not doing so, were negligent.

51. I used to belong to the Haemophilia Society (HS) and received their monthly bulletins. However, the obituary section at the back of these bulletins grew

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longer and longer as the months went by to the point where it became extremely depressing to read so I stopped reading these.

52. Answers are required to allow victims to move forward from the largest tragedy that has ever befallen the NHS.

Anonymity, disclosure and redaction

53. I wish to apply for anonymity and I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed...

GRO-B

Dated... 19-2-2020