Witness Name GRO-B

Statement No: WITN3062001

Exhibits: WITN3062002 - WITN3062003

Dated: 6 May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:

1. I am the mother of GRO-B: S who received contaminated Factor VIII concentrates that transmitted Hepatitis B and C and HIV infection.

2. I have campaigned for an investigation and compensation into the blood contamination that led to my son S being infected since the early 1980's when he was diagnosed. I wanted answers as my son almost died as doctors did not want to treat him for appendicitis. I wanted to ensure that others did not get infected through bad blood products but there was a lot of secrecy. I contacted BBC Derby to attempt to get those in authority to take notice of what was going on. BBC Derby then interviewed Dr Mitchell on the radio and it was only then that I learned about the safety advice given to those infected. I felt helpless and did not know how to proceed as nothing had changed.

3. I have been married twice previously and was first GRO-B and then GRO-B GRO-B I wrote to Margaret Thatcher in 1987 and 1989 to inform her of the issue both with my own son but also about the blood contamination as I wanted something done about it and requested compensation for those affected. At this

stage I knew more as I had made it my business to keep asking questions. I received a response attached as Exhibit WITN3062002 dated 6th November 1987 acknowledging the tragic circumstances and that my letter and the information would be passed on to the Department of Health to get something done about it.

4. I received a response to a second letter on 13th November 1989 attached as Exhibit WITN3062003. I was trying to raise the profile of this and get the government to take some action.

5. I have campaigned since the 1980's trying to get those in authority to listen and understand the plight of those infected. I have campaigned with my local MP (now sadly deceased) to get an inquiry and compensation for those infected.

The Haemophilia Society

6. When my son was first diagnosed with Haemophilia John Gregory from the Haemophilia Society came to my home with his wife to see how I was getting on. I became friendly with them and they did visit my home. After my son was diagnosed with HIV I was sat a local meeting and was appalled that he, as the Derby lead of the Haemophilia Society was critical of those infected with HIV as a result of the blood contamination.

7. This was very upsetting to me and my son and I was disgusted that he took the attitude he did. It created bad feeling within the Haemophilia Society and further stigmatised those infected who essentially were facing a death sentence. It added to the stigma.

Background

8. I was told that it was unlikely that I would ever have children as I had had some health problems. I did not know of the risk of Haemophilia in the family until I was pregnant with S which was a big surprise and my mother explained this to me. I had previously had a daughter who had died at two weeks old due to a

heart defect. The stories she told me were very frightening and that both her brothers had died. I had never heard of Haemophilia.

9. I did tell the hospital about the Haemophilia but I did not know anything about what should happen and no steps were put in place. S was born by normal delivery on 12 January 1971 and he was then diagnosed with a Factor VIII level of less than 1%.

10. S was treated at Derby Royal Infirmary. Issues arose in terms of the suitability of treatment and S was prescribed both cryoprecipitate and Factor VIII concentrates. He was given cryoprecipate and this stopped the bleeding. S had problems and treatment at the hospital from infancy and I was told he would not survive to adulthood. I was told not to let him crawl and had to attend hospital on many occasions with him. One day when he was about 2 years old he had banged his head and Derby did not seem to be that interested in him but said he had a haematoma. I came home but was still worried so I contacted Sheffield Hospital and they said to bring him in. They said I had done the right thing as he had knocked it, the haematoma could have burst open. They gave him Factor VIII, I think this was the first time he had been given it.

11. They made him a foam helmet to wear but he had another knock to the head and this time the bleeding was worse and they had to operate. S had a speech impediment following this.

12. When S started school he had problems with his legs and I would take him to Derby Royal Infirmary for treatment but they said that they did not have enough so I would have to go to Sheffield. It appeared that he was getting better treatment at Sheffield but I had no idea about the risks of being given Factor VIII, this was never discussed with me at either hospital.

13. I got pregnant again and no precautions were put in place when GRO-B was born in 1973. I was told by the hospital that they could not tell me if GRO-B had Haemophilia until he was older or had signs of a bleed. One day GRO-B said his knee hurt so I rushed him to Sheffield where I believe he was given Factor VIII but they then informed me he did not have haemophilia. This was such a relief.

14. S would scream at night and I would have to lie with him on a mattress in the living room so as not to disturb family and neighbours. At no time was I ever informed of any risks associated with Factor VIII concentrate.

15. At times S attended Sheffield Hospital and I was informed that Derby had not given S enough Factor VIII and they would give him more. I was then asked if I would go back to Derby Royal infirmary under the care of Dr McKay (later Dr Mitchell). In 1976 I had a medical emergency and I found out I was pregnant. The treatment I had meant there was a risk that the baby would be severely disabled, and it was a boy and likely to have haemophilia. This resulted in a termination of a pregnancy and this was a very difficult decision to make as I and my family are Catholic. My mother supported me through this time, but it caused the breakdown of my marriage. We were very short of money due to all the health problems S had constant visits to hospital. I received some funding from the Haemophilia Society but life was very difficult. I was on the verge of a nervous breakdown but I could not just leave the children, so I had no choice but to continue on. I do not know where I got the strength from.

16. My husband left me, and I was on my own with two small children. I would often have to go to Sheffield hospital in the middle of the night with S and I would have to bring GRO-B with me. The headmaster of the boys' primary school GRO-B GRO-B Primary was good and he would tell me to keep GRO-B off school until he had had some sleep but I was worried about the effect on GRO-B s education.

17. Whilst S was still in primary school, about aged 10, he looked unwell and became very pale and lethargic; he was then diagnosed with Hepatitis b which was a terrible setback for him and agonising for me as his mother. He had trouble with his teeth and had to attend Sheffield Hospital under Professor Dinsdale. The hospital became like our second home and it was truly exhausting. S had to have teeth out which was very concerning. He has subsequently lost all his teeth due to the medications he has been on.

18. S had a medical emergency when he was aged 13 and required surgery for appendicitis. No doctor wanted to perform the surgery and he was left

overnight. I trusted the doctors. Dr Maine telephoned me and told me S had HIV. Dr Mitchell told me that he thought S would be one of the last people to be infected as he had always had heat treated Factor VIII. I was in complete shock. I was completely devasted.

19. The next day, S heard nurses saying he was HIV positive as he was wheeled into theatre for his emergency surgery. I did not know S had heard in this terribly cruel way he was infected until he told me himself when I started to talk to him. This was heart breaking for me that I was not with him.

20. He was in a room on his own that was cordoned off. He was treated like a leper and all his soiled dressing and dirty linen was shoved under his bed and left. Nothing was permitted to be taken from his room.

21. The hospital was desperate to discharge and he only received in patient care for a couple of days and I was deeply concerned when he was discharged home. I contacted the doctor at Sheffield Hospital and was informed by Sheffield hospital that he should have stayed as an in-patient for about 10 days. The newspapers appear to have been informed by hospital staff that there was a patient with HIV but they did not name him. I believe this is why the hospital wanted S discharged so quickly. I had to nurse him at home.

22. Doctors refused initially to remove S s stitches due to his infection. This was deeply distressing, eventually a very nice doctor agreed that he would do as no one else would. He had compassion and I then found out he had small children of his own.

23. I was trying to find out about S s infection. The Derby Royal Infirmary held a talk on HIV and I invited S s headmaster to the talk with me. The speaker from Newcastle stated that we should not inform the school and S s headmaster made himself known. This headmaster Mr GRO-B was very supportive of S in the face of much discrimination and prejudice. GRO-D GRO-D MP held a meeting and tried to have S removed from school, but the headmaster refused to permit this. S was given a minder and protocols were

put in place but some of the teachers were not nice and he was called names. He was not allowed out to play with other children.

24. GRO-B his brother was a very good swimmer but there were issues around him using the swimming pool due to S s viral status and he stopped swimming. The stigma the boys suffered at school was appalling at times and the public have no idea what they have endured. This was devasting for me as their mother.

25. I was told when S was diagnosed with HIV that he probably have about 12-15 months to live. It is not possible to express how awful it is to be told your child is going to die. I was told to bleach the bath after he used it and to wash all his clothes separately. I felt it was like a ticking timebomb and not knowing when it might explode on me. I was fearful for S and GRO-B.

26. S later developed Hepatitis C. He was not given any treatment for his liver problems.

27. S developed very serious psoriasis as a result of the emotional difficulties that he had due to his diagnosis and the side effects and treatments were very unpleasant. They tried him on something that looked like a sun-bed and he was red raw. His skin broke down into abscesses on his legs. These would have to be dressed daily. He would have to take morphine in order to permit when the district nurse would dress ulcers that had developed.

28. S refused AZT as he was frightened he would die as he had seen others take the treatment as he had watched 2 of his friends subsequently die when taking it. Dr Mitchell was upset when S refused to have the AZT.

29. S became very ill and developed septicaemia when he was about 15 years old and was not expected to live.The doctors signed a Do Not Resuscitate Order and he started to plan his own funeral, no child or mother should ever have to do this. I was told by the funeral director that S would have to be buried in a casket lined with concrete! I was desperate but was told there was nothing could be done. S had acquaintances who had been treated at the

Royal Free who were homosexual and he asked could he go to the Royal Free. The Society wanted to distance itself from the homosexual community and I did not agree with this. I was absolutely desperate, did not want to leave my child to die. I telephoned the Royal Free and asked for help as S was still a child. I was told by Derby Royal Infirmary I was wasting my time and he would not survive the journey. The Royal Free agreed to help.

30. I travelled to London with S as I could not just sit back and do nothing. Taking this chance was the only think I could think of to do. The Royal Free were so very good and they treated him and I believe saved his life. They sent him home with 3 months treatment. I went back to Derby Royal Infirmary to ask for more treatment and they would not prescribe this and asked who would pay for it. I could not believe the level of callousness displayed and the complete disregard for my son. I informed them that if this treatment was not prescribed then I would go public and contact the newspapers. I was asked to leave the room, later when I went back in, I was informed that this was discussed, and the treatment was prescribed.

31. I believe if I had not threatened to go public S would not have been given the continued treatment. I do not think S would be alive today without this. S later saw a note on his file about exposure to v CJD which caused further distress.

32. I and my family suffered terrible stigma as a result in my community as everybody knew. We received no help or counselling.

33. The circumstances in which S found out he was HIV positive should not have occurred and were entirely inappropriate and cruel, he was only 13. S was taken for surgery to prevent a perforated appendix which was very frightening for him and he heard nurses talking as he was wheeled into theatre discussing he was HIV positive. He did not know anything about his diagnosis prior to this and neither did his family.

34. Following the surgery, S told me about the conversation when I was discussing the matter with him and said he already knew. This was deeply

upsetting for me as I had not been able to tell him myself or be with him to comfort him.

35. When he was an adult S met a girl and became engaged. However, it did not last and they broke it off as she had become more like a nurse to S It was deeply distressing for him and he came to live in a portacabin in my back garden. I tried my best to support him.

36. S later had a breakdown and he closed down. He said he did not feel worthy and that life was not worth living. This was heart-breaking for me as a mother. He did not have many friends at school and was isolated and ostracized as a result of his diagnosis. He so desperately wanted to be like everyone else. He had a buddie who came and tried to help him. Watching him go through this made me search my soul. It felt like we were fighting a losing battle one after the other all the time. I do not know how I got through it.

37. S has been to hell and back and I and his brother have been on that journey with him too. I was on call 24 hours a day and S has suffered so much, it never goes away and as a Mother you do not just go to bed and rest.

38. I was given so little information to help me to manage S's condition and I was so worried that because of this someone else might get infected. I even called the council up about the waste water going into the drains because of what I was told.

39. I never knew anything about the possibility of S becoming infected from the Factor VIII and he was infected with Hepatitis B by the time he was 10. There were no options or choices given. I trusted the doctors.

40. My neighbours would not come into my home and I never had anyone come in even for a cup of tea as we were isolated. I got on with things the best I could.

41. S had very little education and became a handyman and worked when he could. He is now very disabled and very unwell due to his infected and his liver problems were not treated when he was young. This has caused me deep distress as his Mother.

I wish, that the Inquiry will clarify the following issues: -

1. The manner in which the Hospital system responded to the infection with HIV of my son and more particularly my requirement for appropriate care on behalf of my son when he was a minor.
2. Whether the policy pursued by the Department of Health in terms of AIDS prevention by scaremongering and creating hysteria was appropriate in the context of the inevitable consequence that would materialise for those persons who had contracted the viral infection and, in this instance, a 13-year-old child.
3. Whether the response of the Hospital concerned was appropriate in the context of the then perceived risks that existed or appropriate in any circumstance at all.
4. Such other matters in relation to the difficulties that a protective mother suffered in the context of caring for my terminally ill or potentially terminally ill child.
5. Why has there been no appropriate response either in terms of provision of assistance in relation to the consequences of viral infections i.e. HIV and Hepatitis C or indeed, in terms of provision of appropriate financial recompense?
6. Why has it taken so long to achieve this particular Inquiry?

Statement of Truth:

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

Dated the 6TH day of MAY 2019

Signed: GRO-B

GRO-B