

ANONYMOUS

Witness Name: Mrs

GRO-B

Statement No: WITN2911001

Exhibits: 0

Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

GRO-B

GRO-B

will say as follows:-

Section 1. Introduction

1. My name is GRO-B. I was born on the GRO-B 1936. I live at GRO-B. I live alone as my husband recently passed away. I am retired.
2. I make this statement as the mother of GRO-B: S who was infected with HIV and Hepatitis C (HCV) as a result of receiving contaminated blood products.
3. My son has already provided a statement for the Inquiry GRO-B.
4. This witness statement has been prepared without the benefit of access to my son's medical records.

Section 2. How Infected

5. S suffers from Haemophilia A classed as severe. He was diagnosed at a young age. He was bruising a lot and he was given numerous blood tests

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to identify why. I remember at one point doctors even performed a lumbar puncture on him at the Derby Children's Hospital, Derby (DCH). The tests resulted in [S] being diagnosed with Haemophilia A.

6. Initially when [S] suffered a bleed he was treated at the DCH with Cryoprecipitate. When he was around 6 or 7 a dispute between the DCH and the Derby Royal Infirmary, Derby (DRI), resulted in us having to take [S] to the DRI for the haematologist there to sanction him travelling by ambulance to Sheffield Children's Hospital, Sheffield (SCH), forty miles away even though there was a Haemophilia Centre at the DRI. On one occasion when I went with [S] to the SCH by ambulance, the ambulance returned to the DRI before [S] had been treated and I was left to make my own way back to GRO-B with [S] who was unable to walk as a result of a bleed.
7. When [S] was admitted into the SCH visiting him was so difficult. Eventually my husband and I contacted our MP who asked questions in Parliament on our behalf, which resulted eventually in [S] being treated at the DRI. Whilst I realise this has no bearing on the Inquiry, it's just one example of the many kinds of problems we were dealing with throughout [S]'s childhood, and why I find it so difficult to be more precise with dates, I wish I had recorded these things, but hindsight is a wonderful thing!
8. [S] started being treated at the (DCH) with Factor concentrate and then at the DRI under the care of Dr Winfield and Dr Mitchell, who was the head Haematologist at the time.
9. Before we were told of [S]'s infection in 1985 we had a meeting at the DRI because we were concerned about the publicity regarding HIV infection in blood products given to Haemophiliacs and I was administering Factor VIII to [S]. At the meeting instigated by my husband we asked Dr Mitchell of the risk of infections and were told the chances of [S] being infected were infinitesimal and we were making a fuss about nothing.

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10. At one point when more information was being released in the newspapers and I called Dr Main who was a Haematologist at the DRI for advice. He spoke to [S] who was bleeding into his ankles at the time and reassured him it was safe to use Factor VIII because [S] was in great pain and I didn't know whether I should use the Factor VIII.
11. We weren't told of [S]'s infections as such; my husband had to corner Dr Mitchell in a ward to get her to tell us what his blood test results were. We knew blood tests had been taken, I can't remember being told explicitly but I can't say we weren't aware.
12. We had heard nothing at all and we had been telephoning constantly to try and find out the result of the tests but they were avoiding us. When my husband went to the hospital and confronted Dr Mitchell she told him that [S] was HIV positive. This was in 1985 when [S] was about 16. Not long after finding out [S] was HIV positive Dr Mitchell called us in for an appointment and told us that [S] was developing full blown AIDS and "it was the start of the end."
13. The diagnosis was only given because [S] had lost the feeling in his feet and for some reason this had led doctors to believe he was developing AIDS, which proved to be totally untrue. The loss of feeling was a result of a bleed in his back. To be told [S] was developing AIDS was the equivalent of giving him a death sentence, it was horrifying. This was only a few months after finding out [S] tested positive for HIV which we were already struggling to deal with. I remember walking along the road afterwards in complete shock, I was like a zombie. We didn't tell [S] that they had told us he was developing AIDS.
14. We were never actually told they were wrong about [S] developing AIDS; we came to the realisation on our own. Nothing was ever said by the doctors at the DRI.

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15. Dr Mitchell avoided us like the plague after all of this. She used to walk her dog at the same park and I saw her once walk through a hedge rather than face me.
16. No advice was provided to [S] or us whatsoever, the medical professionals tried to avoid us. They told us that he had been infected with HIV and that was it. The only advice they gave him was to not have sex.
17. I consider adequate information to understand and manage the infection was not provided to [S] or to us at the time of his diagnosis.
18. Information should have definitely been provided earlier than it was. We should have been told immediately, that [S] tested positive. We shouldn't have had to chase them. It made it much more difficult because our minds were all over the place due to the media campaigns and the news.
19. The way in which we were told of [S]'s infection was matter of fact and not sympathetic or understanding.
20. [S] was older when he found out he had HCV. By this time he was going to the hospital on his own. I think he was around [GRO-B] so it would have in or around 1991, it is difficult to remember because there was so much going on at the time. The diagnosis that he was developing AIDS took over everything, we hadn't told [S]. We couldn't tell anyone. It was a huge burden to carry.
21. I think that after all the things they said about the risk of infection being infinitesimal and that we were making a fuss about nothing they were feeling embarrassed, and as a result they really didn't want to communicate with us and we had become a nuisance to them.

Section 3. Other Infections

22. I am not aware of [S] being infected with anything other than HIV and HCV.

Section 4. Consent

23. I believe that [S] was tested without my husband or I's knowledge or consent and without us being given adequate or full information.

24. I am not sure if [S] was ever tested for the purposes of research.

Section 5. Impact of the Infection

25. [S] left school at 16, he found it difficult to cope with the fact he had been infected with contaminated blood. There's not much incentive to focus on your studies when you have been told you have a death sentence. [S] couldn't talk to anyone or tell anyone about what he was going through. Trying to deal with these infections on top of his Haemophilia was very difficult not only physically but emotionally.

26. [GRO-B] was in a wheelchair for a while due to a bleed he had in his back. This made school an impossible task. Boys of that age don't want to be fussed over by parents and he kept a lot to himself. As a mother I had a good idea of what was going on. He suffered a lot throughout this period.

27. I know [S] was given AZT to treat his infection with HIV. The details of his treatment and any side effects as a result of AZT are a grey area to me. I think [S] kept most things to himself in order to protect us I do not know too much about it.

28. In 2004 [S] had a really rough time. He was treated for HCV with Interferon and Ribavirin. The treatment lasted around 11 months and he said it was like having a constant flu. He had all of the side effects associated with Interferon such as fatigue, headaches and depression. He was very low mentally and physically. Fortunately the treatment cleared the HCV.

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29. [S] did sometimes face difficulties in obtaining treatment. I remember when [S]'s dentist was made aware of his HIV status he refused to treat him. This was his local dentist. With the help of a nurse at the DRI he eventually found a dentist who would treat him.

30. At the time having HIV was akin to having the plague. It was very difficult for a teenager to deal with. We were devastated when we found out [S] had been infected after all the assurances we had been given by doctors, we were always told the blood products were safe.

31. Fear crept into every aspect of our lives. The obvious fear was for [S]'s life and health. Every time [S] was unwell we thought he was developing AIDS and that he was going to die. In addition we also suffered the fear that people may somehow find out that [S] had been infected with HIV and that we would lose our livelihoods as a result. On top of everything we had to worry about our own health we didn't know if these infections could also be transmitted to other family members.

32. People began to assume that [S] had been infected. They were aware he was a Haemophiliac and there was a lot of information about it in the press. You wouldn't believe the way Haemophiliacs were treated as a result. People began to distance themselves from us. I didn't want to believe it at first and tried to play it down but people would no longer come round to the house. I like to think the best of others and up to a point it's understandable. But everyone kept making excuses not to do things or meet up in order to avoid us.

33. Our family is today still impacted by [S]'s infections. The fear is still there even with the modern treatments. Fortunately the HCV has been dealt with so his HCV infection is no longer detectable. But it still feels like we are living life on the edge, we are constantly worried.

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34. [S] couldn't become a father so this scandal has deprived him of having his own family. Obviously in turn it has deprived me and my husband of possible grandchildren. [S] would have made a great father, it is a tragedy. This has had an impact on every aspect of his life
35. [S] having to leave school at an early age had a financial affect on him. He is a bright man and I believe he would have gone on to University in normal circumstances. Unfortunately it wasn't to be. I know that it was his infection and diagnosis with HIV that made him leave school. He had coped up until then.
36. I was a teaching assistant so I am in a good position to judge academic ability. He was more than capable of going to university. He was a Trustee for the MacFarlane trust. He is now volunteering for citizen's advice and was a Samaritan for a while and did some work for the Terrence Higgins Trust.
37. I was working at a school when we found out [S] had been infected with contaminated blood products. I was worried about the backlash I would receive if anyone found out that he had HIV. We didn't tell our two older sons about [S]'s situation for a long time. Our eldest son was working in an [GRO-B] and I was working in a [GRO-B] [GRO-B] We would have lost our jobs if people knew. I remember some people started to assume things because [S] was a Haemophiliac.
38. Unfortunately everything that was going on affected [S]'s relationship with his brothers. The hysteria at the time was unimaginable and I suppose it was inevitable that his brothers wouldn't spend as much time with him as they would have been scared. My older sons saw [S] suffer pain and disruption as a result of his Haemophilia; they are 7 and 8 years older than [S]. When we were able to confide in them and explained that [S] had been infected with HIV due to the blood products he received they had to cope with something even worse. [S] was the youngest, they had always looked out for him but this was something that they couldn't cope with.

39. We couldn't tell relatives or friends what had happened. We had to try and act normal which is a terrible amount of stress to live under.

40. My husband [GRO-C] as a direct result of everything [S] went through. [GRO-C]
[GRO-C] When he was older he was diagnosed with [GRO-C]
[GRO-C] I know how much it affected him; we had to lead a secret life and lived in fear.

41. I have to live with the fact I probably injected my son with a blood product that was contaminated. When you have a son who is agony you are between a rock and a hard place. Because [S] was a severe haemophiliac we felt we had no other choice.

Section 6. Treatment/care/support

42. As mentioned earlier [S] found difficulty in receiving dental treatment after he had been infected with HIV.

43. None of the family was ever offered counselling or psychological therapy as a result of [S]'s condition. We weren't offered anything.

Section 7. Financial Assistance

44. I would like to rely on the relevant paragraphs of [S]'s statement which set out any financial assistance received.

45. I didn't receive any financial help or support. I wasn't even aware that anything was available to us.

Section 8. Other Issues

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46. I would like the Inquiry to get to the bottom of what happened. Those responsible should be held accountable and be made to give us answers as to the extent and reason that this scandal has taken place.

47. I know it's a well worn phrase but this must never happen again and every measure should be taken to ensure this is the last time it does.

Anonymity, disclosure and redaction

48. I wish to remain anonymous and do not wish 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

23-09-2019