

Witness Name:

Statement No: WITN2335001

Dated: 15th April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, will say as follows: -

1. Introduction

1. My name is My date of birth is
and my address is known to the inquiry.
2. I live at the above address with my husband
3. I intend to speak about my son 's infection of HIV, Hepatitis A, B and C and possibly VCJD, which he contracted from contaminated

blood around [GRO-B]. In particular, the nature of his illness and how his illness has affected him, the treatment he received, and the impact it has had on my family and me.

2. How Infected

1. When [S] was about [GRO-B] old he started to develop bruises all over his body. My [GRO-B] and I took him to the local baby clinic and they referred him to [GRO-B] now known as the [GRO-B] [GRO-B]. The name of the doctor who examined [S] there was a Dr. [GRO-B]. I can remember [S] having blood tests. Not long after these tests, a courier came to our house and gave us a letter. The letter was from [GRO-B] inviting [S] to the [GRO-B] also known as the [GRO-B] [GRO-B] to meet with him. Nothing else was explained. It was a little scary for us as [S] was a baby. We went along to see [GRO-B] [GRO-B] and [S] underwent more tests. He was diagnosed with Haemophilia A Severe. [S] was the [GRO-B] male born into our family since [GRO-B]. My [GRO-B] are all carriers.
2. As [S] began to [GRO-B] he developed reoccurring bruises. Most of these bruises were spontaneous and he would often get bleeds in his ankles and elbows. He was always in a lot of pain and his joints were becoming damaged. It was very difficult for him to walk. [S] as a [GRO-B] had a blood transfusion but I can't remember how many.
3. Around early [GRO-B] we had moved house from [GRO-B]. There was no Haemophilia Unit in this area. The [GRO-B] Hospital arranged for [S] to be seen at the [GRO-B]. I didn't like [S] going there, as he did not get the attention he needed as a [GRO-B] so I asked if we could go back to the [GRO-B] where they were more [GRO-B] orientated. This was agreed, so from then on

[S] received his treatment and tests at the [GRO-B]. Around the same time, one of the haematologists, Dr. [GRO-B] took a position at our local hospital, [GRO-B] and it was agreed we could contact him as and when needed if we were concerned or needed advice on home medication.

4. I think [S] was around [] years old when [GRO-B] decided we could home medicate him. We were given vials of Factor VIII blood to keep at home and to inject [S] should he have a bump or develop bruises. I would often contact the haematologist at [GRO-B] and ask if it was okay to inject [S]. Most of the time he would advise us to do so.

5. It was around [GRO-B] when we received a letter from [GRO-B] for [S] to attend where we were told [S] had been given a vial from a batch of Factor VIII that might have been contaminated. They said there was a very small chance he was infected as he had only been given one vial from the contaminated batch and I remember them mentioning the HIV virus. [S] had to have some blood tests. I can remember having to hold him down, as he didn't like having injections or tests done. He would always get very upset.

6. We were later invited to the [GRO-B] to see [GRO-B]. [GRO-B] reiterated [S] had been given a vial from a batch of contaminated blood. However he reassured us it was highly unlikely [S] wasn't infected, as there was such a small risk. [S] underwent further blood tests to check for 'other things'. I am not sure what other things he was tested for, as it was not explained to us.

7. Thinking back, before we had any idea of the contaminated blood, [S] was often having blood tests and we were never informed of why they were testing his blood. I believe something must have come up in those tests for them to further investigate any infections.

8. We were invited back to meet with **GRO-B** for the results. I can remember waiting with **S** outside his Consultant's room, as I didn't want **S** to hear any bad news plus he was too young to perhaps understand. **S**'s father went in alone. I can remember the disbelief; devastation and distress I felt when he walked out of the room and said **S** had contracted HIV through contaminated blood. **S** was just **GRO-B** years old.

3. Other Infections

1. As far as I am aware, the infections **S** contracted through contaminated blood are Hepatitis A, B and C, HIV and possibly VCJD.

4. Consent

1. I believe **S** was being tested for possible infections without our knowledge and before we had any idea he may have been infected.
2. I understand from **S** according to his medical notes, he was treated with chemotherapy. This is something we were never told about.
3. We were never told about any risks with regard to the blood products that were given to **S** at that time.

5. Impact

1. Once **S** was diagnosed with HIV we were informed his life expectancy would be that he wouldn't live past **GRO-B** years old. We were faced with looking after a terminally ill **GRO-B** **S** was given treatment almost immediately to suppress the virus, however this made him very

poorly; he lost weight and was often sick which had an affect on his appetite. It was very difficult to get him to eat.

2. [S] was back and forth to hospital continuously having blood tests and in [GRO-B] [S] was admitted into hospital through severe side affects of his treatment. We thought he was dying.
3. [S] was given AZT for the HIV infection once this was diagnosed. The dosage given to him was too high and it almost killed him. This was subsequently lowered.
4. At the time [S] was undergoing tests for HIV, there was massive news coverage and frenzy with regard to AIDS. It was constantly on the TV, in newspapers and advertisements. AIDS/HIV was associated with drug addicts, prostitution, gay sex and unprotected sex. Because of this and the stigma surrounding the infection we decided not to tell anyone. It was strictly kept between [S] s father and I. We felt we couldn't even tell the [GRO-B] School [S] was attending.
5. Due to [S] s haemophilia and diagnosis of HIV, we felt we had to wrap him up in cotton wool. It was too dangerous for [S] to go and play with other children just in case he cut himself and infected others. It was very hard for [S] as he didn't understand why. He would often get upset seeing other children out playing and he couldn't go out to play. We would have to blame the haemophilia for this amongst other things such as not being able to go to birthday parties, holidays and other recreational activities that 'normal' families do. It was very isolating for us as a family. It was both isolating and alienating for [S] as he could not lead a normal life.
6. [S] missed a lot of school, which further isolated him. He was often very poorly due to treatment. When he became [GRO-B] school age we had to take him out of school after a few months, as he couldn't get around moving from classroom to classroom. [S] had a home tutor

for a while and then he attended a small unit until he left school, but this was for children with behavioural difficulties. He did enjoy it there and achieved four GCSE's. I often think about if [S] wasn't infected he would have achieved a lot more. Education was never a priority, getting [S] better was. The school was unaware of [S]'s illness.

7. It was very rare I would take [S] to our family GP. In fact when I did see the GP he would complain I was keeping him out of the loop. Because we lived in a [GRO-B] I didn't feel confident enough in sharing anything to do with [S]'s illness just in case there was a breach in confidentiality. I don't know why I felt like this, but I really did not want anything to come out because of the stigma surrounding this awful virus at the time. I do know I had lost faith in the medical profession.
8. It was very difficult keeping [S]'s illness a secret. I didn't tell any family member, not even my parents. There were times when family members didn't understand why I was so protective over [S]. My [GRO-B] was most definitely left out a lot of the time, as the main focus was always on [S]. We decided to tell [S] and [GRO-B] when [S] entered [GRO-B]. We told [GRO-B] first as [GRO-B]'s [GRO-B] years older than [S]. It was like a light-bulb moment for [GRO-B] as [GRO-B] could relate to why we were so protective over [S]. [GRO-B] was absolutely devastated and was deeply upset. We decided to tell [GRO-B] first as we knew [GRO-B] would be a great support for [S] once he was made aware of this. Once we told [S] we had to explain why we were telling him then and not before. It's difficult to have to explain to your son, he was entering [GRO-B] and it was because of any relationships he may have and the risk of him infecting others. I think that was the hardest part, telling him that way.
9. Once [S] knew about his illness he was devastated. [S] is quite a deep character and doesn't talk about a lot of things. We had to tell him not to tell anyone, however he did tell a few friends and one of

these betrayed him. After telling [S] he buried himself away and turned to drinks and drugs. HIV still had a huge stigma even in [GRO-B]. I believe [S] was in denial and became very depressed with the realisation of the consequences of being HIV positive.

10. [S] left home at [GRO-B] years old. He got his own place. I believe he was taken advantage of as he had had an award from the Macfarlane Trust. He made some friends but spent a lot of money on them. He squandered his money away and I think he got wise and then used his remaining money towards buying his own house.

11. When [S] was about [GRO-B] years old, I discovered I was [GRO-B] [S] was suffering with a lot of problems being very ill so I decided to have a [GRO-B]. There was no way I could take the risk of [GRO-B] to another boy who was haemophiliac as well as [GRO-B] being given contaminated blood products. My focus had to be on [S]. It was a very sad time for me to have to decide this. If [S] hadn't contracted HIV, I know I wouldn't have even thought about having a [GRO-B]. I often still feel awful for going through a [GRO-B]. I couldn't even confide in my mother over this. I have only recently told my son [S] and [GRO-B] about the [GRO-B].

12. [S]'s illness did indeed impact on us financially as I was never able to work due to looking after [S] during his [GRO-B].

13. Since [S] passed the age of [GRO-B] years old, every birthday has been a milestone as he is still alive. Even though it feels like it is a miracle he is still alive, the worry I have had and still have is tremendous, thinking he may die this year.

14. I still live with the fear that I don't know what is going to happen to [S]. I still feel even now I have got to look after him. I am here if he gets unwell.

15. [S] hasn't told his own [GRO-B] and I believe he now understands why we waited until he was old enough to understand. Even now, other than [S]'s [GRO-B], only those mentioned previously know about [S]'s illness.

6. Treatment/Care/Support

1. When [S] was formally diagnosed and this was confirmed to my [GRO-B] [GRO-B] it was said in a matter of fact way. There was no empathy and to be told our son won't live beyond [GRO-B] years old, no support was offered. We weren't offered any information or even counselling. We were told if we had any questions to ask [GRO-B] however, as we didn't know anything about HIV at the time it was very difficult to ask anything. There was no advice in how to manage this condition. [GRO-B] only offered us information of where the contaminated blood came from. He said it was from a man living [GRO-B] in the [GRO-B].
2. When we first received a letter inviting us to [GRO-B] where we were told [S] might have contracted HIV, I believe the way they handled this was to "drip feed" the information to us. I think they knew [S] had contracted HIV through other tests he underwent a good while before we had any idea. By planting a seed they may have thought this would better prepare us.
3. [S] has been given considerable amounts of different treatments so much so he has become immune to many of the drugs. I can only remember the name of one treatment, which was AZT. I understand the HIV is under control at present.
4. No support or counselling was offered to [S] or the family when we decided to tell him about his illness. We had no advice in how to tell him.

5. [S] has to attend the [GRO-B] Clinic ([GRO-B]) for the HIV, which I feel isn't fair. I understand the consultant is specialised in HIV but I do feel he could hold a clinic in the Haemophilia Unit.
6. [S]'s dental care is carried out by the [GRO-B]

7. Financial Assistance

1. [S] was awarded money from the MacFarlane Trust. I believe at some point we had to sign a disclaimer in order not to litigate. I can't remember the exact details of this.

8. Other Issues

1. Through someone else's mistake I have had to nurse my son through the most horrific illnesses due to side effects, depression and the fear of him dying given the life expectancy. Haemophiliacs can lead relatively normal lives however a spanner was thrown in the works due to contaminated blood. Why give this untested blood to [GRO-B]? Was it to save money? Was it to save time? [GRO-B] do not have a say in the matter and in my son's case if it was to save time and money, then the Government and medical profession should be ashamed of themselves.

Statement of Truth

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

Signed: GRO-B

Dated: 15-4-2019