

Witness Name: **GRO-B**
Statement No: WITN3715001
Dated: 20th September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 17th September 2019. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

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

1.Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** and my address is known to the Inquiry.
2. My brother is **GRO-B: B** who was born with severe haemophilia A and infected with HIV as a result of receiving contaminated blood products.
B passed away on **GRO-B**

2.How Infected

1. **B** was born a haemophiliac and was diagnosed with severe haemophilia A around the age of six months. My parents took **B** for tests at the hospital because they would be picking him up and it would leave him with marks or bruises.
2. Initially **B** was treated with Cryoprecipitate but this would mean that he would have to stay in bed in hospital for weeks for the treatment to be administered by the hospital. When Factor VIII came out it was seen as a great thing as it meant that **B** could be treated at home and didn't always have to go into hospital for his treatment.
3. From my memory I thought **B** had the bleed on his brain at around the age of two but his medical records say it was at the age of three. As I am the oldest of the siblings I do recall Mum taking **B** into hospital as he had bumped his head. She took him to **GRO-B** **GRO-B** and the doctor who saw him in A&E said to my mum that it was just a bump on the head and to take **B** home and for him to rest. Whoever this doctor was had clearly not read **B** medical records or been aware that he was a haemophiliac. It turned out that **B** had a bleed on the brain and nearly died.
4. After the brain bleed **B** had to learn to walk and talk again and it left him with learning issues. He struggled to put his point across and this frustrated him. **B** was a clever boy and taught himself to read again within six months. He had no personal issues and could look after himself. **B** would get frustrated that he couldn't get out what he wanted to say.
5. **B** was diagnosed with HIV sometime in 1985 and we were told that there was a ten year incubation period.

3.Other infections

1. I have nothing to add here in regards to other infections.

4.Consent

1. I have no comments to make regarding consent.

5.Impact

1. When **B** was diagnosed with HIV we lived in a small town and, after certain things had happened, it quickly got around the town that **B** had HIV. People in the town would say don't sit next to him, don't drink with him or that he was gay. People didn't understand that **B** got HIV through no fault of his own and just because he was a haemophiliac.
2. In the mid to late 1980's there was such a stigma to being gay and HIV was often associated with being gay. My son was in school at this time so my job was to protect him so that he didn't get targeted or picked on because of **B** having HIV and the associations that people made with HIV.
3. **B** never seemed to get a break. He was dealt the first blow when he was diagnosed with severe haemophilia then the second blow when he had the bleed on the brain and all of the issues that followed that. Then to top everything off he was given HIV. All that in only 25 years of life. **B** was the bravest boy and he never moaned about anything.
4. Personally I was tested to see if I was a carrier of the haemophilia gene when I was pregnant with my son when I was around the age of 17 or 18. The test confirmed that I wasn't a carrier. When my son was born he was also tested and he did not have haemophilia and again when my daughter was born her test for being a haemophilia carrier also came back negative. My daughter also has a son and he is negative for haemophilia. There has always been

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the worry that the next born may have haemophilia like [B] and we are constantly waiting in case it comes back into the family.

5. I have [B] death certificate and it has the main cause of death being a intercerebral haemorrhage with the secondary causes being haemophilia and HIV encephalopathy resulting from previous administration of contaminated blood products. We didn't see [B] after he died or at the Chapel of Rest because of the AIDS. He was taken in a zipped bag and taken off like he was a criminal.
6. Everything that has happened has spilt my family. At the moment I am not talking to my two sisters and only talking via message to my other brother. We all remember how things happened differently and that has caused a rift recently. I left home at 17 and my other brother and sister were living at home with our parents and [B] We all had different issues but we all loved [B] He was great with me and a lovely kid and all I can comment on is how [B] was with me personally.
7. I looked after my parents in later life and [B] illness and death of course affected them. [B] death has affected the whole family's mental health in different ways. The family has never recovered from [B] death and it did break us. We were offered no counselling either whilst [B] was alive or after he passed away.
8. My brother dying is the worst thing that has happened in my life. I have lost other people including my parents and a niece but losing [B] was the worst. I can't get over it and don't think I ever will. Most of the time I can't talk about [B] and what happened to him and making this statement has been very difficult. I still go to the cemetery to take flowers for [B] but I hate going up there. He is buried in a different cemetery to Mum and Dad. It was Mum's choice not to move [B] to the same cemetery as her and Dad as she felt that [B] had been through enough and didn't want him to be disturbed.

6.Treatment/Care Support

1. [B] attended the Haemophilia Centre at [GRO-B] regularly. He was under [GRO-B] first and I know he has had a lot of bad press since the Inquiry started. I only met him once and I had no issues with him at that time. [B] second haemophilia consultant was [GRO-B] at [GRO-B]
2. Depending on the severity of the bleed [B] would have his haemophilia treatment at [GRO-B] [B] also received treatment at home and it was generally our Father who administered the Factor VIII. I remember the syringe and Dad shaking the bottle to mix the Factor VIII concentrate and the distilled water. Dad always said that it was him who gave [B] the disease and it plagued on my father's mind as he would give [B] the injections at home. He held so much guilt for this and it was a scar on my parent's lives.
3. Towards the end of [B] life he was having some experimental treatment for his HIV. I remember that he had the most horrendous mouth ulcers but again he never moaned and just carried on. The sad thing is that had he been suffering with HIV today he might have lived. [B] was definitely dealt a double blow with the haemophilia and the HIV which he had to fight together and he really didn't stand much of a chance.

7.Financial Assistance

1. I am unable to provide any information regarding financial assistance.

8.Other Issues

1. [B] should not have had to have contaminated blood to survive. Those in power should not have taken chances with people who had to have blood products to survive. It wasn't [B] fault that he was a haemophiliac. All those in power ever seemed to care about was the cost of treating haemophiliacs and it was all about the money. I remember my father telling

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me how much one bottle cost. They were playing with people's lives. B
had the right to live and he needed the blood products for everyday life.

2. The Government should be made to pay. I am not providing my statement for compensation it's not about that. I want the Government to say that they did wrong and own up that they killed my brother. All my mum ever wanted was for someone to admit they had done wrong and that they knew the blood was wrong. My brother was used as a guinea pig and the Government wanted to see how far they could go. Someone knew what they were doing was wrong.
3. I don't really blame the doctors so much. They had their hands tied as they needed the blood products to treat their patients. They didn't go out and get the blood and the doctors were told to use the blood products they were given. Once the infection was in the batch the doctors didn't know who they were giving it to. They might have had an inkling once some of the infections started to show but what could they do they needed the blood products to treat the haemophiliacs.
4. All I want is a piece of paper to say sorry for what happened to B and to admit what they did. I can then attach this to B birth and death certificates to say to B that it wasn't his fault.

Statement of Truth

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

Signed.

GRO-B

Dated.....

20/9/19