Witness Name: GRO-B
Statement No: WITN2464001
Dated: 20th March 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 12th December 2018. 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 1964. My address is known to the Inquiry. I'm not married but I have a partner that I've been with for nearly 20 years. We don't have any children.

2. How Affected

1. My father GRO-B: F was born with Haemophilia type A and was infected with Hepatitis B (HBV) and HIV through infected blood products. I remember asking my mother which contaminated products were used to treat my father and she told me it was Factor VIII. In 1972 he was put on cryoprecipitate,

which I think was the American treatment which contaminated his blood with HIV. I believe that my father was infected with HIV around 1978 although he wasn't told he had been infected until 1984. He was told by Doctor Professor Bloom at the Heath Hospital which is now University Hospital Wales (UHW) in Cardiff and by other staff members at the hospital.

2. Myself and my brother were still going through education at the time and it wasn't until later on when we were teenagers that our parents told us of my father's infection. Since then, we were given no information other that through them.

3. I was in university studying Biology in the early to mid 1980's. That's when all the stories on HIV came out. Not a lot was known about it at the time. As more information came about, treatments were being developed although they were very early treatments and HIV at the time was still considered a death sentence.

4. When I was told about my father's HIV and Hepatitis B infections, to be honest even though it was a shock I wasn't totally surprised. He used to take a huge numbers of different tablets at meal times. I guess it was kind of obvious in a way. I knew that my father would be at risk.

5. At the time, the doctors didn't have a lot of information to give Haemophiliacs. There wasn't a lot of support for them. The advice the doctors gave them was to set up support groups amongst themselves. My father did this. He set up the Birchgrove Group with other Haemophiliacs at the Birchgrove pub which was local to those infected.

3. Other infections

1. My father was infected with Hepatitis B and HIV. He was eventually cleared of Hepatitis B. He was also told he had Hepatitis C antibodies.

2. In 1994 he was told he had Hepatitis C antibodies. Apparently he was so annoyed because some people had been given compensation for this but he had

not. He did not have any symptoms at the time but he was very worried that he would develop that on top of the HIV! In 1998 he had no further symptoms of Hepatitis C and they thought it had cleared. At this time he had a liver function test which was ok.

3. In 1997/1998 he was also tested for CJD following a scare around that in the country. This was done whilst he was having his throat examined during which they requested a tissue sample to test for prions, but that was all clear.

4. Consent

1. In 1972 my father was put on cryoprecipitate which was from America. This was the blood product which contaminated his blood with HIV. My father wasn't told that he was being moved on to a different treatment from America. He wasn't informed that the donors were volunteers who were mostly drug addicts. My mother said that my father and herself were horrified about this and very worried.

2. It saddens me because he could have had the option not to have received the treatment at all. My father had lived for 20 years into early adult hood without treatment. He had received no treatment at all as a child for his Haemophilia which left him disabled. From what I know, as a child my father was very resilient and tried to make the best of everything. He was very strong even with the virus and Haemophilia. The doctors thought that it was amazing that he had lived that long. It must have been horrific for my parents dealing with all of this and having to conceal it from their children.

3. When he was given the blood product Factor VIII he wasn't made aware of the risks. Haemophiliacs were just given the treatment and not told where the blood products had come from. Maybe if they had been informed that the blood was from America, taken from drug addicts and prisoners and that there was a risk of being infected, Haemophiliacs could have made a decision. But that decision was taken away from them. In the early 1980s Professor Bloom told my father that some patients had been having immune system problems with the new

treatment. After that my father was put back on the British treatment but it was too late in hindsight as he was already infected.

4. I think that when people are trying to figure out who is to blame, it's easy to blame the doctors and medical authorities. However, the truth is that we don't really know what information they had available to them at the time.

5. Impact

1. Emotionally, it must have been absolutely hideous for my parents to be told my father had been infected with the virus. People all around him were dying of it. I can't imagine how they felt; the emotional impact must have been awful especially as so little was known about it.

2. My father ended up taking early retirement, something which I didn't understand at the time. My mother worked part time as a school teacher but she had to give this up in order to care for my father.

3. My parents both giving up their jobs obviously had a big impact financially. My brother and I were going through education at the time. My mother was preoccupied with my father's illness and she confessed to me that she feels guilty as she believes that she could have spent more time with us.

4. After university my brother had a mental breakdown. I am not quire sure if this was directly related to my father's illness. As for myself, I remember lying awake at night during my university days in the early to mid 1980s, worrying if my father had been infected and the affects it would have on him. It's difficult to say as to what extent my father's infection impacted me at the time. I didn't talk about it to anyone. Only in hindsight, and when reflecting on my time at university that I think about the effects it had on me. I did get a degree at the end of it but maybe I could have graduated with a better degree. I can't be sure.

5. As for the physical impact on my father, later in his life (after he had been contaminated with HIV) he suffered with colds and coughs. He had a throat problem and subsequently struggled to swallow. This was because of the amount of medication he had to take. He couldn't enjoy the foods he liked anymore. As well as this my father developed fatty deposits which got redistributed, causing lumps on his neck. He got to the stage where he could not do up his shirts or wear a tie. He used to ask me to massage the lump on the back of his neck as it was very painful and would aggravate him. They made that area very stiff and uncomfortable. He was also lacking in energy and lethargic. He lost a lot of weight and his skin was yellowing.

6. At the time that my father was first infected there was a stigma associated with HIV. My mother used to tell me that in the valleys people used to write the word 'AIDS' on people's houses. This never happened to me and my family but those were the things that were happening.

7. It was extremely hard to get support because of the stigma. It was hard to talk about it with family and friends. It was associated with homosexuals and drug addicts. People were very nervous about it. No-one knew exactly how HIV was spread at the time.

8. I remember that my mother was very worried about the stigma. She thought that her friends wouldn't want to come over as they'd be afraid of using the same household items as my father such as glasses.

9. My mother did not tell any of her sisters until many years later despite them being very close to one another. I guess my mother was afraid of how they might react to it.

10. In terms of wider family members, they didn't know as we didn't tell them. There may have been some family members who knew. My mother had one friend who we were very close to but was a bit of a hypochondriac; probably not the best person to tell and so she did not tell them either. She had to suffer alone with my father!

11. My father died in GRO-B 2013, in that same year several other Haemophiliac friends also died that had been infected with HIV and hepatitis. Several of the infected Haemophiliacs died before my father and I remember that this had a severe impact on my father and mother as they were losing friends that were infected just like my father. The Haemophiliacs that died that year all seemed to die in the same way. My parents were both very upset by the deaths of their friends; I expect they were very concerned that my father would be next.

12. I know my father was already preparing himself and also his family for his death. I know this because many months before he died (around the time his other friends were dying) he prepared a letter that he said he wanted to be read at his funeral. He told me this on the day of my niece's christening, it was probably heavy on his mind at that time when we were all together as a family. This was really sad and brought home the reality of the death sentence that my father faced for more than 20 years, not knowing when his time would come. In response to him telling me about this letter I tried to make light of it, but the fact that this letter existed played heavily on my mind from that point until his death. No one read the letter before his death.

13. On the day my father died I remember getting calls at work on my phone, but I was so busy I had no time to take them (I did not realise the calls were from my mother). Eventually I spoke to my mother who told me that my father had apparently fallen over, but this time it was serious. Immediately I left the office and my partner drove me the two hours or so back to my parents house. It was tragic and I was in a terrible state.

14. Sadly, I never made it before my father passed away. I did not want to go and see him after he had died as I wanted to remember him as he was the last time I saw him. I can barely remember the few weeks after his death. I was supporting my mother to organise the funeral whilst my mother dealt with seemingly hundreds of calls and visitors. My mother did not want to go to the bedroom where my father died and I had to really encourage her to try to sleep and eat following my father's death.

15. Not only was my father her husband, but he was also her patient as she gave up a career to care for him. She has not slept in their marital bed since his death. At the time of his death I was both angry and overwhelmingly upset. I was extremely upset by his death, but also it brought home to me what he had to endure during his life, I reflect on this on a daily basis. It must have been like a death sentence hanging over him for all those years since he had been unnecessarily infected with HIV and the hepatitis virus. My father and my family should never have had to endure this during his life time, it could have easily been prevented if sensible decisions had been taken and my father's life had not been put at risk by treating them.

16. His funeral was a large gathering of family and friends and following his death I collated many of his friends and family comments into the "order of service" for the funeral. This was very therapeutic for me at the time. My sister in law read out the letter that he had prepared many months before his death. It was very powerful and I re-read this letter and the order of service comments regularly. The letter is a piece of my father that I still have with me and the comments remind me of the large number of friends he made in his lifetime that also is a reminder of the immense challenges he faced in the latter years of his life managing his life whilst living with a death sentence.

17. He must have been so angry for all those years knowing that he had been given this death sentence and it could have been avoided if better decisions had been taken. I cannot imagine what it must have been like for him and my mother, especially during the years when their children were not aware of his death warrant.

6. Treatment/Care Support

1. My father used to go to the Heath Hospital, which has now changed to the University Hospital Wales (UHW), for treatment. He was then given treatments

which he could inject at home. The doctors told my father that this would make his Haemophilia easier to manage and would help him out greatly as he wouldn't have to go to the hospital. Not everyone wanted to administer their own treatment but fortunately my mother was trained to give this treatment as she had been a nurse in the past so she was able to administer the treatment to my father.

2. In 1976 he fell over and broke his hip which required an operation. After he had the hip operation he was diagnosed with Hepatitis B (Australian antigen). The hospital was horrified because they had not taken appropriate sterilisation procedures following an operation on a patient with Hepatitis B. Following this he was then rejected from his normal dentist and had to go to a specialist dentist.

3. In 1984 it emerged that he had the immune disorder (HIV). My mother said that Haemophiliacs that were treated with him in Cardiff apparently were taken to a room and told in "secretive" circumstances that they had been infected with HIV. She said the room was right down in the basement of the hospital. This is just a fact and one could speculate on the reasons behind this but bearing in mind that there was a lot of stigma around the disease. She is not sure if he had been told before this, but probably. He also used to be a reader of the new scientist and was interested in science so there is a chance that he had asked questions as well.

4. I don't think that there were any obstacles in my father accessing treatment for his infections. I remember that he was given lots of different medication to treat it. He also went on a lot of different medical trials in order to access the best treatments. However, the down-side of clinical trial is that you don't know how safe it is or whether you were being given the placebo or the real thing. I'm not sure if they were placebo controlled trials.

5. He got access to the drugs through the hospital and the clinic. I don't think he had obstacles. As the time progressed and more research was being done, more treatments became available to him. No longer was the scope of treatment very limited. In regards to treatment that ought to have been made available, I think

that, especially for his HIV, all of the treatments he could have had were made available.

6. To further support Haemophiliacs, a lot of social workers were appointed. They were usually young women with little experience. The Haemophiliacs that they were dealing with were mostly older men who had needs that were far too complex for the inexperienced. Later on there was more social support available albeit they were usually not well equipped.

7. I think that the support provided to my father should have been provided earlier. I know from my mother that the support they received wasn't very good initially but that it improved over time. If you are given medication by the doctors for a serious disease such as Cancer or for minor to moderate conditions which require aspirin, it is the norm for the patient to receive an information leaflet explaining the side effects. I don't think Haemophiliacs were told about the risks in such a way.

8. No counselling or psychological support was made available to me. In my dad's case, in the early days very limited social care was made available to him. Furthermore, the social care that was made available was not appropriate for what they were dealing with.

9. These days, people receiving tests for HIV or receiving treatment have had counselling and psychological support. This is something my father never received. Even when my parents decided to tell me and my brother there was no psychological support which I think should have been offered to them.

5. So in summary, when you look at all this over more than a 20 year period it was one long list of blood contaminant after another and stress to go with it, he had a lot to contend with. Overall I think that the HIV impacted him the most. He got progressively more ill with the symptoms.

7. Financial Assistance

1. In terms of financial assistance, my parents received a small lump sum in the early 1980s from The McFarlane Trust. This was 10 years or so after my father had been infected.

2. Later on I think they got some more money but I'm not sure exactly when this was. I know that what they received was peanuts. I asked my mum how much she and my father had received initially to which she said £8,000. This was not a lot at all especially considering that they had both given up their jobs.

3. After my father had died. My mother didn't receive the widow's entitlement straight away from the McFarlane Trust. She had to send a whole series of letters before she got it. This was through Lynne Kelly that my mother realised what she had to do to get what she was entitled to.

4. My mother said that when she got an initial payment they were told to write a letter, which she did. However, she felt that funds weren't being distributed fairly. There was one story of a dying boy who wanted a bike and he was not given the money for it from the McFarlane Trust. Another person received money to fund their private education. I don't think it was managed fairly; people weren't treated the same.

5. When she eventually received the money, my brother and I were still going through education. I think that because she had children she was given more support which is totally understandable. However, I couldn't help but feel sorry for the single Haemophiliacs who had no dependents. They didn't get much at all. The fund managers should have definitely looked at a better way of disturbing funds.

6. Eventually the McFarlane Trust stopped all of my mother's widows payments and gave her a single small lump sum. I think it's unbelievable, baring in mind she had had to give up her job and so she was very dependent on the money. When I started working I did help out, for example I paid off my parent's mortgage.

7. The McFarlane Trust had a lot of money left before it closed. Instead of giving the money to the Haemophiliacs they gave it to the Terrence Higgins Trust which supported infected gay men. I find it unfair as they weren't infected through contaminated blood. It was a considerable amount of money that was given to the Terrance Higgins Trust which had nine beneficiaries. I'm not sure who made the decision to give the money to this Trust.

8. Around the time that my mother was dealing with her widow's payments she got quite sick. She had heart palpitations and had to seek medical attention.

9. Another thing that I find unfair is that English and Welsh people who were infected were treated very differently from those infected in Scotland and Ireland. They receive different compensation and support.

8. Other Issues

1. I know my mother and father both did a lot of campaigning. They wrote letters to MPs. They both thought that it was all very unfair.

2. Personally, I think it was the poor decisions of the Government making bad decisions in the first place. There has been to no understanding given to the impact this has had on Haemophiliacs and those infected with contaminated blood products.

3. Looking at the compensation given to those who were infected it's just not fair. People in England and Wales didn't get the same as those in Ireland and Scotland.

4. If you compare this scandal to Hillsborough, it was in one day alone that people were killed. In this case people had to suffer for years not knowing what the outcome would be. People should be adequately compensated and those

responsible should be held to accountable for their bad decisions so that people can get justice. It's scandalous.

5. Another thing is the Haemophilia Society. They didn't do enough to support the victims through the courts and other institutions through the crisis.

6. The sad thing is that while this Inquiry is on going, those infected are dying all the time.

Statement of Truth

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

Signed GRO-B ....

Dated 20 March 2019