

# ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2463001

Exhibits: WITN2463002 – WITN2463004

Dated: 22<sup>nd</sup> February 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 12<sup>th</sup> 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** 1967 and my address is known to the Inquiry.
2. I have lived at this address with my wife **GRO-B** and our two children since 2010.
3. I am the son of the deceased person, **GRO-B: F**. He passed away in 2012.

2. How Affected

1. My father suffered with severe haemophilia A from birth.
2. I know that my father was a patient at the Haemophilia Centre at the University Hospital Wales (UHW) in Cardiff, previously known as the Heath Hospital. I do not know with certainty where my father was treated prior to UHW as I was only a child at the time, but I assume it was at the Cardiff Royal Infirmary and other hospitals in Exeter, Devon and others in London.
3. He was under the care of Professor Bloom at UHW and before that at Cardiff Royal Infirmary in the early 1990's until he retired in the early 90s. I cannot remember who took over his care thereafter.
4. I remember my father being treated at home by my mum, GRO-B  
GRO-B She was a nurse and so it was all very surgical in that she would put a plastic sheet down to prevent blood spillage and she would also have gloves on. The product my father used was the Factor VIII blood product and we believe it is this particular product that infected him with HIV and Hepatitis C (HCV).
5. I am not entirely sure when exactly he was infected but I remember he and my mother questioning why they were importing the blood from the United States. I am not entirely sure what was said to them in order to assuage their fears but it must have worked as they continued to use it. My mother was a nurse and so I am sure that they would have had faith in the medical professionals at UHW.
6. I cannot be sure as to when exactly my parents were informed of my father's condition, however I believe it was around 1984 that he was provided with the diagnosis. My parents told me that he was HIV positive in the late 80s so it would have been before this. I found out much later on that my father also had HCV.

## ANONYMOUS

7. In hindsight there was what I considered to be at the time strange things happening when I was growing up. For example, I remember there being an emphasis on separate towels and my parents' toothbrushes were in different holders.
8. I couldn't be sure who told them but I assume it would have been Professor Bloom given that he was responsible for my father's care. I'm not sure where he was told either, but as I mentioned, it would likely have been at the haemophilia centre at the UHW.
9. I cannot be sure if they were told by the medical professionals of the risks associated with the illness. The separate towels and toothbrushes would lead one to believe that they aware of the risks, however my mother was a nurse and therefore well informed, so it could quite easily have been through the information she was privy to. Additionally, there was of course the AIDS outbreak among the gay community and so people were informed through reading and listening about what was going on at the time.
10. When I was eventually told of his condition my parents informed me of the risks associated with the illness such as avoiding contact with blood and so on.

### **3. Other infections**

1. In addition to HIV and HCV, my father also contracted hepatitis B.

### **4. Consent**

1. I am unaware as to whether my father was treated or tested without his consent. He was always going back and forth to the hospital and so he could very well have been, but I cannot say with any certainty whether this is in fact the case.
2. Notwithstanding, I think it is fair to say that had he been informed of the risks associated with using Factor VIII blood products, then, I am

## ANONYMOUS

confident that he would have refused this method of treatment and thus sought alternative treatment. I find it highly unlikely that he would have agreed in full knowledge of the potential consequences of using Factor 8.

### 5. Impact

1. It has of course been incredibly difficult growing up watching my father in ill health. He always used crutches to walk and he was back and forth to the hospital regularly. It was undoubtedly difficult for my mum to go through all of this. She was a great support to my father and I can imagine it took its toll at times.
2. He was forced to retire sooner than he would have liked due to his illness. He managed fine in the 1980s and early 1990s, but as we approached the 2000s his health was beginning to substantially decline. For instance, he became very frail, he picked up colds and flu easily and it was suggested at one point that he should use a wheelchair. The best way I can describe his physique in the latter years was like something you would see in concentration camp photos; he was completely emaciated.
3. In addition to the physical impacts it had upon his health, it also impacted upon my parent's way of life. The stigma associated with the illness was something that I am sure everyone in their position can relate to. People immediately drew their own conclusions as there was a lack of information at the time and therefore people conflated certain issues such as, for example, the association of AIDS and homosexuality, or AIDS and drug abusers. In light of these types of prejudice, they kept my father's condition a secret.
4. As I mentioned, growing up watching my father go through what he did was incredibly difficult. It was always in the back of my mind that he could die at any time and this impacted upon my mental health through

## ANONYMOUS

the years. I have spent time in and out of mental health facilities since 1995. I have had numerous breakdowns and I still have difficulties dealing with stressful situations. It is something I will undoubtedly live with for the rest of my life.

5. I find it difficult to deal with that the treatment (Factor VIII) that was meant to prevent my father from further suffering has caused so much more suffering for our family.
6. In 2012 my father had a stroke and he never really recovered from this. He died suddenly in 2012 and we were told by the medical professionals that the HIV drugs gave rise to the stroke. I exhibit to my statement at WITN2463002 a letter dated 19<sup>th</sup> December 1996 from Dr. H Dasani at the Arthur Bloom Haemophilia Centre at the UHW stating that my father was being treated at that time with Zidovudine and DDC (dideoxycytidine).
7. It devastates me that my young children will never get the opportunity to know my father. He was brilliant with my son [GRO-B] when he was a toddler. He was an incredible man.

### 6. Treatment/Care /Support

1. My father tried as many treatments as possible that combated the illness. Home treatments included Kryobulin, Factor VIII, Proliferate, Koate, and Lister. In 1996 He had Zidovudine (ZDV) also known as azidothymidine (AZT) and DDC.
2. In 2003 he was treated with Interferon and Ribavirin. Exhibited at WITN2463003 is a letter dated 3<sup>rd</sup> December 2003 from Dr. [GRO-D] [GRO-D] of the Department of Haematology at the UHW requesting an operational repair for a right inguinal hernia and confirming my father is hepatitis C PCR negative following treatment with Interferon and Ribavirin. My father received treatment of Stavudine, Nelfinavir and Lamivudine for his HIV infection. Exhibited at WITN2463004 is a letter

## ANONYMOUS

dated 17<sup>th</sup> June 2003 from Dr. Dasani to Dr. **GRO-B**(GP) with an update on my father's present condition and advising of his current medications.

3. My father would often have side-effects from the medication he took such as having difficulty swallowing his food, and I remember him having these lumps all over his back and one large lump in particular at the back of his neck. I used to massage this often to help relieve the aches and pain that this caused my father.
4. In the latter years, my parents had to make modifications to their home in order to give him access to it. In addition, he had a support worker that would come to assist him at home. They also had to keep wheelchairs in the home and a stairlift to assist my father.
5. I am unaware as to whether he had any trouble in accessing treatment.

### 7. Financial Assistance

1. I cannot be sure where exactly from where my father received financial assistance but I know that he did get something.

### 8. Other Issues

1. To my knowledge, there are no other issues that I can think of at this time that may assist the inquiry.

# ANONYMOUS

## Statement of Truth

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

Signed.

GRO-B

Dated... 22/2/2019...