

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2888001

Exhibits: 0

Dated: March 2019

## INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

### Section 1. Introduction

1. My date of birth is GRO-B I live at GRO-B  
GRO-B with my husband GRO-B. We have a GRO-B  
called GRO-B
2. I make this statement GRO-B GRO-B: B  
B GRO-B He was infected  
with HIV and Hepatitis C as a result of treatment with contaminated Factor VIII  
concentrate.
3. This witness statement has been prepared without the benefit of access to my  
late brother's full medical records. If and in so far as I have been provided with  
limited records the relevant entries are set out in the medical chronology at  
the end of this statement.

**Section 2. How Affected**

4. [ B ] was diagnosed with Haemophilia A when he was a young boy and was treated with Factor VIII concentrate.
5. He received numerous blood transfusions and other treatments throughout his childhood and adult life and suffered from various illnesses including HIV and Hepatitis C (HCV). He also had several strokes resulting in Subcortical Dementia, Cirrhosis. [ B ] died on [ GRO-B ].
6. He was initially treated under [ GRO-B ] when he was given the contaminated products then went on to be treated under the [ GRO-B ] amongst other places. I am unsure of the precise dates of his treatments.
7. No information was provided to [ B ] and / or my parents prior to him receiving the Factor XIII. We were all totally unaware of the risks and consequences of taking the medication.
8. [ B ] was infected with both HIV and Hepatitis C (HCV).
9. I recall my Mum was contacted by the hospital to inform her that [ B ] may have been infected with HIV. This would have been in or around the early 1980s. My Mum informed my Dad a few days later, but I am not sure exactly when [ B ] was told.
10. No real information was provided to us as a family about the infection. Very little was known about HIV at that time and therefore the information that may have been given was limited at best.
11. Information on the fact that the blood products had a high chance of being contaminated should have been communicated to the victims and without doubt the doctors who knew should have informed the patients and their families of the risks involved and the potential consequences of taking the products. We have since discovered that [ B ] only had mild Haemophilia

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and so there would have been other treatment options open to him which were not discussed.

12. To receive such catastrophic and life changing news in the way they were told is beyond belief and hard to take and I know my Mum and Dad were left devastated and alone.

13. No information was given about the risks of others being infected as a result of the infection. The only information we received was from the scaremongering stories in the press and media which had the effect of ruining our family life.

### **Section 3. Other Infections**

14. [B]'s full medical history is available through our solicitor but I do know that he had sticky blood, several strokes, cirrhosis of the liver, subcortical dementia and other conditions that were directly related to the blood borne viruses that were transmitted to him via contaminated blood products.

### **Section 4. Consent**

15. I believe that [B] was tested without his knowledge or consent and that neither he nor my parents were provided with full or adequate information regarding either the risk of infections or the infections that were passed to [B].

16. I also believe that he was tested for the purposes of research.

17. I believe it is the role of this Inquiry to establish the evidence that proves the answers I have given above. However, I do know my parents and [B] were never informed prior to him receiving Factor VIII of the potential of it being contaminated. As a family we have our own opinions as to how and why this was allowed to happen and why such a cover up took place over many years. It is clear that the truth must be sought to establish that once it

was realised that so many victims had been infected whether a twisted idea of research was at the core of why it took so long to react to things adequately.

### **Section 5. Impact of the Infection**

18. It is hard for me to fully appreciate the effects of having these conditions had on my brother **B** as he was a very private person and always put on a brave face for me and others. He would never openly share his inner thoughts and feelings as he would not want to burden us all with what he was going through. I also believe that his way of dealing with things was to keep it to himself and try and live as normal a life as he could. What I can say is that over many years we all witnessed a highly intelligent, funny, caring and hard working young man deteriorate into a shell of a person that we did not recognise.
19. He suffered from HIV, Hepatitis C, sticky blood, antiphospholipid antibody syndrome, several strokes resulting in Subcortical Dementia, haematuria, severe fibrosis of the liver and cirrhosis. He was also on long term warfarin therapy.
20. My memories of **B** as a child and teenager are of frequent and prolonged hospital visits that affected his confidence and turned him into a shy boy. He was frequently bullied at school when other children discovered he had haemophilia and then, subsequently, HIV which was massively reported by the global media at the time. People at school knew **B** had haemophilia and when it was reported people with haemophilia were contracting HIV they unfortunately were able to put two and two together.
21. Despite all of the medication and constant hospital visits and battles he was fighting he was extremely bright and clever. He managed to pass all of his exams at school and attended **GRO-B** where he obtained a Masters Degree in Computer Science and then went on to get a job at a top **GRO-B** down in **GRO-B**. He was enjoying life and making new friends as best he could.



22. However, the illness eventually started having a dramatic effect and impact on his life. He had several strokes in his late twenties / early thirties which left him with brain damage, changed his character and meant he was unable to continue with the job he loved.
23. He became more and more isolated as he insisted on staying in London and continuing with the life that he had made for himself. We kept in regular contact over the phone and when he visited Liverpool for his hospital appointments. However these visits home became less frequent. When we did see him it was clear that his health was getting worse both physically and mentally.
24. This pattern continued for several years resulting in his untimely death on **GRO-B**
25. I do know that **B**'s case was very complex and he required the services / support of some of the leading clinicians in the UK and beyond. I cannot comment on how difficult he found accessing these services as he kept these details to himself.
26. The impact that being infected with HIV had on **B**'s life was nothing short of catastrophic. It had a negative impact on his confidence and he was the victim of bullying whilst at school and in the local area once people realised that he was infected.
27. Throughout his teenage years **B** attended a Christian church and youth club where he made some friends, but he could never openly tell people that he was infected as he was constantly worried how people would react.
28. **B** was extremely intelligent. I do not know how he did it but he did extremely well academically at school and progressed to attend **GRO-B** **GRO-B** where he obtained a Masters Degree in Computer Science. He then went on to get his dream job with a top **GRO-B** in **GRO-B**. He loved that job and the whole family was so proud of him for achieving his goals and living the life that he so badly wanted to in London.

29. He became very single minded and for a long period he was keen to keep fit and loved mountain climbing. He managed to land a high powered job in London. Sadly as the disease took a hold of his body he was unable to continue working and undertaking the activities he loved. However he had to give up this job when his health began to rapidly deteriorate. His inability to work was inevitably the thing that led to my brother having no hope in life and destroyed any hope he had of a future.
30. From this point the **B** that we all knew began to change dramatically. He had one health issue after another, constant hospital appointments and there was the never ending medication he had to take on a daily basis; this all had a detrimental impact on him.
31. He became a very vulnerable person and relied heavily on the close friends that he had made down in London. Unfortunately, he was the victim of people who took advantage of him financially by pretending to be his friend. This all had the effect of him not trusting people, isolating himself from friends and family and in the years prior to his death he became very depressed which I am convinced had the effect of making his overall health much worse.
32. The only word that describes the effect on me personally is devastating. From a very early age all I remember is of **B** being unwell and in need of support from my Mum and Dad. Our home life was a constant strain as we all struggled to come to terms with what had happened and the cruel frustration of not being able to talk to anybody, including other family members and friends as we did not know how they would react. My parents blamed each other for what had happened to my brother and there was always tension and arguments at home. The pressure became unbearable. I developed severe OCD as a result and suffered with very bad nerves and anxiety from an early age.
33. My health suffered at an early age from the effects of what was happening to my brother and my family. I was unable to concentrate in school and lacked

confidence. I feel I was never able to reach my full potential from an academic point of view.

34. As a family we felt like we were living with a time bomb with this horrendous condition my young brother had been cruelly given. The fear my brother must have felt was just too heart breaking for me to try and comprehend. My Mum suffered nervous breakdowns over the years and in her early 60s developed Alzheimer's disease which I believe was caused by the stress she had gone through over the years. Sadly my Mum died from this condition at the age of **GRO-B**. I was never able to tell my brother **B** that our mum had died because he was too ill to deal with this.

35. In the early 1980s the ignorance surrounding HIV / AIDS was at its height with highly influential media campaigns stoking up the fears of people and creating a society of people who wrongly believed that gay people were responsible for this disease and that they deserved what they got. **B** and my whole family suffered as a result of this propaganda. Living in constant fear of reprisals and worried every time **B** was out on his own. There were numerous incidents which culminated in our house and car being vandalised and daubed with the words "AIDS". We were forced to move house and relocate to an area where people did not know us so we could all make a fresh start and **B** did not feel threatened and focus on creating a life for himself.

36. As previously mentioned, we were unable to share **B**'s situation with any friends or family members which, in itself, was extremely difficult.

37. Our older brother, **GRO-B** has also been affected by what happened to **B**. Like me he has struggled to come to terms with these events and his personality and confidence has been negatively impacted.

**Section 6. Treatment/care/support**

38. I do not have any precise details of [B]'s care and treatments. I do know he was seen by many doctors and specialists over the years and that his health slowly deteriorated which was heartbreaking to watch. He did receive the help of the MacFarlane Trust but I do not know the details of this.

39. I am not sure whether [B] was ever offered or received counselling or psychological support but I do know that myself, my Mum, Dad and older brother definitely did not.

**Section 7. Financial Assistance**

40. I am unaware what [B]'s financial position was or whether he received any help or support. I do know he was unable to work for the vast majority of his life and was in receipt of disability and housing benefits for most of his adult life.

41. The only financial help we received was from the MacFarlane Trust. They paid for some of the expenses we incurred when [B] was dying in the [GRO-B] [GRO-B]. The family had to travel from Liverpool and stay over in hotels for long periods of time and the contribution they made allowed us to be there with [B]. They also contributed to his funeral costs.

**Anonymity, disclosure and redaction**

42. I confirm that I wish to remain anonymous.

43. I do not wish to be called to give oral evidence.



**Statement of Truth**

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

Signed

GRO-B

Dated

28.3.2019