

# ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2682001

Exhibits: 0

Dated: April 2019

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF **GRO-B**

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

### Section 1. Introduction

1. My name is **GRO-B** I was born on the **GRO-B** 1983. My address is **GRO-B** I work as a part time fireman.
2. I am an affected person in relation to my father **GRO-B: F** who received contaminated blood products. I am aware that my father **F** **F** and my mother **GRO-B** also intend to provide witness statements to the Inquiry.
3. This witness statement has been prepared without the benefit of access to my father's full medical records.

### Section 2. How infected

4. My father has severe haemophilia type A. His late brother, **GRO-B: U** **U** also suffered with haemophilia A.

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5. My father attended Heath Hospital in Wales. To my knowledge this was the only hospital at which he was a patient.
6. My father received Factor VIII blood products. I am not sure if he was given any information in regards to the risks involved with receiving Factor VIII. I do not think he would have consented to receiving blood if he knew the risks that it presented.
7. My father was infected with Hepatitis B, Hepatitis C and Human Immunodeficiency Virus (HIV) as a result of receiving contaminated blood products.
8. I believe, especially in regards to my father's HIV, that the doctors knew something was wrong long before my father was diagnosed with anything. I believe that they knew that he had been infected but were unsure as to what he had been infected with. My father was adamant that they knew he had been infected and purposely did not tell him. It is something I have had to try and put to the back of my mind as it is hard to deal with.
9. I am not sure if the doctor's gave my father any information in respect of understanding his infections. I don't believe they told him much in relation to what treatment he should receive or how the infections would affect him.
10. I found out that my father had these infections when I was in comprehensive school when I was around 13 years old. My father was very ill again and he explained to me that he had received contaminated blood and this was why he was so unwell.

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

11. I believe my father was told that he had been exposed to blood that contained vCJD.

**Section 4. Consent**

12. My father was treated without his knowledge and therefore could not give consent to any testing of his blood. As far as I am aware he was never told that his blood was being tested for anything. My father was under the impression his blood was being taken in relation to the fact he was a haemophiliac.

13. I believe my father was used for the purpose of research as he and my uncle were given trials for AZT. My father was given AZT while my uncle received the placebo. My father lived and my uncle ended up passing away.

**Section 5. Impact of the Infection**

14. Physically, the infections my father received from contaminated blood had a huge effect on him. He would spend most of his time in a hospital or in bed unable to move. When I was young I didn't realise this wasn't normal, it was what I was used too. Looking back the amount of times he was near to death during my childhood is striking.

15. It was the HIV virus that was the most devastating and the biggest cause of my father's terrible health. It is something that brought him to near death a handful of times. Due to the immunodeficiency caused by HIV my father has suffered from a countless number of illnesses. My father will never be cured of HIV or be free from the ongoing risks that it carries. He not only has to worry about the virus itself but the complications that are caused by his lowered immunity. It is something he will never be free from.

16. The mental effects on my father were probably even bigger than the physical. Just knowing that you are living with a disease that affects you so much and can kill you at anytime is so damaging. I feel like his health has deteriorated year after year. The amount of tablets he needed just to stay alive was incredible. My father feels it is visibly clear that he is a man who is not well

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and this has affected his ability to make friends. It must be really hard to deal with mentally.

17. My father has constantly been ill. At one point he had PCP Pneumonia, I believe this was in or around 1993 when I was around 9 or 10 years old. I remember that he was very sick.
18. At one point, my father's pancreas was on the verge of exploding. He was touch and go at the time. I remember visiting him and it was quite clear that this could possibly be the last time that I would speak to him. It made me feel terrible; you can't imagine. It is bad enough when someone is old and you feel that they have had a good innings and enjoyed and experienced life but my father was too young to be so close to death; it was a really big shock at the time. There was always a worry that something else was about to go wrong. There has never been a period where things have been good health-wise; he is always ill and constantly stressed.
19. I vividly remember the 3 treatments my father received in order to fight his Hepatitis C infection. It was quite horrific as it affected him terribly. It was so bad that that I could not talk or interact with him as the treatment made him so angry. It wasn't his fault, it was the medication.
20. One of the times he was receiving treatment for Hepatitis C the effects were so bad that he had to take himself off it. He told the doctors that it would lead to his divorce if he carried on. I remember witnessing his personality changing. Things would really irritate him that he wouldn't have worried about before the treatment. He couldn't function at all and physically he was so bad that he would spend most of his time lying on the sofa. It was up to me and my mother to look after him. It is quite difficult to distinguish between the effects of the infections and the treatment for the infections.
21. My father was given Harvoni in 2017 which fortunately was successful and has made the Hepatitis C undetectable. Although this medication was easier to handle he did still suffer some side effects. However, he could function with the treatment, it was manageable and therefore he was prepared to go

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through the effects that it presented. Despite the severity of my fathers Hepatitis C infection and subsequent effects from his treatment, the treatment itself was successful.

22. I believe my father should have been offered alternative treatments that could have helped him, but because of money restraints the NHS would never let him. Even now I believe there is a lot they can offer but because it will cost them financially they do not offer him the chance. He is alive and functioning and I believe that the NHS would rather leave him to it rather than trying to improve the quality of his life.
23. I have looked into potential treatments that I believe could help my father, such as growth hormones. My father fits into the category of people that are in dire need and I believe growth hormone treatment would transform his life. I have seen cases where it has helped people tremendously and even looking at forums online where people have paid for the treatment themselves I can see how much it has helped. I believe my father deserves this treatment; I constantly look into new medical treatments and talk to my father about them. However, whenever he mentions them to his consultants they deny him, mentioning the costs. The technology is there. It is not new it has been around for years.
24. I am not sure whether my father has been refused any care but I know that he has had difficulty in securing mortgages and business loans because they look at his long term future and as he could die at any moment due to his infections they are not keen to give him anything.
25. My father cannot go to a normal dentist; he has to go to a specialist in Cardiff because of his infections. I believe he once received dental treatment from a junior doctor who did something wrong which put him off going to the dentist for years. He now has a real fear of dentists. His teeth are quite bad as a result but he is getting no dental treatment at all at the moment. Again there is technology available that could help my father in this regard but he is never offered it.



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26. From my father's point of view he does not have the social life or circle of friends that most people would have. He has not had the opportunity to live a normal life as he cannot work full time or have hobbies due to his infections. He has had to choose the friends that he does have wisely; he knows he is very unwell and has to explain why. It is a horrible position to be in.
27. My father only tells certain people about his illness. It must be so hard for him to be so ill and have to avoid everyone. The stigma he has faced, especially in the early days, made it difficult for him to open up to anyone. It affected everything really, it knocked his confidence massively. He was constantly conscious that he was very unwell. My father managed to hide it well when I was younger but it gets harder as time goes on. He thinks that everyone judges him.
28. My father's infection has had a huge effect on me. We could not really do anything together. Sometimes he would come and watch me play rugby but it was very rare. His illness robbed me of quality time with my father that I can never get back.
29. Obviously I wanted him there when I was a child but he could never really make it. I used to enter into GRO-B around the country and as my father could not come with me; my grandfather would have to take his place. My father felt terribly guilty that he was not able to do what other fathers would do with their children with me. He never had any confidence; he always thought he looked ill. He would get sick so often and his infections were always at the forefront of his mind.
30. When I was younger I could not bring friends over or have sleepovers because it was not suitable and my father was always ill. I did not understand why at the time but I feel like I missed out a lot. I was always the one who had to go to my friend's houses as they could not come to mine.
31. At sporting events other fathers would be there with their children but mine couldn't. My mother would come every so often but they were usually a pair and she was helping to look after him. I noticed everyone else's parents would

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be actively involved in their children's lives, but my parents felt they had to keep their distance. I think they did this so people wouldn't realise what was going on. I felt there was a massive stigma associated with the infections my father had. My parents wanted me to keep it quiet but I also realised it was something I wouldn't want to tell people in their defence.

32. It was impossible to invite people over to the house. It was hard to tell family that they could not visit because they would ask questions. It is something that is hard to explain. If it was a broken bone or illness that does not have a stigma attached it would have been much easier but because we couldn't tell anyone about my father's infection it meant we had to keep everything to ourselves.
33. When I was told of the infections I knew what they were and what the ramifications would be if I told anyone. Therefore I couldn't really talk to anyone about it other than my parents. I was told when I was very young. It was a massive shock at the time, years later we would talk about it so I could gather more information.
34. I didn't even tell my best friend at school about my father's infections. I have told my most recent partner because I think I had to tell her. My father was quite ill and we had to tell her what was going on. I told her that she could not tell anyone. I have not told anyone else.
35. My father and uncle were both infected with contaminated blood products, but when I was younger I did not know the extent to which they were sick. I realised my uncle was very ill and as a result he passed away very quickly. I was not told why he died; I was just told he was ill. I began to just accept it, like it was somehow normal. I was very close to my cousins so it was a very difficult time. Their lives were changed forever when their dad died. When I was young I didn't realise what my family was really going through. Looking back I feel like I missed out on a lot.
36. I was in secondary school when my parents told me of my father's infections. After this I think subconsciously it was on my mind more than I thought at the

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time. I knew my father could die any moment; he was barely being kept alive by the drugs and could go anytime. Being a teenager I just couldn't deal with it.

37. My father would try to talk to me about school and tried to tell me the things he would have liked to do if he wasn't ill in terms of subjects, paths to take and jobs. Being so young it was hard to listen to because it was advice from someone who hadn't done these things themselves. I didn't want to listen to any of it, it is terrible looking back.
38. I think my parents, especially at that time, were busy with everything going on and they didn't have a lot of time for me. It wasn't terrible but I don't feel I got the support that I needed in regards to my education because they couldn't spare me the time. They were so focused on my father's health and my mum also **GRO-B** at the time and had to bring money in for the family. They were flat out all the time and there was no time for me.
39. We ended up moving house and relocated **GRO-B** I believe I was around 16 at the time. I don't know why we moved. I always wondered about it, it was such a bad thing for me to move house. I am not sure if we moved due to my fathers infections. I had to leave all my friends behind and move miles away. It was also around the time I was taking my GCSE's. This was a really bad thing for me. I was so far away I had to be taken to school by car because it wasn't near any bus routes.
40. I was told that I was capable of doing whatever I wanted when I was at school. I ended up getting mostly C grades in my GCSE's and I went to college to do a **GRO-B** Money was tight at home and my family couldn't support me financially. I didn't expect handouts but I needed more money so I ended up getting a job and had to leave college early when I was around 17.
41. I have worked in mechanics, manufacturing, steel works and sales; I have done quite a lot. I became a fireman in 2013 because I was into fitness and was quite into the armed forces. I did not want to be in the police but I thought



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this would be a challenge as they are big on fitness and discipline and I really enjoy it.

42. There was a point where I didn't talk to my GRO-B cousins for years, they were in a local school and my school was over an hour away. We had been very close before but this stopped when my uncle passed away. I don't really know what happened, but I think my aunt wanted to start afresh and she might have found it difficult because my father had the same infections my uncle had but survived because he had received treatment whereas my uncle was given a placebo. It was so bad my aunt just wanted to start afresh and leave it all behind.

43. Receiving contaminated blood and subsequently the infections that came with it had a huge effect my father's career. I believe that he probably achieved 5% of what he is capable of because he has been held back so much by his illnesses. Not just the infection but the mental effects they caused. He could have done anything he wanted and it is dreadful that something so avoidable, something so out of my fathers own control, has caused so much damage.

44. The effect on my mother has not been far off what my father has had to go through. She has not been able to have a normal life or work in the ways she would have done if my father had not been infected. She has had to spend her life as a carer. She had no social group of friends so all the effects my father has had my mother has had to experience, barring the physical effects. She has also had to live with the fear that her husband could die at any time

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

45. My parents were never offered any counselling or psychological help as far as I am aware.

46. I was never offered any psychological help. I ended up having to get private counselling. I have never told my parents this, growing up and seeing how anxious and self conscious they were I had to go privately because I did not want to add any stress to what they have had to go through.

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47. I had counselling around 10 years ago and alternative therapies in the last year such as hypnotherapy. The psychological therapy has helped a lot and I believe that it should have been provided earlier to support all of us. What I have been through is mild compared to my mother; I can't imagine what she has been through.
48. Last year I was quite ill for a while and I was due to see a consultant. I asked my father to talk to someone at his hospital as he is there every day and my GP thought I might have a bug. They phoned me and I found out that I had never been tested for HIV, Hepatitis B or Hepatitis C, I couldn't believe it. It is terrifying to think that I could have had these infections and the hospital never thought to test me for my own well-being. They told me I did not have HIV because I would be dead by now if I did, which I found to be very insensitive.
49. When I did finally get tested, the results came back clear but I could not believe that they had not tested me or at least made me aware that I should be tested. It should have been the first thing on their agenda once they discovered my father was infected.
50. I suffer with a type of immunodeficiency disorder called celiac disease. I also have food allergies which I believe come under the same category. I believe that my father was infected through contaminated blood before I was conceived, so I was obviously very lucky not to contract any infection myself. Considering that I was not tested for HIV or Hepatitis C until 2018, I do not believe that any research has conducted into how the HIV virus, or any of the other infections, could potentially cause immunodeficiency disorders into children being born under these conditions. I feel this is another area where family's have been let down by a lack of research. There is such a lack of clarity on any issues. We receive no help, no information and no support.

### **Section 7. Financial Assistance**

51. I know my father received a payment from the MacFarlane Trust but I am not sure exactly how much he received.

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52. I remember my father would end up having to write begging letters for financial help or household items because we were not able to afford them. These were usually rejected and it was not good for my father's mental health to add the additional worry. It shows he was not being helped enough financially.

53. I have never received any payments in relation to my father.

### **Section 8. Other Issues**

54. I think looking back there are people that are responsible for this scandal. They were in full knowledge of what they did and need to be held accountable. If this happened in any other field it would be taken more seriously, for example the case of soldier F. This is a case of someone who did something 20 years ago and is being punished for something they did in the past.

55. People receiving contaminated blood has led to a lot of deaths. It was not an accident. It is not like it was unavoidable or there was some kind of outbreak; I believe that this was given with the full knowledge of medical experts.

56. People who have been infected or affected should receive compensation to sort their lives out and should also receive monthly payments in order to have a good quality of life. I recently realised that my father is one of the GRO-B haemophiliacs who was infected with HIV who is still alive.

57. I would like them to sort out all the debts people have not been able to deal with due to their infections. There also needs to be better medical treatment. Those infected with contaminated blood should have access to better treatment such as the growth hormones. The technology is there. They should be doing everything they can to rectify their mistake and make people's lives easier.

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## Anonymity

58. I wish to remain anonymous.

59. I am willing to provide oral evidence if the opportunity is there to remain anonymous.

## **Statement of Truth**

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

Signed.

**GRO-B**

Dated

02/05/19