

# ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0278001

Exhibits: NIL

Dated: 14/11/19

## INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 February 2019.

I, GRO-B will say as follows: -

### Section 1. Introduction

1. My name is name is GRO-B My date of birth is GRO-B 1993 and my address is known to the Inquiry. I am not married and I am a GRO-B at GRO-B I intend to speak about how my father came to be infected with HIV and HCV. In particular, the nature of his illness, how the illness affected me, the treatment he received and the impact it had on our family.
2. I have two sisters (one older, one younger) and we grew up in GRO-B Wales. My father's health had a strong influence on our childhood, and we were quite active within the haemophilia community. As a child, we would often attend holidays with families that we had met through various charities that provided support for people with haemophilia and for those

who had been infected as a result of using infected blood or blood products.

**Section 2. How Affected**

3. My father is a severe haemophiliac and was a regular user of recombinant Factor VIII products.
4. He would use Factor VIII home treatments about three to four times a week, and was very open about it with us when we were growing up. The treatments were administered intravenously and he would often inject Factor VIII in the lounge room when we were around, however I am not aware of the exact name of the products that he was using.
5. I do not believe we have never received any confirmation about exactly what caused my father's infections, however it is most likely as a result of using infected blood products as there is no other plausible explanation for how he was infected. I do not believe he received any blood transfusions as a child. I am also unsure whether my father was provided with any information about the possible risks that were associated with the home treatments.
6. My sisters and I have always been aware that our father was a haemophiliac and that he had HCV, however we were not told that he had been infected with HIV until we were nearly adults. I was 17 years old when my parents told me about the HIV infection and at that stage, it was only my mother, my older sister and my grandparents that were aware of it. My father has remained quite secretive of his infection and to this day it is only our very immediate family and friends who know.
7. I was not alive at the time; however, my father has told me about the day he was diagnosed with HCV and HIV. He was about 17 or 18 years old (in the mid1980s) and he had gone to GRO-B in GRO-B GRO-B for a routine appointment. He was aware of the infected blood scandal as there was a lot of coverage in

## ANONYMOUS

the media, however he had recently been re-assured at a meeting by Arthur Bloom (a prominent haemophilia specialist in Cardiff), that he and the other haemophiliacs had not been infected. Despite this, when my father attended his routine appointment he was told that he had been infected with HCV and HIV.

8. There was no indication of how or when he had been infected, nor was he informed whether it was likely as a result of cryoprecipitate or Factor VIII. I think that he may have been told some basic information about the risks of sharing razors and the importance of covering open wounds, but that would have been about it.
9. My father has always said that he could never really pinpoint a time that he was infected, which could possibly be attributed to his long-term non-progressive status.

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

10. I am not aware of any other infections that have affected my father as a result receiving infected blood or blood products.
11. My father now suffers from destructive arthritis as a result of his haemophilia, which has likely developed from internal bleeding into his joints.
12. He also suffers from cirrhosis of the liver as a result of the HCV and he receives regular treatment for this. It is currently at a stage where it is borderline with fibrosis of the liver.

### **Section 4. Consent**

13. My father reports that he was not informed that he was being investigated for HCV or HIV. He was told about his diagnoses having never been aware of being testing. Subsequent attempts to view his medical record have found that large periods of documentation around this time are missing.

**Section 5. Impact**

14. My parents were never discouraged from having children. My father has a low viral load, which may have been the reason why they weren't discouraged from starting a family, but it equally may have been the case that this was simply something that was not generally communicated to people. My mother is not infected; however, she was still required to have high-risk antenatal care. I believe that my siblings and I would have also had some form of treatment or investigation as infants. My father remains the only haemophiliac in the family, however my sisters are carriers so there is the chance that it may be passed on if they have any male children in the future.
15. As a child, I would regularly attend the hospital with my father. He would typically have to go to the hospital about four times a year and this increased when he took part in the clinical trials. We would also attend the Haemophilia Centre at GRO-B together to collect big boxes of Factor VIII home treatments.
16. Despite the fact that my parents were quite open about the home treatment, they were still very conscious of the risk of infection to us children. I remember on one particular occasion, my father told me off very sternly after catching me attempting to use his razor.
17. The various charities that we were involved with when I was growing up allowed us to form friendships with people who shared the same experiences as we did. The charity events that we would attend were typically run by the Macfarlane Trust or GRO-B (based in GRO-B and aimed at supporting people with HIV and their families).

18. Many of my parent's friendships were also formed in these communities, which has meant that they have subsequently lost friends to illness over the years. It is an unfortunate consequence of having friends with HIV.
19. My father has decided to remain secretive of his HCV and HIV status. Our broader family are unaware, as are his work colleagues. People know he is a haemophiliac, however there are very few people that know more than that.
20. Given the amount of coverage that the infected blood scandal has had in the media, there will be people out there who make the connection between my father being a haemophiliac and the possibility that he may be infected. I currently live in a flat share with three other GRO-B who each know that my father is a haemophiliac – there is every chance that they have already made that connection in their own mind.

#### **Section 6. Treatment/Care/Support**

21. My father has undergone two bouts of treatment for HCV. The first round of treatment was undertaken about seven or eight years ago (around 2011 or 2012) and was an Interferon based treatment. This treatment was ultimately unsuccessful and it was very difficult to watch him go through this process.
22. The Interferon treatment lasted about six months and during that time, he was not himself at all. He was constantly feeling unwell or drained and he eventually ended up taking anti-depressants to deal with the depression that he experienced during the treatment. He did not work at any stage during his treatment.
23. My parents' relationship suffered during this time – there were more arguments around the house, my father suffered mentally and he was unable to contribute daily tasks to assist the household. My personal relationship with my father remained stable, however there were often times when he would be unable to play with us or take us out as he just

did not have the energy to do so. It was hard to watch him go through that experience, only to be told that the treatment had not worked.

24. My father took a break for a few years after the first treatment to take some time to recover physically and mentally.
25. The second round of treatment was undertaken about three or four years ago (2015 or 2016) and was a Ribavirin based treatment. This treatment lasted approximately six months and was ultimately successful.
26. The treatment for HCV is a combinational treatment, meaning that there is an anti-retroviral element to the treatment in addition to the Ribavirin. The anti-retroviral is often also used as treatment for HIV, so this element of the treatment has been continued to maintain his low viral load.
27. When you commence using an anti-retroviral, there is a risk that if the treatment is stopped, it will reduce the effect of that same treatment if you decide to re-commence it in the future. Consequently, my father has continued using the anti-retroviral to ensure that he continues to receive the full benefit of the treatment. Interestingly, there is research that suggests the average life expectancy for someone with HIV who receives continual anti-retroviral treatment is actually higher than the general average life expectancy.
28. My father is now treated in the GRO-B and GRO-B Hospital at GRO-B. When he first began his treatment, he was under the care of Arthur Bloom at the Haemophilia Centre in Cardiff – he was a prominent figure at the time of the infected blood scandal, however he passed away.
29. I do not think that he has experienced any barriers in accessing treatment. The access to treatment is generally very good in GRO-B however there were still often criteria that people had to meet to access the treatments (i.e. treatment was generally offered to people that had been infected via blood products before it was offered to infected drug users).

30. I do not think that my father has ever received any counselling or support, however I understand that it was available through the Macfarlane Trust or GRO-B if we wanted it. I think that he was offered counselling from the NHS when undergoing treatment, however this is the case for any type of treatment – it wasn't necessarily because he had been infected with blood products.

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

31. My parents received a one-off payment of around £20,000 in approximately 1993. I believe this was either a government payment or arranged from the Skipton or Macfarlane trust funds.
32. This payment was a step up for our family, as it was enough to help my parents secure a mortgage for a home in a nicer area.
33. My father has received regular payments ever since receiving the one-off payment in 1993. I am unsure of the exact amount of the regular payments; however, they are slightly less than what my mother is paid as a nurse.
34. I think that my father was happy to accept this payment – he saw it as a form of compensation. He has spoken about the complexity of the payment and that the conditions of the payment involved signing an agreement that no further legal action could be taken against the government in the future.
35. There was certainly a consideration that there should have been more compensation. A close family friend of ours was also infected, however he was based in Ireland and was entitled to receive a much larger payment. His payment was approximately £500,000, which is clearly far more significant than anything my family received. I do not think that my father was particularly bothered by this, however my parents would tell us as children that my father's friend had such a nice house because he had won the Irish lottery.

## ANONYMOUS

36. My parents were certainly aware of the opportunity to apply for subsidies when making purchases for the family home. I am unsure as to whether they went through with many applications, but I recall them discussing whether they should apply when purchasing things like new beds, carpet or whitegoods.
37. I recall my parents encountering some issues when the validity of disability pensions was challenged. They were provided some legal assistance through the MacFarlane Trust and it was all dealt with very quickly – there were no issues with the payments my family received.

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

38. I do not believe that my father has provided any evidence to another Inquiry or been involved in any litigation. He is following this Inquiry and has actively encouraged my family and I to provide a statement.
39. My father and I certainly hope that the work of this Inquiry will achieve a level of accountability for those responsible. Recommendations of further pay-outs would also be well received, as there seems to be a feeling within our community that people are entitled to more compensation than what they have been given.

### **Statement of Truth**

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

Signed GRO-B

Dated 14/11/19