

## INFECTED BLOOD INQUIRY

## FIRST WRITTEN STATEMENT OF GRO-B

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

**Section 1. Introduction**

1. My name is GRO-B  
GRO-B
2. I make this statement as the GRO-B of GRO-B: S GRO-B  
who was infected with HIV and Hepatitis C as a result of receiving contaminated blood products.
3. This statement has been prepared without the benefit of access to my GRO-B full medical records.
4. My GRO-B has also provided a Witness statement to the Inquiry dated GRO-B  
GRO-B

**Section 2. How Affected**

5. My GRO-B was diagnosed with Haemophilia A, classed as severe, with a clotting factor of 0.6% and Haemophilia B with a deficiency of 38.1% at about 16 months old. GRO-B shut GRO-B

## ANONYMOUS

- finger in a door and required hospital treatment as the wound would not stop bleeding. The Tests showed [GRO-B] had a low level of Factor VIII and a deficiency of Factor IX and [GRO-B] was treated with Cryoprecipitate. When receiving this news I was advised not to have anymore children as the doctor was adamant that I was a carrier of the gene that caused Haemophilia.
6. My [GRO-B] received Factor VIII concentrates and blood products on demand from the time of his diagnosis. From 1985 onwards [GRO-B] was given heat-treated Factor VIII. Prior to this [GRO-B] was apparently treated with non-heated Factor VIII. As [GRO-B] was at such a young age, the Factor VIII was administered by doctors and my [GRO-B] spent much of [GRO-B] life in hospital.
7. My [GRO-B] was treated at Freedom Fields Hospital, Plymouth under the care of Dr Harry Baumer (Paediatrician) and Dr Archie Prentice (Haematologist). [GRO-B] was also seen by Dr Charles Hutton (Rheumatologist) and Dr Mike Hammond (Haematologist).
8. In 1995 my [GRO-B] was transferred to [GRO-B] Hospital and came under the care of Dr [GRO-B] [GRO-B] (Paediatrician) Dr [GRO-B] (Consultant) Dr [GRO-B] and [GRO-B] (Clinical Nurse Specialist).
9. I was aware of the risk of AIDS from the start and was very concerned about my [GRO-B] being treated with Factor VIII. I had requested heat treated blood to be used when my [GRO-B] was undergoing treatment for a cut lip. We were told they were only allowed to use the blood product they had available. In addition, we were also told the benefits of the treatment outweighed any risk, which statement I now believe to be false.
10. My [GRO-B] was first tested for HIV in 1985 at our request. The result was negative so we became less worried. After this diagnosis [GRO-B] was given heat treated Factor VIII as it was deemed to be safer. Further to another requested test in 1988, my [GRO-B] was diagnosed as HIV positive. [GRO-B] was 7 years old at the time.
11. My [GRO-B] started treatment with Zidovudine (AZT) for the HIV in November 1993. This consisted of taking four tablets a day for two months. From about 1996 to 1998 [GRO-B] was treated with Didanosine and Stavudine and from 1999 with Lamivudine, Zidovudine and Nevirapene.

## ANONYMOUS

12. My [GRO-B] was tested for Hepatitis B in 1986, 1987 and 1988. [GRO-B] had been vaccinated against Hepatitis B and the tests returned negative.
13. The information that was provided to us by Dr Baumer about HIV was brief, blunt and contained little or no information regarding the risk of further transmission to others. It seemed like the doctors were shocked by the diagnosis. They were more worried about themselves than providing us with information that would be beneficial. We were advised not to tell anyone including our [GRO-B] that [GRO-B] had been infected. I do not believe the information we received from Dr Baumer, or any other medical professional at the time, to have been adequate. We obtained most of our knowledge of HIV from the Haemophilia society and the news.
14. According to the medical records we have been able to obtain my [GRO-B] was tested for Hepatitis C in 1997. The test was taken without mine or my husbands, knowledge or consent. Although the medical staff became aware my [GRO-B] had been infected when they received the results of the test, they did not tell [GRO-B] of his infection.
15. My [GRO-B] was only made aware of Hepatitis C infection in 2001. [GRO-B] had developed [GRO-B] cancer and required surgery in order to remove the tumour. [GRO-B] was told by a doctor that [GRO-B] would need a certain type of treatment due to [GRO-B] infection. Before this neither my [GRO-B] nor any of our family, was aware [GRO-B] had been infected with Hepatitis C.
16. As far as we are aware my [GRO-B] was given no useful advice or help about how to manage being infected with Hepatitis C or the risks of others being infected.

### Section 3. Other Infections

17. I am aware my [GRO-B] received a letter in 2004 from the NHS stating that [GRO-B] was at risk of vCJD.

### Section 4. Consent.

18. I believe my [GRO-B] was tested for Hepatitis C without [GRO-B] or my knowledge or consent. [GRO-B] was having regular blood tests due to [GRO-B] haemophilia but we were not informed that tests were being carried out for anything in particular. In addition we were not made aware of the results when they were confirmed positive.

**Section 5. Impact**

19. My [GRO-B] was kept in a consultation room when we were made aware that [GRO-B] had been infected with HIV from contaminated blood.. Due to [GRO-B] young age and on advice from Dr Baumer we kept the knowledge to ourselves, until [GRO-B] was old enough to understand. We had to keep a devastating secret from our [GRO-B]. We felt we had the responsibility of keeping our [GRO-B] safe. Not just in regards to [GRO-B] illnesses but from society's perception of those with the HIV virus.

20. At Freedom Fields Hospital, the staff refused to go into a room with my [GRO-B]. I remember people were uneducated as to the transmission of HIV and they believed you could transfer the virus through sharing cups.

21. It was difficult to function in a normal way while my [GRO-B] was at school. We had to give [GRO-B] [GRO-B] medication to take along with [GRO-B] packed lunch. [GRO-B] was questioned by other children as to what the tablets were and why [GRO-B] had to take them. This was a very awkward experience for [GRO-B].

22. My [GRO-B] questioned why [GRO-B] was constantly sick. At the age of 13 we explained to [GRO-B] that [GRO-B] had been infected with the HIV virus through contaminated blood as we no longer wanted to hide [GRO-B] from the truth and we thought [GRO-B] was old and mature enough to deal with information.

23. The illnesses that my [GRO-B] suffered due to the contaminated blood were horrendous and stressful to deal with. [GRO-B] suffered from severe Anaemia, Shingles, Osteoporosis and Hypocalcaemia. [GRO-B] immune system was practically non-existent which led to other issues such as severe weight loss. We were told [GRO-B] was suffering from anorexia and in addition [GRO-B] later developed [GRO-B] cancer. I believe these to be physical effects of the HIV and Hepatitis C viruses.

24. My [GRO-B] suffered from thrush due to the HIV virus which affected [GRO-B] throat and digestive system. This caused a lack of appetite and was hard to deal with. We had to regularly call [GRO-B] (Clinical Nurse Specialist) in the middle of the night for advice on how to help ease the effects.

## ANONYMOUS

25. My GRO-B was on AZT which GRO-B didn't tolerate very well. This caused bowel issues which resulted in Irritable Bowel Syndrome (IBS). It also caused nausea and fatigue. We were given no information on the possible side effects of AZT and the solution they gave us was to just take another type of medication. My GRO-B also suffered from regular night shivers.
26. I believe that my GRO-B has suffered discriminatory treatment by medical professionals. In 1989 I remember a particularly horrendous incident at Plymouth hospital when my GRO-B needed some of GRO-B milk teeth removed. The doctors wore protective clothing that reminded me of bio-hazard suits. This made my GRO-B frightened and frantic. We had not been made aware that these precautions would be taken and were therefore unable to prepare GRO-B. I believe this caused my GRO-B to no longer trust medical staff.
27. I believe the effects of the contaminated blood, in conjunction with the medicine GRO-B needed to take, caused my GRO-B to have depression and anxiety.
28. As a result of these ordeals I have lost faith in medical professionals. Information on infected blood should have been provided immediately. I believe they were aware that the blood products were contaminated. I found that we always had to try and stay a step ahead and constantly ask questions. We learnt to not accept what we were told and this caused constant stress in our lives.
29. The diagnosis of HIV made my family withdrawn. We felt like outcasts due to the social stigma attached to the virus, there was a lot of ignorance and scaremongering at the time. The government campaigns at the time also made things very difficult. At school people would cross the road to walk on the other side of the pavement to avoid walking near my GRO-B.
30. The way we were treated by both the medical staff and people in GRO-B influenced our decision to move. Although we did not tell anyone of my GRO-B infection we suspect many people had realised the cause of GRO-B illnesses. Our treatment improved under medical professionals at GRO-B but it was still very difficult.
31. As I was a full time carer for my GRO-B I had an excuse to no longer go out or have a social life. This has been the easiest and least stressful way for me to live my life.

## ANONYMOUS

32. Due to the effects of HIV my family have never been on a proper holiday. My GRO-B was too ill and we couldn't afford the life insurance. The only time in my GRO-B life that our family managed some time away is when GRO-B offered us some time in Cornwall where we went for a couple of days. Others who had been affected or infected by HIV also attended this trip.
33. My GRO-B has had no social life at all. This is down to a combination of the illnesses GRO-B has suffered throughout GRO-B life and the side effects of the treatments for the infections. I believe the Hepatitis C and the HIV infection in particular to be the reasons for the severity of GRO-B illnesses. This has led to GRO-B being isolated from others for the majority of GRO-B life, other than interaction with myself and my husband.
34. My GRO-B started to have a lot of absences from school due to GRO-B illnesses. GRO-B ended up having to be home tutored for a period in 1995 but was never able to finish GRO-B education as GRO-B was not well enough. My belief is that GRO-B absences were due to the HIV virus rather than Haemophilia. Educational officers were sent to ensure my GRO-B was not well. We kept the virus hidden even from them as we were worried about the further hardships and complications it could cause our GRO-B.
35. Due to the impact of GRO-B illnesses and the fact our GRO-B was unable to finish GRO-B education GRO-B has never been able to gain employment. GRO-B is GRO-B due to skill's GRO-B managed to teach GRO-B and works part time in GRO-B when GRO-B is physically able.
36. The illnesses of our GRO-B also had a significant impact on my husband, as he was self-employed, the constant travelling to hospitals meant he was unable to work as much as he previously had. As my husband is the main breadwinner in the family this led to a huge reduction in family income.
37. The financial effect has been devastating to the family. It is difficult to quantify the amount lost by myself, my husband and our GRO-B.

### Section 6. Treatment/Care/Support

38. We were not offered any support by Freedom Fields Hospital at the time of the HIV diagnosis in 1988. When we transferred to GRO-B Hospital we were offered a few types of treatment. The treatments offered at the time were alternative therapies such as reflexology

## ANONYMOUS

and massage therapy. No counselling or psychological support was offered to me and I have never been invited to sit down and talk about how I feel. I do believe counselling would have helped as I have been constantly stressed since my [GRO-B] was diagnosed.

39. If it was not for the support of my parents I do not think I would have been able to cope due to the lack of support from the NHS. There was certainly no help offered and any of the methods of support were less than adequate.

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

40. In the early 1990's an ex gratia payment was made by the McFarlane Trust ("MFT") on behalf of our [GRO-B]. This money was kept in trust until [GRO-B] was old enough to receive it.

41. We received weekly payments from the Macfarlane Trust of £15. My [GRO-B] received regular payments when [GRO-B] became older.

42. My [GRO-B] received some additional payments from the MFT to help [GRO-B] pay for vitamin and minerals supplements.

43. I found out about the possibility of financial assistance through the Haemophilia society who told us about the MFT and the 1991 litigation.

44. My [GRO-B] received the one-off stage 1 payment from the Skipton Fund and now receives annual payments from EIBSS..

45. My [GRO-B] also receives the Special Category Mechanism Payments and that this was awarded at some point in 2018.

46. I do not remember any particular difficulties in regards to obtaining financial assistance.

47. The financial assistance provided certainly wasn't enough. Our daily needs were not dealt with and we continue to struggle.

### **Conclusion**

## ANONYMOUS

48. The injuries and pain that my GRO-B suffered and continues to suffer from are not self inflicted.  
But were caused by those who were supposed to care for GRO-B
49. Those who are responsible for negligently allowing contaminated blood to be imported into the UK and used on unwilling, innocent victims should be held accountable.

### Anonymity, disclosure and redaction

50. I wish to be anonymous and I understand this statement will be published and disclosed as part of the inquiry. I do not wish to give oral evidence.

### Statement of Truth

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

Signed

GRO-B

Dated

27:3:2019