

## IN THE INFECTED BLOOD INQUIRY

STATEMENT OF GRO-B

(NAME TO BE ANONYMISED)

**Introduction**

1. I am a man of 41 years of age at the time of writing this statement. I am a father, partner and an accomplished Psychotherapist. I live in a small town in the South East of England and have resided here all of my life. I am a person living with Haemophilia with an inhibitor, the HIV virus and have been lucky enough to have completed 12 months of Interferon and Ribavirin treatment which cured me of the Hepatitis C Virus in 2008.
  
2. I have a blood condition called Haemophilia A. It is hereditary and comes in different forms of severity. I myself am considered severe, whereas others could be considered moderate or mild. Haemophilia is a condition which prevents my blood from clotting in the usual way and requires me to use a coagulant to prevent bleeding. It is vitally important to administer coagulating treatment as soon as a bleeding event occurs to minimise the damage caused by a 'bleed'.
  
3. I have an additional complication which is referred to as an Inhibitor. In 1998 my immune system created antibodies to the conventional treatment for Haemophilia which is called Factor VIII hence inhibiting its function. The inhibitor complicated my condition thus requiring me to use an alternative treatment which is inferior to Factor VIII in turn leading to increased damage caused by bleeding. The kind of damage a person suffering with Haemophilia can have would usually be joint damage. Damage is caused by blood entering a joint and disrupting the soft tissues, then over time causing Arthritis.

**How Infected**

4. I used Factor VIII for my bleeds from the age of 1 year of age up to the time of my inhibitor which was 21 years of age. The transmission of the HIV virus and the HEP

C virus can only have been from Factor VIII. I received all of my treatment from Lewisham hospital up until I turned 21 years of age and then changed to St Thomas' hospital.

5. I was given Factor VIII for a variety of different bleeds. I mostly suffered from having bleeding episodes in my right ankle. As I am a severe Haemophiliac, I was having frequent infusions of Factor VIII at times. These were as frequent as every 2 weeks. I would have been treated with a variety of different blood clotting products which hopefully can be identified in my hospital notes, these notes are being sourced by my solicitors.
6. I was 7 years old when my parents were told that I was HIV+. My mother and father recollect being told that they should prepare themselves for my death and that I would only live for a couple more years. They weren't given much information at the time of my diagnosis. It was not until the virus progressed to AIDS that they were given information about the virus and I was offered some psychological support. I was told about my HIV status when I was 12 years old.
7. I was in Lewisham hospital and built up a trusting relationship with one of the play supervisors who looked after children on the wards. One day she took me out as I was helping her run postal errands around the hospital. When we had finished she took me to one side and told me that I had contracted the HIV virus and that I should be careful when around girls. She also told me that if I was to be intimate with a girl then I should wear a Condom.
8. I immediately became very introverted and wouldn't talk to anyone, needless to say that when the nurses on the hospital ward found out about this the play supervisor was asked to leave. I saw her one more time just before she left and asked her why she decided to tell me that I was HIV+. In turn she told me that she thought it was unfair that my parents had told the hospital staff not to inform me of my status. I wasn't angry with her, just confused and lonely. It was at this time I began having psychological difficulties.

9. I was informed that I had also been diagnosed with the Hepatitis C virus when I was 12 years old. I was staying in Lewisham hospital at the time due to having an AIDS related illness and a nurse came to my bed and told me that I had Hepatitis C. The nurse went on to say that I shouldn't worry too much about it because I wouldn't be affected by it for around 12 years' time. She then left me on my own, no one was present with me in the room not even my parents were with me. It was at this time my parents decided to change hospitals and took me to a specialist doctor at St Mary's hospital in Paddington.
10. With regard to HIV infection, once I had become properly acquainted with my new physician I felt that I was well educated in its effect on my body and what to expect in the future. I was given excellent care. I feel, given the way in which I was informed about my HIV status, that there was quite a big gap in my becoming informed about what to expect from the virus and this led me to feel very scared. I haven't given much thought to the lack of information I received until writing this statement.
11. The early years were very confusing. Up until this point in my life I would look to my parents for a feeling of reassurance and safety; that they could fix anything in my little world and make everything ok but this wasn't the case anymore and I had to grow up very quickly. Initially even the doctors didn't know what to do. I have not felt the need to blame anyone for the lack of information around HIV or Hep C infection upon being informed of a diagnosis.

### **Impact**

12. Before I reflect upon the memories of my physical age at the time of becoming aware of my diagnosis's I would like to make the reader of my statement aware of the environmental impact on me as a much younger boy. This would be the fact that my parents were aware of the illnesses inside my body before me and how their lives and emotions were changed. I remember how the atmosphere felt in our home and how my sister and I were affected by this; a happy household filled with laughter and dance suddenly became quiet and pensive.
13. The communication between our parents became strained and awkward. Even though my sister and I were very young in 1984 (the year that my parents were

informed), we felt this change on an internal and emotional level. The impact of this news changed all of our lives forever.

14. I became extremely ill in 1988/89 when my HIV diagnosis progressed to AIDS. A new chapter began in my life. I was in my early teens and had just changed schools. This can be a hard time for any teenager and I was no exception. I managed to get through my first year of secondary school and then the illnesses began. I became very depressed, introverted and later on suicidal. I felt as though I could not talk to anyone about my problems as the issues surrounding HIV and AIDS were so big and scary.
15. I was 13 years old and scared and soon became aware that fully grown adults were also afraid of the issues surrounding HIV infection; so for a time felt as though there was no one to talk to.
16. I began to seek out ways to escape the mental torment I was feeling and soon became aware of legal and illegal drugs. My escapism started with opiate painkillers which I had been prescribed for my ailments. At first I would take some as I found that they would relax me, then as my usage advanced it would reflect more of a risk taking behaviour with the amount of pills being considered an overdose.
17. I had been treated with Pethidine and Morphine in hospital so was in no way naive to their effects. My transition from using legal drugs to self-medicate soon progressed to becoming embroiled in illegal drugs which I would use quite frequently.
18. My physical state has been greatly affected by the virus's I was infected with, coupled with the illnesses I had and the effects of the antiretroviral medication which I would take in some vain attempt to keep the HIV infection at bay. Once put together all of this resulted in my feeling continuously weak. I had constant discomfort resulting in headaches and stabbing pains in my abdomen.
19. Although I have never been officially diagnosed with Post Traumatic Stress Disorder (PTSD) I definitely show many signs of it. Whilst the medication for HIV has improved over the years and the virus can be controlled very well now this has not always been

the case. I had many difficult infections when I was younger due to the medication not being good enough. I suffered with HIV related illnesses from the ages of 12 to 21. These included pneumonia, infections in my kidneys and stomach viruses. In regard to further medical conditions I have had to contend with, I was diagnosed with Chronic Kidney Disease (CKD) in 2012.

20. The eventuality of this being that I had to have a kidney transplant in November of 2016. To this date I have not fully recovered and do not think that I ever will. I have very recently been admitted into hospital with heart problems and have been informed that I need a triple heart bypass operation. The doctors that I spoke with have attributed this to HIV infection as my heart has been under immense strain due to all of the illnesses I have experienced throughout my life.
21. I began treatment for Hepatitis C in 2007. This lasted 12 months and was one of the hardest treatment regimes I have ever had to complete. The treatment consisted of two drugs, one called Interferon and the other Ribavirin. These have been the most intrusive drugs to my mental and physical state that I have ever had to take. I do not understand how these drugs work but they changed me on a mental and physical level; gave me severe depression; incited rage and made me extremely weak; and anaemic. Needless to say I was a very unpleasant person to be around.
22. The positive side to all of this was that they cured me of the Hepatitis C virus and for this I am thankful. After I finished the 12 month treatment regime for Hepatitis C, I began having intrusive images which manifested themselves as terrifying flash backs. These 'flash backs' have been likened to Post Traumatic Stress Disorder and always have a violent and personally damaging theme to them whereby I am being attacked and harmed, needless to say this has led me to seek out the help of a Psychologist.
23. When I was diagnosed with CKD I began to put a lot of thought into what had caused my kidneys to fail. The only way to find out what had caused CKD was to have a biopsy and as it was too risky due to the bleeding which would undoubtedly occur, all I could do was think and theorise.

24. With the help of a Nephrologist we came to a conclusion that the Hepatitis C virus could have damaged my kidneys via Glomerulonephritis. Although this was a distinct possibility we couldn't prove it without a biopsy. The not knowing has caused me a lot of emotional torment. My kidneys were destroyed and I have no answer as to why it happened.
25. The Impact of HIV and Hepatitis C infection upon my life has been all encompassing since I would have been infected from the age of 1 year old. I didn't have the chance to experience life without these Viruses. What would my life have been like without HIV and Hepatitis C? This is a question which has affected my mental health considerably over the years, so I came to the conclusion that I must do my best with the hand that I have been dealt.
26. The impact to my private life has been variable. In my early years as a young adult I believed for some time that nobody would ever love me and that having a loving partner and family would be very difficult if not impossible. After feeling distressed and lost for some time I realised it would be possible to find love. I have had some very loving and intimate relationships and now I am settled and about to be married. I have a beautiful daughter with my fiancé and a very supportive extended family.
27. The impact of my contracting HIV and Hepatitis C felt by my family has been huge. My Parents are still haunted by the trauma of the events surrounding these issues and I do not think they will ever be healed. Since the inquiry began my mother has been re-traumatised and although she sees the inquiry as beneficial I cannot talk to her about it. When the inquiry began we had a brief conversation about it and since then she has been having traumatic flashbacks.
28. I feel powerless to help her. I have tried to coax her into thinking about entering into counselling but to no avail. My father began looking into the Inquiry and when it went live he watched some of it but after a while felt that he could not persevere. The Inquiry simply reminds him of the trauma from long ago and how he felt unable to help me when I was a child.

29. Around the time of my mother and father receiving the news of my diagnosis he found it very difficult to communicate his feelings which left him isolated. He became distant from family life and suffered in silence. Many years later when I was a teenager he got involved with medical trials which were set up to try and find a vaccine for the HIV virus. He was dedicated to helping the doctors find an answer and although the trial had some potential, ultimately it did not progress toward a functional vaccine.
30. At the time of my father participating in this study I could not see the sentiment behind what he was trying to achieve. As the years have progressed I can see this was a way in which he could help fight against the suffering which would be felt by others infected by the HIV virus; play a positive role and make up for his distance at home.
31. My sister has been severely affected by this tragedy also. She became quite introverted from childhood. On the few occasions that she has been able to talk about her past she reflects upon feeling alone and neglected as most of the attention from our parents would have been directed to me.

#### **Stigma associated with a diagnosis of HIV**

32. Around the time of my diagnosis there was a lot of scaremongering on TV about Aids. I do not know what the government were thinking but the message that came across was one of fear; as if they wanted to terrify the entire country. As if scaring people would prevent them from being infected. What the advertising campaigns did was ostracise people that were living and dying with the virus; to make them fearful of ever telling anyone about their status hence stifling support networks.
33. I was a young boy at this time and attending school. There were some questions about my health status from the headmaster which ultimately was not made public. From this time on I never felt welcome, I always felt as though I was being watched. I would catch teachers or mid-day supervisors staring at me and scowling. When the day was over and I went to meet my mother at the school gates, parents of my friends would also be staring at me.
34. I later found out from my mother that nobody would talk to her outside the school whilst she was waiting for me. Although I feel this cannot be directly associated with

stigma due to having HIV as nobody at this time knew I had been diagnosed, it was common knowledge that Haemophilia and HIV/Aids were connected as it had been reported on the news.

### **Educational effects**

35. My schooling only became affected from the age of 12 years old. From this time onward my attendance was sparse as I had frequent admissions to hospital from HIV related illnesses. A few years later I remember my teachers telling me that it would be possible for me to catch up with my work as I was bright enough. I couldn't see the point as I had been told that I would not live much longer and should only focus on one month at a time.
36. I left school at 15 years of age without any qualifications. The days turned into months and the months into years. I was alive but constantly suffering with very little quality of life. I did not pursue any avenue of education and just concentrated on survival whilst trying to create some kind of quality existence.
37. When I eventually reached 21 years of age and the medication for HIV had vastly improved I became well as the virus could be controlled. I intended to enroll in college and further my education but was struck by complications with Haemophilia. My immune system had created inhibitor antibodies which made my blood clotting medication ineffective, hence making life very difficult once again. It has not been until quite recently that I felt able to pursue any kind of education.
38. I decided to use the skills that I have learnt throughout my life in a positive way, to be able to help others who are suffering with psychological difficulties and various mental health challenges; and so I embarked on a diploma in counselling/psychotherapy. I began my training in 2012, graduated in 2015 and have been volunteering my services since 2014. I am not yet well enough to work full or part time or to be able to earn money.
39. My family and I live on 'handouts' from the ex gratia support scheme set up by our government as liability has never been claimed for the contaminated blood tragedy, hence allowing us to explore avenues of realistic and fair compensation.



**Financial Assistance**

40. My parents found out financial assistance when the Macfarlane trust (MFT) went live. I do not think they had any issues with applying to the trust. I feel that the ex-gratia payments have been wholly inadequate.
41. My personal opinion to all that have been affected by this tragedy is that we should have been paid rightful compensation based upon damages caused by the viruses we received due to contaminated blood. There was a time when the MFT would set up weekends away for us all to meet up and share our experiences. These weekends were very beneficial to us as a community and it felt extremely cruel when they were stopped without any word of an explanation.
42. Now that the MFT has been closed down and the England Infected Blood Support Scheme (EIBSS) has been set up I cannot see that anything much has changed in the way in which we are supported. With regard to this I can only assume that the beneficiaries of EIBSS will see gradual improvement over time.

**STATEMENT OF TRUTH**

I believe the facts stated in this Witness Statement are true.

Signed: **GRO-B** .....

Dated: 3d/1/19 .....