

# ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN0034001

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 **GRO-B** and I live at **GRO-B**  
**GRO-B**
2. I have been married to my wife, **GRO-B** for **GRO-B** years. I **GRO-B** from  
**GRO-B** due to **GRO-B**.
3. I have 2 sisters who are 14 and 17 years older than me. My younger sister had 2 boys, both with Haemophilia, both were infected with HIV and Hepatitis C (Hep C) and both have now died from the infections. My elder sister has 2 daughters and a son. One of the daughters is a carrier with a Haemophiliac son, fortunately he was born after heat treated FVIII was introduced.
4. My family had no history of Haemophilia other than an uncle who apparently had severe nose bleeds and died before I was born.
5. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited

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records the relevant entries are set out in the medical chronology at the end of this statement.

### Section 2. How Infected

6. I was diagnosed with severe Haemophilia A when I was around 1 year old. During my early months, I would bruise badly and the doctors at the time did not know what was wrong. They suspected I may be being mistreated by my parents. My dad even resorted to making me a suit out of cotton wool to try to prevent some of my injuries.
7. At the time, treatment for haemophilia consisted of whole blood transfusions in the hospital and over the years things progressed and cryoprecipitate was developed which made life considerably easier. Eventually Factor VIII concentrate (FVIII) came on the scene which was hailed as a breakthrough in treatment.
8. As FVIII became available, I was given treatment by most, if not all the companies producing it.
9. I attended a regular school at both junior and senior level so the FVIII treatment was given usually at the hospital. I was a late starter with home treatment. I was mainly treated at the GRO-B My treating doctors at the time were usually the most senior. My current specialist is GRO-B
10. In about GRO-B GRO-B after my GRO-B I was told I was infected with HIV by the GRO-B which came as quite a blow. I was never provided much information after that. Fortunately, my wife had not been infected and thankfully remains free of infection to date. There was certainly no counselling or apology offered.
11. Shortly after this, my wife started volunteering at a HIV helpline in order to understand more about the condition as at the time, it was considered to be a terminal illness with a short life expectancy. She wanted to come to terms with the news and to find out as much factual information as possible.

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12. In 2000, I was told that I had also contracted Hepatitis B (Hep B) and Hep C. I was prepared for this information as it was starting to appear in the press and I felt it was only a matter of time before it would be confirmed in my case.
13. I was not told beforehand about the risk of being exposed to infections from the blood products and neither were my parents.
14. I was given very little information at the time. The news reports were very sensational which did not help.
15. I believe I should have been told of the infection as soon as the hospital knew, but I am not sure when they found out. I also think that the way the news was communicated to me and the lack of follow up or counselling was outrageous.
16. I was not given any information at all about the risks of others being infected as a result of the infection.

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

17. In around 2004, I was informed that I, along with many other Haemophiliacs had had a theoretical exposure to vCJD.
18. My other current medical conditions caused as a result of the infections are Oesophageal Varices, Cirrhosis, Osteoporosis and Type 2 diabetes.

### **Section 4. Consent**

19. I believe that I was tested without my knowledge and consent. I knew I was being treated, but I did not know I was being tested. I was simply told of the results.
20. I have been asked about various research projects since around GRO-B to which I have always given my approval, but prior to this I would not know if I have been part of any research programme.

**Section 5. Impact of the Infection**

21. The mental effects of the infections are huge, I am a changed person. Part of my coping strategy has been to bury my head in the sand. I try not to think about my situation too much as I find my mood darkening very quickly. Part of my "success" in staying positive was through work. As a GRO-B I had a job which was mentally stimulating and physically demanding.

22. I have also suffered physical effects as a result of the infections. In the early 2000s my energy levels started to drop considerably, this was attributed to the Hep C and work became more difficult. My hospital and clinic appointments were becoming more and more frequent and it was getting to the point where I was fitting work in around them instead of the other way round. In 2007 I took the painful decision to stop working, I was starting to falter mid job and began cancelling projects at the last minute. This was having an impact on my reputation and I felt unprofessional. I did not pick a GRO-B up for quite a few years, I had completely lost sense of who I was. I felt worthless.

23. As a result of the infections, I suffered from further medical conditions. In 1994, I had Cryptococcal Meningitis, following in 1998 and 1999 with 3 episodes of Pancreatitis. My memory has been affected and big chunks have gone completely as a result of the Meningitis. I also find my short term memory is not great either.

24. I had tried twice to clear the Hep C using treatment consisting of Pegylated Interferon which proved both unsuccessful and traumatic. I was then denied access to the drug Sofosbuvir to clear the Hep C, as I was "one of a group of patients who have a similar condition and who could potentially all request the same treatment". In other words, I was a Haemophiliac infected with Hep C and if it had worked for me, all the other infected Haemophiliacs would want the same treatment. This was an outrageous situation given the circumstances and I believe the NHS has a moral duty to provide the latest and most efficient treatments to all infected Haemophiliacs. Eventually, thanks to a very persistent consultant, GRO-B at GRO-B



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, I did get the treatment which cleared the Hep C, however not before I had developed Cirrhosis and the Oesophageal Varices.

25. It has been almost GRO-B years since I was diagnosed with HIV and so I do not remember what treatment I may or may not have received for it because as stated above at paragraph 23, I suffer from memory problems. I am now on GRO-B to keep the HIV under control. As a result of this I treatment, I suffer from GRO-B which the doctor told me is as a result of the triple therapy treatment. This causes me to have brittle bones and my teeth to fall out. I also suffer from mood swings but do not know whether it is in relation to the HIV or an aftermath of Hep C even though I have cleared it.

26. The fact that I have been potentially exposed to vCJD has been a problem at various times when having certain procedures and indeed I have been denied treatment on one occasion due to the risk of passing the infection to others. Apparently the equipment used could not be guaranteed to be prion free for the next patient. Of course this begs the question, what if the patient before me had vCJD? This was when I was having one of my regular Endoscopies for Oesophageal Varices (a legacy of the Hep C) at GRO-B GRO-B

27. As a result of my infected status, I also experienced a sudden increase in travel insurance premiums. I did have to avoid working in the USA as I was no longer allowed and I was appalled when undertakers did not want to bury my GRO-B who had died from AIDS.

28. My infected status has had an impact on my private, family and social life. I had never really talked to others about my infections, not because I felt any shame but I did not want to be treated any differently. I had always told people I worked with about my haemophilia, in case I injured myself and some of them put 2 and 2 together when the media and government started linking haemophilia with HIV.

29. My wife and I have always supported ourselves financially through work. I left school with few qualifications which I guess is partly due to missing so much

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education as a child and also because my dad died when I was [GRO-B] and this was a very formative period in my life. My hobby had always been [GRO-B] and on leaving school at seventeen I was able to get a job as a [GRO-B] in a [GRO-B] and worked my way quickly into having my [GRO-B] [GRO-B] by the age of [GRO-B]. Over time my reputation grew and I managed to make a [GRO-B] out of my life long passion. However as my infections took hold I became increasingly aware that I had to slow down and my wife came to work with me, partly so we could spend more time together but also she was a cushion between me and my clients if I was having a bad day. In 2007 we took the very difficult decision to close the [GRO-B] which was due to the Hep C making working impossible.

30. The following years were difficult at times, the lack of purpose in my life and the feeling of failure have been hard to handle and also I really missed my work. Financially it has also been a huge loss. I worked hard and was well rewarded for my effort. I still take photographs, purely for pleasure and I find that helps to keep me mentally stimulated. One of my career highlights was having work included in the [GRO-B] [GRO-B]

31. My relationship with my wife has always been amazing, she has supported me through everything and it is not an overstatement to say I would not be here without her. I have let her down emotionally, I did become paranoid about passing my infections to her and as a consequence of this the physical side of our marriage has suffered. Fortunately we are a strong team and have been married for over [GRO-B] years.

### Section 6. Treatment/care/support

32. It is only in the last few years that counselling or psychological support has been offered.

### Section 7. Financial Assistance

33. I received [GRO-B] dollars from the [GRO-B]

34. I received a Stage 2 payment of [GRO-B] for the Hep C from the Skipton Fund.

35. I also get the annual payments for the Hep C and HIV from the EIBSS which this year will be [GRO-B]

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

36. As a person born with Haemophilia in the [GRO-B] I always knew my life would be different to the norm. I have always been aware of my surroundings and tried to remove physical risk wherever possible. My wife and I had never taken having children for granted as we would not have wanted to perpetuate the condition, but neither of us ever expected to have our worlds turned upside down the way it has. While we both try to lead as normal a life as possible, the realities of living with the conditions I now have is both unexpected and unimaginable. The constant medication, hospital appointments and endless worry and stress sometimes seem too much to bear.

37. As I type this statement it brings back the frightening, life threatening moments from the past, the anger and sadness of the present and another reason for us to relive our tragedy.

38. I just hope this Inquiry will not be yet another lifeline thrown to us made of nothing but words and time.

#### **Anonymity, disclosure and redaction**

39. I wish to remain anonymous.

40. I do not wish to provide oral evidence at the Inquiry.

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**Statement of Truth**

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

Signed.

GRO-B

Dated

30 April 2019.