

Witness Name **GRO-B**  
Statement No: WITN2760001  
Exhibits: WITN2760002  
Dated: MAY 2019

**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**. I was born on **GRO-B** 1967 and I live at **GRO-B** **GRO-B** with my wife.

2. This witness statement has been prepared without full access to my medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

**Section 2. How Infected**

3. I have severe Haemophilia A, diagnosed from the age of 3 years old. I am of **GRO-B**. I am one of three brothers and three sisters but am the only one with haemophilia.

4. My family and I came to England from **GRO-B** when I was 11 years old. My father was at first reluctant to come to the UK but was advised by a specialist doctor in **GRO-B** that I would have a better life and that better, more advanced treatment would be readily available to me here.
5. I was treated at the **GRO-B** initially at **GRO-B** **GRO-B** Hospital under the care of Dr **GRO-B** and Specialist Nurse **GRO-B** and then (at the age of 16 years old) at the **GRO-B** under the care of Dr **GRO-D** and, from the late 1980s, Dr **GRO-D**.
6. I attended a special school for disabled children as my parents were worried about me being knocked and bumped at a mainstream school. The school, The **GRO-B** School, was opposite the **GRO-B** Hospital in **GRO-B**. I would go over to the hospital 2 or 3 times per week for treatment with Factor VIII (FVIII) on a prophylaxis basis. I was trained to self-administer my own FVIII treatment at around the age of 14 years old. We kept the FVIII at home in our fridge after that. No information or advice was provided beforehand to me or my parents about the risk of being exposed to infection.
7. I was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) from contaminated blood products. My initial treatment started with cryoprecipitate but then I was told of the new product on the market more effective and easier to administer. As a result I was moved to FVIII with no choice.
8. In 1982 when I was 15 years old I had a massive brain haematoma. I was about to take my CSE Levels when I suddenly collapsed and was rushed to the **GRO-B**. I was given a craniotomy to relieve the resultant swelling to the right side of my brain (part of skull removed and kept until swelling subsided then put back in). I was in intensive care for a period of six weeks. I developed epilepsy after the operation (fitting two or three times monthly). I was given a lot of FVIII before during and after surgery (blood transfusion) and also had a knee operation

## ANONYMOUS

June/July 1984/85. I have a limited number of medical records but the medical records in relation to what was a very serious operation (and the associated time period) are missing. It is my suspicion that I may have been infected during the blood transfusion. As of today 1982-2019. 37 years later

9. I do not know the product and batch number with which I was infected with HIV. I have never been told when and how I was infected and many of my medical notes and records are missing but I have a strong suspicion that I was infected when I was given the craniotomy.
10. A couple of years later, I attended a routine haemophilia appointment when Dr **GRO-D** cannot be precise as to himself or one of Junior Doctors. But he was certainly the head consultant of department at that period in time told me in a corridor/side room that I had tested HTLV-III positive. He/Junior Doctor told me that it was very early stages and they didn't know much about the virus, but it was serious stuff as it had the potential to develop into AIDS. I remember being blindsided and reeling from shock. I thought I might fall over. I was alone (at aged 18 or 19) without my parents in a hospital corridor. I was given no information, support or counselling. The way I was told was callous and I never saw Dr **GRO-D** again afterwards. I felt let down. Emotionally I was affected badly because I had no support, my parents English was second language and did not understand the gravity of the situation. Nobody bothered to tell them.
11. I was not informed that I had HCV until some time in or around 1992. I was told by Dr **GRO-D**. In doing so, he confirmed that I was HIV positive. I was, again, told in a casual, off-hand way "we think you may be one our patients to have contracted hepatitis C as well as HIV". As nothing further had been said about HIV since Dr **GRO-D** had informed me of the HTLV-III test, I had allowed myself to believe that I did not have it. I did not even know that I had been tested for HCV. No information or advice was given to me about the management and spread of the infections.

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

12. I refer to **Exhibit WITN2760002** being a clinical virology document confirming that I tested HCV Ab positive on 2/12/92. It would also appear that I was exposed to the Hepatitis A Virus (HAV), the Hepatitis B Virus (HBV) and the cytomegalovirus (CMV) in or around that time.

13. I was also informed at one time that I may be at risk of vCJD. That really scared and worried me. It was just more psychological pressure on me.

### **Section 4. Consent.**

14. I had no idea that I had been tested for HIV and HCV. I had no idea that I had been tested for any form of infection and, as such, I could not have consented to these tests. I have not been provided with adequate or full information about the tests and about the results.

15. I think that I was treated like a guinea pig/used for research purposes. I think I was given the FVIII by my doctors with the off-hand attitude 'he doesn't matter, give him the treatment, he won't know, he doesn't matter'. I was a vulnerable child.

### **Section 5. Impact**

16. I told my parents that I had been infected with HIV (and HCV) after my HIV diagnosis was confirmed by Dr GRO-D. They were very upset. No-one offered us any counselling or support. The issue of my HIV status is taboo and not discussed outside of the family. We have kept it to ourselves because of the stigma and out of fear of being ostracised and/or abused. My HIV status would not be understood or tolerated within my culture. I have not told *all* my brothers and sisters and do not go into all the ins and outs with the ones that do know.

## ANONYMOUS

They do not know the extent of my suffering. (At this time AIDS was on the news all the time and with so much stigma attach to it ie gay men)

17. When I first told my parents, my oldest brother turned to my mum and asked if it was safe for them to use the same cutlery as me. I was deeply hurt by that comment. I felt gutted at the realisation that my own brother was scared of being in contact with me and that I may be putting him and my family in jeopardy. I was very upset but, at the same time, so little was known about the virus and how it was spread. The hardest thing for me to accept and stomach was my belief that I was going to contract AIDS and there was no medication to save me.
18. I later had AZT but had to stop the following year as I suffered from tiredness and nausea when on the medication. I have tried several other HIV treatments and medications bringing their own complications and side effects. I currently have a normal CD4 count and an undetectable viral load. Being co-infected with HIV and HCV complicates the medication that can be prescribed for you. It is difficult to identify the cause of my various medical issues and whether or not it is a direct result of a particular infection, a combination of both infections and/or a side effect of the treatment. I have developed peripheral neuropathy and bronchia. I suffer with itching, nausea, mood swings, loss of sleep, loss of appetite, weight loss, bloating, tiredness and fatigue. I am unable to walk more than 50 meters. My health is deteriorating.
19. I have spent most of my life in and out of hospital, relatively recently for 17 days suffering with a bout of pancreatitis.
20. I have had several tests on my liver and I have been told that my liver is scarred. I suffer with memory loss and have difficulty in concentrating. I have seen in my medical notes that I could develop dementia. This isn't something the doctors have discussed with me, but I am very worried about it.

21. I had clearing treatment for HCV in 2017. The (tablet) treatment lasted for 6 months and then I had to be monitored for a further 48 weeks, after which they told me that I had cleared the virus. I suffered from nausea and loss of appetite whilst on the treatment but I coped with it fairly well. It was a long time before I was accepted for treatment. I was told by **GRO-B** that the treatment was expensive and that other people were ahead of me/worse off than me, which meant the treatment was delayed for two or three years. An application had to be made for funding through NHS England.

22. I married in 2002 and wanted to start a family. Children are expected from a marriage in my culture. My wife is a teacher and loves children. Mindful of passing on my infections, we had two cycles of IUI sperm washing at **GRO-B** **GRO-B** Hospital which was unsuccessful and then a further two failed attempts at **GRO-B**. It was a very difficult and distressing process for both of us. Moreover, we had to apply and wait for funding on each occasion. We were refused funding for any more cycles. We are both much older now.

23. When I told my wife about my illness (I took a leap of faith when I did) she was really understanding. She is stronger than me and she is very protective. However, I feel like I have destroyed another life as she has not been able to live a proper life and have children. She is my carer and I rely on her to look after me.

24. I am really worried about the stigma of the infection and people from my culture finding out about it. I would be treated like a leper if people knew. Within my culture it is like living in a goldfish bowl in terms of people wanting to know everything about you. I no longer socialise as I cannot trust myself in what I might say. I also feel judgement from some of my doctors when they see on my notes that I am HIV positive. They act differently around me. I no longer trust the medical profession. I used to be happy and extroverted but I have just become increasingly inside of my shell as I am so scared of people finding out.

25. I have never been able to work which is frowned upon in my culture. I was doing quite well at school before the brain haematoma. My teachers were happy with me. I have an interest in geology and would have loved to have been a Geologist.
26. I am unable to take out life insurance which means I can't get a mortgage. I have really struggled financially as I have not been able to work and my wife is my full time carer. My home has been adapted to meet my physical needs. As such I am unable to move but at the same time, I am penalised with a reduction in benefit for having an extra bedroom.
27. I have suffered with chronic depression. I have felt so low at times that I have felt like taking my own life. There is only so much you can take. I have had to watch everything from the side lines and I feel like my life has diminished. As I'm getting older my depression and health is getting increasingly worse.
28. At night I have very dark/negative thoughts and cannot sleep. The constant depression and thinking 'why me?' – 'what have I done to deserve this?'. I look at my brothers and sisters who have a family and I think 'why have I been deprived of that?'. On one hand I am happy for them but on the other hand I am jealous of everything they have. My life is empty – I have nothing. Everything is negative and there is nothing I can hold on to. I am like a person hanging from a cliff top. My life is gone and I am causing my wife to lose her life as she has to care for me. I have no social life which compounds my stress and depression.
29. From when I was three years old, I accepted that I had haemophilia and I would have to live with it the rest of my life. However, the fact that I have been infected through something that was meant to help me is tough to take. It is too overwhelming for me to deal with. My family and I came to the UK full of hope believing that I would be given good care and that the treatment here would give



me a better life, but instead it has destroyed it. I am now 52 years old. I lost all my adult life. The emptiness is overwhelming.

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

30. I wasn't offered any psychological help and support and it isn't something I felt comfortable going to ask for. Given my culture I have been unable to unburden myself to anyone and feel lonely and isolated.

31. I went without counselling for many years. I have recently (approximately three months ago) started seeing a counsellor after I had a frank and emotional conversation with a sympathetic nurse. That nurse said to me "you need help, counselling". My GP had previously referred me for counselling but the referral took so long and I never received any sessions.

32. I have experienced funding issues in accessing treatment. It is always about money with the NHS. We struggled for funding for the IUI sperm washing treatment and had to wait two to three years to start my HCV treatment due to its expense. Attitude of my haemophilia consultant Professor [GRO-D] was absolutely incredulous. In a GUM ie joint Haemophilia/HIV clinic at point blank he said "it's straight forward have sex on the 14th day of a women's menstrual cycle". I can't recall whether my wife [GRO-B] was with me at the time but I felt so degraded and demeaned at his words. Nurses and doctors were in the room at the time.

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

33. I was part of the USA Group Litigation in what I remember to be 1997/98. I was pressured into signing a waiver and accepting £21,000. I signed a waiver but I did not truly understand the implications and what was happening at that time.



34. I received a lump sum payment through the MacFarlane Trust. I have also applied to the MacFarlane Trust for a variety of grants for goods, such as a fridge and/or washing machine.

35. My dealings with the MacFarlane Trust have always made me feel like I am not worthy of help and made me feel like I am going to them with cap in hand. You have to provide them so much of your information and justify your need before they agree to give you anything. It feels like barriers are put up in front of you to make it as difficult as possible, would have to give them all of your information to receive anything and it felt like they were putting up barriers to make it difficult for people to access money.

36. I received the Skipton Trust Stage 1 payment of £20,000.

37. I receive monthly payments from EIBSS. My experience of EIBSS is not a good one (reincarnation of the Macfarlane, Skipton etc). It is extremely difficult to apply for anything through them. They are rude to you over the telephone and treat you like you are scrounging from them. Their whole purpose is to provide financial support to those who need it and they seem to forget that. And, why is it means tested? I didn't ask for this, they gave it to me. This is not I wanted in life. I had dreams and hopes, taken from me.

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

38. I want the truth to come out through the Inquiry. I want the doctors and nurses and others with first-hand knowledge to open up and tell us exactly what happened. I want them to admit to what I believe to be true, that they knowingly gave high risk products to patients. The medical profession have a duty to look after their patients, and they failed to do so. They broke the trust between doctor and patient.

## ANONYMOUS

39. There is a feeling of hurt inside me knowing that my life has been destroyed through no fault of my own. If they had told me that the products could be bad for me I would have refused to take them in the first place.

### Anonymity, disclosure and redaction

40. I wish to remain anonymous and would like my Statement redacted before being published on the Inquiry website. I would not be able to give oral evidence to the Inquiry

### Statement of Truth

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

Signed

GRO-B

Dated

28-05-2019

**MEDICAL SUMMARY**

**(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)**

This witness statement has been prepared without the benefit of access to my full medical records.

Hepatitis B surface Ab (elisa) positive (*Clinical Virology*) 06/10/1992

Hepatitis C Ab (elisa) positive (*Clinical Virology*) 02/12/1992

Hepatitis A IgG (elisa) positive (*Clinical Virology*) 02/12/1992

Cytomegalovirus IgG (elisa) positive (*Clinical Virology*) 02/12/1992

Hepatitis B surface Ab (elisa) positive (*Clinical Virology*) 03/08/1993