Witness Name: GRO-B
Statement No: WITN0284001
Exhibits: WITN0284002
Dated: NOVEMBER 2018

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 1973 and I live at GRO-B with my wife GRO-B and our sons, GRO-B aged 8 and GRO-B aged 6.

2. 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 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 Haemophila A. I was just 12 months old when I was diagnosed. I fell over and burst my lip open. It would not stop bleeding. I was treated at the Pendlebury Children's Hospital, Manchester under the care of Dr Evans.

4. I was treated with Cryoprecipitate and a variety of Factor VIII products (FVIII). Some (but possibly not all) of the products are listed on my National Database record. I refer to **Exhibit WITN0284002** being the data held by UKHCDO.

5. I am co-infected with Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV).

6. I believe that I was infected with HIV from FVIII treatment I received at Pendlebury Hospital. However I did receive a lot of FVIII at the Truro Haemophilia Centre one particular Summer in 1976, 1977 or 1978. My father was a teacher and we would take family holidays in Cornwall for four weeks at a time back then. According to the data at **Exhibit WITN0284002,** I first tested positive for HIV on 10th November 1979. I was 6 years old. My parents were not informed.

7. In 1984, my parents saw the World in Action programme about haemophiliacs contracting HIV from contaminated blood from prison inmates in the USA. My mother asked Dr Evans about it and he assured her that there was nothing to worry about. She remembers that he told her that "all our blood comes from the bible belt." Later that year my parents received a letter from Dr Evans advising that I was HIV positive. My mother went straight down to the hospital looking for Dr Evans only to be told that he had gone on holiday. Sister Shaw, the haemophilia nurse there, commented to my mother that Dr Evans "has been very naughty" (in misleading my mother and then notifying her of my positive HIV status before embarking on his holiday).

8. My mother caught up with Dr Evans on his return and asked him if I was going to die. He responded by saying "well, everyone has to die sometime." No information was provided to my parents about how to manage or understand the infection. Sister Shaw endeavoured to reassure my mother by saying that I would be fine if she (my mother) continued looking after me. She had a misguided belief that only homosexuals died from HIV/AIDs because they had "dirty habits and did not look after themselves".

9. I was ignorant of my diagnosis until the age of 16. My parents told me at that time because they thought I might become sexually active at around that age. I was in fact quite shy. I had seen reports about HIV/AIDs on the TV and in the papers and there were AIDS related jokes in the school playground. My parents sat me down in the kitchen at home and told me. I remember it being a very emotional conversation and a lot of tears were shed. There was no advice for them to impart to me from the hospital and nothing set up to help me. No-one knew anything much at that time. We were pretty much expected to suck it up and see what happened. I could see that the burden of the diagnosis had knocked my parents and my mother in particular for six. She really struggled.

10. I was told about the HCV diagnosis some time in the late 1990s by Dr Hay at the Manchester Royal Infirmary. I cannot remember when it was for sure and I am unable to recall the detail of what I was told or the circumstances because of the passage of time. I am now having counselling and my counsellor believes that I have conditioned myself to block out things that are difficult or upsetting as a coping mechanism. I do not recall what information was provided to me at that time. I know that I went home and told my parents.

Section 3. Other Infections

11. I am not infected with any other virus.

Section 4. Consent

12. My parents and I were unaware that I had been tested for HIV in 1979 and my parents were not aware of the positive result until 1984. I believe it to be likely that I was tested on other occasions for HIV and HCV without our knowledge and consent.

Section 5. Impact of the Infection

13. Being infected with HIV has been life-changing and has had an impact on every single aspect of my life. It has effected every decision I have ever made and every thought process big or small.

14. When I was first informed of my infection, my parents told me to keep it to myself. We decided as a family that we would not tell anyone, except for very close family. My parents dealt with everything and I was quite sheltered from it all. I have not told many people, just my closest friends and family. I was deeply affected by the television adverts. The stories in the news and media heightened the fear of others. The stigma of HIV made me more concerned about people finding out about my infection.

15. I did not bother starting any relationships with girls. It was an impossible situation for a 16 year old boy to manage. All of my friends were out doing normal things that you would expect of other 16 year old boys, but I closed myself away from everything physically and emotionally.

16. Every time I went with my parents to the hospital the doctors moved the goalposts. At first they said that I had 6 months to live and then the next time we attended they would say 'we will see what happens in another 6 months'. I never had any hope for the future.

17. GRO-B GRO-B My mind set changed overnight. I did not go to university. In my late teens I took it easy. I went to art school. I then worked for a couple of years as a photographer. I just wanted to enjoy myself before my life came to an end. All of my friends went off to university but there was no point in that for me. I went travelling instead. I had saved money whilst working for that purpose.

18. Ironically, I started my travels in the USA with a friend, GRO-B, who very many years later became my now wife. I remember being separated from GRO-B and pulled back by immigration for questioning in Miami whilst trying to catch a

connecting flight despite having declared that I had an 'infectious disease' when applying for my visa. It was a scary experience. I had to return home from travelling every 3 months to collect more medication. My bag was half full of big boxes of medication during my travels. The AZT medication had drastic side effects and made me very sick (not ideal whilst away travelling and trying to enjoy precious time).

19. The other side effects included nausea and weight loss. My face drastically changed shape from the medication, as the treatment caused the fat in my body to move around. I have had to have Newfill treatment on my face to fill my cheeks because I looked so drawn.

20. With regards to my HCV diagnosis, I have undertaken two courses of clearing treatment. The first was a 12 month course of ribavirin tablets and interferon injections into my stomach, in or around 2008. GRO-B and I were married the GRO-B. I would describe the treatment as one of the worst experiences of my life. It was dreadful. I suffered with terrible mood swings, of which GRO-B took the brunt. I spent my time shut away in my bedroom. I was afraid to talk to anyone because I knew I would explode at the smallest thing. I remember screaming with rage at a (very unfortunate) telephone cold caller. I also suffered with severe headaches, weight loss, sickness, night-sweats and my hair became like straw. After the ordeal, I was informed that the treatment had been unsuccessful. It was a big blow to me.

21 GRO-B and I wanted to start a family. We journeyed to and from the Chelsea and Westminster Hospital for (pioneering sperm washing) IUI treatment in 2008 and 2009 and GRO-B was conceived and born after ten attempts. The MacFarlane Trust paid for the first five attempts. We paid for the final five ourselves at a cost of £800-£900 each plus expenses.

22. The travelling to and from London for this treatment and the whole process was incredibly stressful, especially for GRO-B. GRO-B was conceived naturally and born two years later. We did not feel that we would be able to put ourselves through the stress of more IUI treatment. My HIV viral load was

by then barely detectable. Whilst the hospital would never recommend natural conception, it has been implied that all would be 'OK'. The decision to have another child (naturally) was not made without worry.

23. The anti-viral drugs I take are doing their job. Within the last six months my HIV viral load has been placed at zero in terms of risk of transmission.

24. GRO-B

25. GRO-B

26. I have just completed my second attempt at clearing HCV. I started the treatment in August 2018. It was a more manageable three month course of tablets. The side effects were less severe but I have experienced sickness and have been very tired. I have been tested negative for HCV throughout the treatment and I am now waiting for blood test results in January to hopefully confirm that the HCV is still in remission.

27. In the last 10 years, I have been under intense mental strain. Family life has been disrupted and adversely affected. My wife has been very understanding but I know that she worries about me.

28. At this point in my life I feel very lost. I have a lovely family but feel displaced as a person. I have no career or plan for the future. I never planned or expected to still be here. I feel like I am in limbo, aimlessly wandering around. I rarely get close to others and generally push them away. I believe it to be because I have always thought that I am not going to be here for much longer and when I die I will not be missed as much that way.

Section 6. Treatment/care/support

29. I attend counselling on a regular basis and find it very helpful. I was not offered counselling or referred for it. I have had to find my own counsellor for support. My parents were never offered any support or counselling. I believe they should have been.

Section 7. Financial Assistance

30. I received the £20,000 ex gratia payment from the Skipton Trust and am also in receipt of regular payments, which I have chosen to receive quarterly.

31. The MacFarlane Trust was helpful in providing information and financial assistance. It was not always a straightforward process in applying but it generally came through for us in the end. I was sad that the MacFarlane Trust disbanded. As stated, the MacFarlane Trust financed a large proportion of our IUI treatment. They also provided us with grants for home improvements.

32. EIBSS do not fill me with much confidence. The EIBSS staff are not as helpful or as personable as the people at the MacFarlane Trust. When you call it feels like you have made contact with a call centre. I have made enquiries about applying for a new mattress this year. I was told that I am likely to be refused on the basis that the damage to my current mattress caused by my night sweats is nothing more than 'general wear and tear'. I do not believe that to be right and the mattress is becoming what I consider to be unhygienic. I will

need to take the matter further and call the hospital for help and support with the application.

Anonymity, disclosure and redaction

33. I do not want to give oral evidence and I am seeking anonymity and would like my Statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed... GRO-B

Dated 21/12/18

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. I have my UKHCDO patient record and nothing more.