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Witness Name: **GRO-B**

Statement No.: WITN0021001

Exhibits: WITN0021002

Dated: 21st September 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT of **GRO-B**

In preparation for this statement I was asked by the investigators to prepare a 'time line'. I created this in the form of a series of notes. I made use of these to answer the questions put by the investigators. They have assisted me to recall dates and events.

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

1. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 and dated 28th August 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference
- 1.1. My personal details are known to the inquiry. **I do not wish for my identity to be revealed in any way during this procedure.** I do however want my full circumstances, issues and pain to be recorded for the purposes of this inquiry. This is my decision and I have had the various stages of anonymity and redaction explained to me. I am a married woman with two grown up children. I live at home with my husband, who suffers from Parkinson's disease and requires 24-hour care. I intend to speak about my infection with HIV. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my private, social and family life.

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2. On 23rd October 1984, I was admitted as an emergency patient to the Garden Hospital, Sunny Gardens Road, Hendon NW4 with an ectopic pregnancy about six weeks into my first trimester.
 - 2.1. I required two surgeries, including a salpingectomy. My left ovary was retained, but my left fallopian tube was excised. During this, I lost a considerable amount of blood, and required two units to be transfused into me.
 - 2.2. I recall waking from the surgery with a tube, bag, and blood connected to my left arm. I drifted in and out of consciousness. I required a second emergency surgery, as my internal bleeding had not subsided. It was during this that I received my second transfusion. These operations and transfusions all occurred within a 24-hour period.
 - 2.3. Garden Hospital is a private hospital for anybody, in the heart of GRO-B Hendon. Many doctors and patients are from the GRO-B community; people tend to use Garden Hospital as it is small and easy to get seen quickly, providing you have medical insurance (which I had).
 - 2.4. I have never received any other transfusions, nor have I ever taken intravenous drugs. I did have my ears pierced in the early 2000s, prior to my daughter's wedding, but do not have any tattoos, as they are forbidden in my religion. I had an arranged marriage, and have only had sexual intercourse with my husband.
3. I was not infected as a result of a relationship with any other person.
4. I was not given any information about the risks of transfusion though I was not in any fit state to receive this information, due to my lack of consciousness. I had no choice in the matter: it was either receive the transfusion, or die. Even so, no risks were mentioned upon my waking; I had lost a lot of blood when my fallopian tube burst, and this needed replacing.
5. I was infected with HIV. Testing for Hepatitis came back negative. I have not been told which "stage" of HIV I am considered to be, I have only ever been told what my CD4 (cluster of differentiation 4) count is.
6. I was told of my infection in either May or June 2005. I had been to my GP, complaining of mouth ulcers. Blood tests established that I had a raised ESR (erythrocyte sedimentation rate), which suggested some form of infection. I was then sent for further investigation at the 999 Medical Centre on Finchley Road, under the care of a rheumatologist.
 - 6.1. This Doctor did further tests, but struggled to establish what was wrong with me. A few days after dismissing me, he called me and asked me to go back into the Centre, as there was one test he had

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not administered. I was told that I would be tested for HIV, as I had previously discussed my medical history with him, and had mentioned receiving the transfusions in 1984.

- 6.2. Upon receiving the results, I was called into my Doctor's office, as he needed to discuss them with me in person. It was then that I was told of my infection.
- 6.3. The Doctor referred me to an HIV specialist, at the Royal Free Hospital, London. He also suggested that my husband be tested, as we did not know the source of my infection, and wanted to rule him in/out as a possible source. It took three days to receive the results of his test, which came back negative.
- 6.4. Subsequently I was told that my CD4 count was 32 (the normal range is 500-1500). This was so low that she advised me to avoid all stress.
- 6.5. The HIV Specialist provided me with brilliant information; she is the head of the HIV unit at the Royal Free and additionally, is a thoracic surgeon.
- 6.6. I don't see how the information could have been provided to me earlier, as I only learned of my infection in 2005.
- 6.7. I consider the way I was told about my infection to have been an appropriate method.
- 6.8. We were told that in future, my husband would have to wear a condom during intercourse, and also to be careful of any cuts and not to let any of my blood get on anyone else. I was and still am particularly careful with my grandchildren. This information was provided to me by the HIV specialist, though it wasn't anything I didn't already know.
7. As far as I am aware, I have never been treated or tested without my knowledge or consent, or without being given adequate or full information.
- 7.1. Doctors were always open about my course of treatments, including changes to my medication. I was told why this was happening, and never felt that I was receiving new drugs, or that they were being trialed on me. My progress was monitored, and nothing was ever mentioned about research.
8. Being infected with HIV has changed my life enormously.
- 8.1. As a result of my diagnosis, I now suffer from depression. I began treatment for this in 2015. For a long time, I didn't discuss my illness with anyone other than my Doctors and husband.

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- 8.2. When I initially went to see the HIV specialist, I took my husband with me. I was petrified and crying; I didn't know if I was dying, though it previously hadn't entered my mind that I may be seriously ill.
- 8.3. I feel much better mentally; I now have no more reason to die of HIV than any other illness, although I cannot tell how much damage being HIV+ for so many years without knowing I was infected has been done to me. I have had it for years, and am currently able to keep my viral load undetectable. However, that did not stop me getting lymphoma five years ago, and for all I know I may get cancer again due to my low immunity.
- 8.4. I am much more tired than I used to be, this was particularly bad during my first year of taking the medication, and was accompanied by dizziness and bad dreams.
- 8.5. The HIV caused me to develop lymphoma.
- 8.6. The lymphoma caused facial paralysis down the right hand side of my face. My face started to droop, and it was suspected to be Bells Palsy. However, this was actually a lymphoma in my facial nerve. This is a type of blood cancer, and my Doctor said that 'this was a direct consequence of HIV being left untreated for so long'.
- 8.7. The cancer was cut out of my face, during which my facial nerve was cut. I thought I looked disgusting. I was told that my facial paralysis couldn't be treated whilst receiving chemotherapy and radiotherapy, as the need to fight the cancer was more urgent. The facial paralysis affected me terribly.
- 8.8. I began chemotherapy in September 2012 and finished in February 2013. The treatment caused Deep Vein Thrombosis and blood clots. I also had radiotherapy in February 2013, for 3-4 weeks.
- 8.9. Upon completion of my cancer treatment, and being confirmed cancer-free, I began to look for plastic surgeons in England who could repair my paralysis. I consulted with five surgeons, and those who said that they could help, thought it was too late to treat – facial paralysis should be treated immediately. However, I was not prepared to look like that forever, and as such, looked at surgeons in America.
- 8.10. I found the Facial Reanimation Centre at the Mass. Eye and Ear Infirmary in Boston, Massachusetts. They needed to see me before determining whether they could help. I had my first consultation in June 2013, when they confirmed they could perform the required surgeries.
- 8.11. I had a weight inserted in my right eye so that I could close it and had my forehead lifted as the weight of it was pushing down my eye, preventing me from seeing properly.

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- 8.12. In total, I required five trips to Boston for consultations or surgeries. Following this initial surgery, I was put on a waiting list for a major surgery, called Free Gracilis Muscle Transfer surgery. I had this in December 2013 during an eight-hour operation. I was admitted for 3-4 days post-operation.
- 8.13. After the major surgery, I had subsequent surgery to lift my eye and stop it weeping, as my tears don't pool properly. The procedures concluded in 2014.
- 8.14. Initially, I saw my HIV specialist either every week or every month, until my CD4 count began to rise. Once it had, my visits reduced to once every three months, and then once every six months, which is how frequently I see her now.
- 8.15. At first, my HIV medication was 960 mg Septrin (from 2005-2006) until my CD4 levels began to rise. I also took 200mg/245mg Truvada and 600mg Efavirenz daily. I was later alternatively given Atripla, which is a combined dose of Truvada and Efavirenz. I took this until I began chemotherapy in 2012.
- 8.16. I have been on my current medication since starting my cancer treatment. It consists of 600 mg Raltegravir (two taken once a day) and 200mg/245mg Truvada (Emtricitabine/Tenofivir Disproxil) (one taken, once a day).
- 8.17. For the past 2-3 years, I have been taking 10mg Escitalopram (one taken, once a day), though this dose may have been lower initially. I think the Escitalopram helps, but I am scared to stop taking it. I was so depressed I didn't want to get out of bed. Following my husband's Parkinson's diagnosis, I have many responsibilities – he requires 24-hour care, which I provided myself until I was too run down to continue.
- 8.18. I have had no problems accessing treatments for HIV.
- 8.19. I didn't research what medication I should or could get, I trusted what my HIV Specialist suggested for me.
- 8.20. Going to the HIV clinic is awful. I feel like I am out of place and hate going [REDACTED] GRO-B [REDACTED]. I have to psych myself up mentally each time I go because I feel dirty. Maybe this is because, I believe, people think HIV is a dirty disease and it's your own fault for having contracted it.
- 8.21. The HIV medication caused me to have extreme tiredness, which left me unable to function. I also had very violent dreams, though these have since subsided.
- 8.22. If I have ever needed medical or dental treatment, I have always told doctors caring for me that I am HIV+, so that they take appropriate

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care. I am occasionally asked to fill in a form detailing any changes of medication. I always list my HIV medication.

9. I am very, very upset and angry about being infected with HIV. After I began treatment at the Royal Free (in 2006) I was sent to a therapist to get my anger out and talk through my condition. I only attended one session, though I was offered more, on a private-funding basis.
- 9.1. [GRO-B] When I was diagnosed, my daughter was already married, but my son was not. I therefore did not discuss my diagnosis with anyone other than my doctors and husband. I was concerned that my infection would hinder my son's prospects of finding a future wife. He did not marry until June 2012.
- 9.2. Following my husband's Parkinson's diagnosis, I felt my children ought to know about my HIV, in case something happened to one or both of us. I first told my son, who then went for an HIV test, which came back negative.
- 9.3. I only told my daughter in 2017. Though I had earlier raised concerns with my Gynaecologist, (who was aware of my HIV status,) regarding my daughter who had also had an ectopic pregnancy. We share the same Gynaecologist. He assured me not to worry. I suspected she was negative, as she was pregnant at the time and HIV is one of the tests administered to expecting mothers.
- 9.4. I haven't told my 94-year-old mother, or my sisters. The more people that know, the greater the risk of someone else finding out and I don't want it to affect my children's or grandchildren's lives, especially whilst the latter are still in school.
- 9.5. I have to take some of my medication at nighttime, [GRO-B] [GRO-B] I had to take it earlier than usual, [GRO-B] Because the medication makes me drowsy, I was unable to attend [GRO-B] People began to ask why I wasn't going, and I had to tell them I was not well enough to attend.
- 9.6. On each visit to America for treatment for my facial paralysis, I would have to fill in a landing card. I had to lie about being HIV+, as they would not let HIV+ people into the country. I would empty my medication out of its containers and put it in a clear plastic bag. I hate lying, but this was unavoidable.
- 9.7. I also had to lie about my HIV status when going to China and applying for a visa to visit.
10. My HIV specialist is also a thoracic surgeon. I was so scared of the stigma associated with HIV that I was too scared to go to the general HIV clinic. I therefore went to visit her at the Hospital of St. John and

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St Elizabeth under the pretense of a chest infection. She was unable to treat my HIV privately at St John and St Elizabeth because my medical insurance wouldn't cover the cost of the treatment. She therefore told me that I would have to attend the Royal Free Hospital.

- 10.1. I was really worried about people finding out. The HIV clinic only treats those with HIV, and thus everyone knows why you are there. The doctors call out patients by their full name; on two occasions, I have seen two [GRO-B] men there, and I was worried that they would know me or my family. I was upset about my name being called out in front of these [GRO-B] men.
- 10.2. HIV isn't like other illnesses. People always think, "What has she been up to?" I am a very open person, but cannot discuss this with my friends, due to [GRO-B] sometimes being very narrow minded.
11. I will now describe the other effects being infected with HIV has had on my life.
 - 11.1. I have never felt like being HIV+ has held me back from pursuing any further education.
 - 11.2. Although I was working at the time of my infection, I had already stopped work by the time of my diagnosis. This was unrelated to my health and/or infection.
 - 11.3. My facial re-animation surgery was very costly, and was not covered by my insurance, due to being conducted overseas. I have since compiled a spreadsheet detailing my costs related to my treatment. I used my air miles as frequently as possible, but would often have to book flights for me and my husband last minute, and upon being given a date for surgery.
 - 11.4. My husband suffers from claustrophobia. I would therefore upgrade our seats when possible.
 - 11.5. For my major surgery in December 2013, we had to stay in the hotel next to the hospital as there were several feet of snow, and I didn't want to risk missing my surgery by not being able to get to the hospital. It is a 5* hotel, and our stay cost several thousand pounds.
 - 11.6. I estimate the amount I spent on my treatments in America to be approximately £52,000. This is not including the loss of earnings suffered by my husband whilst he took time off work to accompany me. Prior to becoming unwell, he was a West End property lawyer.
 - 11.7. I receive my HIV medication and treatment from the National Health Service.
12. I don't believe I have received any infection other than HIV as a result of being given infected blood or blood products.

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13. My diagnosis affected our marriage. My husband was very worried about me, and it affected our sex life. Every time we had sex, I thought 'I was going to kill him'. It's a horrible thing, and wasn't my fault.
- 13.1. Upon learning of my infection, both of my children were scared for me and thought I was dying. My son was particularly worried until he was tested. He also has small children, and feared he may have caught the infection from me and thus placed them at risk. My children have now come to terms with my infection.
- 13.2. My husband has a full time carer who does not know about my condition.
14. I have detailed the dates and payments I have received from the Eileen Trust below:
 - 14.1. 15 January 2014 - monthly payment of £1,182.50, amounting to approximately £14,191 annually;
 - 14.2. 16 January 2014 – a lump sum of £80,500 based on my status as a married woman with children;
 - 14.3. For the financial year beginning 01 April 2015 and ending 31 March 2016 - £14,749;
 - 14.4. For the financial year beginning 01 April 2016 and ending 31 March 2017 - £14,749;
 - 14.5. For the financial year beginning 01 April 2017 and ending 31 March 2018 - £15,150;
 - 14.6. 3 winter fuel payments at £750 each.
 - 14.7. It was on 16 January 2014 that I received a letter from a woman with the Eileen Trust, stating that I was being paid £80,500. It also stated that I would be receiving MFET backdated regular monthly payments, beginning from the time I contacted the Eileen Trust, in July 2012.
 - 14.8. The MFET backdated payments were as follows:
 - 14.9. 13 July 2012 to 31 March 2013 - £9,966;
 - 14.10. For the financial year beginning 01 April 2013 until 31 December 2013 - £10,643.
 - 14.11. This is a point of grievance for me; I originally contacted the MacFarlane Trust in 2006 but would not give them my name. I am so

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worried about confidentiality, and someone finding out about my infection that I wasn't comfortable doing this. I was told my name would only be made available to certain people from the Trust, in addition to my physician who gave me the transfusion, but this was not enough to allay my concerns, I couldn't trust anybody. If I had given my name at this time, I would have received backdated payments to 2006.

- 14.12. Since the NHS Business Services Authority have taken over from the Eileen Trust, I am now in receipt of the following:
- 14.13. For the financial year beginning 01 April 2018 and ending on 31 March 2019 - £18,000;
- 14.14. 1 winter fuel payment of £505.
- 14.15. I was unaware of the compensation plans available for those who had been infected with HIV as a result of receiving contaminated blood. I was only made aware of them after consulting with my psychotherapist. She put me in touch with a woman from the Eileen Trust, who then interviewed me and my husband at his office. She took details of when I had received my transfusions, from which hospital I received them and my medical history. She then told me she would need to get authorisation for payments to be made to me and that this would come from the lead consultant in transfusion microbiology at the National Blood Service.
- 14.16. Following consultation between the two women, I received payment. It was then that I was told of the issues with backdated payments.
- 14.17. In addition to the backdated payments issue I have raised at paragraph 14.1.10, I received a letter, dated 21 November 2017 and referred to as **(WITN0021002)** from Susan Daniels during the cessation process of the Eileen Trust. This is a typed letter regarding the new function of NHSBSA and that the Eileen Trust would no longer be making payments. However, if I required assistance with any home or health related payments, I could contact them for some of the remaining funds.
- 14.18. This letter had an additional handwritten note from Susan Daniels, which stated, "This probably doesn't apply to you but if you need anything let me know". Although I could understand this remark, to an extent, I was a bit offended.
- 14.19. I should also note that I was refused support for my treatment in America, and that I was offered help with needs I may have in my home, as a compromise.
- 14.20. There were no preconditions imposed on me prior to making an application for financial assistance for HIV.

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- 14.21. I understand why I was refused assistance with my treatment in America, because I am more financially sound than some other people. I can understand this logic to an extent, but we have all been infected by the same tainted blood and so I don't think I should have been discriminated against on such grounds.
- 14.22. Applications shouldn't be means-tested; instead, an objective test is more appropriate. The amount of compensation I received should not be affected by my husband's professional successes.
15. Other than that detailed above, I had no difficulties in obtaining treatment, care and support as a consequence of being infected with HIV.
16. Although I saw a psychotherapist on one occasion for my anger, I did not consider it necessary to pursue this. No counseling was offered to me or recommended by the NHS. I was not offered counseling in relation to my HIV.
17. I have read about people bringing claims in the Republic of Ireland and receiving compensation as a result. However, I avoided this, as I didn't want my name exposed to the public.
- 17.1. I have not been involved in any other inquiries or investigations.
- 17.2. I had read that prior to my infection in October 1984, the Government knew of the risks of transmission already, in July 1984, three months before my blood transfusions. Despite this, they didn't tell people, which I consider to be irresponsible. If they hadn't known, that is one thing, but they did, and did nothing regardless. Transfusions should have been stopped at least three months prior to me receiving mine.
- 17.3. I would like to add to my statement, that I would like some form of anonymity. I obviously am happy to give this statement to the Inquiry, and indeed I may be happy to read it out. This is on the proviso that measures are taken to prevent my identity being revealed at this time.

Statement of Truth

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

Signed

GRO-B

Dated

21/9/18

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