Witness Name: GRO-B
GRO-B
Statement No: WITN5133001
Exhibits: WITN513302
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I, provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 January 2021

I, will say as follows: -

Section 1. Introduction

1. My name is GRO-B and I was born in a village in Sudan. I know I was born between the years of 1964 and 1966, however I am not sure of the exact date. This is very common when you are born in a small village; in fact, we usually associate our date of birth with the season or a special event such as Eid, wedding or funeral.

2. I have two sisters and four brothers who all reside in Sudan and one other sister who resides in Liverpool. My brothers and I suffer with haemophilia A, however I was only diagnosed at the age of 17/18 years old.

3. I live with my wife and four young children, residing in GRO-B London. The full details of my address are known to the Inquiry.

4. I intend to speak about my infection with HIV and hepatitis C, which I contracted from Factor VIII blood products in 1986. In particular, the nature of these illnesses, how they have affected me, the treatment received, and the impact this had on my family and our lives together.

5. I can confirm I am not legally represented and I am happy for the Inquiry Team to assist with my statement.

Section 2. How Infected

6. As a child nobody knew I had haemophilia, despite being known as the *boy that bleeds.* When I was circumcised, I bled profusely and had to stay in hospital for a month. In Sudanese schools' corporal punishment is commonly used, which meant I often suffered severe swelling. I was regularly admitted to hospital, where they would drain the swelling in my joints and contact my relatives to donate blood. I am of O negative blood type which is the same as two of my uncles, GRO-B and GRO-B These were the only two relatives I received blood from and neither had any diseases.

7. It was not until I turned 17/18 years old, that a Doctor noticed I was constantly in and out of hospital to treat bleeds. He decided to test me for haemophilia which came back positive for haemophilia A. My brothers were also tested and they all came back positive. I did some research within my family and found out my mother's brother also had haemophilia, which gave me some clarification on how I became a carrier.

8. The Sudanese Doctor told me that haemophilia is a rare disease, which came from the royals. I vividly remember him calling it: 'the Kings disease', despite there being no knowledge of royal blood in my family. He explained that haemophilia is not curable, nor treatable in Sudan, and suggested I sought treatment in the UK.

9. My family and I were very poor, so we could not afford plane tickets, accommodation, and the treatment, which I would be able to receive in the UK. I was very lucky, because the Saudi government agreed to fund my treatment. As such, three doctors put together a comprehensive medical report which confirmed the specifics of my case, giving me the green light to obtain treatment In the UK.

10. On 13 October 1986 at around age 20/21, I came to England to receive treatment for my haemophilia. Upon arrival at Heathrow at approximately 11am on 14 October, I went to a hotel near GRO-C London, and met an Arabic hotel owner. My leg and knee suffered quite badly during the journey leaving me with severe swelling, so I was sent in an ambulance to the closest hospital. I was initially taken to St Stephen's accident and emergency hospital.

11. At St Stephen's I was treated with 4,000 units of Factor VIII, batch number NHH8Y3414, under the care of Dr Costello. After a few days, on 19 October 1986, I was transferred to St George's Hospital, where I received five bottles of 8Y and another nine bottles of profilate heat treated factor VIII.

12. I have a letter dated 25 November 2007 from Pratima Choudray, Consultant Haematologist at The Royal Free Hospital to the Skipton fund which confirms I was given factor V111 on 19 October 1986 at St Stephens Hospital. However Dr Chowdary is incorrect in her assertion that I had previously received factor V111 and cryoprecipitate in Sudan and Saudi Arabia. The first time I received factor V111 was in October 1986 in this country. I produce the letter as exhibit WITN513302.

13. Two weeks later, I was transferred to the Royal Free Hospital and placed under the care of Dr Peter Kernoff. Whilst at the Royal Free, and since being shown documents from the Inquiry, I know I received alpha heat-treated factor VIII. I cannot recall being asked for consent to the treatment, nor told exactly what they were giving me. In fact, they just told me it was Factor VIII

and injected me. I was not warned of any risks associated with Factor VIII products and I'm not sure if they ever treated me with cryoprecipitate.

14. After 15 days in hospital, I began to improve and I was referred to physiotherapy and hydrotherapy. They also took me to a specialist nurse who taught me how to mix the vials of Factor VIII, and how to inject myself. As I had to come to hospital every other day, I moved to a bed and breakfast in GRO-B which cost about £15 per day.

15. I returned to hospital frequently for about four months, so I eventually moved to a more permanent accommodation in GRO-B I rented a room for £60 a week from a Sudanese man, which was arranged by the Saudi government who paid for my living expenses. GRO-B GRO-B because I had regular visits from a representative at the embassy.

16. Fortunately, Dr Kernoff saw improvements in my health, but he advised that I would need a sponsor from a wealthy country to fund the treatment for life. As such, the Saudi government terminated my treatment and booked my tickets to return to Sudan. I was very grateful to be sent home with additional Factor VIII products, so I could treat myself at home.

17. In April 1987 I travelled via Saudi Arabia back to Sudan, deciding to stay in GRO-B to work. On one occasion I went to GRO-B hospital, because my leg was swollen and bruised. I saw a haematologist who asked for my medical and treatment history, to which I explained I had just arrived from London following treatment for haemophilia. I showed him the medical report that Dr Kernoff provided and he instantly asked me if I had tested for HIV.

18. I was confused and responded, '*no, what is it, why would I*'. He asked for my permission to test and take a full blood count, to which I agreed. After a few days, I received a call from the Doctor requesting I attended the hospital for an appointment.

19. At my appointment I found out I was HIV positive. I didn't understand what it meant to be infected with HIV, so I asked for more information, and the Doctor informed me that some Factor products from America contained the virus. I was also told that I would likely die in three to four years and there was no treatment for HIV. I broke down crying knowing that there was no future for me. I was a young man, knowing that my future was capped, and I worried about how I would tell a partner, whether I could have kids, and above all, how long I had left on this planet. I was extremely emotional, because I knew there was no chance for me; I had nothing meaningful in my life.

20. I stayed in GRO-B for a few days, where I was treated with more Factor VIII, and then returned to GRO-B to see my family. Upon return, I informed the haematologist in Sudan of my HIV, and he suggested my brothers should also get tested. Fortunately, they were all negative for HIV and are healthy, with children of their own.

21. I stayed in Sudan for a short time and became aware I was also infected with hepatitis C. I cannot recall when exactly I found out. I decided I would return to the UK to escape the dangerous war zone in Sudan, and to give myself a chance at a better life. I was successful in obtaining a four-year leave of entry visa, with refugee asylum status and I returned to the UK in 2002. Before travelling to the UK for a second time, I married a HIV positive haemophiliac, but she was unsuccessful in her VISA application. Sadly, not long after, she passed away.

22. When I arrived in the UK, I was admitted to Lewisham Hospital, as I suffered with a number of bleeds. The hospital ran a series of tests and they discovered I was infected with hepatitis C. This was the second time I had heard of hepatitis, as it was something that was mentioned in Sudan, but it was merely referred to as hepatitis, and I was told I may have been infected with it along with HIV, but at that time I only knew of hepatitis A and B.

Section 3. Other Infections

23. To my knowledge I was never infected with any other viruses, or diseases, from Factor VIII products I received throughout my treatment in the UK only HIV and HCV. Although I was told at one stage that I had the hepatitis B antibody.

Section 4. Consent

24. As mentioned earlier, I cannot recall being asked for consent to treatment whilst at St Stephens hospital, St Georges hospital, or at the Royal Free hospital. At the time, my English was very poor and I wasn't entirely sure what they were giving me.

Section 5. Impact

25. When I found out about my HIV status, I worried that I would never find love and never marry. I questioned whether I would have a future and regularly prayed to God. I was realistic about my life; I knew that I would never be normal, and would have to live with HIV for the rest of my life.

26. I endured the hepatitis C treatment, which was a nightmare. The side effects were so severe: I felt dizzy all the time, had extreme fatigue, struggled to concentrate, and I had a skin rash. It was also very difficult to walk, so I used a walking stick.

27. During my treatment in 2002 I also experienced severe depression, to the extent that I felt like a mad man, and my friends told me '*I was different*'. I'm not sure if I was paranoid, or it was the stigma associated with hepatitis C, but I felt people were talking about me behind my back and avoiding me. I noticed differences in the behaviour of others, which impacted me significantly.

28. As a result of numerous bleeds over the years, my knee joints were extremely worn and damaged, which meant my mobility was heavily restricted. Eventually, in 2005 I needed two knee replacement operations.

29. I have a lot of complications with my health, as I suffer with type 2 diabetes and high blood pressure. In addition to problems with my kidneys which I believe has been aggravated by long term medication.

30. After my second diagnosis with hepatitis C, I was very upset, because I had been infected, again and I was promised that I would receive a better treatment, which was never fulfilled by Dr MacDonald. The treatment they provided wasn't awful, but I guess my body was used to filtering a variety of drugs. I attempted to take this Doctor court, as I had been given a kidney with hepatitis C, but a Solicitor told me my claim was out of time due to the expired limitation period.

31. Since my kidney transplant, I have to take anti-rejection drugs, and will have to for the rest of my life. This medication makes my diabetes much worse.

32. Since I was a young man, I've had a long and painful story to tell. I feel as if my health problems all stem from the Factor VIII treatment in 1986, which infected me with HIV and hepatitis C. I've also suffered with kidney problems and was given hepatitis C a second time through a kidney donor. My body is not hygienic and all my conditions, and medications have changed my body.

33. Being infected with hepatitis C has changed my character and I am not the same person I used to be; I struggle to sleep, I am more prone to aggressive behaviour, and I have become weak, suffering from general fatigue.

34. My conditions have prevented me from working, which means I rely on government benefits to support myself and my family. I am in receipt of the enhanced rate for Personal Independence Payment and Employment Support Allowance. I have been stripped of the opportunity to finish my studies, start a career, and play an important role in society.

35. I want to be a normal person and make my family proud. It is difficult for me, because my children know I do not work, and this does not mirror the role model I wish them to aspire to. My life has been destroyed; I could have become another person, completed my education, and been able to do something useful for myself, my family, and my community.

36. There is also a lot of stigma associated with HIV in my culture. In my religion, HIV is often associated with promiscuity, and I feel as if I have to explain and justify how I became infected. I've also experienced questioning from doctors on how I came to be infected with HIV, which on one occasion made me change my GP. He was completely unsympathetic and I didn't like it.

37. It was also challenging to disclose my hepatitis C infection to my Dentist and once I did, I found my appointments would be delayed and when I attended appointments, the Dentists' would wear excessive personal protective equipment, and also open windows.

38. Throughout my treatment for haemophilia and other conditions, it's always apparent that my date of birth is cause for suspicion. Doctors' and other professionals jump to conclusions and assume I am hiding something, or lying.

39. I eventually remarried in 2010 and now have four young children. My wife also has HIV, so she couldn't breast feed our children, and fortunately they are all fine. Before I met my wife, I worried about how I would tell someone about my HIV, but since she was already infected, she understood my situation.

Section 6. Treatment/Care/Support

40. Following my hepatitis C diagnosis in 2002, I was transferred to new refugee accommodation in GRO-B I continued to have bleeds and was seen in GRO-B but the Doctor referred my case to a specialist hepatitis C Doctor in Nottingham.

41. The specialist hepatitis C team in Nottingham put me on treatment for six months, whereby I had injections in my stomach every week and took tablets every day. I saw a specialist nurse who showed me how to inject myself, and after approximately six to eight months I cleared the virus. I was on a lot of medication to treat hepatitis C, but this was explained to me by the specialist nurse.

42. Throughout my treatment, I was regularly contacted by the Doctor and they informed me that my CD4 count was ok. I also went to a HIV clinic every three months to be monitored and to obtain medication.

43. As I mentioned previously, I've suffered with kidney problems for most of my life and in 2009/2010, whilst I was under the treatment of the Royal Free Team, a Doctor informed me that I would require a kidney transplant. I spent a lot of time in hospital for associated problems and in October 2014, I was put on the waiting list for a kidney. I was warned that in the event of my other kidney failing, I should be ready to start dialysis. The Doctor also explained the complications that could arise, including the possibility of relying on relative donors. A brother of mine offered to donate a kidney, however his blood type was not a match.

44. On 21st May 2016, I was called first thing in the morning by the Royal Free Hospital and told there was a kidney available. I immediately made my way to the hospital and waited until seven PM to be seen. The Doctor informed me that the kidney was good, but it had hepatitis C, and expressed it was unlikely It would be transmitted to my body. I remember him saying, '*I don't think you'll get it, but if you do, it's curable*'. I agreed to take the kidney and was in the theatre, until I woke up on Sunday morning connected to lots of machines. Following my surgery, I suffered with a severe bleed and as my haemoglobin was low, the Surgeon took me back to the theatre to reopen the wound, control the bleed, and repair the wound. I remained in hospital for a considerable amount of time due to bleeds and infections.

45. In June/July 2016, I was contacted by the hospital and told I had tested positive for hepatitis C. They referred me to Dr Douglas MacDonald, Gastroenterologist & Hepatologist at the Royal Free. My blood tests showed liver inflammation; however, it was only acute. Dr Macdonald promised I would receive good medication, and the HCV would clear in six to eight weeks. Despite his promise, I waited until the end of December to receive the 'good treatment', because I was categorised within the acute rather than severe group and therefore, the panel decided I would be prescribed another treatment until I was prioritised.

46. Throughout my treatment at the Royal Free, I saw Dr Sanjay Bhagani in the HIV clinic. He kept an eye on me, following up with regular consultations, and visited me whilst I was in hospital for my kidney transplant.

Section 7. Financial Assistance

47. I became aware of the Skipton Fund whilst undergoing my treatment for hepatitis C in Nottingham. The team of doctors and nurses that looked after me suggested I should apply.

48. Following their advice, I decided to register on 21 July 2006 and was successful in my application. Despite this, I never received the £20,000 payment, even after chasing the payment with Nicholas Fish. I have checked my bank statements for the period between 21 May 2006 and 21 December 2006, and I can confirm I did not receive any payments from the Skipton fund. I chased Nicholas Fish through numerous emails and phone calls, but I heard nothing.

49. I applied for a second time in September 2007, which was rejected in January 2008, on the basis that the source of infection was from treatment with blood and blood products I received abroad prior to October 1986. I found this completely unfair, because I only received blood products in Sudan from my two healthy uncles, and not on any other occasion prior to

coming to the UK in 1986. I was unaware of an appeal process and by this point, I had enough of the application process.

50. I also got in touch with The MacFarland Trust, but they didn't seem to get back in contact after that. Deborah, my specialist nurse, asked whether I had registered with the Trust, and this frustrated me, as I was worried about not hearing from them and had no help, or energy to keep pursuing the financial assistance.

51. I sought help from the Haemophilia Society and a very nice lady helped me with my applications. She was able to source the vile numbers of the Factor products I received and I was sent to Birmingham Haemophilia Centre to find my records. When I arrived, it was clear that my multiple names and uncertain date of birth caused suspicion, which meant I had to send my British passport for proof of identity. I had no luck in the search for my records.

Section 8. Other Issues

52. I hope this Inquiry helps to find out what happened to me and all the others affected by contaminated blood products.

53. It is difficult to justify what happened to me. There is such a taboo around HIV and I can't escape my situation. My understanding of English is quite poor, so it is hard for me to express myself, and all I wish is for people to understand how this has affected me.

Statement of Truth

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

Signed GRO-B

Dated 26/02/2021