Witness Name: GRO-B
Statement No: WITN1655001
Exhibits: 0
Dated: March 2020

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 the GRO-B. I am married and live with my wife and our daughter who is GRO-B years old. I currently work as a GRO-B.

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 suffer from severe Haemophilia A. I was diagnosed when I was around 2 or 3 years old. I am the eldest of my siblings. It turns out that there is a history of Haemophilia in my family but my mother didn't know this at the time of my birth. I have a middle brother GRO-B who doesn't have haemophilia but my younger brother GRO-B: B was a Haemophiliac and he succumbed to HIV after being infected as a result of infected blood products.

4. I was initially treated with Factor VIII (FVIII) products at the Sheffield Royal Infirmary (SRI). I have also been treated at Lincoln Hospital (LH). However, while being treated at LH we were still getting blood products from SRI. I believe that LH only ever used BPL blood products. I remember at LH that there were only 3 HIV patients including my younger brother. I believe that I am the only one that survived. SRI was the main treating hospital where I believe I received the contaminated blood products.

5. Prior to receiving FVIII blood products I was treated with cryoprecipitate. I believe that I was one of the first haemophiliacs to receive home treatment from the SRI in or about the late 1970s. I was given several different blood products over time. I think I remember I was on Hemofil plus another make. At the time when my brother and I were diagnosed with HIV I remember we were taking Armour.

6. When I started home treatment, it changed my life. I only required treatment as and when I had a bleed. Prior to starting home FVIII treatment I lived in GRO-B and when I had a bleed I went to the SRI to be treated. This would happen roughly every 10 days. I was treated with cryoprecipitate or whatever it was at the time and then come home. Once home treatment became available we went from being severely disabled to being pretty normal apart from the damage caused by the bleeding. We went from not being able to run the farm to being able to take on a lot more farm work.

7. I believe I was infected in the late 1970s. I would have been one of the early ones. I believe my brother and I were still receiving infected blood products way after I was infected. Even when we tested positive for HIV we weren't given heat treated blood products.

8. I didn't receive any advice or information beforehand about the risk of infection with FVIII. I don't believe most doctors knew about the contaminated blood products themselves except the doctors in the upper echelons. They could see it was a risky business to say the least but the majority of us had no idea as to how it was made.

9. As a result of receiving contaminated blood products, I was infected with HIV and Hepatitis C (Hep C).

10. In or about 1985 (mid 1980s) it was all over the news and it was coming out that the gay community were dying of this mysterious disease. It was then stated in the news that haemophiliacs were also dying from this disease. My brother and I went to the hospital (we always use to attend our appointments together) to speak to the doctor at LH and he told me that "I had as much of a chance of having HIV as I would with a lump of ice falling on me from an aircraft". We both had a blood test. It was when I saw the doctor the second time that he said that he was sorry to say that "a lump of ice has fallen on both of you". I think he was trying to lighten the mood.

11. In or about the late 1980s, I believe I was told that my liver function wasn't correct. I had various liver tests and biopsies and they had kept an eye on my results. I believe Professor Preston at Sheffield Royal Hallamshire (SRHH) called me in and said 'whatever is affecting your liver it will probably kill you'. It wasn't called Hep C at the time, it was called Non A, Non B Hepatitis (NANB), but I was never told that it was hepatitis causing problems to my liver. I was put on a trial course of Interferon treatment by the Professor. I do recall saying 'what is the point in doing something about it as I have HIV' and he said he didn't know if HIV would kill me but the issue that I was having with my liver certainly would if nothing was done about it.

12. I do not believe I was given adequate information at the time about the infections. I recall the only thing they told me was to wear a condom with my wife and to be careful of spilt blood. I was also told not to tell anybody about the infection.

13. I do not know if information should have been provided to me earlier as I believe that they did not know anything themselves. At the time I believe there was no treatment available for HIV.

14. When I was initially told that I was HIV positive, it didn't really sink in. I think it's like going off to war. You think it won't happen to you so you have it at the back of your mind and you just carry on with life.

15. As stated above, the only information that I was given about the risks of others being infected was to use condoms and to be careful with spilt blood.

Section 3. Other Infections

16. I received a letter which stated that I was at risk of vCJD. I cannot remember when I received the letter. I believe that the reason they told me and other haemophiliacs was because a haemophiliac had contracted vCJD from FVIII blood products and died from it.

17. I recall a doctor who specialised in HIV said that, as a result of the FVIII treatment, I could have picked up all sorts of things over the years and not be told about it.

Section 4. Consent

18. I have seen my brother's medical records and found that they had a blood sample in a fridge which was taken in 1982 and it was tested for HIV in 1985. Therefore he must have been infected very early on. As stated above, we were only told that we had tested positive for HIV in 1985.

19. I do not know if I was treated or tested without being given adequate of full information. In those days we had regular blood tests, which we always assumed were in relation to haemophilia.

20. I do not think I was treated or tested for the purposes of research.

Section 5. Impact of the Infection

21. When I found out that I was infected with HIV it was difficult. It turns your life around. I was basically told that I had a death sentence because, at that time, there was no treatment for the infection. It was always at the back of my mind as to whether or not I was going to survive. It does weigh on you, but I

couldn't let it get to me too much. I just tried to live as normal life as possible and just tried to carry on. After seeing my brother die it freaked me out for a while. I do not know what it is like to be a normal person anymore. The infection affected me more mentally then it did physically.

22. My cardiovascular system is weakened and I believe the doctors told me that its because of the HIV. I have had a blood vessel go into my eye and my blood pressure has been slightly higher than normal. The doctors like it lower than what you can usually get away with because of the HIV. I do not know if the above systems were as a result of the infections.

23. I wasn't treated for HIV until 2004 as I didn't require it until then. The doctor told me that I was able to fight the infection for 20 years but I had to start treatment as it was getting the better of me. The initially treatment nearly killed me. I was on deaths door as I was allergic to the treatment. My CD4 count had started to drop.

24. With the treatment that I am currently on I have to have regular tests on my liver and kidney functions. I believe one of the tablets that I am having can damage the kidneys. However, the doctors won't give me alternative treatment until they start seeing damage to the kidneys and I believe it because the alterative treatment is too expensive.

25. In relation to my brother B he suffered a brain haemorrhage in or around GRO- as a result of the HIV. He survived but it was very traumatic. I was working with him on the GRO-B at the time when it happened. It looked like someone had shot him, bitten through his tongue and sprayed blood everywhere. He wasn't breathing at the time and an ambulance was called. He made a recovery from the brain haemorrhage and lived for about 8 years after that. However, he was never quite the same.

26. As stated above I had Interferon treatment for Hep C. The treatment worked and cleared the infection.

27. When we were told that we had been infected with HIV, at the time there was nothing you could do. We were just told that we were positive and would

hope that nothing would happen to us. It wasn't long after we were told about the infection that my little brother started showing symptoms. I believe my brother was given AZT for the HIV and when he started taking it he had horrible side-effects from it. Obviously I wasn't privy to everything he knew and I think he was trying to protect me from it.

28. When I tested positive for HIV, I was married. Fortunately my then wife wasn't infected as a result. We did end up having a divorce as she wanted children and we couldn't at the time because of my diagnosis.

29. As stated above, the doctors will not change my treatment because I am not showing any signs of kidney damage. It seems illogical to wait until I have kidney damage before changing my treatment. I do believe there are treatments that ought to be made available and we should have the very best treatment available regardless of the cost. I have found that if something works the doctors seem to leave it as long as it is not doing major harm; whether this is good practice or not I don't know.

30. I believe that I attended LH and there was only one doctor there dealing with treatment for HIV. I think he was overworked. He gave me Trizivir and I was fine at first however, as time went on, I started getting horrible side-effects. My wife called the doctor at LH and she was told that I had 'norovirus' and I would be fine. She then called SRHH and explained the symptoms to the doctor who told my wife that I should stop taking the drug until he has spoken to someone. The doctor rang back within 5 minutes and said that an ambulance was on its way. I had an allergic reaction to Abacauir a component of Trizivir.

31. I felt very ill and lethargic and couldn't move. I remember feeling sick all the time and I had been physically sick many times with the vomit burning my mouth. I got shivers and would be shaking, which got worse and worse and I couldn't move. When I went to the hospital and they flushed it out of me I was back to normal, it was like someone had flicked a switch. I still get symptoms from my present medication, it's like waking up with a hangover.

32. In relation to the treatment for Hep C I had flu like symptoms for a day or two. I believe I was on the course for around a month, maybe longer.

33. I remember I had to have a colonoscopy and the doctors didn't want to do it. I was refused twice due to higher risk of vCJD contaminating the equipment. When I did have the procedure they had equipment specifically for me because I am at risk of vCJD.

34. There was another time when I was due to have knee replacements. Initially I was told that they didn't have money for the equipment. I did eventually have the knee operations. I recall the surgeons wearing big space suits and I believe this was because the surgeons had a fear of contracting HIV. I also believe that the hospital administrators thought that most things that I required was a waste of money because they didn't think I would survive. I believe the knee replacements cost the NHS over £50k in FVIII products. I saw on my notes that the surgeon wrote a few years later and said that it had been well worth doing. I have had the replacements for 30 years now.

35. Once you had HIV the hospitals wouldn't let you on the ward when you went in for treatment like having a liver biopsy. I remember having a toilet earmarked for me only. I didn't like being in a hospital room on my own. I remember a chap doing a blood test and said 'oh you're the one we have got to be careful of I suppose it wasn't nice but you had to learn to shut it out at the time. In the 1980s it was something you didn't mention, not even to your dentist. I don't think that the GP even knew that I was infected with HIV. It was all dealt with by the doctors at the hospital.

36. As stated above, I was married when I found out that I was HIV positive. My wife at the time had to be tested and she tested negative. The HIV infection contributed to our divorce. My ex-wife wanted children and I believe that the HIV played a part. My current wife had to make a decision as to whether or not she wanted to be with me. She knew of my condition before moving in, which was a big decision for her. As at that time she to could be infected by me and there was no treatment at the time.

37. I told my friends that I work with about the infection and they never made anything of it. They all knew what was wrong with me. The only time I had anything bad happen on the social side was when my friends and I went to the GRO-B and we went to a party somewhere. I was dancing with a girl and she asked why I had a limp and I said because I had haemophilia. She screamed and jumped back and said "they are the ones who have AIDs".

38. It affected my mother dramatically. She always blamed herself for us having haemophilia. My brother GRO-B ever got over B dying. In GRO-B my wife and I were told by the doctors that we could have children and it would probably be safe. When my wife fell pregnant we had to keep it quiet initially as her family would have been angry as they knew I was infected. It was a nervous wait while my wife had a blood test for HIV and once we got the all clear we knew our unborn daughter would be clear too. We have only recently told my daughter about my infection.

39. GRO-B . GRO-D GRO-D My mother never got over what had happened to us. The most tragic thing for her was my brother dying. He died an awful death and I thought to myself that I would go the same way.

40. Having the infection did have an effect as I though I would probably not survive. After seeing my brother die, it really freaked me out for a while. It affected the whole family and my mother was never the same.

41. The infection had a financial effect on me. When my brother had the haemorrhage he was never the same and was unable to work on the GRO-B because he was banned from driving for a year and GRO-B involves a lot of driving big vehicles. We therefore had to go into partnership with two brothers from a differen GRO-B because we couldn't do it on our own. We couldn't make the money that we used too as we had to share the profits out. The two brothers gradually took over when my brother passed away. I had studied bookkeeping at college and wasn't a GRO-B by choice and realised the partnership was not economically viable. I work with neighbours now and my

salary is £800 a month. I couldn't survive without the payments that I receive from the EIBSS. It has had a huge financial impact on me and my family. I have a daughter to support and my wife works part-time.

Section 6. Treatment/care/support

42. It's like anything within the NHS you have to kick up a fuss to get what you need. SRHH are treating me quite well. If there was a new treatment I would have to play LH against SRHH. There was a factor I wanted and I needed 1500 units 3 times a week. LH said I had to use two different doses (1000 units and 500 units). I asked if there was a one dose option and I was told that there was but they didn't provide it as it was to expenses. I was told by the doctors at SRHH that they could provide me with one dose of 1500 units (the more expensive option). I went back to LH about this and they confirmed that they will provide me with the one dose of 1500 units. I guess it was because they didn't want to lose the funding for me, if I had moved to the SRHH.

43. I was not offered any counselling or psychological support in consequence of being infected. I don't think it would have really helped had it been offered.

Section 7. Financial Assistance

44. I believe I was offered a take it or leave it payment in or about the late 1980s/early 1990s. At the time I was with my current wife although we were not married I received approximately £25,000 and my brother received £20,000. I also received a Stage 1 payment for the Hep C. I also received B s Stage 1 payment for Hep C after his death which I shared with my brother and my mother. I can't remember when I received the payments for the Hep C or the amount. I believe it could have been the same time as everybody else.

45. I also received a monthly payment in the sum of £3,366 and I believe it will go up to £3725 in April 2020 from the EIBSS.

46. I was also part of the US litigation and I believe I received a sum of $27,000 (out of Court settlement) at the time.

47. The process of applying for the funds were straight forward. I believe I had to fill in my part and then the doctors at LH filled out their part. The form for the Macfarlane Trust became more and more draconian, the discretionary payments became ridiculous. It started off with how much can we help you to how much can we avoid paying you. For instance I moved house in or about 2008 just across the road and I did receive help from them without to much trouble. In the later years I had to fill out huge forms explaining how much I earned, my daughter and my wife earned etc. They took my daughter's wage into account even though I didn't see any of it she is only 20. You would have to go through the process every year by sending them my payslips to include my wife and daughter (this has now ended as the EIBSS stopped discretionary payments in 2019), it was tedious.

48. I believed we couldn't take the NHS to Court because we signed a waiver. We were told that we have to sign it or otherwise we wouldn't get anything. Even then I believe they were trying to cover this whole scandal.

49. The amount that I receive is ok and I can live with it, but it would be nice to have a lump sum on top of the regular payments so that if I pass away at least I would know that my family would be okay financially.

Section 8. Other Issues

50. I believe its time for the government to look after us now. We have been kicked in the teeth for the last 30-40 years and it's ridiculous. They have never been interested. I believe the Government don't want to pay us extra money. They are always dragging their heels.

51. I applied for my medical records when I was involved in the US litigation and most of my medical records concerning FVIII treatment for the period in question had been taken out of the system. The doctors at LH were surprised that this had happened. I did have a brief look at my medical records before I sent them to the USA.

Anonymity, disclosure and redaction

52. I do wish to remain anonymous.

53. I do not wish to give oral evidence at the Inquiry.

Statement of Truth

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

Signed.. GRO-B ....

Dated 11/3/20