ANONYMOUS

Witness Name: GRO-B
Statement No:WITN1317001
Exhibits:0
Dated: August 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. My date of birth is GRO-B 1968 and I live alone at GRO-B. I am divorced and I have three sons, aged 26, 21 and 18. I do not currently work. I used to work as a minibus driver for the past 20 years but was unable to continue due to the issues I have with my knees.

2. As a result of receiving contaminated blood products I have been infected with the Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV).

3. This witness statement has been prepared the benefit of access to my medical records; however, I do not believe that they were provided to me in full.

Section 2. How infected

4. I was born with severe Hemophilia A which was diagnosed when I was between 12 and 18 months old when I was beginning to teethe. I received a lot of treatment at the Pendlebury Children's Hospital in Manchester (PCH). I was treated both in hospital and at home with bed rest but I was also treated with cryoprecipitate.

5. I started home treatment and Factor VIII concentrate when I was about 11 or 12. I had started High school by then. Initially my Dad was trained to administer it to me but then I was taught how to do it.

6. I would have the treatment whenever I had a bleed. I was a sporty child so I had treatment quite often. I regularly played football. My knee would swell up and I would have to have this drained at the PCH. It kept re-occurring and my knees have never been the same since.

7. As a result of being treated with contaminated blood products, I contracted Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV).

8. I found out about my HIV infection when I was around 17 or 18 years old. At that point I moved from the Children's Hospital to Manchester Royal Infirmary (MRI). I had left school then and I did not have as many hospital visits. Sometime between 1985 and 1987, I went to the hospital for a visit with my Dad. I was called in to the room on my own. My main doctor at the time was Dr Wensley and this is the doctor that I had a meeting with. In the meeting he just told me that I had tested HIV positive and asked how I felt. I did not feel anything at the time. There had been rumours and stuff in the papers about AIDS but I did not know how to take it at the time.

9. I have never spoken to my parents about it, but I do suspect my dad probably already knew about it at that point. There was a lot of media coverage about it at the time and I did come out from that meeting feeling very sad and quiet. On our journey back home we did not speak, so I am certain that Dad knew that there was something wrong.

10. I do not believe that I was given any information or guidance in that meeting regarding my infection; all I remember him saying is that I should not be too bad if I have a sensible diet. I do not think that he had much to tell me at the time. The realities were that there this was a new disease and people were dying from it.

11. I did not find out nor was I told about my HCV until approximately 13 years later. I found out about it by an accident. This was when my wife at the time was pregnant with our middle son. I had an appointment with a doctor in or around February/March 1998. GRO-B my wife, was there with me and she was taken into a room whilst I was in my appointment. When she came out of the room she was in tears and at first I thought that something was wrong with the baby. The doctor told her that she had tested HCV positive and that she had contracted it from me. It was a complete shock because I did not know that I had it. At the time I had no symptoms of HCV and I was completely unaware of having anything other than HIV.

12. Our middle son was born in GRO-B 1998 and we then had another son in GRO-B 2000 that we were not trying for. Thankfully none of the boys were infected.

13. I was never made aware as to when I was infected with HIV or HCV or why I was not told about the second infection until my wife at the time was tested and diagnosed. I believe that I was infected while I was still at the GRO-B GRO-B and that the doctors did not tell me about my infections for a long time as they thought that I was too young to know.

Section 3. Other Infections

14. I received a letter which indicated that I might have been exposed to Variant Creutzfeldt–Jakob disease (vCJD). I do not recall when it was. When I received the letter I thought to myself, not something else as well.

15. I was not offered any counselling in relation to my infection.

Section 4. Consent

16. I was a minor at the time when I was told I was HIV positive and therefore a minor when I was tested for HIV. I am not sure when I was tested for HCV. I am not aware whether my parents gave consent for me to be tested at the time. I have not spoken with my parents about this so I am unable to say whether I was tested without consent.

17. I do not believe that my parents were made aware of the fact that my blood was being tested; I certainly was not. I also do not know whether the blood tests for HIV and HCV took place on two different occasions, or on the same occasion.

18. I do believe that I might have been tested for research purposes, as in the past 30 years I had every drug that came out in relation to HIV.

Section 5. Impact of the Infection

19. When I was first told that I was HIV positive, I did not think much of it. I did not feel unwell in the early days. I had just left school and I started a Youth Training Scheme (YTS) at GRO-B involving computers. When I first started it was fine but I only did half of the time. I had health issues relating to my haemophilia and looking back I was not in the right frame of mind. Whilst one part of my wanted to shut the HIV out the rest of me felt that I could not plan.

20. I was living with Mum at the time, as my parents split up and Dad was working abroad. I then started a job at a chicken factory, where I lasted for about 6 months, but I suffered from another bleed which put me out of action and

caused me to stop working for a few months. Eventually, I decided not to go back.

21. I did not have a job or bother with meeting people for a period of time, as I felt like I had no future and I could not apply for anything as a result of HIV. I recall that a doctor (I cannot recall his name) said in one of my hospital visits that I might still be alive and speaking to him in 5 years time. I think that they were trying to reassure me, but I did not think that a prognosis of 5 years was much. Looking back at it, I do not think that they knew much about the virus at the time.

22. I eventually found a job in a pub at the end of the street where I used to live with Mum. I worked there for a few months. When we finished work one night we stayed for a drink at the end of the shift. The landlord gave me a pint glass with my name on it as a joke. To this day I do not know how he found out about my infection but I never went back there again. The pub was very close to where we used to live so knowing that someone else knew about my infection was horrendous. Now there is less stigma relating to HIV, but at the time it was a disgusting thing to have.

23. As the pub was too close to where I was living with my mum I asked to go and live with my Aunt and Uncle at a different end of GRO-B. Eventually Mum moved over there too so I was able to move back in with her.

24. I never told anyone about my infection. In fact, when I started having problems with my knees I would say that it was because of the sports I used to play, not because of Haemophilia. The media made Haemophilia into a nasty word that people started to associate with HIV, so I preferred not to tell people about it.

25. Mum knew about my infection; I think it hit her in a hard way. They had divorced when I was about 15/16 years old. . She was not very well and she was on different medications and tranquilisers for 10 years.

26. I met my girlfriend who later became my wife when I was 21. GRO-B was about 17/18. I met her through my cousin who was in a relationship with her sister. I was unable to tell her about my HIV for a very long time.

27. However, around Christmas 1993 GRO-B told me that she was pregnant. We were not trying for a baby so it was a shock and it made me feel guilty, as it was a massive mistake on my part. This is when I had to tell her about my HIV.

28. We were both very upset. She did not know what exactly it was, she only knew about it from what she had seen on TV.

29. We decided to ring the Children's Hospital to speak to Sister Shaw. I had left the PCH four years previously but as we were both upset; I knew that she would be able to help. She told me not to worry and to come to see her that same day. GRO-B was very distressed at the time and I just could not believe what I had done.

30 GRO-B had an HIV test and thankfully it came back negative. She then had to wait for 6 weeks and was tested again. Once again the tests came back negative. At that point we went from being devastated to being over the moon all at the same time. Our first son was born in GRO-B 1993.

31. The reason I had not told GRO-B in the first place was because I felt I could not tell or talk to her about it. I was scared of losing her. I knew that I had made a big mistake.

32. My health then started to deteriorate and I was started on HIV medication.

33. Around this time I had severe side-effects from my HIV treatments. A new drug came out ever 3-6 months and I had been given many. The very first treatment I had was AZT and I went on it when I was around 20 or 21 years old. I do not recall the name of the other drugs. Every couple of months it seemed like I was getting thrush in my throat and had to keep getting prescribed treatment. I remember getting pulled up at the chemist because of the large dose I had been prescribed. That was in 1996.

34. In 1997 GRO-B eventually wanted to have another child but we wanted to do it properly, so we went to the MRI and saw Dr Hay. We were told that with the drugs I was taking my viral load was 0; the virus was not detectable in my blood. He said that it would be a good time to try for a baby. I do not know why Dr Hay did not tell me that I had HCV.

35. GRO-B was told that she had Hepatitis C whilst she was pregnant with our second child. That was the first time I had ever been told I had HCV. I had had no symptoms. Being told about HCV and the fact that I passed it onto my wife affected our relationship greatly. I did not have liver biopsies due to my Haemophilia, but GRO-B had a couple and I know that she did not like them. In GRO-B 2000 our third son GRO-B was born. Thankfully our children were not infected.

36. In 2000 we started getting on our feet, we moved to a nicer house, we were both working and we had our 3 boys. We got married in GRO-B. When we were getting married the hospital mentioned the Interferon treatment several times for our HCV. We decided not to go on it then. We got married and went on our honeymoon.

37. I started Interferon and Ribavirin treatment in 2005. It was the most horrendous and lowest point of my life. From the very first time I put the injection in my stomach I have never been the same since. I was given an antidepressant to take at the same time which I was not keen on doing but my life has never been the same.

38. I suffered from terrible fatigue and I lost about a stone and a half in weight. I felt and looked awful. I used to hear people say that this treatment is very similar to chemotherapy, but it also completely changed me as a person. I recall that one day I went to a pub and I drank to the point that I could not physically stand because I did not care about anything or anybody.

39. I continued on working, but some days I was so tired that when I returned home I went straight to bed.

40. I was on the treatment for 12 months and I also had to start taking antidepressants due to the side-effects of it, which I also was not very keen on. Unfortunately, the treatment was not successful and I did not clear the virus. Looking back at it I wish that I stopped after two months of being on it. The treatment affected my relationship with GRO-B, and we were never the same after that.

41. I finished my treatment in 2006 and in 2008 GRO-B left. I am certain that we would not have split up if it was not for the infections and the treatment. Before the treatment we were just a normal family and after I had the treatment it all changed. It is fair to say that my infections destroyed my life. I had been living a life with no future; I just existed month by month.

42. I did not have another treatment after that. I was too afraid of the negative consequences again, but I was asked whether I would like to go on it again once or twice.

43. GRO-B went on a new form of treatment around 2 or 3 years ago and she managed to clear the infection. I told her that I was pleased that she cleared it but I did not want to go on it.

44. I went to see a liver specialist a year ago who advised me about a new treatment. It was an 8 week-long course but I was advised to go on it for 16 weeks, rather than 8. I do not recall the name of the drug, it began with a Z. He wanted me to take Ribavirin alongside the new drug, which I was not happy with. It was explained to me that Ribavirin is a kind of drug that helps the main drug, just like it was with Interferon and Ribavirin being taken together. I did not want to take Ribavirin again. I agreed to take it, but I said that if I started losing weight I would stop taking it, as I was not prepared to go through the same side-effects I had with the first treatment. After a week I lost 5lbs. I told the doctor that I was only prepared to carry on with the drug without the Ribavirin. I did the whole course of the new drug alone and thankfully that was enough; I cleared the virus.

45. I used to have regular liver scans to monitor the state of my liver. This is not the case anymore. I think that the next appointment that I will have is in a year to check whether everything is fine.

46. What worries me is that I was told that I cleared the virus, but I am aware that the virus is never fully cleared, so it could potentially return.

47. I have chopped and changed with my HIV treatment. It is steady and stable at the moment, but I am soon to change my treatment to a new one, because it is meant to have fewer side-effects. I feel like whenever a new drug comes out and it is cheaper than previous drugs, the doctors change it to the cheaper drug. I do not think that the price of drugs should matter in this situation.

48. A side-effect of HIV medications, which I found particularly upsetting, was lipodystrophy. This is where the medication kills the fat cells in a specific area of the body, leading to a loss of fat tissue. Unfortunately, in my case it was significant on my face. It began around 15 years ago and my face looked saggy, which reminded me of what people with AIDS were portrayed as. This was particularly problematic for me, as my major concern was not to look unwell. I asked my consultant for cosmetic surgery, a procedure to transfer fat from my stomach to my face which has improved my facial features and does not make me look ill and gaunt. I have a phobia about looking unwell and losing weight bothers me enormously.

49. It took them so many years to do it, because of the potential bleeding complications relating to my Haemophilia. It is also a very expensive procedure.

50. All the other side-effects such as being sick and having flu did not bother me, but losing weight from my face and looking unwell bothered me a lot. I told my doctor that whoever invented Interferon was an awful person and it is extremely unfortunate that they still use it. It makes me wonder whether this is also a way of them cutting costs.

51. I still have not told many people about my infections. The only people who know are possibly my parents although I have never discussed it with them, my brother and my ex-wife. We never told our children about mine or GRO-B infection, as we wanted them to have a normal life. It is a massive thing for me, as I am 51 years old and not only do I live with Haemophilia but I have HIV and have cleared HCV. I have a large family (my mum was one of 14 siblings), but not many people know about what I have been through. It is awful that I still feel like that. I feel like when I was a child the media portrayed HIV as the modern day leprosy.

52. I think that my life would have been a lot different if it was not for my infections. I left school when I was told about HIV and I believe that if it was not for being told, I would have pursued something further. I would most likely have continued with the full training at GRO-B Instead I "bumbled along" between the age of 18 and 22. I just existed and I had basic jobs here and there. I lacked confidence to do anything and I feared that somebody might have found out. My biggest fear and worry was not to get AIDS.

Section 6. Treatment/care/support

53. I have never had counselling. The only form of counselling which I vaguely remember was when I was 19 or 20 years old and I was invited to go to Pendlebury Children's Hospital with 4 or 5 other Haemophiliacs to have a chat. It was meant to serve as counselling sessions, but none of us knew what we were actually talking about.

54. There was another meeting I had which took place in someone's house. I was around 20 at the time and the other men attending were around 30. I was not very comfortable there but I still did it.

Section 7. Financial Assistance

55. I was part of the 1991 HIV litigation. I had to sign a waiver and I received £20,000. At the time I did not know how much longer I had to live so I thought that the best thing to do was to sign it.

56. I have been receiving monthly payments from the MacFarlane Trust, and now from England Infected Blood Support Scheme (EIBSS). I do not remember the amount that I receive. I have been having those payments for years now and they have increased considerably this year.

57. I believe that we also received something around 1999 or 2000 when we moved into our new house but I cannot remember how much.

58. I do not think I have received anything from the Skipton Fund.

Section 8. Other Issues

59. What I do find rather strange is that I applied to the MRI and my GP for my medical notes and they arrived within 24 hours of each other; I think this was an unusual coincidence and one which I would like to highlight.

60. I also feel like some of my medical records have been missing and are also in the wrong order. For example, the records show that between 1985 and 1986 I was seen only once by medical staff. I find this extremely unlikely, as even now I have appointments every 6 weeks and my need for is much less.

61. I believe that HCV got a lot less stigma than HIV purely because of how the government portrayed it. There were never advertisements for HCV as there were for HIV. I believe it could have been handed a lot better.

62. I would like for the Inquiry to find out who the people behind this tragedy were. I have seen the documents published by the Inquiry and it is clear that it was

known that there was a risk of infection but they carried on using the contaminated blood products.

63. I am also interested to hear what the Government has to say about everything that happened.

64. I am waiting for surgery to have a double knee replacement. I have been waiting for this for some time. Unfortunately the operation keeps being cancelled.

Anonymity, disclosure and redaction

65. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

66. I do not wish to be called to give oral evidence.

Statement of Truth

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

Signed...... GRO-B ....

GRO-B

Dated.............30/09/18.................