Witness Name: GRO-B
Statement No:WITN3049001
Exhibits:0
Dated: July 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. I was born on GRO-B, and I live at GRO-B. I live with my long term partner and our two dogs.

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 and I was diagnosed at an early age as my older brother had been diagnosed with this. My father has said that I was approximately 4 months old. I was infected with Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV) from contaminated blood products. My brother is also co-infected.

4. My father and stepmother were told that we were infected with HIV in 1984 and in the early 90s advised that we had HCV.

5. I was not told about my infection until 1993, when my father sat me down and explained my illness. I was only 13 at the time and too young to understand the full consequences. It wasn't until I was 15 or 16 years old that I realised the impact it would have on my future and my life.

6. I was infected at GRO-B hospital but I do not have any information on what batch numbers were used although I understand that the Factor VIII was supplied by Cardiff Haemophilia Centre.

7. When I was younger I only received treatment as and when I needed it for example when I was injured or suffered from a bleed. Now I am on a prophylactic treatment schedule and I use Factor VIII every other day.

8. I should never have been given Factor VIII at such a young age. I should have received cryoprecipitate as treatment. I believe the decision to use Factor VIII was on the recommendation of Dr Bloom. I don't remember meeting Dr Bloom as I was only 3 or 4 when we moved to GRO-B.

9. My parents were never given any information on how to manage my HIV or HCV. I understand that they were just told to be careful and in future I would have to use protection when having sex intercourse.

10. My parents told me about always using protection and being extremely careful when I was about 14 or 15.

Section 3. Other Infections

11. I believe in 2010 I received a letter in the post informing me that I may have been infected with vCJD. This was a random letter and completely out of the blue.

Section 4. Consent

12. I personally do not know whether I was ever tested or treated without the consent of my parents. I certainly would not have been able to consent as I was so young at the time.

13. Every time I get tested a lot of blood is always taken and I do not know what it is being tested for is for, but I don't believe there is anything more sinister behind it. I think they are just testing to make sure I am healthy and haven't caught any further infections.

Section 5. Impact of the Infection

14. I started managing my Haemophilia on my own when I was 15, but it wasn't until I was 17 when I could drive myself to the hospital that I truly became independent in the management of my treatment.

15. At that time I only received treatment when I was injured or had a bleed. I also had regular six monthly check up appointments.

16. I think physically, I have been very lucky and I haven't really suffered at all with it, even in my teenage years. However, as I was infected when I was so young, I never really knew any different.

17. I think that the effects mentally really affected me in my teenage years, right through to being a young adult. I was told I had a life expectancy up to the age of between 30-35. This really brought my life down and I felt that my life had lost all meaning. Suddenly there was no point in life at all. I had no long term goals and didn't feel any interest in marriage or in a career. I didn't see any point in pursuing long term goals.

18. I have a great partner now and she is very supportive. She helps me talk about it all. I used to have a lot of trouble dealing with it all until my late 20's.

19. When I was younger I used to take a lot of risks, especially in the sports I enjoyed. I used to be very into skateboarding and downhill mountain biking. Everyone knows that certain risky sports really aren't appropriate for Haemophiliacs, let alone someone who is infected with HIV and Hepatitis C.

20. For me, I knew that death would be coming at a young age. I just felt I didn't want to die of a degenerative disease, leading to AIDs and so I led a very reckless life. I ended up binge drinking a lot every weekend and smoking marijuana pretty much everyday. I was incredibly angry all the time.

21. I now lead a very healthy lifestyle and I have done so for the last 15 years. I no longer smoke or drink alcohol at all and I try to remain healthy and active.

22. When I was younger sometimes I came across as very confident but in closer relationships I had a severe paranoia that people would find out about my infections. I really worried about how they would treat me if they knew. I was also increasingly worried about infecting anyone. I buried a lot of my feelings and never really dealt with it all.

23. I think that my GCSEs were the last time I ever really put any effort into any kind of schooling and I did very well. However by the time I got to A levels I felt there was very little reason in continuing. I just felt there was no point because I wasn't going to live long enough to get a good career. I felt that all the goals that people had, such as a family or marriage, were never going to be an option for me.

24. Despite putting very little effort into my A Levels I did well enough to get into University. I studied Environmental Conservation Science and Geology at GRO-B, South Wales.

25. However I found it very difficult to cope at University, especially in my final year. I just kind of gave up on everything and ended up dropping out before completing my degree. Although I still received a diploma but it wasn't an actual degree.

26. When I left University, I needed an escape and I went travelling around Australia and Asia with a friend. When we came back to the UK, I immediately applied for a work visa and headed back to Australia and I worked there for a year.

27. When I returned, I was just as lost as I was before I went. I got a job at the local quarry for a while and after that I worked in garden and maintenance at the local caravan site. However there wasn't any real career path for me in any of those jobs.

28. After working in garden and maintenance for a while I was trained by a friend to fit carpets and to this day I am still a carpet fitter.

29. Physically it can be a very demanding and draining job. It often causes me injuries and bleeds. More recently I have had to cut down to working only a couple of days a week because of my physical health.

30. I believe that being infected with HIV and Hepatitis C has probably distanced me from my family. I have always struggled to talk about it and share my problems. I think this stems from not wanting to rock the boat or burden others because I don't want people to know that I am struggling.

31. My mother died when I was only 2 years old and I have always felt that my father had enough on his plate with me and my four siblings. I have never wanted to cause him any worry or concern.

32. I suspect people thought that I was quite reckless when I was younger but I couldn't tell anyone about my deep personal issues because of the stigma

surrounding HIV and Hepatitis C. I became a closed off person who didn't let people in.

33. This had a serious effect on my personal life because I found it impossible to have a proper relationship with anyone. I have been with my current partner for 12 years and she is the only serious long term relationship I have ever had.

34. Before I went to University I don't recall seeing anyone from the medical profession for my HIV or Hepatitis C and I think I was just monitored.

35. Whilst I was at University I was treated at Cardiff Heath Hospital. All my care was covered in one clinic and I saw just one specialist who dealt with everything in one appointment.

36. When I moved back home after University in 2002 all my treatment took place at the Haemophilia clinic at Southampton. I have one appointment a year for my HIV at Royal South Hants Hospital. I had 2 appointments a year for my Haemophilia.

37. It wasn't until 2011 that I received any treatment for any of my infections. I was treated with Interferon for the Hepatitis C. I remember it being an awful regime of treatment and I had to inject it into my stomach.

38. The side effects of Interferon were absolutely shocking. I had spasms in my brain, essentially causing the effect of having a transient ischaemic attack. At one point I lost all the feeling on the left side of my body. I recall being in Sainsburys with my partner and I had a spasm. I couldn't feel the left side of my body and it felt like my brain was working but I couldn't speak at all. I couldn't remember the PIN number for my bank card when we reached the checkout.

39. I went into hospital and I had an MRI but the neurologist couldn't find anything wrong with my brain. The spasms had stopped because I stopped the Interferon treatment.

40. I attempted to start the Interferon treatment again and I was only taking the treatment for 2 weeks when the spasms started again. I was told that each time I had the spasms my body would suffer the side effects of a stroke. It was absolutely terrifying to be told you were basically having a stroke at the age of 30. I had no choice but to come off the interferon.

41. When I stopped taking the Interferon I realised that it had sucked my personality away and given me serious brain fog. It wasn't until I stopped the treatment that I realised how much it had taken my personality away.

42. In 2013 I started treatment for my HIV because my viral load dropped below 350. I felt very let down because it seemed to me that they just didn't really want to treat me until I was very ill. In my mind I was a constant risk to everyone around me until I received treatment for my HIV.

43. Once I started the treatment for HIV my viral load dropped to undetectable and this means I am as close to being cured as possible and at this time not contagious anymore.

44. The treatment I now receive for my HIV is Raltegarvir and Tenofovir and this was changed last year. I used to take tablets once in the morning and once in the evening. Now I have to take 3 tablets once a day.

45. Prior to having the treatment for my HIV I was only having check ups annually but now I have a check up every six months.

46. In 2015 my HIV doctor retired and before I was allocated a new consultant I saw a few different doctors. I now have an excellent consultant, called Dr Sundarum at the Royal Southampton Hospital. When she took over my care she was furious that I still had Hepatitis C and had not received any treatment

for it. She claimed it was ridiculous that I had lived with Hepatitis C for over 30 years and nothing had been done about it. Dr Sundarum pushed the liver clinic and I received Hepatitis C treatment. I was treated with Harvoni and I took a tablet a day for three months and in 2016 I cleared the virus.

47. I felt absolutely fine on the treatment and I had no side effects whatsoever. I was monitored for 6 months after finishing the treatment. I am effectively cured with very little likelihood of it ever coming back. I do not believe I have any lasting symptoms from using interferon or from having Hepatitis C and I no longer see anyone for the Hepatitis C.

48. I think the stigma behind HIV is very detrimental. When I was in between HIV doctors everyone I saw in the interim was always shocked when I referred to my partner as a female. I remember thinking to myself, if professional doctors can't wrap their heads around it, how can I expect the general public to understand what I am going through. I just felt there was very little understanding of my case or what I had been through.

49. I recall an incident when I had an infection on my shoulder and I went to see my GP. I was prescribed Flucloxacillin which is an antibiotic. I went back 3 weeks later because it wasn't getting any better and the lump had increased in size comparable to that of a fist. My GP told me that usually he would lance the infection but because of my HIV and Hepatitis C he would not put himself or others at risk and he refused to treat it with anything but medication. I was sent home with a further prescription for Flucloxacillin and I was not even referred to hospital. Eventually the infection became so bad I felt I had no choice but to operate on myself in my bathroom at home.

50. The hospital that I attend for my check ups is taking part in a haemophilia gene therapy trial. However the whole trial for HIV patients has been halted because one of the patients suffered from liver failure as a direct result of the trial. I am incredibly disappointed because I was second on the waiting list. It is possible that I could have been cured of my haemophilia if I had never been infected.

51. I am aware that the gene therapy trial for Haemophiliacs infected with HIV is due to recommence. Dr Sundarum, my HIV consultant, has looked into the trial on my behalf and reassured me that I am not on the same treatment for my HIV as the patient who died. I therefore shouldn't react in the same way and hopefully it will be successful.

52. I understand that I am a good candidate for the trial because I lead a healthy and active lifestyle and I have my condition under control. I am required for the trial to send my records in once a week in order to show how often my bleeds occur. I also have to send information about how I treat my bleeds and any medications I take. The monitoring for the trial ends soon and I will have a meeting to discuss how we move forward. I understand that my last appointment for the trial will be in August 2019.

53. Thankfully I am physically very healthy, I do not drink or smoke and I try to remain as active as possible. I mainly focus on surfing now which I took up at a young age. I find it to be an excellent sport, both for my physical and mental health and it is a low impact sport.

54. I suffer from severe arthritis in my left ankle and I consider this to be my target joint. It often bleeds and it causes me a lot of pain. In the morning I often have a sharp stabbing pain through my ankle and by the evening it becomes a dull ache. I have been told the reason it hurts so much is because I have very little cartilage left in my left ankle which means I essentially have bone grinding on bone.

55. My doctor has offered to fuse my ankle together. This would require breaking my ankle and putting it back together with pins and glue. I understand that I would lose mobility in my left ankle. At this time I do not believe the pain is so unbearable that I would consider losing the little amount of mobility in my ankle.

56. I recall when I was 17 and I went into the Haemophilia centre at Southampton hospital for a check up and there was a sign up saying *"Why should I have to go and live on a rock in the middle of the ocean?"* This was probably the first time I felt that the best thing for my family and loved ones would be for me to disappear. I think the sign was likely put there to try to encourage people to reach out when they were struggling. For me, it had the complete opposite effect and it distanced me a lot. It was the first time I had thought maybe it would be easier and best on my loved ones if I wasn't around anymore to burden them. I have carried a lot of guilt around throughout my life and have always worried that my loved ones were at risk.

57. In my opinion, there is still a lot of stigma surrounding HIV. The optimist in me likes to think things have changed but if I am honest, I am not sure it really has. Whist I am glad that the Inquiry is taking place, it also concerns me because I worry people are going to make assumptions about me and question me on my private life. I have never been particularly secretive with my haemophilia and I am pretty much the only haemophiliac my friends know. Whilst it is not something I am ashamed of, nor am I defined by it, I would be lying if I said I didn't find it a little bit concerning.

58. I had kind of expected that I wouldn't still be here at this age and I almost feel like I have had more than one life and each chapter is a new life.

59. In regards to a family life, I personally never expected to have children and it is not something I am concerned about. Sometimes I wonder if my view would be different had I never been infected with HIV and Hepatitis C. My partner also does not want children but sometimes I wonder whether she feels this way because of me. When we got together she was in her mid to early 20s and it wasn't high on her list of priorities to have kids. Through time it's been reinforced into her that I can't really have children. I don't feel that I have lost out on being able to get married, as my partner and I could get married if we wanted to, however we chose not to as we have other things we would rather do with our money. If I'm honest, I always thought I wouldn't even have what I

do now and I feel very lucky to have such an understanding partner, a good house and a life.

60. I have two brothers, one of which is an infected haemophiliac and two sisters. Unfortunately we lost one of my sisters 5 years ago.

61. My brother, GRO-B, suffers far more than I do from his HIV and Hepatitis C. He also struggles with serious depression. Whereas my other brother is healthy and has no problems. He is a surgeon and has a young child.

62. My sister lives in New York and she is very successful and recognised as such within her field of work. Sometimes I wonder where I would be had I not been born a haemophilic. I am not resentful in anyway and incredibly proud of what my siblings have achieved, but GRO-B and I are pretty much unemployable and have never had the opportunity to build a career. I always figured that I would have some sort of career in environmental conservation but I lost the focus and the drive for it. Now I just don't care, I stopped caring a long time ago.

63. My sister has lived in America for many years. For quite a few years I was unable to visit because I was HIV positive. I have been to America a couple of times now but each time I have been pulled to one side. When I went to Costa Rica in 2005 we went through Atlanta. I was travelling with a friend and I was taken to one side. I glanced over at the computer screen and saw on their system "May have AIDS". I have no idea how they were aware of this but eventually they let me travel through. However, I am wary about going back and worried that the same thing will happen again.

Section 6. Treatment/care/support

64. I was never offered any official kind of support or counselling. When I was being treated at Cardiff Haemophilia Centre, a man came up to me and gave me the card of a counsellor and said if I needed to talk to someone I should call the number on the card.

65. It was very unofficial and inadequate. In my opinion, it should have been a lot more structured and when you have an appointment at the Haemophilia Centre you should have to see a counsellor directly afterwards.

66. I feel like it was left to me to go out of my way to try and find help. It is only recently that I have become less angry and frustrated. I think this is hugely down to my partner, who has always encouraged me to speak openly and honestly about any problems or issues I am facing. I think just having someone there to listen and support me has helped massively.

Section 7. Financial Assistance

67. Because I was very young when I was infected my father received financial assistance on my behalf however I do not know where from or how much was paid to him. He invested any money he received on my behalf and saved it for years. When I bought my house in 2008 he had a lot of money in stocks and shares and was able to pay the deposit for my house.

68. Up until 2 years ago I was getting payments from the MacFarlane Trust, which now comes from the EIBSS. Currently, I receive about £18,000 a year from the EIBSS which covers my mortgage and the bills. The money that I earn from my job covers my living costs. I also receive a DLA allowance of £260 per month. As of mid July, the allowance I receive from the EIBSS will be going up to £38,000 a year.

69. I am thankful for the financial support I receive, but I do worry that one day I will get a letter through the post telling me that its been stopped. I feel incredibly dependant on handouts from the government and I would prefer a single lump sum payment that I could invest for my future. I think that would stop me worrying that it was going to be withdrawn.

Section 8. Other Issues

70. Whilst I feel very lucky to have the life I do, sometimes it can be hard. I am in a place I never thought I would be and I am as healthy as can be expected. I have a wonderful partner and a lovely house near the beach. It is difficult for me to say things are tough when I have so much to be grateful for, but I look back at all the depression and the desire I had for an escape. I have had so many opportunities taken from me. I don't have a job that I like and I don't have what one would consider a normal life. I feel like this has been ignored. It is almost like they were just waiting for us all to die, but that has not happened and that's why the inquiry is going ahead. I feel a lot of anger and frustration about everything that has happened.

71. Whilst it is good that the inquiry is going ahead, I just don't see how it is going to make any kind of difference to my life. I feel that those who were responsible for this scandal will not be punished in any kind of way and I don't see anyone ever being held accountable for this.

72. It seems selfish that I just want a lump sum payment, but I felt so abandoned at such a young age. Sometimes, I am treated like I should be grateful for the treatment I have received because without it I would be dead.

73. I have learnt to live day by day but I still find it hard to plan for the future because I never thought I would have one. I essentially now have a normal healthy life and I find it difficult to get my head around it. The concept of having a future is all a bit foreign.

Anonymity

74. I wish to remain anonymous.

75. I do not wish to provide oral evidence to the inquiry.

Statement of Truth

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

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

GRO-B

Dated........07/10/2019........................