

Witness Name **GRO-B**

Statement No: WITN3368001

Exhibits: WITN3368002-11

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** of **GRO-B** My date of birth is **GRO-B**
2. I am currently living with my partner **GRO-B** who I have been with for 22 years, in our home which we now own outright. We have no dependants.
3. I had been working for 38 years of my life but decided to take a temporary break from work at the end of October last year, leaving my job of 27 years because I was finding life extremely stressful. I thought that my health would suffer if I continued as I had been. However, I intend to return to work on a part time basis in the near future.
4. The announcement of the Inquiry got me thinking quite negatively about the impact which my infections have had upon both myself and the people around me. The infections have caused added pressures and difficulties within relationships, particularly so in the earlier stages of my infections; although these pressures and difficulties are still ongoing.
5. I was infected with HIV, Hepatitis C and Hepatitis B as a result of receiving contaminated Factor VIII concentrates.

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6. This statement has been prepared without the benefit of access to my full medical records.

Section 2. How Infected

7. I have Severe Haemophilia A and was originally treated in the early stages of my life with Cryoprecipitate in response to any bleeding episodes. I suffered some joint damage due to spontaneous bleeds before the advent of Factor VIII concentrates and home treatment; both of which I went onto around the age of 13. Injections were administered by my father until I took over around the age of 15.
8. I don't know whether my parents or I were given any advice or information regarding the risks of receiving Factor VIII concentrates. My father has now sadly passed away and my mother is very elderly and would not recall such matters.
9. I have always been under the care of the local health authority; the Norfolk and Norwich Hospital, which has a Haemophilia Centre and I have attended specialist clinics under this authority for both HIV and HCV (Hepatitis C) concerns.
10. I believe that I was infected with HIV in or around 1985. There is mention of this in my medical records and I attach the first page of a letter dated 16th March 1999 which states "*He was found to be HIV positive on testing in 1985*" as **Exhibit WITN3368002**. I am unaware as to which particular batch or product name caused my HIV infection.
11. My consultant at this time was Dr John Leslie (now deceased). He informed me that I had been infected with HIV during a routine clinic appointment. **Exhibit WINT3368003** is an extract from my medical records dated 11th September 1985 which states "*Fine. Told positive for HTLV III*". I cannot recall specific details or even whether I knew what HIV was at the time. I do, however, remember being referred to the Genitourinary (GU) Clinic for further advice. I didn't like the consultant who I saw at the GU clinic. I was aged 20 or 21 at the time and was basically sent there on my own which felt both daunting and inappropriate.
12. As I acquired more knowledge, both from my own research and the medical professionals at the GU Clinic, I realised that I wouldn't have long to live and that it wouldn't be an honourable ending. I believe that I may have been given some leaflets at the GU clinic about HIV and safe sex. There were posters and horrendous adverts around at this time

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which all pointed to a death sentence. This was a really harrowing and very scary time and it upsets me now as I try to recall it.

13. I do not know when I contracted HCV (Hepatitis C) but my medical records record that I was Hepatitis C antibody positive on **GRO-B** to which **Exhibit WITN3368004** refers.

14. I don't remember having a specific conversation about Hepatitis C with my consultant but I do recall thinking that I was going to die from AIDS so at the time I considered Hepatitis C to be a complete irrelevancy.

15. I was also infected with Hepatitis B to which **Exhibits WITN3368005** and **WITN3368006** refer.

Section 3. Other Infections

16. I was told by my consultant that I had a marker for vCJD and I attach **Exhibits WITN3368007** and **WITN3368008** in this regard.

Section 4. Consent

17. I don't believe that I was tested for HIV, Hepatitis B or Hepatitis C without my knowledge or consent. I have not seen anything in the medical records which are in my possession which point to the fact that I was tested and not advised about such tests. However, if the relevant records of such testing had been removed from my records then it is possible that I could have been tested without my knowledge and therefore impliedly without my consent.

18. I don't think that I was treated or used for the purposes of research without my knowledge or consent.

Section 5. Impact

19. Several years after my HIV diagnosis my platelet levels decreased and I am unsure as to whether my HIV or my Hepatitis C was responsible for this. According to my medical records this was monitored for some time. This reduction in my platelet levels necessitated a short inpatient stay at the **GRO-B** in or around 1987/1988, where I was

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treated with Sandoglobulin. Unfortunately, my platelet levels continued to drop and I experienced extensive bleeds and bruising during this time.

20. As a result, I was prescribed Interferon Intron A, subcutaneously every other day, although I am unsure exactly when this commenced. Although Interferon was widely used for Hepatitis C treatment, the Intron A type was given to me for a period of 4 or 5 years in an attempt to improve my platelet levels as evidenced by **Exhibits WITN3368009** and **Exhibits WITN3368010**.

21. Unfortunately, the side effects of the Interferon Intron A treatment were not pleasant; I suffered flu like symptoms, aches, tiredness, fatigue and felt very low as a result. I couldn't have been easy to live with and I'm sure that this had a negative impact on my relationship with my wife at the time.

22. During my late twenties, I suffered from a number of minor fungal and other infections, bleeding gums and the like which suggested that my immune system was low. During this time my CD4 count also significantly dropped. My Haematology Consultant therefore asked me to consider embarking upon AZT medication for my HIV. I was extremely reluctant to agree to the same because I was aware that such medication had horrendous side effects. I did not want anything to impede upon my ability to continue in full time employment.

23. Mentally, I felt that commencing HIV treatment was going to be a bit of a game changer and that I was now on the slippery slope.

24. I therefore pressed on with my life and put off embarking upon AZT.

25. However, my CD4 count continued to drop and actually reached dangerous levels (Level 4) in February 1999. I was losing weight and according to my medical notes, I was progressing towards AIDS.

26. Despite my failing health, I was still very concerned about both the side effects of the HIV medication and what long term physical effect it would have on my body.

27. I was therefore again referred to the GU Clinic in a final attempt to persuade me to start AZT. After a considerable amount of soul searching, support from Consultant John

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Meaden, who was also an avid support and season ticket holder at Norwich City Football Club and the fact that my health was so bad, I took the decision to embark upon AZT.

28. I therefore started AZT, specifically Combination Therapy and Septrin. The Septrin was given to guard against opportunist infections but after about 8 weeks I developed an allergic reaction to the Septrin which necessitated a short period of hospitalisation to control the same.

29. When I came out of hospital, I commenced a triple anti-retroviral regime consisting of Combivir (AZT and 3TC) and Nevirapine in April 1999 to which **Exhibit WITN3368011** refers. I was also put on Pentamidine which is an alternative to Septrin. Penamidine is a gas which is breathed in through a mask which was unpleasant. I remember having this gas at the GU Clinic. They put me in separate room for this treatment and I remember the vent exiting out of the window. I remember that this continued until about December 1999 or January 2000 which was when my CD4 count levels finally improved.

30. The "*Pentamidine*" period was a very stressful time in my life which involved multiple visits to the GU Clinic and time away from work. I felt like I was a bit of a liability to my boss during this time, despite the fact that I was a really good employee. I was very fortunate because I was a GRO-B at this time which meant that I had my own office at certain sites. This meant that I could take some time out to recover and catch up with my thoughts after each clinic visit. In fact, as I reflect now whilst writing this statement, I am not sure how I got through this period in my life. I would have been lost without the support of my partner and my boss.

31. Over time my CD4 count continued to rise and I felt more positive and that I possibly had longer to live. However, shortly after the improvement I had to suspend all HIV treatment, thankfully for only a short time, due to difficulties with my liver. In fact, at this time and as time went on, I became less worried about my HIV and more concerned about the Hepatitis C in my body. I started to experience horrible thoughts of dying of Liver Cancer. I was, however, determined to continue working and I tried to bury these very real worries.

32. I promised myself that I would keep as fit as I possibly could to give myself every chance of surviving and I was careful not to become self indulgent in any way, shape or form.

33. I was monitored over time by the Liver clinic and I've had two liver biopsies in 2004 and 2008 which showed mild inflammation of the liver and some scarring. Treatment for

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Hepatitis C was considered during some of these regular clinic visits. The treatment, which was Interferon and Ribavirin, was explained to me as being complicated and not hugely successful for those, like me, who were co-infected. There were also funding issues in relation to receiving such treatment.

34. The decision was made by the consultants that we would wait it out and see how my Hepatitis C progressed. This was very stressful because I worried that Liver Cancer was on its way to me. I also thought that maybe I would be one of the lucky ones who would avoid this diagnosis.

35. It was not until 2016 that I was finally offered treatment for my Hepatitis C. I was told that the NHS now had a budget and that there was a new treatment which I could receive. I commenced a 12 week course of Zepatier which necessitated a change to one element of my HIV Combination Therapy due to way in which the two drugs would react with each other. I was worried about the Hepatitis C treatment and worried about any potential side effects and how these may have impacted upon my ability to work throughout this period. However, despite my very real reservations, the Hepatitis C treatment went well with minimal side effects and tests showed that the virus was undetectable following completion of the course and this is still the case in 2019.

36. I believe my infections, resulting medications and treatments have had a huge effect on my relationships especially with my ex wife. I feel guilty about the stress I put her through and the fact that I lived only on a day-to-day basis and focused less on having a family with her and planning for the future. I didn't want my children growing up without a father. At the time, this was the lowest point of my life and one which I believe could now have been avoided.

37. Personal relationships have been hard because I come with and carry a lot of baggage. Going over what happened to me does not get any easier each time. I have to drag up the past that I had hoped to bury. I am never sure of what sort of reaction it will create in me.

38. Confiding the existence of my infections to friends has been onerous and very emotional. I have had to think long and hard before deciding to deliver such news to others. That said, it has gone reasonably well to date. However, there remain people who I have not told because I considered that they had their own worries to deal with.

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39. At times I have felt dirty and my mood is still up and down and I don't know whether it's me, the infections, the medications or the treatments. I've often wondered whether I should burden others with my life and problems or just remain on my own. It has been a lot for someone to take on and a lot for me to consider and deal with.

40. I was working full time when I first learnt of my HIV status and I don't recall any specific health complications at the time, other than the increased hospital visits. I went to work for a local **GRO-B** in or around 1991 and remained with them up until October last year. My diagnosis and treatment was known only, to my knowledge, to one individual who was my Manager and who then became an **GRO-B** as the company grew. He was always sympathetic and very supportive over the 27 years that I worked with him. The benefit of sharing news of my infections with him was that it made multiple clinic and hospital appointments logistically simple to attend from a work perspective. He was someone to confide in at work when things were tough and without this level of support at a senior level in the company I don't think I would have done as well as I did with the added medical issues going on. I finished as a **GRO-B** in this group with a Post Graduate Diploma in **GRO-B**. I feel that I could have done much better, but the thought of impending illness always held me back as I didn't want to let anyone down. In fact, one of the reasons why I stayed with this company was because they made it easy for me to attend so many medical appointments.

41. Over the last four years things have become increasingly difficult with both my health and due to the death of my father, which made me think a lot harder about my quality of life and my past. My role as a **GRO-B** has always been reasonably stressful and I'm really surprised I coped with it for the length of time that I did. This, coupled with the thought of the Infected Blood campaign looming meant that things were getting too much for me and I knew that I had to make a drastic change to my life. I decided to take a break from work to cope with the anger and frustration which was building up inside me.

Section 6. Treatment/Care/Support

42. In the early days of my HIV diagnosis, it was a difficult period, and somewhat unnerving being faced with clinicians in gowns and masks. This made me feel very dirty and already deceased. I always found their behaviour rather strange because they would fully gown up to take blood from those with infections yet took no such precautions when taking blood from patients whose statuses they were not aware of.

43. As my HIV health improved with the stabilisation of my CD4 count levels I felt it necessary to look after my teeth, which was something I felt hitherto unimportant. I therefore sought a sympathetic dentist who happened to be private as I struggled to find any NHS spaces due to my infections. My private dentist was fine with my health status which was a relief. I still have the same dentist today. However, we did have one slight mishap whereby he received a needle stick injury from the local anaesthetic needle whilst numbing my mouth in order to carry out a filling. I was very worried that I may have infected him but fortunately this was not the case.

44. I haven't been offered or sought any psychological help. There were times when I felt I couldn't cope and might need assistance, but I wanted to work through this myself with the support of my friends and partner.

45. It is fair to say that to the best of my knowledge I don't believe I have been precluded from any treatment which has had a negative impact on my health.

Section 7. Financial Assistance

46. I have been with the Macfarlane Trust (MFT) and the Skipton Fund from inception. I received ex gratia payments (not sure when as was some time ago) for HIV and Hepatitis C. I also received regular payments from both Trusts.

47. I also applied for a couple of small grants, from both Trusts, some years ago.

48. I have not had any issues with either of the Trusts that spring to mind.

49. I have sought no legal redress in the past although I can recall signing something with the first ex gratia payment as I believe everyone had to.

50. I now receive financial support from the EIBSS and I don't have any strong thoughts on administration of the present set up.

Section 8. Other Issues

51. Writing this statement has been very difficult because I have had to compartmentalise my feelings and memories of this in order to cope with my life.

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52. I have had unwavering support from my friends, family, partner and other individuals all of whom I am eternally grateful to. I would also like to thank those persons who I have come into contact with during my many hospital and clinic attendances and who have carried me to where I am today.

53. I believed at the start of this when I was first diagnosed that it was just the luck of the draw and that it couldn't have been avoided. As I have acquired more knowledge of the situation I realise there had been darker forces at work and it is now, I hope, time to hold those individuals and organisations to account in what I now believe to be a situation that was wholly avoidable. The truth needs to be told and just and proper recompense paid to those that have suffered under successive governments.

Anonymity, disclosure and redaction

54. I wish to apply for anonymity and I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed

GRO-B

Dated

22/07/19