

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1633001

Exhibits: 0

Dated: May 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 the GRO-B My address is GRO-B GRO-B
2. I am currently employed and I have worked for GRO-B GRO-B for the past 35 years. I am married but currently separated from my wife, GRO-B who is also providing a written statement (GRO-B) for the Inquiry.
3. I live with my two daughters, GRO-B who is GRO-B and currently studying at GRO-B GRO-B and GRO-B who is GRO-B and about to start her GRO-B
4. 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

5. I have severe Haemophilia A, with a 0% clotting factor. I was diagnosed when I was [GRO-B] old after I developed a bleed in [GRO-B]
6. I was under the care of [GRO-B] and [GRO-B] at [GRO-B] [GRO-B] from [GRO-B] to [GRO-B]. I was then transferred to [GRO-B] because of the time it would take me to travel. At some point between [GRO-B] and [GRO-B] I transferred to [GRO-B] [GRO-B] where I was under the care of [GRO-B] until [GRO-B]. As [GRO-B] did not have a Haemophilia Centre I remained under the care of [GRO-B] and [GRO-B] [GRO-B] at the [GRO-B] throughout this period. My care was then transferred to [GRO-B]
7. From [GRO-B] I was treated with Cryoprecipitate (Cryo). I received Cryo to treat my haemophilia for about 10 years.
8. I was offered Factor VIII concentrate (FVIII) from [GRO-B] onwards. At this point I was also given FVIII home treatment. My mother would administer the injections as I was only [GRO-B] years old at the time. I had regular 3 to 6 months check-ups at the hospital.
9. I would receive FVIII on demand. As I got older my requirement for FVIII increased. In [GRO-B] when I first started home treatment I would not need it very often and could go a whole year with only 4 or 5 bleeds. As I got older I started to experience more bleeds and in the 1980s there were periods that I suffered up to 30 bleeds in a month, which would require me to have FVIII. I am currently on prophylaxis and have 3 injections a week. This regime started in the early [GRO-B]
10. My parents were never told beforehand that there was a risk in using FVIII concentrate. If they had known they wouldn't have let me take it.
11. As a result of the FVIII concentrate I was infected with Hepatitis C (HCV) and Human Immunodeficiency Virus (HIV).

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12. In [GRO-B], when I was [GRO-B] years old, two letters arrived at my mother's house. One was addressed in my name and the other was for my [GRO-B: B] but addressed to my mother as my [B] was only [GRO-B] at the time. My mother had opened my [B] letter and it stated that my [B] had tested negative for HIV.

13. I wasn't living with my mother at the time. When I went to her house I took the letter upstairs to the bedroom to read. The letter stated that I had tested positive for HIV which came as a complete shock. I cried my eyes out and had to go downstairs and tell my family that I had been infected.

14. I remember when I told my mother she called [GRO-B] and he said just because I had HIV it didn't mean it would develop into AIDS. Other than that I received no information. I was never told of the risks it would present to me or the dangers of anyone else being infected through me. I was [GRO-B] at the time and potentially sexually active so I should have been provided with some information.

15. I was not given adequate information and learnt most of what I knew from the news. I wasn't offered an appointment to discuss my results with a consultant. The next hospital appointment I had was in [GRO-B] [GRO-B] months later.

16. At the time I didn't really think too much about the lack of information. I was too devastated by the diagnosis. Looking back the fact they only sent a letter with limited information and a lack of thought as to how a teenager would cope with this news is dreadful.

17. When I had an appointment with the doctor, I was told that my tests showed I had a very high T-cell count and my viral load count was low. Therefore I wasn't required to go onto treatment. On one hand it was good that I had a strong immune system that could battle HIV but on the other hand I'm not sure this should have excused the medical professionals from offering me treatment as soon as was possible.

18. In [GRO-B] I do recall a consultant [GRO-B] sat me and my wife and said I had Non-A Non-B Hepatitis. Neither my wife nor I really understood

what this meant. I should have been sat down and it should have been explained to me of the potential complications the infection could cause. Instead it was just a few informal chats. I don't have any recollection of any consultants sitting me down at either OHC or CH even though I had regular check-ups. I believe they must have known.

19. I wasn't told that I had HCV until the early GRO-B. I was never really given any information about it. I remember I had been sent an information pack in GRO-B about HCV but there was never an indication that I had it myself. It just seemed to have been sent too all haemophiliacs.

20. It was only when I started having regular fibroscans at GRO-B that I realised how serious the HCV was.

Section 3. Other Infections

21. I received a letter in the late GRO-B stating that I had possibly been exposed to vCJD through the blood products I had received. I remember laughing my head off when I read the letter at the thought I could also have 'mad cow disease', I didn't really take it seriously as I was already preoccupied with HIV.

22. I have never received any follow-up letters or information in regards to vCJD. I have never been asked to undergo any tests in relation to it.

Section 4. Consent

23. I am not sure if I have was ever treated or tested without my knowledge. This all happened a long time ago.

24. I believe I was treated and tested for the purposes of research.

Section 5. Impact of the Infection

25. Within three months of receiving the letter stating that I was HIV positive I moved back home with my mother and stepfather. I couldn't cope on my own with the news. I started drinking heavily in order to deal with the anguish that it caused.

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26. Around 6 months after my diagnosis the grand scale of the 'Aids Epidemic' or the 'Gay Disease' as it was then known started to become apparent. There was a regular advert on the telly that pictured a huge tombstone with the words 'AIDS' written in bold letters emblazoned across it. It was really horrendous to watch. We made a pact as a family to never talk about the infections to anyone. We didn't even mention it to each other.
27. I suffered from a lot of mood swings which worsened my relationship with my stepfather which already wasn't great at the time. My whole life became extremely difficult as a result of the infections.
28. My personal life was affected. The topic of HIV would be brought up at work or at social gatherings such as the pubs. It was a strain pretending to those who knew I was a haemophiliac that I wasn't one of those infected. People weren't sensitive and would ask me directly if I had received contaminated blood. I remember thinking at the time that if the news did get out I would probably end my life as I wouldn't be able to cope with the stigma that was attached to it.
29. I refused to read any 'AIDS' related literature and eventually even stopped reading the newspaper due to the constant headlines about HIV.
30. I remember realising that I would likely never be able to have a relationship or children. My whole life had fallen apart through no fault of my own.
31. In or around GRO-B I remember a nurse offered me counselling. I remember I said *"go and f*** yourself, it's a bit f***ing late now"* as by this time I was aware of how serious HIV was and I felt completely let down by the medical professionals and institutions. They were supposed to support and care for me, but had in fact given me what I then perceived as a death sentence.
32. I can't remember who it was but one of the consultants had told me that I had between 2 and 5 years left to live shortly after being diagnosed. This hit me really hard. I thought to myself that there was no point saving money so I

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started to gamble heavily. I didn't see any point in trying to build my career. I just felt hopeless.

33. Every time I felt ill I thought that was going to be it for me. I had constant stress and anxiety with every cough and sneeze I had. I truly believed I was going to die.

34. I felt I couldn't have sex with anyone when I was diagnosed with HIV. At the time condoms were frowned upon and I refused to have unprotected sex as it wasn't right to put anyone else in danger. Even now sex is still an issue due to the constant guilt I feel. I subconsciously felt I could infect anyone I had a relationship with.

35. Being a haemophiliac I already had enough to deal with. I have constant pains and arthritis. This gets mixed in with how I feel I've been treated and also the complications that are added by the infections. It makes me very angry.

36. I didn't really care about anything. I wasn't a nice person at the time, I thought I was going to die so there was no point. I knew I had no future and I had nothing to live for. I wasn't suicidal but if it had got out I probably would have done something.

37. In [GRO-B] I started dating [GRO-B]. We had been friends for a year before we got together and I had feelings for her for a long time. When I started the relationship it was very difficult. I had to tell her about the infection as it was not right to withhold something like that.

38. Prior to [GRO-B] I was in a relationship and I had to tell my then girlfriend about the infection. The relationship didn't work out but not due to the infection. She had dealt well with it. So I had been through the conversation before.

39. I told [GRO-B] about the infection when I was at her mother's house. It's a very difficult and a delicate subject. You want to be intimate with someone but you can't until you have explained the situation to them. You have to be able to trust the person and hope that they understand but at the same time protect

yourself. It took me 3 months to tell her and 11 months before we had any kind of physical intimacy. The guilt stayed with me throughout and I still feel guilty about it now even though I haven't done anything wrong.

40. In the [GRO-B] I had a tooth ache and it had caused a huge hole that required an operation. I remember being prepped for theatre and saw the words 'HIV' highlighted at the front of the bed. I remember the nurse standing by the bed putting her hands on her hips and saying "*how did you get that little lot then*". HIV was always connected to sex or drugs at the time. It wasn't until quite a few years later that people became publicly aware of the real reasons. It hit me hard and I just said 'actually I'm a haemophiliac'. I remember the change on her face when she realised what I meant. What she said will always stay with me forever and that's part of the reason I didn't want anyone to know.

41. The only way I can cope with it all is to box things up. Over the years, I think with my frustration I've become quite explosive with things. It certainly affected my relationship with my then wife. I was never violent but there was always an undertone of anger. When counselling was offered so many years later I didn't want any help or anything. I had learnt how to deal with it in my own way.

42. It wasn't until [GRO-B] when our marriage was on the rocks that I approached the hospital for counselling. I started the treatment in [GRO-B] and had a session once a month. I was very sceptical at first. [GRO-B] had wanted us to do it for years. The counselling changed me completely; I have no doubt about that.

43. My wife [GRO-B] left in [GRO-B] which was extremely difficult to cope with. I continued receiving counselling and I will ask for more when I have completed it. I think it's the best thing I've ever done but there's still a lot of guilt there. I should have done it sooner. It should have been offered to me when I was told about the infection. It makes me wonder if I could have saved my marriage if I had the help earlier. I have become a better person after having the counselling.

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44. My infection affected **GRO-B** and the kids a lot. They never knew what mood I was going to be in. It makes me feel like I was a bad husband and a bad father. Now I can sit here and say I made the right decision to have counselling.
45. I think because of the way I processed and attempted to cope with everything made it difficult for me to show my emotions. It seemed like I didn't care even though I did. There was a lot of guilt. I feel like if I hadn't met **GRO-B** she would have been free of any hardships caused by the infections. I feel mentally broken at times. I am emotionally stunted and have massive feelings of inadequacy. I have lived like this for 34 years and I still think at any time, this could be the year where I get that call. It's always on my mind that the infections can cause me to die at anytime. It's so hard to get on with daily life and it takes its toll.
46. I do still wonder what I did to deserve all of this. At one point I hated my mother and blamed her for me being a haemophiliac. I also resented my **B** at a point because we were both haemophiliacs and lived in the same house. We had the same treatment and it just so happened that I had a particularly bad month in regards to my bleeds and used the whole batch of FVIII that was infected with HIV. My **B** has his own issues with that as a result. I know it wasn't my family's fault but it is hard to think rationally when you have something so damaging happen to you. This is something that I believe will affect me for the rest of my life.
47. I used to get thrush in my mouth as a result of the HIV. I also have liver complications as a result of the HCV that includes a swollen stomach, liver enlargement and near liver cirrhosis.
48. I started receiving treatment for HCV in **GRO-B**. I was put on a combination treatment of Interferon and Ribavirin. The course was for 52 weeks and required me to take daily tablets and an injection into my stomach once a week. I was given some literature about the possible side effects which scared me at the time but my consultant told me I would be fine. **GRO-B**

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was pregnant with our second daughter, [GRO-B] when I was put on the treatment. The treatment was the worst thing I've ever had to endure.

49. As previously stated, I was told that I did not initially require treatment in relation to HIV. I had a blood test approximately 4 years ago and from the results the doctors told me that I should start treatment. I take Descovy and Raltegravir daily.

50. I have faced terrible mental and physical effects from the treatment I received for the HCV. I had just changed departments at work and had become an auditor so I was travelling most of the time. My daughter [GRO-B] was [GRO-B] and [GRO-B] was pregnant with [GRO-B] and was on maternity leave.

51. I had to accommodate the treatment around work. I would have the injection on a Friday and it would wipe me out for the weekend. I would stay in bed for the whole weekend. The symptoms were horrendous; I can best describe it as having a constant flu for a year. It was the worst experience I've ever had. I couldn't stand loud noises and I had paranoia which was really bad. I lost weight and I couldn't sleep. I wasn't pleasant to be around. It was the worst year of my life. I have no idea how we managed to cope.

52. [GRO-B] had to cope with me being on this awful treatment as well as looking after our new born baby, it was horrendous. The treatment was successful but after 3 months of the infection being cleared, I was told that it had returned.

53. I wasn't offered any more treatment for HCV until [GRO-B] [GRO-B] where I was given Harvoni. They wouldn't put me on it at first because they said that it was too expensive and the treatment was only offered to people who urgently required it.

54. Dr Terry Wong who was the HCV consultant at [GRO-B] asked me about my alcohol consumption. He said that even though I qualified for the Harvoni treatment he would not put me on it, because he thought I was an alcoholic. He told me he would start doing random blood tests to check my alcohol levels. I told him that I wasn't an alcoholic and I wouldn't drink during

the treatment. When I was on the Interferon/Ribavirin treatment in **GRO-B** I didn't drink alcohol, not even a sip. I was so angry with him.

55. Eventually I did what he wanted me to do and was subjected to alcohol tests. I finally received the treatment. The side effects were very minimal compared to the first treatment. The treatment successful cleared the HCV. The best thing about it all was I didn't have to see Dr Wong again.
56. My social life was impacted as I was unable to tell anyone. My friends didn't even know I had the infections. It was difficult being a teenager living with HIV. Everyone is sexually active, they are the years you should be carefree and not have to worry but I felt as if I had to make up excuses. I would sometimes avoid going out.
57. The reason I kept everything to myself was because of the stigma attached to HIV. People would be treated terribly if it was discovered they had HIV, especially back then. I had to protect myself and my family.
58. When I was diagnosed with HIV I had finished my studies so it didn't directly affect my studies. However I did take on an accountancy course when I was at the **GRO-B** but I had to stop the course after the first year as I was unable to cope. Mentally I wasn't able to do it with everything I was dealing with. So unfortunately it did effect my potential progress at work.
59. I carried on working after I was diagnosed with HIV, I have always worked. As much as I tried it was really hard to block everything out and focus on work completely but I learnt to do it. I used alcohol as a coping mechanism and I still do to an extent. When I was working early on I didn't see it as a career I didn't think I would live for very long because that's what I was told.
60. Both **GRO-B** and I have always worked. We never stopped. I could never obtain life insurance or medical cover due to the infections. You would expect there to be some help, but there wasn't. I was given infected blood products by those who were supposed to care for me and then had to live with consequences as if being infected was my fault.

61. Because I became so emotionally stunted and believed I would die at a young age, I protected myself by not being as emotional, loving or caring as I should have been. My family and [GRO-B] were the ones who felt the consequence of this. Even though it was subconsciously an effort to protect myself I can see how it has effected my relationships with the people I love.

62. I didn't tell my children about the infections. I only told my eldest daughter in [GRO-B] my youngest daughter still doesn't know.

Section 6. Treatment/care/support

63. The only difficulty I had is obtaining Harvoni treatment. All of the consultant's and specialists at [GRO-B] had been there for a number of years and had built a strong rapport with the hemophiliacs. I always felt I had been supported by them.

64. As previously stated, I was not offered any counselling when I was first told of the infection. I was offered counselling at a later date, but refused it because I felt it was offered too late.

65. As previously stated I started counselling in [GRO-B] and as a result I now I actually like myself. This is a huge thing for me. It is the best thing that I have done for myself.

66. The NHS have offered me counselling that is indefinite and it is something I will definitely take them up on. The biggest regret I have is that counselling was never offered to [GRO-B] as I believe it would have really helped her.

Section 7. Financial Assistance

67. In the 1990s I was offered an ex-gratia payment of £23,500 provided I signed a waiver stating I would not take any further action in regards to HIV or other future infections. I signed the waiver as at the time I didn't know I had also been infected with the HCV.

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68. I was never informed that I could receive grants from the Macfarlane Trust and didn't find out until a few years ago. I had used the whole ex gratia payment to do work on the property my grandparents had left when they passed away. When I became aware that I was able to apply for the grants for things like renovations I approached the Macfarlane Trust. They told me they don't give grants in retrospect. This seemed very unfair. I should have been made aware that such financial assistance was available.

69. Once I was aware of the grants, I did receive financial assistance for new windows and some other menial jobs that needed doing around the house. Everything was means tested and tedious. I would have to provide 3 separate quotes for anything I needed doing. I remember it felt like I was going to them with a begging cap which left a sour taste in my mouth.

70. I also received a Stage 1 payment in the sum of £20,000 from the Skipton Fund. I applied for the Stage 2 payment but it was rejected on the grounds that the level of damage to my liver was just below the amount that entitled me to it. I wasn't offered room for appeal.

71. I approached the Macfarlane Trust for a grant to pay for an IUI as I wanted to have children with GRO-B. This was declined. They said the treatment was too expensive and it would 'open the flood gates' for other couples who had been infected through contaminated blood to apply. This was very distressing for us. Prior to this we were on a trial for IUI and I believe we had 9 attempts before the doctors told us that we were no longer needed as another couple had fallen pregnant. We were told that if we wanted another treatment then we would have to pay for it privately. The price was outrageous and we couldn't afford it.

72. I now receive a quarterly payment from the EIBSS. I believe I started to receive it in the early 1990s.

Section 8. Other Issues

73. We both desperately wanted to have children. However we were not being supported by the NHS or the Macfarlane Trust. As we did not receive any

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support we took a risk under the doctors' advice. We tried for a child on the basis that my viral load was low and my T-cell count high because the risks of **GRO-B** being infected was low. Obviously there was still a risk that was presented but we decided to try. The worst thing was that at the time I hadn't been told that I had the HCV and to this day I still feel terrible guilty from the idea that I could have infected **GRO-B** and my **GRO-B** with the dreadful infections.

74. Our eldest daughter **GRO-B** was born almost **GRO-B** weeks premature. She was in a special baby care unit for 2 weeks and her heart stopped twice. I believe that this may have been caused because of all the stress that **GRO-B** had suffered as a result of the infections.

Anonymity, disclosure and redaction

75. I wish to remain anonymous.

76. I do not wish 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

18/7/2019