

Witness Name: **GRO-B**

Statement No: WITN1406001

Exhibits: 1

Dated: June 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** of **GRO-B**. My date of birth is **GRO-B**. I live with my girlfriend and I work on a zero-hour contract basis.
2. I was infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C virus as a result of receiving contaminated blood products.
3. **This witness statement has been prepared without the benefit of access to my full medical records.**

Section 2. How Infected

4. I suffer from severe Haemophilia A.

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5. I attended boarding schools since the age of 7 as a result of requiring regular Haemophilia treatment. I attended a boarding school in [GRO-B] between the ages of 7 and 12. Between [GRO-B] I attended Treloars School.
6. I received Cryoprecipitate from birth from the [GRO-B] and from the boarding school in [GRO-B] during my time there. When I started school at Treloars my treatment changed to Factor VIII concentrate. I continued home treatment with Factor VIII after I had finished at the school and I returned to the care of [GRO-B] again.
7. My mother and I were never told about the risks of infection following treatment with Factor VIII. I was told that I required treatment for bleeds and that it would ease my pain.
8. I received Factor VIII frequently due to elbow and ankle bleeds. I received the concentrate too many times to be able to even estimate the amount I had been given over time.
9. When I was younger I was under the care of [GRO-B] at [GRO-B] [GRO-B]
10. During my time at Treloars School my treating physician was [GRO-B]
11. I was under the care of [GRO-B] at [GRO-B] after I finished attending Treloars School.
12. I am currently under the care of [GRO-B] for my Haemophilia at [GRO-B] Hospital, who also monitors my HCV.
13. During my time at Treloars my mum visited me regularly. On one occasion she was called into the school by someone in an authoritative position. When she arrived something felt strange and there was something in the air the entire day. She called me into a room with two staff from the school and told me that I had HIV. She was upset and did not quite understand what she was

telling me. I was told that I may have a couple of years to live. I do not know how long I had been infected by the time I had been told.

14. We were not provided with any information in relation to how to manage or understand the infection. After my mum told me we carried on with her visit. When my mum came to visit to me we would go to the local pub or take other children in wheelchairs out on country walks. My mum used to embrace the whole visit but I vividly recall on that occasion it was very different and when we said goodbye to each other we both felt frightened and alone.

15. The way in which my diagnosis was communicated to me was absolutely shocking and I still cannot believe it was done in the way that it was. We should have been told in a private room and given information about the infection and how to deal with it.

16. The way in which I had been informed was very different from many other infected haemophiliacs at Treloars. The usual practice was that a group of boys were called into a room and the doctor would tell each one whether they were infected or not in front of their peers.

17. I was first made aware about having been infected with Hepatitis C in a routine appointment at GRO-B the Consultant Haematologist, casually asked me whether I had given any thought in relation to treatment for my Hepatitis C. I was confused as I did not know that I had been infected with anything other than HIV.

Section 3. Other Infections.

18. I do not know whether I was exposed to a risk of any other infections.

Section 4. Consent.

19. I did not know that I had been tested for HIV. I underwent regular blood tests as a haemophiliac and the nurse used to take full 50ml to 60ml syringes of

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blood from me. I never questioned when I gave blood because it was just a routine occurrence.

20. I was tested without my knowledge, without my consent and without being given full information in order for me to give informed consent.

21. I think I have been used for the purposes of research which makes me feel angry.

Section 5. Impact

22. I have found it so difficult living with the HIV diagnosis and growing up has been a very tough experience. I have never been able to talk about my health condition or infection and for the most part I still live in silence. It makes me feel alone and only my immediate family and a few close friends are aware of my condition.

23. The stigma has impacted me throughout my life and I find it hurtful to this day. Many of the haemophiliacs from Treloars knew about me but we used to keep it between ourselves.

24. I stayed at Treloars after finding out that I had been infected with HIV but I went off the rails and went through a brief period of alcohol and drug misuse.

25. I had a few girlfriends but nothing too serious. When I was 15 years old which was about a year after being told about my HIV diagnosis a young lady arrived at the school and we ended up in a relationship. I did not tell her about my infected status straight away.

26. The school knew about our relationship and the teachers took it upon themselves to telephone my girlfriend's parents to tell them that she was going out with a haemophiliac. I do not know whether they disclosed my HIV status at that time. The teachers asked me whether I had told her about the HIV and pressured me to tell her and said if I didn't they would do it themselves. I had no choice and I felt completely backed into a corner. I took

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my girlfriend to one side and sat her down in a private room. I told her that I was HIV positive and I think because of the adverts with the tombstones she had some knowledge about it. She said that she loved me and that she did not care. She told me that her family had been told and they were not happy that we were seeing each other. Her family removed her from Treloars to prevent us from being together. I remained there and she had to leave against her will.

27. That kind of attitude at Treloars was endemic and these situations happened regularly at the school.

28. After she had left Treloars we stayed in touch although it was very difficult. We used to make sneaky phone calls to each other and I left the school early because I was so devastated by her departure.

29. I went on to attend [GRO-B] and I lived with my mum again. My girlfriend lived in [GRO-B] and we used to meet up secretly. Her parents would not accept our relationship at all and in the end she came to live with me and my mum. My mum took her under her wing. The first time she ran away her family came to collect her but she did not want to go back so we called the police. Her parents claimed that she was not in the right frame of mind and because she was still only aged 17 we could not stop her parents taking her back. The second time my friend and I went to pick her up by car because she did not want to stay with her parents. Eventually her parents realised that she wanted to be with me and they let it go.

30. We spent 10 lovely years together as a couple before we married in [GRO-B] when I was 25 and she was 26. She was born with a hole in heart and tragically she died in [GRO-B]. She was my soul mate and grief tore me apart for years.

31. I remember that I had not started HIV treatment when my wife was alive and I think it was in [GRO-B] but I do not recall precisely when. I had heard stories about the symptoms from the HIV medication and it never appealed to me.

ANONYMOUS

32. In 2017 I underwent the Hepatitis C treatment which lasted 12 weeks. As a result of the treatment I suffered from a lot of anger issues. Since the completion of the treatment I have never felt 'me' again and I would say that I am now half the man that I used to be. I suffered from fatigue and sickness. I was monitored throughout the treatment and I cleared the Hepatitis C within 2 weeks of treatment. Although I did complete the entire course of the treatment.
33. I now suffer from liver cirrhosis and fatigue. I regularly have fibro scan tests for my liver function and I have been told that my liver is extremely scarred. I lost a lot of weight and I still suffer from a lack of appetite. I suffered from jaundice and turned yellow. I continuously suffer from depression, anxiety and night terrors.
34. In February 2019 I suffered from severe abdominal and groin pains. I was monitored but nothing was being done about my pain. During that time, I was taking HIV medication which had been changed because I was suffering with night terrors. I recall that on my day off work my partner woke me up to ask if I wanted a cup of tea. I recall that I lay on the side of the bed trying to get myself together to go downstairs but I collapsed and passed out. I was taken by ambulance to GRO-B and diagnosed with a stomach bleed. All I can remember was being woken up by the ambulance crew. Luckily, the stomach bleeding stopped because I was minutes away from being operated on. I had to spend five days in the ICU and four days on the hospital ward and I am still recovering from that incident, I was told I very nearly died. I have not felt well enough to return to work since that admission.
35. A year after my wife passed away I got a job as a driver transporting special needs children to school locally. I progressed and worked for the local University in the transport of supplies. My employers do not know about my medical condition or my infected status. My job involved shift work which meant that I could rest between my morning and evening shifts. It was a part-time job which I needed in order to stay focussed. After my wife passed away

ANONYMOUS

I thought about killing myself and my decision to get a job helped me to have a reason to get out of bed every day.

36. Once I began working part-time my benefits stopped.
37. Although I feel more functional on my current HIV treatment I still find myself very anxious around groups of people. I have struggled physically and mentally as a result of not working since February 2019.
38. My liver continues to be monitored at [GRO-B] and I am currently under the care of [GRO-B] and my haemophilia nurse both retired in the same year from [GRO-B]. The transition was not smooth because a proportion of my medical records had been lost. I have a small batch of my records dated from the 1970s to 1980s but I do not know what is in there because I have been unable to bring myself to look through them. I am currently trying to organise for my medication to be home delivered.
39. I met my current partner approximately a year after I lost my wife. It was not an easy start to our relationship because I was grieving for my wife and undergoing treatment for HIV. I did not disclose my infected status to my partner but a friend from College took it upon herself and told her that I had HIV. I also found out that the same friend disclosed it to another friend. That friend had completely broken my trust and we parted company for quite a few years.
40. I had a terrible incident with the second friend that had been told. On one occasion that friend grabbed me by my throat and told me that I had put all of his family at risk. For that reason I had no choice but to live with my infected status in silence. That friendship was also torn to shreds for a few years. It hasn't been until recently that my friendships have been rekindled. People are very slowly beginning to understand the reality and the truth about what went on and what the infections mean. It helps to share with people closest to me about what has happened to me but my professional life remains very different to my personal life.

41. The infections have broken my family apart and my mum and sister used to be very close before the diagnosis. I find it very hard to talk, particularly with my sister. I do not think she can deal with it and she finds it very hard. She keeps her distance from us despite living in the same neighbourhood. My mum's health was deteriorating and unfortunately she passed away two weeks after we provided our witness statements. She was unable to sign her statement so I exhibit it to mine under WITN1406002. I think my sister knows that when we both pass away she will be left alone. My sister has her own family and struggles to face what is happening to me.

42. I found it very difficult to speak with my mum because I knew it affected her and I did not want to upset her. I felt a continuous notion of resentment towards my mum because she sent me to those boarding schools and that is where I became infected. On the other side I also know that it ate her up too and I know she was there for me.

43. I attended College to study Animal Care because I wanted to be a vet when I left school. I was a year into the two year course but I left because of the situation with my late wife's family. My life was so complicated at that time and it was too difficult for me to pursue studying. My primary responsibility was to make sure that my late wife was safe.

44. Had I not been infected I would be in a well paid job, spent lots of time travelling, owned my own house, had a family and children of my own. All of which I have always wanted. My current partner and I have tried IVF twice but on both occasions it failed.

45. I have been unable to get life and travel insurance and a mortgage.

Section 6. Treatment/Care/Support

46. I have been petrified to go to the dentist and the thought of disclosing my infected status terrifies me. I am quite sure that it would be difficult to find a dentist who would take me on.

47. On a positive note since the beginning of the Inquiry my friendship with fellow haemophiliacs from Treloars has reignited and it has helped to have other people supporting me through this journey.

48. I have never been offered counselling and I feel that it should have been offered to me. I spent my whole life keeping everything secret and I would find it difficult to speak with people I did not know. I did not receive bereavement counselling and I think I would have liked to have had that opportunity.

Section 7. Financial Assistance

49. My finances depended on benefits until I got the part-time job and then my benefits stopped.

50. I was awarded Disability Living Allowance from birth but I lost it when they changed the scheme. This happened just after I lost my wife and we were living in a council house.

51. I received £20,000 from the MacFarlane Trust a year after I had been told that I had been infected with HIV. This went straight into my bank account and I received no financial advice.

52. During the litigation in 1991 I was told to sign the waiver on the condition that unless everyone signed it nobody would get compensation and I received £20,000.

53. In the late 1990s I received the Stage One payment of £20,000 from the Skipton Fund. This was automatic and I tried to make this money last as long as I could.

54. I had avoided filling out the Stage Two forms because I found it difficult to face the application. The sheer anxiety of having to bring my experiences to the surface again prevented me from applying. When I finally found the courage to do it they turned me down.

55. I receive approximately £1,500 per month from the EIBSS.

56. I believe that my mum applied for a fridge and I think the process was relatively straightforward. I think she had to obtain three estimates for the item in order to obtain the grant. However, my mum struggled financially as she was a single parent and she did not receive any adequate financial help.

57. I simply did not know that any financial assistance was available and I find it stressful to have to apply.

Section 8. Other Issues

58. I want to know whether my Local Authority were aware about what was going on at Treloars School before they sent me there.

ANONYMOUS

Anonymity, disclosure and redaction

59. I do wish to apply to retain my anonymity and understand that my statement will be published as part of the Inquiry.

60. 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.....

1-6-20