

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2734001

Exhibits: WITN 2734002/4

Dated: 8th April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I, **GRO-B** will say as follows:-

Section 1. Introduction

1. **GRO-B**
GRO-B
GRO-B

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

3. I was infected with HIV and Hepatitis B, C and E as a result of receiving contaminated blood products.

Section 2. How infected

4. I suffer from Haemophilia A classed as mild with a clotting factor of 8% and was diagnosed in or about 1973, as my brother was a Haemophiliac.

5. I have been treated at the Royal Victoria Infirmary (RVI) Haemophiliac Centre, Newcastle upon Tyne since birth. Initially under the care of Consultant

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Haematologist Dr Peter Jones, then Dr Hamilton and now Dr Kate Talks, and Dr M L Schmid, a consultant in infectious Diseases.

6. I was treated with Cryoprecipitate up until about May 1980 when I was to have my tonsils and adenoids removed. I was 8 years old at the time. However the surgery didn't go ahead as I had an adverse reaction to the Cryoprecipitate and developed an acute allergic pulmonary oedema whilst being prepped for surgery. I refer to **Exhibit WITN2734002**. I believe the only reason I am still alive is because a man visiting the patient in the bed next to me ran to find a doctor.
7. I just remember a scratch on my right hand from Dr. Jones and I came back to consciousness. I was taken for an X-ray of my lungs to check everything and I was sitting in the x-ray department with my father and Dr Jones when my father asked Dr Jones what he could do if I had a bleed he replied "we have this new fantastic and revolutionary treatment called Factor VIII, it will change your life", and from then on I was treated with Factor VIII. I believe this was when I was infected with HIV. Since this time I have received Factor VIII on various occasions. I refer to **Exhibit WITN2734003** which is the information received from the National Haemophilia Database ("NHD").
8. Neither of my parents were given any information or advice beforehand about there being any risk of being exposed to infection from blood products.
9. My father was told I was HIV positive in or about 1984. We had been at the RVI and were about to go home, when Dr. Jones came running out and asked to speak to my father. At the time I didn't realise that, Dr. Jones was telling my father I was HIV positive. I was aged 11 coming up to 12 at the time and I didn't know what was wrong but I do remember that he came out the hospital with red eyes. I had never seen my father cry before. My father told my mother and brothers that I had HIV but he did not tell me until much later.
10. Over the next 18 or so months my mother, father, and brothers started to change in the way they treated and talked to me. It felt like everyone's attitude towards me changed. I started to notice little things; my brother GRO-B

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wouldn't play with me; my eldest brother [GRO-B] would read out loud an article in a newspaper about the government setting up a trust for Haemophiliacs who had contracted HIV, giving out small hints such as "£8250, imagine what you could do with that money?" [GRO-B]

[GRO-B]

11. Although it had started to sink in that I may be infected with HIV. I was stuck in a horrible position as I was not able to speak to my parents because I didn't want to just come straight out and ask "do I have HIV?". We were all in a difficult position as we all knew but couldn't say anything.
12. I have been told by my father that he was not given any advice or guidance on how to deal with or manage the HIV infection or about the risks of others becoming infected. One day I came home with a cut eye after a boy with a ring on had punched me. There was blood everywhere, my father didn't know about the risk he was putting himself in and helped clean me up. It was lucky he didn't contract anything.
13. I used to go into the bathroom and talk to the mirror as I felt I had no one else to talk about it to. I used to whisper so no one else could hear me, "you've got it no wife no kids" which was a huge blow for me as even then I wanted kids.
14. I now know that I tested positive in 1983, about 8 months before they told my father. It was suspected to be the first the batch of Factor VIII which infected me.
15. In or about 1986 (nearly two years after he was told) my father told me that I had HIV. I understand now how hard having to tell your 14 year old son such awful news must have been. He waited until everyone was out of the house. I was lying on the floor next to the heater and my father was sitting in front of the television. He asked me to come and sit next to him, and he put his arm around me. Normally I would fall asleep next to him however my father and I were not huggy or touchy feely, so it felt different. He said 'you know in the papers they have all the stuff on the Haemophiliacs'. I think it was my dark

sense of humour that made me think at that moment, should I tell him I know, or let him struggle on but I could not do that to my father, I said " I have it don't I " and he said "yes" I had already done my crying in the bathroom so I did not cry but I turned and asked my father "am I going to die?" and he replied "No" My mum came home and just looked at us and my father said "he knows" and she burst into tears.

16. My father installed in me the attitude 'its mind over matter'; if you don't mind it doesn't matter. I am living with it and I've been through the worst of times. I had a friend who died aged twenty one and His mum held his hand for six months until he died.

17. I was completely unaware I was Hepatitis C positive until February 2000. My son would have been only a few months old and I was lying in bed with him. A around 8:30am, I heard the postman, and a little later my wife came upstairs very angry and wanted to know why I hadn't told her I was Hepatitis A, B, and C positive?" I replied " I didn't know that I was", and she showed to me a letter from the Haemophilia Centre (which she had opened) which confirmed it. I eventually managed to persuade my wife that I had not known I was infected and we agreed and that I would find out more at my next appointment with Dr Hamilton.

18. What appears to have happened is that, as we had just moved to **GRO-B** **GRO-B** and needed a new GP, the Haemophilia Centre sent information about my last appointment (to my house rather than my GP) so we found out that I had been infected with Hepatitis A, B, and C by accident.

19. I attended the appointment with Dr Hamilton and after he told me everything was okay, I asked him how long I had Hepatitis. He replied "Oh don't worry we told your parents in 1990" I was surprised as I was sure if they knew they would have told me so I queried this and Dr Hamilton reassured me they had been informed, and went on to say "don't worry about it you cleared it all naturally". I went home and asked my parents and they were adamant they were never told. (This was not something you would forget). As I was 18 in

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1990 Dr Hamilton had no right to tell them and, if he had, it would have been a breach of his duty of confidentiality to me.

20. According to the NHD records I was jaundiced in April 1982, this information was kept from my parent's and I for about 18 years and only revealed by accident as set out above, although the date seems incorrect as the medical records I have been able to obtain show I tested positive for HBs antibodies in February 1981. I refer to **Exhibit WITN2734004**

Section 3. Other Infections

21. I received letters from the NHS in 2004 and 2009 saying I was at risk of vCJD as a result of receiving contaminated blood.

Section 4. Consent

22. I believe I was tested without my parents or my knowledge, consent or adequate information being provided, and for the purposes of research. The tests taken for HIV and Hepatitis are examples of this practice as we had no idea I was being tested for these infections.

Section 5. Impact of the Infection

23. In 1981 I went with my parents to see Dr Jones as I was jaundiced, and feeling tired and all he told me to do was to go home. Although I cleared the Hepatitis B infection naturally it was an extremely hard time.
24. My parents and I went to Edinburgh in or around 1983/84. I had been ill for a while however this time I was really bad. I thought I was going to die. Every joint hurt, I couldn't open my eyes. I had already lost a lot of weight; I had gone from a normal sized child to seeing my ribs and stomach inverted. We were on an escalator, going up and my parents had to hold me up I was so weak. I asked them last week if, at any point from when they were told to now, "did you think I was going to die?" They both responded "yes in Edinburgh".

25. I went a bit wild between the age of fifteen and eighteen I took drugs and got drunk, and generally got into trouble. At the time I felt like I had a death sentence hanging over me. However when I met my wife to be [GRO-B], I stopped all that. She saved my bacon!

26. My wife and I met because her [GRO-B] She was fifteen and I was eighteen. I didn't tell her about my infections straight away and my family often used to say "why haven't you told her?" It was difficult as we had just started going out so it was too soon and then the next thing it's after two years and too late. After a while I wanted to tell her, but I realised I loved her, and I didn't want to hurt her. I recall that I broke up with her at one stage, so she could have a family and because I couldn't face telling her. However, a week later we were back together but I still couldn't tell her.

27. In early January 1999 I went skiing with some friends. Before I left, [GRO-B] told me she was pregnant. I called every night during the holiday, and when I got back I became ill from all the worrying about whether she and the baby were infected, and her possible reaction to me telling her about my infections. [GRO-B] went to her doctor a few days later and he confirmed that she was pregnant and she rang and told me. I instantly felt the colour drain from my face; I was so worried I cried my eyes out. [GRO-B] came to the house that night and just comforted me. Once she had gone I went downstairs to sit with my parents and told them the situation. My dad jumped up and said "we will sort it".

28. We had to go to the hospital as I had become very ill. I was told by one of the nurses my antibody count was two above full blown AIDS. The nurses put me in a cubical and took all razors away. This was the one time I felt like I had had enough. [GRO-B] kept ringing and wanted to come and see me but I said I was too ill. However, [GRO-B] ignored me and came to see me with Maureen Ferens, my nurse and I finally summoned up the courage to tell [GRO-B] I had never heard half the swear words I heard that day.

29. **GRO-B** went with Maureen to her office to be tested immediately for HIV.

While she was waiting for the results she then came back and asked me a lot of questions which I wasn't in a fit state to answer. However, after **GRO-B** got on to the bed and hugged me, Maureen came in and said **GRO-B** was negative. I called my parents and told them. My feeling of relief was indescribable. However I was still terrified of her telling her parents and their reaction. I went with **GRO-B** to see her parents after she had told them and they both hugged and me then kissed me on the cheek. It had been an emotional roller-coaster of a ride to get to this point.

30. When I was told I was HIV positive there was little or no treatment available.

However In or about October 1988 I took part in a clinical trial, a randomised double blind placebo controlled study to determine the efficacy of Zidovudine (AZT) and was treated with 50 mgs Dapsone 50 three times a week and Vallerigin 10mgs weekly (The Concorde trial) which lasted several years. I was also on Combivir 1bd, Indinavir 600mgs tds, Nelfinavir 1250 twice daily (this was changed to Effivirins 600mgs 3 times a week in 2001) I believe I was receiving AZT. In 2006 I changed from Combivir to Truvada.

31. Dr. Hamilton once said he would prescribe a drug which wasn't licenced and he could get in trouble. I don't understand how he would have been able to do this. When the Inquiry started my current specialist Dr.Schmidd asked me , "how much trust and confidence do you have in me?" I replied "80%, as Dr. Jones was my old doctor and I thought he was treating me like a son, which I now know he wasn't"

32. I have experienced many side effects from the various treatments I have received for HIV. A few examples include stomach cramps, bloated stomach, sickness, fever, night sweats and gross fatigue. I still have night sweats to this day but luckily my teeth are not too bad. A possible side effect of the drugs I'm on today is brittle bones. Sometimes if I take the medication less than an hour before bed, I can feel tipsy it's not pleasant. If I move my head too quickly it takes a while for my brain to catch up. One of the first times I experienced this

side effect I couldn't even get up the stairs. I have lost a lot of my hair which I believe is down to the medication, as my father still has a full head of hair. I have also lost 5% or more of my body weight.

33. I have had kidney problems: intermittent- Renal colic, caused by one of the drugs I was taking. I first experienced it with Dr Jones and then Dr Hamilton. It took about 8 years for them admit it could be one of the pills I was taking. I now have to keep hydrated otherwise it feels like someone is putting a knife into my kidney. The last time it happened I had to leave work, I couldn't move I tried to get home but couldn't, so went to my parents house and curled up into a ball and cried and screamed with pain. My father took me to hospital and I spent 3 days in the RVI.

Stigma

34. In the early days, the stigma associated with HIV was especially bad and made worse by the governments AID's campaign with the "Don't die of Ignorance" slogan.
35. One of first times I experienced the stigma was after I was aware I was HIV positive. I went to see Dr Jones who had carried out many examinations but now that he was aware that I knew I was HIV positive there were a few extra questions. He asked "what is my sexual orientation" and carried out an anal examination. When I questioned this he said he was "checking my glands".
36. As time went on people on the estate knew we were haemophiliacs and therefore associated us with HIV/AIDS. On one occasion my GRO-B and GRO-B went to the local chip shop and group of boys followed them and them started chanting "Have you got Aids yet!?" My GRO-B kept going but eventually had enough and turned around and dealt with them because it wasn't him, it was me they were talking about.
37. I have always attended the RVI dental hospital and I have had no issues with dental care. Apart from one occasion; when I was about 19 and I needed a

tooth extraction, I didn't go to the regular area, at the hospital I went to the general out patient's area. I remember the dentist closed the door, I didn't understand why as it wasn't partitioned well. He turned around and said "well I have your medical notes and I see you have AIDS how did you get it? Shooting up?" I turned around and said "no it's because of you bastards". He shoved cotton wool in my mouth to shut me up.

38. Even today people think HIV = gay or drug addict It doesn't matter who you are or what you do, the discrimination is everywhere. For instance I went to work a couple of months ago and the supervisor had tried to get some staff fired. He came to the bay and acted like he wanted to be included in the conversation we were having but no one liked him so no one talked to him. As he was leaving one of the staff members said 'He deserves to get AIDS' This is just one example of the ongoing prejudice against HIV sufferers and the stigma which is still associated with the diagnosis of HIV.

39. In fact, I have only recently told my **GRO-B** that I am HIV positive. My **GRO-B** still doesn't know as I don't think she would cope very well with this knowledge so I have decided not to tell her at this time. This is, of course, added stress for the family.

40. The effect on my education was huge. I missed three out of five years of high school. My condition affected my attitude towards school and probably went hand in hand with going off the rails. I didn't achieve any GCSE's as I was in hospital. I had an interest in Geography and Geology however with no GCSE's it was difficult to pursue this interest.

41. When I look at my son now I push him hard because I didn't have the opportunities he now has and I want him to advantage of them. I am a little envious as HIV has deprived me of a career I may have enjoyed.

42. However, I was also was lucky in some ways. After my father learnt of my HIV diagnosis he was worried that I would struggle to find employment so he

decided to quit his job at the GRO-B and set up a business I could work in. The business took off and was very successful and I received a good wage without having to do much work as my father didn't want me to have the stress of working full time, however, this upset me because my family were doing all the work and I was having the benefits.

43. When my GRO-B was 18 month old I felt very down about the situation as I didn't want GRO-B to have a bad work ethic so it was agreed I would start working for the family business.

44. I think it's been hard for people living with me, as they are worried and trying to be careful all the time. I believe that it ahs been hardest for my mother, she started anti depressants about 35 years ago and is still on them now. My father doesn't talk about how it's affected him; I think it's been hard. It is only natural. Whilst there is said to be no rule book for bringing up a kid there is definitely no rule book on bringing up a kid with HIV.

Section 6. Treatment/care/support

45. There was one occasion when I went for a check up, at the RVI the nurse said if I was ill say with the flu I should go to a GP not the hospital, I replied "I was told to come back here whenever I felt my health was at risk so I will keep coming back". When I went back for my next appointment a doctor pulled me aside and asked me what happened and that I had made the nurse cry. I had to explain to him what happened.

46. Neither I nor my parents were offered counselling or psychological support to deal with the situation until recently. Only in the last 2 years. The support back then was non existent. Dr. Jones said "you have more chance of dying by being hit by a bus then HIV".

47. My HIV medication has changed recently from one pill to two and I understand this has only been done for financial reasons. And I think this is wrong.
48. I was initially awarded welfare benefits "for life" and the person making the award was in tears after hearing my story. [GRO-B] one of the social workers, asked if I was working with the family. I said I was about to start, and a week later I started receiving letters asking for my car back, and my other benefits were cancelled. That month we had to pay full mortgage, insurance and bills we had £27 for two weeks. I am sure it was her as the only others which knew were my family.

Section 7. Financial Assistance

49. We have received some financial assistance. My parents received on my behalf £32,000 plus an additional £1000 for each of them from the McFarlane Trust ("MFT"). [GRO-B] our social worker at the time helped to secure this, in addition my father received an £1800 grant to start his business. When we first applied to the MFT for the grant they refused. He told them it was for a business for me. [GRO-B] got in touch and argued with the MFT on our behalf. One night one of the directors of the MFT and Dr Jones and someone else came up to see us and they argued and this went on for months however eventually they caved and gave it us.
50. At first I was received £250 per month from the MFT and after a few years it was increased £500. When my father sold the company I reapplied and I now receive roughly £1400 monthly.
51. We have not received any money from the Skipton Trust because I couldn't show the ill effect of Hepatitis C on my life. I even went to my MP, but he was useless. I've tried to claim about three times but because I cleared the Hepatitis C naturally they say there is no way to prove the ill effect it has had on my life.

52. I have had issues with Trusts; the money should be taken away from them and distributed equally to the remaining families which are left.
53. Although the EIBSS have all my details I have to re-apply and send in all my details every year when nothing has or will change. [GRO-B] my present social worker helped us battle for money; she said she felt like she was banging her head against a wall. They did not believe my wife stayed at home and they thought the reason we hadn't claimed benefits for her was because we were lying and that she was working. I have been infected with multiple infections through no fault of myself and they are making me jump through multiple hoops just to live.
54. When I spoke to the EIBSS the girl on the phone was reading off a script. I emailed them saying [GRO-B] had my permission to talk to them about me and received confirmation that they accepted that. However, a month later [GRO-B] called them, as we had no movement and they said that they had received her letter the previous month but could not open it because they didn't have my permission! I had to call them again and point out they already had my permission and that they had confirmed this. A month later they back dated the payments. This was one of the hardest 3 months of my life.
55. I do not understand why it is so hard to obtain support? It should be made very easy; they have access to records, and documents. Why do we have to keep doing this? When I work I try to do overtime. In December my wage was low, In January I had a lot of overtime however in February my wife was ill so the money was very tight.

Section 8. Other Issues

56. I want the truth about what has happened and who is responsible for it to come out. I would like the people responsible to be held accountable. It is impossible to deny that there has been cover up once you see the evidence. I

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don't just want the local doctors to catch the fall I would like the people at the top to be revealed.

57. I would like Dr Jones to be called to give evidence. I would also like Maureen Ferens, to be called give evidence as I was close with her, and she was like a mother to me in hospital, [GRO-B] as she and Dr Jones were very close friends. She has been around the world with Dr Jones going to Pharmaceutical company seminars. I want her to tell the truth; also as I was close with her I want to know whether she knew or not.

58. I would like to thank people like Jason Evans for starting the shouting. When I found out about the Inquiry I burst into tears [GRO-B]

59. I understand the MFT are transferring or have transferred all my personal data to the Terrace Higgins Trust without my consent and I would like this action to be investigated.

Anonymity, disclosure and redaction

60. I wish to be anonymous and do not wish to give evidence.

Statement of Truth

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

Signed

[GRO-B]

Dated..... 8-4-2019