

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1452001

Exhibits: WITN 1452002

Dated 21 March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

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

Section 1. Introduction

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2. I make this statement as the **GRO-B** **GRO-B: F** **GRO-B** who was infected with HIV, Hepatitis B and C as a result of receiving contaminated blood products and **GRO-B**
3. This statement has been prepared without the benefit of access to my fathers' full medical records.
4. My mother has also provided a Witness Statement to the Inquiry dated 8th March 2019 (WITN1330001).

Section 2. How Affected

5. My father had severe Haemophilia A with 0% clotting factor and attended the Haemophilia Centre at Lord Mayor Treloar College ("Trelors") near Alton in Hampshire under the care of Doctor Aronstam and Doctor Wasseff where he was treated with Factor VIII products Kryobulin, Cutter VIII, (Koate) and Travnil/Hyland/Hemofil from about 1968 until his death in GRO-B 1995. I do not know where he was treated prior to 1968 although I am aware his family lived in Herefordshire. I refer to the National Haemophilia Database ("NHD") Records at Exhibit WITN1452002.
6. As far as my mother and I are aware no information was given to my father or his parents about there being any risk of him being exposed to infection before he was given Factor VIII products.
7. I understand from my mother that my father found out that he was HIV positive by letter in 1985 whilst she was pregnant with me. He first tested positive for HIV in 1984 (prior to my conception) as shown in the NHD records. The delay in informing him of his HIV status, put myself and my Mother at terrible and unnecessary risk. Being informed by letter was a terrible way to find out and certainly not a secure way. We lived on a busy housing estate where mail was delivered to the wrong addresses regularly. Should this letter have been opened by someone other than my mother or father, the resulting social stigma for my family would have been catastrophic.
8. My mother informed me that she and my father were given very little information about the HIV infection and how to manage it.
9. The doctors certainly did not provide adequate information on how to reduce the risk of being infected. We had no idea how bad it was until the terrifying government adverts started appearing on TV and in the newspapers.

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10. My father found out that he had Hepatitis C around 1986/87, long after he contracted it in March 1974, as shown in the NHD records. At the time it was called Non A Non B Hepatitis. It was presented to him as being of very little consequence. He was told that the HIV infection would kill him long before he ever needed to worry about having Hepatitis.

11. I consider my parents should have been given adequate information as soon as my father tested positive for HIV and Hepatitis C.

Section 3. Other Infections

12. I am not aware if my father was infected with any infections other than HIV and Hepatitis C.

Section 4. Consent

13. I believe that my father was treated and tested without his knowledge or consent to do so and without being supplied with full or adequate information as the records from the HND refer to "Dr Craske research work" and my father would not have signed up for this.

Section 5. Impact of the Infection

14. I remember when I was about 8 or 9 my father having what I was told at the time was a mental breakdown. He was quite scary to live with. He was incredibly paranoid and couldn't sit still and would always be looking out the window worrying that people were looking in and watching him, there was a couple of times he went off missing. I can remember going out with my Mum to look for him. I can remember being very scared.

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15. Due to my father's ill health in his final years he had to retire early and that was a big blow for him. He was proud of his job. Retiring in his mid-thirties was humiliating for him.
16. Before he became ill, he enjoyed working with his hands and would make me all kinds of things. He made me a full-size slide, dolls furniture, a hutch for my Guinea pig and other things, however once he became ill that all stopped and in the last couple of years of his life it hurts me to say but I was scared to be around him.
17. I remember he would use pineapple juice to try and reduce the thrush in his mouth.
18. As the illness progressed, he had little patience for my brother, and this has affected my brother's life a lot as he suffers from depression and has had problems with drink and drugs.
19. I was aware of a shotgun in the house and my father's suicidal thoughts. At points he became childlike, I can remember meal times in particular being very stressful. My mother was trying to teach my younger brother table manners, teaching him to use the knife and fork but my father would also not use his knife and fork; which caused a lot of stress for my mum. I can remember my Father staying with his parents in Wales when he was ill. I felt guilty as it felt he had been sent away. I know my grandmother struggled with my father's behaviour and physical illness as I heard my mother talking to her on the phone and it was clear she was complaining about him, and this made me resent my grandmother and really affected my relationship with her in the last part of my Dads life.
20. I remember my father going into respite care. It was really far away. Again, I felt guilty that he had been sent away. It was meant to be a respite however my mother would visit every day. I went to visit my father whilst he was in respite. I didn't understand why he was there. He was very unhappy to be

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there. It made me sad. The place smelled musty and like disinfectant. I felt very guilty when it was time to leave.

21. When my father died, we lost his side of the family, I think they had a lot of guilt and shame about AIDS and the stigma attached so they disowned us. The Haemophilia came from their side of the family. I am a carrier for Haemophilia, which has had a major impact on the choices I have made about starting a family of my own. My paternal grandmother and auntie are also carriers for the gene. Since they broke contact with me, I have not had anyone in my life that I share this experience in common with. I have had no one to talk to about it. When my father died, I not only lost him, but the whole of his family. This has destroyed part of my roots. There is no one who can tell me about my fathers childhood. There is no one who can tell me my medical history on my father's side.

22. My father died a couple of days after my birthday. I felt isolated at school. Everyone had been briefed, that he had died, it felt like everyone was looking at me and talking about me. The kids asked horrible questions, such as 'did you see him dead'. My father dying was a complete shock for me. I didn't realise that would be the outcome. I knew he was ill, but I had no idea that he would die. My mother came into my bedroom to wake me and tell me that he had died. I also remember my mother telling my brother, who screamed and tore at his face. From then on, I had to grow up quickly. My mother struggled for a few years. I felt I had to be the adult from then on.

23. Something I am bitter about is not being allowed to see my father when he was in hospital when they knew he was dying. My mother asked for me to be allowed to visit, but my father was in isolation because he had HIV and children were not allowed in his room.

24. In my adult life I've have had to deal with depression and anxiety. I have struggled with thinking people I care about will die on me and I feel especially

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anxious that people I love will commit suicide. I was very aware of my Father being suicidal when he was ill. My mother also told me when I was a child that she had attempted to drive her and my Father into a wall at speed, with a wish to kill herself and my father. He was really unwell, and she could not cope. My brother has been suicidal too and has made attempts on his life. All of this stems from the infected blood my Father was given and the catastrophic effect his illness and death had on my family. I live in fear daily that someone I love will commit suicide

25. We lived on a housing estate, and when my parents found out about the HIV infection, they wanted to move to the country side to live more anonymously. . They were desperately worried that someone would find out my Father had HIV. They had heard of other Haemophiliacs having 'AIDS Scum' graffitied on their properties. I became isolated as we didn't have people over and I couldn't go over to my friends. My family didn't want anyone to know my father was a Haemophiliac because of the instant association with HIV. My mother told me not to tell my friends that my father had died of AIDs, this put a lot of pressure on my shoulders. I thought my mother was wrong for asking me not to tell anyone. However, since the Inquiry, I have met people whose relatives died around the same time and they were labelled and sometimes even had to leave school due to the stigma, so I now realise my mother was right. It affects your relationships with people when you can't be open with them from the start. Until very recently I had told very few people about my Father having HIV and dying of AIDs. Sadly, when I have told people, even in these more enlightened times I have had some negative responses. People have assumed I have HIV and have been scared.

26. As mentioned in paragraph 18 my brother has battled mental health issues and drinks and drug problems. I consider these issues and problems are a result of losing our father and how and why he died.

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27. I left school at 16 and tried to go college however I couldn't settle as things at home were not good, my brother had started his downward spiral. It just didn't seem important to compared to other things I was dealing with. I have as an adult completed a Masters degree in Human Resources.

Section 6. Treatment/care/support

28. I am presently having counselling, which I pay for myself however it is becoming too expensive. I have contacted the EIBBSS to see if I could receive support for the counselling and their answer was a straight "no." Additionally I have tried the number on the Inquiry website however it is a crisis line rather than therapy.

29. I was never every offered counselling or psychological support when I found out my father was infected or when he died.

Section 7. Financial Assistance

30. I am not sure how my mother paid the mortgage as she didn't work. Losing my father took away my opportunity to go to university. I have not received any financial assistance from the Trusts or Funds and no one has given me any information about the Trusts or Funds giving assistance.

31. I refer to paragraphs 45 to 53 of my mother's statement which provides all the information in relation to the financial assistance she received.

Section 8. Other Issues

32. It is upsetting that my father was part of some research that he was unaware of. He wouldn't have wanted to be. No one offered us support or anything at the time so why would he have wanted to be part of research? All the affects and times I have described above were bad enough, but to then to find out he

was part of secret research makes me feel angry. It makes me feel like my father's life and wishes was considered of no value. He was given no dignity.

33. What has happened is horrible and awful but not having the truth is worse. It feels like 'gas lighting'. You know what happened, the evidence is there that the risks of giving these blood products were known. But you are told no, you are told you are wrong. You start to question your own sanity. It feels like a conspiracy of lies and silence. If you started talking about this with people who had no idea about the contaminated blood scandal it is the sort of thing that would get you sectioned. I am scared of what I will find out as the inquiry progresses.

34. I am worried that we will go through the whole process, and the Inquiry will make recommendations which will not be accepted, or they will just be forgotten, and it will be just like nothing has been done. It would mean the world for someone to stand up and say sorry properly. I just want closure so I can move on in my life.

Anonymity, disclosure and redaction

35. I wish to be anonymous, but I would like to give oral evidence.

Statement of Truth

I believe that the facts stated in this statement are true

Signed

GRO-B

Dated

21/3/19