

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1154001

Exhibits: 0

Dated: April 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B. I was born on GRO-B and I live at GRO-B.
GRO-B
2. My son, GRO-B:S (born on GRO-B, was co-infected with the Hepatitis B Virus (HBV), the Hepatitis C Virus (HCV) and the Human Immunodeficiency Virus (HIV) through contaminated blood products. GRO-B's health deteriorated, advancing to AIDS Related Complex (ARC) and he died on GRO-B aged GRO-B.
3. My son S2 (born on GRO-B, was also co-infected with HBV, HCV and HIV through contaminated blood products. S2 had a brain haemorrhage and died on GRO-B aged GRO-B.

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4. My daughter, [GRO-B:D] has provided a Statement to the Inquiry on 17th March 2019 (under Witness Number WITN2725001).
5. This witness statement has been prepared without the benefit of access to [s1] or [s2] full medical records. I have tried to obtain [GRO-B]'s medical notes and records without success. I was ultimately informed by the health authority that they had been destroyed in a fire. I have not endeavoured to obtain [s2] medical records. [s2] was married and his widow is his next of kin.

Section 2. How Affected

6. [s1] and [s2] were diagnosed with severe Haemophilia A at birth. [D] and I are haemophilia carriers.
7. My boys were initially treated at the Pendlebury Children's Hospital in Salford under the care of Dr Evans (and a Dr Stevens who curiously killed himself in the 1990s). The boys then attended the Lord Mayor Treloar College, Hampshire boarding alongside a large cohort of haemophiliac pupils. [s1] joined the school from September 1978 and [s2] joined the school from September 1979. The boys received treatment from the haemophilia centre at school under the care of Dr Wassef and Dr Aronstam.
8. Manchester Royal Infirmary (MRI) was responsible for the boys' treatment away from school and after they had left school. Dr Charles Hay was one of the consultants there. The boys were responsible for their own haemophilia care after they left school. Parents were frozen out and discouraged from attending appointments with their sons once they reached majority age. My knowledge of the advice and/or information the boys were provided with is therefore limited from when they reached adulthood.
9. My husband died when the children were young. I was never pre-warned about any risk of infection through Factor VIII (FVIII) blood treatment. I was

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told that FVIII concentrate would enable my sons to live a normal, healthy and full life. I administered their treatment at home on a prophylactic basis and until they were old enough to treat themselves.

10. In August 1985 I received a letter from Dr Evans in the post (and that in itself was strange given that the boys were no longer under Pendlebury) informing me that the boys had tested positive for HTLVIII. The letter was a bolt out of the blue but the gist of the letter was that it was not something I should worry about. The term 'HTLVIII' meant nothing to me. I knew that HBV could be passed on through treatment (I think that by then the boys had been infected with HBV previously) and I thought HTLVIII to be something transient like that. I wasn't too concerned as I didn't know what HTLVIII meant until later on.

11. At the time, I was unaware that some of the boys at Treloars were HIV positive. A strange incident had occurred when [redacted] and I went to visit the boys at Treloars over an exeat weekend (most of the other boys had gone home) in the early 1980s. The remaining boys were called into the hall (without us) for a meeting. I remember asking the boys what the meeting had been about. [redacted] s2 remarked that it had been about 'aids'. Given that the school accommodated disabled children, I thought the word 'aids' meant mobility aids like wheelchairs and frames. [redacted] s2 then corrected me. He said 'No, no. It was about AIDS mum and haemophiliacs in America. They said we were not to worry. We won't have it here.' I have since reflected as to why, as a parent present at the school, I wasn't invited into that meeting and why the parents were not informed of the concern. I was not aware that the boys were being tested for infections.

12. I became aware that the boys had HIV through the extensive media coverage. No information or advice was given to me. I was a single parent with no-one to discuss my fears with. I drove the boys mad with my own warnings to stay safe and use protection. I know that the boys seroconverted between June 1982 and April 1983. That time period was established through the later involvement of Pannone Napier solicitors in Manchester due to the

HIV litigation. I wasn't notified that the boys were HIV positive until I received the letter from Dr Evans in August 1985.

13. Some time after [s1] death in 1992, [s2] was informed that he was HCV positive. We then made enquiries and were informed that [s1] was also likely to have been infected with HCV. Eventually, and after some denial and uncertainty on the matter, I received a stage 1 Skipton Fund payment for [s1]

Section 3. Other Infections

14. [s2] was notified that he was exposed to vCJD. I suspect that [s1] was also exposed to vCJD. I have an underlying fear that [s1] had vCJD and that the infection played a part in the very distressing way [s1] died.

Section 4. Consent

15. I had no idea that [s1] and [s2] were being tested for HIV. They were undoubtedly treated and tested without my knowledge and consent and without adequate or full information.
16. I also believe the boys to have been tested for the purposes of research although, at the time, it never even entered my head.

Section 5. Impact of the Infection

17. The HIV diagnosis was of course horrendous for us all. The boys were then in their late teens. They were careful about what they told me to include what they themselves had been told in terms of life expectancy. I think that they were trying to protect me. [s1] was angry and incensed about it and [s2] was in a state of denial. We kept it to ourselves and didn't tell anybody outside of the family. That became difficult when people started putting two and two (haemophilia and HIV) together. Through the fear and stigma associated with HIV/AIDS, the boys' lives were turned upside down.

S1

18 S1 had physical limitations through having a brain haemorrhage at 6 months old and he was left with poor co-ordination. He always disclosed his haemophilia to prospective employers. He found it almost impossible to find work because of the fear and stigma associated with HIV. He was a charming, articulate and capable person. He found that he had a talent in sales and was excellent on the telephone. He started one particularly job and was called in to be told just how impressed his new employer was after just one week. The very next week it was an entirely different story and, out of the blue, he was told that he was fired. He asked 'why?' and they said that they didn't have to give him a reason.

19 S1 was very determined and he tried really, really hard. He often got up and ready in the morning in order to set off on the train to Manchester with the intention not to return home until he had secured a job. He had lots of knock backs. In the end, S1 started his own company and, on day two, he was headhunted and offered a job. After a couple of weeks S1 boss took him for lunch and he asked him whether he had HIV. S1 ever honest, told him the truth and his boss said it was not a problem provided S1 told the rest of the staff. S1 then bravely informed his colleagues of his HIV diagnosis at a meeting, explaining in detail how haemophiliacs had contracted HIV through their FVIII treatment. Some of the women in the office talked to their husbands at home and came back and reported that their husbands were not happy about S1 being employed there. S1 was elated when his boss informed the women (not S1 that they would then have to leave. S1 worked until he became too sick to continue.

20 S1 was very courageous. He went on to do radio and local TV interviews in order to highlight what had happened to him and other haemophiliacs. He did a fantastic job as he had to be very careful not to mention S2 and my brother, GRO-B:B (also infected with HIV through contaminated FVIII

concentrate). They did not want others to find out about their own HIV infections.

21. [s1] mental health really suffered. He was under so much stress that he had a mental health break down in the latter part of his life. [s1] physical health was also very badly affected. He was in and out of hospital all the time and in the 12 months before his death his health deteriorated rapidly. He was so thin through dramatic weight loss and he also lost his eye sight. He became confused with what appeared to be dementia, agitated and angry.

22. [s1] was always ordinarily such a gentle, very kind and considerate young man. He was extremely popular. When [s1] died (at just [GRO-B] years old) there were around [GRO-B] people at the funeral. Before [s1] death I had heard about funeral directors refusing to accept AIDS victims and that worried me. I had however heard that the Co-Op had had the requisite training and they were very good.

[s2]

23. Both my boys were real characters. [s2] had a different approach to [s1]. He had a 'this is not going to get to me' attitude. His way of dealing with being infected with HIV was to shut the door in his mind to what had happened. [s2] only told two very close friends and the very few that I told were also very supportive. [s2] kept his health issues to himself and was able to work all the time, doing a variety of jobs to include car sales and working as a driver and car sales.

24. [s2] was very outgoing and had a lot of friends. He never (outwardly) took things (to include himself) too seriously. He was a real joker. He played drums in a band and learned the guitar. He worked hard and did very well. He married and whilst having HIV proved difficult for him in getting a mortgage, he eventually obtained one (on an interest only basis with an endowment) and bought his own house.

25. s2 had a brain haemorrhage on the anniversary of s1 death 17 years later (and s2 then died two days later). It was so sudden and out of the blue. s2 didn't tell people that s1 died with AIDS. Ironically, he always told people that s1 had died after a brain haemorrhage.

Section 6. Treatment/care/support

26. The boys were given AZT as a drug trial for HIV. They were both poorly and suffered with depression but they were urged to continue with it. It was all that was available at the time.
27. s2 tried to clear HCV through treatment. By that time he was married and had left home. The side effects were awful and he took the treatment for a month before they took him off it.
28. s1 had no HCV treatment. He died without knowing that he also had HCV
29. I do not believe that s2 received any form of psychological support or counselling.
30. In hospital in 1991, s1 was offered some form of counselling but it was too little, too late given s1 statement of mind at that time. He was placed in an isolation ward and had become upset and angry because the doctors appeared unwilling to treat him anymore.
31. I was never offered any form of psychological support or counselling. I sought it out on one occasion (through the local authority service) and I spoke about my husband committing suicide and about my two boys and what had happened to them. The counsellor jumped up and said she couldn't deal with me, leaving me somewhat aghast. I do not know whether she thought me too complex a case or that I was a health risk to her but I thought a counsellor's role was to listen. Years later I did a counselling course myself. I would never have turned anyone away.

Section 7. Financial Assistance

32. I do not recall any particular issue with the various trusts and funds.

Section 8. Other Issues

33. I do not recall the precise details but, in or around 1986, when I was looking for a mortgage provider, I was asked to take an HIV test by a mortgage advisor who had been to my house. He rang me after the visit to say that I could have the money provided I had the test. I was angry about it all. I thought 'yes. I have administered FVIII treatment to my sons but it's not like I've slept with them!' People were so afraid at the time.

Anonymity

34. I wish to remain anonymous.

35. 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 20.04.2020