

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3024001

Exhibits: 0

Dated: March 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 of GRO-B
GRO-B. I was born on GRO-B I have recently been offered a
new job as the GRO-B at GRO-B which is a
GRO-B

2. I prepare this statement as an affected son of my mother, GRO-B: M
GRO-B: M, who was born on GRO-B: M and who passed away in
1993 as a result of receiving a contaminated whole blood transfusion.

3. This statement has been prepared without the benefit of access to my
mother's full medical records.

Section 2. How Affected

4. Between GRO-B my mother had a
miscarriage and underwent a hysterectomy during which she received a
whole blood transfusion.

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5. My mother was infected with HIV as a result of receiving the whole blood transfusion at this time.
6. My mother underwent this procedure at Birmingham General Hospital or Queen Elizabeth Hospital, Birmingham. I do not recollect the names of the consultants who treated her.
7. I have no knowledge as to whether my mother was given any advice regarding the risks of receiving a whole blood transfusion.
8. It is important to highlight that nobody in my family was aware of the exact circumstances of what was happening at this time because some of the family had moved to GRO-B. In GRO-B I moved to GRO-B with my mother GRO-B. GRO-B. We resided in GRO-B. GRO-B although towards the end of my mother's life we moved to GRO-B which coincided with my grandparents reconciling and remarrying. I believe a big part of their reunion was due my mother's HIV infection.
9. My mother found out that she was infected with HIV in GRO-B. I do not know exactly how my mother found out, but she disclosed her diagnosis to our family in GRO-B.
10. Based on the account of my maternal grandparents, who have now passed away, my mother first disclosed her infection to my aunt; her older sister.
11. My aunt informed me that she recollects my mother found out about her HIV infection when she underwent a medical examination in order to apply for life insurance. This was in or around the early GRO-B. It is also possible that my mother could have found out about her HIV infection during one of her annual medical check-ups GRO-B. I sincerely doubt that my mother would have kept the news of her diagnosis from the family for very long. She was the youngest, well-liked and often in touch with everyone, and it would have been a hard secret to carry.

Section 3. Other Infections

12. I do not know whether my mother was exposed to any other infections at the time of her whole blood transfusion.

Section 4. Consent.

13. It seems logical for me to believe that it was highly unlikely that my mother was tested for HIV prior to her move GRO-B

Section 5. Impact

14. When we lived in GRO-B my mother worked as a GRO-B and my grandmother in a GRO-B.

15. It is impossible to capture in words the effect my mother's death had on me as a child, or the effect it has had on the rest of my life. I think of her every day, to this day. She was the centre of my life and the centre of my entire world. Because we were very close, I recall picking up changes in her behaviour that seemed strange. In hindsight, she was almost certainly depressed. At the time there was a huge stigma about HIV/AIDS and, of course, it was death sentence – and where we lived, many people thought that those infected deserved it. Around the time she found out about her diagnosis she dramatically increased her attendance at church. My mother was very religious person GRO-B, but became more religious after her diagnosis and increasingly active in church activities.

16. In GRO-B, my mother booked a trip to GRO-B, which was unusual. I remember I wanted to go, and felt a bit jealous, but she invited only her older sister, my aunt, to accompany her. It was on this trip that she divulged to my

aunt the news of her infection. Shortly before the trip, I believe that my mother also told my grandmother the news.

17. After returning from **GRO-B** my mother told me that she had cancer. This was unbelievably destabilising for me, a boy aged 10, and I started asking many questions. I didn't know much about cancer, but knew it could be treated, so I wanted to know about what would happen. She was relatively quiet on the subject of what would occur and, possibly, this provoked my suspicion. I was young, and maybe naïve for it, but it felt her demeanour didn't match her diagnosis.
18. I snooped around and saw that she had hidden away some books on AIDS and asked why. She said that people who went through AIDS had similar experiences to people with cancer. I kept probing and probing.
19. Although I do not remember her being clearly depressed, I certainly saw a dip in her mental wellbeing. As I said, I can't imagine the burden she was carrying. Even now, older than she was then, and in an environment where HIV/AIDS is treatable and without the stigma it carried, I would find receiving that diagnosis hard to bear. For her, especially as a religious person, and a mother of an only child, I can barely conceive how she felt.
20. My mother must have had so much to worry about in terms of what would happen to her and what would happen to me once she was no longer with us. Eventually my questioning about why she had such an interest in HIV/AIDS and what would happen to us led to her telling me the truth, that she did in fact have HIV.
21. I think at the time when my mother found out that she was HIV positive she ensured that we did nice things together. I believe the realisation that time was running out was an awful awakening for her. I'm not sure if it still works this way now, but she regularly received updates on her T cell count, and the number was falling and falling, like a clock ticking down. One of the best memories I have of my mother at this time is when we both recorded some church songs together. It was an odd thing to do, in hindsight, just the two of

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us in our small flat, singing acapella into an old cassette recorder, but I know that she was trying to combine two things that were in the middle of her life into something good and memorable: our small family unit and her faith. I am acutely aware that my mother made a huge conscious effort to make nice memories with me in the short time that she knew she had left. She also tried to work to shield me from the worst of her illness.

22. Sadly, her decline was very rapid and taxing. She passed away in GRO-B which was only 2 years after she had revealed her diagnosis of HIV to the family.
23. My mother tried as many experimental medications as she could in an attempt to keep her HIV at bay, amongst which was the AZT treatment. I'm not sure what caused what but she suffered from extreme side effects. I remember sky-high temperatures which meant that she had to take ice baths. I recall that my mother suffered with seizures; and on one occasion, I remember seeing her fitting and the family closing the door to protect me from seeing it. I had seizures myself as a young child and knew well what it felt like to lose total control in that way – to see it from the outside and know it from the inside was frightening. You see your parents as invulnerable growing up, and to witness her decline was at times almost unbearable. Near the end of her life, my mother was wheelchair bound. She was completely incapable of taking care of herself – couldn't use a bathroom on her own, couldn't feed herself properly, eventually struggled to speak complete sentences.
24. Despite her state she continued to care for me until it was physically impossible. I recall that on one evening, in her final month or so, I started coughing and sneezing in the night and she crawled out of bed to get some tissues from the bathroom and then crawled into my bedroom to give them to me. It's one of my clearest memories. She was so unbelievably sick, but she still wanted to look after me, to be a mother to me. I remember at the time wishing she'd stayed where she was, knowing how much energy it would have taken from her to do such a simple thing. I remember wishing I wasn't

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there to distract her from recovering. I think, until the end, I thought she might bounce back somehow.

25. To see such a change in a loved one was horrific. My whole family has been affected by my mother's infection with HIV. Many of her siblings have suffered from depression in the wake, her brother, my uncle, still has problems. I'd say I come from a family of quite proud people, who really believe that you ought to be able to fight through any difficulties you face in life. But we were all rendered powerless, just witnesses to my mother's illness. I was only 12 years old when she passed away.
26. The attitudes surrounding HIV are somewhat different now in comparison to what they used to be in GRO-B the 1980s and 1990s. There was a horrendous stigma surrounding being infected. It was seen as a lifestyle illness which affected only gay men and intravenous drug users. As I mentioned, a lot of people said people who were infected deserved to be because of the choices they made. That was, and is, absurd, but it allowed people to amplify their existing prejudices and justify social exclusion and sometimes violence towards people infected with HIV. My family saw it as an impossibility to disclose the truth. We had to live a life of secrecy and we told everyone that my mother was suffering with cancer. I continued to do that well into my twenties. Some people in my extended family still don't know the truth.
27. At the time, people did not know exactly how HIV could be transmitted. There were various scares GRO-B and there was a high uncertainty and fear about using the same utensils as an infected person, even being in the same room as them. At home, at points, we wore face masks for fear of contamination, and made sure we slept in a separate part of the flat from my mother. The ignorance then was profound, and it could have only added to the pain of the diagnosis for people who received it.
28. Now, if somebody asks me why my mother passed away, I do tell them the real cause of her death. But, if I'm honest, sometimes I still hesitate. I think because it was so ingrained in me that it was something to be ashamed of.

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I'm now not ashamed, but connected to everything is such a great sadness I find it difficult to talk about.

29. Financially, my mother struggled following her infection with HIV. Due to the infection she had to eventually go part-time before having to stop work completely. We ended up on relying on government support.

30. Unfortunately, my mother's death overshadows everything in terms of my memories of her. Watching someone die slowly over time becomes a memory that overshadows all other memories, like the static that blocks the images on old video tapes. The unjustness of it all makes it even worse. No one deserves illness but where things could have been prevented it feels even more painful.

31. My mother was such a lovely person. She was the baby of the family and loved by all. She had GRO-B siblings, and she strongly believed that it was important to be charitable to others and did a great deal for my family, including my cousins, her in-laws, everyone.

32. There are always complications in people's lives. At the time that she was infected with HIV GRO-B
GRO-B My aunt believes that the violence which my mother suffered was the reason why she had the miscarriage which led to the hysterectomy. It was all a secret. I did not know this at first as I was so young GRO-B
GRO-B

33. GRO-B

34. Following my mother's passing, a custody battle ensued between my grandmother and my father GRO-B He now wanted to look after me, but had had very little or no involvement in my life beforehand. All of

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that, and the anger that came out in the fight, made the loss of my mother even more difficult. It was like everything was thrown up into the air.

35. In my mother's last months we moved **GRO-B** I had been very happy living in **GRO-B** and I found our move **GRO-B** very difficult. Due to the stigma surrounding HIV, I could not talk about it or share my mother's struggles with anyone. I didn't have any friends in the new place anyway. I suffered a great deal of childhood trauma which left me resentful of the situation that I was being raised in. I stayed away from the family home a lot as I grew up. I withdrew a lot into myself and, although my family don't know the extent of it, behaved pretty badly into my late teens. I got involved with a group of boys who mostly, like me, had gone through tough times as kids. We were troublemakers – starting fights, doing petty crime, drinking too much, eventually taking drugs. I think a lot of us felt that we didn't have much to live for.

36. As a result of my mother's passing, I lived a destabilised adolescence and I punished myself for the loss. But I was lucky, I think. In my twenties, I met someone who inspired me to turn the anger I felt away from what I was doing with my friends and channel it into work, and studying. I started working extremely hard. It wasn't healthy; ultimately, it was just an inversion of what I was up to as a teenager. Instead of wanting to disappear, I started constantly thinking I had to achieve as much as I could to justify why I was still alive when my mother had died. It wasn't healthy, but it was better than the path I was on.

37. I constantly thought I had to prove something to the world, and I constantly beat myself up.

38. I ended up powering through the last two years of an undergraduate Bachelor's Degree at the **GRO-B** our local university, **GRO-B**
GRO-B
GRO-B I continued with education with the same mad desire to justify my survival, over the years building up to the completion of a PhD. **GRO-B**
GRO-B Pursuing

achievements, and especially external recognition, was my way of coping with the loss of my mother. I had to do something with my anger and powerlessness. And I only found worth in the eyes of others, not my own. I didn't have any sense of the value of myself. I think it's important to say, for the sake of anyone who thinks that my mother passing away had a silver lining, that I'd take back everything I've achieved since then for an hour in the same room with her now. No achievement has ever compensated for her loss.

39. The way I'd been working and treating myself came to a head when I turned

GRO-B I had a complete breakdown. I was acutely aware that it was at the age of

GRO-B that my mother had passed away. I realised in that moment that she would

have been younger than I was at this time and I just collapsed. I really

struggled with the idea that I had outlived my mother and I fell into severe

depression. **GRO-B**

GRO-B

GRO-B I lost all motivation and became suicidal. I'd plan out ways to

take my own life, walk around drafting and adjusting my suicide note in my

head. I was married by then and was held back mostly by the fact that I didn't

want my wife to find my body. But I came close a few times. I got to the state

where dying seemed much more logical than living. I know now that the

anticipation of death at the same age as a lost parent is something that

happens often to bereaved children. At the time I struggled to think clearly

about anything. Thankfully my wife supported me, eventually encouraging me

to seek counselling which we self-funded. Without her patience I doubt I

would be here. And, over a period of about three years, I've slowly turned

around.

40. The fundamental powerlessness and the injustice of this tragedy has been, at

times, too much. Hospital workers are supposed to care for you. My mother

received NHS treatment at a time of huge need in her life, in the midst of

tragedy, and though she was treated well enough to return home, she

returned home carrying a timebomb that went on to rip our lives apart.

41. I have had to deal with the impossible up to the age of GRO-B when I found it within myself to seek out counselling. I am now aged GRO-B and I realise the extent my mother's death has taken a huge toll on me. I have kept the reason behind her death a secret for years, which itself has been a challenge. It feels crazy that some of my extended family members still do not know. It's even crazier that I can't find the courage to tell them.

Section 6. Treatment/Care/Support

42. Due to the stigma surrounding HIV my mother could not collect her medication from a regular pharmacy as they had been the targets of arson attacks and protests due to the extreme, often homophobic views which were prevalent about HIV/AIDS sufferers in GRO-B at that time.

43. On my mother's behalf, my family had to attend a special dispensary which was disguised as a "normal house" in order to collect her HIV medication. It was a huge obstacle. In GRO-B my mother, and many others, struggled access services.

44. Various dental practices refused to treat my mother which meant that she was denied a fair choice in selecting those services.

45. I am unsure as to whether my mother was offered any type of psychological support.

46. I was offered psychological support in GRO-B when I was aged about 10 or 11. However, I did not really know what it was, at the time. I saw a lady for a few games of Monopoly and she asked how I was feeling. I don't remember saying much. I believe this was counselling and I have not been offered counselling since and received no counselling at all after my mother's death.

47. I self-funded counselling at age GRO-B

Section 7. Financial Assistance

48. Neither my mother nor I have ever been offered any financial support.

Section 8. Other Issues

49. I followed the Red Ribbon Quilt Campaign and I believed this was a successful effort at destigmatising HIV.

50. It also helped when celebrities in **GRO-B** came forward about having been infected. For example, **GRO-C** and **GRO-C** raised awareness about the transmission of HIV. They made it seem that 'normal people' got the disease. It did change things, but, honestly, thinking about it now, I don't think it would have helped everyone. Famous straight people with HIV wouldn't have dislodged the homophobia that inspired many of the protests.

Ultimately, the whole response to HIV/AIDs in **GRO-B** revealed to me something I think we still see everyday. Some deaths matter more to people than others. Some lives lost receive public sympathy; others don't. Only some deaths are deemed worthy of grief.

51. I would like people to be comprehensively compensated.

52. People have suffered tremendously and they deserve a real apology and a true recognition of what they've gone through. I know mine is only one of hundreds of stories.

53. I would like to see a full report released to the public explaining what happened and providing definitive reassurance that this tragedy will never be repeated.

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54. Additionally, I would like a tangible and concrete commemoration; a memorial for those who have passed away as a result of receiving contaminated blood and blood products as a way to recognise their and their families' suffering. A ceremony for those families who want to attend. A hospital wing or a treatment centre named in honour – something that marks this is a massive avoidable tragedy that the government accepts responsibility for.

Anonymity, disclosure and redaction

55. I wish to apply to retain my anonymity and I am unsure as to whether I would like to give oral evidence to the Inquiry. I think if I felt strongly my testimony might help others, then I would be interested in participating. But all this is difficult to talk about for me.

Statement of Truth

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

Signed

GRO-B

Dated 17.09.19