

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1054001

Exhibit: WITN1054002 - 004

Dated: 20 October 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B of GRO-B Kent GRO-B will say as follows:

Section 1: Introduction

1. I am the eldest daughter of the late GRO-B: F who was born on the GRO-B 1928 in London and who died on the GRO-B 1991. My father had severe haemophilia which was diagnosed at 18 months old at St Bart's Hospital, London.
2. In the late 60's, he became quite ill and his skin had a yellow tone to it. Subsequently, he was informed that he had jaundice and that it was nothing to be worried about, however it turned out to be Hepatitis B. Furthermore, the doctors failed to diagnose Hepatitis until the late 1980's. Exhibit WITN1054002.
3. He was diagnosed in around 1986 with HIV at Kings Hospital College London, but it is believed he was infected since 1983. My father died on GRO-B 1991 at the Queen Elizabeth, The Queen Mother Hospital in Margate, Kent.

Section 2: How Affected

4. My sisters and I were very young when we cared for our father and we would help him carry his haemophilia treatment after his hospital appointments. My father's joints, especially his elbows were fused. He suffered with his hip and his knees, which would lock from time to time. For the most part we were not fully aware of how much pain he was in.
5. My sisters and I always knew that my father had a bleeding disorder. It was part of our lives.
6. My father would go to a centre that was set up for people with disabilities where he had his own carpentry workshop and he would create all sorts of crafts. He would also help others, teaching them how to re-upholster items.
7. Gradually, as time passed, he was physically unable to continue going to the workshop. He was no longer able to stand up for long periods of time.
8. In 1980, my father was placed on home treatment by King's College Hospital and he was able to give himself Factor VIII for his bleeds as and when it was needed. **Exhibit WITN1054003**
9. This changed his life and made his bleeds far more manageable. He spent less time at hospital and very little hospital admissions followed. Also, due to the treatment, he was able to be treated quickly which resulted in a speedy recovery time. However, he was told in 1986 that he had contracted the HIV virus from his Factor VIII treatment; my father was informed of this approximately 3 years after the health service had first become aware that he might have received contaminated blood products and yet despite this, nothing was said to him sooner, ultimately putting three generations of his family in danger and at risk, including his wife. **Exhibit WITN1054004**

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10. My father suffered hugely as a result of the horrific TV and media campaigns and because of the overall stigma attached to HIV which left him feeling ashamed.

11. He was given no counselling, no home help and no support whatsoever after his diagnosis. This in turn had a negative impact on our family; in particular, my mother and 2 sisters, GRO-B as well as myself. As a family, we tried to help my father as much as we could but it was a very depressing time in our lives, watching our much-loved father die a slow and painful death.

12. It is incredible that my mother, as far as the doctors were aware, never contracted this virus.

13. This stress filtered through the family with so much sadness.

Section 3: Other Infections

N/A

Section 4: Consent

14. I do not believe that there was any discussion about the potential risks of any treatment that my father received.

Section 5: Impact

15. Even though we stuck together as a tight knit family unit, my father had always been a strong role model in our family but it took its toll.

16. He and all of us kept this secret due to the stigma attached to HIV/AIDS. The media and the government hyped and stigmatised this so badly with dreadful TV adverts, the news showed abuse and trauma of infected people from the general public because of the lack of correct information being available during this time. This just generated fears, miss-understandings and worse of all feeling ashamed.

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17. We were not permitted to talk about it outside of the house. My mother told her younger brother later on, that was the only family member outside our immediate family that was aware.
18. My father had no professional help or support during this time of terrible suffering. He had no counselling, home help or a nurse.
19. As a family, we all tried to help both parents as much as possible, which was extremely hard on all of us. It was a very depressing time in all our lives watching my father suffer a slow painful death. We learned to deal with all of our emotions quietly.
20. The last few months of his life were mainly in hospital, then when he was home he had a nurse visit.
21. My mother had next to no support during this time, she saw a bereavement counsellor just prior to his death and for a short period after.
22. My sister [GRO-B] has suffered with bipolar since she was 18 and my parents tried to support her through her life even when she had twin daughters. They lived together but this changed dramatically when dad became ill. [GRO-B] had to help them as much as she could with 2 young girls.
23. We are a small family, my parents had three daughters. I have a daughter [GRO-B] [GRO-B] has daughters [GRO-B] and [GRO-B] and [GRO-B] has two boys, [GRO-B] who both suffer from severe haemophilia.
24. My daughter was the oldest when my father died. She was only 10 but luckily she has memories of her grandparents. The twins would have only been 5 years old at the time and [GRO-B] boys would have been 2 years and 1 year old. [GRO-B] boys were diagnosed with severe Haemophilia A i.e. the exact same Factor level as their Granddad.

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25. My daughter **GRO-B** can recall when her granddad was having treatment, she knew that she had to be very cautious around him as he was very conscious that she or her cousins would get too close.
26. The impact from my father suffering so badly had an enormous effect on all of the family, we all gave up parts of our lives to be there to support both parents, even when we had our own commitments – in my case my daughter, husband and my job.
27. I spent less and less time looking after my other commitments during my father's final months so that I could focus properly on looking after both my father and mother who was devastated by her husband's impending death.
28. My marriage went downhill during the final months of my father's life and my daughter never got to grow up with grandparents.
29. I suffered with depression and still do to this day. Whilst my depression was already there, it was amplified due to my dad's health and the stress associated with it. I spent my childhood worrying about my father, knowing that a small accident could easily kill him. I became very secretive about my father's illnesses which added to my anxieties.
30. We have all missed out on so much and had to deal with things which were so awful.

Section 6: Treatment/Care/Support

31. I never received any counselling. My mother had therapy before and after my dad died, which was not of much benefit to her.
32. Towards the end of my dad's days, we were assigned with a bereavement nurse/councillor.

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33. When my dad was in hospital, due to the stigma surrounding the media, it was very obvious that the nurses were petrified to go near him. So it was left to my sisters and I to help out with tasks that the nurses refused to carry out. There was an incident where my dad was bleeding profusely from his mouth, the blood was gushing everywhere. We were left to assist and comfort my dad, helping to catch the blood in kidney dishes while the nurses were too afraid to come over to help.

34. So we were left with no alternative option but to take care of our dad in shifts, where my brother in law and my mum would go into hospital in the day time and my sister **GRO-B** and I in the evenings, sometimes staying overnight.

Section 7: Financial Assistance

35. I believe my parents received a meagre compensation in the 1990's, which was accepted under duress. I cannot recall the amount however it was settlement of the HIV litigation.

36. My parents were constantly told that they were entitled to grants etc but they felt like beggars on the street.

37. The McFarlane Trust covered the cost of some driving lessons for **GRO-B** so that she could drive my dad to his appointments.

38. After my father died, my mother was entitled to a widow's payment, which was paid by the McFarlane Trust for a period of 6 months. Although this was later extended, my mother was no longer entitled and at the time, there was an implied expectation that you should move on.

39. In 2017 my two sisters and I received the Skipton Fund payment and shared it between the three of us. We were refused stage 2.

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Section 8: Other Issues

40. Despite how difficult I find it, I have made a conscious effort to watch the Inquiries hearings. I find it incredibly sad and cannot spend too much watching it as it raises a lot of emotions and memories.

41. My father was 62 when he died so we had him for all of those years, he got to meet his grandchildren and was able to watch them grow. I feel incredibly lucky to have had that and so it is heart breaking to listen to younger families that have lost family members and lost out on so much more.

42. As a family, we have so many questions. Why the use of Factor VIII blood products continued even after the trusts became aware that it was seriously harming and killing people. The hospitals were told to use up stocks of Factor VIII due to their cost yet the trusts were aware that the Factor VIII product was infecting thousands of innocent lives with viruses so why was this decision made to continue using this dangerous product?

43. Furthermore, I would also like to know why I and thousands of others have had to wait for this Inquiry for so long.

Statement of Truth

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

Signed GRO-B

GRO-B

Dated 20-10-2021