

Witness Name: GRO-B

Statement No: WITN3228001

Exhibits: 0

Dated: July 2020

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. I was born on GRO-B and I live at GRO-B.
GRO-B.
2. My brother, GRO-B: B (born on GRO-B), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated blood products. He died as a result of liver failure on GRO-B
GRO-B aged 44.
3. B's former long term partner, his daughter and my mother have also produced witness statements for the Inquiry GRO-B
GRO-B
4. This witness statement has been prepared without the benefit of access to B's full medical records.

Section 2. How Affected

5. [B] had severe Haemophilia B, diagnosed at 18 months. He was under the care of Dr Savage at St Thomas' and Guy's Hospitals and he was treated with Factor IX (FIX) concentrate.
6. No information was given to me, [B] or to any of our family at all about the risk of infection. None of our family were aware that [B] was at any risk.
7. [B] was in his early twenties when he was told that he was infected with HIV at St Thomas' Hospital. He was told not to tell anybody and to go away and get on with his life. He was told that he probably had just three years to live. No information was provided at all to help him to understand and manage the infection. No information was given to him at that time about the risks of transmission and the risk to others.
8. I am appalled about how [B] was told that he had HIV in such a blunt and uncaring manner. No preparation, counselling, advice and/or support was provided to him.
9. Some years later, [B] was told that he was infected with HCV at St Thomas' Hospital. He was left totally devastated and angry that, yet again, his world was blown apart.

Section 3. Other Infections

10. I am not aware of [B] being infected with anything other than HIV and HCV.

Section 4. Consent

11. I firmly believe that my brother was tested and treated without his knowledge, without his consent and without any adequate information at all. I believe that he

was used for the purposes of research and that he had no idea that any research was being carried out.

Section 5. Impact of the Infection

12. The impact of the infection on my brother's life was massive. It affected every area of his personal and working life. His illness and his physical and mental state, especially after the HIV diagnosis, presented him with serious changes and difficulties in getting and maintaining work. He turned to alcohol to escape the feelings of inadequacy and fear from the pressures of his infection and the social stigma that was attached to it all.

13. **B** was scared to get close to people in case they found out about it and because he knew he was going to die and would have to leave them. **B** tried to appear as if he was coping but he was not. He really needed help but never got it. He could not just meet girls like other young men as there was never a right time to tell them he was infected with HIV and it was always going to be many years before that right time presented itself. He was unable to have a relationship during the prime of his life. He felt inadequate as a man. He felt worthless and useless as he was often not able to work either. He felt that he was on the outside of society, always hiding everything because of his health status and the stigma attached to it.

14. My brother wasn't able to pursue any form of career (he was a **GRO-B** when diagnosed with HIV). He never did any further educational courses or study due to his illness and status. It was impossible for him. He worked at times but, again, his infections and the resulting issues with his physical health caused him problems and got in the way. This had a huge financial impact on his whole life. He could not get mortgages or insurance. When he had his own family later in life he felt upset and inadequate. He struggled to provide for them financially whilst he was alive and he knew that he would not be able to when the

inevitable happened and he died. This bothered him greatly as every man wants to take care of his loved ones. [B] could not get any local treatment for his medical and dental needs and always had to attend St Thomas' or Guy's.

15. It all had a massive mental and physical impact on my brother. He was never the same person. After being told he was infected with HIV, [B] knew he had to live a lie. He felt alienated from others and very alone, alone and living with the ticking time bomb that a horrendous death would come to him without warning at any time. I cannot find enough words or adequate words to describe the total devastation and change I saw in my brother.
16. I didn't tell anyone about it for a long time and shut myself off from it emotionally. I pretended for years it wasn't happening because the fear and stigma associated with HIV/AIDs was so bad at that time. I eventually told just one friend but it wasn't for very many more years later (and when I was a lot older) that I confided in just a few trusted friends. It was the same for my whole family. My mum never even told her own parents. Our parents were both devastated. My mum will talk about it now but my dad never ever did. It was a family secret. It was always there in the back of my mind although I tried to ignore it as much as possible. It is still a huge worry for me to this day as I fear a negative impact on my brother's daughter should someone find out about it. I believe that she would be hurt by the stigma that still exists and so it all still goes on. No one is ever really free of it. None of our family were given any support or counselling. My brother never really spoke to me about it all. It shattered all our lives.
17. My brother's physical health deteriorated and he was left without any treatment for either HIV or HCV. [B] developed liver cirrhosis and had to have his spleen removed.

Section 6. Treatment/care/support

18. [B] lost faith in the medical profession. He had no treatment for HIV or HCV. I do not believe that [B] was ever offered counselling or support. No one ever contacted me to offer any support or counselling.

Section 7. Financial Assistance

19. I am not aware of what my brother's financial situation was and am unable to comment in relation to the assistance he received from the trusts and funds.

Section 8. Other Issues

20. I find it absolutely abhorrent that my brother and my family trusted in the doctors, medical staff and centres, the NHS and the drug companies in the hope of better health and a better life for my brother when it actually led instead to him being given horrendous infections that ruined his life. The stigma attached to his infections given by the treatment and the devastation and impact upon him living with a constant death sentence hanging over his head and never knowing what would come next, ultimately led to his early death. The fact that he was used for research and tested like some lab rat is beyond comprehension. Whilst this was all going on, no support for him or any of us was given. Words could not convey how deep the anger goes as this whole situation is absolutely outrageous and should never have happened.

Anonymity, redaction, disclosure

21. I want to be anonymous and would like the identifying features of my family redacted from my witness statement.
22. I do not wish to give oral evidence at the Inquiry.

Statement of Truth

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

Signed...

GRO-B

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Dated 28/7/2020.