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Witness Name: GRO-B

Statement No: WITN0128002

Exhibits: None

Dated:

INFECTED BLOOD INQUIRY

ADDENDUM TO WRITTEN STATEMENT OF GRO-B

I, GRO-B will say, further to my previous statement dated 15 November 2018 as follows: -

Clarifications:

1. I would like to clarify that my date of birth is: GRO-B 1965, not GRO-B 1965 as recorded in paragraph 1 of my previous statement.
2. In paragraph 48 of my statement I refer to being asked "Why are you crying? Look on the bright side, he will never die of a stroke". For clarification, it was the haematologist who said this, not the obstetrician.

Additional points I want to make:

3. Even today, I feel a deep sorrow and anger that as I make this statement, I cannot be open and transparent. My statement has been carefully and heavily redacted. There are other issues, other tragic events, that happened to my family that I can't even mention as they are too scared of the truth coming out. Can you imagine what it feels like to talk about the loss of your brother and you can't even mention his name? That important, significant part of a person's identity and I am forced to speak in code? I want to utter his name, to honour him in public and I am denied that basic right due to the fear and secrecy that still pervades the haemophiliac community.

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4. The injustices I experienced myself were utterly trivial in comparison to that which those infected had to endure but I would still like to record my personal distressing experiences.
5. Several months prior to my brother's death, I was working at a major blue-chip company. I was becoming increasingly stressed and distressed and I asked the HR manager if I could take some unpaid leave to spend more time with my dying brother. My request was declined. I then decided to reveal the full circumstances in the hope that they would be more understanding.
6. To my horror, I was hauled into a meeting with the HR Director, who informed me that he had been made aware of my request and my brother's condition and his only concern was that I might be "an infective risk." Their attitude was appalling and sadly indicative of the wider attitudes of much of society at the time. I felt utterly alone and in despair that the one professional person I had entrusted, betrayed my trust. They did not grant me my request. And I never opened up again to anyone in authority. You learned very quickly and very painfully that people's fears transcend any compassion they may feel for your predicament.
7. One person showed me an incredible kindness. A senior Marketing manager who was aware my brother was dying (but not the reasons) loaned me her company car so I could do the 400 mile round trip at the weekend. The HR Director told her she was flouting company policy to lend it to me and she apparently told him "*to discipline her then.*" I have never, ever forgotten her kindness and the fact that she stood up for me. She moved to Australia and I sought her out several years ago on LinkedIn to thank her again. Even so, she will never know how much her kindness meant to me at such a dark time in my life. Small kindnesses mean so much when you are surrounded by indifference and denial and fear.
8. When I was pregnant with my son, I worried about the future my child might have. I knew there was a 50% chance that if I had a boy, he would have haemophilia. It prays on your mind and you worry in case there will be another problem with the treatment. So even during a time which should have been positive and joyful, there is worry and anxiety about the future he may have.

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9. I genuinely believe there are people who, to this day, are aware there was wrongdoing but remained silent. As far as I am concerned, saying nothing and doing nothing is not a neutral stance. You are complicit. I believe this message must be learned to help avoid future medical and political mistakes and corruption. I don't think this catastrophe came about because of one or two evil people – I believe the issues and suffering have come about because too many people were silent – it was too convenient to look away or walk away. I always stand up for the underdog. I have many faults but I know one of the strengths is that I can't bear to see people, particularly leaders and others in authority do nothing in the face of wrongdoing. This belief informs the work I do.
10. I also wish to express my anger and contempt that successive governments have looked away and abdicated responsibility. I have often wondered, how many of those responsible have ever met a family infected or affected by this scandal? Have they taken the time and trouble to do this? It is all too easy to sit in your Ivory Tower and protect yourself from the hurt, the pain, the raw anger that their actions caused – and still cause. I think every government official who has had a hand in this scandal should be obliged to expose themselves to the reality of their actions.
11. And a plea from me, can the government please stop hiding behind the word "tragedy?" And can the press please report this catastrophic incident for what it was – i.e. a scandal. Yes, it was tragic but a tragedy implies an event that could not be foreseen or prevented and I do not believe that is the case.
12. As far as I am concerned, the state killed my brother and it still has not owned up to its culpability or its responsibility.
13. If you provide products to people which kill them then you are responsible. And if you provide products to people, which kill them, in the full knowledge that this could happen, then you are as guilty as hell. Apologies for the crude expression, but I know of no better way to express my view. And if clinicians and researchers conduct trials on patients or conduct covert research using patients' medical histories, without their permission or knowledge, then this scandal also needs to be exposed.

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14. Since I provided my initial statement, I have spent many weeks reflecting on the trauma victims and their families suffered. And the word that kept coming back to me was lepers – I feel that many people regarded the haemophilia community as modern-day lepers. They were the Unclean, the Untouchables, the Suspect – for ever to be banished to the margins of society. Repeatedly told to be silent, to live their lives in secrecy and fear and shame. A community whose suffering was conveniently invisible to the outside world. A community that could not campaign for justice in public because this could cause unintended harmful consequences.
In short, a community that suffered an appalling injustice and then was denied justice.
15. I want to express my dismay at the lack of understanding or compassion that was shown to this community. For example, I will never understand the attitude that prompted Kenneth Clarke to say “only haemophiliacs.” This shows a contempt, a condescension and a callous attitude and disregard to those who have suffered cruelly.
16. I loved my brother intensely. He was four years older than me and the light of my life. We were very close – we both have a fiery temperament and we used to clash but I knew he loved me deeply as I loved him. All of his siblings were really protective of him and yet he used to swat away our concerns. He wanted to live life to the full – he was charismatic, intelligent, witty, funny, brave and incredibly determined. He also had a huge sense of fair play. He could not bear to see people being victimised or bullied. It still pains me to this day to imagine the psychological torment he endured knowing he was never going to see his son grown up. And how betrayed he felt by those whose job it was to protect him.
17. I think one of the unique factors about my brothers’ death is the layers of suffering and injustice. Firstly, that it happened in the way that it did – so many young people died at the prime of their lives. Then the fact that you couldn’t talk about it. Then the fact that no-one took responsibility or provided adequate compensation or support. Then the possibility there has been a cover-up. And the fact that people are still dying without adequate redress so the torment endures. They say that a mark of a society is how it treats its most vulnerable– on this account we have failed spectacularly.
18. My brother's wife and his child meant everything to him. He only experienced family life for a few very short years and even then he was having to deal with the terrible reality of his

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condition. But I believe my brother and his wife managed to find some happiness despite the incredible stress. His wife was/is a remarkable woman. I am still in contact with her and that is the one positive thing that has come from this. Their son is now a wonderful young man, with a family of his own and when I see them, I think of how proud my brother would be. However, that is not to overlook the terrible wound of losing his father at such a young age.

19. I want to finish by saying a few words about the medical community, who cared for the haemophiliac community. I have focused on the negligence of some but I also want to make the point that my son has received excellent care for most of his life. I also know that many of the staff were committed to doing the best for my brother but I believe they must have been overwhelmed themselves. I wonder what support they received? It must have been utterly horrific to watch patient after patient die in the same dreadful way. I think they also endured a terrible burden as they battled to support patients tolerate the intolerable.
20. I am immensely glad that I have had this opportunity to express my thoughts and feelings about this situation. It is healing to feel that someone is finally listening, that someone cares.
21. Whatever the lessons and conclusions are from this tragedy, I hope that all of those impacted will be able to achieve some measure of closure and move on with their lives.
22. For the first time ever in over 35 years, when I first learned that my brother was infected, I have some measure of hope that my brother's suffering will be fully acknowledged and lessons will be learned. I am speaking up not for attention but because it is my intention that justice will be served and healing will come. Please let that be the case.

Statement of Truth

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

Signed

GRO-B

Dated

05/12/19