

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1647001

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- I was born on **GRO-B** 1976.
2. I make this statement in relation to my late father, **GRO-B**
who was born on **GRO-B** 1944 and died on 25 September 1998.
3. This witness statement has been prepared without the benefit of access to my late father's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

4. My father was diagnosed with severe haemophilia A. I believe he received Factor VIII products from the mid 1970s onwards. He was only treated at the Royal Free Hospital in London and was under the care of Dr Christine Lee.

ANONYMOUS

5. As far as I am aware no advice was provided to my father that the blood products he was being treated with were contaminated or would put him at risk of infection. As a consequence of receiving contaminated blood products, my father was infected with HIV, Hepatitis C and Hepatitis B.
6. My understanding is that my mother phoned the hospital with concerns after hearing things on the news and noticing a deterioration in my father's health. She was told not to worry; in fact she was told that the symptoms she was describing meant it was not HIV that my father was suffering from.
7. I believe my father was subsequently told in 1983 at a regular clinical appointment that he was HIV positive.
8. The information provided to understand and manage the infection was not adequate and in any event the hospital should have asked my father to be tested as soon as my mother had phoned the hospital. It would have revealed the infection sooner. I cannot say how the results were communicated to him when he was eventually told or what information and advice was given or even if he was told as soon as the Royal Free Hospital knew.
9. I believe at the very least my parents must have been told about sexual intercourse and the risks of transmission. I recall being told not to touch my father's blood. He frequently had nose bleeds after which he would lean over the sink bleeding into it until it completely stopped. He would then have a rather frantic cleaning up routine, something we could never help him with no matter how light headed he felt.
10. My father died of pneumonia in GRO-B in September 1998, this was the reason put on the death certificate, but my father only had pneumonia as a result of the HIV illness and what it had done to him.

Section 3. Other Infections

11. I'm not sure if my father was ever diagnosed, but I believe that vCJD was a concern at one point.

ANONYMOUS

Section 4. Consent

12. I believe that my father was treated and tested without his knowledge, without his consent and without being given adequate or full information.
13. I do not know if my father was also tested for the purposes of research however I would not be surprised if he was.

Section 5. Impact of the Infection

14. My father became quite depressed after his diagnosis. He spent a lot of time thinking things through on his own. Physically he became weaker, his skin was thin and this affected his immune system. He got strange rashes and later on he got bed sores, lost weight and his mind began to get confused. His whole character changed over the course of his illness, and in September 1998 he became increasingly weak he died. I look back now at photos of him and am amazed that my family and myself could not see how ill he looked.
15. For my father his HIV diagnosis blew his world apart. It decimated and stole his future, and it affected him in a negative way in every single aspect of his life. It left his realities irreconcilable. He had fought hard to achieve a life against the odds of living with haemophilia and then had to fight again through being HIV positive.
16. Ever since I can remember we had to be careful around my father as his body was badly affected by numerous bleeds over the years. When he was young there was no treatment for the bleeds and over the years he suffered chronic deterioration of his joints and many long and excruciatingly painful stays in hospital. He was however, an amazingly and impressively physical man. As a child I remember him taking the top off his old Mini, winching one Mini engine up and replacing it with another, wielding chainsaws in the wood, beating my brother at table tennis, mowing the lawn, and engaging in building works. I was fiercely proud of my dad and held on tight to his hand when I felt people

ANONYMOUS

looking as he walked with a pronounced limp. He was a very funny, loving, intelligent and philosophical man, never empty of content.

17. At home my father was having regular blood tests and we waited anxiously for the results from each one, terrified of what news they would bring. Every new symptom or change in his body we read with anxiety and fear, wondering if this was yet another sign that he was declining with his illness. New drugs were offered to him and we hoped that he would live long enough for more drugs that would work. I remember that my Dad tried everything that was thought might work to cure HIV. At a time when money was tight, my parents spent money they did not have on expensive honey; he drank strange concoctions and swallowed pills all in an attempt to beat his illness.

18. My parents had always loved the North West coast of Scotland and my father really wanted to go on holiday. Looking back I can see how crazy this was as my Dad was so ill. However, my mother packed up the campervan and off they went. Half way, whilst Mum was getting fuel, my Dad found the hidden liquid morphine, in his extremely weak state of health this made him extremely ill; they made it to Inverness where he died the next day.

19. Before they went on holiday my father had been in a hospice to give my Mum some much needed respite. At this point I was at university, but I came back to see him. In a blue thermos I smuggled in a gin and tonic and in some miraculous moment we told each other very clearly how much we loved each other. That was the last time I saw my father alive.

20. When my Mum phoned from Inverness to tell me that she thought he was dying, I came north from Wolverhampton straight away. It wasn't the first time she had called me in state of emergency and I suppose I didn't really believe it. I arrived in Hexham at my older sister's house, where she met me and had to tell me that our Dad had died. I cannot imagine how hard that was for her. We drove through the night to get to Inverness where we met my brother and mother. We went to say goodbye to my father who was lying stone cold and dead in a mortuary at the age of 54.

ANONYMOUS

21. For years I had thought how that moment would be, I had thought what it would be like not to have him around. But you can never ever imagine what it is like not to have someone, whatever your worst dreams, thoughts and ideas are, they do not compare. Now, twenty years later, I feel the loss of my father just as keenly as I did then, if not more so. I miss him terribly and desperately as a father, and sometimes this overwhelms me, especially with the start of this Inquiry which has opened up emotions I had very firmly put the lid on over the years.
22. When I was about eight, I remember my parents talking to me in the sitting room, I remember the sunshine and shade outside, I remember the door ajar and I remember them telling me that Dad had HIV. Of course at that age I had no knowledge of what that meant, but I can remember the seriousness of what they were saying and I understood the impact on our lives and that Dad might die soon. It was all utterly miserable. I remember my parents telling me that no one could know, that it had to be a secret and if anyone knew then our lives would become really difficult. As a result, I wasn't to tell anyone.
23. I had never had such a dark and ugly secret to keep before. Secrets are horrid, ugly brutes that eat away at you from the inside at you and set you apart from your peers and the rest of society. As the whole AIDS fear and mania took over it touched everything - adverts, newspapers, TV, playgrounds, jokes. I was a child trying to grow up in this, not only having to deal with the realities of living with HIV and what that meant to us and my father that I adored, I was also battling in my everyday life in the playground and even in the classroom.
24. In secondary school, the height of fear had truly gripped the nation. It was 1988 and in the playground you would frequently hear talk of AIDS and the sheer unholy stigma of it and the jokes that I would have to laugh along with. In my religious education class I had to listen to my teacher talk about the horror of AIDS in such a callous and unpleasant way. In biology, my A' level teacher said that if haemophiliacs had not died due to their 'condition',

ANONYMOUS

then they would die from AIDS. My biology teacher knew my father and knew that he had haemophilia. Such was the perceived 'right' of people to say what they thought and cast such judgments about AIDS.

25. I struggled at school to keep the balance of a 'normal' happy child with friends and the internal horror of the dark secret I knew. I wrestled with the question of how could I really have any genuine friendships if nobody knew the real me. I was truly very unhappy, I felt duplicitous in my behaviour and seriously contemplated killing myself. Every night ever since I could remember I had wished on the first star I saw at night and every birthday cake wish that my Dad would be ok.

26. Both my brother and sister had left home for university and jobs, I was the only one of three children left at home as my father's health steadily declined. I felt the weight and responsibility to keep my family home light and easy as much as I could, I was always keen to please and always keen to change the darkening atmosphere if I could. I have no idea if this was really the case, but I certainly felt the responsibility to do so and it increasingly made me feel lousy inside and increased ever more the darkness and secrecy.

27. When I was fifteen I was struggling so much at school that I asked my parents if I could tell my head teacher that I was having such emotional difficulties and the reason why. At this point I had not told anyone. The head teacher was very nice and I asked him if he would give me a smile in the corridor if he saw me, just so I knew that I was not entirely alone. Around the time of my GCSE's I felt I really needed some help. My lovely English teacher became the second person I told and she opened her door for me whenever I needed her – she became like a counsellor to me, helping me through a very dark time in my life. Even then, I struggled at school to complete coursework, to study for exams and to pay attention in class. I also struggled at university and returned home frequently because I felt I was needed.

28. I am now left with an overwhelming anger, anger that I have no opportunity to vent. It is very destructive emotion, counter productive to living my daily life

ANONYMOUS

with a positive outlook and affects those close to me. The secrecy and stigma have not left me, though my husband assures me that I don't need to fear it any longer. Despite that I continue to fear; I fear for my children at school; I fear that when the Inquiry is in the news they will feel the repercussions from their peers.

29. My son has severe haemophilia. In GRO-B 2017 I went to his school to reassure them that he did not have contaminated blood products. I asked them to keep a close ear and eye out for him if any of his peers should taunt him. During that conversation I was in tears. To this date, I have only ever told a handful of trusted friends. I have kept the secret mostly due to the stigma and fear, but also because I have had direct experience of people not believing that this was really done to my father and thousands of others. People cannot believe it because they think that if it was really so it would have been out there in the news and justice would have been served.

30. My parents had always had a very loving and equal relationship, but suddenly my mother was forced into the position of carer, jailer and spy, and whilst there were still definite parts of their loving relationship there, they were pushed into this dreadful dark and tortured end of life for my dad – there was no beautiful peace in the relationship. Twenty years later, my mother still struggles with everything that happened. The guilt should not be hers; it should belong to those who did this to my father!

31. As the illness progressed my father was no longer able to work, my mother also gave up her job to look after him in a way that she had never imagined. He ran up huge debts on credit cards, he flattered and cajoled people on the telephone into giving him what he wanted; he hassled inappropriately and was banned from Tesco for helping himself to the prawns. The illness itself infected my father's brain and he became uninhibited with spending money on credit. This was obviously disastrous and he became a man not always recognisable as himself.

32. There was no significant financial help for my parents and without the astonishingly generous gift of £120,000 by a friend I cannot begin to imagine

ANONYMOUS

where my mother would be now. Dad's illness left her with nothing and with no support.

33. My mother now 71 is still working to provide for herself. She had no life insurance for my father, no pension of his to fall back on so she only has what she has and continues to work hard for. She continues to repay the gift from her friend. Every day she struggles with the legacy of the contaminated blood products; every day she misses my father and certainly at times it is almost too much for her. I have witnessed at close quarters what intense loneliness does to you, how crippling and mean it is. In some ways my mother had her life taken from her when Dad died; she was only 50 years old at the time. I am fortunate to live close to my mother; however this means that I too am living with the frightening lonely legacy it has left her with.

34. Since my father died, as a family we are unable to talk about the impact, we are all quite separate in our grief and that is a tragedy in itself. Such is the stigma and secrecy that we don't talk to each other about it. It is divisive to us as a family as we all experience our loss from such different perspectives and my mother, for example, cannot countenance our grief as she cannot bear the consequences of that as a sole parent and the guilt and trauma.

35. To ask my mother for the information needed to answer these questions has been an ordeal, has caused me very high levels of stress and my mother is deeply upset having to think of details and face up to things she too has tried to bury.

36. The stigma of a death from AIDS means that my father was and is not mourned publicly while other friends who have lost parents from cancer and other like diseases can talk about that freely. My father's cause of death remains a secret.

ANONYMOUS

Section 6. Treatment/care/support

37. I believe my father had AZT. I do not know if there were further treatments which should have been made available to him as I am not a medical professional.

38. I know that my father found it difficult to access dental care.

39. No counselling or psychological support was ever made available to me.

Section 7. Financial Assistance

40. I assume that the Macfarlane Trust must have got in contact with my father through the hospital. I believe they received around £70,000 in total in addition to around £250 a month. I do not know when this £250 stopped. The precondition was that my father had to agree that he would not pursue any further claim.

41. In terms of financial assistance given versus loss of earnings my father suffered, the financial assistance was negligible. The lack of financial assistance at the time of my father's illness added a lot more stress and pressure to my mother at a time when she was already at the maximum of those emotions and struggling to cope.

Section 8. Other Issues

42. My father missed out on so much GRO-B three of his children have families. He has eight grandchildren, two of whom have haemophilia. All of the children need him and the two grandsons with haemophilia could sorely do with him. In the last twenty years I have changed and grown up, I have a husband that I love and wish that my father had known. My husband is going to be 54 this year, the age my father was when he died. It is a very young age to die.

ANONYMOUS

43. Even after my father was told he was infected he had to continue to entrust his care to the NHS, the very ones who had done this to him. Everybody knew this was criminal from the start. I have to continue to trust the NHS with my son's treatment and am dealing with the very institution that did this to my father. I have to do this with commitment and positivity as it concerns my son's future.
44. I feel that my father was murdered; I want someone to take responsibility for what was done to him and to all the others. The only reason this has remained quiet for so long when one thinks of the number of people infected and affected is the sheer fear and stigma of AIDS and that is most shameful of the Government to take advantage of this.
45. Having read in the paper today that thirty years ago the negligence of the Department of Health was internally noted, that Ken Clarke knew, that barristers had given advice, I feel sick with horror and disbelief – was my father so dispensable? Did he count so little that he didn't even deserve the truth – having already been consigned to death?
46. Even now I am frightened to have my voice heard, but I want justice and accountability for all of the people affected, I have a voice for my father who is not able to use his own, I hope you are listening.

Anonymity

43. I do wish to remain anonymous and I understand that this statement will be published on the Inquiry's website.
44. I am happy 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

GRO-B

Dated 24/03/2019