

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN0349001

Exhibits: WITN0349002;

WITN0349003; WITN0349004;

WITN0349005.

Dated: 04/01/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30 October 2018.

I, **GRO-B** will say as follows: -

1. Introduction

1. My name is **GRO-B** My date of birth and address are known to the Inquiry. I am single with no dependents. I am an only child, whose father was a haemophiliac and whose mother died when I was nine years old.
2. I confirm that I am not legally represented and am happy for the Inquiry team to assist me in drafting my own statement.

2. How Affected

3. My father, GRO-B: F (date of birth GRO-B 1938), was a registered haemophiliac under the care of St Thomas's Haemophilia Centre. He was treated by Dr Savidge. He had severe Christmas Disease for which he had to take blood products.
4. He was looked after GRO-B by St Peter's Hospital, Chertsey. His consultant at St Peters was Doctor R Vaughan-Jones, who is now retired. As a child I remember my father being in and out of hospital whenever he had a severe bleed. Many of these bleeds went into his knee joints.
5. When the recombinant factor was introduced in the mid to late 1970s/early 1980s this revolutionised his treatment as he was able to treat himself at home. Indeed a whole shelf in our fridge together with a thermometer was dedicated to his factor IX.
6. In the early 1980s he elected to have knee replacement surgery at St Thomas's to help with the increasing immobility in his joints. As part of this surgery my father was given blood products to help avoid complications.
7. I do not know if it was the new factor IX he used for home treatment or the products given to him when his knee was replaced that infected him with HIV. In any case his disease developed into full blown AIDS in 1984/5.
8. I do not know when and how my dad found out he was infected.
9. I am unable to comment on the information or advice given to my father when he was diagnosed as HIV positive. I am therefore also unable to comment on the adequacy of the information or advice my father received at the time.
10. In terms of the information given to me, I had a meeting at St Thomas's with Dr Savidge and my aunt (dad's sister) when I was told what was wrong with my dad.

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11. Dad had previously been unwell and in and out of hospital. Dr Savidge advised me very calmly and factually that Dad had HIV which had turned into AIDS. I was really shocked as it had not even crossed my mind what might be wrong with my father.
12. He explained that from now on I would have to be careful not to get infected and informed me that the infection was spread through bodily fluids. I was looking after Dad at home and so was told I had to be extra careful.
13. My aunt and I then discussed who in the wider family would be told. At that point I was told we were not going to tell my dad's mum the truth of what was wrong, just that he had a complication with his haemophilia. We as a family wanted to spare her as much heartache as possible: she was seventy-five and had cared for him all his life and didn't need to know what a dreadful thing had happened to her boy.
14. My father died on the GRO-B 1986 after a battle with the disease. In the final three months of his life he was hospitalised at St Thomas' some twenty-five miles from our home.
15. My father was treated in a side ward due to the infectious nature of the disease. The nursing team at that time were terrific as we were allowed to visit and stay until 10 o'clock in the evening when the night staff came on shift. I was working full time, so visiting in the daytime was not an option.
16. My dad was one of six children and his siblings also visited on a regular basis. The hardest part of his hospitalisation was that his parents were unable to visit him in London due to the distance to travel and my grandmother's rheumatism. When I was a child Granny used to visit my father at hospital at St Peters every afternoon he was in there. She never missed an afternoon. This could not continue however when he was admitted with AIDS. This was very painful for her.

17. I note that whenever Dad was admitted to hospital his clothing book was labelled "Infected" to mark him as an AIDS sufferer (WITN0349002).

3. Other Infections

18. As far as I am aware my father was infected with the HIV virus only. I am unable to comment on whether he was also infected with any of the Hepatitis viruses.

4. Consent

19. As I have limited knowledge of the treatment provided to my dad, I am unable to comment on this aspect of the Inquiry's Terms of Reference.

5. Impact

20. I have been asked to comment on the mental impact of Dad's HIV infection. It is hard for me to comment on this. We did not have the kind of father/daughter relationship where feelings were discussed openly. He would have discussed these with his youngest brother or sister, not me. He always spared me as much as possible.
21. In terms of the physical impact of his illness, my dad became weaker and bed-ridden. My dad never stayed in bed before his infection with HIV!!
22. My dad developed mouth ulcers and sores on his lips. He developed shakes and tremors and just got progressively weaker as the disease took hold. In the last three months of his illness he was hospitalised and eventually could only "eat" Complan type shakes through a straw.

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23. Initially Dad's social life was not affected much at all. However, as the disease took hold, and he became bed ridden, and eventually hospitalised, then it was really only family that visited him.
24. In the summer of 1985 Dad was on holiday with his parents, sister, brother-in-law and two nieces. They had gone down to Devon in two cars: Dad's and my uncles. Dad was taken poorly and unable to drive home on the Saturday. I asked at work if I could have the Friday off or leave early to go to Devon by train so I could drive him and his parents back in his car. The holiday request was declined due to a lack of staff in our office. Therefore I had to travel down on the Saturday morning to Exeter and then on to Barnstaple to be collected from there and drive Dad home. Not ideal and very stressful.
25. During Christmas 1985 my father was at home. We have traditionally spent the day with his family (who lived in the road opposite to us), but Dad was unable to come over the road due to his illness. He spent the day at home.
26. I had breakfast with him and we opened our presents. My presents from Dad were bought and wrapped by his sister and sister-in-law as he was unable to do this.
27. Dad's lunch was taken over to him on a tray and also his tea later in the day. He spent the majority of the day in bed. Dad was visited by his sister, brother and brother-in-law through the day.
28. On my birthday at the end of January I got a card and money as he could not get out to get me a present.
29. The impact on me was that as Dad became more ill and infirm I had to help more by doing the shopping and household chores on my own. Jobs we had always shared in the past were now completed alone.

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30. During the autumn I had to organise a new gas fire for the flat; ours had been condemned by the gas board. I had never had to deal with any of these matters before and as the flat was rented I had to get Council approval before we could get the new fire fitted. All this with the added pressure that whilst Dad was again in hospital for a week he was due home to a house with no heating.
31. Once he was hospitalised, my routine was to get up and go to work, come home, get dinner and drive to London to St Thomas's to visit my dad.
32. I did tell my best friend, who is still my best friend after all these years what was wrong with Dad, but other than that it was only me, Dad's brothers and sister and their spouses who were told what was wrong with him. His mother-in-law, sister-in-law and brother-in-law were told the same as my granny: just a complication with his haemophilia. This was the story I told people as the stigma meant that I couldn't tell them Dad had AIDS. I recall the hue and cry in the media at the time.
33. I am blessed with a close and supportive family. Granny, who could not visit Dad when he was in St Thomas's, was the co-ordinator of hospital visiting. I let her know what evenings and weekend days I could visit and she organised the rest. Sometimes I drove to London after work with an uncle, sometimes I was driven by one of them to see Dad. I visited at least two evenings a week and either Saturday or Sunday.
34. My hobby is following Crystal Palace Football Club home and away and no-one ever asked that I miss a match. This was my outlet and I think kept me sane and gave some normality to my life: that and work. Work and football basically became my social life.
35. In January 1986 I moved in with my best friend. Her mum did my washing and ironing and she would sort my dinners and lunch for work for me. This took some of the day-to-day living burden off of me.

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She always treated me like an extra daughter and I shall be eternally grateful to her for the support she gave.

36. I continued to be responsible for ensuring all our bills were paid, including the rent, as well as ensuring our home was safe and secure and dealing with any other post that came in. My aunts did any of Dad's washing for him and this was returned to Granny's for collection by whoever was visiting, along with the day's paper and anything else Dad needed: toiletries etc.
37. We celebrated Dad's 48th birthday just short of a month before he died. I visited him on the Monday GRO-B the night before he died. He slept a lot by this time; I do not know if this was due to his medication or just the illness taking over.
38. On the Tuesday night I went to football: Palace were at home to Stoke City – we still had terracing then and about 7 o'clock I went really cold. I said to my best friend 'a goose had just walked across my grave'. This was in the era before everyone had a mobile phone!
39. When we got back to her house, her mum said my uncle had telephoned and could I call him back. I called him back when I returned to my friend's home around 10.30/11pm. He came round to see me to tell me Dad had died earlier that evening. So my shivers were not a 'goose' but Dad saying goodbye.
40. It was a complete shock to learn that my father had died even though I was aware he was very ill and did not have long to live. I balled my eyes out and my uncle did the same.
41. After this I had to sort out with the Council whether they would still house me in the flat as a single person with no dependents: in a two-bedroom property this was not a given. Fortunately, Dad had put me on the rent book and I was allowed to continue living there after his death.

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42. Because Dad died in hospital of HIV, there had to be an inquest following his death, before the death certificate could be issued. I have provided a copy of the certificate to the Inquiry team (WITN0349003). Although we were able to bury him at the end of March 1986 we had to arrange for the local undertakers to collect the body which had to be placed in a lead lined coffin before burial. It was very difficult having to explain to a stranger he had died of AIDS.
43. The inquest was held in May. I did not attend as I was on holiday visiting my maternal grandmother in Sheffield.
44. Whilst staying with her I had an asthma attack. I had never had one before. When we visited her GP she told me it was probably brought on by the stress of losing my dad. Since then I have suffered with hay fever every summer which can be quite severe and am prone to chest infections when I get a cold. My eczema was also very bad at the time and continues to flare up badly when I am stressed.
45. Dad's death had quite a big impact on our family. My family were very close geographically and emotionally. A large hole was left in it when Dad passed away.
46. My dad use to visit my aunt every Thursday and help my cousin with her maths homework whilst she was still at school. My cousin was twenty when dad died. They had a close relationship and his disease and his eventual death prevented the visits from continuing and this caused quite an impact on my aunt and cousin, her younger sister, and his brother-in-law.
47. As I have mentioned above, I have limited knowledge of the treatment provided to Dad. I do remember he was taking some minute bright blue pills but I do not know what for; I only recall how tiny they were. Things were different back then. We didn't have the internet to look things up.

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48. In the last year of his life I do not remember my dad ever visiting his dentist.
49. He did however visit his GP one day, around four months before he passed away. We lived in a second floor flat and I had to come home from work to take him to the surgery.
50. I had to help Dad down the stairs as he was not as strong as before. I also had to help him in and out of the car and then back up the stairs when we got home. I then had to go back to work.
51. When I came home from work Dad was in bed as the whole trip had wiped him out. Dr Savidge was extremely angry when he found out and spoke to our GPs to advise that from now on they should carry out home visits to my dad if required/requested and not expect him to go to the surgery. He also told me off for taking him. I did explain that Dad had asked and I had done as requested. I had to make up the time at work.
52. Apart from the above, I am unable to comment any further on whether my father faced any difficulties in accessing treatment. Dad was a very private person and so didn't discuss his treatment with me. The only treatment I am aware of is the recombinant factor for Haemophilia. Whilst Dr Savidge was very good at describing what AIDS was and how things would progress he didn't discuss the patient side of things as that was between him and Dad. I have also spoken with Dad's sister and he did not discuss any treatment with her either despite them being very close.
53. I do not have enough knowledge of the treatment given to Dad to comment on whether they were the primary cause of his symptoms or whether his symptoms were simply caused by the disease taking hold of him. I do know that hair loss was one of the consequences of treatment but my dad's hair did grow back afterwards.

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54. In terms of the impact of all of this on me I remember filling out insurance forms in the 80s and being asked whether or not I had had an HIV test. I had to answer truthfully and say that I had. This was hard for me as I do not see why it was a relevant question and it resulted in larger premiums despite the fact that I had never had the disease myself.

6. Treatment/Care/Support

55. I do not remember being offered any counselling at the time. My support was my family and my best friend and her family. I do not know if Dad was offered this. I think Dr Savidge may have mentioned something, but I was far too shaken to take this in.

7. Financial Assistance

56. As far as I am aware, Dad was not provided with any financial assistance, nor have I seen any evidence that any was claimed.
57. I was notified by the Haemophilia Society in November 1989 about the ex-gratia payment being made by the Government to each person with Haemophilia following the Society's campaign (WITN0349004).
58. I received a letter from the Macfarlane Special Payments Trust in February 1990 to ask for confirmation as to who the payment should be paid to in line with Dad's estate. The claim was dealt with through the solicitors who administered his estate and payment was made to me in late 1991. I have copies of some of the correspondence which I have provided to the Inquiry (WITN0349005).
59. I do not have any of my father's medical records, but am willing to give the Inquiry team access to them.

8. Other Issues

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60. I would prefer for my name to be removed from this statement before it is disclosed or published.

Statement of Truth

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

Signed

GRO-B

Dated 10.01.2019