

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GLENDA ANNE WEST

I, Glenda Anne West, will say as follows:

Section 1. Introduction

1. My name is Glenda Anne West of [GRO-C] Essex, [GRO-C]
[GRO-C] My date of birth is [GRO-C] 1956.

2. I retired 3.5 years ago to care for my mother who sadly passed away on Sunday 13th January 2019. I also devote a large proportion of my time to caring for my late cousin's, Barry Ray Panicop's mother; Hilda Panicop.

3. **This statement has been prepared without the benefit of access to Barry's medical records.**

Section 2. How Affected

4. I am an affected person in relation to Barry. Barry had Haemophilia and contracted HIV and Hepatitis C as a result of receiving contaminated Factor VIII. He passed away on [GRO-C] 1996 aged 39.

5. Barry was advised that Factor VIII was a "*miracle drug*" which would have excellent results. As far as I am aware Barry was not given any advice regarding the risk of receiving Factor VIII. Barry received Factor VIII for the majority of his life but I am unsure as to either the dates or time frames when he received the same.
6. Barry predominantly received treatment at the Katharine Dormandy Haemophilia and Thrombosis Centre which was located at The Royal Free Hospital in London. I believe that his consultant was Eleanor Goldman.
7. Barry was told that he had HIV by his consultant approximately 10 years before he passed away. His close friend, who does not want to be named, accompanied Barry to this routine appointment. I am unsure as to when or whether Barry was told that he had also contracted Hepatitis C.
8. I do not know whether Barry was given sufficient information in relation to his HIV infection because he never really discussed medical matters with me.

Section 3. Other Infections

9. I am unaware as to whether Barry was exposed to any other infections.

Section 4. Consent

10. I am unsure as to whether Barry was treated or tested without his knowledge or consent.

Section 5. Impact

11. Barry was a wonderful character. He accepted his life without any feelings of discontentment or feeling that he had been mistreated, despite the terrible mode of his infection.

12. Barry was a private person and he never really discussed his infections. His paramount concern has always been for his parents; Barry was an only child and he was well aware that, towards the latter stages of his life, he was not going to be on this earth for very much longer. In fact, it was during the later stages of his illness that he confided to me the existence of his infections. Barry and I were always close and he knew that I was the type of person who would be able to compartmentalise matters, and deal with the difficult road ahead in a pragmatic way. Barry wanted me to "*step into his shoes*" and care for his parents who, unfortunately, had health issues of their own.
13. In hindsight I realise how ill Barry was when I got married in 1995. He attended my wedding and on the surface appeared jovial but he looked very poorly. His skin had a somewhat yellow tinge to it and he was a shadow of his former self. I think that everyone thought that he was poorly but no one really had any idea, at this stage, that he was infected with HIV and Hepatitis C.
14. By the end of 1995, Barry's physical health was deteriorating quickly. He lost a substantial amount of weight and his face was patchy; it displayed an orange and yellow colour and his eyes were dull. However, Barry being Barry just continued with life. He never complained and just accepted his lot. I do believe that people could learn so much from the way in which Barry dealt with matters.
15. In or around March 1996, Barry visited me at my home and it was on this visit that he delivered the bombshell news that he was infected with HIV. He told me in his usual professional manner and I recall that he said "*look, I have something to tell you and I just want to deal with this in a practical way*". He continued with "*unfortunately, I have contracted AIDS from the bloods I was given and it is not looking very good for me*".
16. I asked him for how long had he known and I expressed concern that he was dealing with this alone. Barry told me that he had known for about 10 years and that his close friend was supporting him on both a practical and emotional

level. I do feel that Barry ended his romantic relationship with his partner due to his infections because he parted company with his girlfriend immediately upon being told that he had HIV.

17. Barry made me the executor of his will along with his good friend and a solicitor.

18. I advised Barry that he should tell his parents and told him that I felt they already knew that he was poorly. Unfortunately, his mother Hilda always believed that a good dinner would make him better and she liked to brush matters under the carpet. Unfortunately, good food does not fix everything and it was certainly not going to make light of this problem.

19. In the last 2.5 years of his life, Barry started to do things like embarking upon round the world trips. He visited our cousins who lived in Australia at the time and went to the Ayres Rock. I never understood why Barry was doing all of this but of course now everything makes sense in that he wanted to experience as much as he could before he passed.

20. Barry used to work for the London Electricity Board in Leyton and he had a loyal circle of friends. Barry was an outgoing and sociable person. He supported both Arsenal and Leyton Orient football teams with a vengeance.

21. We were at the height of the AIDS epidemic and stigma was rife. Barry told his close friend everything and this close friend was a financial expert and he was able to advise Barry in relation to both finances and practical decisions towards the latter stages of his life.

22. However, despite the incessant stigma, I do not believe that Barry would have shied away from telling people merely for fear of reprisals. Barry was just a very private man. Barry had the most phenomenal "*get on with it attitude*".

23. I told my husband about Barry's infections, although, I was not able to confide in my mother due to her closeness with Hilda. My mother would have felt

duty bound to disclose this personal information to Hilda and I knew that I could not break Barry's trust.

24. However, in April and May 1996 Barry's health plummeted and he was admitted to The Royal Free Hospital. This was a turning point and for the first time Barry's mother and father gained some insight into their son's condition.

25. This was where my role came to the forefront. I needed to support my aunt and uncle (Barry's mother and father) which I feel that I did to the very best of my ability. I was able to step, as far as possible, into Barry's shoes and fulfil the role with which he had cast upon me.

26. Undoubtedly, the "AIDS Ward" at the Royal Free Hospital was the most devastating thing I have ever seen in my entire life. Barry's physical health had really deteriorated by this time, his eyes were bulging, his face was red and he did not look like the same man anymore. I remember seeing all of the patients on the ward so vividly; and it was the most terrifying sight I have ever seen.

27. The penny dropped in respect of his mother and father and I really felt for them. I never spoke Barry's mother, my aunt, about his infections and I still remember that she thought there would be some miracle cure. It was as if she had completely buried her head in the sand, despite the stark reality of what was facing her. Barry's father was able to accept the terminal nature of his son's disease but he angrily questioned "Why would this happen to my son?". However, he was able to have very sensible conversations with Barry's close friend and confidant about the stark realities of what was happening.

28. Barry's last wish was to pass away at home. We made arrangements for this to happen and once we got our dear Barry home he only lasted a few weeks.

29. [GRO-C]
[GRO-C] Barry passed away on [GRO-C] 1996 and was buried on 11.11.1996. Therefore, the family did not have sufficient time to come to terms with their grief. The burial was difficult. It was a very cold day

and the whole family were reeling from the shock of the death and the nature of the infection. In Jewish faith, it is known that you are born with nothing and we leave with nothing; therefore flowers do not feature in ceremonies. However, I recall that someone brought a red rose for Barry's mother to hold and this was such a poignant gesture. My father broke down in the synagogue.

30. Barry asked me to be involved in his mother's and father's lives because he knew that his death would drive them apart. Indeed, there were times when the anger would overflow due to the different stages of their respective grief cycles. I tried to help them through this tragedy in as many ways as I possibly could. NOT RELEVANT

and I would say that neither of them ever got over Barry's passing. As I write this, my aunt is entering the final stage of her life. It is pitiful to experience the raw grief she still has.

31. Barry's father developed Motor Neurone Disease and died in 2010. Barry's mother was too poorly to visit him at the hospital, so I took on this role and fulfilled Barry's last wishes.

32. It has been mentally exhausting. I worked in the City in the insurance sector. In 2005, myself and colleagues formed our own insurance broking business which we sold in 2013. During this period, I was raising a family of 3 children and continued to commit a lot of my time looking after Barry's family. My husband might even say I was miserable during those times even though I did my best to be everything to everyone.

33. Every Saturday was taken up with visits to Barry's mother and father which was a day when I should have been spending time with my children and my husband. It was difficult for all of us. Although I never resented it and knew it was my role, I still experience an occasional 'wobble'. However, I believe that my pragmatic outlook on life has greatly assisted me.

34. My mother was at her most poorly just before she passed away last Sunday. Despite this I found myself attending to Barry's mother twice on the Saturday NOT RELEVANT and her need for almost round the clock assistance and reassurance. I have had an awful lot to deal with although I don't think I ever complain about this as I just see myself as fulfilling our dear Barry's role.

35. Barry's mother is very poorly and my life and my family's life has effectively been put on hold and I feel that I cannot even really grieve for my own mother because I am caring for Barry's mother.

Section 6. Treatment/Care/Support

36. I do not believe that counselling was ever offered to Barry.

Section 7. Financial Assistance

37. I believe that Barry received financial assistance but I am unsure as to which Trust provided this.

38. Barry's parents were not offered any support after he passed away.

Section 8. Other Issues

39. When Barry passed away, he donated to the Katharine Dormandy Trust because the people there were so kind to him and I feel that this was such a touching and fitting tribute.

Anonymity, redaction and disclosure

40. I do not wish to apply for anonymity and I want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed..... GRO-C

Dated..... *24.1.19*.....