

Witness Name: J H Johnson
Statement No: WITN1755001
Exhibits: WITN1755002-17
Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JANETTE HILARY JOHNSON

I, Janette Hilary Johnson will say as follows:-

Section 1. Introduction

1. My name is Janette Hilary Johnson and I was born on GRO-C 1947. I live at GRO-C. I have two grandchildren aged 4 and 7.
2. I had a subarachnoid haemorrhage in March 2019 which sadly resulted in significant damage to my memory.
3. I make this statement as an affected mother of my late son, Graham Angelo Pumbo, who was born on GRO-C 1971 and passed away, aged only 15, on 12th November 1986 as a result of receiving contaminated Factor VIII concentrates.
4. My late son was infected with HIV via his use of contaminated Factor VIII concentrates.

5. **This witness statement has been prepared without the benefit of access to my late son's full medical records.** I strongly suspect that some of the records have been intentionally removed.
6. My father was also a Haemophiliac who passed away (for reasons unrelated to this matter) in 1956 when I was aged only 9.

Section 2. How Affected

7. My son had severe Haemophilia A with a zero percent clotting factor. He had no antibodies to Factor VIII and was diagnosed at birth. He required treatment for bleeding episodes at intervals varying from 1 to 3 weeks. **Exhibit WITN1755002** is a copy of a letter dated 2nd November 1978 from Dr J M Matthews to Dr F Mancuso, Paediatrician which confirms these facts. The letter also states *"In 1975 he received treatment for 7 bleeding episodes; in 1976 for 8 bleeding episodes; in 1977 he received 37 doses for 19 episodes; in 1978 he received 28 doses for 9 episodes...he suffered his most serious bleed in May 1974, when he had an intracranial haemorrhage which developed two days after a fall from a chair.."*
8. **Exhibit WITN1755003** is my son's hospital treatment record from 8th May 1974 to 16th February 1978 which illustrates the sheer volume of factor concentrates which he received.
9. **Exhibit WITN1755004** is my son's home record treatment record from 18th August 1982 to 12th November 1986 (the day my son passed away). This again illustrates the vast amount of factor concentrates that I had to give to my son.
10. **Exhibit WITN1755005** is my son's hospital treatment record 9th January 1985 until 12th November 1986, although there is one record which is dated post my son's death (4th December 1986).
11. My son was treated at the Haemophilia Centre at the Churchill Hospital under the care of Dr GRO-D and Dr Matthews.

12. At no point was I given any information or advice regarding any risk of infection from the use of Factor VIII.
13. **Exhibit WITN1755006** is a copy of a letter dated 12th November 1986 from H Dasani, Senior House Officer to Dr P Millard, Consultant Histopathologist which states *"he has been HIV antibody positive since we first tested him in June 1985"*. I was not aware that any test was being carried at this time.
14. **Exhibit WITN1755007** is a copy of a letter dated 14th February 1986 from Dr A J Martin, General Practitioner to Dr Dawber which states *"He is unfortunately HTLV III positive and his mother is aware of this. Further information can be obtained from Dr [GRO-D] at the Centre on this"*. I am unaware as to who inserted an exclamation mark and circled the portion of the record containing the words *"HTLV III Positive"*.
15. **Exhibit WITN1755008** is a copy of a letter dated as postmark which confirms that I had been told that my son was HIV positive by 14th February 1986. This letter also confirms that my son had, at this point, been tested 5 times (without my knowledge or consent) for HIV.
16. **Exhibit WITN1755009** provides examples of my son's medical records being stamped in bold with *"HTLV III RISK"* from as early as 14th August 1985.
17. I believe Dr [GRO-D] told me that my son was infected with HIV and that this conversation took place at a routine clinic appointment. My mother and Graham would have been with me but I am unsure of the exact date of this appointment. However, I can confirm that I was aware of my son's HIV status from early 1986. I was told in a very matter of fact manner and I remember that I was also tested for HIV with the result being negative.
18. As far as I am aware my son was not infected with Non-A Non-B [NANB] Hepatitis which later became known as Hepatitis C. However, it is interesting that there is a copy of a letter in my son's medical records dated 5th July 1974 from J M Matthews (who was a Medical Assistant at this point in time) to Dr A. J Martin which states *"I would be grateful if you could confirm in writing that*

*this patient, as far as you know, has not developed jaundice since he was treated in Oxford with human A. H.G between 8.5.74 and 25.5.74. I would, of course, be grateful if you would report any future occurrence of jaundice in this patient". I attach a copy of this letter at **Exhibit WITN175510**. The reply is attached at **Exhibit WITN175511** which states "...as far as we know in the practice, Graham Polumbo has not been jaundiced since the administration of A.H.G in May. I will make further enquiries and let you know".*

19. I can confirm that my son was jaundiced and that is shocking that medical professionals have suggested otherwise. I would go as far as to say that they have deliberately withheld the truth in this regard. Furthermore, I had no idea that such correspondence existed.

Section 3. Other Infections

20. As far as I am aware my son was not put at risk of vCJD.

Section 4. Consent

21. **Exhibit WITN175512** is an extract from my son's medical records which confirms that he was tested for Hepatitis B on 27th August 1986 without my knowledge or consent.

22. I was not aware that they had tested my son for HIV on at least 5 occasions as recorded in **Exhibit WITN175508** as discussed above.

23. **Exhibit WITN175513** is copy of a letter dated 12th June 1974 from **GRO-D** **GRO-D** Consultant Physician to me which states "*As you may already know, we are carrying out research at this Centre to try to develop tests which will enable us to diagnose the carriers of haemophilia. I wonder if you would be willing to help us in this research by giving us a small sample of your blood...*". I am of the view that there was probably something more sinister to this but I am unable to provide any concrete evidence of this.

Section 5. Impact

24. Graham was a wonderful son who loved nature and wildlife. He was an extremely kind hearted boy. He was a very talented artist; I have retained much of his artwork. He was a complete perfectionist so if he got one tiny element of his drawing wrong he would start all over again. He loved going to concerts to see Bucks Fizz and he adored Olivia Newton John.
25. Unfortunately Graham suffered an intracranial haemorrhage in 1974 which resulted in partial left hemiplegia. He also had severe epilepsy which was treated with Tegretol. Graham also suffered from chronic haemarthrosis of his left ankle and had a splint as a result of this. He also caught pneumonia and had aplastic anaemia.
26. Graham already had to deal with so many health complications and that was before the HIV came along. I remember breaking the news to Graham about his infection; I did it with my mother present because Graham absolutely adored her. We lived with my mother which strengthened the bond between grandmother and son.
27. Graham was extremely poorly as a result of the HIV but he still managed to attend school. It was heart breaking to see him come home upset after school, and in tears, every day because the other children had been so cruel to him. They used to call him Rock Hudson.
28. I remember having the press at the door and doing a few articles. However, the reporting was inaccurate which led to further bad behaviour aimed at our family and increased the bullying of Graham at school.
29. I ended up going to the school to speak to the Headmaster about the bullying behaviour. I think this somewhat lessened the behaviour but it still continued. My daughter was at the same school and was taunted because her brother had AIDS.

30. I also suffered a lot of stigma due to Graham's HIV. I used to do a lot of fundraising for the Oxford Haemophilia Centre and someone spat at me in the street once. Another time I recall going to a shop to ask for a raffle prize to be donated and I was turned down; the shop keeper made a horrid derogatory comment to me about AIDS.

31. The HIV ravaged Graham and I do believe that the medication he was put on to combat this contributed to his death. He suffered so many severe episodes of bleeding gums for which he was hospitalised for.

32. Unfortunately not long after his HIV diagnosis, Graham passed away aged only 15 on 12th November 1986. GRO-C

GRO-C I was utterly devastated. I remember coming home from the hospital and crying uncontrollably whilst sat on my bed. A butterfly then appeared in my bedroom which was very strange for November. Another one appeared shortly afterwards as well. I now associate Graham with butterflies and I have so many butterfly ornaments, pictures and clothes. I find butterflies very comforting as I associate them with Graham. When my grandchildren see a butterfly they say "*Uncle Graham*", he is referred to as "*Graham Butterfly*". My granddaughter is now very into butterflies which is lovely and a way of keeping Graham's memory alive. Every year on Graham's birthday our family visit a butterfly house and the grandchildren sing happy birthday to me.

33. I don't know how I managed to cope in the days and months after Graham's passing. I just existed. If I did not have my daughter I would have done myself in. I was both the mother and father figure for Graham as his father was very much absent in our lives. He did not come to the funeral although his American family did attend which was lovely of them.

34. **Exhibit WITN175514** is a copy of my son's post mortem report.

Section 6. Treatment/care/support

35. **Exhibit WITN175515** is an extract from my son's medical records dated 30th September 1986 to 5th October 1986 which confirms that he was placed in isolation due to his HTLV III positive status. It states *"To protect other patients and staff...whilst Graham is bleeding he must be barrier nursed. Instructions are on the door to his room. Provide lots of activities for Graham and spend time talking to him to reduce his isolation...isolation continued...Graham fed up on his own, needs company. Isolation continued. Please damp dust cubicle daily with detergent...."*

36. I used to think that Graham was extremely well cared for by the medical experts and I even attended Dr Matthew's retirement party. However, the more information I find out the more I begin to think that Dr **GRO-D** was definitely in the know about what was going on at that time. I am still not sure about Dr Matthew's state of knowledge.

37. Neither Graham nor I were offered any counselling. If they were to offer this now I would say that it was *"too little too late"*. I have dealt with matters alone although my new husband, Bob, has been a fantastic support. I met him at a singles night and we have now been married for 26 years. Bob has a lovely personality and he makes me laugh. I do wish that he had met Graham as I think they would have got on well due to their fantastic personalities and kind natures.

Section 7. Financial Assistance

38. I either found out about the Macfarlane Trust (MFT) through the hospital or a friend.

39. My son received £20,000 from the MFT on 7th March 1990 and I enclose a letter confirming both the amount and date at **Exhibit WITN175516**.

40. My son was a party to the 1991 HIV Litigation but I am unsure as to whether we signed a waiver in connection to this. I believe that he received approximately £21,000 on 20th September 1991 to which **Exhibit WITN175517** refers.

41. I was not aware that the MFT provided grants.

Section 8. Other Issues

42. I want justice for Graham and I want people to admit what happened and to apologise. There are so many unanswered questions including why it happened and who took the decisions which led to this tragedy occurring.

43. I have done some campaigning with Tainted Blood which included attending David Cameron's office in Witney. I also campaigned at Westminster last year.

44. I am very disappointed and upset not to have been awarded Core Participant status in this Inquiry. I can't really believe that the Inquiry made such a decision and would welcome some insight into how this decision was reached.

Anonymity

45. I do not want to apply for anonymity. I am currently unable to give oral evidence to the Inquiry due to ill health. However, if my health improves in the future I would like to be considered for the same.

Statement of Truth

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

Signed GRO-C

Dated.....9/9/2019.....