Witness Name: Mrs Nayna Alonso
Statement No: WITN 1075001
Dated: January 2019

# INFECTED BLOOD INQUIRY

---

# FIRST WRITTEN STATEMENT OF NAYNA ALONSO

---

## Section 1: Introduction

1. My name is Nayna Alonso (nee Vaghela).I was born on GRO-C 1967 and live at GRO-C Manchester GRO-C with my second husband and two children.

2. I make this statement as the widow of Praful Vaghela (deceased) who was infected with HIV as a result of receiving contaminated blood products and who died on 2 July 1995.

3. This witness statement has been prepared without the benefit of access to my late husband's medical records.

## Section 2: How Affected

4. Praful had Hemophilia B classed as moderate to severe. He was born in Kenya where he lived until about the age of 7. I was told by him that, during his childhood there were incidents of heavy or abnormal bleeding and bruising but that he was not formally diagnosed with haemophilia until he came to England in or about 1968. Praful was diagnosed and treated at the Manchester Royal Infirmary.

5. Both Praful and GRO-C suffered from Haemophilia. Unfortunately, in Kenya as they were not diagnosed, people interpreted their bruises as a sign of abuse. I remember Praful telling me that both his parents were accused of abusing their children.

6. Praful's parents sent him to Hereward College in Coventry. It was a residential school for children with disabilities. I believe this is where he was introduced to Factor VIII and where he was taught how to self-administer. Praful was only ever treated with blood products from the Manchester Royal Infirmary or Hereward College.

7. I was told by Praful that no information or advice was given to him about the risk of being exposed to infection from blood products before they were administered to him.

8. Praful was told he was HIV positive in or about 1985 and he told me that at the time he did not know that he was being tested for any infections. I think he was told at the Manchester Royal Infirmary either by his specialist nurse or his consultant, Doctor Hayes (now Prof Hayes). As far as I am aware, the only information Praful had about his infection was from what he heard on the news and read in the press. At the time there was heavy media coverage on HIV and AIDS. The nature of the infection and how it was spread was controversial and trigged lot of bad press. Unfortunately, there was very little information available and a lot of the information out there, was mostly incorrect. After Praful and I met in 1985 we sought more information about the HIV.

11 I consider that the NHS should have provided him with information about his HIV infection including how to manage it and how to prevent it from spreading.

## Section 3: Other Infections

12 I do not think Praful had Hepatitis C. I believe that if he was infected we would have been told by the Manchester Royal Infirmary as GRO-C GRO-C who is also a Haemophiliac was told about his Hepatitis C infection.

## Section 4: Consent

13 As previously mentioned, Praful was not told that he was going to be tested for HIV and did not know he had been until he was told he had tested positive.

14 The topic of research or being tested for the purpose of research never came up. Therefore, I cannot be sure, if Praful was tested for the purposes of research. If he was, this was without his consent.

## Section 5: Impact

15 I believe being diagnosed with HIV upset Praful a lot as the risks or possibility of any infection through the Factor VIII were never discussed with him. The HIV infection came out of nowhere. Coming from an Indian background and living in an Indian community, he was looked down on just for having Haemophilia. If people knew about his HIV infection he would have been excluded ,it became our biggest secret. There was a lot of incorrect information around and people were scared. To this day Praful's parents do not fully understand the consequences of HIV.

16 Praful and I met in 1985 and married in 1989. When we first started to get to know each other I knew about his Haemophilia but he did not tell me that he was HIV positive. At the time just knowing that he suffered from Haemophilia made my family question whether we should get married. I was told about Praful's infection by a mutual friend, who was asked by Praful to break the news to me before Praful and I engaged.

17 I think a lot of the problems came from our culture. In the Indian community Haemophiliacs and other disabled people are considered to be less and are looked down on by certain members of the community. Some even consider them to be cursed people and that the illness occurred as a result of Karma for something bad that the family did in the past.

18 After our marriage I moved to Preston and worked as a nurse and Praful worked in an NHS laboratory. Due to his infection, he later moved onto being a community officer. Because of the nature of our jobs and the way the Indian community would react we kept Praful's HIV a secret. We were worried what the community and our co-workers would think and whether we would be forced to leave our jobs.

19 Our relationship caused some friction between my parents and I as they were concerned about my well being. Due to Praful's infection we knew that he was not going to be well enough to look after his parents which, in my culture, he was expected to do as the oldest son, and my family worried that this duty would fall onto me, and I would have to look after him as well.

20 I consider both of our parents had problems understanding the nature HIV. Unlike Praful's parents my mother and father spoke English fluently and were able to read up more on it. Regardless, they still worried about my health. It was difficult, especially at the beginning. My close family wanted me to end the relationship and this caused a lot of tension. They loved Praful as a person but there were very worried about his health. In the end my family realised that I was not budging and they eventually came around.

21 Unfortunately, keeping the big secret of Praful's HIV infection caused us to withdraw from the majority of social interaction. He was always hesitant to tell anyone and as a couple we became very secretive. I

could not tell anyone about the HIV apart from the immediate family. For example, our parents and siblings knew but I could not tell my uncles and aunties. This caused our social circle to be very small. We did not go out often, only on special occasions. As a result we stopped being invited. We only went on holiday only once. (In my eyes with Praful's Haemophilia and HIV it was more effort than it was worth) when we went to Tunisia to celebrate our 5th wedding anniversary. We felt that we were only able to travel that far as Praful was well at the time, and with much support from the Haemophilia Centre.

22 When I met Praful, he seemed healthy. He managed his Hemophilia and HIV really well. Unfortunately, over time his HIV infection started to manifest itself more and more. Praful started to suffer from various infections and stopped being the active person he once was.

23 As a result of his HIV, Praful would often suffer from fungal infections. They would often be very serious and would make him sick. He was also always cold.

24 We knew we would not be able to have children. I had to accept that fact really early on. However, in the back of my head there was always a bit of hope. Praful was always very responsible and we knew that trying for a child naturally would expose me to a lot of risk. However, we obtained information that a doctor in America was offering sperm washing. Both of us saw this as an opportunity to start a family. We enquired with the hospital about the possibility of it but we were told that sperm washing was still a new process and was not available on the NHS. We were told that there was a possibility we could qualify for IVF treatment. Sadly, nothing ever came out of that.

25 I do believe that there were periods of Praful's life when he was depressed. One specific moment in his life was when he was stopped working for the NHS as a laboratory officer. He enjoyed his work and

hoped to build career in it. He quit his job in the laboratory soon after he found out that he was infected with HIV. The nature of his work required him to use needles and scalpels and he was wary that this increased the chance of him infecting anyone else. Making this decision was hard for him but he was always very responsible and wanted to have his conscience clear. It was hard for me to see him giving up something he enjoyed, especially as I knew that the infection was not his fault. In the end he needed an arteriovenous fistula because he could not self administer the Factor VIII anymore. In the last year of Praful's life we spend his last few weeks in hospital.

26 After Praful left the NHS he became a community officer for a local council. His work mostly focused on working with different minority groups. He was very involved and ended up being quite successful. Praful set up a lot of different clubs were children could meet and spend time together. At the time we lived in Preston which had a big Ethnic Minority and Black/Caribbean community. Praful created a space that they could make their own. At the time that was the only such place in Preston. His work was fundamental to the community. Sadly, despite his success his contract was not renewed. He was told that he was taking too much time off work. Unfortunately, that was his HIV taking over his life. He was very committed to his work. When he was "well" he would work late hours to prepare for events and develop new projects for the center but the Council did not see it. Praful developed an excellent reputation so after he was let go by the Council he was given a fixed 12 month contract as a fostering officer. Again, due to his health problems the contract was not renewed.

27 Due to Praful's health status I made a decision to leave my job as a nurse and started working as a school nurse. Working for the NHS in schools enabled me to have more time off. I only worked during the term and the hours were shorter. It was essentially part-time work so I could spend more time with Praful. On the flip side, it meant that I was not earnng as much. In addition, it was not something I wanted to do.

After Praful passed away I qualified as a midwife and completed a degree in health visiting. This was something that I always wanted to pursue.

28 I do not know whether Praful's work as a laboratory officer was more lucrative than his work as a community officer. When he worked in the laboratory he was just starting his career and he was on an entry level salary.

29 After Praful passed away, I became depressed, and at times, even suicidal. Following our tradition I continued to live with my in-laws. I was alone in Preston. I am originally from London and moved up North after Praful and I married. GRO-D

GRO-D

30 GRO-D

GRO-D In the end it was the Hemophilia Centre counsellor who helped me to devise a plan. I told my in-laws that I was going to train and study in Manchester, as a midwife, but would have to move to Manchester in order to complete the practical element of the course. GRO-D

GRO-D

31 GRO-D I was met with disapproval from some friends and family. I went against tradition and failed to do what was expected of me, but I knew I could not live my life like that. A lot of people did not understand my actions. GRO-D

GRO-D

## Section 6: Treatment

32 I know that Praful was given an antiviral for his HIV. I think it was AZT but I am not sure. He was being treated around the time that new medications were coming out. We tried to obtain as much information about new treatments, as possible but it was difficult. I think we were just given what was available at the time.

33 I am not aware if there were any obstacles in obtaining treatment for Praful's HIV. However, I do recall problems with obtaining dental treatment. There was only one dentist in Preston that would treat Praful. It was not a local to us. There were dentists closer to our home but Praful had no choice. He had to declare to dentist that he was HIV positive. We also had to declare Praful's HIV status on our mortgage and of course we were refused sperm washing on the NHS, or any kind of life insurance.

34 We only had a psychological support during the last two years of Praful's life when Manchester Royal Infirmary obtained funding for a specialist counsellor. She was available for the both of us and helped us immensely. I think this help should have been available from the beginning. However, it was still difficult. There was only one counselor in the whole of Lancashire, so there was some difficulty with arranging appointments. She would do home visits too. Sometimes, we would travel to Manchester medical appointments and would have liked to see her and we would then find out that she was away. There should have been more counsellors and at least one counselor available on site. We needed more counselling. Due to the stigma around the HIV I did not feel that we were able to seek help elsewhere. I did not want to speak to someone outside the Hemophiliac Centre as I would have to go through the entire process of explaining about HIV and how the infection occurred.

## Section 7: Financial Assistance

35 We did not know that there was a financial assistance available until the specialist counselor started working at the Manchester Royal Infirmary. She informed us about it and helped us with the application.

36 We were mainly in contact with the Macfarlane Trust. I think we received a couple of one off payments to help us with the heating bills. We needed heating on all the time because Praful was always cold. We also received a grant for a deposit for the mobility scheme to obtain a car. However, I am not sure of the exact amount.

37 I recall that to obtain any kind of payments we were required to fill out lengthy forms. We also needed to provide a lot of information about our financial status and justify what the money was needed for. Even at the time I thought that those forms were unnecessary. Obtaining the financial assistance could have been made easier for example, when you were diagnosed they could have stored that information so you

would not have to repeatedly give the same information. I also think that there was a yearly cap on how much you could claim.

38 I do not think that the existence of the Trusts was public enough. For example we did not know about them until really late on. It was not common knowledge. I also think that they did not have enough money or do enough to help us. When Praful died I was lost and it would have been helpful to have more support from them. Maybe even a package with information on what to do when a loved one passes and who to contact. I think they had the appropriate information and resources to do something like that. They just chose not to.

39 Praful and I were also a part of the Birchgrove Group. I remember that once we went on a weekend away that was paid by them. I think it was a conference organised by them about living with HIV.

40 My husband was part of the 1980/90's litigation. He was represented by Panonne Napier Solicitors in Manchester. The litigation resulted in out-of-court settlement and he was awarded a lump sum of £20,000. This went towards the mortgage.

41 Overall, I think the Trust that we dealt with was sometimes hard to contact and were difficult to deal with. The funding was not good enough and as a result you had to justify everything.

## **Section 8: Other issues**

42 It has taken the government a considerable amount of time to deal with this issue and here is still a lot of secrecy, and a lot of the crucial information is no longer available. Consultants who treated people like my husband are either retired or no longer alive.

43 I believe that there was a cover up and as more and more stories are heard they all seem to support my view that there has been a cover up I think this was intentional because the NHS made a mistake.

44 I am not sure how accurate the documentaries on TV were, but if you consider where the NHS went to get the blood/blood products the possibility of any blood-borne virus arises should have been obvious. They should have known, they should have put safeguards in place.

45 I think the entire process of the Inquiry is taking too long. It feels like they are waiting for those who are alive to die. As a result of the delays even more information will be lost. Even now I cannot tell you the names of the medication Praful was on and gaps in peoples memories are only going to increase.

46 They have affected millions of lives, including families and potential families. We all lost people that we love and we want to prevent this happening again.

## Anonymity, disclosure and redaction

47 I am prepared to give evidence.

## Statement of Truth

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

Signed...................................

Dated...................................

common knowledge. I also think that they did not have enough money or do enough to help us. When Praful died I was lost and it would have been helpful to have more support from them. Maybe even a package with information on what to do when a loved one passes and who to contact. I think they had the appropriate information and resources to do something like that. They just chose not to.

39 Praful and I were also a part of the Birchgrove Group. I remember that once we went on a weekend away that was paid by them. I think it was a conference organised by them about living with HIV.

40 My husband was part of the 1980/90's litigation. He was represented by Panonne Napier Solicitors in Manchester. The litigation resulted in out-of-court settlement and he was awarded a lump sum of £20,000. This went towards the mortgage.

41 Overall, I think the Trust that we dealt with was sometimes hard to contact and were difficult to deal with. The funding was not good enough and as a result you had to justify everything.

## Section 8: Other issues

42 It has taken the government a considerable amount of time to deal with this issue and here is still a lot of secrecy, and a lot of the crucial information is no longer available. Consultants who treated people like my husband are either retired or no longer alive.

43 I believe that there was a cover up and as more and more stories are heard they all seem to support my view that there has been a cover up I think this was intentional because the NHS made a mistake.

44 I am not sure how accurate the documentaries on TV were, but if you consider where the NHS went to get the blood/blood products the possibility of any blood-borne virus arises should have been obvious. They should have known, they should have put safeguards in place.

45 I think the entire process of the Inquiry is taking too long. It feels like they are waiting for those who are alive to die. As a result of the delays even more information will be lost. Even now I cannot tell you the names of the medication Praful was on and gaps in peoples memories are only going to increase.

46 They have affected millions of lives, including families and potential families. We all lost people that we love and we want to prevent this happening again.

## Anonymity, disclosure and redaction

47 I am prepared to give evidence.

**Statement of Truth**

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

Signed.. GRO-C

Dated.....10th January 2019