Witness Name: Sheila Patel
Statement No.: WITN3146001
Exhibits: WITN3146002

Dated: 14 October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SHEILA PATEL

1. I, **Sheila Patel**, will say as follows: -

Section 1: Introduction

2. My name is Sheila Patel. My date of birth is GRO-C 1960 and I live at GRO-C GRO-C Middlesex GRO-C I am currently employed as a Sales Assistant at John Lewis, and I have a daughter, Alisha, who is 35 years old.

3. My late husband, Girish Patel, was infected with HIV through contaminated blood products and he died as a result of HIV and AIDS. This statement is made based on my recollection of events; I have not yet received my husband's medical records. I intend to use this statement to talk about the impact of my husband's death and my hopes for the Inquiry.

Section 2: How affected

4. My husband, Girish, and I met in early 1981 when we were introduced to each other. In October of the same year we were married. He was always open with me about his health and I knew that he had haemophilia, which was severe, although I am unsure of the type.

5. My husband was born on GRO-C 1958 in Zambia. He moved to the United Kingdom from Zambia in 1975 when he was 17 years old and he was treated with Factor VIII blood products for as long as he was in this country. We

received a supply of Factor VIII from Hammersmith Hospital, which he took regularly. He used to self-administer the Factor VIII at home, although if he had a particularly severe bleed, for example in his knee, we would go to Hammersmith Hospital for assistance. Despite his haemophilia, my husband was a very active and healthy man.

6. In 1984, our daughter Alisha was born. My husband's health was still fine at this point, although in hindsight, looking at photographs I can see that he had lost a lot of weight. GRO-C GRO-C.

7. I do not know when he received the diagnosis of an infection with HIV as he did not tell me straight away, I believe in an attempt to protect me. I do wonder if he had already been diagnosed when Alisha was born.

8. At this time, I was working at Marks and Spencer, whilst my husband worked as a graphic designer. In 1986 we began the process of buying a new home. We had decided to have a mortgage with an endowment policy, which usually required a medical assessment, but due to his illness my husband could not have a policy which required him to disclose medical information. At the time I believed that he could not find a policy due to his haemophilia. Eventually we found an endowment policy which paid £30,000 in the event of death, without a medical, but I was still left with a £40,000 mortgage when my husband died. When we moved into our new house in February 1987, I still did not know about my husband's diagnosis with HIV.

9. While Alisha was still young, at some point in 1987, my husband developed a bad cough. It lasted for a long time and for some reason it would not clear; he seemed to be getting very tired. This was very unusual for him, as he was normally a healthy man and very rarely ill. He was registered with a GP surgery but he never seemed to have any reason to visit them. When I asked him why he was coughing and why he was always tired, he told me that he had been diagnosed with HIV. This is the first that I knew about his infection and I do not know when he was diagnosed.

Diagnosis with HIV

10. When I became aware of his infection, my husband had very little information, and he told me "*Don't worry, I'm not just going to die*". I did not believe he was going to die either at this point, but we received very little support. He was prescribed treatment with Azidothymidine ("AZT") tablets to be taken at specific times. I remember that if we were out of the house, he had to remember to take the tablets, as you could not delay taking them.

11. My husband told me, at some point, he was asked to take part in a discussion about HIV on television, but he did not want to, as he did not want to risk anyone else knowing. My husband was worried about the stigma of the HIV, which was terrible in around 1986 or 1987. I can still recall the "tombstone" advert on television in the 1980's, and being worried about potential co-infection. The tombstone advert was on television daily. This advert was so shocking that if you were HIV positive, like my husband, and having to endure watching it on a daily basis, psychologically it was enough to push you over the edge. According to the advert, you were facing certain death and the world was coming to an end.

12. As time went by my husband's condition began to deteriorate. He started suffering from night sweats, tiredness and he was given blood transfusions at this time. His energy levels continued to drop. I was beginning to get really worried at this point, and by the late 1980s my husband had been told there was nothing the doctors could do for him anymore. I was crying a lot at this point, and would stand on the train coming back from work crying and thinking "*He won't die, he just won't*".

13. My daughter Alisha can recall seeing her dad walk through the door in the late 1980's and his appearance shocked her. He was walking with a stick, and while she knew that he was ill, she associated the stick with her grandparents and not her dad, which shocked her. We had not told her about the HIV, we simply told her that her father was ill.

14. In January 1990 we were called to a meeting with Dr Prem at Hammersmith Hospital with regards to headaches that my husband was suffering. I can remember being shocked to be told by the doctor that my husband only had

two weeks left to live. I just cried and my husband said nothing, but what could he possibly say?

15. My husband survived longer than the two weeks expected. However, on Thursday 2 August I discovered that he had gone alone to visit Hammersmith Hospital. Kathy, one of the haemophilia nurses, told me that he had gone to the hospital because he was frightened about his condition and wanted to talk to them. Later that Thursday evening, he suffered a brain haemorrhage. He was rushed to Northwick Park Hospital, which was closer than Hammersmith Hospital. On Friday morning he had a CT scan, as he was still unconscious.

16. The doctors had initially said that it looked worse than it was, however following the CT scan the doctor told me that he would not regain consciousness because he had a haemorrhage and the haemorrhage was too large to treat. The doctor also told me that my husband's HIV had progressed to AIDS, which was the first I had heard of this. I think it is likely my husband knew that it had progressed to AIDS but did not tell me.

17. My husband fought with all that he had but at 9:45am on Saturday 4 August 1990, my husband sadly died. The cause of death on his death certificate is listed as 1a brain haemorrhage, 1b haemophilia and 2 AIDS [WITN3146002].

18. I recall the doctor saying that to die from a brain haemorrhage was the kindest thing for my husband, rather than him having to go through the continued degradation caused by AIDS. My daughter has said that the rest of the family must have been shocked by his death, as he did not have many of the physical symptoms of the illness; many of them did not even know that he was ill.

Section 3: Other infections

19. I only discovered that my husband's HIV had developed into AIDS whilst he was comatose, shortly before his death. Subsequent to his death I have discovered that he may also have had Hepatitis. Professor Mike Lafanne wrote to inform me that my husband also had Hepatitis and suggested I apply to the Skipton Fund for financial assistance. I am unsure which type of Hepatitis my husband was diagnosed with.

Section 4: Consent

20. My husband was not informed of any risks associated with the Factor VIII product, which he had begun to receive at the age of 17 when he came to this country. I do not know at which point he was given the contaminated blood product that led to his infection. We were also never given any information about managing my husband's HIV, although we were warned about the risk of transmission and so had to be very careful. We could not have any more children due to the risk of transmission, and therefore could not take any risk by having sex again.

21. I do not know if he ever knew or consented to the tests for HIV or Hepatitis, as I believe he tried to keep a lot of the details from me, in order to protect me. GRO-C I have GRO-C been tested for HIV, but not Hepatitis C.

Section 5: Impact

Impact on my husband

22. The impact of my husband's diagnosis with HIV and subsequent illness was enormous. He had always been a very active man and haemophilia had never stopped him. My daughter has said that her GRO-C, who also has haemophilia, has completely adapted to life with the condition, and is not troubled by it, and my husband was the same before his HIV infection. However, the HIV brought him to his knees and completely wiped him out. I always thought he would overcome it and usually he bounced back, but eventually it destroyed him and he just could not control it.

23. He suffered huge weight loss, although I cannot tell if this was a side-effect of the AZT or because of the HIV itself. He turned a deathly grey colour and began to suffer from bad headaches, as well as quickly getting out of breath and losing the ability to walk well. My husband became very weak, very slow, suffered from night sweats and poor sleep. He also lost his appetite, which was a marked change, as he used to eat and sleep well. My husband was never the sort to visit his GP. During this period, he was still getting his regular bleeds due to his haemophilia and continued self-treating with Factor VIII. For the

duration of his illness, my husband always received Factor VIII and was never given any other factor treatments.

24. Psychologically, I believe that he knew he was going to die. He would say things like "*I'm going to miss Alisha growing up*", and my father-in-law recalls that he said to him, "*Who is going to look after Alisha when I am gone?*". As we had not told the rest of the family about his HIV infection, my father-in-law had no idea at the time why he had said that.

25. How would you feel if you were told that you were going to die and you were never going to get better? He did the right thing by taking his medication and going to the hospital, but the lack of support and the huge responsibility and secrecy he carried left him feeling incredibly isolated.

Stigma

26. For much of his time my husband was infected, I was the only person who was aware of it. I believe that he was very worried about the stigma, as we all were. Keeping quiet about it all was his way of dealing with it.

27. The stigma we felt meant that when my husband died we told people that it was due to a brain haemorrhage and left it at that.

28. After my husband's death I effectively became a single mother which came with a stigma all of its own. I recall explaining my current status to a cashier who responded with, "*A widow? But you're young*". This shocked me deeply. The stigma of the HIV itself also had a big impact, and the effort to keep it all a secret led to huge isolation. The loneliness of keeping such a secret was incredible. This has continued after my husband's death.

29. My daughter, Alisha also faces stigma from the medical profession, needing to be referred whenever she goes to an orthodontist because of her family's medical history. **GRO-C**

GRO-C

30. The stigma behind AIDS and HIV has also affected Alisha and she often does not even say that her father had haemophilia, in case people make that leap from haemophilia, to HIV or AIDS.

31. I also know that the stigma of haemophilia has gone further than affecting me and my daughter. My brother-in-law was planning to get married, and when his fiancée's family discovered his brother had haemophilia and died, they would not allow her to marry him. They did not want to marry into the condition, even though my brother-in-law does not have haemophilia. The stigma around haemophilia stopped him getting married.

Impact on me

32. I believe my husband was trying to protect me for much of the time he was infected, not telling me about various things in order to shield me from the reality. He had always been the one who took care of everything and supported us all; the whole family. My daughter can recall her great-uncle, my husband's uncle, being shocked following his death as he was going to ask her father to look after his family, should anything bad happen to him. None of us could have imagined what would happen to him.

33. My husband's diagnosis and subsequent loss of my husband was incredibly difficult. I can remember just crying to myself on the train coming home from work and being incredibly worried not knowing what was going to happen. I can remember calling the doctors at Hammersmith Hospital one day to ask them "*Do you think that his HIV will become AIDS?*". I spoke with one of the haemophilia nurses. I desperately wanted them to tell me "*No it will not*", but they responded that they thought it would and that it was important for them to be honest.

34. I could not discuss my husband's HIV with anyone; I could not tell my friends at work what I was going through. It was something we had to deal with on our own.

35. I still suffer from the psychological effects of my husband's death. I see father's and couples everywhere and it is still painful to see them. I have had no support and have lost that rock, that my husband was to us. It has been very difficult having to cope, and sometimes you just want to close the door on everything. But life continues.

Impact on my daughter

36. My husband's death has had a huge impact upon my daughter, Alisha as well. At the time she was only six years old and too young to fully understand what was happening. She can remember seeing it all, the hospital, the funeral, but she did not understand it, nor did she understand death. She has told me that she kept expecting him to walk through the door, and she used to speak about him in the present tense, until she was at least 16 years old.

37. I can recall one incident where I broke down crying saying "*What are we going to do? What shall we do with all of his things?*" and Alisha saying to me "*We can post them to him*". She simply did not understand that he was gone.

38. Since then I believe that she has been impacted by the loneliness of losing her father as well. The loneliness has shaped her and she is still lonely now; she is not who she should or could have been.

39. My daughter suspects that the death of her father has also had an impact upon her education. She believes that she would probably have gone to a better school and have done better in her education had she grown up with her father. He was always there to help push her and encourage her to do things out of her comfort zone. Without him here, she does not have that drive. She does not have that same rapport with her uncles in order for them to provide that push.

40. Other children do lose their grandparents but to lose a parent that young is very unusual and she became lonely and isolated growing up, which has shaped her since. All of the other children had a mother and a father. She has told me that it was often easier in the playground to say that her father was away with work rather than to explain that he had died.

41. After keeping her father's HIV a secret for so long, it became easier for Alisha to say something else or to change the subject away from her father. When she was growing up she did not know what to say to people about her father's death. If she gets married she will need to explain this as well.

42. I know that my husband was very worried about what would happen to Alisha after his death and voiced this many times to different people. Shortly before

he died we celebrated Alisha's sixth birthday, and I can still remember him wrapping her presents. He had insisted upon a big party; I think because he wanted it to be normal for Alisha or because he knew that there would not be another birthday party for him. It was a really nice day and we took a photo of Alisha blowing out all of her candles. That photograph went with him to the hospital when he died.

Impact on family

43. The death of my husband came as a shock to much of the wider family, as we had not told them that he was ill, and as my daughter has pointed out, he did not have any of the physical symptoms.

44. In Indian society, you lose a certain level of respect when you lose your husband, and I felt that his family began to look down on us a little bit. We lost that connection to him and his family; we became increasingly isolated. My husband was the one that had held the whole family together and without him we lost the support from his side of the family. The feeling of isolation continues to this day and sometimes I feel lonely in rooms full of people. I do not think that loneliness will ever really leave.

45. Fortunately, my family have been very supportive and particularly helpful financially. Whenever we have difficulties they are there to help us, replacing broken washing machines, broken watches, and helping us with holidays. They are based in Lancashire and not London and so this distance is difficult, but they have been very helpful and kind to us.

Impact on finances

46. Financially, the impact of my husband's infection with HIV and subsequent death has been huge. I had worked in a part-time job at Marks and Spencer when my husband was alive, however I had to give this up in order to raise our daughter.

47. I had to go on income support after my husband's death which was a huge struggle. This was a dreadful period, the worst time of my life, and I was having to count the pennies in order to survive. I was living on £62 a week, which was later increased to £68 a week, which was simply not enough. I worried about

my pension, how to get back to work and how to put food on the table. I was also doing my best to support Alisha, although we could not afford any treats or special trips at this time. I was out of work and on income support until 1999, when I went back to work at John Lewis full-time.

48. We did receive some financial assistance from my family who helped where they could, although this was made harder by the distance between us; I could not easily afford to travel to Lancashire from London.

Section 6: Treatment, care and support

49. Apart from when he was rushed to Northwick Park Hospital before his death, my husband was treated entirely at Hammersmith Hospital. I cannot say a bad thing about the treatment he received there. They did what they could, and a lot of the time I think the doctors were as much in the dark as we were. Beyond giving him AZT and the medicine that was available, what else could they do?

50. Some of the staff there were excellent, in particular Kathy, the haemophilia nurse, was very caring. However, the information that we received was very limited and never improved as the infection progressed.

Obstacles to treatment

51. I cannot recall there ever being any difficulties in obtaining treatment for my husband, although dental treatment could be difficult, and often required referral to a hospital.

Psychological support

52. The psychological support was non-existent. We were never offered counselling at all and after my husband's death, that was it. There was no follow-up, we simply had to get on with it. The loss of my husband was so great that I do not know if any sort of psychological support or counselling would have assisted.

53. My daughter Alisha, however, has found that the meetings conducted by The Haemophilia Society have been helpful. It is an environment where we can talk openly about our experiences and where people understand what you

have been through. It is one place we do not have to keep things a secret. Alisha finds that there is warmth there, although it is a little isolating as there is no-one else there from our culture. I do not know why this is, maybe culturally, it is not as open, as I have to assume it has affected people from our culture too.

Section 7: Financial assistance

54. In 2002, when Alisha was 18 years old, we were contacted by the Macfarlane Trust about the possibility of receiving monthly payments from them to support Alisha's university education. These payments continued until 2006 when she finished university. We were told the monthly payments were only available whilst my child was in education.

55. Subsequently I have received contact from EIBSS, the Macfarlane Trust's successor. EIBSS have refused to pay anything, because their payments are based upon household income. EIBSS has made a decision regarding eligibility for monthly payments based upon mine and Alisha's combined income, as my daughter lives with me.

56. I think that this is incredibly unfair and I have written to them explaining my circumstances, although they have not changed their mind. Alisha is my daughter, not my partner or my spouse and so it seems very unfair that the amount that we should not receive support from EIBSS because of this. I believe that widows should be treated in their own right and eligibility should be calculated on their own merit, instead of having their compensation denied due to the support of their children.

57. It was suggested to us by Professor Mike Lafanne, at Hammersmith Hospital that we contact the Skipton Fund as my husband was believed to have suffered from Hepatitis. However, we received no support from the Skipton Fund, we were told we were ineligible for financial assistance on the basis of insufficient medical evidence, even though Professor Mike Lafanne had signed a document in proof of the matter.

58. Professor Lafanne was very kind and caring and had also suggested that we contact the Macfarlane Trust, although at this point our payments from them had already ended. The Skipton Fund on the other hand provided no further follow up or support to us.

59. The Haemophilia Society has always been there; however, they have suffered from having no funding. They have been fighting as well, but very little is within their control. It has always seemed like the Government has taken no responsibility for what was within their control, and has brushed a lot of it aside. As I have already stated, my daughter Alisha finds the meetings organised by The Haemophilia Society to be very helpful, in particular to have somewhere where we can talk openly about our experiences with people who will understand them.

Section 8: Other issues

60. My hopes for the Inquiry are that we receive compensation, or rather that, our children will be compensated. It has taken so long and my husband has been dead for 29 years. As we have waited 30 years for an Inquiry, there reaches a point where you have to ask yourself what is the point. People are still dying but my husband certainly will not benefit from the Inquiry, as it is too late for him.

61. My daughter and I have both been left destroyed; we were a normal family with a future ahead of us. I will never have a pension from my husband, because he died too young. I feel that the Government should at least pay a pension to the widows of those that died as a result of contaminated blood products, and compensate us for the loss of earnings we suffered, as a result of our spouse's untimely deaths.

62. Compensation will certainly be helpful but why was there no help earlier? It felt like we were cut off, silenced, with nowhere to turn and with no support. The support would have been far more helpful if it was given at the time. Although, I do not know how the Inquiry will be able to put a price on someone's life.

63. I hope that the Inquiry can help uncover the untruths that were told about the infected blood product. My husband did not know that the Factor VIII was contaminated and he was not the only one. I could have been infected and could have died and my daughter could also have contracted it. Both of us are blessed to still be alive.

64. However, this is not just about compensation. We have experienced an unbearable loss that has changed our life forever. We will spend the rest of our lives grieving for a life that I and my daughter should have led and the people that we should be now. The secrecy has been incredibly hard and we can only be open at The Haemophilia Society events we attend. I still feel the "taboo" and the stigma and I no longer admit that my husband had haemophilia. People are more liberal minded than there were at the time of his illness, but the stigma still exists. I hope that the Inquiry can uncover the untruths that have been told.

Statement of Truth

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

Signed ..**GRO-C**..................

Dated....14 OCT 2019..........