Witness Name: Tina Jean Barton
Statement No: WITN5492001
Exhibits: WITN5492002 - WITN5492011
Dated: 24 June 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF TINA JEAN BARTON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 January 2021.

I, Tina Jean Barton, will say as follows: -

Section 1. Introduction

1. My date of birth is GRO-C 1960. I reside at GRO-C GRO-C. I married my husband Robert Mark Barton ("Mark") in 1979, and we had two children together. My son Daniel Mark Barton was eleven years old at the point of his death, and my daughter Elizabeth is twenty-five years old.

2. For the past twenty-three years, I have been employed as a Shop Assistance Supervisor on the Isle of Wight.

3. My husband and I currently live in a property on the Isle of Wight in the countryside. We love the outdoors and we keep dogs and horses. Horses are something I have enjoyed all of my life. We are lucky that as Mark is now retired, he is able to look after our house and our land. Before Mark retired, he was employed in a number of jobs similar to my father. He has been a builder, worked in removals, and he even worked as a roof tiler with my father at one point.

4. I intend to speak about my son Daniel Mark Barton's infection with HIV, after having received contaminated Factor VIII as treatment for his haemophilia. In particular, I wish to discuss the nature of how we had learnt about his infection, how the illness had affected him and our family thereafter, and the treatment he had received. Daniel's date of birth is GRO-C 1981, and his date of death was 19 January 1993.

5. I also intend to touch on my late father Philip Norman Pugsley's infection with HIV, which was contracted in similar circumstances to that of my son Daniel. Dad's date of birth is GRO-C 1941, and his date of death was GRO-C 1991. Daniels 10th birthday.

6. My mother Joan Elizabeth Pugsley also provides a witness statement to the Infected Blood Inquiry ("IBI") at **WITN4603001**. She discusses my father's infection with HIV in detail, and also touches on her grandson Daniel's infection with HIV.

7. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I am not seeking anonymity as I wish for Daniel's story to be known in full.

8. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

9. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

10. I have constructed this statement without access to both my father and Daniel's medical records.

11. In 1991, my father Philip, my mother Joan, a couple named GRO-A GRO-A and Mark and I were approached by Mark Mildred to start a medical negligence claim against the Government. The purpose of this claim was to gain compensation for my father, Daniel, and Brian and GRO-A's son, who had all contracted HIV as a result of being given contaminated Factor VIII. My mother and father were involved on behalf of my father's infection, and Mark and I were involved on behalf of our son Daniel.

12. Before we were due to go to court, the Government offered us an out of court settlement. However, we had to sign a disclaimer, which included a condition that we had to return all of my father's, Daniel's and GRO-A's son's medical records to the Heath Authority. We signed the disclaimer, and as per the Judge's ruling, their medical records were returned to the Health Authority.

13. Since the point at which my son Daniel's medical records being returned to the Health Authority, I have not gained access to his records thereafter. However, I am now at a point whereby I would like to gain access to his records, as I believe that they may hold the answers to the questions I have surrounding my son's infection and subsequent death.

14. In the event that I am unsuccessful at gaining access to Daniel's medical records, I have provided my authority to the IBI to find and locate his medical records on my behalf.

Section 2. How Affected

15. I was born at St Mary's Hospital ("St Mary's"), Parkhurst Road, Newport, PO30 5TG, on GRO-C 1960. I am the eldest of my siblings. I have one sister Trudy Bailey, who was born on GRO-C 1962, and my brother Philip Pugsley (Anderson) was born in 1964.

16. Growing up, I had always been aware that my father had haemophilia. However, I did not fully understand the potential impact this would have on his health; other than he was more susceptible to injury and that he would bleed more profusely. Also, that he would require treatment for his bleeds. Due to dad's 'get up and go' attitude, I did not think that his haemophilia debilitated him.

17. My memories of my dad when I was younger, was that he was always fit and active. When he was not at work, he loved to be out on the beach; diving and swimming. He was the greatest dad and I could not have asked for more. He always gave us 100% and he would try to go to work and finish early so that he could spend more time with us.

18. In 1979, when I was aged nineteen years old, I married my husband Mark. We have been married for over forty-two years on the date in which I write this witness statement. After our marriage, my husband and I rented a property on the Isle of Wight, so that we could raise a family. We went onto purchase the property at a later date.

19. On GRO-C 1981 I gave birth to my son Daniel at St Mary's. Before his birth, I cannot recall ever having been told about the possibility that I could have been a carrier for haemophilia, or, that I could possibly have passed it onto my future children. I had previously thought that haemophilia was on my father's side and that it would have stopped with my father.

20. However, as a precaution measure and due to my family history of haemophilia, I decided that not long after Daniel's birth I would get him tested to see whether he had haemophilia like his grandfather. Before Mark and I were discharged from St Mary's with Daniel, he was tested. Then again at the age of around three months old, it was then confirmed that Daniel suffered with Haemophilia A, he registered as having 5% clotting factor.

21. Once I had learnt more about how Daniel's haemophilia had affected him, and that any future children could potentially have developed haemophilia, I decided that I did not wish to have any more children. I did not want them to have to go through any further pain, in the same way as Daniel. I was sterilised around 1985 at the age of twenty-five years old at St Mary's. I was cut and clipped so that my sterilisation could be reversed at any point if I changed my mind.

22. As life progressed with haemophilia, Daniel did not experience many bleeds. That was until between 1981 and 1982, when he suffered two injuries, which required treatment with Factor VIII. Around the end of 1981 or the start of 1982; which was before his first birthday, Daniel was in his pram and I was sorting out the straps to clip him in, as I turned to pick them up Daniel fell out and landed face down on the floor. He instantly developed bruising on his body, so we took him to seek medical assistance from our General Practitioner ("GP") at Sandown Medical Centre.

23. At a face to face consultation with our GP, we had shown the GP Daniel's bruising. We were immediately referred to St Mary's for treatment. After initial observations by the medical staff at St Mary's, we were told that Daniel was in need of treatment for his bleeds and that he would be given Factor VIII. This was the first time at which he had been given Factor VIII. Thereafter, Daniel was kept on a ward at St Mary's for a few days before he was discharged to go home and rest. He was given the Factor VIIII intravenously through his arm.

24. At the end of 1982, Daniel tripped over and bit his lip. This had caused him to develop a large bump on his lip, which was filled with blood. My father looked at him straight away, and due to his personal experience with haemophilia related injuries, he said that Daniel would need to be taken to St Mary's to gain medical assistance.

25. When we reached St Mary's, we were told that Daniel would need to be treated for his injury. He was given his second dose of Factor VIII, and the swelling had gone down almost instantly. Similar to our earlier experience in 1981, Daniel remained at St Mary's for a few days so that the medical staff could keep an eye on his health and for general observations. He was discharged to go home to rest thereafter. Later he tripped over and fell, we were referred to the Social Services at that point. I think a member of the public reported Daniels bruises. The health visitor attended and agreed that he was not at risk and that was that.

26. After this point, Daniel did not get many other bleeds. I had taught him that if he was to do something silly, he may end up with a bleed and would need to go to the hospital for treatment. Daniel did not like the hospital much, so he was extra careful not to injure himself thereafter.

27. In 1984, I become aware that my dad had been diagnosed with HIV at the Churchill Hospital ("Churchill"), Old Road, Headington, Oxford, OX3 7LE. Also, that he had contracted HIV as a result of contaminated Factor VIII he had received as treatment for his haemophilia. As far as I can recall, it was my dad who had told me about his infection. I was devastated at this news. My dad was my world.

28. After learning of my dad's diagnosis, I did wonder whether Daniel was at risk of having contracted HIV. After all, Daniel had also been given Factor VIII the same as my father. However, when I had a conversation with my dad, he had said that he would be fine. The chances of becoming infected was very slim, as after all, he had only been given two doses of Factor VIII.

29. We got on with our lives thereafter, and we tried to be there to support my father through his diagnosis. However, in 1985, our whole world came crashing down around us.

30. In 1985, when Daniel was aged around five years old, he started school at Gatten and Lake Primary School. Around the same time, on 02 September 1985, Daniel had a number of his baby teeth extracted at the Churchill. They were rotting as a result of all the antibiotics he had received. After the surgery had taken place, Daniel remained in hospital for a number of days thereafter, so that the medical staff could observe his recovery, and for bed rest. He was discharged to go home shortly after.

31. One to two weeks after Daniel had undergone the surgery at Churchill we received a telephone call from our GP. We were asked if we could attend our GP surgery for a face to face consultation.

32. At the face to face consultation with our GP, only Mark and I attended. We had left Daniel with my mother. It was at this point; that we were informed that whilst Daniel was in attendance at the Churchill, undergoing his dental surgery, a blood test had been undertaken which was unbeknown to me. When the test results had returned, it had shown that Daniel had tested positive for the presence of HIV. I had no idea that this test was being done.

33. We were so shocked. We could not believe what we had just been told. Not our Daniel. Our GP just kept saying to us "*my deepest apologies*." Also, something along the lines of "*Daniel is okay at the moment, and in the future, hopefully medical treatments would advance. Do not worry about it, just go home and try to forget about it.*"

34. Within a letter, dated 22 December 1993, from Dr Paul L F Giangrande, Consultant Haematologist, Oxford Haemophilia Centre, Churchill Hospital, to Mrs Tina Barton **(Exhibited as WITN5492011),** it outlines that I had made inquiries into the exact point of time at which Daniel had tested positive for the presence of HIV. The relevant section of the letter states as follows:

> ***"On reviewing the notes, the positive result which I can find relates to a blood sample taken on September 2, 1985."***

35. Daniel was only 4 years old. Thereafter, as in those days you did not question doctors and their methods; and they were considered gods, we did not question Daniel's diagnosis. On the way home, Mark and I did not know what to say to one another, we just sat there in the car in silence.

36. As soon as I got home, I phoned my dad to tell him about Daniel's HIV diagnosis. Dad was absolutely devastated. We all were. Not only had my father been infected with HIV, but also my son Daniel. My father gave me a lot of advice and support around that time which I relied upon. I will forever be grateful.

37. Upon reflection, when we had been told about Daniel's HIV diagnosis, we were given quite a lot of information by our GP to help understand and manage his infection. I would consider this to be adequate information. We were also told about the risks of others being infected as a result of his HIV.

38. Mark and I were told that we should wear gloves at all times when we were in contact with any of Daniel's bodily fluids. This included saliva, dirty tissues, faeces, and urine. These safe practices would have allowed us to be protected at all times. I was also told not to touch any surfaces which had bodily fluids on, due to the risks of transmission of Daniel's HIV. I didn't take any notice of this advice, Daniel was my son, I didn't want him to see me or his dad treating him any differently. My view is if I got it then so be it. My son came first.

39. I do not consider that information should have been provided earlier surrounding Daniel's HIV infection. As far as I was aware, Mark and I were told about his diagnosis as soon as the medical professionals had become aware themselves.

40. Although Mark and I were told about how to manage Daniel's infection for the period of here and now, we were not told about what his HIV meant with regards to the effects it would have on his health in the future. As far as we knew; and looking at my dad as a role model, no one was getting ill. I thought, dad and Daniel were fine at the moment. They were both healthy, and that there was nothing to worry about. I tried not to let it get to me too much.

41. However, not long after Daniel's diagnosis, I could see that dad's health had deteriorated, so I knew that the same would eventually happen to my Daniel. I feel that we should have been told the relevant information surrounding the likely effects Daniel's HIV would have had in the future, as it would have allowed us to adequately prepare for what was to come.

42. Mark and I knew that there was one cause of Daniel's HIV infection. Similar to my father, he had been given Factor VIII as treatment for his bleeds in 1981 and 1982, which, had been contaminated with the blood borne virus HIV.

43. Although Daniel had only been given two doses of Factor VIII, he was very unlucky. I have since learnt that as the Factor VIII he was given was American sourced, (this information was given to me by Mary Fletcher the health visitor) it carried a higher risk of having been contaminated with blood borne infection.

44. When Daniel had been given his treatment with Factor VIII between 1981 and 1982, we were not provided with any information or advice beforehand, surrounding the associated risks of being exposed to infection.

45. I consider that Mark and I should have been provided with this information before the point at which he was given the Factor VIII. This would have allowed us to make a fully informed decision regarding our consent on Daniel's behalf for his treatment, as he was a minor at that point. We would have need able to Risk assess his treatment.

46. Thereafter, from the point of Daniel's diagnosis, he was registered with Dr Mucklo at St Marys so that he could undergo regular check-ups. This included taking his weight and his height.

47. Mark and I had decided, that after Daniel's diagnosis that we did not want to tell him about his HIV, as we did not want him to worry. We did not think it was appropriate to tell him this information, as he was so young. We did not speak about it, until Mary Fletcher, a Health Worker at the Churchill had told him about his HIV at the age of eight years old. I had reluctantly agreed to this and was not present when Mary told him. My view was that he should have been told a lot later on when his hormones had started to kick in.

48. Around the time that he had found out about his infection, HIV was all over the news so he had found out quite a lot of information. At one point, he had asked me whether he was going to get very ill and die, to which I replied stating something along the lines of "*you are not going to die for a very long time. Everyone on the earth dies, it is a natural cycle.*" At that moment, I knew that was the biggest lie I had ever told him. However, you did not tell kids things such as the truth in this case. I wanted to protect him. As a mum this was and remains very upsetting. Can you imagine having that conversation with your young child?

49. On GRO-C 1991, my dad and Daniels grandfather died. I was unsure whether Daniel had connected the dots between his grandad's death and his HIV infection. That was until he had told his father that he knew that he was going to die like granddad did. Also, that when he died, he did not want a church service, but for his ashes to be scattered with his granddads. This was a hard thing for us to have comprehended that our son at such a young age, knew that he was going to die.

50. Sadly, not long after his granddad's passing, Daniel's health started to deteriorate. Within a letter, dated 04 June 1992, from Dr J S Kroll, University Lecturer in Paediatrics, Honorary Consultant in Paediatric Infectious Diseases, The University of Oxford, to Master R L Turner, Queens Bench

Division of Justice, Royal Court of Justice **(Exhibited as WITN5492008),** the extent to which his HIV had on his health is outlined. The relevant section of the letter states as follows:

> "*By 1989 his CD4 lymphocyte count was very low – an indication that he would become increasingly susceptible to infection by opportunistic microbes. Despite this there were no serious mishaps until late 1991. Then he gradually became non-specifically unwell, readily exhausted and depressed, and on 8/4/92 he presented to us with severe pneumocystis pneumonia. This is a life-threatening infection to which HIV infected people are particularly prone, and one which indicates that the disease has advanced to the point of AIDS.*"

51. By April 1992, Daniel was admitted to the Churchill, where he was diagnosed as having developed pneumocystis pneumonia. Thereafter, due to the magnitude of his ill-health, he was transferred to the John Radcliffe as they had an infectious diseases unit and were able to provide specialist care for Daniel's medical needs.

52. Eventually, towards the end of 1992, Daniel's health had deteriorated further, and he was prescribed with pentamidine. This was an antimicrobial medication, which was given by inhalation to prevent a serious lung infection. It worked to kill the organism that causes the infection.

53. Daniel was also given regular blood transfusions towards the end of his life, as his blood platelets were very low. We could always tell when Daniel had been given a blood transfusion, as instead of his usual ghostly white complexion, his skin would become flushed.

54. Thereafter, as Daniel's health was not getting any better, we decided that we would bring him home. His treatment and care were transferred from the John Radcliffe to St Marys, so that he could be treated closer to home.

55. Throughout the Christmas period of 1992, we had all tried to make his last Christmas one to remember, as we did not think that he would live much longer. St Mary's had prescribed him oral diamorphine to help ease his pain, but even this strong painkiller was not enough to calm Daniel's pain and suffering. It was very hard seeing my son like this.

56. When Sister Wheeler, a children's ward nurse from St Mary's visited our home, I had asked her about the quantities of diamorphine and how much I could give him. From what I understood, he was to be given a certain amount. I then asked the nurse something along the lines of "*what would happen if I had accidentally given him too much diamorphine?*" to which the nurse had said "*it would not make any difference*"

57. Thereafter, on 19 January 1993, I gave Daniel his diamorphine as and when I could see that he was suffering with the pain. He peacefully passed away in his bed at our family home. He was surrounded by all of his family when he passed.

58. Within Daniel's Death certificate, dated 20 January 1993, **(Exhibited as WITN5492010),** the cause of his death is outlined as:

> *1a. Acquired Immune Deficiency Syndrome*
> *II. Haemophilia"*

59. On Friday 29 January 1993, Daniel's death was reported in a Newspaper Article by Suzanne Pert, the Isle of Wight County Press. The Article consists of three columns, totalling a quarter of a page. The Article reads as follows:

> Entitled: *"Infected plasma to blame for death of boy, 11"*

> ***BRAVE DANIEL TRAGIC VICTIM OF HIV VIRUS***

BRAVE haemophilia victim Daniel Barton finally lost the greatest battle of his young life when he died - GRO-C GRO-C.

Daniel, whose cheerfulness and determination impressed everybody, had lived with illness after contracting the HIV virus through infected Factor 8 plasma, imported from America in the early 1980s.

The youngest developed full blown AIDS last spring but still managed to fight back until he finally became an innocent victim of the killer disease on January 19.

But his parents Tina and Mark Barton, have decided to tell their son's story to ensure his name will be remembered and his courage never forgotten.

Speaking from their home in GRO-C*, the couple told how they decided to pack a whole lifetime into the last two years of Daniel's life, yet still somehow look to the future because that was what he wanted.*

Daniel was born in 1981 with haemophilia a hereditary bleeding disorder which affects only males. Tina's father, Mr Philip Pugsley was also a haemophiliac, say the Bartons knew what to expect.

But fears about infected imported Factor 8, a blood product used to stem the bleeding in haemophiliacs, set alarms bells ringing. All haemophiliacs why screened in 1985 to see if they had contracted the HIV virus from plasma.

To the couple's horror they were told that both Daniel and his grandfather were positive.

"It was a bombshell," said Tina. "We were horrorstruck, devastated."

Mark said, "how do you come to terms with something like that – yet that is what we had to do."

Altogether, 1,200 haemophiliacs in this country were infected with the HIV virus but the Bartons have no bitterness about it.

"I think we just have to accept that we were extremely unlucky," said Mark.

Because of the media attention on AIDS at the time and to keep Daniel's life as normal as possible, the Bartons decided to tell only very close friends and relatives the truth.

"We told only his headmaster and a couple of other key people," said Mark.

Daniel attended Gatten and Lake Primary School, followed by Lake Middle School. But his illness meant he missed a lot of lessons until he switched to Watergate school for a time until he was too ill to attend.

Tragically, Tina's dad, to whom Daniel was very close, died through a HIV infection two years ago, strangely on Daniel's birthday, GRO-C

"Daniel knew he had HIV as well and he worked out for himself that he could die too."

"He told us then that he didn't want a church service and that he wanted his ashes to be scattered with his grandads," said Mark, 39, an unemployed roofer.

Over the years the Bartons paid many visits to the Haemophilia Centre in Oxford, especially when Daniel had any bad bleeds.

Tina, 32, said, "we were going to Disney World in America at the end of November but by then he was bedridden. Even so he would not let us cancel the trip until a week before we were due to depart when he finally admitted he wasn't well enough."

And Mark added, "we learnt to live with the fact that he could develop AIDS at any time. It makes you appreciate the time you have left and try to make the most of it."

"We thought we were going to lose him then but he fought back. He was left very weak and from then on it was downhill," said Tina.

In the end Daniel contracted a final infection but this time he was too weak to fight it off.

His funeral at the crematorium on Monday was attended by more than 100 friends and relatives, including his sister Zara, 17, who lives in Lincolnshire.

Daniel's coffin was accompanied by a cortege of 30 motorcyclists, led by members of the Heretics Motorcycle Club, off, which Mark is a member."

60. We did not experience any issues with regards to the service we were provided with by the funeral directors, as a result of Daniel's HIV. The funeral directors (Downer & White) were family friends, so we were given such a great service. I had asked them if I was able to dress Daniel for his funeral to which they had said yes. They were very professional and I have no complaints.

61. On Monday 24 January 1993, we held Daniel's funeral. It was attended by more than one hundred friends and relatives, and his coffin was accompanied by a cortege of 30 motorcyclists, led by members of the Heretics Motorcycle

Club; of which Mark is a member. Daniels ashes were scattered at the same location as his grandfathers

Section 3. Other Infections.

62. I do not believe that Daniel had received any other infection or infections other than HIV as a result of being given contaminated Factor VIII.

Section 4. Consent

63. I do not know whether Daniel was treated or tested for the purposes of research.

64. I do not believe that Daniel had been treated without prior consent having been obtained, as, I am sure that I would have provided consent for the two doses of Factor VIII he had been given in 1981 and 1982. I would have been led to believe that the treatment was beneficial for Daniel's health, and that it was on the advice of the doctors in charge of his care. Therefore, I would have given consent.

65. However, I do consider that I should have been given full and adequate information surrounding the potential associated risks of blood borne infection attached to Factor VIII. At no point was I told about the risks associated with the treatment, or that it could have possibly been contaminated. It was never discussed. As a mum, I believe that I should have been given this information, so that I was able to make a more informed decision on whether to give him this treatment. Had I known of the potential risks, I would have questioned whether I would have given consent. I was not able to provide fully informed consent on Daniel's behalf.

66. As previously stated, I do believe that when a blood test was taken from Daniel on 02 September 1985 at the Churchill, I should have given prior to

consent. I had no knowledge that the blood test had taken place, until I was notified that the results had returned two to three weeks later.

Section 5. Impact.

Mental/Physical Effect.

67. As my dad's health had taken a turn for the worst prior to Daniel, I had some knowledge of both the physical and mental effects his HIV infection would have had on his body.

68. By 1989, we had been told that Daniel's CD4 lymphocyte count was very low, and this meant that he would become increasingly susceptible to infection. It was not until late 1991 when he gradually became non-specifically unwell. He had complained of being physically exhausted. He was always tired and fatigued, and spent large lengths of time in bed resting. Daniel was the type of boy who tried to disguise his ill-health. He wanted very much to be well, so he often did not tell us when he felt unwell. This may indicate that we may not know the true extent of the physical effects his HIV had on his body.

69. In April 1992, Daniel was admitted to the John Radcliffe with severe pneumocystis pneumonia. This was a life-threatening infection to which HIV infected people were particularly prone, and one, which indicates that the disease had advanced to the point of the development of AIDS.

70. Alongside his physical health, Daniel's mental health had also been affected by his HIV. In late 1991, we had noticed that he had become gradually low in his mood, to the point that we believed him to be depressed. There is no wonder. It must have been scary for Daniel, to have seen his grandfather die from HIV in GRO-C 1991, from an infection he had also developed due to the same treatment of Factor VIII.

71. For Daniel to have told his father that he did not want a church service, but for his ashes to be scattered with his granddads this just goes to show he must have thought long and hard about it. He must have been fully aware that he was not going to live for very long, and that he was eventually going to die. No boy of that young age should have to think about his own own death. There is no wonder that his mental health had been impacted upon, as it was a lot for him to have taken on.

Treatment

72. Between November 1988 and December 1988, Daniel was admitted to the John Radcliffe due to his ill-health. During his stay in hospital, he was offered Zidovudine (more commonly referred to as AZT). This was an antiretroviral medication, which was initially offered in tablet form. It was to be administered twice each day; once in the morning and once in the evening, ideally with or after food.

73. However, due to the associated side effects explained to us, we had turned it down as it was really new. However, in December 1988 we were offered the treatment of AZT again, to which we decided that we would try him on the course of treatment. After one day of treatment, we had noticed that his health had immediately deteriorated.

74. My mother had taken him out for a bike ride around the Island, and when they returned, she had told me that Daniel had complained of a really bad headache. His headache did not clear for an extended period, to which he was in a great deal of pain. I immediately knew that it was a side effect of the AZT, so I made an appointment at the John Radcliffe to see the consultant in charge of his treatment. After I had explained the side effect Daniel had experienced, he was quickly taken off the treatment thereafter.

75. I do not consider that Daniel faced any difficulties or obstacles in accessing treatment for his infection, or, that there are treatments which I consider ought

to have been made available to him prior to the point at which he was offered treatment.

Impact

76. Losing my father in GRO-C 1991; two years before Daniel's death on 19 January 1993 it was a tough period for me. I had always been my daddy's little girl and I always looked up to him. He was my rock, so when he died, I was devastated. He was such a young man and I felt as though I had lost everything. My support, and my rock. If someone was of an old age, at some point you would expect death to be on the cards. However, as my dad was taken from us when he was in his prime, it was a shock to us all; especially as his death was attributable to contaminated blood product, which he had been given as treatment. He was only 49 years old.

77. However, when Daniel died at the age of eleven years old on 19 January 1993, my whole world had completely collapsed around me. My little boy. I immediately become depressed; as I had to contemplate that my life would now be full of sadness and sorrow. I went into a depression and I ended up having a mental breakdown. I was admitted to a psychiatric hospital for a period of around three weeks where I received treatment and counselling for my depression.

78. It took me a long time to be able to pull myself together to the point that I was able to face the real world. Whenever I would step out of my house, I had put on this visard that I was doing well, and that I was slowly but surely moving on with my life. However, deep down inside, I was hurting. I put on my 'plastic smile' and placed all my bad thoughts surrounding my father's and Daniel's deaths away in a box and padlocked it with a key. Then, at a later date when I would feel brave enough to open up the box ever so slightly, I could face whatever bad thought was released, and then shut it back up again quickly when I had started to feel low. I had placed my bad memories surrounding Daniel into compartments as a coping strategy.

79. I find family gatherings and the anniversary of his death particularly difficult to handle. People would ask how I was coping now that Daniel had passed, and it was not a question I was ready to face. I now take the anniversary of his death off of work every year. I have taken the whole week off work to see you as I know I will be affected by speaking about the loss of my dad and my son.

80. After Daniel's death, I started to look at things in a different light. I became very cynical about everything and I developed an attitude that I did not give a damn what I said, what I did or who I offended. I no longer cared for material things, nice clothes, or nice cars. As long as I had a roof over my head I was happy. My priorities shifted to health and security.

81. After Daniel's HIV diagnosis, Mark and I began to drift apart a bit. We led our own lives. Whilst we did stay together, it was a difficult time for us both. In the end, I ended up separating from Mark for a period of time after Daniel's death. However, not long after, we got back together and I had a hole in my life that needed to be filled. I decided that I wanted another child.

82. Thereafter, I got my sterilisation reversed so that we could try for another child. At this point, I was going through menopause early, so I did not think that my chances of becoming pregnant were very hopeful. However, I have since learnt that during the menopause, women often get a last burst of fertility, of which, I was lucky enough to fall pregnant as a result. In 1996, I gave birth to my daughter Elizabeth, three years after Daniel died.

83. My daughter Elizabeth was tested for haemophilia as I was worried that she would be a carrier of haemophilia. However, when the results had returned, it had shown that she was not a carrier of the condition.

84. Whilst Elizabeth did not get the opportunity to meet her brother, she knows the family story. I have never covered it up as there is no reason to. It was a different chapter of my life. She knows that the pain surrounding his death is still there and it is still raw. I do not go on about him a lot during conversation,

but when asked, we do talk about Daniel. This is usually around the time of his death or Christmas.

85. Not long after Daniel passed, his best friend Ian moved into our family home to live with us. In a way, Elizabeth looks at Ian as a surrogate brother. She has that relationship with Ian that she did not have with brother.

86. Us as a family did not tell anyone about my Dad's or Daniel's HIV infection. We had only told close family and friends, this was due to the stigma attached to HIV at the time, back then it was seen as the plague.

87. We did not want to tell Daniel's school about his HIV, as we feared that this would lead to the community knowing about his infection through word of mouth. However, after a conversation with Mary Fletcher a health worker at Churchill, she had stated that we would need to tell his school due to the risks associated with coming into contact with his blood when he would suffer a bleed. I knew that I had to tell his school, and that I could trust them not to tell anyone about his HIV as they were bound by the law of confidentiality not to disclose information about their pupils.

88. When I took the opportunity to tell Daniel's school about his HIV, I told them that they would need to put on gloves whenever he suffered a cut or a bleed due to the risks of contracting HIV when coming into contact with his blood. However, I had said that they would also need to put gloves on whenever they treated any other pupil in the school for injuries. I did not want Daniel singled out, as it would be picked up on that he was being treated different to the other pupils. Children can be cruel.

89. Around the time of Daniel's diagnosis, the prevalence of AIDS was continuously reported on the news. I can recall watching the "*AIDS: Don't Die of Ignorance Campaign*" which was launched in 1986 by the Department of Health and Social Security ("DHSS"). I understand that this campaign was being used as an education tool to inform persons on HIV, but it enhanced a real fear factor in the community surrounding the infection. It was hard hitting

scare tactics, which gave the impression that you were not to go near anyone or touch anyone.

90. The advert was particularly hard for us as a family to watch as HIV and AIDS was a topic, which was too close to home for us.

91. I cannot say that Mark, Daniel or I had experienced the stigma attached to Daniel's HIV infection as we did not tell anyone that we did not trust to keep a secret. That was until after Daniel's death when as previously discussed, a Newspaper Article published on Friday 29 January 1993 by Suzanne Pert, the Isle of Wight County Press, had reported on his death. We had a number of members of the community who had given us dirty looks in the street, and had taken it upon them to go out of their way to avoid us.

92. I cannot say that the stigma we had experience associated with Daniel's HIV was anything in comparison to that of the stigma my mother had experienced with regards to my father's HIV infection. This is outlined in more detail in her witness statement at **WITN4603001**.

93. To date, none of my new friends know about the circumstances surrounding my son's death. However, recently, I told my boss and my supervisor about Daniel, as I had known them for a very long time. They had known I had a son who had died and that I always booked the anniversary of his death off of work each year. They were fine when they had found out. Times have moved on and people are more informed about the virus, It caries less stigma.

94. When I was at work one day in 2020 after the first Coronavirus lockdown was lifted, a little lad with whom I worked with, had stated something along the lines of "*Covid is like what it was in the 1980s with AIDS. No one talked about it, and when they do, it is all about the fear factor. Do not touch anyone, do not go near anyone*." This comment had summarised exactly what the attitudes were of the community when AIDS became more prevalent in the 1980s. It is a comparison that I hope everyone can now relate to, and now, understand how those infected and affected had felt.

95. Daniel's education had been seriously affected, particularly in his older years. As his health deteriorated, he had more and more time off school. At one point, we placed him into a specialist school named Watergate School ("Watergate"), which was a school for pupils with serious illnesses and learning difficulties. The idea that was as he had lost a large volume of schooling, he would be put in good stead to catch up as quickly as possible. However, due to his ill health, he had remained at Watergate only for a few weeks.

Section 6. Treatment/Care/Support

96. I do not consider that Daniel faced any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with HIV.

97. I also do not consider that Daniel's infected status impacted upon the dental care he had received. When he had a number of his baby teeth extracted, this had taken place at the Churchill. This was due to the risks associated with his haemophilia. Other than that, for general dentistry, he would attend our family dentist, Mr Fradgley.

98. I had noticed that Daniel was always the last in the queue for his dental appointments. It was often at the end of the day, and after his school day. I had also noticed that the dentist would wear protective equipment to attend to Daniel; such as double gowns or masks, but I knew the reasoning behind this. This being, the risk of transmission of HIV through contact with his blood. I did not have any problems with his experiences in the dentistry setting.

99. Counselling or psychological support has not ever been made available to either Daniel, Mark, or I as a consequence of Daniel's HIV diagnosis. Mark and I were also not offered any counselling or psychological support as a result of Daniel's death.

Section 7. Financial Assistance

100. In the late 1980's, my mother, father, Mark, and I, were involved in the HIV Haemophilia Litigation which was brought by those individuals who had been infected with or affected by HIV through infected blood products. Mark and I were involved on behalf of Daniel, and my mother and father were involved on behalf of my father's infection. The Litigation led to every individual infected with HIV receiving an ex-gratia payment of £20,000.

101. The ex-gratia payment of £20,000 Mark and I had received in February 1990 is confirmed within a letter, dated 14 February 1990, from the Rev Alan J Turner, Chairman of Trustees, The Macfarlane Special Payments Trust, to Mr and Mrs Barton. **(Exhibited as WITN5492002)** the relevant sections of the letter state as follows:

> *"Enclosed is a cheque for £20,000 which represents the ex-gratia payment promised by the Government on 23 November 1989 and paid to you as parents and guardians of Daniel.*
>
> *This payment is made to you through the Macfarlane Special Payments Trust acting to meet the intentions for which the government has provided the funds. It is emphasised that this is not a compensation payment and does not affect rights as an individual or collectively to pursue a case for compensation."*

102. In 1991, Mark, my mother, my father, myself and a couple named GRO-A and GRO-A were approached by Mark Mildred, a Solicitor who, as stated before in my mothers statement was representing a lot of haemophiliacs. We were asked whether we would consider being involved in a medical negligence claim against the Government. The aim of the case was to gain compensation for Dad, Daniel, and GRO-A and GRO-A's son; who was only a few years older than Daniel, with whom they had all been infected with HIV due to contaminated blood product they had received as treatment for their

haemophilia. Mark and I were involved on behalf of Daniel, my mother and father were involved behalf of my father, and GRO-A and GRO-A on behalf of their son.

103. We met with Mark Mildred a solicitor at Pannone Napier Solicitors in London who started the claim on our behalf. We were told that we had a good case, as it was obvious that GRO-A and Daniel would have contracted HIV from blood treatment and no other source. It was a very cut and dry case.

104. However, before we were due to go to court, the Health Authority offered us an out of court settlement. My father was offered £85,000, and we were offered £50,000 on behalf of Daniel.

105. The amount offered during the medical negligence claim is outlined within a letter, dated 09 April 1991, from Mark Mildred, Pannone Napier Solicitors, to Mr and Mrs Barton, entitled "Medical Negligence Claim." **(Exhibited as WITN5492003)** the relevant section of the letter states as follows:

> *"In your case the offer is £50,000. This represents their assessment of the full value of your claim on ordinary principles less than money payable to you by the Department of Health and less also a discount to reflect the fact that the Health Authority does not concede liability but is prepared to make a settlement on compromise basis to reflect the risk of litigation."*

106. In return for accepting the amount offered within the settlement, we were told that we would have to sign a disclaimer. This disclaimer consisted of two conditions. The first condition being that, upon accepting the payment, we were no long able to bring about further legal action against the Government with regards to their HIV infections. The second condition, was that all of Dad's, Daniel's and GRO-A and GRO-A s son's medical records had to all be returned to the Heath Authority.

107. The point at which Daniel's medical records were returned to the Heath Authority, is confirmed within a letter dated 23 April 1991, from Mark Mildred, Pannone Napier Solicitors, to Mr and Mrs Barton, entitled "Action No 1989L 653" **(Exhibited as WITN5492004).** The relevant section of the letter states as follows:

> *"12. Although I have written some of you asking what you would like done with your son's medical notes and records I must now tell you that the Judge has ordered that they be returned to the Health Authority which provided them and this is happening in all cases."*

108. As we wished to gain the sum playable under the settlement for Daniel for when he grew older, we agreed to sign the disclaimer. I was very disappointed that we were not allowed to see his records; I felt stitched and set up. We were both very angry at this decision. To this day I want to read them.

109. However, within the aforementioned letter **(Exhibited as WITN5492004)** it is outlined that after many weeks of negotiation over the details of the settlement, I would receive from the Macfarlane Trust the sum of £21,500 free from any income. This sum would be placed into the Court Funds Office where it would earn interest and will be released to Daniel on his eighteenth birthday.

110. I was given £1,000 upfront to spend as I wished on Daniel before his eighteenth birthday. This is confirmed within a letter, dated 11 June 1991, from Mark Mildred, Pannone Napier Solicitors, to Mr and Mrs Barton **(Exhibited as WITN5492005).**

111. Within a letter, dated 19 June 1991, from The Rev Alan Tanner, Chairman, and John Williams, Clerk to the Trustees, The Macfarlane Special Payments (No2) Trust, entitled "Settlement payment to Litigant," **(Exhibited**

as WITN5492006), it is outlined that the sum of £20,500 was paid in respect of this settlement.

112. We had also been told that if we wished to apply for any of the settlement moneys before the point of Daniel's eighteenth birthday, we would have to apply to court to have the money released.

113. In October 1991, I asked the Royal Courts of Justice, if they could release the settlement monies that had been placed into trust for Daniel, before his eighteen birthday. This was for the purposes of using the monies to buy our family council house in his name. We wanted to be able to afford Daniel the security of a home, so that he did not have to worry about it in future. We thought that this was the best way to invest in his future as we were provided with the opportunity to buy our council house at a discounted rate at that time.

114. Within a letter, dated 10 October 1991, from Master R L Turner, Queens Bench Division, Royal Court of Justice, to Mrs TJ Barton **(Exhibited as WITN5492007),** the outcome of my request is outlined as follows:

> *"I fully understand why the idea of using the money to buy a house did appear attractive to you. However there are very sound reasons why this particular form of investment is not prudent in this type of case.*
>
> *The cost of purchasing a house in the name of a minor is very considerable and there are many hidden costs and expenses. It uses up the fund immediately and prevents use of the money if there is a crisis and urgent access to the fund is needed. Although house prices did rise in the 1980s the same is not so true at the moment and I can not be sure that in eight years time when I have to account to your son that such an investment would have proved to have been in his best interests.*

> *In the circumstances I am sure that you are wise to have the money placed in an interest earning form of the investment and then to make use of the interest as and when the need arises. Although you mention the Special account, it might be prudent to place a portion of this money in other forms of investment as there still remains 8 years till Daniel is 18 and I will discus this with the investment managers in the Court Funds Office."*

115. Towards the end of Daniel's life, we wanted to make sure that he had great memories. We decided that we would take him to Disneyland in American on holiday as a last holiday together. We asked the Royal Courts of Justice if they could release some of the aforementioned fund so that we could pay for his holiday trip. Daniel had always wanted to travel to America to see friends and family and to see Disneyland.

116. On 19 June 1992, it was confirmed that the fund would be released. This is confirmed within a letter, dated 19 June 1992, from Master R L Turner, Queens Bench Division of Justice, Royal Court of Justice, to Mrs T Barton **(Exhibited as WITN5492009).** The relevant section of the letter states as follows:

> *"I quite understand your anxiety that Daniel should be provided with those things which make his life a little easier and the doctors certainly think that a holiday in the U.S.A will do him good at this stage. I also agree to the idea of visiting friends and the need for equipment you mention.*
>
> *I am quite happy to release the £20,000 you request and I enclose a copy statement of Daniel's account.*

117. Unfortunately, the effects Daniel's HIV had on his body had meant that he was too unwell to go to Disneyland as he was bedridden. Daniel was so desperate to go on the trip that he did not let us cancel the trip until a week

before we were due to depart. It was only at this point that he finally admitted he was not well enough.

118. After Daniel's death, the Macfarlane Trust had told us we could have the settlement funds now. However, they did not tell us that this money was taxable. Not long after, I received a telephone call from HM Revenue and Customs to say that we owed tax on the sum in our savings. We thought, we had just lost our son, and they told us that we needed to pay tax. They showed no empathy for the loss of our son.

119. We have not received any financial assistance from the point of Daniel's death. The Macfarlane trust did not offer to pay for his funeral, and we struggled.

Section 8. Other Issues

120. The money we have received throughout the years does not give us Daniel back. It will not replace him and I would give it all back tomorrow if it meant that I could get Daniel back. My Daniel is gone and he was taken from us at the very young age of eleven years old. He was not able to live his life and live out his dreams. Daniel was only a baby, and the Factor VIII he had received as treatment for his bleeds associated with his haemophilia had changed his life. It took his life.

121. It was not only my son who was taken from us, but my father. He was my rock and I looked up to him in many ways. They were both taken through contaminated blood within two years of each other. This is a lot of grief to have faced as a family, but we pulled through it together.

122. We have a place that our family can visit where we scattered both Dad's and Daniel's ashes, so that they could be together. Mum had told me that Daniel had told her one-day something along the lines of *"Nan, I cannot wait to die so that I can see grandad again."* This was heart breaking, but it

was his wish, so we scattered their ashes in the same place so that they could be with one another.

123. I feel there is a lot of information I would want to know surrounding how my father and Daniel became infected with HIV. I would want the IBI to find out when the NHS had become aware of the prevalence of the blood and blood product they were providing as treatment having been infected. Why did they continue to use it? I know there is no other form of medication they could have used which compared, but they should have informed people and so they can make better decisions on whether to proceed with their treatment irrespective of the risks associated.

124. Why did Pharmaceutical Companies not stop production of their blood product as soon as they had knowledge of the issues surrounding the safety of their product? Yes, Factor VIII is a wonder drug; it is a product, which can in many ways save a life. But, it was making people really ill, and they carried on regardless of the consequences. They should have just come out and said when they first detected infection in the blood product.

125. I now have no trust in the National Health Service ("NHS"). They had not been up front from the beginning with regards to the Contaminated Blood Scandal, and I believe that they knew a long way down the line that the blood product they were sourcing from America was not safe.

126. I also do not trust the Pharmaceutical Companies that developed Factor VIII in the first place, as they should have tested their product before it was sold to the NHS. I do not believe that the Government had taken the time to realise just how much it would impact on such a large amount of people.

127. I believe that my distrust in the NHS is the main reason why I have not had the Coronavirus vaccine. During the Contaminated Blood Scandal they told us that the blood product was safe, they did not think about the long-term effects or associated risks. The same analogy applies with the Coronavirus vaccine.

Statement of Truth

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

Signed GRO-C

Dated 24-6-21.

Table of Exhibits:

Date	Description	Exhibit
14 February 1990	Letter, from the Rev Alan J Turner, Chairman of Trustees, The Macfarlane Special Payments Trust, to Mr and Mrs Barton, re ex-gratia payment for the sum of £20,000	**WITN5492002**
9 April 1991	Letter, from Mark Mildred, Pannone Napier Solicitors, to Mr and Mrs Barton, entitled "Medical Negligence Claim."	**WITN5492003**
23 April 1991	Letter, from Mark Mildred, Pannone Napier Solicitors, to Mr and Mrs Barton, entitled "Action No 1989L 653."	**WITN5492004**

11 June 1991	Letter from Mark Mildred, Pannone Napier Solicitors, to Mr and Mrs Barton, re cheque for £1000.	**WITN5492005**
19 June 1991	Letter from The Rev Alan Tanner, Chairman, and John Williams, Clerk to the Trustees, The Macfarlane Special Payments (No 2) Trust, entitled "Settlement payment to Litigant."	**WITN5492006**
10 October 1991	Letter from Master R L Turner, Queens Bench Division, Royal Court of Justice, to Mrs TJ Barton, refusing request to release funds to buy a house.	**WITN5492007**
4 June 1992	Letter, from Dr J S Kroll, University Lecturer in Paediatrics, Honorary Consultant in Paediatric Infectious Diseases, The University of Oxford, to Master R L Turner, Queens Bench Division of Justice, Royal Court of Justice, re request to release funds to improve Daniel's quality of life.	**WITN5492008**
19 June 1992	Letter, from Master R L Turner, Queens Bench Division of Justice, Royal Court of Justice, to Mrs T Barton, re release of funds for the sum of £20.000.	**WITN5492009**
20 January 1993	Death certificate in the name of Daniel Mark Barton	**WITN5492010**
22 December 1993	Letter, from Dr Paul L F Giangrande, Consultant Haematologist, Oxford Haemophilia Centre, Churchill Hospital, to Mrs Tina Barton re date	**WITN5492011**

	Daniel tested positive for HIV. (02-09-1985)	