

Witness Name: **Owen Kiely**

Statement No: **WITN3810001**

Exhibits: **Nil**

Dated:

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF OWEN KIELY**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 31 October 2019.

I, Owen Kiely, will say as follows:

#### **Section 1. Introduction**

1. My name is Owen Kiely. My address is known to the Inquiry, and my date of birth is GRO-C 1956. I am currently retired; I used to work for the railways for 36 years as an engineer, part of my duties was being in charge of breakdown and recovery. I am married and have two adult sons aged 34 and 18.
2. I intend to speak about how my nephews, Damien Kiely and Taylan Hikmet were infected with Human Immunodeficiency Virus ("HIV") and how Taylan was additionally infected with Hepatitis C ("HCV"). In particular, their illnesses, how it affected them, their death and the impact on our family.

3. I can confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me in writing my statement. The Inquiry team has explained anonymity to me and I do not require any information to be kept private.
4. I have not had access to either Damien or Taylan's medical records.

## **Section 2. How affected**

5. Damien was born on GRO-C 1973 at Guy's Hospital ("Guy's"), London. Taylan was born on GRO-C 1979 at Guy's. Damien and Taylan were the sons of my late sister, Lorraine Kiely.
6. Damien and Taylan both had severe haemophilia A and contracted HIV through infected Factor VIII. Taylan also contracted HCV through infected Factor VIII.
7. Damien was diagnosed with haemophilia when he was 10 months old.
8. At Taylan's birth, Lorraine was told she would have to have a C-section. However, her notes were not read regarding her first son Damien having been diagnosed with haemophilia, and Taylan was delivered with forceps resulting in Taylan having a bleed to his brain. This meant the first time Taylan received Factor VIII was at one day old.
9. During their childhood, both Damien and Taylan were receiving Factor VIII regularly, on average, two to three times a week.
10. In 1985, Damien who was 12 at the time, and Taylan 6, were diagnosed with HIV. My sister received a phone call to say that she needed to come to the hospital because the two boys had the HIV virus. My sister could not cope with going to the hospital alone and waited for our mother to accompany her. My mother and father were on

holiday at the time. I went to pick them up from the airport and had to break the news to them that the boys had HIV.

11. At some point, Taylan was diagnosed with HCV. In 2011, Taylan underwent a liver transplant, which his body rejected. He was readmitted to Kings College Hospital ("King's") and suffered a brain haemorrhage and died on 15 September 2011, GRO-C aged 32.

12. In 1999 Damien battled and overcame Hodgkin Lymphoma. However, in 2014, Damien was diagnosed again with Hodgkin Lymphoma and passed away on 28 November 2014, aged 41.

### **Section 3. Other Infections**

13. To the best of my knowledge Damien did not have any infections other than HIV as result of using Factor VIII.

14. I know that Taylan was infected with both HIV and HCV, but I am not aware of any other infections contracted through his Factor VIII use.

### **Section 4. Consent**

15. As far as I am aware, neither my sister nor my mother gave consent for Damien and Taylan to be tested for HIV or HCV.

16. My late mother, Bridget Kiely, Damien and Taylan's grandmother, was always present at all of the boys' nurses and doctors' appointments because she was a nurse herself. My mother was also very involved with the boys' treatment from the outset due to Lorraine's mental health.

17. I never heard my mother say that Factor VIII carried any potential exposure to HIV or HCV. I believe that if my mother had heard of any

risk, she would have been the first to ask about any side effects or raise concerns. As she never discussed with the family any meetings with doctors regarding the safety of Factor VIII, I believe she was never told of any risk of contracting HIV or HCV from the Factor VIII.

## **Section 5. Impact**

### **Haemophilia diagnosis**

18. Haemophilia was not present in our large family, therefore, when Damien was diagnosed with haemophilia at 10 months old it came as a huge shock. After the initial disbelief we quickly armed ourselves with as much knowledge as we could.
19. We were confident that whilst special care would be needed, Damien could live a normal life. As time passed we were proved correct that haemophilia, when managed and monitored correctly, and even with some obvious limitations, need not mean a fulfilling life was unattainable. I can remember my sister sewing padding into his clothes for protection. Damien was cherished by us all.
20. With my mother's support and that of Damien's Haematologist, Dr Hamley of King's, home treatment of Factor VIII commenced which greatly reduced the need to attend hospital so frequently and great strides were made in normalising life.
21. Taylan was born 5.5 years after Damien and we knew there would be a 50% chance that he would also have haemophilia. Whilst we hoped that he would beat the odds, we were far more adept and knowledgeable about living with the condition, proof being Damien who was leading a near-to-normal life. As mentioned above, due to the use of forceps during his birth, it was known straight away that Taylan had haemophilia. I now wonder whether the bleed to his brain at birth have anything to do with Taylan's death.

### HIV diagnosis

22. As mentioned above, in 1985 Lorraine had received a phone call to say that she had to come to the hospital because the both boys were HIV positive. Due to my sister's fragile mental health she could not face going to the hospital without my mother being there. My mother and father were returning from a holiday at the time. I had to pick them up from the airport and break the news that Damien and Taylan were HIV positive.

23. It is extremely difficult to comprehend how Damien and Taylan must have felt being told they were HIV positive by my mother. Firstly, having to take on board being a haemophiliac and then the additional stress of managing HIV, all whilst going through puberty in Damien's case, it must have created a whirlwind of emotions. AIDS was prevalent in the media, from a young age they were aware that people with AIDS were shunned from society. They had to come to terms with the full implications of being HIV positive.

24. It was my mother who was told that Factor VIII was the cause of the boys being infected with HIV.

25. It is hard to imagine that anything could equal the physical suffering that Damien and Taylan endured, but being infected with HIV also had an equally devastating effect on every other aspect of their lives; they suffered exclusion, discrimination, limited life options, psychological suffering, fear and trauma.

### Damien and Taylan's education

26. At the time of the boys' diagnosis with HIV, Damien had just completed primary school at St Patricks RC and had gained a place at Alleyn's Grammar School.

27. Taylan had recently started at Rosemead Preparatory School. Lorraine was called to Taylan's school and advised that a group of parents had raised concerns after seeing in the media reports of haemophiliacs being infected with HIV. The parents demanded to know if Taylan was HIV positive. We were under the misconception that if he went to a fee-paying school he would be better protected from the stigma. However, we were wrong.
28. Lorraine had consulted with medical professionals with regards to the risk of infecting other pupils at the school and she was advised that in their opinion there was no risk. She provided all of this information and health and safety procedures to the school. One morning Lorraine was asked to go to the school office where she was told that there was a large group of parents who had fears that their children would 'catch AIDS' from being in close proximity to Taylan. The school decided to exclude Taylan from school. I would like to make the point that the parents concerned were educated professionals including those working in the medical field, and they still refused to accept any of the evidence that their children would not be at risk.
29. We initially fought the exclusion but truthfully, we did not want Taylan to return to a school where he was not welcomed. It took us a year to find a school that would accept Taylan. Due to this, he was left without a formal education. The friendships he had made were denied to him and he was alienated from his peer group. Taylan became very withdrawn, lost his confidence and became painfully shy in social situations. The repercussions of this event followed him into adulthood.
30. Fortunately, Damien's education did not suffer in the way that Taylan's did. He did not experience any segregation at school, his friends remained by his side and he did not experience any bullying.

#### Impact on Taylan

31. Taylan had been co-infected with HIV and HCV. His HCV was diagnosed in his late 20s. Lorraine used to worry more about Taylan than Damien because she knew that without a liver transplant Taylan would die. I think my mother knew about Taylan's HCV diagnosis before anyone else. I was not aware what HCV was, which I feel ashamed about now.
32. Damian was very angry and upset about his HIV diagnoses. He immersed himself in research about American pharmaceutical companies. He used to visit me a lot in Ireland and would discuss with me what they found out. It is a real shame because everything he told me is being revealed to be true.
33. Medication was developing and the prognosis looked better than ever for the both of them. This led to a period of calm for both Taylan and Damien. Taylan was in a serious relationship and was engaged to be married. He was also scheduled for a liver transplant and was looking into sperm washing.
34. Taylan started Interferon treatment for HCV during the time that his mother was terminally ill with cancer. (I speak further about Lorraine's health and death below.) During this time, he was not the same Taylan that I knew, but because of his mother's illness he kept all the suffering to himself. He played down his own declining health and impact of the medication to protect his mother.
35. Taylan's health started to rapidly decline in 2010. He knew for some time that he would need a liver transplant. There were many false alarms with potential liver transplants for Taylan. Eventually he was given the green light. He received a transplant; however, the liver was rejected. On 15 September 2011, whilst back in hospital he suffered a brain haemorrhage and died.

36. At the time of Taylan's death, my mother was in hospital. My sister, wife and I went to the hospital to tell her that Taylan had died. I had to physically restrain her, she was completely hysterical, she was screaming and shouting. Losing her daughter just eight months earlier, and then her grandson. She was never the same after that. She became a recluse, very bitter and very angry.

#### Impact on Damien

37. After leaving school Damien became a croupier. It became apparent that he had made a mistake by telling another member of staff about his HIV status. He experienced blind discrimination at work, for example, cups were thrown away that he had used, and staff made work uncomfortable for him. Because of this and his health, he could not carry on with work. Damien eventually left his job and became a semi-professional poker player. He was also very much into making his own music.

38. Damien became unwell in 1999, aged 27. His blood work was not good and he was diagnosed with Hodgkin's Lymphoma. Due to the HIV compromising his immune system, his doctors did not think that he would be strong enough to undergo treatment. However, Damien insisted on and commenced a gruelling 10 months of fortnightly chemotherapy coupled with fortnightly bone marrow stimulant. He was placed in the private ward of King's as it was more isolated. The staff at the hospital were great with him

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He had neurotropy and was in terrible pain.

39. Damien cleared his Hodgkin Lymphoma but not without struggle. The treatment had left him with severe damage to the nerve endings in his feet and lower limbs causing constant excruciating pain. The treatment for Hodgkin Lymphoma impacted him mentally and physically for 20 years.



40. Damien tried to live an ordinary life after beating Hodgkin Lymphoma. However, he became increasingly dependent and addicted to prescription medication, eventually becoming reliant on morphine. Every time he would come from the hospital he would have carrier bags of drugs with him. As a result of his addiction his personality changed. He experienced mood swings and became fiery. Instead of acknowledging his addiction, the hospital referred him to a pain clinic that continued to prescribe him medication. It is a testament to Damien that in his last three years of his life he addressed his addiction himself and weaned himself off the prescribed medication even though this left him in excruciating pain.

41. Damien had started to get his life on track, he had a girlfriend who he was living with at the time. Damien became involved with the charity "Body & Soul" who work with teenagers living with HIV. It was the first time I had seen him with a purpose.

42. In 2014 I received a call from Damien who was in Barcelona at the time. He told me that he was really not well. I got him booked on a flight home and picked him up from Gatwick Airport. As soon as I saw him I knew I had to get him to hospital as he looked very unwell. Damien was seen at St Thomas' Hospital ("St Thomas"), and was told that they thought his Hodgkin Lymphoma had come back.

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44. Damien's health slowly deteriorated. Whilst at Guy's he asked me to shave his head and I did. Damien's mental health declined while undergoing treatment; he sent me a text saying that "he had had enough of this fucking shitty life". I responded telling him that I was coming up to see him. When I got to the hospital he did not look in a

good way, but the doctors wouldn't tell me anything. He was then transferred to the Intensive Care Unit.

45. On 28 November 2014, I went to visit Damien at Guy's Intensive Care Unit. I asked where Damien was and I was told that he had died. I collapsed when hearing the news. I do not think that Damien ever recovered from losing his mother and then eight months later watching his brother die. He fought hard for the second time to beat the cancer, not for himself but for his family. He did not want to 'put us through it again' but he was broken and his body could not win the fight.

46. When I became aware that Damien was likely going to die I had a conversation with him about his funeral. He told me that he wanted the exact same funeral as his mother, but not the same funeral directors. Both Damien's and Taylan's bodies were red tagged. At Damien's funeral an elderly woman who I did not recognise approached me and commented on how wonderful a man Damien was. It turns out that she lived on Damien's street and he paid her parking fine for her as they were about to tow her car away.

47. I feel that Damien pushed his girlfriend away because he knew he was going to die. My sister, Jacky, had contacted her for more information before I came to the Inquiry. I was nervous to discuss Damien with her because I did not want her to have to revisit the trauma, but I was told that I was to never worry about contacting her because she, 'talked to Damien every day of the week'.

#### Impact on my sister

48. Lorraine could not come to terms with the boy's HIV diagnosis and how this could have happened. The thought that she could lose both of her adored children spiralled her into deep depression that she never came back from. Lorraine lived on a knife's edge and developed a severe phobia of hospitals. She began suffering anxiety attacks, becoming so

fragile that she could no longer be present at her son's medical appointments. My sister spent all of her life researching every religion, homeopathic remedy and foods that could potentially help cure the boys. She divorced in 1988.

49. My sister became so withdrawn and struggled to focus and be present. At one point, she went away for the week and we decided to install a new kitchen for her. Upon her return, she walked into the house and did not even recognise the work that had been done. A week later, there was black soot everywhere because she started researching white witchcraft for a cure and tried to do a spell that blew up. She really tried to do everything in her power to save her sons.

50. As a direct consequence of Damien's and Taylan's diagnoses, Lorraine neglected her own health and was diagnosed with cervical cancer. It came to light that she had never attended the screening appointments. Lorraine went through a very intense period of treatment and luckily went into remission.

51. Lorraine was then diagnosed with pelvic area cancer which spread to her bowel. She was given a colostomy bag and slowly started to deteriorate. Due to my sister's severe decline in health, my other sisters and my mother moved into her house to look after her, we all did.

52. The Oncologist at Guy's said that Lorraine had around three months to live. Taylan had heard about a treatment in Japan and wanted to send her there, but it wasn't to be. Lorraine wanted to make it to Christmas 2010 for her boys. We took her home from the hospital and she fell into a coma on Boxing Day in 2010. The Macmillan Nurses were fantastic; I spoke to the nurses and I asked how she was still alive and they said that she was waiting for someone. It was at that moment that there was a knock at the door and it was my son, Lorraine's godson.

My son went over to Lorraine, kissed her on her head and she then passed away. She died 10 days after going into a coma.

53. We were all devastated. The boys struggled to cope with the loss of their mother. After her death, Damien could not return to his house so he moved in with his dad.

54. I truly believe that both my sister and mother would have lived a longer life had they not had to deal with the stress of Damien's and Taylan's health conditions.

#### Family life

55. We are an extremely close family and have a large circle of friends from all backgrounds. We were never neglected by our friends or families, we were very fortunate to have the support.

### **Section 6. Treatment/Care/Support**

#### Treatment

56. I cannot recall the exact medication that Damien and Taylan were on but there were many.

57. As mentioned above, Taylan underwent Interferon treatment for his HCV.

#### Counselling

58. My sister's mental health had suffered after her eldest son's diagnosis of haemophilia, because she felt that it was somehow her fault. Lorraine did receive counselling when Damian was diagnosed with haemophilia, but it was not a very positive experience. She was told that Damien would be wheelchair bound by 12 years old.

59. Lorraine had counselling again post Damien's and Taylan's HIV diagnoses. Again, this was not a positive experience and she was told to face the fact that the boys were going to die.

60. I received counselling because of the nature of my job. I went through a period of taking anti-depressants mainly because of my personal life. I think it was because my job was very stressful and then I had the pressure of my sister and mum relying on me. I didn't mind but it was a burden at times. I would be often working 24 hours and then my mum would ring me up to say that I had to come help because Damien had flown into a rage. I would be the one that would have to calm him down. We were very close.

61. As far as I am aware, neither Damien or Taylan were offered or attended counselling.

#### **Section 7. Financial Assistance**

62. I used to look after Taylan's finances from when he was young. I believe both Damien and Taylan were receiving money from the MacFarlane Trust. I believe at one point both Taylan and Damien received £20,000. I think Taylan also received a further £20,000 because he was HCV positive. They were also receiving Disability Living Allowance payments.

63. I have been surprised to hear that so many people have had issues with the MacFarlane Trust. I never heard anything detrimental about the trust from any of my family.

#### **Section 8. Other**

64. I would like to say a big thank you to the Terence Higgins Trust. They were a never-ending source of support to my family and were truly wonderful.
65. I hope that this Inquiry gets to the bottom of what this is all about. It is not about the money, it is about the accountability. To me this seems like corporate manslaughter. I feel that the government are dragging their heels and waiting for people to die.
66. I would like people to know that Damien and Taylan never wanted sympathy but they did want the truth. They were like chalk and cheese in personality, one feisty and one laid back. One who did not want to rant about injustice, and the other so very angry. Both handsome, charming, charismatic (in their different ways). They never gave up hope they were so brave, they travelled, rode bikes, they fell in love, they were so popular and had so many friends from different walks of life. They never wanted to be defined by or treated differently because of their medical condition.
67. Haemophiliacs being infected with HIV were almost expected to accept this as an unfortunate side effect of their treatment. They never came to terms that the death sentence they were given was unavoidable and nor do we. We will forever wonder how different their lives, and the lives of our families would have been if only imported blood products from America had not been slightly cheaper.
68. Lastly, they say it takes a "village to raise a child", for us "it took a whole family". Everybody's life was impacted, and those of us who are left behind will never recover from seeing our two beautiful boys endure so much pain and fight so bravely to live, we will never recover from burying them. We will never forgive the cover up and the lies, and that so many suffered and lost their lives quite simply because it is beyond forgiveness.

**Statement of Truth**

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

Signed

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Dated

10/21/2020

