Witness Name: Georgia Andrea HALWANI

Statement No. WITN0956001

Exhibits: WITN0956002 – WITN0956007

Dated: 19 / 10 / 2022

INFECTED BLOOD INQUIRY

WRITTEN WITNESS STATEMENT

OF

GEORGIA ANDREA HALWANI

I provide this witness statement in response to a request made under Rule 9 of The Inquiry Rules, 2006 dated 22nd September, 2019.

I, Georgia Andrea Halwani, will say as follows:-

Section 1 - Introduction

1. My full name is **Georgia Andrea HALWANI** (née KOUNTOUROU), but I am more commonly known as '**Gina**.' I was born on GRO-C, 1957 and live with my family at an address that is known to the Infected Blood Inquiry.
2. I intend to speak about my late brother, **Costas KOUNTOUROU** (GRO-C 1961 - 19.10.2009), who was also known to some as **Costas GEORGIOU**. My brother was a Thalassaemia patient who by virtue of his treatment by the National Health Service (NHS), contracted Hepatitis C (also known as Hep' C and / or HcV), a disease he was given as a result of their use of contaminated blood.

3. I will describe his condition (Thalassaemia), how he came to be infected (with Hepatitis C), and the impact his infection and eventual death had on him, his family, friends and the broader community.

Section 2 - How Infected

4. My brother Costas was born at The Royal Free Hospital, in Hampstead, London on GRO-C, 1961 and I was his elder sister. Our parents were **Andreas KOUNTOUROU** and **Mirianthi KOUNTOUROU**.

5. Our parents moved from their native Cyprus to England in the 1950's, my mother first, followed by my dad. They both left family and friends behind them in Cyprus, where some family remain to this day. They married in 1953 in Camden, London and settled in the city.

6. Our parents were proud of their heritage and native Greek speakers when they first came to the United Kingdom. They encouraged us to speak both English and Greek (at home or whilst engaged with other Greek Cypriot emigrés, and GRO-C.

7. I was their first born child, followed a few years later by Costas. At about six months old, Costas was diagnosed as having Thalassaemia.

8. Thalassaemia is an hereditary blood disorder which can be life-threatening if untreated. Treatments are available to manage the condition, but there is no known cure and is it is inherited, the person with thalassaemia will have had no means of preventing its transmission to him / her.

9. Thalassaemia is relatively common within the Greek Cypriot community, both here and in Cyprus, but this was not commonly known at the time, certainly not by my parents GRO-C GRO-C

10. At the time of Costas' diagnosis, the only treatment available to Thalassaemia patients was for them to be given a blood transfusion.

11. Thalassaemia greatly impacted upon Costas' early life, as he would have to attend hospital on a regular basis to receive blood transfusions, some two to three units of blood on each occasion he visited the hospital.

12. Unfortunately, my parents knowledge and use of the English language was something of a barrier to their being able to fully engage with the clinicians treating Costas, so they were unaware of specific details such as where the blood he may have been given had come from, or of any risks it may have posed.

13. They spoke very little English, and not in any depth, so this would have proven to be a barrier to their effectively questioning anything. They had to accept what was being offered, as without intervention Costas would have been placed in greater jeopardy.

14. The Royal Free Hospital in Hampstead became something of a second home for Costas as he was growing up, as his condition and the frequent need for treatment meant that he was often there receiving blood or other treatment related to his condition.

15. When he had been just eighteen months old, he had been particularly poorly and was hospitalised for treatment over a lengthier period than had been usual, causing our mother a great deal of distress, her anguish only being heightened when she was told that Costas would require a Splenectomy as a result of the impact which Thalassaemia was already having upon his organs.

16. Although I was only young myself, I distinctly recall Costas having become jaundiced, notably 'yellow' in appearance, and that his stomach appeared to be enlarged.

17. I can also recall a journalist from the local newspaper, 'The Ham & High' as it was known (The Hampstead And Highgate News), having visited the hospital and taken photographs of Costas form publication in the paper – at the time Costas was in his hospital bed recovering from surgery with tubes going into or coming out of him. Apparently, he was the first child in the U.K. to have undergone a splenectomy, hence their interest.

18. At fourteen years of age, Costas began using what we understood to be an iron pump, something which administered Desferal to him, a medication which meant that he required less hospital treatment for his condition, which was a real boost to his personal development and encouraged him to embrace the treatment(s) which they may be given and to use them in the correct way – something he continued to do as time progressed.

19. Costas was very open about his having Thalassaemia, something which culturally isn't usually the case as those with Thalassaemia generally seek to keep themselves to themselves and conceal the issues they face rather than make them known. There's a stigma attached to Thalassaemia in its own right, and it is often difficult for patients and their families to talk about it for fear of others thinking poorly of them or avoiding contact, which in a small relatively tight-knit community can be a major issue.

20. However, Costas was never afraid of discussing his situation with other patients with Thalassaemia, but this was the complete opposite when it came to his family or friends who didn't know of his condition. He was very private about his condition and only provided our mother and father with certain information about it. He found it extremely difficult to discuss, or express his feelings, and at times this left his family feeling helpless and at times quite distraught.

21. All the same, he did not let it get the better of his lifestyle whilst growing up, and at around the age of seventeen, he learned of the existence of The Thalassaemia Society within which he quickly became a key member.

22. He was one of a small group of boys with Thalassaemia who would meet regularly, at least once a week, and who gradually became the core of the society itself. In 1976, Costas was one of the founding members of The United Kingdom Thalassaemia Society, the rationale behind which was to raise awareness of the condition, its symptoms, impact and treatment(s); to fundraise to support the society and its operations and help sufferers; and to make known and discuss the available treatment(s) whilst at the same time providing a self-help support group.

23. Despite his active engagement with others through and with the society, Costas was someone who preferred to keep his Thalassaemia Society activities and his family life separated from one another wherever possible – they were two separate worlds to him, and home was home.

24. In spite of his condition, Costas had a normal childhood, made many friends at school and was considered a popular boy amongst his peers. At just sixteen years of age he left school and commenced working in a factory with our father. He also learned to drive as soon as he could, and my father bought him his first car.

25. Costas was a hard-working, caring, supportive, friendly and popular person with long-term friendships / relationships. He enjoyed travelling, and worked in a family-run travel agency for quite a few years alongside his cousin before joining ARGO, a Greek travel and shipping company.

26. Over the years, from infancy, Costas had been treated in different ways in an effort to control or at least manage his Thalassaemia, but the majority of the treatment he received, in particular as a youngster, was with whole blood by way of transfusion.

27. In 1995, Costas was diagnosed as having contracted Hepatitis C. Prior to this, he had been wholly unaware of just how ill he had become, or to any particular symptoms of Hep' C he may have been experiencing – some are very similar to the ill effects of Thalassaemia, so he may well not have been able to tell the two apart and merely put things down to the condition he knew.

28. In 1987, Costas had to have his gallbladder removed, again as an apparent result of the impact Thalassaemia was having on his body. We don't know, but he was again given blood whilst an inpatient of The Royal Free for this operation, and it is also possible that he contracted HcV at this time as a result.

29. All the same, no mention of any risk associated with the blood he was given was mentioned at this time, but equally it may have been attributable to any of the other blood transfusions he received over the years.

30. In 1995, when he was diagnosed as having Hepatitis C, I was living in Bahrain with my husband and children. Costas rang me immediately and told me of the diagnosis. Apparently, the doctor who told him stated at the time that it had most probably come about as a result of his having been given contaminated blood at some time in his past as there were no other known risk factors in his case. Costas told me that although he had the disease, specific overt symptoms may not present themselves for some years to come and that once they did, possibly twenty years ahead, he would have to go onto medication.

31. I was both distraught and confused, both on his behalf and personally, My family and I relocated back to the U.K. soon afterwards, so that I was nearby to offer him any help or support he may have required.

32. Moving back to the United Kingdom was hugely important because I felt the need to support both him and my mother. Our mother was not told that Costas had contracted Hepatitis C, nor was she told of this after his death. It would have been too much for her to bear, knowing that his life had been so tragically shortened by the very treatment that was supposed to have been keeping him alive.

33. I know that Costas was told by the hospital of the risks he posed to others in so far as his passing on the infection may have been concerned, but I do not know how, or by whom, he was told. Following the diagnosis of Hep' C, he became very conscious of this illness and was careful to keep his things separate from those of others, to reduce any risks he posed.

34. I was unfamiliar with HcV, frightened and confused by what I had been told by Costas and continued to live in fear of him and concern for our family. The fact that he was always so careful with his personal belongings, especially around his nephews and niece caused extreme anxiety for us all. We were always on edge during family gatherings, times when we should have been able to enjoy each other's company which were overshadowed by worry and anxiety.

35. As with his Thalassaemia, Costas tried not to let his having HcV adversely impact upon his ability to work, and he was a hard worker with a strong work ethic. He worked for ARGO until just a week before his eventual death. Prior to this, Costas would use his leave entitlement to attend hospital for blood transfusions or for trips with the Thalassaemia Society, rather than take time off of work.

36. In 1996, in an effort to eradicate Hepatitis C, Costas was put on a course of treatment with Interferon, this was to be the first of three separate courses of treatment he underwent for Hep' C, but they were all unsuccessful.

37. His use of Interferon caused him a great deal of pain, in particular his legs ached a great deal, he was constantly nauseous and suffered from frequent headaches.

38. I cannot recall how long the first course of treatment lasted, but he was unable to complete the full course due to its side effects, but sought very hard to do so in the hope that it would prove successful.

39. I do not know what he was given for the second and third courses of treatment, only that once again Interferon was an integral part of at least one of them, and again he failed to complete that course, but was always optimistic and willing to 'give it a try,' sadly to no good effect and his health between the second and third courses of treatment left him with joint issues

40. In Costas' final days he was treated using some form of radioactive process which required him to be kept in isolation. It caused him a great deal of physical pain and discomfort and he uncharacteristically became extremely rude to people.

41. I found it extremely difficult to cope with him being in hospital under these conditions, and suffering as he was, but it would have been even harder for Costas to come to terms with – he was a 'people-person' and being isolated would not have been what he would have wanted, his mood-swing was wholly out of character and would have been difficult for him to address, and he was additionally in considerable pain.

42. My family and I would visit Costas every day. On some occasions I slept in the hospital overnight so that I could ensure that someone was there for him, for company and comfort as and when it he may have needed it. My daughter spent her 18th Birthday in hospital with him, talking to him and rubbing his feet to comfort him and alleviate some of the discomfort he was experiencing.

43. At this point in time, Costas was lying in bed and most probably knew that he was dying, but he still asked his niece what her birthday plans were, what she would be doing to celebrate and so on, he always showed an interest in others and wanted to see or know that they were happy.

44. A few days before he passed away, a doctor called me in and told me that it was then unlikely that Costas would survive much longer. GRO-C GRO-C I wanted Costas to be able to receive Holy Communion before he died.

45 GRO-C GRO-C, Costas had done a great deal in support of the church and was by then an important community figure. Seeing him in this condition, and at such a tender age, was devastating for everyone who knew him and especially those like the priest who visited.

46. On the Saturday before his death, I went to visit Costas in The Royal Free Hospital and was able to help him wash. It was the last day when he was able to leave his bed as he was very weak. I stayed with him in the hospital, laying alongside him on his bed, holding his hand as a comfort, until the Monday, 19th October, 2009, when he passed away.

47. Over those three days, so many people wanted to visit Costas that the hospital became very busy, too busy for them to cater for, and some had to be asked to leave.

48. Costas' funeral was held on 30th October 2009 at the St Andrew's Church, Kentish Town, London, NW5 and he was subsequently interred at the New Southgate Cemetery.

Section 4 - Other Infections

49. I am unaware of any other infections Costas may have become infected with as a result of his having been given blood transfusions whilst being treated by the NHS – his only treatment provider, with all of his care having been conducted at the Royal Free Hospital.

50. Costas was a clean-living individual who, aware of his health condition (i.e. the Thalassaemia) from a very young age, looked after himself by maintaining a healthy lifestyle. He did not have any tattoos, piercings, only took prescribed medication and was not promiscuous.

Section 4 - Consent

51. In the early years of his Thalassaemia treatment, my parents were responsible for any issues of consent, and language was a barrier for effective communication between them and the medical authorities, as I have detailed.

52. However, as he aged and had a better command of English than his parents, he took more and more control of his own position and would have provided consent for treatment or tests to be conducted where it would have offered an opportunity to better understand and therefore treat Thalassaemia.

53. In later years, I do not know what happened as regards his consent to any particular procedure having taken place, but we were very open in our relationship with one another and had anything been untoward or questioned by Costas, I believe that he would have told me – he did not.

Section 5 - Impact

54. My brother suffered from both the physical and mental side effects of Hepatitis C infection and the Interferon based treatments he received in an effort to rid him of this disease. He found the challenging physical side effects of the Interferon too much to cope with, leaving him unable to complete any course with the same.

55. Costas developed a lifelong love of travelling. He undertook a lot of travel with the Thalassaemia Society (for example, he visited India where he met with and helped children suffering with Thalassaemia). However, following his diagnosis as having Hepatitis C, he found it difficult to secure the necessary visas to enter different countries as he would have liked, and found it very difficult to obtain travel insurance, in particular for the United States of America.

56. My brother's death had a huge impact upon my family and I. My children were very close to their Uncle Costas who treated my children as if they were his own. Their witnessing him becoming ever more unwell with HcV was very hard for them to come to terms with.

57. My eldest son GRO-C, who was Costas' Godson, was very close to his uncle and had to stop visiting him in hospital towards the end, as he simply found it all far too distressing. His uncle's death left a huge void in his life and many unanswered questions GRO-C.

58. Following our father's death, Costas looked after our mother and they had a very close bond. When he fell ill from the impact of HcV and had to be hospitalised, she found it very hard to accept, but when he passed away she became inconsolable and cried every day for many months afterwards. She wrote poetry about him GRO-C GRO-C - she never recovered.

59. I found the loss of my beloved brother devastating and life changing. Following his death, I took on the care of our mother as she was unable to look after because she was so grief stricken. I had to give up my job in order to care for her full time for the first year after his death, a duty Costas and I would otherwise have shared between us.

60. As a consequence, our mother had to move in with my family and I a few years later. Costas had been extremely close to our mother and would have wanted the best for her. I had promised to look after her, always. GRO-C GRO-C.

61. Having lost my brother, then lost my job (as above), a job I really enjoyed, and having to care for my mother without having had time to grieve for the loss of Costas left me depressed and I lost confidence.

62. Costas had been a hugely popular, caring man with an infectious personality who was well respected and active within a number of groups he believed to be important, especially the Thalassaemia Society and our church. Such was the high esteem in which he was held, that over a thousand people attended his funeral service.

63. Following his death, I received a large number of cards of condolence and flowers from Thalassaemia Society members, a group he had helped form and within which he rose to be Vice-President, a position he held at the time of his death. Following his passing, the society decided that 19th October, the date of his death, would be adopted as the National Thalassaemia Day, a huge mark of respect.

Section 6 - Treatment / Care / Support

64. I am not aware of Costas having ever been offered any form of psychiatric support or counselling as a result of his having had hepatitis C, or having been treated, unsuccessfully, three times in an effort to rid him of this disease.

65. I have not been offered any form of psychiatric support or counselling following his death, but strongly believe that it may have proven beneficial at the time. Even after twelve years of his passing, my family and I are still grieving at his untimely death.

66. The death of Costas has had a detrimental impact upon our mental health and wellbeing, and left a void in our lives which is unfathomable. It has left our family broken.

67. Over the past few months, my family and I have endured the most difficult time since my brother's passing GRO-C

GRO-C

68. My family and I had hoped that using respite care would give us the time in which to decide, as a family, on how best we could manage her care thereafter.

GRO-C

69. On more than one occasion, whilst being looked after in the home or by the NHS, she has been failed through negligence, so yet again as a family we find ourselves being let down by the very people who are there to help. As a result, I want our story to be heard, for my statement to be recorded, as I am now the voice of both my late brother and our mother.

Section 7 - Financial Assistance

70. I know that Costas applied to and received a payment from The Skipton Fund, something which he described to me at the time as having been 'like winning the lottery.' It was money he told me that he wanted to use to ensure that my children were safe and supported. Following his death, we found that the money he received had been left to them from his estate.

Section 8 - Other

71. In order to better assist The Infected Blood Inquiry with their understanding of Thalassaemia, my brother, and his actions, I now produce the following documentary exhibits:

72. **WITN0956002** - An extract from the U.K. Thalassaemia Society booklet, 'All You Need To Know About Being A Carrier Of Beta Thalassaemia.' This includes a paragraph on Desferal, previously mentioned within this statement.

73. **WITN0956003** - A copy of the flier / poster produced for a UK Thalassaemia Society 'Open Day' held on the 10th Anniversary of the death of Costas Kountourou.

74. **WITN09856004 and WITN0956005** - Published personal obituaries

75. **WITN0956006** - Two pages extracted from an issue of Thalassaemia News, showing an article profiling Costas Kountourou including questions and answers of him as a thalassaemia patient. This provides Costas, although now deceased, with 'a voice' showing how he addressed his having thalassaemia and the founding of the UKTS.

76. **WITN0956007** - A copy of the death certificate of Costas Kountourou, showing his actual cause of death as having been

I (a) Fulminant Hepatic Failure

(b) Hepatocellular Carcinoma (Metastatic)

II E Coli Septicaemia and Thalassaemia Major and Hepatitis C

Statement of Truth

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

Signed: GRO-C

Dated: 19 October 2022