

Witness Name: JE Scott  
Statement No: WITN1703001  
Exhibits: WITN1703002-3  
Dated: February 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF JULIE ELIZABETH SCOTT

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I, Julie Elizabeth Scott, will say as follows: -

#### Section 1. Introduction

1. My name is Julie Elizabeth Scott of GRO-C  
GRO-C and my date of birth is GRO-C 1957.
2. I have been married to Barry Scott for 21 years. Barry owns a tyre business and I work as the company secretary. I am the youngest of 4 siblings (Michael Douglas Howton, Brenda Margaret Millard and Dorothy June Metcalfe), all of whom have provided witness statements.
3. I am an affected person in relation to my late father Douglas Alfred Howton and my late nephews Russell Wayne Millard and Robert Paul Millard; all of whom were infected with HIV and Hepatitis C as a result of receiving contaminated Factor VIII. Douglas died on 15<sup>th</sup> June 1989, Russell on 5<sup>th</sup> October 1990 and Robert on 14<sup>th</sup> November 2012.

4. This witness statement has been prepared without the benefit of access to Douglas', Russell's or Robert's full medical records. I confirm that there are a large proportion of medical records which have gone "*missing*".

## **Section 2. How Affected**

*In relation to Douglas:*

5. My father had severe Haemophilia A and was infected with HIV and Hepatitis C as a result of receiving contaminated Factor VIII throughout the later stages of his life. **Exhibit WITN1703002** is a copy of my father's death certificate which lists the causes of death as pneumocystic pneumonia and acquired immune deficiency syndrome and confirms that he "*contracted virus through treatment for Haemophilia*".
6. My father was never given any information or advice regarding the risks of receiving Factor VIII.
7. He received treatment at the Churchill Hospital, Oxford and his consultants were Dr Rizza and Dr Matthews.
8. I do not know when my father was infected with HIV or Hepatitis C.
9. My mother opened a letter from the Churchill Hospital which was addressed to my father and was dated in or around November/December 1985. This letter advised that my father was HIV positive and it also enclosed raffle tickets for purchase.
10. My mother did not advise my father about the contents of this letter but she did tell me and my 3 siblings and we were asked not to divulge the news to anyone; least of all my father. My mother wanted to protect my father because she knew that he would worry about such a diagnosis.
11. In any event, some months later my father also found out about his HIV diagnosis purely by chance. He attended his GP to obtain the results of a chest x-ray which had been undertaken following a recent chest infection. The GP said to my father

*"Your chest is clear but you have HIV".* The news was conveyed in a very matter of fact manner. This was a terrible way to find out such devastating news. My father returned from this appointment and did not tell my mother; not realising that she already knew.

12. My father was not given any information about how to manage the infection and he was not provided with any information regarding the risks of transmission. However, my father would have carried out his own research regarding what HIV was and how it was going to now shape his life. I recall that from the moment he returned from that GP appointment, he took up residence in the back bedroom and my mother and father slept apart from that time onwards.

13. My father was also infected with Hepatitis C but he was never told that he had this infection.

*In relation to Russell:*

14. Russell had severe Haemophilia A and received Factor VIII from the age of approximately 18 months until his death. He received treatment at the Churchill Hospital, Oxford and his consultants were Dr Rizza and Dr Matthews.

15. Russell was infected with HIV and Hepatitis C as a result of receiving contaminated Factor VIII.

16. In or around the mid 1980's, Brenda accidentally found out about her son's HIV positive status. She was standing outside his hospital room and overheard one of the consultants, who was briefing a group of trainee doctors, say *"he should be on AZT"*, whilst pointing to Russell's room.

17. Ironically, a short time after this, I believe that Russell also found out about his HIV infection by chance. He too overheard a conversation between medical professionals. Following this, Russell told Brenda that he was HIV positive, not knowing that she was already aware of this.

18. Sometime after Russell found out about his HIV, he discovered that he had Hepatitis C. Dr Rizza told Russell that he would have to be careful with his liver but rather worryingly he was not given any further information about how to manage Hepatitis C or about the risks of transmission.
19. Russell never received any information in relation to the risks of receiving Factor VIII. After he had been infected, he did not receive any adequate information in relation to how to manage his infections or regarding the risk of transmission.
20. **Exhibit WITN1703003** contains extracts from Russell's medical records which clearly demonstrate that medical staff have redacted copious amounts of information.

*In relation to Robert:*

21. Robert had mild Haemophilia A and received Factor VIII on an intermittent and "as and when required" basis. He was treated at the Churchill Hospital and his consultants were Dr Rizza and Dr Matthews.
22. Robert was told that he had HIV by Dr Rizza at the Churchill Hospital in the latter part of 1986, GRO-C Robert attended a routine appointment and did not expect to be told this devastating news but to some extent he had suspected that he may have been HIV positive because both his brother (Russell) and grandfather (Douglas) had been infected with HIV.
23. Robert was never given any information about the risks of receiving Factor VIII.
24. I do not know how Robert found out about having been infected with Hepatitis C but I do know that he was told at some point.
25. Robert was not given adequate information about how to manage his infections or regarding the risk of transmission.

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

26. I believe that my father and my nephews were definitely put at risk of vCJD and I believe that they all developed vCJD and I set out below why I believe this.
27. In relation to my father, I distinctly remember that his coordination deteriorated towards the latter stages of his life. Furthermore, my sister-in-law, Mary Howton, recalled an occasion when my father dropped a lit cigarette on his lap which burned his leg quite badly. He had not even noticed; it was like his nerve endings had died.
28. In relation to Russell, I vividly recall that he moved like a '*rag doll*'. On the Sunday before he passed away, I received a telephone call from Brenda asking me to come and help her look after Russell whilst they were waiting for ambulance to take him into hospital. When I arrived, he could not even hold himself up and it was like his muscles had gone limp. He had no coordination and it was a shocking sight; I had never previously seen anything like that.
29. Russell's death certificate records that he passed away due to encephalopathy and this further persuades me to think that he definitely had vCJD.
30. In relation to Robert, I vividly recall that he walked as though he could not feel the ground under his feet. His walk was both laboured and disjointed. He was also diagnosed with an inflammation of spinal fluids but I believe that this was vCJD.

### **Section 4. Consent**

31. I strongly believe that my father and nephews were all tested and treated without their knowledge and therefore impliedly without their consent.
32. Russell had a test conducted on his "*stored blood*" after he passed away and I believe that this was a test for Hepatitis C which had clearly been undertaken without his knowledge or consent.

33. During most hospital visits, Mary Fletcher who was a nurse at the Churchill Hospital would take my father's blood and I believe that his blood was used for the purposes of research.

34. Both Russell and Robert received Hepatitis B vaccines without their knowledge and therefore impliedly without their consent.

### **Section 5. Impact**

35. I would terrify myself about what would happen to my father. My mother and father were amazing people who worked tirelessly throughout their lives; they did not deserve this set of cards.

36. My father had emphysema and picked up various infections. He had a very bad chest and a poor immune system. He always felt poorly but refused to go to the Churchill Hospital whenever I offered to take him. I literally begged him. We almost had a row because he kept refusing my help. I told him that it was not fair and that if he did not seek medical assistance his health would deteriorate further. I therefore encouraged him to go to the hospital before it was too late. He finally agreed to go and this was the start of an absolute nightmare.

37. My poor father endured a number of physical symptoms. He always had a rash and used to say "*You can get rid of pain but you can't get rid of a bloody itch*". Doctors were unable to determine what the rash was or how best to help my father. On one occasion, my father's consultant gathered about 20 doctors into the consulting room to examine my father's skin. My father was so ashamed as he knew that it was related to his HIV but he bravely said "*I hope that my illness helps you to find things out*". Following about 4 months of deliberations the doctors, unbelievably, advised my father that his rash was thrush.

38. My father changed massively as a result of his infection with HIV. He was extremely careful and worried to death about everything. For example, he would quickly throw all of his clothes in the washing machine after having a shower. Mentally, it was an

absolute torture for him and his mental wellbeing declined. I felt that he totally disintegrated as a person.

39. He was a quiet man and our mother was the talker. However, he would quietly influence her and they had a phenomenal relationship. She was more eloquent and able to express herself and he was more reticent.
40. I remember my father as a strong man with big hands; but as his illness took effect his hands and muscles shrunk. I was most upset about my father's dramatic weight loss. I wanted to make sure that he always ate but he struggled to swallow, particularly towards the latter stages of his life.
41. My mother used to wake up at midnight and then again at 6am to give my father his AZT treatment. She doted on my father. She used to cover him in cream and give him antihistamines in an attempt to calm his rashes. Furthermore, my mother would not accept it when my father was unable to eat. She would place a number of tasty food choices on a beautiful doily for him; everything looked spectacular but he was still unable to eat anything.
42. The impact upon my mother was that she became overworked and her feet were like two great big puddings. She suffered greatly but she just ploughed on like a true martyr. She was so desperate to keep my father alive and kept saying "*Look, we will beat this*" and after he passed away she said to me "*How stupid was I...*" But I could not fault her for her bravery in believing that things could get better. She was there for him every step of the way. She was like the most remarkable and unsinkable ship.
43. The AZT treatment was toxic. It was like a poison and it made my father feel very poorly. However, he put on such a brave face and said he would take anything if it made him feel better. He wanted to believe that he could get better. Yet, emotionally, he really struggled and suffered because he felt terribly ashamed.
44. As Mary, my sister-in-law, also recalls, it was a battle with the pharmacies to get my father's AZT treatment. When Mary was collecting his cocktail of medication, the pharmacists would gather around to look at her. We all felt like we were a little isolated group, unable to speak out. My father would always ask Mary if everything

was alright after she had collected his medication, and of course, she always reassured him and told him that everything was fine because she wanted to protect him. Mary would then take him to the pub for a few pints of beer because they both celebrated the fact that the nasty ordeal of collecting his medication was over.

45. The news portrayed HIV as the thing to be feared. The TV advert of the gravestone remains etched in my memory. I used to cringe when it came on when I was in the room with my father. I remember that he used to flick his newspaper and position it to a higher position to cover his face. I can't even begin to imagine what he must have felt. It was distasteful and horrific. My poor father; he was a man who was moral and family oriented. It was devastating for him. Haemophiliacs were treated like they had the plague.

46. Frequently, we would be at the receiving end of the nasty stigma that multiplied quickly. Whilst my father was still alive the neighbours would rev their motorbikes directly outside his window when he was really poorly. This was disgusting and disrespectful behaviour which I wish that my father never had to endure. One of my mother and father's neighbours (who I call "GRO-D") said to my mother "*we know what's wrong with your husband, are you the same?*".

47. Following my father's passing, we suffered further stigma. I used to stay with mother due to her health problems. I owned a little Fiesta which I parked in my father's garage. One morning the neighbours had blocked my car in my father's garage with their motorbikes. I politely asked if they could move their motorbikes so that I could get my car out the garage. They refused and the next morning when I came outside they had sprayed my little car with anti-freeze; it was literally covered in the stuff. My mother and I were so upset by this type of behaviour which we unfortunately had to endure.

48. On the Sunday before my father passed away, he asked me to fetch him the newspaper. I literally ran out of the door to the shop in a flurry of excitement and hope and thought "*they must have got it wrong, he is alright after all*". I gave him the newspaper and went upstairs to do something. When I came back into the room, moments later, I realised that he was holding the newspaper upside down and my heart sank.



49. I think that my mother would have happily died when my father passed away; but I didn't let her. I loved her to bits. She used to say to me *"I don't know how I have lived so long without him"*. She used to write to him every day. My father used to give her the first and the last rose of summer. Following his passing, she did the same for him by putting the petals in his slippers. I was heartbroken from losing my father and then having to care for my mother through such a terribly sad time; all of what has happened to our family could have been avoided.
50. I was closer to Russell than I was to Robert. Russell was born when I was aged 6. Brenda and I lived a couple of doors away from each other so I felt like I had *"adopted"* Russell as my little brother. We were always together and I had a little bike which I was lethal on. I used to make Russell get on the bike and I used to buy him toys every week. We were close in age and played together regularly. Russell was very similar to my father. Russell liked to get his telescope out and was generally an introverted child. He hated the fact that he had Haemophilia and that something made him stand out. He did not want to be different. He was a good little footballer but he was unable to play because of the risk of bleeding.
51. As Russell grew up things were difficult emotionally because he was acutely aware of his HIV diagnosis. Russell cried one day and said that he did not want to die now. He died a thousand deaths, especially after my father passed away because he fully appreciated that he would be next.
52. Russell was sensitive in nature and he really suffered; he was terrified. He was so proud of his children as well but he did not live long enough to see them grow up. It was like a horrible nightmare. It was disgraceful. I could not look at Russell towards the end of his life. Every time I tried to my eyes welled up with tears because he looked so poorly. I had to keep walking off all the time, and I would say random things to him all the time to try and take his mind off things. However, it was very difficult when we were sat down watching TV together and the horrible adverts appeared entitled *"Don't die of ignorance"*.

53. Robert was a fiery character. He said it like it was. Russell and Robert were like chalk and cheese; the absolute polar opposites of each other.
54. Towards the end of his life, Robert stopped listening; he was poorly and fatigued. His last Facebook post said "*I've never felt so ill in my life*" and he was not someone to moan about anything. His attitude had always been that he was going to beat HIV.
55. I remember that Brenda telephoned me in the night and said "*Hello Julie, Robert has died*". I was in complete shock. I then rang Mary and she could not believe it either. It was totally unexpected and so sudden. Our family had now a third person to this avoidable tragedy.
56. Personally, I have always felt that I was living a double life. I would go to work and I would put on a happy face. I had to lie to everyone for so many years. What has happened has moulded and shaped my life beyond recognition to before tragedy struck. It has really affected the decisions I made throughout my life.
57. I realised that I was in the wrong relationship with my ex-husband, Neil, as I was newly wed yet spent most of the time at my mother and father's house. My father was always very wise about my relationship with Neil and he was wonderful with me and told me that there was always a home with him for me. My current husband, Barry, knows everything and supports me; we have a good relationship. Unfortunately, as a result of a number of reasons, we have no children and I am very saddened at this.
58. I always felt disadvantaged with the situation that I was in. My work colleagues would laugh at AIDS jokes and I would never laugh. I felt that I was just treading water with people. I was acutely aware of my own mortality with each family member's passing. I used to sit alone in my bedroom worrying myself sick about my father and I always wondered whether my mother was going to survive after his death. My parents were my whole world and I adored them.
59. My father's infection created a rift in our family. My mother's sister, Susan, did not want anything to do with us in fear that her granddaughter might somehow become infected. Furthermore, my cousin said to Mary "*you know what they've all got*" as though we were all dirty and infectious.

60. My father's passing had a massive impact on my life which further exacerbated by the passing of my nephews. I was young and quite thin then but my blood pressure rose to over 200. I deteriorated into a very unhealthy state and I drifted through my 20's and 30's firstly caring for my poorly father, then trying to help my mother and then trying to figure out what on earth had happened to our family following the passing of my nephews.

61. We always struggled financially but my parents did the best they could in such dire and unfair circumstances. We had each other and our strong family values have helped me to grow into the person I am today.

62. In summary, the impact this had on my life and that of my family was enormous. It was like an atom bomb had been dropped on us and it dictated everything we thought and did. I was frozen with fear, the newest and most deadly virus in the world had visited us and we didn't know what to do. That is when the shame and isolation started and it imploded on all of us as if we had done something terrible.

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

63. I recall that my father was placed in an isolated side room following his bronchoscopy. His body went into shock and he had a seizure. It was lucky that my mother was with him when this happened because he was almost completely ignored by the medical staff.

64. I also recall my father being given a very large and extremely tough jacket potato which was covered in mud, when he was in the John Waring Ward at the Churchill Hospital. My father was so weak at this point he could hardly even pick up a fork, let alone tackle this potato which was certainly not fit for human consumption. My mother picked up the potato and handed it back to the hospital staff. This was such an upsetting sight.

65. The medical staff were always fully gloved and masked when treating my father and I also recall him being in a very cold isolation room with broken blinds in the John Waring Ward.

66. My father had his hearing tested at the Churchill Hospital and the doctor just stuck something very abruptly into his ear, without pre-warning my father. The way my father was treated was brutal and horrific. The doctors did not usually want to touch him and when they did, they made sure that it was over and done with very quickly.
67. My father was refused dental care; no private or NHS dentist was prepared to deal with him and as a result he ended up with a full set of dentures.
68. On one occasion, I recall that social workers visited our family home and they acted as though the whole house was contaminated and as though the whole family were infectious.
69. As far as I am aware, neither my father nor my nephews were offered any counselling or psychiatric support.
70. I have never been offered any counselling or psychiatric support.

## **Section 7. Financial Assistance**

71. The Macfarlane Trust decreased my mother's widow's pension and we challenged this after she received a snotty letter from them. The process was a real pain and I feel that the Macfarlane Trust was a complete waste of time; the staff displayed tones of superiority and were particularly unhelpful.
72. I believe that my father received grants from the Macfarlane Trust for a washing machine, bed and mattress.
73. My mother received the Stage 1 lump sum payment of £20,000 from the Skipton Fund but this was after my father had passed away.
74. I never received a penny from any of the trusts and I was happy to hear that the Macfarlane Trust has now dissolved.
75. My nephew's wives dealt with their financial affairs so I do not know which or how much financial assistance they received.

## **Section 8. Other Issues**

76. In internet terms I would be described as a dinosaur. I have only just started following the Tainted Blood Support Group on Facebook which I found really helpful. I think that it is a fantastic way for like minded survivors of this tragedy to connect. I recall that my mother used to say that she wished she had known that there were others out there, like her, who had experienced similar things. I think she would have found a great deal of comfort having such support.

## **Conclusion**

77. I want the people who killed my family and put money above people's lives to be held accountable. I do not believe that the Government cared about the victims and their families who have suffered in such a terrible way.

78. I do not trust consultants or politicians and with good reason. My family put their entire trust and faith in these people and we were let down in an unimaginable way. Thoughts run through my head like the number of times I used my father's razor to shave my legs and the fact that I, like so many others were put at risk of infection. I will not rest until I obtain justice for my father and my nephews.

## **Anonymity, disclosure and redaction**

79. I do not wish to apply for anonymity and I would like to give oral evidence to the Inquiry.

**Statement of Truth**

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

Signed 

GRO-C

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Dated 21/2/19. .....