

Witness Name: Katie Scott

Statement No: WITN3463001

Exhibits: N/A

Dated: 4 November 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KATIE SCOTT

Section 1: Introduction

I, Katie Scott of GRO-C will say as follows:

1. I am the eldest child of the late Ronald Scott who was born on the GRO-C 1943 and who died at the age of 50 on the GRO-C 1993.
2. My dad had severe Haemophilia A, GRO-C.
3. It would appear that he developed Hepatitis C after becoming jaundiced in 1977 and then infected with HIV infection whilst receiving Factor VIII concentrate replacement therapy from St. Thomas's Hospital in 1983.
4. I was born in 1974 and I have 2 brothers, Dougal and Nicol. I was 19 years old when my father died as a consequence of receiving contaminated blood products. My brothers were aged 12 and 17.

Section 2: How Affected

5. My father was home schooled until the age of 13 due to his severe haemophilia. His elder brother died in childhood. He went on to study Maths at University. He always spoke about what an amazing life he had, never complained about the pain or challenges he suffered. He remained extremely

close to his parents throughout his life and was survived by his Father. His mother died two years before he did. He attributed his happy life to my Mum and having children, which he had never anticipated being a feature of his life when he was younger.

6. I would describe my childhood as being normal and the same applies to the period during which I attended secondary school. My father was a Governor at my school and he was an active member of the GRO-C. He had a passion for education, music and politics and I can remember when I was 16 years old how happy he was when Nelson Mandela was released.
7. In terms of my father's health, I didn't think there was any imminent danger to him when I was a child and I was not aware of his infections for many years. He shared this news only when he felt he his death was imminent. He explained he had wanted to spare his Mum (my paternal grandmother) any more pain (the loss of their first son was never really recovered from).
8. I can recall that my father had a very swollen knee and as a child, I knew I could not sit on it. He couldn't lift us up. He walked with a limp and a walking stick. I remember strangers asking many questions about my father's leg but to me, his leg was normal, his mobility, was completely normal and didn't really occur to me until I was in my early teens. My father did lose a lot of weight at one point when I was about 15/16 and began to look old and frail quite quickly. On a holiday he was violently sick one day, and on another, had a seizure whilst we were on a day boat trip. He grabbed hold of me for the duration of the fit. This was a terrifying and very public event.
9. From a very young age, I recall seeing him getting injections in the back of his hand. I also remember regularly seeing syringes and butterfly needles in my home. The mixing of dried Factor VIII and water was a lengthy process and all had to be transported in a picnic box when we went on holiday. Customs sometimes questioned the possession of needles. His legs were very painful and he was clearly in a lot of pain a lot of the time. That said, he never complained or compromised his ambition for what we did as a family: travel,

trips to the cinema, theatre, opera, ballet. He never allowed excuses to be made. Education was everything. He knew his education had enabled him to lead a fulfilling life. He never took time off work and therefore my attendance at school was 100% over 5 years bar one morning for a funeral.

10. At the age of 12, I recall that my father was being taken care of by a barrier nurse and then remember from that point that his toothbrush and towel were always kept separate from the rest of the family. I can also recall a legion being removed from his tongue on another occasion from which he never healed.

11. I have a very vivid memory of a boat trip which my family went on as part of a holiday in 1992. I remember whilst on the boat, my father had some kind of fit and he just grabbed my arm. It was frightening as I thought that he was going to die. Then he was suddenly fine; we went swimming and then had lunch so we could make the most of the family holiday. I did find this incident to be very strange at the time. When we returned, a scan was performed and the findings indicated that he had some severe changes to his brain.

12. My father always spoke about his own childhood very positively. He used to swim a lot and always encouraged us to make the most of our potential. He was always very supportive throughout my life and encouraged me to go to university. When my father's own mother died in 1991, this affected him quite badly.

13. When I was aged 13, I noticed a number of frequent topics that appeared in the news such as HIV. I asked my mum questions about this and I also asked her whether my father was okay. My mother maintained that he was fine. At this point, I was not aware that my father was infected.

14. When I eventually found out the truth a number of years later, I felt that not being told the truth sooner caused a lot of damage. I became bitter and angry towards my mother for lying and shutting us out. I now understand that my mother was only trying to protect me and my brothers but I wish she had told me the truth sooner as I would have been less moody and sarcastic and more

gracious towards them. I reflect on those decisions differently. As a parent of a child older than I was when my dad died, I can understand the desire to protect normality. I also have a much better understanding of the stigma that would have affected my dad, Mum, my brothers and I, had people at school, work etc found out his status. However, the 'lie' was something that impacted upon my relationship with my Mum, especially in the years immediately after my Dad's death. It has been nearly three decades so I can now understand his desire to protect his parents, wife and children, his employment... the 1980s were not a tolerant or kind decade. I still wish I could have known how little time we had together so that I could have made the most of it.

15. I shared an interest in politics with my father and would go canvassing with him. I looked up to my father and was largely influenced by him at the time. I really miss the interaction I had with him and the political engagement. I also feel the loss of intellectual conversations with my father which had set me up for my A-Levels.
16. Previously, my father had helped me with maths as he was very good at this subject but as statistics at university became more difficult, he could no longer help me with them. This was the beginning of a rapid deterioration thereafter, that we witnessed on a daily basis. December 1996
17. I did very well in my A-Levels and on the last day of exams, I can recall being very happy and had planned to go to the pub that day to celebrate. I went home, excited, but was told that my parents were at the hospital (St Thomas'). I went straight to the Haemophilia centre and I can recall that both of my parents looked devastated. There were loads of doctors around and I heard a story that there had been a road traffic accident.
18. Then the truth was revealed, my father spoke to me alone (being the eldest child) and I can remember clearly that my father started to cry. It was at this point that my father told me that he was HIV positive. I was so shocked and cross and I remember crying uncontrollably with my head on his chest. I asked him how long he had known this for and he told me 10 years.

19. I can only recall my father crying 3 times ever in my life. The other two: trapping fingers in a garage door and GRO-C losing another general election.
20. My father then told me which of my friends he did not want me to tell because he felt they would be unkind and couldn't be trusted not to share the information more widely I had seen the same storyline about HIV on the EastEnders storyline, campaigns, and in the news and it felt surreal that this was happening to me and our family. This shows the level of stigma and the importance of secrecy at the time, even at ones most vulnerable moment.
21. I was aged 18 at the time and my friend had lost her mum to cancer a few years earlier and was aware of the pain of regret. I didn't want to have any regrets and I wanted to spend as much time as possible with my father and to have meaningful conversations with him that would last with me. I was determined to be there for him as much as I could.
22. My father was glad that he had finally told me about his illness and that he didn't have to hide taking his medication anymore.
23. He was later diagnosed with Toxoplasmosis and therefore it was no longer safe for him to drive and so I would take him anywhere he needed to go.
24. He was a very proud man and refused to get a disabled badge.
25. Our last meal out as a family was on my father's 50th birthday. It was the last time he went out. My two siblings and I wanted to get him something special and since he loved listening to music, we got him a device (CD Walkman) which he could listen to music on which he loved. He died 10 days later. The deterioration from August to December 1996 was physical and rapid. Over that Christmas his confusion was evident. I decided to drop out of university and remain at home to help my Mum look after him and spend as much time as possible.

26. Eurovision and election nights bring back memories as we used to watch these together. It was the political coring, not the music that was the pull for Eurovision.

27. He died at home on GRO-C 1993, 10 days after his 50th birthday. The palliative nurse, Kate, who sat with me all night as I sat with him was brilliant and made an unbearable night, possible.

Section 3: Other Infections

28. N/A

Section 4: Consent

29. I know that there were issues surrounding consent relating to the transmission and risks associated with Factor VIII treatment. My mother says she was not given much explanation or any information.

Section 5: Impact

30. My father died when I was 19 years old. I was left traumatized by seeing him die and even today, his death was horrific and nothing like what they show on the TV. The night he died, there was a nurse with him. Up until that point, my Mum had cared for him.

31. I can remember that my uncle came over to see him with his wife who would not touch him due to the HIV.

32. I remember sitting with the nurse and my mum had taken a sleeping pill. When I knew something was going wrong, I immediately woke up my mum. I saw my father drown in his own phlegm, green liquid came out of his mouth which was horrific to witness. His hands and his face went blue and a strange smell filled the room.

33. My father died at 3am on the GRO-C 1993. I still remember the cries of our dog that lasted days after he died.

34. On the day of his funeral, the crematorium was packed with people who came to pay their respects. I can recall my grandad crying in the car leaving the crematorium.

35. My father's Death Certificate noted Bronchopneumonia, Dementia, Acquired Immune Deficiency Syndrome, Haemophilia.

36. To this day, every election brings back memories of my father due to his interest in politics. Bittersweet as I enjoy remembering the things we shared but it always makes me sad because we should have enjoyed more of them together.

37. After my father's death, I couldn't go back to university for about 6 months. I was studying Psychology at the time. Instead, I disappeared to Italy to where the last family holiday had been just so I could hide and get away. It was not a good decision as I denied myself family support. I was not processing any grief at the time as I had run away.

38. I then returned to university in GRO-C 1993 to study Italian and History. I can recall having breakdowns on the dance floor when I went out at night. I felt as if I was being pushed further and further away from my dad as none of my new friends knew him. After a few years, I managed to get a good degree and on my graduation day, I cried uncontrollably as sadly my father was not there to celebrate my achievement. This is a memory embedded in my mind that I will never forget. It was certainly not how my peers were enjoying their graduation day.

39. I subsequently met a partner and had a daughter, aged 26. Despite never regretting having my daughter, the relationship started shortly after I lost my Dad. GRO-D was a direct result of wanting to build a family again, replace what I had lost. I

was thereafter a single parent; there was much I could have learned from my dad as a parent and sadly never got the chance.

40. Overall, from the ages 18-28, I can recall that this was a very grim period in my life. My grief separated me from my peers. I was also still conscious of the stigma surrounding HIV. The few people I shared this with would find it hard to hide their shock.

41. To this day, I still suffer significantly with anxiety and trust issues. I often think that if things are going well, it's because someone is keeping something from me. My ability to maintain relationships has also been impacted and relationships do not work for very long as a result.

42. Despite the challenges, the values that he raised me with, have remained influential and have shaped my career as an educational leader. I'd like to think that these experiences and my understanding that education made his life possible, has shaped my belief in the importance of education for all. His resilience and commitment to his family have always been an inspiration however hard I have found things.

Section 6: Treatment/Care/Support

43. I had multiple counselling sessions and was on anti-depressants on and off. I wished that I had died instead of my father as it felt as if it would have left less of a loss all round; I was one of three children. My mum had other kids, my brothers had each other. My dad was our only Dad and my Mum's only husband. I was extremely lonely.

Section 7: Financial Assistance

44. The McFarland's payment made a difference to my father when he was no longer able to drive which meant he could go from door to door wherever he needed to go.

45. However my mother was left to support children in full-time education with very limited support from the McFarland Trust after my father died.

Section 8: Other Issues

46. On one occasion, my parents tried to adopt a child with haemophilia who was older than me at the time and I feel that this reflects what kind of person my father was. He was ever appreciative of his life and felt he had had a wonderful life, so kind and thoughtful.

47. I witnessed the effects associated with both HIV and Hepatitis Non -A Non-B whilst growing up and endured the pain of losing my much loved father at a very young age. The loss of a parent, at an age when one is learning to become independent, the supervision and assistance of a parent has a considerable value and is a loss that shapes a personality and opportunities in life.

48. Political engagement, accompanying him on campaigns, having intellectual conversations helped set me up for good academics and a passion to achieve educationally. That bond, that political and intellectual engagement I had with my father, has left a void that no one can fill.

49. My father was ambitious for his children. The continued support, care and assistance would have been of great assistance throughout my life and in achievement of educational potential and to progress towards creative development. I also feel that my daughter has missed out hugely, on having a grandfather but also because there were times in her childhood when I was simply very sad.

50. The impact on my family and I, due to the circumstances of my father's death have had the most devastating effect. I still feel traumatised by the events despite 28 years having elapsed. We are an extremely close family and his absence is felt at every gathering and meal.

Questions for the Inquiry:

1. I want to know firstly the source of my father's HIV infection.
2. I want to find out when it was first known that he had contracted Hepatitis Non A- Non B.
3. I want to find out when my father first exhibited abnormal liver function test results and why these were never followed up.
4. I want to know if his infection could have been avoided, and if so, why decisions were made that meant they weren't.

Statement of Truth

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

Signed

GRO-C

Katie Scott

Date

4/4/21