

Witness Name: Dougal James Edward Scott

Statement No: WITN3058001

Exhibits: N/A

Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DOUGAL JAMES EDWARD SCOTT

I, Dougal James Edward Scott, will say as follows:

1. I am the youngest of three siblings and the son of the late Ronald Scott who had severe Haemophilia A and was infected with HIV and Hepatitis C from contaminated Factor VIII he received. He was also later diagnosed with Multifocal Leukoencephalopathy.
2. My Dad was born on GRO-C 1943 and tragically died on 11th March 1993 when I was just eleven years old. I knew my Dad had haemophilia.
3. I have no memory of when my Dad was diagnosed with HIV as I now know I would have only been about 3 years old and did not learn about his viral status until just before he died. Mum and Dad decided not to tell me as I was so young and they did not want me to suffer fear and prejudice.
4. I remember Dad having bleeds into his joints and from a very young age I learned that I could not run up to him and jump on him as other children could. I also remember Dad administering his treatment to himself at home. He was extremely cautious about needles and I could not be in the room.

5. Mum and Dad, my paternal grandparents and my siblings all shared a home. We got on well and Dad had brought his parents to live with us. My grandmother died but my grandfather was still alive at the time of Dad's death. My Dad's brother, I understand had died of issues relating to his haemophilia previously.
6. I recall Dad had a biopsy on his tongue which was painful and slow to heal. This made it difficult for him to eat resulting in huge weight loss. This was horrible to see.
7. Dad worked until a few months before his death. I realise now he was worried about money and trying to provide for us. I would have had more time with him if there had been proper provision for him.
8. We were on a family holiday to Italy in 1992 and I felt something was not right. There had been some incidents prior to the holiday when Dad had fallen and hit his head at my brother's school.
9. I recall people appearing to be worried about Dad. Whilst we were in Pompeii Dad fell over and I knew then something was wrong. It was very frightening witnessing him have what I now understand to be a fit.
10. It was still some time after this that my Mum then told me that Dad had HIV and he would not get better.
11. I did somewhat understand the nature of what HIV was because this was at a time where there was a lot in the media and, this was post 'Mark Fowler' on the soap opera Eastenders but I did not understand about the options for treatment.
12. I was told not to talk about it, and I recall a slight problem concerning a neighbour where I may have made reference to it that my Mother had to brush over.
13. Dad very clever and was very good at rapid calculations. He was diagnosed with Multifocal Leukoencephalopathy(MLE), a demyelinating disease of the white matter of the brain that causes mental deterioration, ataxia, speech disturbance, paralysis, coma and eventually death. It was desperately hard to

watch him his deterioration and I really did not properly comprehend what was happening.

14. Dad's MLE was extremely distressing, it was like he was someone else and at times he did not recognise me which was devastating for a young boy. I remember him lying in bed unresponsive. Mum worked so desperately hard to run a family and to keep Dad at home and look after him.
15. However as young boy I did not truly understand the nature and scope of Dad's illness and I never expected him to die. I was off school just before he died, however, I was due to play in a school football match and persuaded my parents to let me go to school and play in the match. I have always felt guilty for doing this as I lost time with my Dad.
16. I was summoned from the school playground to say Dad was more unwell.
17. I remember the morning I was told Dad had died very well. Mum came into my room in the night and said that he had died. It was devastating news. I did not want to see him and I have an abiding memory of my sister wailing with grief.
18. The effect of my Dad's death on my Mum was profound and her grief was overwhelming. I remember trying to take her cups of tea and felt I had the task with my siblings of trying to alleviate her grief. I still feel this even now. My grandfather lived with us and was alive at the time my Dad died. For my grandpa to lose a son was so very upsetting for him. My Mum and the family could just not talk about this. Any time my Dad's name was mentioned my Mum would weep and it became 'the elephant in the room'. Watching him deteriorate meant that those memories came to the fore and that is why we could not speak about it. It was an unbearably sad time. I remember a time trying to talk to my sister about Dad but she said she did not want to talk about it. I realise now she was trying to deal with her own grief.
19. I wanted to be strong for my Mum. She had made clear that we could not opt out of life and had to carry on.

20. However, my grandfather could not deal with losing my Dad and never got over his death. Now that I have my own son I have come to a better understanding of his being grief-stricken but it was hard to deal with as a small boy. He entered a care home some time later.
21. My siblings left home within a year after Dad died and we went from 5 people down to 2 with just me and my Mum and I am not sure how she managed.
22. After my Dad's tragic death, I felt very strongly there was a stigma surrounding his death that could not be discussed. I was sixteen before I told anyone about it. I had to figure out a whole new way to be in a family without Dad.
23. I always felt I had to behave at school. My Mum was on a committee at the school and there was one minor incident and she was very insistent that I had to behave well or it was a reflection of her ability to manage on her own as a single parent and I did not want to let her down. She worked so hard to keep the family going I did not want to cause her any problems.
24. I did well at school. I was concerned about leaving Mum when I got into university and what should have been a very happy milestone in my life was marred by this concern. I would come home regularly to spend time with Mum.
25. Not having the benefit of a father had a profound effect on me that I carry to this day. I missed the comfort and reassurance others had from their fathers sharing anxieties and life challenges. Learning how to grow up and become a man. There are many moments I would have liked to have shared with him , milestones in my life like success in exam results and getting into and graduating from university, starting my career as a teacher, meeting my life partner and having our child.
26. Our family will never get over my Dad not being with us, his family. Growing up people assume you have a Dad and ask about him then you have to explain that he has died. I have got more used to this over time but there are times I feel resentful having to soak up their embarrassment

27. Dad took hundreds of photographs perhaps in an attempt to build a lasting memory, but it was upsetting to look at these as it was painful for us. Recently my brother converted them to digital format to share with the family but seeing his name brought many suppressed feelings to the fore and a deeper understanding of the lost opportunities.
28. The biggest impact for me was that I was robbed of time to be with him, my Mum and siblings had so much more time with him. My siblings being respectively 5 and 7 years older than me. I did not get a fair run at having a Dad and there were times growing up when I was resentful of this. I love my brother and sister, but it appears to me they had so much more of him although they both feel his loss and have suffered in their own ways because of his very tragic death. I now realise that they had a different experience to me being older and having a greater understanding of Dad's suffering and illness.
29. Time in relation to Dad can be somewhat abstract for me as there are gaps in my memories being so young and I believe at times that I created things to fill in those gaps. I missed out on making those memories with him to sustain and comfort me.
30. Although my Mum was and is fantastic, I missed out on a male role model and I have a much deeper understanding of the importance of this as I have grown older and in my role as a teacher, I see the benefits in other children of having a father and also see how it affects those who do not.
31. I have a bit of an issue with males in positions of authority and do feel more comfortable around women; I think this may be because of the shock of losing him and my Dad was not there in my formative years when I was growing up.
32. My Dad would have been proud of me in my profession and he would have shown a great interest in it. My Dad had overcome the odds with gaps in his schooling due to his health problems and graduated from Edinburgh University and later went on to obtain a Diploma in Computer Science from Newcastle University and joined ICL as a computer programmer in the early days of computer in the 1960s.

33. I spoke to the Haemophilia Society after Dad died but then I stopped talking about it and was never again offered any help or counselling. In my work with young people now, I understand the profound importance of this and getting people to voice their distress. No one wanted to hear my story and successive governments have avoided this.
34. I now have a beautiful son and it has been a very special time in our lives. However, it has been marred because I find myself thinking what would happen to my wonderful partner and my beautiful son if I died prematurely and it makes me anxious. There are so many repressed feelings that continue to come to the fore as life moves on. The pain and suffering does not just stop and fade away and occasionally it takes me unaware, when I was on the train to give my statement I found myself crying uncontrollably and I did not expect this to happen.
35. It also reinforces the pain and worry my Mum and Dad must have gone through finding out he effectively had a death sentence given to him when I was just 3 years old. Also, the anxiety and possible accidental transmission to his children. There was so much ignorance and misinformation. Mum and Dad strived to try to keep my childhood as normal as possible because of this. However in sheltering me from the devastating life-altering news of Dad's infection from his Factor VIII, I was ill-prepared for his deteriorating health and never expected him to die.
36. My mother never remarried and gave all her life to me and my siblings and I now feel responsible to look after her. I worry about her, particularly as she gets older as many older people are not so sociable and can become isolated.
37. The Penrose Inquiry brought out feelings of bitterness and anger at the injustice of it all, it was ignorance that led to the infection of my Dad and so many others and stating that it could not have been avoided was questionable. Listening to others in the media to say they know or feel or speculate that it could have been avoided was very hard on me. I came to an understanding and realisation of

the timelines and history. It made me angrier because until that time I had accepted Mum's narrative and perhaps she had tried to spare me from the realisation that this should never have happened as I was such a young boy.

38. There was so much secrecy, voices became weaker until those involved had no voice. Having to go through it all again is unbelievably hard, and I am concerned there will be a whitewash as I have heard that documents have been destroyed.

39. I can never find the words to adequately describe the terrible tragedy of my Dad's premature death and how profoundly it has affected me and my family. I feel strongly that I need to speak out for those who do not have a voice and were silenced.

40. I feel really angry at the lack of true remorse and indeed any lack of candour from many Government administrations over many years. If Government exists to protect its Citizens and act in their best interests, those Governments failed my Dad, my family and myself. I believe that attempts to uncover the true truth have been frustrated by every successive administration. I don't believe that we as a Community i.e. people with Haemophilia have been treated fairly. Also, I believe that there has been a policy to conceal events, and the true extent of the losses and injuries sustained.

Statement of Truth

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

Signed

GRO-C

Dougal James Edward Scott

Dated

08/05/19