Witness Name: Barbara Scott

Statement No: WITN1020001

Exhibits: WITN1020002

Dated: 4 May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF BARBARA SCOTT

I Barbara Scott of GRO-C will say as follows:

1. I am the wife of the late Ronald Scott who was born on GRO-C 1943 to John and Mary Scott in Edinburgh. I am now aged 71 years. My late husband died on 11th March 1993 some 26 years ago. I have been a widow for longer than I lived with my late husband as we only managed to have time together for 22 years.

2. Also, for many of the years that I have been without my husband I have been the sole carer for our children.

3. My late husband Ronald was the second son of John and Mary Scott. Like his older brother John, he had severe Haemophilia A.

4. A cousin, also named John, a child of Mary's sister Meg, also had Haemophilia.

5. Unfortunately, my husband's late brother John Junior died from a gastric bleed in mid childhood. This was an extremely traumatic event for my husband's parents. John Junior had been admitted to the Burns Ward of the Children's Hospital where visitors were not allowed. It wasn't until he was almost at the

point of death that they were allowed to visit. By that time, he took their lack of visits as a rejection. It is hard to imagine a more difficult or brutal scenario involving the death of a sick child and a more painful episode in the life of a family. Unsurprisingly that had a devastating effect on both John and Mary. Accordingly, my husband's parents were always fearful that they would lose their other child and were extremely protective of him. They were very attentive and committed parents who did everything possible to protect their sole surviving Haemophiliac child. Also, my husband's cousin died as a young adult from complications following a fracture further complicated by the development of an inhibitor. All of the foregoing reinforced the belief that life was extremely risky for anyone with Haemophilia.

6. I understand that after my husband started Primary School he experienced a number of bleeds into his joints and it was decided that he should be educated at home. Accordingly, he had around two hours tuition each week with homework being set.

7. My impression was that he was happy pursuing his own interests and designing timetables for buses, trains, writing and playing Scrabble and Subbuteo etc. Also, he was self-taught in that he read voraciously anything that he could get his hands on. Television and radio were somewhat in their infancy and they were his best friends and it must have been quite lonely.

8. My husband had a talent for Maths and his home teacher really worked hard at building those skills. At the age of 13, it was decided that he should have another attempt at going to school. Accordingly, he took the entrance exam for the Royal High School and after some initial misgivings on the part of the School, he started and adapted well to school life but was not allowed to take part in any physical activity or contact sports.

9. Undoubtedly, he loved school, made friends and was an excellent pupil. Excelling in Maths and Physics, he had found his own niche. Undoubtedly his Haemophilia condition resulted in some absences from school but overall his

progress in terms of educational achievement was not impaired. Accordingly, he went to Edinburgh University to study Maths and after that he did a Diploma in Computer Science in Newcastle.

10. After completing the Diploma in Computer Science, he joined ICL as a Computer Programmer and had a good time in the late 1960s in London. In 1969 he slipped on an icy pavement and injured his knee. As a result, he was in hospital for several weeks with bed rest, the treatment of choice then. I was a student nurse on the ward where he was a patient for those weeks.

11. We married in December 1970, a lifetime ago. Whilst I was aware that this might be a slightly risky venture in terms of my husband's Haemophilia condition I could not have foreseen the nature of the entire risk.

12. Life was good, we were young, and things were going well for us. It was a time of expanding horizons, travelling abroad, getting married, buying our first house and having a good job in an exciting and emerging industry i.e. the computer industry.

13. The icing on the cake for my husband and indeed his parents was the arrival of children. Our daughter was born in 1974, our first son in 1976 and our youngest son in 1981. Our first child was born in London and our two children later born were born in Edinburgh. Our horizons were broad, and the world offered great possibilities for us. We had a busy social life, lots of contact with family and work was going well for Ronald.

14. Although I think my husband had poor expectations for life as an adult and had been quite pessimistic about what life could bring, he now had a very positive and proactive outlook.

15. His continued delight in what we could do, and experience created a very positive attitude, he wished to be involved in politics, education and was absolutely absorbed in music.

16. In 1975 when we moved to Edinburgh because my father-in-law had serious health problems, we took my mother with us as she had developed dementia and established in effect what was a multi-generational household quite near to Ronald's parents.

17. The first sign that perhaps all was not quite as well as it seemed emerged in 1977. Ronald became jaundiced and quite unwell. At that time, he was diagnosed with having Hepatitis Non-A Non-B. He was hospitalised, and he did recover. I have a vague recollection that GRO-C and myself were given a large dose of Gamma Globulin at that time. Also, there wasn't much explanation and when I asked whether the baby and my mother, who wasn't well as indicated should be treated, there was an indication that there was no necessity for same.

18. I didn't realise that this jaundice was a beginning of a serious spiral of ill-health.

19. On reflection, I wish I had asked many more searching questions by all of the experiences that we had around that Hepatitis Non-A Non-B episode.

20. In 1982, Ronald got another new job and we decided to return to London with the three children and yet again my mother. His Haemophilia Treatment Centre changed from The Royal Infirmary in Edinburgh to St. Thomas's in London. For a short while he was treated in both Centres.

21. The treatment of Haemophilia had improved, freeze dried Factor VIII was now available. Also, prophylactic treatment was being actively promoted. Accordingly, with regular doses of Factor VIII bleeds could be dealt with efficiently and life therefore for Ronald was much more manageable. Also Factor VIII was freeze dried and could be kept in the fridge ready for self-treatment to immediately counteract the effects of a bleed.

The Storm Clouds of 1984

22. Some time in 1984, Ronald came home after picking up his Factor VIII from St. Thomas's Hospital Treatment Centre and said that he had been told somewhat casually by the Nurse that he was HIV positive. Subsequently I found out from the UK Haemophilia Centre Director Organisation Records that his HIV seroconversion occurred some time between 4th March 1983 and 20th March 1983. Also, I have noted correspondence from his former Solicitors, indicating his proliferation of Factor VIII Replacement Therapy treatments i.e. Concentrates manufactured by the NHS or NHS products. I understand that the infection with HIV occurred some time between 4th March 1983 and 20th December 1983. I cannot explain how stunned Ronald was associated with this diagnosis. We didn't really understand the full implications, but we knew enough to make us think that this was a big problem on the horizon.

23. Like many citizens, we had followed the emerging stories about HIV/AIDS on the radio and TV and indeed in the press. We appreciated there was something very disturbing about these stories relating to AIDS and indeed, what was a very ill-informed response or a somewhat sensational approach from some parts of the press.

24. I knew from working in healthcare that blood and blood products should be treated with caution. Also, I knew that outbreaks of blood borne illnesses in Dialysis Units had caused deaths of both patients and staff.

25. Although I can remember hospital attendances for blood tests being stepped up and some prophylactic treatment for PCP being given, it did feel as if we just had to deal with this intrusion into our own lives as best we could ourselves and learn to live with a chronic illness.

26. Our lives changed. Ronald's diagnosis created anxiety. Also, we were concerned about the possible accidental transmission to the children through cooking utensils, towels etc. Also, we were concerned about accidental or deliberate disclosure of Ronald's HIV diagnosis with the consequences and effect that it would have created problems for the family, Ronald and myself. The frequent measurement of Ronald's T-Cell counts and Ronald's weight loss caused concern.

27. A testimony to Ronald's endurance or efforts to maintain normality was that he continued to work and we both managed to keep our community and political activities ongoing. It was a critical time and we endeavoured to maintain as much normality as we could achieve both for the benefit of our family and ourselves.

The Beginning of The End

28. In the Summer of 1992, Ronald started to seem a lot more fragile. He had a biopsy on his tongue and a chunk was removed because of an abnormal type lesion. This was extremely painful in that there are a lot of vessels in the tongue and the wound was extremely slow to heal. During that time, he lost a lot of weight as he found it difficult to eat.

29. In the following Summer of 1992, Ronald had a fit whilst on holiday in Italy and it felt at that time as if something very seriously was going wrong. A fit is a very alarming event for children to see and indeed, it created worry within the family. On our return to the UK, the cause of the fit event was investigated and the conclusion from some of the scans was the effect that Ronald's brain showed some serious changes or degeneration. We were told after the scan results that his brain was not that of a man of his age. Accordingly, he had to stop driving immediately but due to perseverance, he managed to keep working and indeed commuting each day.

30. His CD4 counts or T-Cells were less than 200. He was at risk of an AIDS defining illness.

31. Yet Ronald managed to continue to work until Christmas 1992.

32. I noticed in November 1992 that Ronald's ability to do rapid calculations was diminishing. This was extraordinary who had a natural flair for Maths and had completed a Maths degree. Also, his keyboard skills were diminishing.

33. At this point I started to go to Hospital appointments with him as the seriousness of the deteriorating situation was now becoming apparent.

34. It was around summer 1991 that Ronald was prescribed AZT and had been taking AZT for a long time before this. He demeanour, his capacity to be active in terms of his intellectual ability was diminishing. He was on a downward trajectory and I was in some denial. I believe that I hoped that he had longer than he did have. Many days I recall that when I got into the car to drive to work I would cry. I didn't want to be seen crying in front of the children or my father-in-law who was residing at that time in the basement flat.

35. After Christmas 1992 I persuaded Ronald that he could just stay at home. It was very clear to me that his ability to find words had massively deteriorated and it was also confirmed that he had progressive multi-focal leukoencephalopathy. This is a demyelinating disease of the white matter of the brain and causes mental deterioration, ataxia, speech disturbance, paralysis, coma and eventually results in death.

36. Eventually, Ronald succumbed and tragically died from the effects of HIV infection, 10 days after his 50 birthday on GRO-C 1993.

37. His last weeks were horrible and indeed left a lasting consequence for all of us. Our daughter returned from University at Christmas and remained at home and

did not return to University until September 1993. Our eldest son was in Lower 6th Grade and our youngest son was at Primary School. My father-in-law lost his second son, this time to the consequences not of Haemophilia but of the treatment for Haemophilia. He was absolutely uncomprehending about what happened.

38. My mother-in-law had died in 1992.

39. I have very little memory of the weeks after Ronald's death. Also, I was very conscious that I should return to work quite shortly after Ronald's death and did so within a couple of weeks as I didn't want the children thinking that it was all right to opt out of life. Our family became a very sad family and any minor domestic problem was somewhat overwhelming.

Support

40. Whilst the children were in full-time education we had some limited support from the McFarland Trust. Also, I received a small amount of money for the first three years. Education and well-paid work are what have ensured that our children have progressed in life. We did have a lot of personal support from friends. Life was busy in that work; the children and my father-in-law occupied a lot of my waking hours.

41. Also, it was difficult for my father-in-law in that we hadn't disclosed to them what was wrong in the immediate period preceding death and the only persons who knew the true situation were both the doctors and myself. Also, we tried to maintain a semblance of normality and would invite people for dinner, but Ronald then would get tired and would have gone to bed or would go upstairs during the course of dinner never to return.

42. We were somewhat fortunate financially as Ronald had an Occupational Pension and indeed I had a reasonable income from my work and our mortgage had been paid off.

43. Yet, Katie, our daughter, who was attending Sussex University and studying Psychology as I indicated above stayed at home and returned later. She subsequently did complete a degree in History.

44. My son, Nicol, recalls waking up his father to encourage him to watch TV programmes he would be interested in.

45. I believe that the loss of my husband when my children were quite young, aged 12 years, 17 years and 19 years approximately had a long-term detrimental consequence. Also, my children depend upon me to a large extent and maintain a very close contact with myself.

46. The psychosocial impact of Ronald's death from these illnesses is arguably the greatest problem for all of us. My lack of candour with the children about Ronald's diagnosis in the weeks before his death caused a difficulty between my daughter and myself. She had viewed it as a breach of trust because I had not disclosed detail when she specifically asked me if he had HIV. Also, I believe that my sons lost their Dad at a critical time when his direction would have been of considerable assistance to them. How do you measure the loss of companionship, care and support that parental attention and love can deliver?

47. My husband Ronald was always clear that he did not want our children to be burdened by his HIV diagnosis. He wished them to live the best possible childhood. However, the loss of your clever and attentive father when you're 19, 17 and 12 is less than proper preparation for life. The shape of our family life changed. My 80-year-old father-in-law was devastated and, I believe he never fully recovered. The loss of his wife and then Ronald in 1993 was far too much grief for him to tolerate.

48. It is 26 years since Ronald died and we have all survived. I feel the loss of my partner quite acutely at times. Part of the loss for me is not being able to share the children's success and worries. Never being able to share this with someone who is equally invested in their lives and those of the grandchildren. This is a loss which cannot quantified.

49. The anxiety and sadness of the period leading up to Ronald's death and from life and community, will remain with me to my dying days.

50. I have to force myself to think about all the times we were really happy together and there were some times even in the last few years when we did have an enjoyable time and we momentarily forgot how bleak Ronald's prospects were and I wished I could have frozen our lives at that particular moment forever. Finally, I decided after Ronald's death that my priority was to provide the best life that I could for my children and I threw myself into that objective. Also, I tried to find fulfilment through work and to be grateful for the time that we had together rather than the loss that I had sustained.

51. 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 Ronald, 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

I wish, that the Inquiry will clarify the following issues: -

1. From Ronald's U.K. Haemophilia Centre Director Treatment Details so provided, it would appear that he only received National Health Service Factor VIII Concentrate prior to his HIV diagnosis. It would appear that the bulk of the products received were manufactured either by BPL or PFC. Admittedly, one product seems to have been a product by the name of Cryopolin.

2. Were St. Thomas's assessing patients for signs of AIDS prior to Ronald being diagnosed with HIV?
3. Was there consent to HIV testing?
4. Were stored serum samples created for retrospective analysis in terms of HIV testing prior to Ronald's diagnosis?
5. What product or Factor Concentrate caused Ronald's HIV infection?
6. When did Ronald first exhibit an abnormal liver function test result? Was it after the jaundice episode in 1997 and why if so, was he not informed that such a viral infection could cause liver cirrhosis?
7. I refer to Exhibit WITN1020002 which is a handwritten note together with extracts of Ronald's medical notes which suggest in 1976 ongoing investigations relating to Hepatitis, where I would like to know the significance of this note.
8. Why has there been no appropriate response either in terms of provision of assistance in relation to the consequences of viral infections i.e. HIV and Hepatitis C or indeed, in terms of provision of appropriate financial recompense?
9. Why has it taken so long to achieve this particular Inquiry?

I have never been in a position to move on from Ronald's loss. I ought to have had him with me in my retirement years so that we could enjoy each other's company and comfort. I am now alone, and I believe the loss of my life partner ought not to have occurred.

Statement of Truth

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

Signed **GRO-C**

Barbara Scott

Dated 04.05.2019

NOT RELEVANT