Witness Name: Elizabeth Jane MacRae
Statement No: WITN1361001
Exhibit: 0
Dated: 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF ELIZABETH JANE MACRAE

I, Elizabeth Jane MacRae will say as follows:-

Section 1. Introduction

1. My name is Elizabeth Jane MacRae. My date of birth is GRO-C 1979 and I live at GRO-C Cambridgeshire GRO-C I am separated from my husband GRO-C We do not have any children. I am employed full time at the University of Cambridge in the Department of Zoology as a Principal Assistant which means that I act as a deputy department administrator, and am in charge of technical research and teaching staff and facilities.

2. I make this statement in relation to my late father, Peter MacRae, (my father) who was born on the GRO-C 1948. My mother is Shirley Amy MacRae and my parents married on the 28th July 1973. I have a younger sister Kirsty. My father sadly passed away on the 7th November 1991 at the age of 43, as a result of Acquired Immunodeficiency Syndrome (AIDS). He contracted Human Immunodeficiency Virus (HIV) as well as Hepatitis C (HCV) as a result of being treated with contaminated blood products.

3. I understand my mother and sister have also made statements to the Inquiry.

4. This witness statement has been prepared without the benefit of access to my father's full medical records.

Section 2. How affected

5. My father had severe Haemophilia A. I understand he was diagnosed in early childhood and his older brother also had Haemophilia.

6. According to a statement made by my father (as part of a psychiatric referral) in 1979, he was first treated with Cryoprecipitate (Cryo) when he was 16 years old, there previously having been no treatment available for the bleeding associated with haemophilia. Later he was treated with Factor VIII concentrate at the Royal Liverpool Infirmary (RLI). I believe he started being treated with Factor VIII from the time when it first became available, possibly about 1980 (according to his partial notes), well after my parents were married, until he died.

7. I understand my father preferred Cryo as my mother said he reacted to Factor VIII but he had to attend hospital to be treated with Cryo whereas he was taught to inject himself with Factor VIII at home.

8. My father was initially treated at the Ormskirk General Hospital and when he was 18 years old he was transferred to the RLI now the Royal Liverpool University Hospital. He also had annual check-ups in Manchester.

9. He was treated by Dr Frank Boulton, AJ Sheridan, Dr B A McVerry, PM Green, Julia Phillips, Dr Galloway, M Williams, BJ Hunt, J Davies, P Currie, C S Bowles, V Godfrey, Dr J Nilkkhah, P M Green, Professor DJ Weatherall, Dr T Black, Dr Charles Hay, S M Donohue, Dr M J Mackie, Professor A J Bellingham and Dr G

Summerfield (the names are drawn from my mother's memory and from my father's medical records).

10. I do not believe that prior to receiving blood products, any information was provided to my father's parents regarding the potential risk of him being exposed to infection from blood products. Certainly I have no evidence to say that advice and information was given to him or at least his parents.

11. As a result of receiving contaminated blood products my father contracted HIV and HCV.

12. Looking at my father's medical records it seems that he might have been diagnosed with HCV earlier but perhaps it was missed by the medical staff. There is a note in my father's records dated 26 June 1980 saying that he attended RLI on 23 June 1980 and it was noted that he was jaundiced, and that blood was taken for a test, but that the notes from that visit appear to be lost. The doctor later appears to have updated the notes stating that the test results are Hep B S Antigen negative.

13. There are also notes dated from later on 26 June 1980 when Dr. McVerry refers to this appearing to be non-A non-B hepatitis.

14. A short time after my father died, it was determined that it was likely he had also contracted HCV. I believe the specific test for HCV only became available a few months before he died and as he was already dying of AIDS he was not specifically tested. After my father died, my mother applied to the Skipton Fund for financial assistance and she received a payment based on medical evidence submitted, so I can only assume that it was obvious that he had HCV too. As far as I am aware, my father was never told that he had HCV specifically, though he was aware that he had had bouts of "hepatitis".

15. The first entry in my father's partial medical records that refers to a positive test for HIV is on 27 November 1985 in a letter sent to his GP, Dr P Nayak, it starts "As you know...." So obviously the diagnosis was already on file. It is also noted that he attended RLI complaining with flu-like symptoms, following the administration of Factor VIII a few days earlier. He had reported a similar reaction before. Dr Donohue appears to have given him a full Haemophilia examination including taking his temperature, after which my father was reassured by Dr Donohue.

16. The next entry is 11 March 1986 stating "review clinic see letter" with a heavy note in different coloured pen stating "HTVL 3 positive" (HIV).

17. I do not know when exactly the diagnosis was given to my father, but the implication from his records is that he was not given it straight away after the test results. From the records it appears he was not told of the infection until 19 March 1986. This is referred to in the notes as "patient phoned, situation explained", and there is also a letter from the consultant to my father's GP saying "As you know he is HVLT3 positive" and it talks about my father knowing about it.

18. My mother remembers that he received a telephone call in the Spring of 1986 when he became upset. However, he did not tell my mother the details for a few months after that, possibly mid/late 1986. She remembers him being very upset and worried, as well as being scared of what might happen to him and his family.

19. From my father's medical records the letter in March 1986 from the consultant refers to my father being infected, but general information about HIV and safe sex is not mentioned until 3 November 1986. It seems at that point my father did not want my mother to be tested so she was presumably not told until then that she was at risk.

20. There appears to be gaps in my father's medical records between March and November 1986 but there are some notes.

21. I do not know if my father was given any information about the infection and its management when he was told of the diagnosis. Apparently all he said to my mother at the time was that he had been told he had HIV.

22. I do not consider that a telephone call was a suitable manner to communicate the diagnosis of HIV to my father, if that was the case. It also seems from his notes that he was not given adequate information for another 6 or 7 months, which I do not consider appropriate. The notes also suggest that the result of the test was known at least three months before he was told, which again I consider to be inappropriate.

Section 3. Other Infections

23. I am not aware that my father had any other infections as a result of being treated with contaminated blood products.

Section 4. Consent

24. I am not aware that my father was treated or tested without his knowledge or consent; however, I do not believe that he knew he was being tested for HIV.

25. However, I understand my father was requested to attend the Churchill Hospital Haemophilia Centre in Oxford for annual check-ups. I am not aware of the purpose of these check-ups; although it appears that they were collecting some sort of information.

26. I was not aware that any research had been undertaken on my father until I received his medical records. The records contain a letter showing research was undertaken on my father's liver in 1991. I am not sure as to whether he was aware of the research. Additionally, a letter dated 8 January 1986 from a

Registrar in Haematology to the department of Oral Surgery asks them to see my father, a HTLV III positive haemophiliac, to remove some teeth. At the end of the letter, the Registrar mentions informing them later about the results of the HTLV III studies that were requested on three patients.

27. Also contained in my father's records was a statement (the statement) he had written for a psychiatrist which said it was for the purpose of "this study" though I'm not sure what the study was about but clearly he knew about it.

Section 5. Impact

28. I know my father was very nervous of me and my younger sister being near his needles when he was injecting himself with Factor VIII. Also I recall one occasion when I was about 8 or 9 years old, in about 1987/88. This was after he already knew he had HIV. My sister and I were playing in his bedroom where there was a sharps bin. I took the lid off the bin which I saw contained needles and he screamed at me. I remember this occasion very vividly as he never screamed at me and I was very scared.

29. As to the physical symptoms of the illness, my father lost a lot of weight in 1987/88 and from about 1989 I remember he never left the house very much. His mobility was also affected as the time passed and his health deteriorated.

30. He became frustrated with the hospitals. He said he preferred to wait to go to the hospital at night to seek treatment, as he said that the staff were readily available to inject him at that time, whereas during the day they were too busy to help.

31. My father also suffered from an addiction to prescription painkillers, which gradually became worse. From the statement my father wrote for a psychiatrist he said the addiction had developed from childhood. I understand he tried to cut

down after he married but once he received the HIV diagnosis he stopped worrying about try to cut down.

32. In about 1990 he had to collect me from high school as I was ill, and I recall he was in substantial pain, I felt guilty that he had to collect me. From 1991 he never really left his bed. I understand he was very depressed.

33. In August 1991 he was admitted to hospital. He had muscle wastage, thrush in his mouth and sores on his body. I believe that this to have been when HIV developed into AIDS as his consultant said to my mother that he had AIDS, that there was no hope and that she should get his will in order.

34. He died on the 7th November 1991 at the age of 43. I was 12 years old when my father died.

35. I understand there was no specific treatment for HIV at the time so he just received palliative care and painkillers as well as Factor VIII. I believe that the antiviral drugs became available some years after my father passed away. Therefore, he could not have been offered any treatment at the time.

36. His medical records suggest he had liver damage but that appears to have been pushed to one side, as the hospital knew he was going to die from AIDS and I do not know if he had any treatment for HCV. Though his cause of death on at least one form appears to have been recorded as "AIDS and liver disease".

37. When my father was in hospital and towards the end of his life he did not want to see anyone. I was 12 at the time and my sister was 9. I only visited him in hospital once a week, on Sundays. A few weeks before he died, we also took our dog into hospital to visit him. I knew that this would not normally be allowed, and when we were there my father did not recognise my sister or I. Consequently I was very scared, and refused to go and see him in the hospital

for the remaining weeks of his life, something which I have regretted and felt guilty for ever since.

38. Due to my father's illness we had been appointed a social worker and about six weeks before he died she sat me and my sister down and explained to us that our father was going to die. It was to help my mother and to make us understand what was happening, but we did not find it very helpful at the time. There was only this one visit that I recall.

39. In the early 1970s my father had his top teeth removed and he wore dentures. In his medical records I have found notes between his GP and hospital pointing out that extra care had to be taken during dental procedures due to his HIV; however, I do not think that it impacted on anything treatment-wise. After that I do not believe he saw a dentist or that he had any dental treatment or procedures.

40. My father's illness had a massive impact on our private and social life. He did not have any social life from about 1985/6, I do not know if it was self-inflicted. He shut himself in the bedroom and did not want to go out. As a result of this we did not do a lot of family things together. When I was a child he could not go on family holidays, as he was too unwell, so I only remember going on holidays with my mother, my nanna and grandad, my father would stay at home.

41. My nanna and grandad (my mother's parents) lived across the road from us. We would always go to them for Sunday lunch, but my father would never come with us, as he was in too much pain to get downstairs and walk across the road. We would bring him his dinner back when we came home.

42. My father was very isolated; my mother recalls that she saw him crying but he did not speak much about his illness perhaps he did not feel able to even to her. I also recall overhearing my mother on the phone to my Auntie when my father was in hospital for the last time. She was crying as she told my Auntie that my

father had cried on a nurse that day and said he “didn’t want to die” and that he was scared.

43. I recall only really going out shopping with my father once before Christmas and once for my mother’s birthday each year as it was too painful for him, his joints were not good and he could not walk very far.

44. We kept my father’s illness to ourselves and the only people who knew were our immediate family members.

45. I was also tested for HIV. I recall this happening in the December after my father died - 1991. GRO-C GRO-C I had done a lot of reading about HIV in the University Library (in secret) before my father died, being a bright child, so at that point I was left feeling like I knew a lot more about it than the nurses. Before I went to have my test, I already knew the implications of GRO-C having HIV; it was extremely stressful. I was also (and still am) terrified of having blood taken, in part due to how often my father bled, and I fainted during the process GRO-C

46. My father’s illnesses, both haemophilia and HIV affected me GRO-C greatly. GRO-C

GRO-C

GRO-C This single experience shaped my choices for most of my adult life, and is something that I am very angry about.

47. After my father passed away, I found it very difficult to deal with. From the age of 12 until around 18 I ate as little as I could get away with, which caused me to be very thin, I had control issues and I self-harmed, cutting my arms. I did not receive any treatment from doctors as I never told anyone. My mother still does not know about any of this. This was my way of dealing with the pain and the emotions. After I started university I learned to ignore it, but the Inquiry has brought much of it back.

48. Due to the fact that I decided not to have children, a number of relationships have been impacted, GRO-C GRO-C However, as a result of this Inquiry, not having children has become an issue for me. Through Facebook groups I have met people in a similar situation as myself, carriers who did have children, and I realise that I might want to have children despite my age, which is now against me. GRO-C

GRO-C

49. Whilst I was at the University of Newcastle, when I was 19, GRO-C GRO-C becoming pregnant as a result. GRO-C GRO-C I then had to deal with choosing to terminate the pregnancy as I could not cope with the idea of having a boy with haemophilia as I was convinced it would be a boy and that if I had him I would be responsible for his suffering. To make matters worse, I was forced into having the contraceptive injection as I came around from the general anaesthetic, whilst still groggy, and this led to me bleeding heavily for 9 months and becoming very anaemic and unwell. I suspect this to have been due to my carrier status. My local doctor dismissed my concerns, and it was only when my mother took me to her doctor that I was listened to and given some medication to stop the bleeding. My mother still doesn't know that this was related to the above events, only the

contraceptive injection. These events traumatised me further as regards being a carrier and my prospects for having children.

50. I am aware that my mother wanted to have more children, but she could not, as a direct result of my father's illness. She is also very keen on grandchildren, GRO-C GRO-C Understandably, she is very sad about that.

51. Growing up was difficult but nanna and granddad lived across the road and we were well looked after so there was less of an impact.

52. Losing a parent at such a young age affected my outlook on life. It made me realise that nothing is permanent, which in turn affected my relationships and life choices. I have moved around regularly for work, as a research scientist, and have had a lot of relationships, but I could never really see anything as secure and permanent.

53. Fortunately, I have not experienced any stigma, as a direct result of my father's illness. Nobody knew what exactly was wrong with my father until later in my life, and we never talked about it and no one guessed what he had so we did not suffer.

54. I recall the teachers at school questioning me about what happened to my father when I returned to school after my father died, but I could not tell them as I was scared to, I let them believe he had cancer. Also there was an occasion when my religious education teacher said all those with HIV were homosexuals being punished by God, which really upset me and my friends could not understand why I was so distressed. There was also another instance at University in Newcastle, when my housemate had a rant about HIV. Other than that, I have not experienced any stigma, which is likely because nobody knew.

55. My father's death also had a huge impact on my mother. She never had another partner after he passed away. GRO-C

GRO-C

GRO-C

56. Since the Inquiry started we have disclosed my father's illness to the wider members of our family. I have also become involved with Facebook groups relating to the contaminated blood scandal and I now feel able to ask questions. Everyone is very supportive and interested.

57. My grandparents who lived over the road have now died. My father's mother was alive when my father died, she lost her husband before I was born and unfortunately buried both her sons who both had Haemophilia. She died when I was at university.

58. Financially it was very difficult for us. My father was rarely at school due to bleeds into his joints as a result of his haemophilia condition. He was very disabled and I did not know him to work. However, I am aware that my father tried a number of different jobs, including being an electrical engineer, a taxi driver, a junior medical technician at the LRI, and working in insurance. However he never had a permanent job that I was aware of as a child.

59. He tried to work until around 1981/82. This is when his health went downhill. I know that it bothered him that he did not have a job as it is referred to in the statement he wrote for the purpose of the psychiatric study. He said he felt guilty about the fact that the entire financial burden was placed on my mother. We always struggled for money, with only one parent working.

60. My father's illness sparked my interest in medical research and I threw myself into school, especially the sciences. I was reading about haemophilia, HIV, and

the immune system from a very young age, due to the desire to understand what was happening to my father and as I wanted to find a cure.

61. I applied to study medical microbiology at the University of Newcastle, and achieved my BSc. I then went on do my PhD at the University of Sheffield on cancer and immunology. In 2005 I received a job offer from the University of Oxford; however, I had to decline it, as it meant working on HIV research, and I knew that it would be too painful for me to deal with and I would not be able to do it without being biased. So I accepted a job at Harvard University instead, working on other infectious diseases such as TB. I enjoyed performing the research, but I did not like living in the US, so I moved to Cambridge University and joined a laboratory researching stem cells, and later I moved to a laboratory studying auto-immune diseases, also at Cambridge. Finally, I have now chosen to move away from active research, into a position where I manage the research and teaching aspects of an entire Department at the University.

62. Money was always a struggle growing up so I was not used to having any, and as I have experienced death at such a crucial age, I tend to take the view that "I could die tomorrow", so when I have money now I spend it!

Section 6. Treatment/Care/Support

63. I am not aware, as to whether my father was offered any counselling. If he did, I am certain that he did not take it up, based on my mother's recollection.

64. None of us, my mother, sister or myself, were offered any counselling other than that one occasion when my father was dying and the hospital arranged for social services talk to me and my sister about what was happening, in that my father was never coming home as he was going to die. I found it less than helpful at the time as I did not believe my father was going to die and it made me hate the ladies who were trying to help us.

65. In the summer of 2017 I applied for some counselling via the University of Cambridge Counselling Service, as I realised that the Inquiry (and subsequent break-up of my marriage) was taking a mental toll on me. It probably would have helped to work through the trauma earlier as I might have realised that I wanted children before I was 39/40.

Section 7. Financial Assistance

66. My father was party to the 1991 litigation and he received a one off payment from it, but I am not sure how much it was. He did not tell my mother that he was party to the litigation; she found out about it when he received the money which was just before he died.

67. I benefitted from the money received as some of it helped to fund my attendance at university. My mother also paid some debts.

68. My father did not receive any financial assistance from the MacFarlane Trust, nor the Skipton Fund while he was alive.

69. In 2011 I joined various Facebook groups, and as a result I found out about the second stage payment from the Skipton Fund. I told my mother about it and that she might be eligible. We paid for his medical records and applied for the payment. My mother received a pay-out from the Skipton Fund. I am not sure how much it was; I believe it was around £12,000.

70. My mother went on the Skipton Fund website and completed the forms and she also contacted a consultant at the RLI, a lady called Vanessa Martlew. She helped to fill in the relevant forms and provided information about my father's HCV and sent it directly to the Fund. Overall, I believe that the process was relatively straightforward with Vanessa's assistance.

71. One particular point which bothers me is the fact that we did not find out about our entitlement to financial assistance through official channels. Had I not been part of the Facebook groups, we would not have known anything about it being available to us. My mother was certainly not contacted in any official way, and she still lives at the address my father was registered at when he died.

72. I am not aware of any pre-conditions being put in place, other than the fact that my father had to sign a waiver to receive the pay-out from the 1991 litigation otherwise no claimant would have received the ex-gratia payment offered, meaning that he felt pressured to sign otherwise he would be depriving others of the payout too.

73. Now that the Inquiry has started, one of my main observations about the trusts and funds, is that there are a lot of people who were never made aware of their eligibility to financial assistance. I believe that the Skipton Fund and MacFarlane Trust were not proactive in keeping people informed, there was no mailing list. The availability of funding was by word of mouth and if you were not pro-active you would have missed out. Communication was clearly an issue. Additionally, there is an entire generation of children (the "father-less generation") who lost their fathers, and in some case mothers too (from passing on the HIV), and as far as I am aware there is no specific financial assistance that has been made available to that category of person. The same is true of parents of children who died.

74. I also find it unfair that there are discrepancies in the funding, such as people in Scotland and Wales are entitled to different amounts of money to those in England, as well as differences made between married and unmarried people. I feel there are many inconsistencies.

75. My personal perspective on the financial help in our family situation is that I believe that financial help would have been of greater assistance when my father was alive and we were growing than receiving it after he died.

76. I have personally received no financial assistance.

Section 8. Other Issues

77. My mother paid for a copy of my father's medical records but whilst we received some records, it appears a lot have been redacted or perhaps lost.

Anonymity, disclosure and redaction

78. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

79. I do wish to be called 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** ....
Elizabeth Jane MacRae

Dated 19th February 2020