Witness Name: Shirley Amy MacRae
Statement no: WITN1363001
Exhibit: 0
Dated: 10 June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF SHIRLEY AMY MACRAE

I, Shirley Amy MacRae will say as follows:-

Section 1 Introduction

1. My name is Shirley Amy MacRae. My date of birth is GRO-C 1952 and I live at GRO-C, Liverpool GRO-C I am a widow and a retired infant school teacher. I retired almost 6 years ago after teaching at the same school for 40 years. I am now 66 years old.

2. This statement is made in relation to my late husband, Peter MacRae (Peter) who was born on the GRO-C 1948. We married on the 28th July 1973 and we had two daughters, Elizabeth 39 and Kirsty 36. Peter sadly passed away on the 7th November 1991, aged 43 as a result of AIDS. He contracted HIV as well as Hepatitis C (HCV) from contaminated blood products. I was 39 when my husband died.

3. This Witness Statement has been prepared without the benefit of access to my Peter's full medical records.

Section 2 How affected

4. Peter had severe Haemophilia A. I believe he was diagnosed at or soon after birth as his older brother was also a haemophiliac. I believe Peter was infected in the early/mid 1980s from the use of Factor VIII.

5. When treatment became available for bleeds Peter was given Cryoprecipitate (Cryo) and had to go to hospital to receive it. (Royal Liverpool Infirmary (RLI)). I believe he started being treated with Factor VIII from when it first became available until he died.

6. He was taught how to administer Factor VIII and was able to bring boxes and equipment home with him. This meant he did not have to go to hospital so often for treatment unless the bleeds were severe. Unfortunately he did not react well to the treatment as he always got "the shakes" - a bad reaction which left him needing antihistamine to counteract the effects of the treatment. He much preferred going to the hospital and having Cryo as he did not have any adverse effects from this. The only drawback was he could not treat himself at home with Cryo. He did not start using Factor VIII until well after we were married (possibly 1980 ish).

7. Peter was treated at the RLI by a number of different doctors - Dr Frank Boulton, A J Sheridan, Dr B A McVerry, P M Green, Julia Phillips, Dr Galloway, J Davies, Dr J Nikkhah, Professor D J Weatherall, S M Donohue, Dr M J Mackie, Professor A J Bellingham and Dr G Summerfield. (Some of these doctors I remember Peter talking about as he knew them quite well, others are from his medical records).

8. I believe that prior to receiving blood products, very little or no information was provided to Peter's parents or to himself regarding the potential risk of him being

exposed to infection from blood products. Further, as far as I know, no information was provided to me or Peter at any later stage of his treatment, about any risk of infection from blood products.

9. As a result of receiving contaminated blood products Peter first contracted hepatitis around ~~1980/81~~ 1979 and then HIV in the mid 80s.

10. The first entry in Peter's medical records that refers to a positive test for HIV is on 27th November 1985 in a letter sent to our GP Dr P Nayak - but it starts "As you know" so obviously this knowledge was already on file. It would seem that Peter did not know until early March 1986 when another letter was sent to our GP.

11. I only found out because I wanted another baby and Peter's response was that he did not think his doctors would be very happy. I asked him what it had to do with them and it was then that he told me that he had been diagnosed with HIV some months earlier. He was very upset. I think this was some time in mid/late 1986.

12. He had not wanted to tell me of the diagnosis as he was so upset and worried about what it would mean for me and our daughters. He was very worried that I would leave him and also other people finding out. He was very scared of what might happen to him and us.

13. I do not know if Peter was given any information about HIV and its management or consequences at the time he was told. All he told me at the time was that he was HIV positive. All I knew was the information gained from the media. No doctor asked to speak to me and I was not sent any information about anything.

14. Peter had been diagnosed with hepatitis sometime around 81/early 82. He put on a lot of weight and was very yellow in colour. At the time I did not realise that

there were different types of hepatitis and once he appeared better thought he had recovered. However I now know that that was not the case.

15. After Peter died (20 years later) I applied to the Skipton Fund for financial assistance and it was from his hospital records that Dr Vanessa Martlew, who very kindly looked into this, told me that Peter had had HCV and it had contributed to his death.

Section 3 Other Infections

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

Section 4 Consent

17. I am not aware that Peter was treated or tested without his knowledge or consent.

18. However, in Peter's records there is a letter from the Haemophilia Centre, Oxford, Churchill Hospital that asks for Annual Returns to be sent "ASAP re Peter MacRae". This is dated 21st July 1992 and asks for AIDS/3 form as he "...was listed on Form A(8) as having diedon 07/11/91 from AIDS and liver disease".

19. I was not aware that any research had been undertaken on Peter until I found this letter in his records. It appears that some sort of data collecting was being collated for research purposes perhaps.

Section 5 Impact

20. Peter's health problems resulting from HIV and HCV were numerous. He suffered severe depression, was in constant pain, was very often bedridden for days at a time, suffered severe weight loss, bowel problems and general weakness and mobility problems. It was from the early/mid 1980s that Peter also became addicted to painkillers – mainly prescribed dihydracodeine.

21. Peter was in constant pain due to his haemophilia and osteoarthritis and as a result obtained prescriptions for painkilling drugs from other sources as well as the LRI. His depression meant that he would not go out even if he was well enough. He was terrified of people finding out he had HIV and became very easily upset. He lost interest in everything and was often bad tempered. He found it difficult to get up in the mornings and often did not fall asleep until 1 a.m./2 a.m. He felt shut in at home but was not well enough to venture out. He was bedridden for most of the final six months at home.

22. In the last months of his life - April 91 - August 91, when he was at home he deteriorated rapidly. He had lost such a lot of weight that his dentures wouldn't fit and due to reaction to Factor VIII had bitten a large chunk out of his tongue. This made it difficult for him to eat and eventually almost stopped eating altogether. He was mainly confined to bed and the only reason he got up was to go into the hospital to collect his medication. Eventually in July he stopped being able to do this so I went for him.

23. In the late 1970s Peter's mobility worsened due to bleeds and osteoarthritis in his joints, knees, ankles, shoulders and elbows were all affected - sometimes one after the other. It was like a vicious circle. All of this affected him to a much greater degree and he had to give up work.

24. He became frustrated with the hospital and preferred to go into the ward at night to seek treatment, as he said the staff were more readily available to help when they were not so busy. During the day he had to wait longer if he needed help.

25. Peter's addiction to painkillers (prescription) gradually became worse to the extent that he was obtaining them from a number of difference sources, including his GP, my mother-in-law's GP and a friend who was also a GP, as well as the hospital. I contacted the hospital about this and I was told that he should not be taking that number of painkillers but I thought it would be too difficult to take charge of his medication as it would lead to problems with our relationship. I also worked full time so was not home during the day.

26. In April 1991 Peter became severely ill with thrush. (I had no idea this was a symptom of AIDS at the time) and, as above, had great difficult eating. His mobility worsened and only went out to attend hospital. During the last few weeks he was at home; My mother came each lunch time to try to coax him to eat something. Peter would not let me ring the doctor or try to get a district nurse to visit. He could not get up to use the toilet but somehow we managed. I was going 2 or 3 times a week to the hospital to pick up his medication. He had started hallucinating and was very upset at times. He seemed to be in a great deal of pain. One morning in early August (11th or 12th I think) I went as usual to the ward to pick up his medication. I spoke to one of the nurses I knew and talked to her about all the problems he had. She organised an ambulance for later that day and Peter was admitted with septicaemia.

27. At that point I did not know that Peter had developed full blown AIDS. The day after I received a call from my GP Dr P Nayak asking me to see him the following morning. I was also contacted by the LRI and asked to attend an appointment with one of the doctors the following afternoon. I went first to my GP who did not tell me that Peter had AIDS but did say <u>if</u> he came out of hospital we would all have to be very careful with personal hygiene. I would have to sleep separately and obviously certain things could not happen.

28. I went straight from my GP to see the doctor at the LRI and he told me that Peter now had full blown AIDS, that there was nothing anybody could do. There was no hope of recovery and I needed to prepare myself. He said that Peter had "buried his head in the sand" by attending the hospital at night. Also that I needed to get his will sorted and to bring it in for him to sign. There was no possibility of him recovering. He also told me that in all likelihood no funeral director would deal with his body once he had died, his body would be put in a body bag and that would be it. I was told he should have sought treatment at the LRI sooner and he had not communicated with doctors in the previous weeks.

29. Peter died on the 7th November 1991 at the age of 43. The day he died I had been with him until about 6.30 p.m. when I left to go home and put the girls to bed. That day he had been extremely agitated and upset and shouted out in pain when I tried to hug him. At 9.30 p.m. I received a phone call from the LRI asking me to go back as he had further deteriorated. My parents came to look after the girls but by the time I arrived on the ward Peter had already died. He had been transferred to a normal hospital bed and all equipment etc had been removed.

30. I had obviously been very worried about finding a funeral director but luckily my auntie had a cousin who was an independent funeral director and he sorted everything - for which I was very grateful.

31. During the last few months that Peter was in hospital (August - November 1991) he did not want anyone visiting him. Quite often he was very upset and he was very reluctant for any family to see him so ill. He saw his mother once and I took my daughters each weekend. Elizabeth was 12 and Kirsty was just 9 at the time.

32. Because of Peter's illness we had been appointed a social worker for myself and my daughters, just after he was taken into hospital. About 6 weeks before Peter died she advised me that Elizabeth and Kirsty needed to be told how serious his

illness was and that in all likelihood he was going to die. I sat them down and tried to explain to them how ill their dad was and that he was not going to get better. Linda (our social worker) sat with us while we were talking. It was one of the hardest things I have ever had to do.

33. One of the worst things I had to do was telling my head teacher and local authority advisor that Peter was dying of AIDS. I had taught at the school since I left college and although all my colleagues were very kind and understanding the authority was very worried that parents would panic and therefore asked me not to let it be known what his illness was. I also had to go into both my daughters' schools to inform them of the situation in case of the affect this might have on them. Both schools were very understanding despite the stigma attached to the illness at the time.

34. As far as I know Peter did not receive any treatment for HIV. I do not believe that any was available at the time. To my knowledge he only received prescription painkillers, including dihydracodeine/DF118s as well as diazepam and medication for constipation.

35. I do not know if he had any treatment for HCV if he did the information may be in his medical notes.

36. In about 1971/72 Peter had his top teeth extracted because he was suffering from constant bleeds from his teeth. After that he did not see a dentist or have any dental treatment or procedures as far as I know.

37. Peter's illness had a massive impact on our private and social and family life. As a teenager he had lots of friends and spent a lot of time at a local youth club. He was a member of a music group and later sold his guitar to buy disco equipment. He played at weddings etc. for a number of years. He was very sociable, friendly and funny. Everyone liked him. As the years went by and depression hit he

became more and more withdrawn and isolated. He would shut the bedroom door and did not want to socialise with anyone or see anyone at home.

38. After a few years of being married we no longer went on holiday as a family. I would take Elizabeth and Kirsty away with my parents or family. We inevitably did things together without Peter.

39. Financially it was very difficult. Peter was unable to work from 1978/79. He had tried a few different jobs but he could not hold them down because of his physical problems. His first job was as a lab technician at the Royal Liverpool University Hospital. Then he tried a job as a sales representative and then a taxi driver. However, due to his poor health and constant bleeds which led to more painful osteoarthritis he was not able to continue working. We existed on my salary and his disability allowance/invalidity benefit. We had always had to buy used cars (old bangers really) but when Peter was awarded motability benefit we were able to use a new reliable vehicle. He was very uncomfortable with me being the main bread winner and having to work full time and also with the fact that he was unable to do most jobs around the house. My dad helped us a lot whenever he could.

40. I was unable to leave the girls with him when they were little as he could not safely take care of them. I would not ask my parents at the weekend because they helped so much during the week when I was at work. He could do very little and spent most of his time in bed e.g. getting up and down out of a chair repeatedly caused bleeds in his shoulders and knees.

41. I did everything in the home, including decorating and gardening as we could not afford to pay for jobs to be done. We did redeem a life insurance policy around 1979 to have a new bathroom (I did the tiling) but when we came to renew it Peter was worse and it was impossible to get cover.

42. I was very busy with full time teaching and facing the responsibility of making most of the decisions. I was kept very busy with my job and the girls, who were my saving grace as I did not have time to stop and think about things or spend my time worrying.

43. I did have a lot of support from my parents who lived opposite us. I do not know how I would have coped had it not been for their help. They cared for the girls before and after school as well as days out and holidays. My mum went over every lunchtime towards the end of Peter's time at home in order to make him some lunch.

44. Only my immediate family and good friends and colleagues knew Peter was HIV+. Even my mother-in-law did not know until after Peter died that AIDS was the cause of his death. No-one else knew and no-one asked questions because he was often very poorly and in bed so it wasn't unusual I did not talk to anyone about it except for my best friend. I tried to keep as much as I could to myself as I did not want my parents to worry more than they already were.

45. I received no communication from anyone during all this time. No-one offered me advice as to what to look out for or what to do. I just tried to carry on as normal. Looking back I am so lucky that I was not infected with HIV GRO-C

GRO-C

It was a very worrying time waiting for the results. GRO-C GRO-C I think I had my test whilst Peter was in hospital in August/September 1991.

46. As stated above I wanted another baby but that was impossible so instead we decided to move house which we did in 1987.

47. The school where I worked knew Peter for years before he contracted HIV as he often dropped me off and picked me up. They all knew he had haemophilia and were aware that his condition had deteriorated over time. When he was hospitalised and they were aware that he was very ill they were very understanding, kind and upset for us.

48. Once Peter was diagnosed with AIDS I became worried that friends would not want to continue our friendship but fortunately they were extremely supportive. I was also very concerned that my daughters' friends at school would discover the seriousness of Peter's illness and that they would lose friends and possibly have problems but thankfully again everyone proved to be very understanding. By this time Peter had lost touch with most of his own friends as he was unable to see them very often.

49. Peter's mother did not know how ill he was and did not know he had AIDS until after his death when I was able to tell her. This was because Peter did not want her to worry about him. Peter's brother died in 1971 - he was also a haemophiliac and his father died after a leg amputation in 1977. This meant that she was on her own and I think she must have speculated a lot about Peter but she never asked. It must have been dreadful for her as she only saw him once whilst he was in hospital as he did not want her to see him so poorly.

50. Whilst Peter was in hospital just before he died we were allowed to visit any time. However, I was really the only person he saw daily. I took the girls in to see him at the weekends and he even asked to see our dog at one point - which went ahead. My sister, brother and parents each saw him only once. He was too upset to see anyone else and of course very concerned about all of us.

51. The impact of Peter's death caused by his illness was devastating on everyone. He was so young to die in such a dreadful way. It was very difficult for his mum as she lived on her own and Peter was the last of her immediate family as her

sister had died 10 years previously. She was a very stoic lady, always cheerful and kind, regardless of the fact that from once her eldest son was born she had had a very difficult life. She coped with two very ill boys and when they were young had to take them by bus to Manchester if they needed treatment. In later life she had problems with her knees and skin cancer but she never complained and never showed the extent to which she had been affected, which must have been completely devastating for her. Indeed she was so upset that she did not want to attend Peter's funeral. She died in April 1999.

52. Our youngest daughter Kirsty (born in GRO-C 1982) and only 8 when Peter was first admitted to hospital) does not have many positive memories of her father as he was very often ill as she was growing up.

53. Our oldest daughter Elizabeth (born in GRO-C 1979) was very close to her father. He had been healthier when she was born and often got up to her in the night and they enjoyed each other's company. She is a scientist and has joined all the support groups on Facebook and as a result knows a lot more about what is currently happening within the Haemophilia Society and the Infected Blood Inquiry than I do. In fact she keeps me up-to-date. Peter's death had a huge impact on both of their lives.

Section 6 Treatment/Care/Support

54. The only support or counselling that I am aware that Peter received was from a specialist haemophilia nurse called Alison. I think she was allocated to Peter about a year before he died. I only met her once or twice as she visited him at home, usually when I was at work. I do not know what they talked about I only found out about her when I arrived home earlier than expected and he was reluctant to talk about her visits.

62. As regards the application to the Skipton Fund it was my daughter Elizabeth who discovered we may be eligible due to her involvement with the support groups she belonged to. It was Dr Vanessa Martlew from the LRI who helped us complete the forms and she found the evidence in Peter's medical records.

Section 8 Other Issues

63. I paid for a copy of Peter's medical records during the Skipton Fund application and whilst I received quite a large amount of Peter's records a lot had been redacted.

Anonymity, disclosure and redaction

64. 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.

65. I do wish to be called to give oral evidence to the Inquiry.

Statement of Trust

I believe that the facts stated in this Witness Statement are true.

Signed:.. **GRO-C**

Shirley Anne MacRae

Dated: 10th June 2019