Witness Name: C.A. KERR
Statement No: WITN1023001
Exhibits: 0
Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CATHERINE ANNE KERR

I, CATHERINE ANNE KERR will say as follows:-

Section 1. Introduction

1. My name is Catherine Anne Kerr of GRO-C Belfast, GRO-C. My date of birth is GRO-C 1958. I have recently retired and I used to work as a Senior Manager within the National Health Service. I now spend my retirement looking after my grandchildren. I have two older grandchildren and two younger ones, two of whom have Haemophilia. I live with my sister in our old family home which belonged to my father.

2. I make this statement in relation to my late husband, Mr Neil John Henry Kerr, who was born on GRO-C 1957 and who passed away on 14 March 2000 aged 42. I married Neil in 1976 and together we had three beautiful children.

3. Neil was infected with HIV and Hepatitis C as a result of being treated with Factor VIII Concentrate in order to manage his haemophilia.

4. This witness statement has been prepared without the benefit of access to my late husband's full medical records. If and in so far as I have been provided

with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

5. My husband suffered from severe Haemophilia A. As a result of his condition Neil had joint bleeds in his knees and ankles. In 1976, Neil was one of the first people to be given Cryoprecipitate to treat his bleeds. Eventually, he moved onto Factor VIII concentrate and I specifically remember a product named Cryobulin. As far as I am aware, Neil was treated for his Haemophilia in hospital on average at least three times a month and on occasions more frequently.

6. Neil attended the Haemophilia Adult Centre at the Royal Victoria Hospital (RVH) in Belfast under the care of Consultant Haematologist, Dr Mayne Née Butler. Neil trusted Dr Mayne and she was very old fashioned in the way she practiced medicine. Dr Mayne believed she knew what was best for her patients and you were not it a position to question or argue with her.

7. Neil and I were never informed about the potential risks associated with these products. It was our understanding that he required these products in order to survive.

8. In 1984 we went on a family holiday to Spain. I was reading a Spanish newspaper and read a story about contaminated blood being imported from America. I was concerned about my husband as I knew he had received blood products. When we returned to the UK we raised our concerns with Dr Mayne and she informed us that there was a shortage of Factor VIII in the UK. She did not tell us where the imported blood came from instead our fears were dismissed. We were accused of scaremongering and Neil was asked to stop spreading panic amongst the Northern Ireland Haemophilia Society. I would have expected the doctor to either attempt to admit the truth or at the very least find out more information for us and not merely dismiss our

concerns. The irony of course is that Neil was one of the fourteen Haemophiliacs who had been infected with HIV in Northern Ireland in 1986.

9. In 1986 Neil and I were called to attend an open meeting at RVH where there were about 140 people present. At that meeting we were told that there was a risk that patients who had received blood products may have been infected with HIV due to contamination. Neil went for a blood test and shortly after received a letter from RVH which told him that he had been infected with HIV. The hospital also confirmed that he had been tested for HIV in 1982 and he was in fact positive. Neil had not been told and for four years he was infected without being informed or advised to take precautions.

10. It was so absolutely outrageous for the hospital to convey such tragic news to my husband by letter. They should not have told him in that way and no other information was provided. The letter was just so very matter of fact. We were terrified because our daughter was born in 1981.

11. We made an appointment and went straight back to the RVH. We were frightened because we had three children and there was a massive stigma attached to the virus which could have impacted us all. Dr Mayne was at the consultation with us and we mentioned that we had brought the risk to the hospital's attention in 1984 after our holiday in Spain. We told her that our concerns had been completely ignored and yet in the end we were completely right. Dr Mayne tried to explain that the hospital didn't realise the implications back then and apologised. I find that hard to believe because there is plenty of evidence to suggest that they knew and they deliberately withheld the information.

12. Even at the face to face consultation Dr Mayne did not provide any information about how to manage the HIV infection. I felt that I needed to know what was going on so over time I joined various organisations through the internet. I looked up people in the USA and the UK to source the information myself. I found out what treatments were available and information on how to be careful about transmission. I knew from my own

research that there was a very minimal risk of the infection being passed on via bodily fluids such as saliva or by mere contact.

13. In 1982 after the birth of our third child, to prevent passing on the Haemophilia gene, I underwent a sterilisation. It wasn't until 1986 that we found out that Neil had HIV. Through the research that I had conducted, I knew that I was at risk of HIV through sexual intercourse and had to use protection again. No information was provided to either one of us in relation to the risk of sexual transmission by the doctors.

14. We should have been told about earlier and I believe the hospital had their suspicions so far back as the late 1970s because Neil was tested for Hepatitis B in 1976. That was so early and I cannot understand why they would do that if they did not have concerns about the risk of contamination. I do not know if Dr Mayne herself knew.

15. I am unsure when Neil was diagnosed with Hepatitis C but this could have been in the early 1990s at a routine appointment.

Section 3. Other Infections

16. I don't know if Neil had any other infections besides those aforementioned above. If there was something else, I do not think they would tell us as they kept so much from us. As I have mentioned, Dr Mayne in particular was very old fashioned in the way she practised and the information she gave us was very minimal.

Section 4. Consent

17. Without question, I believe that Neil was tested without his knowledge, without consent and without being given full or adequate information.

18. I find it suspicious because after Neil had some blood taken he received a letter from the Haemophilia Clinic Director which thanked him for taking part in

the blood tests. I cannot be sure on how many occasions he received a letter. This gave me the impression that they had tested for a specific reason and to find something in particular.

19. Prior to Neil's diagnosis, my children and I were all called to the hospital for blood tests. We did not know what we were being tested for and we did not give our consent.

Section 5. Impact of the Infection

20. Neil was very young when he passed away. He had always had health problems relating to his haemophilia and when he found out that he had HIV as well, it really hit him hard. Suddenly, we had to separate and isolate his items in the house, like his toothbrush. On top of that, if Neil ever cut himself, or noticed blood somewhere in the house, he would freak out as he was paranoid that someone else could get infected. He had to know that the children were kept at a distance from his blood until it was cleaned up and he would not be fully calm. Despite that, Neil never complained about ill health and carried on the best he could. He had a fear that he would not be able to see his children grow up or have children of their own.

21. In the beginning when Neil found out that he had HIV he was in good health. Then he felt fatigued and experienced aches and pains. Then he started having panic attacks purely based on the fact that he was HIV positive. The attacks got so bad that he needed a psychiatrist to help him and it did help. By the early 1990s, Neil became immobile and had to be taken around in a wheelchair. In 1993 he had knee replacement surgery and Neil changed from being HIV positive to having AIDS Related Complex. Towards the end of 1993 he had a scare with AIDS related Pneumonia and he nearly died. Due to Hepatitis C, around that time, his liver also developed problems, his skin became itchy and he generally felt really unwell all the time.

22. In 1996 or 1997, Neil had developed full blown AIDS. We had conversations with the hospital about resuscitation and were told that he may have only 6 months to live.

23. Neil was admitted into hospital in 2000 and had stopped responding to all treatments. The doctor's were unable to stabilise his liver, despite trying several drugs and treatments. He was always nauseous and constantly in pain. He didn't want anyone near him at that point and to die was a release for Neil.

24. Neil died in the Haematology Ward 22, RVH on the 14 March 2000 and was buried on St Patrick's Day on the 17 March 2000.

25. In or around 1993, Neil went on the AZT trial for HIV alongside a cocktail of drugs for full blown AIDS. Neil was either going to be given AZT or a placebo and he went to hospital for four months. It turned out that Neil received AZT and not the placebo. Neil trialled two of three different regimes of drugs until the hospital found a combination he was able to tolerate. From then on, his condition worsened drastically to the point where he had to retire in 1995.

26. For the Hepatitis C Neil was treated with Alpha Interferon. This was coupled with a mix of other drugs including Gamma Globulin. Neil had stomach ulcers and in January 2000 he underwent chemotherapy which was two months prior to his death. The treatments for Hepatitis C made Neil feel extremely fatigued and he spent a lot of time bed ridden. He lost a lot of weight, felt exhausted all the time, was jaundiced and his personality changed. He was never the same man he was prior to treatment.

27. My personal view is that the medication, if anything, worsened Neil's condition. He was fit and healthy prior to any medication, yet after undergoing treatment, the more he had, the worse he became. In fact, the drugs I believe acted as a catalyst and only increased the time it took to get to his death. I feel that all treatments were conducted for research purposes and nothing actually worked. Despite all the side effects of treatment, Neil was willing to try

anything if it had a chance of making him better and help him fight the disease.

28. Before Neil passed away, I didn't want his final years to be spent lying in a hospital bed. Neil enjoyed travelling and there were so many places he wanted to see so I booked us a holiday to Paris. The staff at the hospital thought I was mad at the time, but I have no regrets and I am glad I did it as we both enjoyed ourselves and created special memories that will last forever.

29. In 1982, I underwent a sterilisation to avoid becoming pregnant again and passing on the Haemophilia gene. This was not an easy decision to make but it turned out to be a waste of pain and stress given that we had to continue using protection following Neil's diagnosis of HIV and Hepatitis C.

30. What we had to go through was terrible. Since I had three teenagers, I had to stay positive for everyone and I know it wasn't healthy to bottle up my feelings. I found it hard to stay strong and thankfully, my sister and father were a great support to me, but beyond that there was no help. I was left entirely to my own devices. When Neil was unwell, I developed reactive depression and had to take antidepressants. On one occasion I almost overdosed, not because I wanted to end my life but because it became so difficult to cope. I had to seek psychiatric help and saw a psychiatrist for five months. I then had six months of Cognitive Behavioural Therapy. All in all, it took me five years after Neil's death to put my life back together and recover from the loss.

31. The stigma surrounding HIV was very marked in the 1990s and we had to become very secretive about Neil's condition. This meant that outside of the family unit the topic was not to be discussed. Even when Neil was dying, we could not tell anyone about his HIV and Neil wouldn't let friends or family visit him.

32. We have all suffered with depression and other mental health issues without resolution. Neil had missed out on seeing his family grow up. Growing up with Neil, in the condition he was, was very difficult for my children. We tried our

best to make their lives as normal as possible, but much of their childhood was spent in hospitals visiting their father particularly from 1994 to 1995. They were also told to remain quiet about their father's illness therefore they couldn't talk about their father openly. Also, seeing their father going through prophylactic treatment was difficult to bear.

33. After Neil passed away, my children found it hard to cope with the loss. They were only in their teens. There were organisations such as The Rainbow Project that provided support for my children, but there was nothing that helped. At that time there was very little help for families or the psychological trauma they had to endure. They are still affected to this day and I know that they miss their father dearly.

34. Neil was self-employed for several years prior to joining the Northern Ireland Civil Service in 1995 as a clerical officer. Prior to 1995, he owned a record shop, and I used to help him run it, however Neil became too ill to carry on and had to sell the shop. I embarked on a two year diploma course and a three year degree in order to support my family should anything happen to Neil. I graduated from Ulster University at Jordanstown with a 2.1 BA (Hons) degree in 1993. When Neil became sick, I took a part time job as a hospital secretary so I could care for him. Money became very tight and there was not enough money to cover everything.

35. Neil suffered quite a bit with HIV related infections and Hepatitis C issues coupled with skin rashes and other symptoms and he retired on ill health grounds in 1998.

36. In 1995 Neil received an ex gracia payment of £40,000 and we used this to purchase a family home for which I also took out a mortgage. Thereafter, Neil became very ill and was unable to work. I cut my hours down even more and our mortgage repayments went into arrears due to the lack of income and it kept on building. Following Neil's death, in order to manage our financial situation, I had to sell the family home to pay off the mortgage and other debts leaving me and my family homeless. It was a complete waste of the £40,000

ex gracia payment. We had to move into rented accommodation. I also sold my car which I owned due to Neil being eligible for Disability Living Allowance.

37. It took me a while to return to work and I was lucky enough to have good and understanding employers who allowed me to take six months paid leave.

38. The lack of income meant that I was unable to get my children what I would have been able to had I been able to work. The children have done well but I was unable to pay for them to go to university.

Section 6. Treatment/care/support

39. Neil may have been assigned a social worker however I do not recall him ever being counselled or supported by her.

40. No counselling or psychological support was made available to me in consequence of what happened and all the psychiatric help I sourced myself.

Section 7. Financial Assistance

41. We received MacFarlane Trust (MFT) support with an ex Gracia payment in the 1990s in the sum of £40,000 which I used to buy the family home. I also received approximately four years of widow's payments following Neil's death in 2000. The children were all 18 by 2004 and I was working full time so all widow support stopped.

42. It was Dr Mayne who had arranged for the MFT support and this was in response to a class action. In exchange for the payment, I had to sign a waiver agreeing not to pursue any further claims.

43. I did not receive a government widow's pension as I was deemed too young at 41 to be eligible. The threshold was 45 years of age. I find this ridiculous as I was married to Neil for 24 years.

44. I also received a Skipton Fund payment of approximately £70,000 in 2011 or 2012. This helped us a lot, but not as much as I would have liked. In order to receive that lump sum, the Fund required proof that my husband was diagnosed with Hepatitis C. I was informed that the hospital had destroyed Neil's medical records. I only had his death certificate and I had to contact the director of the hospital who sorted the issue for us.

Section 8. Other Issues

45. This statement has been very difficult to compile and the feelings I learned to bury deep inside are resurfacing. I find the whole process of remembering this period of our lives nearly unbearable to recall. Hopefully the Public Inquiry will provide closure for this terrible tragedy for me and my children.

46. They stole my husband's life from me and my children. After Neil died, I was angry for so long. It was unfair what they did and Neil was only 42. I wouldn't wish this to happen to anyone else.

47. Two of my grandsons, aged 19 and 4, have severe Haemophilia A. They depend on regular recombinant Factor VIII infusions and it terrifies me that this could happen again. I do not believe lessons have been learnt from what happened. When my grandson was taken to the Haemophiliac Centre, I brought up the topic of contaminated blood from the 1980s and in response, the doctor said that it would not be useful for my grandson to know about that. They still have not learnt anything and I feel are still trying to cover things up.

48. I want to know who knew that the blood was contaminated and whether it was a money saving exercise. Whose decision was it to get Factor VIII imported from the US and why did they continue purchasing that blood despite knowing the risks? I know in the 1980s they had suspicions about Factor VIII and if I knew that, then whoever was responsible certainly knew that too. Somebody should be held responsible for what happened and I want someone to tell me why they did it and why would they put so many people's lives at risk.

Anonymity

49. I do not wish to remain anonymous.

50. I am willing 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** ......

Dated....20/4/20.......