Witness Name: R.CALDER
Statement No: WITN1134001
Exhibits: 0
Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ROSEMARY CALDER

I, ROSEMARY CALDER will say as follows:-

Section 1. Introduction

1. I am Rosemary Calder of GRO-C Northampton, GRO-C I was born on GRO-C 1948.

2. I make this witness statement in relation to my late son Nicholas James Calder who sadly passed away at the age of twenty five. He was born on GRO-C GRO-C 1974 and died on 20 December 1999.

3. Nicholas was my youngest child. I have a daughter named Julie, who is my eldest, and another son, Darren who is not a haemophiliac. I am divorced from their father and am currently retired.

4. Nicholas had a wife named Lyndsey whom he married in 1996 GRO-C GRO-C I am still in close contact with Lyndsey GRO-C

5. This witness statement has been prepared without the benefit of access to all of my late son's full medical records. I have asked for my son's medical records from Northwick Park Hospital but they claim that there is no record of

him ever being treated there and they assume his records must have been destroyed. I have received records from Royal Free and Milton Keynes Hospital's.

Section 2. How infected

6. Nicholas suffered from Severe Haemophilia A. He was diagnosed when he was eight months old at Northwick Park Hospital. My family has no history of haemophilia, but when Nicholas was ten we took part in a TV show, The Human Factor, where my family's DNA was tested and it revealed that I was a carrier.

7. As a child my son suffered from numerous bleeds and bruising. Nicholas was treated for his bleeds at Northwick Park Hospital until he was age six. We then started treating him at home with Factor VIII supplied by the same hospital. For the first four years of his life he was treated with Cryoprecipitate but from 1978 onwards he was transferred to Factor VIII concentrate. I was advised by the hospital that the use of Factor VIII would be a great improvement in his care allowing us to eventually go on to home treatment. I was never asked if I was agreeable to the change and I was never informed that there was a risk of viruses being carried in the blood product. The hospital said the Factor VIII was purer. I was told it would make life simpler and easier for us and that the home treatment would reduce the number of hospital visits and disruption to our home life.

8. My son was treated at Northwick Park Hospital between 1975 and 1989 and was under the care of Dr Valman, paediatrician. He was also under the care of consultant haematologist Dr Cecil Reid. I believe he was infected as a result of treatment here or as a result of Factor VIII supplied from here for his home treatment. During his time at Northwick Park, Nicholas had to be registered with a haemophilia centre and that is why he was registered with Great Ormond Street Hospital. At the age of ten, Nicholas had a very bad knee and he needed to undergo an operation but Great Ormond Street lacked the expertise to deal with his treatment so they referred him to the Royal Free

Hospital in 1989. Nicholas had a lot of treatment at the Royal Free and was under the care of Dr Eleanor Goldman. From then on his treatment was shared between the Royal Free and Milton Keynes Hospital, as we had moved to Milton Keynes in 1987.

9. I have acquired records from the UKHCO which shows that Nicholas was mostly treated with home grown Factor VIII but had also received commercial products on a number of occasions and he was also administered the American blood product from Armour in 1982.

10. In 1983 HIV was a hot topic in the news and there were suggestions that haemophiliacs were susceptible to HIV. At this time, I contacted Dr Reid and the Haemophilia Society. I was told to carry on his home treatment as normal as the risk of him contracting an infection was minimal. In 1983 they must have known that there was some risk. I was never given an option for Nicholas to go back on Cryoprecipitate.

11. When Nicholas was nine, he was on prophylactic treatment, three injections a week. As I had then become aware of the possible risk of the blood product being contaminated, I decided to take him off this and only treat him on demand in order to reduce the risk of him contracting an infection. The doctors were not happy with my decision. Mostly the treatment was NHS Factor VIII, but if they were running low, he would be given commercial products.

12. The doctors conducted a blood test on Nicholas in May 1985. I was never told what the blood test was for but I never heard anything back from it. When I took Nicholas for a routine check up in July of that year they told me they would have to repeat the test as they had lost the first one. It was only at that time that I was informed that they were testing all haemophiliacs for HIV and I consented to this test. In September of the same year, when Nicholas was due to start secondary school, I got a letter through the post from Dr Reid telling me that he had tested positive for HIV. As I recall, the essence of the letter was that although very little was known about being infected with HIV, it

was thought that children who were infected with HIV were unlikely to go on to develop AIDS. I was told in the letter that I could contact Dr Reid or I could talk to him at my son's next appointment. I do not have this letter as it would be in Nicholas' Northwick Park medical records which I cannot obtain.

13. Following the letter notifying us of his HIV infection there was very little follow up consultation and we had to rely on the wording in the letter that it was thought children would not go on to develop AIDS. We discussed the risk of cross contamination with the doctors and we were very aware we had to be careful with blood spillages, and when treating him with Factor VIII. We were also aware that it could not be spread simply through day to day contact. We were then pretty much left to get on with it.

14. I feel Dr Reid should have made an appointment to see me to inform me of the HIV diagnosis face to face and to enable me to be able to ask immediate questions on the implications of it. All I knew was what I seen in the media. To receive a letter like that, at a time when there was so much hysteria in the media, and so little actual facts known, was devastating. If the letter had got lost in the post how long would it have taken before we knew and, more so, if the letter had been delivered to the wrong address and opened by somebody else my son would have been severely stigmatised. A matter as confidential as this should have been approached much more personally and I feel it was deplorable treatment.

15. On 9 August 1990, we were informed that Nicholas has been infected with the Hepatitis C virus. Again, the results were communicated by a letter addressed jointly to myself, Nicholas' father and Nicholas. The letter came from Dr Christine Lee, Senior Haematologist, of the Royal Free Hospital, a doctor my son had seen on many occasions. The letter stated that many haemophiliacs treated with unheated clotting factors had been exposed to the Hepatitis C Virus. It also stated that Nicholas' anti HCV test conducted on 20 June 1990 was positive. We knew nothing about this test until we received the results. No further information regarding treatment was provided. The letter also stated that some people who had been exposed may experience chronic

Hepatitis, but they could not say who would do so. They said it was possible that HCV could be spread sexually, though information in that area was very limited and very little was known. They again said that they would be willing to discuss it further at an appointment or my son's next check-up.

16. I do not know which treatment led to this infection but I strongly suspect it was the Armour Factor VIII.

Section 3. Other Infections

17. As far as I am aware, my son only received HIV and Hepatitis C as a result of being given infected blood products.

Section 4. Consent

18. The doctors carried the first HIV test without my knowledge and consent. As I have mentioned above, the doctors lost my sons blood sample at first and only on my check did I find out that the first blood sample was taken for the purposes of testing my son for HIV.

19. As far as I am aware, there was no treatment available for HIV at the time that Nicholas was infected.

20. The doctors tested my son for Hepatitis C without my knowledge and consent and without his knowledge or consent. According to the letter dated 9 August 1990, they were only trialling treatment that was not available for haemophiliacs and therefore my son was not permitted to undergo treatment. There was no treatment available for my son.

21. I do not know if his blood was ever used for research purposes.

Section 5. Impact of the Infection

22. I did not tell my son he had HIV until 1989, when he was 15. In 1985 he was 11, and the doctor's never advised us on how we could convey this news to a young child. His father and I felt he was far too young to know or be able to understand the implications. Our family was clinging onto the hope written in the letter that in children, HIV would not progress into full blown AIDS. My son kept healthy for quite a few years, but having read his medical notes I could see that the doctors had been concerned about his deteriorating health. The lab tests all revealed his counts went down and viral load went high.

23. I had told my eldest daughter who was twenty at the time. We felt she was old enough to cope with it and as parents we needed someone else to know to be able to share it with. We told Darren at the same time as we told Nicholas as we felt Darren would be able to give his brother some support. They had a very close relationship.

24. I was never told that the HIV had developed into AIDS. As Nicholas got older and became more independent, he went to the hospital himself and later with his wife, so I do not know if he was told but I believe that Nicholas would have told someone if he had known, however, we only had to look at him to see how his health was declining.

25. There was a lot of hysteria and stigma attached to HIV at the time. My son only told his best friend. When we told him he just took it on board. Straight away, he dismissed it and just said to his brother, "are we going out then?" Nicholas never dwelled on it and never discussed it unless we brought it up. He got on with his life and accepted that this was the card he had been dealt in life. He would deal with it in the same way he had his haemophilia. Nicholas appeared to take everything in his stride. In hindsight we now believe that he was trying to protect us from the terrible worry surrounding his condition. He did not want to show his true feelings to us. As he became more ill, he must have suspected himself that he had been cheated and lied to about the possibility of HIV seroconverting into AIDS.

26. Soon after telling him, when he was approximately seventeen, he started getting little infections. At Milton Keynes Hospital, Dr Miller who cared for him suggested he should go on AZT which was the only treatment available for HIV. He was on this drug course for many years from 1987. I do not know if there were side effects from this drug but in his records, it says that it may have offset something else. He was on no medication for Hepatitis C and no treatment was offered. There were trials of treatment for liver disease, but we were told that none were being offered to haemophiliacs.

27. In terms of schooling and education, he never really thought about the fact that his infections could cause him to lose his life. He'd always had a lot of time off due to his haemophilia. He then had shingles, an ulcerated mouth and rashes in his mouth which caused him to lose his appetite and to drastically lose weight. His bleeding episodes became less over time as he was less likely to fall over, but he lost a lot of time from school due to HIV and many hospital appointments. He finished school and went to sixth form to do retakes, but overall his education was adversely affected.

28. In 1992, when he was eighteen Nicholas met Lyndsey. They formed a relationship however Nicholas did not know how to go about telling her about his HIV. This was a constant concern for him that he would often tell us about. The doctors at hospital pressurised him to tell her. He was reluctant until he was certain about the relationship. He did not know if she would finish with him, or if she would tell her parents' or worse, that she would tell other people. We had always kept it within our family unit. He tried to tell her several times but could never quite find the courage. Two years into their relationship, when he eventually told her, he sought the help of his sister in conveying the news. Lyndsey took it very well and asked a lot of questions and the next day they got engaged. We didn't have many answers to give her.

29. In 1996 they brought a house together and got married. For Nicholas and Lyndsey the run up to their wedding was a very stressful time as Nicholas got pneumonia and had to go into the Royal Free. He was discharged only two

days before the wedding but until then they were uncertain about whether the wedding would be able to proceed.

30. GRO-C

31. After leaving school, Nicholas was unemployed for a while, but he often helped his sister look after her children alongside his wife. He had a few temporary jobs through agencies but he was very passionate about driving and wanted this as a career. He passed his test at 16. Luckily, his father had his own business which he started so that he could employ Nicholas because he knew that his son would have difficulties in holding down a job elsewhere due to his health conditions and the amount of sick leave he would need to take. Nicholas used to drive forklifts and lorries for him; however, he was often too ill to work. As he was working for his father he had flexibility to take sick leave as and when he needed to. Being employed gave Nicholas a better sense of self esteem to be able to provide for himself and his family.

32. In his last five years his condition deteriorated. He had several bouts of pneumonia, he lost weight and he looked very gaunt and emaciated. He lost a lot of energy and had to spend long periods of time resting. It was like looking at a different person. He was living with Lyndsey up until July 1999. His health problems put a great strain on the relationship and they separated for 3

months and sold their house and he moved back to live with us. In October 1999 they got back together and they all moved in with myself and Nicholas' father. This was just 2 months before he died.

33. The medical staff mentioned getting MacMillan nurses to support Nicholas but he did not want that as I was caring for him. In the three months he lived with us his health seemed to improve slightly. I managed to get him eating more and taking his medication regularly. On average he had to take forty tablets a day for his HIV infection. Many of these were very large tablets which he struggled to swallow. In his own words he felt he was being used as a guinea pig. He was constantly swapping and changing tablets due to various side effects. On the 19th December 1999 he was clearly very ill and we took him to A & E at the Royal Free on the advice of his GP who had been to see him on a home visit. He passed away a couple of hours after arriving there. When we left home that day we had no idea that he would not be coming back home.

34. When Nicholas died, the following day I received a phone call from Dr Eleanor Goldman, of the Royal Free to say she was very sorry to have heard of Nicholas' death. She told me that, if I would prefer, it wasn't necessary to put HIV on the death certificate to which I agreed. I felt at the time that they were trying to protect us from the stigma, however, I now wonder if there was an ulterior motive in not showing it as a cause of death. When I obtained his medical records from the Royal Free, I noticed that they had sent a letter to his GP a couple of months after he died saying that he had died as a result of Negative Bar Septicaemia, Pulmonary Haemorrhage, Bronchia Pneumonia, Retroviral Infection and Hepatitis C. That was the first time in twenty years I had heard about the Negative Bar Septicaemia. I phoned the lead nurse in the Royal Free Haemophilia Centre who remembered Nicholas and she confirmed this to me.

35. Personally, when I got the letter in 1985 telling me of his HIV infection it was the scariest time of my life, which was made worse by the lack of information available and the amount of stigma and hysteria attached to HIV. It was not easy for us to keep it a secret from Nicholas. At one point I read an article

saying that those who have HIV should be locked away in institutions so that they could not pass on the disease. I feared that someone would knock on my door and drag my child away from me. One day my Nicholas returned home from school upset as he had gotten into a quarrel with a boy who had called him 'AIDS boy'. That boy automatically associated haemophilia with AIDS. Nicholas had heard of AIDS on TV and was very upset about it. At this time, Nicholas did not know he had HIV. This was a very upsetting and difficult time for my husband and myself.

36. In terms of extended family, there were often gatherings and parties but a cousin of mine, knowing that Nicholas was a haemophiliac no longer attended or visited us as he thought there was a risk of his daughter contracting HIV. That cousin did not know my son was HIV positive, but he associated Haemophilia with HIV due to the media coverage.

37. For years we lived with the knowledge that Nicholas' years were likely to be limited. During his last year, when his health was obviously declining was when it really hit me that Nicholas may not be with us much longer.as his health had clearly deteriorated considerably. But we still always lived in hope. But even when it happened, it happened so quickly that it came as a shock, but in a way I prefer it that way as that weekend our family had all been together. I did not want him to have to go into a hospice and wait to die. My son would not have coped with that and I could not bear to see him suffer for a longer period in a hospice or hospital. Even in his final months he would always put on a brave face and he never complained about it to us. He never once asked, 'Why me?'

38. I used to work in a school, and it was summer holidays when Nicholas came to live back with us. To have lost a child changes you forever and I have never been the same person. Even after he died there was still the stigma and I never told people how he had died, just that he had died as the result of a bleed, whereas really I wanted to shout from the rooftops about the terrible suffering he had been put through and how proud I was of him.

39. The loss of our son resulted in the breakdown of the relationship I had with his father and we were divorced in 2003, after a 38 year marriage. When Nicholas died, we drifted further and further apart and grieved separately. His father did not cope very well, and it still impacts him today. My ex husband blamed me for the loss of his son as I was the Haemophilia carrier. Somehow being together seemed to serve as a constant reminder of what we lost.

40. Nicholas' death has had a massive impact on our family and the circumstances have never really allowed us to move on. More recently with the Inquiry, ploughing through medical records, media reports, ongoing investigations and listening to others harrowing stories we are constantly having to relive the events and go through the bereavement cycle over and over again, something that has been dictated and forced on us and never by our own choice.

Section 6. Treatment/care/support

41. No counselling or psychological support was made available to Nicholas or any member of my family in consequence of what happened. The hospital had referred Nicholas to see a psychiatrist at one point as they felt he was depressed, but they did not find that there was a problem and determined that he did not need any further psychiatric assistance. My son always put on a brave face no matter who he was speaking to.

42. I think Nicholas and our family should have been given more support from day one particularly given that we were not being told about the implications of the viruses.

Section 7. Financial Assistance

43. Nicholas received discretionary payments from the Treasury Department in 1991 that the Government paid. My son was a minor and single and was therefore given a reduced payment of between £19,000 and £20,000. They

retained the payment in their account until he turned eighteen. Prior to this, if he requested some money then we could ask for it and they would pay us.

44. Nicholas and our family should have been given more support. Nicholas received monthly payments from them a few years prior to his passing; however I do not know how much he received. The MacFarlane Trust assisted Nicholas and his wife to put down a deposit on their house. After he passed away, a letter was sent from the Trust to Lyndsey saying that they would award £1000 towards funeral costs. For six months after Nicholas' death, they continued paying Lyndsey the monthly payments he would have received less the health supplements. I do not know how much this was. After June 2000, the MacFarlane Trust paid Lyndsey £73 per week GRO-C GRO-C. She was entitled to this until Connor reached maturity.

45. I am unsure if Nicholas or Lyndsey received a payment from the Skipton Fund.

Section 8. Other Issues

46. I was a party to the 1991 Litigation and received an Ex Gracia payment, but I cannot recall whether I signed a waiver or disclaimer agreeing not to take further action. My son was a minor then.

47. For many years I thought this was an unfortunate accident but then I started seeing and hearing bits and pieces through the media suggesting otherwise. I then begun to research and investigate and I joined the Tainted Blood support group in 2017.

Anonymity

48. GRO-C I do not want 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 ..

Rosemary Calder

Dated 15\3\19