

Witness Name: Margaret Madden

Statement No: WITN1364001

Exhibits: WITN1364002

Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARGARET MADDEN

I, Margaret Madden will say as follows:-

Section 1: Introduction

1. My name is Margaret Madden Jr. My date of birth is 1950 and I live at Cheshire with my wife. I make this statement on behalf of my son, Daniel Leah who was born on 1971 and died on 19 August 1992.
2. This witness statement has been prepared without the benefit of access to my son, Daniel Leah's full medical records although I do have some limited records and the relevant entries are set out in the medical chronology at the end of this statement.

Section 2: How Affected

3. I provide this statement because my son was infected with HIV and Hepatitis C (Hep C) by infected blood products. I believe my mother, who was a haemophiliac, was also infected with Hep C from infected blood products and I have provided a separate statement with regards to this.

4. By way of background, I was tested at the age of 15 to see if I was a haemophilia carrier, which I was as my mother had haemophilia A. I was told that my first child would be a haemophiliac if it was a boy and any girls that I had would be haemophilia gene carriers.
5. My GRO-B was born in 1969 and my second son, Paul was born in 1970, thankfully neither were haemophiliacs. My third son, Daniel was born black and blue, so I knew then that he was a haemophiliac. The doctors confirmed at birth that Daniel had severe haemophilia A with low factor VIII level.
6. I was well acquainted with the problems that my son, Daniel would face and the pain that he would experience. I was my mother's main carer at the same time and travelled between hospitals to assist my mother and take Daniel to their medical appointments.
7. I was heart broken knowing the pain that Daniel would endure and also that I could lose him if he had a heavy bleed. I knew Daniel's haemophilia would have a very big impact on the family especially his two brothers, which it did.
8. The early years for Daniel were relatively trouble free in relation to his haemophilia, but from the age of 6 he started to have recurrent bleeds.
9. During this time I was also helping my mother and father, going backwards and forwards to Manchester Royal Infirmary with my mother in relation to her haemophilia as well as going back and forth to Pendlebury Children's Hospital, Manchester with Daniel. When I was attending hospital appointments my two other sons, GRO-B and Paul would have to leave school early and at times slept in the hospital. This started to affect GRO-B and Paul's education. My husband, Jack was a farmer so was rarely around. He did reliefs for farmers all over the country when other farmers were on holiday or required extra help so I was very much left to cope on my own.
10. In or about 1977 Daniel was treated with cryoprecipitate at Pendlebury Children's Hospital by Dr Clarke and Nurse Shaw. As time went by the

treatments for haemophiliacs improved and the latest treatment, Factor VIII could be kept in the fridge at home.

11. In or about 1974 I was offered the opportunity to learn how to give intravenous injections at Pendlebury Children's Hospital, Manchester. Dr Clarke offered to teach me how to administer the treatment and of course I jumped at the chance. This meant no more rushing to the hospital at all hours of the day or night with my two other sons. It became a lot easier to manage Daniel's bleeds as I was able to administer Factor VIII injection the minute he had a bleed. I was required to administer Factor VIII many times, because Daniel was a severe Haemophiliac and I was required to administer Factor VIII for every bleed. I was also able to administer Factor VIII at home for my mother and my cousin, Ronald who was also a haemophiliac.
12. In or about 1978 Daniel was prescribed Monoclate-P, Factor VIII (Armour Pharmaceutical Company Limited).
13. In or about 1979 when Daniel was about 8 years old he started to complain about his leg, arm, elbow and knee. Daniel was administered Factor VIII at Royal Victoria Infirmary, Newcastle (Newcastle, RVI) and he was given FVIII on alternate days.
14. Daniel was given more Factor VIII in February 1979 for his ankle, March 1979 for his knee joints, April 1979 and May 1979 and for left ankle. A more detailed copy of this record is exhibited at **WITN1364002**.
15. Later that year, I received a letter from Dr Peter Jones inviting us to see him in the Newcastle Haemophilia Centre to discuss Daniel's future care in the Newcastle region.
16. In or about the same year, I recall attending a meeting in Pendlebury Children's Hospital and we were all asked to give back the Factor VIII that we had. We were told that the batch numbers were not labelled correctly in the lab. We were later given new Factor VIII to take home.

17. With the new treatment we were all able to live a normal healthy life. My two older sons, GRO-B and Paul were able to have a better education and my cousin Ronald went to school and college. Once I was confident in administering the injection on Daniel, I was able to teach Daniel and my husband, Jack. I was also able to teach Ronald to administer the injection himself, which assisted me. We lived a normal family life and Jack was able to spend more time with our three children.
18. In or about 1980 Daniel went to a special school in Salters Lane, Darlington. We took him out of that school as we moved home to reside in the Cleveland area. I was told by Cleveland L.E.A to home tutor Daniel until the Easter Holidays and after the holidays he would be admitted to Welburn Hall School. This was a residential school that he attended for few weeks as my mental health was suffering.
19. In or about early 1981 Daniel went to Summerhouse School, Norton. The staff members, who were aware of his haemophilia, were great with him and he was loved there. Daniel was receiving Factor VIII by the nurses at the school on alternate days.
20. Around this time, I started to notice Daniel constantly having a sore throat and a cold. At the time I was not too concerned as I just assumed it was because he was attending school more regularly and it was normal for children to catch a cold. I also started to notice that he was sleeping a lot more and he started to lose weight. I was concerned about this. He had regular checks at Garside Street, a local children's haemophilia clinic, and at his school by the school nurse. I was always told that Daniel was okay and there was nothing to worry about.
21. Daniel had ongoing right knee symptoms and as a result he had a right knee synovectomy in 1982. Following the operation Daniel's right knee was suspended in a Thomas splint with a Pearson knee piece. He made a good recovery from the anaesthetic and there were no problems with bleeding.

Daniel was given Factor VIII and his Factor VIII levels had been satisfactory. This is recorded in Daniel's medical records, Newcastle RVI, dated 27/04/1982.

22. Daniel's medical records are missing from 1984 to early 1985. There are blood tests results from this period.

23. In or about 1985 Daniel woke up in the middle of the night feeling very sick. I noticed spots on his stomach. I was really worried so I called the GP. He came to the house and examined Daniel. At this time, we lived in a two-up and two-down terraced house and the living room was on the same level as the street. When the doctor arrived I opened the door and invited him into the house, but the doctor stood outside without attempting to come into the house. Daniel was standing next to me when I opened the door to the doctor. The doctor asked Daniel to lift up his pyjama top, which he did. He briefly looked at Daniel's stomach and said 'oh it's nothing serious, it's just chickenpox'. He put calamine lotion on the spots and gave him Calpol and then he left. He did not give any information for further treatment. I found it very strange that the doctor did not come into the house and stood at the door to examine Daniel. I did not think anything of it at the time and I just thought it was because he did not want to catch chickenpox. It did cross my mind as to whether a child can have chickenpox twice as Daniel had chickenpox in 1979. After reviewing Daniel's medical records, there is a letter from the Community Child Health Service, dated 5/11/1985 that states that Daniel had a 'chest infection and jaundice and then developed shingles'. I therefore believe that Daniel had shingles when the doctor attended the house and not chickenpox.

24. A few days went by and Daniel's condition did not improve. The spots were turning into sores and they were now bleeding. Daniel was also off his food and he was vomiting and rapidly losing weight.

25. Paul my middle child primarily lived with his father, but when he stayed with me all three of them would share the same bedroom. I was constantly

checking [GRO-B] and Paul for any signs of spots. At the back of my mind I was thinking something was not right.

26. Several nights after the doctor had visited our house and after our usual evening routine, my eldest child, [GRO-B] came running into my room and woke me up. He shouted "Daniel is bleeding bad". I jumped out of bed and dashed to their room. I was shocked to see that the bed was covered in blood and Daniel was sitting in bed oblivious as to what was happening. I panicked and gave him two bottles of Factor VIII. I stripped back the bedding and I put my other two sons back to bed and sat Daniel down on the couch. After he was given Factor VIII, the bleeding started to ease. There was something about Daniel's sores that were niggling at the back of my mind.

27. The following day, which I think was a Friday I took [GRO-B] and Paul to school and cancelled Daniel's taxi to school. I called an ambulance for Daniel and we were taken to Pendlebury Children's Hospital. When we arrived the haemophilia nurse came out and met us in the ambulance and told us to stay in the ambulance. I found this strange when the nurse left me and Daniel in the ambulance. The ambulance driver even commented on how unusual this was. I did not think anything of it at the time as I had told the nurse that the doctor told me that Daniel had chickenpox. A few minutes later the ambulance door's opened and the same nurse was wearing gloves and a mask. She took a quick look at Daniel and said 'yes it's chickenpox and the spots are bleeding because he was scratching them'. The nurse informed me to give Daniel another two bottles of Factor VIII and if there is no change then to bring him back. I did as I was advised. A few hours later the bleeding slowed down but the sores were constantly weeping and I had to change his dressing regularly.

28. On Sunday there was a knock at the door and it was a couple of Jehovah's witnesses. I bought a magazine from them as I always did. I noticed the headline stating 'Gay Plague' and 'People Dying' so I continued to read it. The magazine read that people were dying of an unknown virus and the

symptoms were bad fatigue, colds, flu like symptoms, loss of weight and sores around their stomach starting with a rash. My heart sank and my head started spinning. I felt very sick after reading that article.

29. The following day I rang Pendlebury Children's Hospital and insisted they gave me an appointment straight away, which they did. I got the boys together and drove straight there. When I arrived at the hospital I was shaking like a leaf and fighting back my tears. The article that I read kept playing in my head. My heart was racing and I thought I was going to pass out. When we were called to the doctor's room I noticed the doctor and nurse wearing gloves, apron and masks over their faces. I was not sure why they were wearing such items. Daniel said 'what are they going to do to me mum'. I told the doctor and nurse what I had read and that I was well aware that people got paid for giving blood in the United States and that Factor VIII came from there. I requested a blood test for Daniel and they refused to do it. They blatantly lied to me and said 'there was only a slight chance that Daniel could have contracted HIV but this was very unlikely'. I just knew they were lying and I figured that the masks, gloves and aprons were not just for 'chickenpox'. I shouted at the doctors and told them that I knew everything. The doctors said it was all in my imagination because I had read it in a magazine and they banned me from the hospital. As I was leaving I told everyone on the ward that the staff were liars and that they were trying to kill my son. I was ordered off the premises and advised that if I did not leave I would be escorted out.

30. At this time it was well over a month since the doctor stood at my front door glued to the step outside my house. The sores were still not healing and were spreading into each other. It was haunting me all the way home I was unable to rest.

31. That same night I was awake all night and I just could not close my eyes. I was constantly going into the boys' room to check that Daniel had not got into bed with his brothers just in case Daniel was infectious. I was feeling

so guilty thinking that Daniel could be infectious and that he could possibly infect his brothers, but I was so terrified of losing my sons.

32. The following morning, I spoke to my mum and dad and told them everything. I also spoke to my cousin, Ronald to see if he was ok. He said 'apart from feeling tired he was fine'.

33. I kept my children out of school, due to Daniel's condition.

34. In or about early September 1985, at night I was woken up by Daniel. He stood at the side of my bed and said 'mum I am bleeding'. I jumped out of bed and saw that the sores on his stomach started to bleed again. I ran to the fridge and gave him Factor VIII.

35. I then rang the haematology department in Newcastle RVI as I had lost faith in Pendlebury Children's Hospital. I asked if I could book an urgent appointment to see a doctor. I was going out of my mind with worry. I was put on hold and when she returned she asked me if I was able to get to the hospital before 6am as a doctor would be able to examine Daniel. I looked in my purse and I only had £30.00. I got [GRO-B] and Paul out of bed got them dressed and made our way to the hospital.

36. On my way to Newcastle RVI I stopped to put petrol in my car. I continued my journey and as I approached to join the A1 to Newcastle [GRO-B] said 'mum Daniel is bleeding again'. I screamed 'don't touch him', the look of terror on my face must have frightened him. [GRO-B] said that 'I'm not, I haven't done it'. I was crying so much that I was unable to stop the tears. In that moment of time, I was frightened of my own son, Daniel and the danger that my other two sons were in. I prayed I was wrong about what I read in the magazine. I removed the gauze and put one of my blouses and a towel tight around Daniel to stop the blood from steeping through.

37. I was running out of petrol and Daniel was still bleeding. I therefore had no choice but to drive to Middlesbrough General Hospital and rushed Daniel to A&E. The doctors and nurses took one look at us and took Daniel off me. I was covered in blood and my other two sons were crying and also covered

in blood. I explained what had happened in babbled English and explained that I was actually on my way to Newcastle RVI.

38. The receptionist at Middlesbrough General Hospital telephoned Newcastle RVI. An ambulance was sent to collect us from Middlesbrough General Hospital and take us to Newcastle RVI. We remained at the hospital for around 3 hours and Daniel was given a blood transfusion. The ambulance arrived just after Daniel was stabilised. I was later informed by the doctor at Middlesbrough General Hospital that Daniel had approximately 3.5 pints of blood in his body and was close to death. I told them that I was running out of money and I did not have enough money to fill in petrol to get to Newcastle RVI. Middlesbrough General Hospital then gave me £50.00, which I signed for. I was really grateful for their help. The matron from Newcastle RVI came down and travelled in the ambulance with Daniel, and we followed behind them.

39. When we arrived at Newcastle RVI the staff at the hospital were ready for Daniel. He was put in ward 13, which eventually became the AIDS ward. They comforted us by providing sandwiches and pots of tea. All I could think about was that I was having a nightmare and kept asking myself if this was really happening. When Daniel was safe and fast asleep I put the boys to bed and checked again if they had any spots. We were all very exhausted and my two sons were confused.

40. I went outside and sat down and tried to recall everything that had happened that day. I could not even account for how I had got to Newcastle RVI. I do not remember the journey. One minute we were at home and the next minute we were in a strange room at Newcastle RVI. All I could remember was my little boys' faces not knowing what was going on. I went back into the hospital room and fell asleep.

41. I woke up to hear the hustle and bustle of the breakfast trolley coming down the corridor, still in a daze. I felt numb and sat for a while which seemed like hours. It was actually six minutes past six. I showered the boys and got changed and we went to see Daniel. He was awake and looked a lot rosier

than he had the day before. The hospital staff asked where we were going to stay whilst Daniel was in hospital. I told them I had a friend, Kate in Darlington and I would contact her and arrange to stay with her. The nurses were fabulous and fed the boys for me and made a good fuss over them. They told me Maureen Firnes who was the head of the centre was on her way to see me.

42. Maureen arrived shortly after. I told her everything I knew about Daniel's condition and the article that I read in the magazine. GRO-B and Paul were in the day room and they looked more relaxed. Maureen took me into the office to use the phone. I telephoned Kate, to ask her if we could stay with her. Thankfully Kate said yes. She had plenty of room because she lived in a public house on the Horse Market. I told her that I would tell her everything when I got to her house.

43. Later in September 1985, Dr Jones who was treating Daniel and who was the head doctor for the haemophilia centre arrived at the hospital. I checked up on Daniel and he was sat on his bed playing on his space invaders game. I gave him a kiss and said 'see you later alligator'. Maureen stayed with me along with the social worker, Jean Lovie, and the boys were taken to the play room.

44. We waited in the office for Dr Jones. He came in and gave me a hand shake and a hug. I started crying again and tried to explain the events that led us to the hospital. Dr Jones started by explaining he has done a lot of blood tests on Daniel and had the results. He sat beside me and said "I do not know how to tell you this but all your fears that brought you here are true." He continued to say that Daniel had herpes zoster not chickenpox as told by the previous doctor and nurse. He said Daniel has an Immune Deficiency Syndrome, which was a virus. I was shocked and asked how he got the virus and Dr Jones confirmed that he had HIV (medical record, dated 11.09.1985). I was stunned. I felt it in my heart and heard it in my head but hearing it from a doctor was a completely different feeling.

45. I asked Dr Jones if there was anything that could be done or if it could be cured. I was screaming saying that 'I have killed my son'. I asked about my other two boys, as I was aware that all three children had been sharing a bedroom. Dr Jones said he doubted that the other two boys had caught the virus. He said that he would do blood tests on the whole family to confirm this. Dr Jones explained that unfortunately there was no cure and Daniel had 6 weeks to live. Dr Jones told me that he would put Daniel on tablets called AZT, which was supposed to help stabilise the spread of the virus and he would do the blood tests to check if AZT had worked.

46. I could not believe what I was hearing, I was so confused, my head was all over the place. I was told that because I did not live within 30 miles, it would be difficult for Dr Jones to assist. However, he did say off the record that he would do everything he possibly could to help Daniel. He told me not to tell Daniel or my other sons and to pretend that we were on holiday here.

47. Dr Jones then explained that he had a few patients at the same stage of the virus as Daniel and they were still alive and apparently sometimes the virus goes into remission. He also told me that it had an incubation period of 18 months to 2 years. I sat there for a while trying to come to terms as to what he had told me. He said that if I gave him the go ahead he would bombard Daniel with everything he had and every prayer he could muster. He told me how it could be spread to other people, which was through body fluids. Dr Jones was unable to tell me as to how long Daniel had been infected. We were all tested that day and we were given the all clear.

Advice Given regarding the Risk of Infected Blood Products

48. The only information that I was given about Factor VIII was that Daniel was able to have the treatment at home without the need to go to the hospital.

49. No advice was given to me at the time in relation to the use of or risks associated with blood products.

50. I believe that had we been given adequate information about Factor VIII and the potential risks involved, I would not have agreed for Daniel to have such treatment.

Section 3: Other infections

51. I believe that Daniel had been exposed to other infections through the use of contaminated blood products.

52. I received a letter from the Skipton Trust in or about 2010/2011. It stated that Daniel had also contracted HCV and I was eligible for a payment. I was unaware that he had been tested for HCV, but later discovered that this test was done after his death.

Section 4: Consent

53. I believe that Daniel was treated with Factor VIII without being given adequate or full information of the risks associated with blood products.

54. I also believe that Daniel had previously been tested for HIV without my knowledge or consent, as prior to his diagnosis the doctors and nurses acted as though they were aware of his infection when they were reluctant to treat him without gloves and full-gowns.

55. Having reviewed Daniel's medical records, I noticed that they were regularly stamped with 'trial' and 'pups', as such I believe that he was treated and tested for the purposes of research without my knowledge or consent.

Section 5: Impact

56. After meeting with Dr Jones and trying to get my head round everything, reality came rushing in. I kept blaming myself, 'I have killed my son' all because I thought it would make life easier for us to give him Factor VIII. I struggle with this every day of my life. I cannot get to grips with all the pain

and suffering this has caused me and my family. Even now I can see Daniel in pain like a video on a constant loop.

57. Although I knew my family and I were clear from the blood tests, I thought to myself how could I stay at Kate's house, she might be scared of catching it herself and she could lose business if her customers found out.

58. I kept thinking how I would tell Daniel, my husband, GRO-B and Paul. I would also have to tell my mum and cousin Ronald. All these thoughts were making my head spin. Dr Jones, Maureen and Jean Lovie assured me that they would do all they could for me and my boys.

59. GRO-B and Paul could see how upset I was and asked me why. I had to pretend and say that one of my favourite nurses had died and that was the reason why I was upset. I knew that I would have to sit them all down at some point and tell them the truth. I just did not know how to approach the subject and did not know when it would be the best time.

60. We stayed another night at Newcastle RVI and noticed that Daniel was looking and feeling a little better. I left the hospital and drove to Kate's pub in Darlington. She was brilliant with us. Kate offered us the top floor of the pub as a base camp for as long as we needed.

61. As the days went by Daniel started to get stronger. We visited Newcastle RVI everyday and spent most of the day there. With the grace of God and lots of help from the Newcastle RVI, the virus went into remission. I returned to Manchester and spoke in depth with my husband and he was heart broken. My husband was also tested and the results were negative.

62. I decided to move closer to the hospital to ensure the best care for Daniel and to save time in travelling. I had completely lost all faith in Pendlebury Children's Hospital. We stayed with Kate until I had enough money to rent somewhere. I found a farmhouse, Cleveland in a secluded area where we would be safe from prying eyes and nasty gossip. I had tried to rent a

house through the council, but they would not rent a house to me because they must have thought that Daniel may contaminate the whole estate. I had the same problem trying to get Daniel into school, I just could not find a school that would accept him. Eventually he was accepted at a special school in Eston. I spoke to [GRO-B] and Paul and told them not to tell anyone about Daniel's condition and they both went to school as if nothing was wrong.

63. Once we moved into the farmhouse, I finally had the courage to sit Daniel down and explain that he had a virus and how he got the virus. I explained that other people could catch it. I spoke to Daniel and made sure that he understood that nobody else could be with him when he was having the injection or preparing it.

64. We lived in the farmhouse for about 6 months. One day I received a letter from the farmer asking us to vacate the property immediately. Apparently, someone had told him that Daniel had AIDs and he was worried that he could contaminate his stock of 2000 turkeys. I did not know how the information got to the farmer as the only people that knew about his condition were the social security and the local social worker.

65. A couple of days later my car was vandalised and my tyres were slashed. The word AIDS was daubed down the side of it. At this time, Paul was living with his father in Manchester and [GRO-B] was living with me. I decided it would be best if [GRO-B] joined Paul and his father in Manchester.

66. I moved from the farmhouse and put all my furniture in storage. I was running round trying to find somewhere to live and was finding it very difficult. We were homeless for about two weeks and lived in my car. Eventually I found a property to rent and we were able to move to Acklam, Middlesborough.

67. We stayed for approximately three months and then we were back to the same situation as we were at the farmhouse. The neighbours found out about Daniel's illness and were making our lives hell. We had the word

'AIDS' sprayed on the front door and someone even tried to set fire to the house whilst we were in bed. The ironic thing was the reason that the general public knew about AIDS was because I started a campaign called 'Innocent Victims' and I had told the government that if people were not informed about AIDS then I would go to the media with my story. They agreed to publicise it and started running adverts on TV with tombstones warning people about it.

68. Again we were homeless and searching yet again for a place to live. This was becoming a recurring nightmare and in total it happened 4 times.

69. I remember going to the local shop and I was served first so I would not contaminate anyone. The shop keeper tipped the change into my hands from height, so he did not have to touch me. Sometimes the money would fall to the floor and I would scabble around floor to pick it up. I was treated as though I had leprosy.

70. In or about 1987, Daniel selected to do a BTEC course. The course, however, proved too demanding and he had been opting out of his lessons and turning up late. This is confirmed in his medical records dated, 8/02/1988.

71. In 1992, Daniel's virus had returned and he was in and out of Newcastle RVI with pneumonia and thrush in his mouth and down his gullet. He was not eating and was becoming weak. He was sucking ice cubes made from crushed up fruit and juice because that was the only thing that did not hurt his throat. By now Daniel was approximately 20 years old and old enough to understand what was happening to him. We would spend hours talking about his illness. We even talked about driving the car over a cliff just to put an end to all the pain and suffering. Daniel had informed me that his wishes were that he wanted to go home, as he did not want to spend his remaining days in the hospital. Around this time, we were informed by the doctors to keep 'the infected person' healthy and that they should eat 3 square meals per day and ensure they were kept warm. The government raised our benefits to accommodate this.

72. Around this time the Government offered compensation. However, this offer came with strings. The only way we could accept the offer was if we agreed to sign the Official Secrets Act and never talked about how Daniel was infected with HIV. Not only did we have to agree to this condition but so did every other haemophiliac who was infected and if we had not all agreed then nobody would have received it. It took a long time for everyone to decide whether or not to sign the agreement; I think it was the government's way to put pressure on us by stopping the extra benefits they had initially given us. This meant that we were unable to afford to eat proper meals and as a result I was forced to shoplift to survive. Daniel and I eventually signed the agreement in or around 1992. The final requirement was that I had to stop my campaign.

73. I could not believe how my life had changed. I had gone from owning my own house and cleaning business to literally having to steal in order to feed my sick child. I spoke to Kate's friend and she put me in touch with another friend of hers who was a financial adviser and a mortgage consultant. He took me to the Bradford and Bingley building society and gave me a mortgage, on the premise that I would shortly receive the gratuitous payment. I then bought a property in Stockton-on-Tees. It had a granny flat at the side which was perfect for when my family from Manchester came to stay.

74. I was getting more and more depressed seeing my son slowly die in front of me and even though I had been forced into signing the Official Secrets Act, I still secretly carried on fighting the 'Innocent Victims Campaign'. I appealed to them to change the adverts on TV to reflect the fact that AIDS was not just a "gay disease" and to explain to people that it could not be contracted by touching alone.

75. I think that the general public were ill-informed, and as a result Daniel and I were widely ostracised.

76. Shortly after we moved into the property in Stockton-on-Tees Daniel became sick again and was rushed to the hospital suffering with pneumonia and thrush, which resulted in further weight loss. He was so ill that he could not walk and a porter came out of the hospital to help us get inside. Daniel was in hospital for approximately 5 weeks. My two sons were driving up and down the motorway constantly checking on Daniel and bringing his friends from Manchester to see him to keep his spirits up.
77. Daniel was released approximately 5 weeks later and was receiving oxygen at home. Unfortunately, he was rushed back into hospital 3 weeks later on the 18 August 1992 and died the following day at 5.50am a month before his 21st birthday.
78. When Daniel passed away, my mother came to live with me and I cared for her until she moved into sheltered housing a few years later. I also cared for my cousin Ronald, who suffered from Haemophilia.
79. I will never forgive the government for what happened to Daniel. The way in which they handled the situation and bullied people into signing the official secrets act in order to cover their tracks was a despicable act.
80. Daniel's wish was to be buried at home in Manchester. The undertaker wanted to put him in a wooden box and cover it in sawdust. His brothers would not allow it and instead they took the front seat out of my car and propped his coffin up in the front and drove him back home in the middle of the night. The undertaker in Manchester could not believe what we had done and thankfully managed to smooth things over with the authorities because apparently it was illegal for us to do this. As a final insult to Daniel he had to be buried in a lead lined coffin so that he could not contaminate the dead.
81. With everything that had happened to Daniel, I was 2 months behind with the mortgage payments. I had tried to talk to Bradford and Bingley about setting up a payment plan to pay the outstanding arrears, but they were not interested. I was thrown out of the property after approximately 8 months.

Section 6: Treatment/Care/Support

82. As previously mentioned, Daniel faced difficulty receiving treatment for HIV due to the poor service from my local hospital in Manchester. Although he was diagnosed in Newcastle RVI and they were very helpful with his treatment, we did not live within 30 miles and fell outside of the catchment area to be treated there. As such, we were required to move nearly 150 miles away from our home in order to ensure Daniel could receive adequate treatment.

83. No counselling or psychological support had ever been offered to me in consequence of what happened to my son. Additionally, no support was offered to Daniel to help him cope with his diagnosis. I found it very difficult to cope with what happened, as I did not have anyone to talk to about Daniel's infection. My mother did not wish to talk about it, as she blamed herself for having given the family Haemophilia. Apart from social security and social services, I did not discuss this with anyone.

Section 7: Financial Assistance

84. In or about 1992, we received a payment in the sum of £60,000 from the Macfarlane Trust. In order to receive this money, Daniel and I had to agree to sign the Official Secrets Act and not discuss how Daniel had contracted AIDS. I also had to stop my Innocent Victims Campaign, as outlined in paragraph 72 above. This money was used to purchase a house, where Daniel died in 1992. The Newcastle RVI assisted us with any forms that we were required to complete for the financial assistance and I do not recall facing any difficulties obtaining this, other than the preconditions that were imposed.

85. Following Daniel's death, I received a letter from the Skipton Trust in or about 2010/2011 stating that I was eligible for a payment as a result of Daniel contracting Hep C from infected blood products. I received a

£50,000 lump sum payment, which I shared between my family as I believe they had all suffered. No preconditions were imposed on this payment.

86. I made another application to the Skipton Trust for additional payment in or about 2013. Unfortunately, the application was rejected as Skipton states he did not suffer from cirrhosis.

87. Whilst I have given this statement on behalf of my son, Daniel Leah I have not given a statement on behalf of my mother, Margaret Madden (deceased) because either no or otherwise sufficient Award has been made available for this purpose.

Anonymity, disclosure and redaction

88. 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.

89. I wish to give oral evidence at the Inquiry.

Statement of Truth

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

Signed.

GRO-C

Dated

30/11/2018

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

Virology Results

1979	Factor VIII was given at Pendlebury Children's Hospital, Manchester
23.01.1980	Hep B – Negative
11.08.1980	Australia antigen – Negative
3.03.1981	Australia antigen – Negative
06.08.1985	HBs antigen – Negative HBs antibody – Negative HBc antibody – Positive
10.02.1985	HTLV III – Untested
06.08.1985	HTLV III – unknown
11.09.1985	HTLV III – Positive
17.07.1986	HTLV III Antibody – Positive
16.10.1986	Haem A review – HIV A/B Pos
09.01.1987	Severe Haemophilia A – HIV A/B Pos
26.06.1987	Haem A – HIV A/B Pos

22.02.1988	Haem A review – HIV +
16.05.1988	HIV (HTLV III) Antibody: Positive
22.09.1988	HIV (HTLV III) Antibody: Positive Anti P24 antibody weak: Positive
20.10.1988	HIV (HTLV III) Antibody: Positive
08.12.1988	HIV (HTLV III) Antibody: Positive
5.01.1989	MRC HIV Trial Trial no: AT24015 Date: Specimen: V Blood HIV (HTLV III) Antibody: Positive
24.01.1989	MRC HIV Trial Trial no: AT24015 Date: Specimen: HIV (HTLV III) Antibody: Positive
25.04.1989	MRC HIV Trial Trial no: AT24015 Date: Specimen: HIV (HTLV III) Antibody: Positive
21.07.1989	MRC HIV Trial Trial no: AT24015 Date: Specimen:

HIV (HTLV III) Antibody: Positive

10.10.1989

MRC HIV Trial

Trial no: AT24015

Date:

Specimen:

HIV (HTLV III) Antibody: Positive

11.01.1990

MRC HIV Trial

Trial no: AT24015

Date:

Specimen: V Blood

HIV (HTLV III) Antibody: Positive

30.06.1991

IFAT Pneumocystis carinii Negative

10.03.1992

Hep B surface antigen and Hepatitis B core antibody Not tested.

See previous results.

HBs antibody Negative

Vaccination not indicated

28.04.1992

chest x-ray – there is a right upper lobar and left basal nodular shadowing consistent with pneumonia. Further consolidation is seen behind the right atrium.

20.05.1992

IFAT Pneumocystis carinii Negative

Significant Entries

04.09.1979

Letter from Dr Jones to Mrs Leah (Ms Madden), inviting mother and Daniel to Newcastle Haemophilia Centre to discuss Daniel's future.

- 2.10.1979 Record card – shoulders, hips, R.elbow & L.knee: nil abnormal. L.Elbow, R.Knee and L.Ankle: show changes of hemophilic arthropathy - C.K.Warrick
- 30.09.1979 Letter from Middlesbrough General Hospital
- 5.10.1979 Letter from J.Lovie, social work to Dr Jones – living temporarily at the Market Tavern Place, Darlington.
- 12.10.1979 Record card – rather poor, patchy uptake of radioactivity has been recorded in the liver with excessive spillover into the spleen. Hepatosplenomegaly is evident. These appearance are presumably due to increased extramedullary erythropoiesis, although with the relatively poor liver uptake these features could be equally compatible with chronic liver disease. – Dr Jones.
- 17.10.1979 Letter from National blood transfusion service to Dr Hamilton – the following tissue type was determined on the sample of blood from your patient, DL group O Rh Positive.
- 25.10.1979 Medical note – from Dr P Jones to Dr Steele, Mr T Gavies-Isaac and Mrs Lovie - Mrs Leah's stable relationship is a lesbian one and I thought that you should know this before she visited the school..... however, I think that this is an additional reason for the boy going to Welburn where in the absence of any close male relative in the Middlesbrough area, he will be more able to form associations with mature males, which is essential for his emotional development.
- 12.12.1979 Record card – Large Spleen, probably liver disease.
- 23.01.1980 Letter from A M Crone, Registrar to Dr R.V Dubberley and Dr J.S Charlton. Recently changed his treatment to Factorate

since which he has come out in an itchy rash. This was clinically and microscopically proven scabies. Given Lorexane with instructions to treat the whole family.

- 14.03.1980 Daniel was in Salters Lane School, Darlington, moved in the Cleveland area and arrangements will be made for Daniel to be admitted to Welburn Hall School.
- 7.08.1980 Liver function test and Protein
Ultrasound upper abdomen (4500) – the liver is slightly bulky and shows uniform internal echo return. Normal hepatic and portal venous radioles.... The spleen is bulky but defects in its internal echo pattern is seen here. – Dr P Jones.
Anti nuclear, parietal cell, mitochondria, smooth muscle, thyroid – negative.
- 11.08.1980 compared with the scintigraphic finding of 12.10.1979, uptake by the liver is now somewhat increased and there is marked reduction of the hepatosplenomegaly. The liver is now normal in size although the spleen remains moderately enlarged.
- 15.05.1981 RVI – referred for an opinion regarding his right knee.
x-rays – show evidence of early degenerative disease but the joint space is still reasonably well preserved. Opinion – He would benefit from synovectomy.... The joint surface is still of reasonably quality and removing the thickened boggy synovium would help him.
- 6.04.1981 Letter from Middlesbrough General Hospital to Dr Jones -
.....mother told me that while Daniel was at Wellburn Hall school, Kirby Moorside she was told that he was unhappy.....Daniel has now been at Summerhouse School for about a month, and as you are aware he is receiving Factor VIII Concentrate on alternate days.

In your absence I have contacted Peter Hamilton, and the arrangement now is that you will be supplying Factor VIII Concentrate (Koate) to Middlesbrough General Hospital.....

- 6.05.1981 letter from Dr Jones to Mr David Stainsby – gross haemophilic synovitis of the right knee which has not responded to prophylaxis or steroids. Operation would not be appropriate. We can do no more than fit him with a caliper.
- 18.09.1981 Letter to Mr and Mrs Leah from Secretary to Mr D Stainsby – arrangements for operation on the 21 October.
- 27.04.1982 form of consent for operation to right knee
- 27.04.1982 Admission Summary Sheet – There is a strong family history of haemophilia in that his maternal grandmother is one of the few female haemophiliacs.
Hb. 10.5, white count 2,500. Australia antigen negative. Liver function tests normal. Serum haptoglobin 2.1 mg/l.
- Undated pre factor viii lever 1%. Post factor viii lever 60%
- 27.04.198x Pre-op factor viii 5%
- 15.06.1982 Letter from Dr Peter Jones to Dr C. P Gartner.....managed to fox his physiotherapist completely on 9 June when he came for his first follow-up following his synovectomy. Wound is fine. He has gained strength in the right quadriceps group and I have arranged to see him again in a month's time, having kept him on alternate day prophylaxis with 250 units of factor viii.
- 1985 Visit to Middlesbrough Hospital and Newcastle RVI – Missing medical records.

- 5.05.1985 Letter from Mr Calderwood to Dr Evans – 'I understand the family moved to Stockton on 4 June 1985 but he had a chest infection and jaundice and then developed Shingles which was investigated and treated at the Regional Haemophilia Centre.....'
- 8.02.1988 Letter from Dr P Jones – school staff report memory reduction. Daniel has had a lot to carry emotionally recently. Whether his poor school performance reflects the strain he has been under or HIV issue will perhaps only become clearer in the next few months. If Daniel's medical care is to change and involve an increased involvement with the centre, more visits etc, please could you let me know. The family will need financial help to get here.
- Feb 1988 Medical record – Gross haemophilic arthropathy with hepatosplenomegaly, persistent generalised lymphadenopathy, previous history of herpes zoster. Becoming AIDS symptomatic. Last weight 50kg to a height of 65.5. A candidate for AZT in the future. T4 count 0.3 in November 1987 (normal range 0.6 – 1.6).
- 08.02.1988 Memo to Dr P Jones from Mrs Jean Lovie, Social Worker – This time last year Daniel selected to do a B TEC course in school. The course has provide too demanding and Daniel has been opting out of lessons and turning up late. He wants ultimately to do painting and decorating.
When I spoke to Daniel on his own, he said he was most angry about the haemophilia and HIV. He came across as a normal adolescent kicking out at his medial condition as you have seen so much before. He has been careless with needles and swops at home, leaving them lying about, partly I think in defiance and because he has been fed up. I was shown a cupboard full of black bags of used bottles and sharps box full to the top.

Margaret Madden (formerly Leah_ fears Daniel will infect her companion's young daughter. She is using Daniel's HIV stats to try to get the Council to rehouse her companion.

- 19.05.1988 Letter from Dr Peter Jones to Dr Brown – Daniel is in better health than I have ever known him, with good functioning joints and musculature. Other than his persistent generalised lymphadenopathy he has none of the symptomatology of HIV disease.
- 11.07.1988 Letter to Mrs C Wilson, Careers Services to Dr Peter Jones – trained to inject himself when bleeds occur. Prefer to keep his treatment at home for the present. Work capabilities – welding, decorating and gardening. Some difficulties with his maths. First two months of work men with haemophilia can bleed a little more. It is possible to control this by us suggesting to Daniel that he gives himself a prophylactic does of treatment.
- 8.01.1992 Dietetic Report – W 48.5kg, hg 1.74m. BMI 16.0. BMI is below acceptable minimum of 20.
Problem identified: Thrush affecting nutrition resulting in weight loss, taste changes affecting appetite.
- 19.05.1992 blood transfusion – no irregular antibodies detected
- 4.06.1992 Chest Lateral – The right upper zone and lower zone nodular shadowing persists. There is possible cavity formation now on the right. Suggests further follow up.
- 15.06.1992 Chest infection – IFAT for Pneumocystis carinii Negative
- 19.06.1992 Blood Transfusion - no irregular antibodies detected
- 22.07.1992 Microscopy (respire) – Scanty Pus cells seen in film

Culture (respire) – Light growth of candida sp. Isolated
Light growth of Bacteroides Isolated
Microsoft (AFB) - No Acid fast bacilli seen in film.
Culture (AFB) - Mycobacteria not isolated after 6 weeks
incubation.

29.07.1992 Blood Transfusion – no irregular antibodies detected.

18.08.1992 Admitted to A&E – chest infection

19.08.1992 Counterfoil – date of death – 19.08.1992
Place of death - RVI