

Witness Name: Martin Macleod

Statement No.: WITN2028001

Exhibits: [WITN2028002 –
WITN2028005]

Dated: 20 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARTIN MACLEOD

Section 1. Introduction

1. My name is Martin Macleod. My date of birth and address are known to the Inquiry.
2. I am the son of Janet and Keith Root. I make this statement in relation to my father, Keith, who was the infected individual. He is now deceased. I make this statement as an affected individual. I was born Martin Root, I am Keith and Janet's eldest child and I have a younger brother and sister. My last name is different now as I got married in August 2018 and took my husband's name.

Section 2. How Affected

3. My father was always a very outgoing person. He was landlord of the village pub and ran a successful business with my mum. He was very popular and very well known. He took part in all aspects of village life;

cricket, sports, and involvement with the local school – everyone knew him. He loved his holidays, loved family life, loved doing things with us as children all the time, the friends we had and later on in life his grandchildren were a source of constant joy; he just generally loved life.

4. My mum met dad in London in 1966. He was late for their first date, his excuse was that the tube train had broken down and he had to carry it on his shoulders! He always was a quick thinker and a bit cheeky with it! They were married in 1968.
5. Dad had suffered from a bad right knee since he was a teenager which was due to cartilage problems. In the late 1980s, dad was introduced to a surgical procedure called an arthroscopy making it more comfortable for him. He was told he could have that done every 6 months to keep him pain free. This surgical procedure was done at the Nuffield through Bupa. However, during a procedure in October 1988, dad developed a chronic infection and his right knee became so badly damaged that he had to have a knee replacement. (**WITN2028002** – letter from Dr J E D Meads (Blackdown Practice) to Dr GRO-D dated 24 August 1995).
6. It was common practice for people to have a blood transfusion when they had a knee replacement in 1991, which is when dad had his operation. Dad was in the Nuffield hospital in Taunton on 18 January 1991 for his replacement knee operation. I believe the blood came from Bristol – from their blood bank.
7. I believe that due to the common practice of blood transfusion during this kind of surgical procedure, dad would not have been informed in any depth about having a blood transfusion.
8. I do not think dad had any real knowledge of the significance of having a blood transfusion during his routine operation and would not have signed any consent forms with an understanding that he could contract

infections during a blood transfusion. As far as I am aware at no time did anyone say to my dad that there was a risk of the blood being contaminated. If anyone had told him there was a risk he would not have consented to a blood transfusion.

9. The practice of giving blood transfusions during knee replacement operations ceased soon after dad's operation. The first knee replacement was not a success and he had to have subsequent knee replacements. I believe he did not have any other blood transfusions as part of further knee surgery after that first operation.
10. Dad found out about his contamination on 24 August 1995 during the National Blood Service's Hepatitis C Look-Back exercise which reviewed the records of previous donations from donors known to be infected with Hepatitis C. A letter from the National Blood Service confirmed that the transfusion of infected blood took place on 18 Jan 1991. (**WITN2028003** – letter from J Bennett on behalf of Dr S Johnson to Mr Marsh, signed by Mr Marsh on 13 June 1995).
11. No one told my dad about the risks. My mum confirms this in her statement. She said does not recall being told that he would have a blood transfusion through the operation. I believe any conversations between dad and mum with the surgical staff concentrated solely on dad having a knee replacement.
12. The first we had heard of it was when we received the letter in July 1995. The letter states Musgrove Park Hospital – assuming that the blood went to Musgrove Park, was taken over to the Nuffield. This was the first time that we were told that he had a transfusion during that operation.
13. When dad got the letter he was bemused as was my mum because they did not know that he had had a transfusion. Dad phoned the National Blood Service and made an appointment on 9th August at midday to see

what it was all about. (**WITN2028004** – letter from National Blood Service to Keith Root dated 31 July 1995 with handwritten note of appointment date and time in left corner of letter).

14. The doctor said that that there was a possibility that he had been infected. Dad was shocked and bewildered. He and mum did not fully understand the severity of what they were being told. Dad did not know what Hepatitis C was at that time. He wasn't given any initial information – it was a very scary time. He and mum just had to go along and have the test and wait until they were recalled. Mum has described the total disbelief and shock when they went back and got the result and were told that Dad was infected.
15. My dad's first thought was that he going to die immediately. Then he was worried about his future – was he going to have a future – and he was worried for his family's future. Dad was also very concerned that in interim years, from the date of the blood transfusion until the time he was told that he had contracted Hepatitis C, whether he had infected his wife and children. Also, during that time, he had been a blood donor so that played on his mind.
16. A follow up letter from dad's GP to Dr **GRO-D** at Musgrove Hospital mentions discussions about infections and that mum was prepared to have a blood test to see if she had been infected. It was left for the hospital to undertake this test. Mum does not recall this test ever taking place. As a family we were never offered any blood checks. (**WITN2028002** – letter from Dr J E D Meads to Dr **GRO-D** dated 24 August 1995).
17. From the time he was told about Hepatitis C, those early consultations either with his GP or with Musgrove Hospital, and the advice offered, it haunted him for the rest of his life. Even years later after the grandchildren were born, if he hurt himself he would get everyone out of

the room – no one was allowed to administer plasters or anything. At the beginning, dad became obsessed about the possibility of him infecting others with Hepatitis C – he used his own towels, his own flannel, at one point his own knives and forks. It took him a long time to get that out of his mind – it terrified him. He would always tell the nurses he was infected, he always made a point of saying it– he did become obsessive about it. (WITN2028005 – letter from Dr [GRO-D] to Dr J E D Meads dated 24 October 1995).

18. My mum and dad were never offered counselling or told who they could contact. They were not told if there was any help out there to understand or get their heads round anything. Dad and mum were offered a leaflet which, upon reflection, seems wholly inadequate and insensitive and mum cannot remember whatever happened to it which is not surprising considering the shock they had just suffered.
19. Once my dad got over the shock they contacted the Haemophilia Society to try to get some advice and help but they the society did not want to know. Dad did not know what to do. Dad was told there was no way of fighting it; that is what he understood. It felt like dad and mum had very little offered to educate them about Hepatitis C and we as a family were left to get on with it.
20. During a consultation with Mr [GRO-D] at Musgrove Hospital on 23 October 1995, dad was advised against telling anybody about his condition apart from his dentist, medical attendants, and other healthcare attendants. At this moment, Hepatitis C became our family's secret. Dad found very little comfort from these early days and he was left without hope or knowing what might happen to him or his family. Dad felt he had been delivered a death sentence. No one said – *we can help you* or *we can do this for you*. He was simply abandoned and told to keep to himself. Dad was a changed man from this moment onwards.

(WITN2028005 – letter from Dr GRO-D to Dr J E D Meads dated 24 October 1995).

21. Following these early experiences, dad went from being from being outgoing to being quite introverted.
22. Dad had come out of the business in 1992; he was unable to work because of his leg problem. After he was told about the Hepatitis C he withdrew; he did not take part of village life, his circle friends became very narrow. It was like his life did shut down.
23. He should have been given more information at the point of confirming he was infected with Hepatitis C. In the letter from Mr GRO-D to dad's GP he called Hepatitis C a 'disease' and a 'disorder'. Mr GRO-D seemed to think that the leaflet he provided was enough to help with 'its management'. (WITN2028005)
24. Essentially he was given the results and very little else; the whole process in having you back and saying you were positive took place in a ten minute appointment with the GP. Follow up consultations were just as time limited and lacked support. Considering that, at these appointments, my parents were being given such devastating news; more care should have been taken.

Section 3: Other Infections

25. I do not think my dad had any other blood borne virus.

Section 4: Consent

26. I believe that due to the complex nature of dad's situation (i.e. his post-operative knee problems - which were significant - as well as being

infected with Hepatitis C) it led to doctors and specialists throwing everything at him whenever they could. Dad was included in a number of clinical trials and when one failed he was simply added to a list for another. The concoction of medicines in his body at any one time during these trials was mind boggling. I am sure dad would have struggled to keep up with these trials and whilst I am sure they were all undertaken for the best of intentions, dad did become a guinea pig for the purposes of research. Some of these trials were very hard on his body and we as a family are convinced that some of them had a detrimental effect on his physical and mental long term health.

Section 5: Impact

27. After he was diagnosed with Hepatitis C, my dad became withdrawn. He felt degraded; he had to tell the dentist and every medical professional he met that he was infected with Hepatitis C. He hated going through all the 'rigmarole' (as he described it) because it often changed people's attitudes towards him. Some would back away, frightful of catching his infection while others would judge his circumstances to be as a result of immoral or illicit behaviour. He was always mindful of others though and made sure that all medical professionals wore gloves no matter what activity was taking place - he was obsessed in protecting everyone around him. At one point, he even made us all buy gloves as well so we were able to protect ourselves if he had an accident etc.
28. It bothered him that when he went for regular blood tests he would have to walk around with papers and files that had red stickers on them. He felt he was being highlighted as someone with an infection regardless of whether they needed to know or not.
29. He always worried what people would say if they found out; he worried that people would think that he had a history of sexual promiscuity or was a drug addict or an alcoholic. One doctor came in to examine him and

thought nothing about asking whether his Hepatitis C was as a result of a misspent adolescence. Mum said he was so upset he rang her and was crying. This was his dread that everyone thought that he had brought it on himself. There was still a lot of ignorance about Hepatitis C and other blood infections; even in hospitals you were still a bit ostracised and put into a little box containing those perceived as deviants and delinquents.

30. Dad did have a number of treatments for Hepatitis C. During these treatments and as a consequence of them, he developed dreadful piles; his skin was dry and prone to terrible skin irritations and was always felt extremely cold.
31. As these medical trials came and went, dad's energy levels depleted to the point of lethargic. He would sit with fingerless gloves on. He always looked a bit yellow; you could always tell when he really wasn't feeling well by the whites of his eyes. He lost a lot of weight. Following successful treatment for Hep. C during 2014/15, dad went to the Royal Devon and Exeter Hospital on 16 May 2016 for a planned knee replacement operation. Unfortunately, dad suffered kidney failure following the operation as his damaged liver was unable to support the kidneys whilst they processed the anaesthetic and drugs received during the operation.
32. Dad was transferred from the Royal Devon and Exeter Hospital to Derriford Hospital on 13 June 2016 to receive specialist treatment for his kidneys and be reviewed for a liver transplant at King's College Hospital, London. Despite these complications dad arrived at Derriford Hospital a strong, well man in good spirit.
33. Due to the condition of his kidneys, dad would retain fluid around his abdomen which required draining. Dad had a series of paracentesis to drain the fluid. At around 16:00hrs on 27 June 2016, dad had a paracentesis which dad described as initially very painful and had to be restarted as the first incision failed. This one was out of the ordinary and

did not feel the same as previous procedures. On 2 July 2016, dad became critically ill and needed an emergency operation. It is generally recognised that the last paracentesis caused internal bleeding and this was then exacerbated when dad was given anticoagulation treatment on 1 July 2016.

34. Dad was moved into intensive care; he regained consciousness on 10 July 2016. Throughout his time in the ICU, dad received dialysis to support his kidneys and liver. Upon leaving ICU, the family were told that the dialysis would continue on a local machine as ICU equipment did not leave that area. Dad returned to his ward on 14 July 2016.
35. Dad's medical records show mum making enquiries as to when the dialysis would begin again on the Ward. On 15 July 2016 at 07:00hrs without the family present, dad's medical records show that the Active Care Team were too busy to review dad properly and whilst not undertaking a full review the team appears to have decided at that moment, under these rushed conditions, that dialysis was not necessary. Mum is recorded asking time and again for dialysis to begin but it appears that the decision made during the initial, incomplete review of dad's condition was never overturned although there were clear indications of dad's condition deteriorating over a number of days as his body became more and more toxic.
36. After just days back in the ward, with little intervention to support his weak body, dad lost consciousness and died on Sunday 24 July 2016 at 13:45hrs.
37. As a family, and having read dad's medical records, we believe that the build-up of toxins on an already weakened body without medical intervention is a major attributable factor to dad's premature death. Dad was trying to recover from a medical blunder during the last paracentesis and in our opinion the medical teams should have used every support system available to them (such as the dialysis machines used by the

ICU) to help dad improve his strength. We literally begged for help and felt ignored.

38. In summary, dad's death was premature. He did not come to Derriford Hospital in any condition that suggested he was about to die. I believe the paracentesis incident and subsequent clinical decisions which, in our opinion, were based on a perception that dad was a 'healthy patient' and largely ignored the damage caused by Hepatitis C all combined to cause my dad's death.
39. It is important for the Inquiry to note that neither Derriford Hospital nor the Health Ombudsman have upheld our complaints surrounding the death of dad. The compliant process has not changed our opinion on what we witnessed and experienced.
40. Dad suffered a drawn out, distressing death which was preventable. My family has lost a wonderful and loving husband, father and grandfather who has gone too soon. We have all been left devastated.
41. The impact on us as a family was extensive. Mum became dad's carer and by default, so did we. If mum had to go out and if dad was poorly, we as a family would all have to step in. Dad could not be left on his own during the medical trials; some trials were very aggressive on his body and made him really weak. We were always afraid that he would fall if he tried to move about on his own.
42. Mum was the full time carer and we were part time carers. Some trials entailed drugs being administered at hospital. This would place additional strain on mum and this in turn would make dad anxious and stressed at the sight of mum trying to hold everything together. We would take turns so that mum did not have to drive him so much although I suspect she hated not being with him when he was so vulnerable. Luckily we are a close knit family, not only is our love for each other strong, we are close in proximity too so we could all provide help and support. These times

required continued effort and commitment from the whole family and we did it because we all loved dad so much.

43. I do remember being told of the infection and Hepatitis C – being told we can't share this with anyone else. As the years progressed, the need to keep it a secret became more difficult because dad was becoming increasingly ill. Initially he had the distraction of the knee – we could use that, but then Hepatitis C started to have more of an impact on dad's health.
44. Dad carried a lot of this himself – he tried to protect the family and he worried a lot about prejudice and fear that people demonstrated against others who had been infected. Dad responded by not getting involved in social activities or village life as he did not want to explain himself if he was feeling unwell. He withdrew and as a result mum withdrew, we became used to not having dad around at events he would normally attend. Dad was such a strong character, his absence at these events were always felt.
45. It was almost as if he was resigned to own demise –he would sometime feel that it was all stacked up against him – sometimes met with humour and sometimes with despair. It was difficult to accept – dad followed every instruction, every request given to him by doctors – he stopped drinking, lost weight, reluctantly ate more healthily – he would only have one glass of red wine on Christmas day – he enjoyed every moment of that drink. The last couple of Christmases he even stopped that because it would make him feel guilty – he did not want anything to happen and it be associated with a single glass of wine.
46. We all rallied round during the trials, visiting dad when he was in hospital, coming to see him when he was ill – it did take a lot out of him. I took him to Exeter, we all did trips, giving my mum a rest – we would do all this as a family. We tried very hard to keep going as a family. We tried to remain

as normal as we could. It was never normal. Life for us all had changed and could never be taken back.

47. Dad's health is something that we all took on board, all took it as a responsibility as part of our problem as well as his problem. We would spend a lot of time coming down when he was in hospital and on trials to lift his spirits and to help him through – as time went on we became a lot more aware of his condition and we educated ourselves and we would all know the state of his liver and his blood results
48. We as family feel that Hepatitis C had a profound impact on dad's body, which led to his rapid demise and his untimely death. Losing dad the way we did was very traumatic for all of us because it was very sudden, undignified and unnecessary. That is the tragedy, dad fought all the way to try to combat Hepatitis C and keep his body well, we all fought so hard to help him and now all we have is a feeling of loss without dad and living with the impact of losing him in that way.
49. We all feared dad's life was going to be cut short by Hepatitis C but we were not prepared for just how traumatic his death would be. What became clear to us was that following the accident (whilst he was in hospital) which left dad with internal bleeding, the drugs they were using to try to help dad were in fact poisoning him – his liver could not disperse those drugs.
50. We did raise these concerns both with the hospital and the Health Ombudsman but neither of them upheld our complaints. In hindsight, I would implore all those who are caring for someone with Hepatitis C to ensure they have Power of Attorney over that person's health so you can speak on behalf of, and make decisions for your loved one if they are unable to do so. We did not have Power of Attorney for dad and were subsequently treated as silent observers. All the knowledge and experiences we had gained over the years about dad's condition and

what his body had gone through, all the times we begged for doctors to reconsider their treatment for dad and bear in mind his weakened liver fell on deaf ears. We felt that dad was treated as if he was healthy and assumptions were made that he was going to respond to drugs as they were intended. Treatments such as dialysis were dismissed even as we asked time and time again to help him clear his body of poisons. If we had had Power of Attorney, we could have given dad a voice and who knows how we could have improved his situation for him.

51. The infection and the trials – the care and attention that dad needed became engrossing for us as a family – the effort we took as a family to help and then suddenly to not have him here – it is very difficult thing to let go.
52. Arranging holidays and time off to support the family was difficult when my dad became very ill at the end having time off. As I was in the hospital my work was covered because of T&Cs at work but my brother and sister suffered financially.

Section 6: Treatment/Care/Support

53. There were no obstacles to obtaining treatment- the one thing he did not like was the red dots – for the folders to have this mark on it was very upsetting.
54. Dad was never offered counselling.

Section 7: Financial Assistance

55. Dad and mum received the first payment (known as stage 1 which reflected dad's state of health) and then there was nothing; it all seemed quite arbitrary. The amount did not seem to reflect the stress and anxiety dad and mum had gone through, it fell short of reflecting their situation.

56. About a year later, dad was in stage 2 because his health had deteriorated and so he was able to apply for another payment. I do not remember the stage 2 application – I do not think it was as complicated. We do recall that dad had 5803 as his claim number for Skipton.
57. The Stage 2 payment was different as I know we got a letter stating that dad and mum could take the money as a lump sum or as monthly payments. Dad decided to take it monthly because that helped him and mum to better plan their regular outgoings. When dad died, these payments stopped and we are sure he got the same amount of payments as if he had chosen to receive the lump sum.
58. Mum used the Caxton Foundation to help cover some costs during dad's illness and following his death. They seemed to be very personable and would respond in a timely way to her enquiries. Whilst decisions would appear arbitrary and there were many times when she seemed to not be eligible, she did appreciate being able to speak to people.
59. Now mum has moved to EIBSS. Mum applied by providing the details required and got a letter saying how much she would receive each month – but there was no breakdown provided – just the result. Mum unable to clarify how they had come to their funding decisions. She got so worried that the payments were inaccurate, to the point that she took money out of account and saved it. She was worried that they were going to take the money back; she did not want to be in financial state of paying it back. There was no explanation about the money it just appeared. We found the whole area of financial assistance very confusing – the rules and regulations and what we can and cannot apply for. It now appears that mum has to apply for payments on an annual basis. This does not provide her any sense of financial security as payments could go up, down or just be taken away with no apparent explanation offered.

Section 8: Other Issues

- 60. To me, one of the lessons we learnt which we would like to share with the Inquiry is directed at people who are affected who still have relatives who are infected. I would like to stress the importance of having Power of Attorney over loved ones (as stated above) – when the infected become ill they can deteriorate quickly and patients can easily lose their voice if they are gravely ill.

- 61. In our experience, doctors do not always have the time or inclination to investigate the impact infected blood may have on a patient’s ability to recover using conventional medicine. If we had Power of Attorney we could have had a stronger voice for dad and I truly believe we could have made him much more comfortable and maybe we could have saved him. I would very much like to emphasise that to the Inquiry.

Statement of Truth

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

Signed

GRO-C

Dated20 February 2019.....