

Witness Name: M S Kusnierek

Statement No: WITN3515001

Exhibits: 0

Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MICHELLE SUZANNE KUSNIEREK

I, Michelle Suzanne Kusnierek will say as follows:-

Section 1. Introduction

1. My name is Michelle Suzanne Kusnierek and I was born on GRO-C 1956. I live at GRO-C Bristol, GRO-C I have two twin daughters, Claire and Suzanne and a son, Simon, who has also provided a witness statement to the Inquiry.
2. I make this statement as an affected wife of my late husband, Alan Edmund Kusnierek, who was born on GRO-C 1953 and passed away aged 51 on 23rd April 2005 as a result of receiving contaminated blood transfusions.
3. Alan was infected with Hepatitis C as a result of receiving contaminated blood transfusions.
4. **This witness statement has been prepared without the benefit of access to Alan's medical records.** I recently applied for the records but am aware that it is highly probable that they have now been destroyed.

Section 2. How Affected

5. Alan attended Southmead Hospital ("the hospital") in Bristol in 1978 due to having severe kidney problems. He was diagnosed with Medullary Sponge Kidney which is a congenital disorder of the kidneys characterised by cystic dilation of the collecting tubules. He was therefore at increased risk of kidney stones and urinary tract infections.
6. Alan was therefore frequently in and out of hospital undergoing hundreds of procedures in relation to his kidneys which meant that he had numerous blood transfusions from 1978 until he passed away in 2005.
7. We did not find out about Alan's Hepatitis C infection until in or around July 2004, which was only 9 months before his death. A new gastroenterologist examined Alan's hands and announced that he had Hepatitis C. Tests undertaken confirmed the same.
8. However, the diagnosis had come far too late in the day because by this time Alan was in a really bad way. Alan's liver was already very cirrhotic and he was then placed on the transplant list.
9. Unbeknown to everyone, Alan had been battling Hepatitis C for many years and finding out about this diagnosis actually meant that we finally had an explanation for the numerous health problems and constant pain which Alan had so quietly and bravely endured. Everyone had blindly assumed that these had been caused by his kidney problems without ever thoroughly investigating matters and taking Alan seriously.
10. Alan underwent the liver transplant in March 2005 at the Birmingham Royal Infirmary (BRI). Unfortunately he was given a poor quality liver which meant that his body rejected it almost immediately, despite the fact that he was on a high dose of immunosuppressant drugs. Alan then contracted Sepsis, Clostridioides Difficile and MRSA and ultimately died from multiple organ failure.

Section 3. Other Infections

11. As far as I am aware Alan was not exposed to any other infections.

Section 4. Consent

12. I don't think that Alan was tested, treated or used for the purposes of research without his knowledge or consent.

Section 5. Impact

13. It was really hard to understand and decipher where Alan's kidney illness ended and where his Hepatitis C started. However, the Hepatitis C diagnosis answered some many questions because Alan should not have been having the pain and symptoms he was from the kidney problems alone.

14. Alan passed hundreds of kidney stones over the years which caused him severe and debilitating pain; apparently the pain is akin to childbirth. He was in and out of the hospital between 1978 and 2005 enduring numerous agonisingly painful procedures which included having tubes inserted through his penis in an attempt to remove the kidney stones. During this time, Alan received numerous blood transfusions in order to enable the procedures and operations connected to his kidneys to take place.

15. Looking back I should have paid far more attention to what was happening with Alan but you get swept up in things and the days turned into months and then the months turned into years. During all of this time I had no family support and was trying to bring up three children, including a disabled daughter. I remember that we were all at the hospital for Clare and Suzanne's 12th birthday and Simon's 11th birthday (and many other birthdays) and looking back I can see that the children had a difficult childhood.

16. So many people admired Alan because he had this ability to get on with life despite the constant pain he was in. Alan was a marvellous man with a fabulous brain who was far too polite to complain about any of his treatment. Alan was a very strong man who never let his low mood show and he never felt sorry for himself or moaned. His strength of character and resilience was astounding. Alan was also a very good artist and the most wonderful father to our children.

1978-1992

17. Alan was put on pethidine from the mid 1980s to try and control his pain. His health continued to decline and he became very sick to the extent that he was unable to hold down a job so, in 1989, he was placed on Incapacity Benefit.

18. However, he never received the full benefits to which was entitled to. I later found out that Dr Mayes, GP from Horfield Medical Centre, recorded that Alan was a pethidine addict. This was deeply upsetting and made my blood boil. I believe that this was why he was denied the benefits to which he was entitled. I taught exercise to music to both able bodied and disabled students and it was a real struggle to make ends meet. I had trained as a community worker and obtained a place at Bristol University but was unable to take this up due to our financial position and the fact that I had to care for Alan.

19. In 1990 I learned to drive so that I could take Alan on little holidays on the rare occasions that his health allowed this.

20. Alan's renal consultant was called Mr. Gingole and due to Alan's worsening condition he took the decision to perform an operation which involved him removing half of Alan's left kidney. I remember Alan being particularly poorly just before this operation. The surgery finally went ahead in 1992 following a six week wait, during which time Alan was so ill and sweated profusely which meant that his bed sheets had to be constantly changed. He also became out of breath very quickly and would be exhausted after a very short bicycle ride.

21. Throughout all of this the medical professionals were only focused on Alan's pethidine "*problem*" which they tried to make out that it was. By now he was on 200mg of pethidine per day and his whole body was rotting. He was passing hundreds of kidney stones and his urethra was blocked up with uric acid. The only way poor Alan could function at all due to his high pain threshold was by taking pethidine.
22. I was fighting Alan's corner at this stage and to top it off the decided to prescribe him Diclofenac which I told them he could not have due to fact that he now only had one kidney. However, they had already given Alan some of this drug which caused him to have great difficulties with his breathing. I kept asking them to continue giving him pethidine; I remember asking a senior registrar who was so insulting and rude to me and just repeatedly stated that my husband was a pethidine addict. It was horrific that he was accused of this on the very same day that they took half his kidney out.
23. Whilst he was still in hospital his body had swollen to such an extent due to the build up of fluid. He looked like Popeye and they had to drain the fluid from him. After spending about a week on the ward, I was finally able to take him home but I remember it being a very stressful time.
24. Following this serious operation, Alan's condition failed to improve. We were embroiled in a living nightmare which was just full of hospital visits, stays, procedures and operations.
25. Over the years Alan and I were systematically abused by his consultants and a lot of the registrars were very unkind to both of us. One particular incident springs to mind which involved bad treatment of me by Dr [GRO-D] in or around 1992. He visited Alan at home and looked down on me because I am a very expressive Jew with a tremor living in North London. He looked at Alan and then back at me and told me that there was nothing wrong with Alan and he waved his hand dismissively and condescendingly at me. It was like we were worthless and did not matter to him.

1993-1999

26. In or around 1995 Dr. Mayes referred Alan to a psychological unit because he thought that he was making his pain up in order to obtain more pethidine to satisfy his "*so called addiction*". Alan was then seen in the pain clinic in or around 1995 where they used a TENS machine on him.
27. In 1997 Alan was admitted to the hospital due to severe kidney stones. They punctured a hole through his back and passed a tube through his kidney and left him like that. They were trying to draw the stones out of his kidney and out through his back. He did not receive very good care and I feel he was neglected and I was most certainly labelled as "*the neurotic wife*".
28. Shortly after this procedure, Alan came home and within moments he screamed my name from the toilet. Blood was pumping out of him and covered the entire toilet. The hospital had failed to check his platelets which were dangerously low. I managed to stem the bleeding, eventually, and mop up the blood bath. Alan refused to go to hospital so I telephoned Dr Hayes who turned up but did nothing. Poor Alan had to go round for the next three weeks with a tube hanging out of his back and a huge gaping hole. Alan's mother also came over and she was useless.
29. Alan had to go back to the hospital after the 3 week period was up. He was in absolute agony. The hospital took the tube out and his kidney was full of blood clots. I remained with Alan until 2am the following morning because I was scared to leave him with the nurses who were abusive to him and failed to flush out his kidney properly. I was crying inside. It was horrendous and Alan the sweet natured and kind man never once complained. He was too weak to moan and therefore I continued the fight on his behalf.
30. In or around 1998 Alan was treated by a new urologist called Professor Feast. He did his best for Alan and it was he who took the decision to remove the remaining half of the left kidney. Alan was very sick at this time. Both Alan and I focused on the remaining portion of the left kidney and I think mentally we told ourselves that once this had been removed the problems would

somehow evaporate. We thought that this was the entire source of both the pain and discomfort.

31. Alan went into surgery in 1998 and again his body filled with fluid. He was huge and looked like someone had inflated him with air. His blood pressure plummeted and he was basically dying. They rushed him straight back to theatre and opened him up again. Alan was bleeding profusely and his body continued to retain fluid. Looking back it is evident that it was due to his severely damaged liver but no one thought to check for any other cause.

32. Somehow he managed to get through the second opening up. His platelet count was 40 after the procedure; no one had bothered to check the figure before the surgery. It would often take the medical professionals 7 or 8 hours to cross match Alan's blood because he had usually lost pints and pints the matter of cross matching was both a complex and lengthy one. Medical professionals also struggled to put cannulas in because most of Alan's veins had collapsed.

33. I remember that a few years before this operation Alan and I wondered why his jaw had receded to such an extent that there was insufficient bone to prevent his teeth from falling out. He had to undergo an operation where bone was taken from his chin in order to combat the problem of the receding jaw.

34. My children had started to live their own lives by this point GRO-C

GRO-C	
GRO-C	I do recall Simon struggling at this time as he was greatly affected by his father's health problems.

35. In 1999 he had what I would call a few good months although the sweating never ceased. My uncle had given us some money and we used this to purchase two push bikes. We went on a holiday and rode our push bikes. He was exhausted but somehow we managed although he did say he needed a larger cog. Whilst we were away Alan injured his leg and it never really healed. This reminded me that when we were on a caravan holiday in or

around 1996 Alan returned from an archery session with swollen and bruised arms. I presume that his platelet levels must have been low for a long time.

36. Alan used to have very strange sleeping habits and he ended up staying up most of the night. I now know that when the liver is damaged it can play havoc with sleeping routines.

37. During 1999 Alan declined really quickly and by now he could never visit anyone or see any friends. Our only trips out were to the hospital and I accompanied him to them all. I remember him looking really yellow around this time. I was well aware of the jaundice look because my father died from liver cancer. He started to vomit blood on a regular basis and I was trying to care for him and my alcoholic mother at this time. Life was incredibly stressful. I kept having to leave Alan to go to my mother and vice versa. Both were in a really bad way by this time.

38. No one had time for me and the entire family thought that I was some kind of drama queen. On top of this I was also being bullied

GRO-D

GRO-D

GRO-D

I don't think you could find anyone who did not like Alan which shows how nasty she was as Alan did not have a bad bone in his body. I was the only person who could look after Alan as no one else was.

GRO-D

GRO-D

39. I then received a telephone call in the middle of January 1999 from my mother reporting that she had a really bad headache. In actual fact she had suffered a fit and did not have long to live. I spent three weeks with my mother, who was in intensive care in a neurological hospital in Euston, London.

40. We switched off my mother's life support machine on 9th February 1999. Alan was too ill to attend my mother's funeral so I attended alone.

41. During this time, Alan's health continued to deteriorate. The Haematology Unit at the Hospital were monitoring him constantly at this time and he was

having his blood taken on a regular basis. I was still being given a hard time by the medical professionals at this time.

42. Looking back we just got so used to Alan being sick and ill all the time; it became the norm.

2000-2003

43. During this time we were doing more of the same and were going back and forth to Haematology and also having regular consultations with the renal team. I cannot recall the name of the lady doctor we were seeing in Haematology but I believe she replaced Dr Eve.

44. Alan's sister tragically died in 2003 and things started to go from bad to worse. During the summer of 2003 Professor Feast told Alan and I that there was something really bad happening with his organs. They had swelled up so much by this time. Professor Feast told us that he needed to get Alan's Haematology Consultant to refer him to the BRI. I had a lot of time for Professor Feast. He was really good and actually examined Alan whereas other doctors did not.

45. By this time Alan was still taking pethidine and was too ill to do anything. I did all the gardening and cooking and was exhausted. However, throughout all of Alan's hospital appointments he never failed to smile and was always so polite.

46. Every time and including at this meeting, we were always asked "*so can you tell me what is wrong with Alan?*" During this meeting, I said "*excuse me, you were told to refer my husband to the liver unit because his organs are swollen and I would like to know why you have not done so*". This was an awful meeting because Alan was so angry with me and told me to "*get out*" because he did not like me taking them on in any way. This female doctor was very rude to me and made both Alan and I feel uncomfortable.

47. Every time I said something it seemed to lead to poor Alan being punished. They would send him home without his pills, talk to him like shit and they

never believed that he was ill. Yet Alan just smiled throughout and somehow managed to appear happy despite the very real and horrid predicament he found himself in.

48. Alan was never sent to the Liver Unit and all the while his platelet levels were continuously dropping. He was given some platelets which boosted the levels for a short time.

49. In or around November/December 2003 I went back to the hospital with Alan and his big issue was now the platelets. He was so grey in appearance and very poorly by this time. However, no one looked beyond his "*pethidine addiction*". He as labelled as a drug addict.

50. Up until this point I had never really heard about Hepatitis C. However, things sometimes just pop up in your head and I remember looking at this female doctor during one of the consultations and I said "*Do you think my husband has Hepatitis C?*". She told me not to be so stupid and said that he probably just had a minor virus.

51. Alan sent me out of the consulting room at this point and the outcome was that she prescribed him steroids for the next three months. I was losing my ability to keep fighting due to being constantly put down by the medical professionals.

52. We were told that his platelet levels could be increased by giving Alan steroids. Even worse than that was Dr Hayes' decision to place him on amitriptyline. Alan has never been depressed in his life; he exuded positivity. However, Dr Hayes concluded that Alan was depressed and said that was why he never had any motivation. Alan's platelet levels remained low.

53. I remember saying to the female consultant "*have you not noticed that the steroids have not worked? I think you need to give him platelets*". Quite predictably, Alan got cross again and threw me out of the meeting. Alan's health further deteriorated and particularly so after the steroid treatment.

2004

54. During the Spring of 2004 Alan started to continuously vomit blood. Despite all of this he was not on sickness benefit. I was trying to keep a roof over our head by teaching 14 dance and fitness classes per week. We had purchased our house by this time and there were a lot of bills to meet.
55. In April 2004 Alan was looking at me, vomiting up buckets of blood. I said "*alright Al, ok, ok*". I then telephoned the BRI who arranged for an ambulance to collect Alan from our house. The varices had exploded in his stomach and the bleeding had become severe. However, no one had made any contact or referred Alan to the Liver Unit. The BRI patched up his varices and then sent him home again.
56. Alan continued to vomit blood so we went to the Haematology Consultant again and she sent Alan to the Gastroenterology Department for an endoscopy. This was very painful for Alan and this Department just thought that he was being pathetic. His tubes were very narrow but no one knew this. However, the Gastroenterology Consultant was really nice and he said you don't have the picture that Alan was presenting with unless you have a severely damaged liver.
57. By the June of 2004 they were binding Alan's varices with an elastic band. I was doing a Peace Event in Birmingham at this time but I could hardly leave Alan's side because he looked so ill. He was incredibly thin and looked gaunt. Around this time the awful female consultant telephoned the house and told me that there was nothing wrong with Alan's liver. Alan was still vomiting blood and was very poorly.
58. Only a week after the telephone call, we had a meeting with the gastroenterologist which was in July 2004. He took one look at Alan's hands and said to Alan "*you have got Hepatitis C*". He then said "*there is nothing we can do to help you because you have cirrhosis of the liver*". However, he did start to talk about liver transplants. The Gastroenterologist said that he would need to liaise with the female doctor but she basically went to ground. The Gastroenterologist was really angry because she failed to respond to him

so he made the necessary arrangements for the transfer to the Liver Unit to take place.

59. It was sad that Hepatitis C was something that people were ashamed and embarrassed about. We came home from that meeting and sat on the sofa together, which was something we never usually did. Alan looked at me and I looked at him. We both realised that we would have to get on together and deal with this awful news. Prior to this, Alan and I had had a number of angry rows because we were both so stressed after years of illness and hospital visits.

60. Alan then said something very poignant and sad which was "*all that patience wasted*".

61. Alan was a passionate painter before he became ill. He also used to relish in trying and eating a wide variety of foods from various cultures. He used to love the Indian Café in Bristol but once he became ill he could not tolerate such foods nor would he venture out of the house. He used to remain curled up on the sofa or huddled in the corner in a chair.

62. Alan was finally transferred to the Liver Unit and we saw a consultant called Rebecca Jones who was like an angel to us. She was incredible. It was in stark contrast to the female haematologist who had gone to ground. I still believe that if she had acted when she should have then Alan's life could have been saved.

63. Rebecca Jones took Alan behind a screen to examine him and by this time he was the size of a house; all of his organs had swollen. She acted really promptly and was fully aware of how desperately poorly Alan was. She said that she would try and save his life. She said that the difficulty was that his liver was almost too poorly for a transplant.

64. Between then and Christmas Alan suffered a number of episodes of bleeding varices. In October the main vein through his liver exploded and when I say exploded I mean exploded. Claire and I rushed him to the Liver Unit and I

remember it being a Sunday and they could not get the theatre open. Alan had vomited blood continuously for 7 hours.

65. Simon was in London and Suzanne was goodness knows where. Claire sat with him for the 7 hours but they could not stop the explosion and I was pacing around the ward trying to get the theatre opened.

66. After 7 hours they finally opened the theatre and Alan was placed on a ventilator and life support machine. It was a tiny little room and I was there all on my own because Claire had to return home to continue her job. Alan's family were useless and could not care less about him. I had to sleep there and none of my friends had any idea about the severity of the situation, with the exception of my very good friend Mary.

67. I never once broke down whilst I was supporting Alan in this tiny room. I was always there. When he came out of intensive care his body was swollen like a balloon and his brain was on another planet.

68. During this time Alan was also suffering from encephalitis and had been so for the last 6 years. His body was poisoned and he was continuously getting infections and I believe the toxins were going to his brain because his liver was unable to process them. Alan started to become confused and was acting strangely at times.

69. All of Alan's teeth were removed in the space of only 2 days. Rebecca Jones told us that if Alan did not present immediately for the transplant then he would lose it. Alan had lost half his body weight and almost half of his blood. He was constantly being pumped full of transfusion blood because they could not match the rate at which he was losing it. They wheeled him over the road to the dental hospital for a full tooth extraction.

70. He was in a really bad state and on so much medication. He was still hugely swollen. The next day I drove to the hospital with Claire and Alan was taken by ambulance to the BRI for an assessment to see whether he was well enough for the transplant to go ahead.

71. We then had to face another nightmare in relation to the pethidine. Alan got a bed for the assessment almost straight away. However, he had now been taking pethidine for almost 17 years. No one understood that this was the only drug that assisted him with his pain levels. However, he was treated appallingly at the BRI. Alan was in his bed and the beds on either side of him were occupied by a drug addict and an alcoholic.
72. Following a number of tests, Alan was accepted for the transplant. However, he remained an inpatient at the BRI.
73. Alan was terrified by this point because he knew that his blood did not clot and he said to me *"if I don't die from the transplant I will die from my blood failing to clot because my platelet levels are only 10"*.
74. It sounds strange but I actually thought that Alan getting a new liver could signal a fresh start for him; away from all of the pain and multiple health problems that had plagued him throughout his life to date.
75. We returned to the hospital and back to Rebecca Jones. She gave us rubber bands to stop his varices exploding. They kept exploding and we kept putting more rubber bands on. There was no sign of a transplant and I believe this was due to what was happening with George Best at the time.
76. We were now approaching Christmas and Alan was so poorly that I decided to stop working in the afternoons and spend more time with him. By this time he was on 40-50 tablets per day. Mary, my best friend, knew that Alan was dying; I think she could see it.
77. By this time I could not stop crying although I never did this in front of Alan. I kept thinking that as soon as he got his transplant he would be fine. December arrived and Alan said that this could be his last Christmas so we tried to make it really nice. We wanted the children to enjoy it and I remember taking a photograph of Alan and excuse my language but he looked like shit. He had massive ascites and was the size of a house. No one had bothered to find out why they were regularly draining 20 pints of water out of his body.

78. It was about 3 or 4 days before Christmas and disaster struck. Alan was rushed into hospital and Rebecca Jones told me that he was too ill to come home for Christmas. He was in the hospital toilets crying his eyes out. He looked so gaunt and thin. He always liked to look clean and smart and he had a drug addict in the bed next to him, who was, excuse my language, shitting himself. Alan was so proud despite all of this. Rebecca Jones gave in and said "*ok you can go home for Christmas*". When Alan telephoned me to tell me I was in the town doing some shopping at the time. I remember being on my push bike with all the Christmas presents and I also bought Rebecca Jones one. I therefore got Christmas "*wrapped up*" in 2 days. Alan was happy at home but he could not eat a lot.

2005

79. January came and went. Alan went to the dentist who lived around the corner from us. He fitted Alan with the most expensive and amazing set of teeth and did not charge him a penny. He was a wonderful man and he did all that for my Alan.

80. February arrived and Suzanne decided to continue with her planned trip to New Zealand. I think her head was in the clouds. Simon was not coping very well with his father's poorly health. Claire was always there, trying to support her father and I. Alan and I pressed on through the next couple of months whilst trying to keep his ascites under control and waiting for the transplant.

81. Then towards the end of March we got a call to say that Alan would need to get to the BRI immediately for the transplant. I took Alan in my arms and told him that I did not want him to die. He told me not to be a drama queen.

82. Therefore we all made our way to the BRI. There was Alan, myself, Claire, Simon and his girlfriend at the time who was called Catherine. Suzanne was in New Zealand. I told Alan that he must speak to Suzanne because she would be worried. My mother passed away when Suzanne was in Australia and it nearly broke her.

GRO-C

I managed to get Alan to telephone Suzanne on the way to hospital and that was the last time he ever spoke to her.

83. We all walked with him down to the theatre and Alan looks at me and I look at him. Everyone was saying that he was going to be fine. He said that more people, like his mother, would come and visit him if he had something to give them. None of his family took his poor health seriously. The only friends who visited him were Pete and Graham.

84. Alan kept saying to me that the reason he would not survive the transplant was because he would bleed to death. He was well aware that the medical professionals had not fully appreciated the fact that his blood struggled to clot. The only friends who visited him were Pete and Graham.

85. Alan walked into the theatre and that was the last time he ever stood up. Everyone stayed up in Birmingham and it was a very difficult time. Some transplants take only 4 hours, but his lasted for 13 hours during which he lost 20 pints of blood and had 4 heart attacks. They managed to transplant the liver but by the following day it was not working very well.

86. In times of stress I don't drink or smoke but I do eat. I had to have my wedding ring cut off because my fingers had grown in size. I immediately knew what this signified; which was that I was going to lose Alan.

87. They had given Alan a liver from a 60 year old male donor which was apparently not in a great state in the first place. It was of poor quality and was fatty. Alan remained in intensive care and was taking numerous immunosuppressant drugs in an attempt to combat any difficulties in this regard. However, they failed to work.

88. The medical professionals planned to carry out a further liver transplant once they had sourced another liver. After a few more days I was told that he was recovering a little bit so they changed their plans regarding a further transplant. I do think that these doctors did their best; some patients don't

survive transplantation. I strongly believe that the Hepatitis C played the biggest role in terms of the why the transplant failed.

89. I think the medical professionals thought that Alan was going to make it. He remained in intensive care for about 5 weeks. In that time he was trying to hard to recover but had to remain in an unconscious state but he was initiating his own breath once they took him off the ventilator.

90. My children had all returned home to their jobs (although they still visited) and I was left up there, alone, with Alan. Mary came to the hospital on the same afternoon that Alan had been taken off the ventilator. Alan had sufficient time to thank the surgeons for what they had done and told me that he would always love me to which I had replied that I would always love him. Only a few hours after this, Alan's encephalitis set in and he knew that he was not going to make it as he was placed on life support. Alan was the most loyal, committed, polite and unassuming man who had, in his last moments, only thought of others in giving the surgeons his heartfelt thanks.

91. Mary also told me that afternoon that about 2 weeks prior to the liver transplant Alan had told her that he could not do this anymore. He said "*I can't fight this anymore*". He also said "*Michelle will be fine*".

92. Whilst Alan was in intensive care they allowed so many people to come in and out and there must have been so many disgusting viruses present. I recall that there was an Asian prisoner in there who was dying and about 20 of his family were allowed in. The police and someone with handcuffs also came to visit him.

93. Due to Alan's poor health he had absolutely no immune system and zero resistance to the many germs in there. Furthermore, his blood would not clot. I would sit with Alan and then go to my room in the hospital to sleep. About 4am one morning, I received a telephone call from intensive care reporting that Alan was unconscious. The most powerful thing is your breath and 4 days before he died he was taken off the ventilator. I was sat there and I remember telephoning my mother as I was in an awful state. I told her that I

was unsure as to how much more of this I could handle. She said *"well if you can't handle it how do you think we are supposed to?"*

94. On Thursday 21st April I was taken into a room by the medical professionals and they told me that they could not do anymore to help him. I went completely mad. I was furious and so angry with them. I could not handle it. I went berserk. However, the medical professionals who were treating Alan in intensive care had so much respect for Alan and me. They loved how polite he was. I then had to pull myself together and contact the children. Everyone came including partners and everyone was incredible at such a devastating moment.

95. We all sat around Alan's bed; there were 9 of us in total. Just before everyone arrived I had spoken to the medical professionals to tell them that the most important thing was someone's breath and I told them that they were not to rush his death. I told them that he would be initiating his own death and that he would not need any painkillers. Alan's mother turned up too but only for a short while before disappearing again. She passed away 18 months later as a result of lung cancer.

96. Claire was praying GRO-C. About 10 or 11pm on the Friday night, they wanted to give him morphine but I declined this and said that he was fine. Alan's brother also arrived. We all kept talking and ensured that he had good company to the end. Suzanne was holding his hand when he passed away at 7am on the Saturday morning.

97. Following Alan's passing, I went to sit in the waiting room leaving Alan on the ward. I then did something that no one had done before in the hospital. I fought them regarding the decision they took of keeping his body at the hospital. I told them that I would not leave the hospital without Alan. I told them that they were not going to take him down and put him in a drawer somewhere and I won that fight.

98. On the Monday the Inquest took place. I could not believe that it took place so quickly; it was only 2 days after his death. We found out that he had contracted MRSA and died of multiple organ failure. The hospital's cleanliness in intensive care was horrific. I did not want to hurt the surgeons who had tried so hard with Alan's transplant but equally I was hurt and angry about the state of cleanliness which appeared to go completely unnoticed. I should have done something there and then regarding a clinical negligence claim. They were putting peoples' lives in danger.

99. Ironically about 2 years before Alan died that I saw an advert for the Woodland Memorial in Cornbury, Bristol and I thought to myself "*I am going to need them*". The Woodland Memorial did such a good job with his funeral and Simon did all of the music.

100. I think I was in complete shock throughout all of this. However, I did not sit around and bawl my eyes out. I could not return to the home which I had shared with Alan for the last 16 years so I stayed with Claire. When I finally managed to return to our home, I slept on the dining room floor for 6 weeks and then the sofa for 9 months because I could not bring myself to return to the bedroom.

101. My life has never been the same again. This tragedy has changed me as a person and there is not a day that goes by when I don't miss my kind, gentle and polite Alan.

Section 6. Treatment/care/support

102. Neither Alan nor any of our family were offered any counselling or psychological support.

103. The resounding theme throughout Alan's many interactions with the NHS was one of neglect. The NHS failed to properly diagnose, manage or treat Alan in connection with his many health problems and his Hepatitis C. I refer to the contents of section 5 above.

Section 7. Financial Assistance

104. Neither Alan nor any member of my family received any support from the Skipton Fund or the EIBSS.

Section 8. Other Issues

105. I want the truth from this Inquiry. I want to know why the medical professionals took so long and were so reluctant to diagnose Alan with Hepatitis C. I believe that what happened with Alan was a cover up.

106. I want the people responsible for this tragedy to be held to account.

107. I would like a proper apology for the trauma, pain and hell that my family and I were put through.

108. I want proper financial recompense.

109. This tragedy does not just stop with the infected. Thousands of people were also affected by this tragedy and that includes the fact that my GRO-C GRO-C did not receive the attention that she deserved because I was so focused on Alan at the time.

Anonymity

110. I do not want to apply for anonymity and, if required, I am prepared to give oral evidence to the Inquiry.

Statement of Truth

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

Signed

GRO-C

Dated.....16.12.19.....